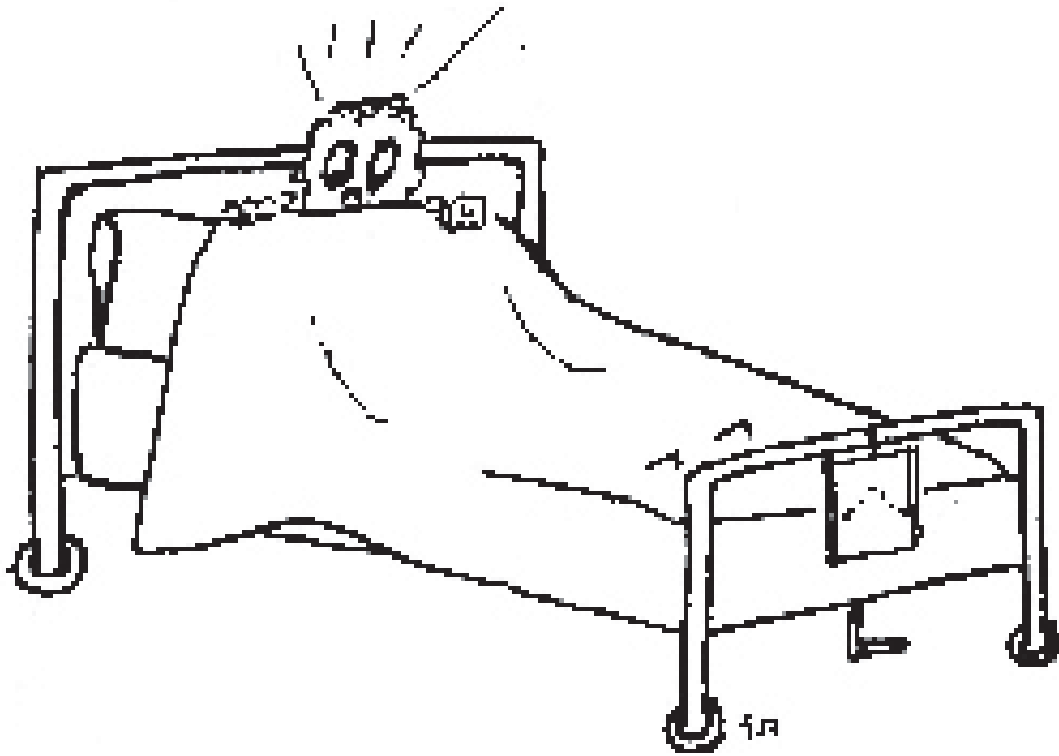


# Life's In The Pink

How to maintain a quality of life,  
by a prostate cancer survivor



Barry L Oakley

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by a Prostate Cancer survivor

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By Barry L Oakley

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## *Comments from fellow travellers*

I'm afraid that if this task was handed to professionals we would end up with a huge tome of textbook language and proportions — it has to be written by a man who has been 'through the mill'. It should eventually be read by all men who are diagnosed with prostate cancer and therefore needs to be kept brief. You have succeeded in all aspects with this book... Due to a recurrence of my cancer, I found that I related to so much of what you had to say in this book. Congratulations on your effort to help men through this difficult part of life.

- *Trevor Hunt*

It was a pleasure to read ... You made so many important points about life and how we should strive to attain a wonderful lifestyle. Every man and his partner should take time to read and absorb what life is really about. Great book, a must for everyone's library.

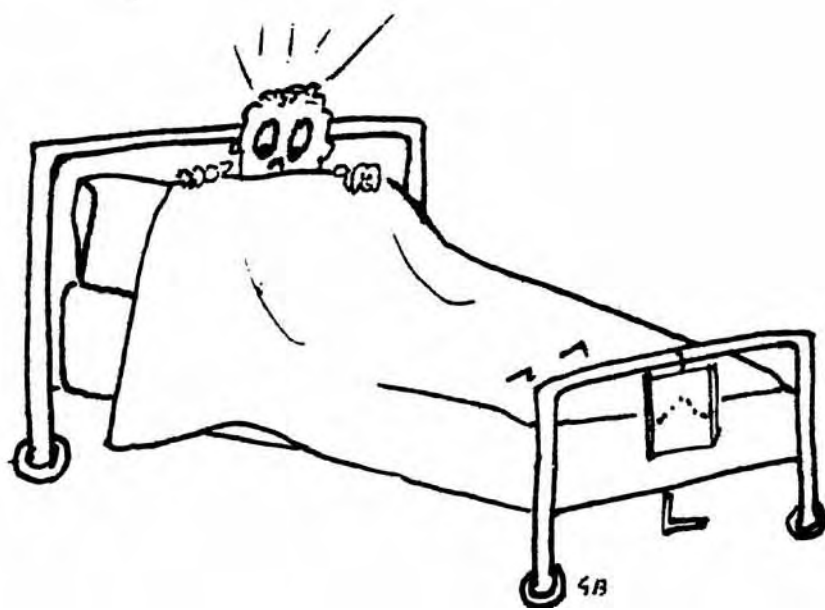
- *Gerry McCreanor*

I found your book very interesting and informative. It fulfils a need because as you quite rightly say, information on post treatment situations and care is lacking. Some of this information may be available in various brochures but rarely in one publication... The book gives a good coverage of practical situations facing patients and their carers. There is a touch of humour running through the book, which I found positive and refreshing.

- *Jeff Roberts*

I am a younger man but know that one day I may have to face these issues. I am very encouraged by the fact that this kind of book is available for when and if that time comes. I am deeply grateful that Barry Oakley, as someone who has been there, has shared this with us.

- *Grant Hand*



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# *Acknowledgments*

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To Geoff Oakley, for his meticulous work and suggestions on the formatting and layout.

I am also indebted to Gary Bowes, a fellow traveller, for the cartoons. They are a valuable part of the presentation.

To all those who have helped in so many ways, thank you.

Barry Oakley

# *Foreword*

Barry Oakley, diagnosed with prostate cancer nine years ago, has assisted the Urology Unit at the Repatriation General Hospital as a consumer adviser over the past six years. He played an important role in the development of the widely used "Mr. PHIP" patient information series, and is sometimes himself known as "Mr. PHIP"! In addition he has contributed to a video and booklet prepared by the Commonwealth Department of Veterans Affairs, to GP training and peer support training. It gives me great pleasure to introduce his latest and uniquely helpful publication.

The experience of a life-threatening illness is probably the greatest challenge that we all face. While there is expert, skilled and caring professional support available, it ultimately is something to be dealt with by each person on an individual basis. Barry has shown in his first book, "There's some good years left yet - the experience of a prostate cancer survivor", that he can do that with courage, humour and intelligence. His writing doesn't pull any punches about the emotional highs and lows, the struggles involved. However he also seems to be able to extract tools for dealing with each stress or attitudes and approaches which can be helpful to others, to all of us. Reading a book of Barry's is like having a friend walking with you as you negotiate each uncertainty, anxiety, new source of stress.

In this his second book, Barry explains how facing uncertainty, knowledge that life will never be the same again, physical effects of illness that can affect our most deeply valued gifts - relations, freedoms, a sense of future. He provides approaches for dealing with these that he found helpful. These approaches range from practical things to do such as meditation and a prostate-friendly diet, through to communication with loved ones and to embracing grieving. Despite the difficulty of these topics, this is a very easy book to read. I feel that the book gives us much that is helpful - to action, to ponder and to take with us as we try to move forward in understanding this difficult condition.

Carole Pinnock PhD  
Principal Research Scientist, Urology Unit  
Repatriation General Hospital.  
Chair, Education Committee  
Australian Prostate Cancer Collaboration.



# *Introduction*

Most literature about prostate cancer is written by professionals, from which we can learn much and be greatly helped, but it often lacks the personal experience. This little book is an attempt to see it from a fellow traveller's point of view, for those of us who have been in the trenches together.

Living in uncertainty is an issue for many who have been treated for cancer. For too long there has been a huge hole in this post treatment area of health care. Medical energy, scientific research and doctors' skills have been focused on detection and treatment. I am very grateful for that. But after diagnosis and treatment you are on your own. You live with your fears; and your ignorance. It is like, and I characterise here, a pat on the back and 'Until something goes wrong we can't do any more for you.' And off you go with your bag full of anxieties.

*An example:* After I had a radical prostatectomy and they found a microscopic speck of cancer in a lymph node my PSA initially dropped to 0.1. Six months later I developed gallstones. The pain during the attacks was intense and in my case, a little dodgy to diagnose. In the meantime I managed to convince myself that my microscopic speck of cancer had got loose and was on the rampage. Not a good feeling! Later a chance comment by a doctor at a meeting said, 'If your PSA goes up it will probably be 3 to 5 years before there will be any detectable secondaries.' All that fear, sweat and anxiety for nothing!

Even if you don't have gallstones you live with uncertainty, with the possibility of a return of your disease. Every back spasm or arthritic joint or overindulgence of your favourite food, reminds you of this. I heard on the radio the other day this great description, 'Your cancer never goes away. It's like it is on the end of a big long rope that is attached to the back of your head. It stretches way back and a lot of the time you don't even think about it, it's just there. But then, when you go for your PSA test, or a new pain starts up (as you get older they seem to become more frequent) it is like it is on a big spring and *wham!* There it is again, right up at the back of your head.'

I believe that if we are looking at holistic health care, then there is something more. What is missing is perhaps a most important ally or ingredient to the wellness process, that is, the 'Quality of Life'. Cancer

awareness groups now acknowledge that for tens of thousands, cancer is a *chronic* disease. A world body of professionals, pledged to the prevention and cure of cancer in the Charter of Paris Against Cancer\*, say in their introduction to the Charter, ‘...and to maintain the highest quality of life for those living with and dying from this disease.’

I have been a cancer survivor for nine years but I am always conscious of living in uncertainty. For the first three years my PSA blood count was less than 0.5. Nothing to worry about there, even if I did get a bit twitchy at blood test time. Since then it has been slowly rising up to 7.3 and rising. I have to live with that. I am fortunate in having a good urologist who is positive and encouraging but I only see him every six months and then it is like ‘Good result, nothing to worry about yet’. Then six months wondering what my PSA will be up to next time.

I have found there are four areas we need to give attention to if we wish to live a quality of life that is satisfying to us. They are:

- 1 Quality of life on the other side of treatment
- 2 Caring for relationships
- 3 Support for the journey
- 4 Preparing for life's great transition.

I call them the **Big Four**.

This little book is not meant to be all inclusive but a way to look at these issues seriously and perhaps give you some helpful stepping stones into the future.



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\* Copies of this Charter may be seen at The Cancer Council South Australia, 202 Greenhill Rd, Eastwood



*It can only get better!*

# *The Big Four*

## *One: Quality of life on the other side of treatment*

From my experience in the first of the Big Four, four things are extremely important in relation to the quality of life that are possible and indeed achievable on the other side of treatment for prostate cancer. As we have never been there before, most of us need some know-how and perhaps a little help. It may be different things for different people but perhaps these could be a starting point.

### *The importance of a positive story*

**Acknowledge your disease:** First, acknowledge your disease and accept the fact that you have it then decide to fight it. When I was first diagnosed I prepared myself to die. Then as I stood in my backyard one day and the sun came out from behind a cloud and warmed me it suddenly occurred to me that... 'Oakley, now is the time to prepare to live, not to die'.

**Be positive:** The next thing is to decide what to do about it. How to be positive about it. How in the midst of all the possibilities you can give it your best shot. What treatment, what support, what positive reinforcements.

**Meditation:** (see page 16) Stress is your enemy. You have a lot of time to think so make that thinking *positive*. I found meditation a great ally. The basics are not difficult, just be still and quiet in your favourite spot for a few minutes and concentrate on bringing a *quiet* to your mind, a *relaxation* to your body and a *deep, deep calm* to your inner being. You can lengthen the time as you get used to it. I also found healing visualisations very helpful. That is, visualising your body healing itself. Our body has a tremendous capacity to do this.

**Give it your best shot:** Decide that you are going to give this thing one hell-of-a-run for its money and be a bit 'bloody-minded' about it.

## *The importance of goals*

**First experience:** Your first experience may be that you have difficulty in seeing any further than next week. Following the operation to remove my prostate I ended up with a pulmonary embolism (a blood clot on my lungs)\*. The head doctors of the place came and stood around my bed and said, 'Barry, you have to understand that this is very serious'. I decided my first goal was to get through the night and that tomorrow would be the first day of my recuperation.

**Short term goals:** Have some short term goals like getting out of hospital, getting the catheter out and going for a walk, making it longer each time. Something to surprise your loved one or carer.

**Long term goals:** or projects. Something that gets you out in the shed to make something or into the garden to plant something. We bought an old caravan to fix up and get ready for our retirement. I must admit that on some of my down days I cursed the waste of money but it really was a great boon to have as a goal and we have now enjoyed a couple of great trips around Australia and some fine weekends away. I even bought an Akubra hat that I plan to wear until it is worn out.

**The importance of goals:** Goals pull you forward. It is like throwing an anchor out into the distance then pulling yourself in on the rope. While you are doing that you are more concerned about the achievement of getting there than what might or might not be happening and you experience a much richer and satisfying quality of life.



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\*This is a relatively uncommon complication of major surgery and after a radical prostatectomy occurs approximately only one per hundred. The most common treatment is to thin the blood to prevent further clotting.

## *The importance of the sense of being in control*

**Have back-up plans:** Plan A, plan B, plan C, etc. If this doesn't work we'll try plan B... Every time I go for a PSA test I believe we have got it beat but even if we haven't, we can handle that too. I have a back up plan.

Put your body in a position of advantage:

1. Exercise regularly, enough to sweat and puff a bit.
2. Meditate and reduce stress. Stress suppresses our key ally, our immune system.
3. Eat well: plenty of fresh fruit and vegetables and stay away from junk foods.
4. Look after your immune system. Plan A for me was added vitamins and antioxidants, not over the top but just to supplement my diet. Since my PSA has begun to rise a little I discovered in some research by Dr. Charles Myers (Cancer Centre Director and Professor of Medicine and Urology at the University of Virginia) that red meats have an arachidonic acid in their fats that in clinical tests aid the growth of cancer.\* A part of 'Plan B' for me was to cut out red meat from my diet. Hence I have a sense of regaining some control.
5. Laugh a lot. The endorphins it releases are helpful to your body's healing process and it just feels jolly good. Laughter is a mood changer, especially if you can laugh at yourself. There is nothing better.

**Do something worthwhile:** You need to feel important, needed, valuable to others even if it is only your style or attitude that is helpful.

**Be in control:** The sense that you are in control of your situation instead of 'it' being in control of you cannot be over emphasised. It is the basis to a good quality of life.

## *The importance of support*

**Loved ones:** Allow yourself to be loved. A stiff upper lip doesn't help. It is not the time to be macho. Then let that love flow through you. Don't keep it to yourself, let it flow on to others. As much as it has been given to you, give it away and its value will be greatly increased.

---

\*From Dr Myers book '*Eating your way to health*' published in 2000. Dr Myers began his career in cancer research in 1971 at the National Cancer Institute. He was diagnosed with prostate cancer in 1988 then 55 years of age.

**Talk to peers:** There are people who are going through what you are. Share their ups and downs, and yours. There is a lot of support to be gained by travelling together, by being in the trenches shoulder to shoulder and by being able to laugh together.

**Join a support group:** I was travelling OK until my PSA began to rise. Another part of plan B was to join a support group. The first night that we attended we were made so welcome and the whole spirit of the people was so positive and buoyant we were overwhelmed and uplifted.

**Support goes both ways:** Be important to someone else or a group. They depend on you too.

**In summary, this is what has helped me:**

- **Acknowledge your diagnosis, accept it and build a plan to deal with it.**
- **Have a strong positive attitude and plan for the future: some long and short term goals.**
- **Put your body in a position of advantage, look after your diet, exercise and learn to relax.**
- **Allow yourself to be loved and pass that love on. Laugh a lot and keep hope in your heart.**
- **Surround yourself with love and the support of others and you will live longer, happier and be more fulfilled. You have some good years left yet.**

No doctor told me these things, yet most doctors agree that people who have a positive attitude will do better, live longer and have a better quality of life than a patient who worries and has little hope. This is not a miracle, just the facts.



# *The Big Four*

## *Two: caring for relationships*

This brings us to the second of the 'Big Four'. To deal with the physical side of this disease is only one side of the question of the quality of life. The other side is how do we *live* with this chronic disease? Again, in this area of relationships we are left to fend for ourselves. Most of our relationships have been given a new twist. Relationships with our *partner*, our relationship to the *normal*, a relationship to our *disease* and a relationship to *living in uncertainty*. Some of them are very personal, some very deep and some fill us with fear or anxiety. How we respond to these relationships determines, to a large extent, the quality of life we can enjoy.



### *Relationship with your partner*

**Rejection:** Sometimes we can feel rejected. That is quite natural. I did.

We are a different person, in many cases incapable of responding sexually as we once did and we don't know how to handle that. I found it easier to *shut down* my feelings so I didn't have to wrestle with them. Or you or your spouse may *just do nothing* and ride it out because you don't want the hassle or know what to do.

Our partners too can feel rejected. We have been the centre of attention. Everybody asks how we are, we get the sympathy, yet she does a major share of the work and worrying on our behalf. Or it may be that we no longer know how to relate to our partner now we have lost some of our manhood. That can lead to a sense of rejection by both parties.

These experiences of rejection may be quite out in the open or very, very subtle. But if we can *talk* about them, acknowledge them and work our



way through them, they can greatly enhance our relationship and our quality of life. If they are not dealt with then each person's quality of life will suffer and we tend to dry up inside.

**Abandonment:** Along with rejection, we may feel a sense of abandonment. We now are on our own. People have stopped fussing. But we still have many of the same fears and anxieties. It seems others are saying, 'They fixed you up, you should be happy. Get on with your life!' and we are left to face our deepest fears by ourselves. We bottle them up — you can't spill your guts all the time — and we put on a happy face which we don't feel, a kind of bravado. It's only late at night that we don't feel so brave.

We feel guilty if we are not coping as well as we think others are expecting us to be. I found this sense of being totally on my own devastating and brought on moods of depression or anxiety attacks. When this happens, quality of life goes down the drain.

The good news is that the sense of abandonment is reversible. You do not have to be on your own. There are people waiting to love you and share with you, to understand how you are *really* feeling but you have to tell them. I find it difficult to get started. It is like admitting I'm not able to cope but when I screw up my courage and confess how I am feeling, I find it very rewarding.

**Cracks can appear so easily:** Our treatment often prevents us from having a normal relationship with our partner. We can go through the motions of caring for our loved one but the personal touch and affection becomes awkward. It is difficult to know how to get started again. It seems easier just to drift along. The cracks widen and before long each of you have found your own way of living in this new situation. You settle down into a lifestyle that you didn't expect, nor want. It just happened and the further you drift the harder it is to bridge that gap.

**Building the bridge:** Take your courage in both hands and share how you feel. Don't be afraid to talk to one another at the deepest level. It is an essential part of enriching your lives. Experiment in new ways to express your affection. You may even make a game of it. Being prepared to have a bit of a giggle at yourselves is very bonding. Plan things that you can do together. Special events, celebrations, outings, interests you can share together. Also plan things that you do separately but have an interest in each other's activities and achievements.

## *Relationship to the normal*

**'When things get back to normal I'll be OK':** I found myself driven to make things normal again. I tended to live out of the 'if only's' but they weren't there. Things were not normal, like they used to be and never would be. My hopes of getting back to the normal took a battering. When that happens you experience a grief at the loss of the normal. Something has died. That grieving process is an essential part of moving on. It is only a problem when we continue to grieve for the past and can't accept the *new* normal and learn to live with it.

### **Life will never be normal again:**

*Sex:* I had a 'love urge' the other day so I got the caverject out of the freezer with the intent of using the injection to help me achieve an erection but I balked and did nothing further about it. When we got to bed I confessed to my wife, 'I don't know how to love you any more!' We talked a bit and I asked her what she did when she had a 'love urge'. 'I just put it under the pillow because I don't know either,' she said.

*Goals for our life:* Many of us feel that someone has shifted the goal posts. Things that once mattered don't seem so important any more and we are not sure where the new goal posts are.

*Expectations:* What I expect out of life is now different. When I was kicked up against the wall with the word 'cancer' I came out of it in a bit of a spin. I felt a bit cheated. Not angry. Just that some of the things I had hoped for were drastically changed.

*Work, retirement, family:* Grandchildren? Would I see them grow up as I hoped... I found I had to take a new relationship to many things that were very important to me.

**The 'new' is now the normal:** I found I was stuck with something new. I was different but it was still the same 'me'. It was the same life I had to live but things were different. That difference is *now* the normal. A failure to deal with that is the cause of much stress.

In the past much of life just oozed along. It is like you are caught in the way things were, like being on a conveyer belt. It's damned hard to get off. But now you *are* off and now you have multiple new options. Now you have a chance to improve on that oozing. Now you can make a whole raft of new decisions that will enhance your quality of life.

## Plan what the 'new' normal can be

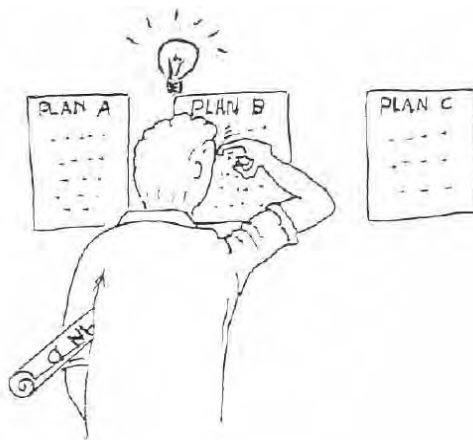
*Sex:* A lot of men, having worked through creating new relationships and ways of being intimate, find that their love life is now better, deeper, than it has been, for both them and their partner. That's a plus for the quality of life!

*Goals for your life:* Don't just ooze along, set for yourself new goals, the things you always wanted to do but never got around to or had time for.

*Life's expectations:* Life is not measured by length alone but by what you put into it and get out of it. The more you put in, the more you will get out and your fulfilment of life will be greater.

*Work, retirement, family:* One of the things the experience of prostate cancer has done for me is that it raised the question of how do I want my grandchildren to remember me. Some cranky old coot who dribbles in his beard? Or someone who left little gems of life for them to remember and draw on in their years to come.

For me, eventually the 'new' normal became the *real normal* and I now feel quite comfortable with it. In fact, I am glad of it.



## *Relationship to your disease*

**A rotten crutch:** A chronic disease can be seductive! Never fall in love with your disease. It will let you down like a rotten crutch. In a queer way we can fall in love with our disease, sucking life out of the attention we get. Or we let it give us a *justifiably* negative attitude, which leads to anger or despair. Or we give up, which leads to hopelessness. Or we may play at ignoring it, which leads to a false 'normal', a false reality, then despair. It is important to recognise such rotten crutches and learn to walk without them.

**You still hold onto it in some way:** Yes we still live with our disease, live with it every day. It can still invade every relationship and colour all our decisions. I have found that having people express their concern for me or asking how I am getting on, gives me the will and the strength to go on. That is one of the important roles of a support group. We know that cancer is a chronic disease and needs to be seen as such. If we break our leg or have our gall bladder out, it is over and done with. With cancer our disease is still a part of our lives. We have to find new ways to own it, to live with it.

**A major event that has changed your life:** For a lot of men nothing more major has happened in their life. It has turned their life around. We who have been diagnosed with prostate cancer and have had treatment have been to the edge and back again. Together with all the problems that may be associated with it, it is something that has changed our lives. We are *now* who we are, because of it, because of our experience. That event cannot be denied or forgotten. If we are on a regular regime of PSA tests or hormone therapy there is *no way* we can forget it. It has to be acknowledged.

**Hold on to it but give it a new content:** It is like a journal of life's experience that we keep, we clutch to ourself. It is *my* life. Others see us and think it contains all the old trauma and pain and fear and despair. They want to take it from us and throw it away. They want to take it away from us but they can't. And we can't give it up. But we can rewrite it.

I have found that the secret is to give it new content. When we have written new pages in that journal, of accepting the 'new' normal we discover a *new* quality of life. For it now contains pages of strength and hope, of love and care, new goals and new possibilities. Then we can clutch it to ourselves in a positive way, a healthy way, for it gives us life.



*It's the only one you have  
Love it!*

## *Relationship to living in uncertainty*

**Fear of return:** I guess for me, especially in the early years, there was always the thought that there could be a return of the disease. Even though we may put on an outward bravado it can cause an inner trauma. That is one of the aspects of it being a chronic disease. That fear is something that we have to learn to live with. While I think I am OK most of the time, my wife tells me I get a bit twitchy every time I go for a blood test.

In the midst of the possibility of a return of our disease we have to deal with those simplistic comments we get, like 'You'll be right...' which does not take seriously what we have to live with. Yet worrying about what 'might' be is to carry around a load of useless baggage because it also *might not* be.

**Recurrence:** If the disease does return, and for some it does, it raises a whole set of new questions. What treatments are available? Which would be best for my situation? What's the prognosis? If I go onto hormone treatment will I lose my libido? How will the disease proceed? Where will the secondaries show up? What sort of death will it be? These questions and many like them can throw quite a blanket over our quality of life unless we can find a way to deal with them. For myself, the more I can find out about things, the better I can handle them. And to live with hope in my heart. That may not be so for some but whatever is the best way for you, pursue it eagerly.

**Changed priorities:** In the midst of this we grasp around for those things that make sense. We find that things that were once important to us slip into oblivion. Priorities change, expectations change. Our view on life may change. To make sense of the rest of our lives becomes important to us in a way that it had never done before. 'What story do I live out of now? I thought I had it beat but now...? How do I live my last years... last months? How do I deal with all these uncertainties?' These questions take on a new importance.

**You can be in control of your life:** One of the observations of life that I have become sure about is that when something comes along that threatens our very existence somehow, from somewhere we are given strength to deal with it. The human capacity to deal with adversity is quite unique and almost always surprising.

A positive aspect is that there is a new comfortable intimacy with things that do matter. It can be a new intimacy with life, with relationships and life's expectations. Even, might I add, a new intimacy with handling the idea of death itself.

Life takes on a new meaning. It's a bit like my 50th birthday which I was dreading. After fifty you can no longer kid yourself that you are avoiding the downhill slope. So when I turned fifty I decided I would start again. Another lifetime. Now I'm the most experienced twenty year old there is around.

We have only one reality and that is our experience of life. Fill it full with love and life and hope and possibility. We may not be able to control the cause of our experience but we can control the way we relate to it.

Your quality of life is something that you can decide, it is in your hands.

In summary the following have been helpful to me:

- **Talk to your partner. Try to understand your emotions and feelings and share them. Don't shut them down or put them under the pillow.**
- **Decide how the new normal can be richer than the old normal and in what ways it will be richer.**
- **Reflect on your experience and how and where it has given you a better quality of life.**
- **Be proactive at any and every stage, even perhaps the final stage. Be in control and keep hope in your heart.**

# *The Big Four*

## *Three: Support for the journey*

### **A position of advantage**

*(Looking after your body so your body can look after you)*

This section contains a pallet of things that you may find useful in caring for yourself. While they are individual things which some may find more helpful than others, they are all worthy of serious thought and a bit of a try. Many have found them quite helpful. Meditation and visualisation are what you put into your mind. Relaxation is how you relieve the stress of your body and mind. Food is the 'what' you put into your body, the building blocks. To care about these things is to put you in a position of advantage in caring for yourself and, I believe, stunting the growth of any lurking cancer cells. I also believe they add significantly to our quality of life, both health-wise and in giving you a sense that you are actively involved in a plan to deal with your disease, of being in control.

### ***Meditation\****

Meditation, relaxation and stress relief go hand in hand. The important thing to remember is that you don't have to sit at the feet of a Guru to learn to meditate. Some like to make it complicated but it is really very simple. It is like *positive daydreaming*. It can be learned easily and quickly and can be done in any comfy chair or pleasant surroundings. Of course there are deeper levels but you don't have to get into them. The following is a one page printout that I have given to some blokes who have been diagnosed with prostate cancer. They tell me they have found it helpful. My wife, Margaret, and I certainly have.

---

\*The Cancer Care Centre (see page 46) conducts individual and corporate meditation classes many have found helpful. They also have an extensive range of books and tapes.

## Steps for body relaxation and meditation

- 1 Start with some deep even breaths.
- 2 Relaxation — start with feet and ankles — tense your muscles then slowly release them:
  - calves and knees
  - thighs and buttocks
  - pelvic area, stomach and chest
  - back: lower, middle and upper
  - hands and arms
  - shoulders and neck
  - throat, jaw, lips, face, eyes, forehead and over the top of your head.
- 3 Visualise the healing that is going on in your body.
- 4 Visualise 'that peace of God,\* the peace that passes all understanding' descending upon you, like a cocoon:
  - to quiet your mind,
  - relax your body,
  - and bring a deep, deep calm to your soul.
- 5 Meditate on the Love — Grace — and the Compassion of God.\*
- 6 Take your consciousness to your body, be aware of your skin, feel it tingling as your blood is coursing through it, bringing healing; savour it for a moment or two.
- 7 Lock in the residue of this feeling, so it will travel with you.
- 8 Open your eyes when you feel ready (there is no hurry).

*Take it slowly and pause along the way, repeat sections where you want to slow down. Let the thoughts conjure up images in your mind, feel comfortable with them and let them linger.*

*\* If you wish, the exercise is just as effective as a meditation if you prefer to drop the word 'God' from the text.*



## *Visualisation*

Another aspect of meditation is visualisation. Visualisation puts the doctor inside you in a position of advantage in the most simple way. There are no secret formulas. It is simply a way of life that sees beauty in the ordinary; peace descend in the midst of chaos; hope, kindled in the midst of despair; and dark clouds turned inside out.

The following sample exercises look at life 'totally'. Our whole being is made up of body, mind and spirit. By spirit I mean the essence of who we are, that part of us that is the source of our emotions, our hopes, our dreams.

The way these three work together is illustrated graphically by what I call the Dodger Dobbs Syndrome. I grew up with Dodger. We played football together in a country town. If Dodger had a good game he would strut off the field with great style, no matter how many hard knocks he had received. If our team lost and Dodger had one of his bad days he would develop a severe limp. His 'mind' telling his 'body' that if he limped the spectators and his friends would understand why he played so poorly and feel sorry for him. That made him 'feel' better. — Catch a glimpse of yourself here?

These exercises help you to balance your mind, body and spirit, to align them. Often our mind, body and spirit are at war with each other. 'Why am I too fat?' *The mind blaming the body and depressing the spirit.* 'If only this damn leg would stop aching I could get on and do something.' *An inadequate body calling the tune on my well-being and happiness by using the mind.*

With your body, mind and spirit aligned, in tune, you will find a calm or peace within yourself and with the world in which you live. When this happens healing is enabled.

The body is a magnificent healing organism, growing new cells continually at an incredible rate. We are constantly being recreated, remade. Take the incision of an operation or a skin graft, within days healing has occurred. Our bodies are continually healing themselves. These Alignment Exercises help that natural healing process by providing the maximum enabling environment. That environment is provided by the mind and spirit and puts our bodies in a *position of advantage*. 30% of placebos work the same.

**'Ah, through the open door  
Is there an almond tree  
Aflame with blossom!  
-Let us fight no more.'**

D.H.Lawrence  
'Spring Morning'

***Through visualization***

*'an almond tree aflame with blossom'  
can be the possession of every person.*



*(Putting your whole self in a position of advantage)*

*With the following exercises take your time and let the experience seep into you, let your mind go where it will and linger there.*

*Say the 'Affirmations' three times slowly and thoughtfully. They are a way of counteracting the power of negative images.*

*Here are some sample visualisations from my book "Roses, Dewdrops and a Good Laugh"\*.*

## ***DEW DROPS***

See in your mind's eye sparkling dew drops glistening on rose petals; dew drops hanging from the pendant leaves of trees; like jewels scattered across the emerald grass, dripping from the tips of long slender blades. The sun, just risen, sends shafts of light, they reflect from the drops in a sparkling delight of the early morn. The air is crisp and clean, there is a freshness everywhere delighting all the senses with its purity.

See each dew drop as a cleansing agent in your body. Each crystal clear drop, a symbol of purity and healing. As the dew drops cover the earth cleansing it and purifying it — so they cover you, in a cool freshness, purifying and cleansing your body, taking away the heaviness, the sluggishness of your mind; cleansing and renewing every cell of your body, leaving them pure and sparkling clean. As each dew-studded morning has cleansed and made new the unfolding day, your whole body is cleansed, refreshed and made new for the day ahead. Oh, how you want to share this peace and purity with others.

Repeat three times:

**I am clean -**

**I am pure -**

**I am whole -**

**I am at peace.**

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\* "Roses, Dewdrops and a Good Laugh", available from BL Oakley, 15 Rednall Street, Tea Tree Gully SA 5091, Phone (08) 8265 3446.

## FLOWING WATER

Imagine that you are standing on the grassy bank of a swift flowing stream, high in the hills. The sun is warm, it has been a long walk from the hot dry plains. But now you can smell the coolness and the freshness of the bubbling refreshing water the smell of the soft green grass. Up stream a little is a waterfall, crowned by a rainbow in its mist. Under the fall is a shelf of rock in the form of a seat. You look into the cascading water, it is cool.

The shelf of rock beckons you. Imagine you are there letting the cool water wash past your feet and legs, cooling between your toes. You feel the water gently cascading over your body — you have become porous, the cool cleansing water is flowing through you, through your body, washing between every cell, between every atom, flowing through and through and through you. You begin to tingle with freshness, squeaky clean throughout your whole body; impurities are washed away; blood now courses through your body with life and energy. You feel you are alive, every cell is alive, your body is vibrant with life, ready to live, longing to live, to live the life you have.

Repeat three times:

**I am alive -**

**I am freshness -**

**I sparkle -**

**I am at peace.**

## **A FRESH BREEZE**

Remember when you have stood on a hill top or a cliff, overlooking the sea and a fresh breeze was blowing in your face. You feel the wind ruffle your hair, flap your clothes, buffet you. There is a freshness in the wind. You can smell it bearing the freshness of the sea. It is a long time since you have felt such a freshness in the air as it caresses and plays with your body.

Imagine the wind, in your hair, penetrating through your clothes, drawing from your body the pain and the weariness. Feel it caressing your body — imagine you have no clothes to hamper the caress of the breeze. It plays over your skin, cooling it, refreshing it; drawing from your body the heaviness and lethargy that makes you tired. Your body begins to lighten; lighter, lighter. It blows free with the wind, fresh and pure. The caressing of your body is like a light massage, leaving your flesh tingling, you feel your muscles ripple with the wind, you feel strength entering your body again, a newness, a vibrancy. You are exhilarated.

Repeat three times:

**I feel light -**

**I am free -**

**I am vibrant -**

**I am at peace.**

## **WAVES WASHING AWAY FIGURES IN THE SAND**

You are walking along the beach, shoes off, feeling the sand firm beneath you as waves wash over your feet. You feel the drag as the water rushes over your feet when the waves recede. Ahead you see someone has written and drawn in the sand leaving the even rippled sand scarred with gouges and bumps. You watch the waves wash over the figures and recede, slowly washing them away, leaving the sand smooth and natural again.

Perhaps, your body has been wounded. Pain and anger, or despair may have left gouges and bumps as they have written on your life. Relax — imagine the sea caressing you. Imagine the sea is washing over you, the waves flowing in over you, and as they recede they smooth away the scars, carrying the wounds far, far out to sea. The waves are comforting too, in that they regularly ebb and flow. They are always there, washing, washing, washing, leaving you smooth and clean, firm and strong. You have been washed clean. All the scars have been washed away, gone! You are whole.

Repeat three times:

**The scars have gone -**

**I am washed clean -**

**I am made whole -**

**I am at peace.**

## THE RISING SUN

You are up before dawn and there is a chill in the air, a chill that penetrates your bones. How you long for the sun to rise. Slowly the east tinges with pink, the chill becomes more intense. Then a great red dome slowly appears as it edges its way above the distant horizon. As the first shaft of sunlight strikes you, you can feel the warmth. Slowly those first rays bring a warmth that penetrates and saturates your whole body.

Feel that warmth on your cold skin, it feels like a glow as the first rays touch your skin. Feel the chill in your bones — your stiffness and tensions begin to melt and relax as the sun sends its warm healing rays to play over your body. Remember the cause of that chill, the tensions, the hurts, the pain and feel the sun's rays penetrating your body, warming. The warmth and the purity of the sun shines into your body, purifying it, leaving it aglow with freshness and vibrancy. The healing warmth of the early morning sun has saturated your whole being. The chill is gone. You radiate. You radiate your warmth to others. You now embody the warmth of the sun.

Repeat three times:

**I am warm -**

**I glow -**

**I radiate -**

**I am at peace.**

## *Good food*

Our bodies need food. The food we give them greatly determines the health of our body. There is good stuff and there is not so good stuff. Junk foods are a good illustration of the not so good stuff. Obesity and the many health problems related to it are obvious to us. Equally obvious ought to be those who have a good diet, but strangely they are not. They are just ordinary people.

The important thing to remember is that sensible eating and good eating habits are *healthy* and generally much more important than special diets. But first we want to look at some of the chemical reasons for eating well. For the following I am indebted to Dr Charles Myers in his book '*Eating Your Way to Better Health*'. There are many other options and a much wider range than presented here\*.

Doing *something* about it, however, gives you a sense of being in control and at the very least gives you better health and a good shot at stunting the cancer's growth. More and more research is currently being undertaken justifying a focus on nutrition.

*I do not claim that food and supplements are a cure for prostate cancer, but they do put your body in a position of advantage in the fight. Further, I strongly recommend that you tell your health practitioner of any alternative treatments you may be considering.*



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\*For other sources see: 'Prostate Puzzles; by Sandy Weeks, Medical Scientist, E&E Productions, Australia; CaP CURE, a non profit public charity (USA) dedicated to finding a cure for prostate cancer. Visit <[www.capcure.org](http://www.capcure.org)> and search under 'Focus on Nutrition'; and on a wider scale, National Centre of Complementary and Alternative Medicine US <<http://nccam.nih.gov>> .



## *Arachidonic Acid*

Why it may be useful to avoid red meats.

Arachidonic acid is necessary for normal body functions but normally you can get enough through a good diet. Foods such as red meats, dairy products and egg yolks are high in arachidonic acid. Omega 6 fatty acids, especially corn oils and linoleic acids, plant oils are also high contributors. It is suggested therefore that high consumption of these foods may not be helpful.

Prostate cancer cells convert arachidonic acid into hormones, 'eicosanoids'. Of these hormones, 5-HETE, 12-HETE and PGE2 are known to be made by prostate cancer cells and play a role in the growth and spread of the disease. Our bodies need food but the food we give them therefore greatly influences what happens in our bodies.

These hormones can aid the growth of prostate cancer in the following ways:

**5-HETE** stimulates the growth of prostate cancer and assures its survival. In laboratory tests where 5-HETE was blocked from human cancer cells, the cells stop growing and died.

**12-HETE** As cancer grows it needs more oxygen and food hence the necessity for new blood vessels. 12-HETE has the capacity to form new blood vessels (angiogenesis) which are essential to the growth of cancer and the invasion of surrounding tissue.

**PGE2** has the ability to evade being destroyed by the immune system and in turn is very toxic to killer cells and T cells.

The immune system has killer cells and T cells that search out, recognise and kill free radicals and cancer cells. With a Gleason score of over 7 it is uncommon to find them in prostate cancer cells and surrounding tissue. Prostate cancer produces huge amounts of PGE2 — it is the basic way prostate cancer defeats the immune system.

## *Antioxidants*

Clinical studies suggest that antioxidants, whether in supplement or food form, can play an important role in the control of prostate cancer.

- Androgen, a product of testosterone and dihydrotestosterone, trigger the production of hydrogen peroxide.

- Hydrogen peroxide is a major source of free radicals.
- Free radicals are highly reactive elements that damage cells\*, including the cell's DNA in particular, causing the uncontrolled cell multiplication characteristic of cancer.
- Prostate cancer cells themselves have no, or reduced levels, of several proteins important in reducing the toxicity of these free radicals.

Antioxidants work by aiding the conversion of hydrogen peroxide to water and by binding with and neutralising free radicals. Antioxidants are a boost to the immune system.

### *Common and easy supplements*

The following supplements are thought to be useful in controlling prostate cancer cells. They are among the most common and powerful antioxidants.

I have arranged the data loosely in the following sequence:

- 1) what it is
- 2) what it does
- 3) where it is from
- 4) recommended dosage.

#### **Selenium**

- 1) Selenium (a mineral) is an essential nutrient.
- 2) It is the most effective means available in turning hydrogen peroxide into water.
- 3) It is found in the earth in its natural form and some areas are selenium deficient. A significantly lower incidence of prostate cancer is noted in areas that are rich in selenium. You can supplement your intake through taking it in a yeast form, now available as powder or in capsules.
- 4) 200mcg per day for a maintenance dose, 600 to 800mcg the upper limit for a secondary prevention dose. Higher doses can be taken, up to 2000-3000mcg per day but only for limited periods, maximum four months. Higher doses have toxic side effects. (Side effects with extreme high dosage might include dry hair and fingernails, skin lesions and blisters, brain damage and death.)

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\*This action can be observed in a sliced apple going brown.

## **Vitamin E**

- 1) Vitamin E dissolves in fat and is found in your fatty tissue and in globules in your blood.
- 2) It forms a fatty membrane around each cell and in the membrane itself where it acts as an antioxidant by attacking and being attacked by free radical cells. In the process both are neutralised. The greater number of oxygen radicals being produced, the greater amount of vitamin E is needed. In a Finnish randomised controlled trial over five - eight years involving 23,000 men, those taking doses of Vitamin E of 50IU (International Units) were far less likely to develop active prostate cancer (32% fewer) and there were 41% fewer deaths from prostate cancer.
- 3) Capsules are the easiest way to supplement your intake. It must be natural vitamin E (d-alpha).
- 4) Normal dose is 500IU daily. High doses (above 1,000IU) may give an increased risk of bleeding.

## **Green tea**

- 1) Green tea is rich in compounds called polyphenols. One of these polyphenols, epigallocatechin gallate (EGCG), is a potent antioxidant. It is apparent it can not only prevent cancer but, in clinical trials with human prostate cancer cells growing in mice, cause rapid shrinkage and the death of cancer cells.
- 2) It does this by preventing one cancer cell from splitting into two and therefore halts the growth, especially the cancer line DU145, which is most aggressive and therapy resistant.
- 3) Normal green tea contains EGCG but it oxidises rapidly when exposed to the air. Vitamin C will prevent this; a little lemon juice adds to the flavour and prevents the oxidation. Then either drink immediately or chill quickly for cold tea.
- 4) High doses, such as 10 cups per day contain enough EGCG to affect prostate cancer cells. You can get extracts with reduced caffeine content from some health food shops. Doses as high as 1,000 milligrams a day have had no reported side effects.

## **Quercetin**

- 1) Quercetin is a chemical found in plants and is a powerful antioxidant shown to prevent damage caused by hydrogen peroxide.
- 2) Bcl2 is a protein found in many cancer cells that allows cancer cells to escape death during radiation therapy, chemotherapy and hormone therapy by producing abnormally large amounts of this protein. Quercetin reduces the amount of Bcl2 in the cells. It also blocks the development of the mitotic spindle that causes the cancer cells to divide in two and so replicate.
- 3) Quercetin is present in many fruits and vegetables. Rich sources include strawberries, raspberries, broccoli, chocolate, red wine and red and yellow onions. White onions have a low content.
- 4) Use the above foods in your diet.

## **Lycopene**

- 1) Lycopene, of the carotenoids, is the most effective antioxidant. It has red pigment instead of yellow, as with other carotenoids.
- 2) Lycopene is an antioxidant that fights free radicals in the body and repairs damaged cells. One study (Harvard School of Medicine, 47,894 men) indicated 35% reduced risk of prostate cancer and 47% reduction of advanced and aggressive prostate cancers. In another cell culture study, lycopene combined with Vitamin E prevented the growth of cancer cells.
- 3) It is found in tomatoes, watermelon, guava and red grapefruit. Its most concentrated form is in tomatoes where it is contained in little sacks that are not easily digestible. Cooking (heat) breaks down the sacks. The cheapest most concentrated form is in tomato paste.
- 4) A 8oz glass of tomato juice or V8 every morning or 10 tomato based meals a week would be an appropriate intake. A teaspoon full of tomato paste twice a day together with other tomato dishes will help reduce the risk of cancer and metastatic development. (Leggo's is quite palatable to the taste.)

## **Chocolate**

- 1) The most important component of chocolate is cacao liquor, which gives it its dark colour, flavour and aroma.

- 2) Cacao contains steric acid. In one of the largest studies of diet and prostate cancer close to 15,000 physicians were involved. Those with the high level of steric acid had a 70% reduction in the risk of metastatic cancer.
- 3) Plain dark chocolate is a good form to take it or cocoa drinks with low fat milk. The popular chocolates are full of milk and sugar and best avoided.
- 4) Two or three squares a day is better than having a binge on chocolate or perhaps a cup of cocoa before bed.

### **Soybeans and genistein**

- 1) Soybeans contain a rich quality protein that is low in saturated fat and cholesterol free. They contain chemicals called isoflavones that act like female sex hormone, estrogen. They are called phyto-(from plants) estrogens.
- 2) In men a hormone (HL) released by the brain stimulates testosterone which feeds prostate cancer, estrogen turns it off. However a man would have to eat 1.5 to 2lb of soybeans a day to get enough. Genistein, an isoflavone of the highest concentration, is found in soybean. Cancer cells need oxygen and food from new blood cells to develop (angiogenesis) or they stop growing. Genistein prevents cancers from forming new blood vessels. Prostate cancer cells are capable of self-destruction. This can be triggered by the removal of testosterone by surgery, radiotherapy or chemicals. Genistein, in high concentrates, can also cause this to happen and slow the growth of cancer.
- 3) The source of all this is the soybean and its many food derivatives. One such is a drink Ecogen 851. (I do not know if it is available in Australia.) Another is Genistein capsules.
- 4) Dosage of these is unknown but it is thought that a dosage from 500 - 1,000mg would be necessary to make any difference to advanced cancer. However 30-40mg of genistein a day from a soybean food source could be a daily preventative dose. The following suggestions are approximate:
 

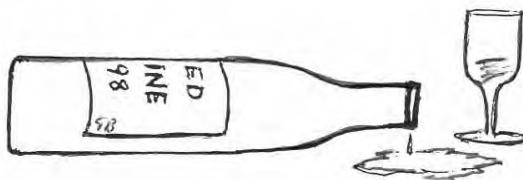
50gm of whole soybean	50gm of soy flour
50gm of roasted soy	50gm of green soy
50gm of soybean flakes	225gm of soy tofu
100gm of miso paste	2 cups or more of soy milk

*Research is beginning to be done on soy but to date no human randomised trials on the efficacy of genistein have been held. In Japan men are as likely to develop latent prostate cancer as men in the West, but 80% less likely to develop metastatic spread. When Japanese men move to the West, however, and adopt a Western diet, they are equally likely to develop metastatic spread as Western men. **Trinovin**, a natural dietary supplement made from red clove also has genistein and other isoflavins.*

## **Red Wine**

It contains compounds known as epicatechins and catechins that account for the anti-cancer activity, the same as green tea. It also contains quercetin. A glass or two in the evening is pleasant and healthy.

The above is a brief summary of the book by Charles E (Snuffy) Myers Jr. M.D. '*Eating Your Way to Health*'. Published in 2000. As a summary it is consequently inadequate for a full treatment of the subject matter.



## ***Try your own simple recipes***

I first thought that I would include some simple recipes and menus but, as I looked over some of the recipes in a number of books I have, I decided that I would be just churning out another 'Cook Book'. That we don't need. You probably have a number yourself. Instead I want to give you some hints on what foods you can use and how you can make use of them and then rely on your own creativity and experimentation. *Remember you are looking after your body so your body can look after you.*

**Fresh lively salads:** There are many good and interesting combinations. Here is a list:

all kinds of canned beans	all kinds of sprouts
all kinds of lettuce and cabbage	onions (red preferred) or spring
peppers	cucumbers
carrots (sticks or grated)	beetroot, raw and grated or canned
tomatoes	corn, canned or on the cob
apples and most kinds of fruits	parsley/walnuts/dill
zucchini	turnip (grated)
spinach (shredded)	peas, green or snow
green beans (sliced thin)	cauliflower/broccoli (finely chopped)
raisins/celery/nuts...	and try some noodle salads.

For dressings try extra virgin olive oil and balsamic vinegar or fat reduced mayonnaise.

*As you can see, there is plenty to work on, and it is all good for you.*

**Soy:** How to increase your intake of 'Genistein'.

- Try the frozen foods, 'soy burgers'
- Tofu, especially good in a stirfry.
- Soy milk, have a glass every morning and evening or on your breakfast cereal.
- Soybeans, canned or dry (canned is easier). There are some good recipes for soy (meat) loaf and soy burgers. Look for recipes that have soybeans as their base.
- Soy ice cream.
- Soy nibbles.
- Soy flour. You can buy it in bread or if you make your own bread throw in a handful.

Have a look around your supermarket, you will be surprised how many soy products there are.

**Soups/stews:** anything (or everything) goes into the pot. Be a bit experimental. Dullness in an eating habit is your worst enemy. Try different blends and flavours.

**Chicken and fish:** You know what to do with these. Have plenty of fish, deep sea is best but not in batter.

**Eggplant/zucchini:** Experiment with slicing them 10mm thick, spread with olive oil and tomato paste and sprinkle on a little basil and grill.

**The humble potato:** See how many different ways you can eat it, even if mashed is your favourite.

**Lasagnas and pastas (meatless):** The tomato base is good for you, full of lycopene. You can use partly blended soybean in place of mince and you have the best of both worlds. You can also use mushrooms.

**Spices:** Experiment a little with spices, things like basil, oregano, cumin, ginger and coriander. Also make a friend of garlic.

**Desserts:** Enjoy them, but stay away from the 'fatties'. You can't beat fresh fruit or canned/preserved fruit so long as it is in its own juice.

**Juicing:** Is an excellent way to get the freshest fix of good food. Carrots, tomatoes, celery, capsicum, apples, the list is endless... be creative and work out your own mixes.

**Whole grain breads**

**Nuts and seed nibbles**

And this is just the beginning. Have fun and eat well.

**Prostate cancer is such a varied and contrary disease that you should not expect the 'right' diet will prevent you from dying from the disease. What you can expect is that a prostate healthy diet may lower your risk of dying of this disease and if the cancer has spread, may stunt its growth and help you to live longer. Consider your diet coming under the category of 'giving it your best shot', which certainly induces a better quality of life.**





# *The Big Four*

## *Four: Preparing for life's great transition*

(Some practical information for survivors and their carers)

This brings us to the last of the 'Big Four'. There are many things that can contribute to the 'quality of life' as you prepare for the latter stages of your life. Most people joke that it would be nice just to fall over dead but in reality most of us would prefer to know that we had everything under control before we die. In my conversations with others, to do so relieves an immense amount of anxiety and they feel they can make that 'great transition' in peace.

This section deals with *palliative care, final preparations, the grieving process and care for the carers*. These are things we think about. To have them under control in some way adds to a satisfying quality of life, even in the latter stages.

Some resist thinking about such things because they feel it is morbid or too sad and emotional. There is a deep sadness there, of course, but dying is a very natural thing and as much a part of life as birth. We can, if we accept it and plan for it, make it the most important event of our lives; even a beautiful thing. This is true whether we have prostate cancer or are just getting old. As a retired clergyman I have seen many people, religious or otherwise, bring a kind of grace and beauty to their own death that is truly admirable.

### *Palliative care\**

#### **What is it?**

**Euthanasia?** Palliative care has nothing to do with euthanasia. It has to do with making you as comfortable as possible and caring for your many and particular needs when there is no real prospect of a cure. Its intent is to care for the whole of you: body, mind and spirit.

**When is it necessary?** Sometimes when we have a terminal disease we come to a point where we need special treatment and care yet it is not necessary for us to be hospitalised. Fortunately people who are specialists in this kind of care are available and are able to provide this extraordinary service.

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\* I acknowledge my indebtedness to the Palliative Care Council of South Australia (see page 47) and in particular their booklet '*Palliative Caring at Home*'.

**Where is it given?** Palliative care is mostly given at **home**, which is where most people prefer to die. This is enabled by your doctor, home care services, family and friends and volunteer services. It is also given at a **hospice**, where a professional staff of doctors and nurses care for you. Hospice is also used when complications need special treatment or to give your home carers respite. It is usually possible to return home for your final days. Many have found these services a comfort and aid in their time of need.

**What about the pain?** This is a question that is often asked. In almost all cases pain can be controlled by the use of drugs. Morphine can be monitored in such a way as to control the pain with minimum side effects of drowsiness or hallucinations. At the end you will most likely slip into a deep sleep or coma with your family and friends around you and just drift away.

*'As the morning mist rises at the dawning of the sun, so your spirit rises unto God, who gave it.'*

**What assistance is available?** Generally your local GP can and will still attend to you. Palliative care also provides specialist consultative care including practical physical support, counselling, coordinating and supervising care.

The palliative care team consists of doctors, nurses, social workers and volunteers. They can also call on other professionals, specialists, physiotherapists, dietitians, clergy etc.

There will be costs attached to many of the services. Ask about them and if you are having difficulty a social worker can assist you. There are also many services that are provided by the government that are available at little cost for pensioners.\*

### **How do I organise palliative care?**

- Contact your nearest palliative carer service.
- Talk to your local GP.
- Contact the Palliative Care Council of South Australia, 202 Greenhill Road, Eastwood 5063. Ph 8291 4137. They also have a good supply of comprehensive literature and brochures that you may find helpful. I recommend you read them carefully.

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\* See section 'Caring organisations' pages 46-47.

## ***Putting Your Affairs in Order***

### **Power of Attorney**

You may want someone to be able to manage your affairs, bank accounts, bill paying, etc. if and when you are unable to do so yourself, either through illness or travel. You can choose whomever you would like, providing they are over 18 years of age. Things to consider are their availability, that is, local is more convenient than interstate; someone with whom you feel confident, knows you well and would have your best interests at heart, such as your partner, a child or a good friend. (This criteria is the same for all the following categories.) A solicitor, accountant or Public Trustee can fulfil this role also but there will be a charge.

This can be arranged through Information SA, Ph 8204 1900 or any solicitor but you would have to pay for their services.

### **Enduring Power of Attorney**

It has the same application as Power of Attorney but the patient must have lost the mental capacity to make decisions.

This can be arranged through Information SA, Ph 8204 1900 or any solicitor but you would have to pay for their services.

Also a do-it-yourself Enduring Power of Attorney Kit, available from Legal Services Commission. *No one else can make an Enduring Power of Attorney for you. You must do it yourself while you are of sound mind.*

### **Enduring Guardian**

This means the named person can make lifestyle decisions which include:

- medical decisions
- where you live, if different from your present situation
- who may see you.

*The Enduring Guardian has no authority to deal with financial affairs.*

Details are available from the Office of the Public Advocate, 85 North East Road Collinswood. Ph 8269 7575 or 1800 066 969 (free call).

## Medical Power of Attorney

This allows someone else to be your 'Medical Agent'. This agent may say 'yes' or 'no' to treatment but cannot refuse food or water or drugs that may reduce pain or treatment that may make the person well enough to make their own decisions. They can also act on your wish for any medical treatment you may want or not want if you have written it out for them. This person cannot be a health professional who is involved with your care. This one and the one below, 'Anticipatory Direction', deal with 'pulling the plug' on life support if you are in a last stage of a terminal illness or a permanent vegetative state or reviving you if your condition is terminal and you have had heart failure for example.

You may organise a 'Medical Agent' by filling out a Medical Power of Attorney '*Schedule 1*' form. This form is available from:

- Information SA, Ph 8204 1900
- Department of Human Services, Ph 8226 8800
- Palliative Care Council of South Australia, Ph 8291 4137
- Department of Veteran Affairs, Ph 1300 550456 (free call).

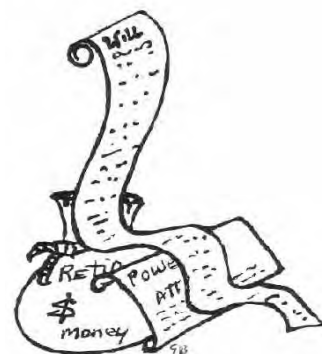
## Anticipatory Directions

You can also write down your wishes rather than have a Medical Agent. To do this you fill out '*Schedule 2*' form of the Medical Power of Attorney. This is also available from the above sources.

This may all seem very confusing. I suggest that you see someone or phone the Department of Human Services, Ph 8226 8800 and tell them your situation and your needs so they can explain to you what is available and what may best suit your situation. They can also tell you how to go about it, where to get the forms, who has to sign them, etc.

## Wills

A will is a legal document setting out how you want your assets and belongings distributed after your death. Otherwise your estate is shared out according to a formula in legislation. This may not be what you want. You can also state in your will who you want to be the executor and trustee of



your will, it can be one or several of your family members. This means that they can handle the paper work without extra legal costs. This and other legal and financial matters and wishes are important to be clarified.

A social worker can help with this or for about \$150 a solicitor can draft a simple will.

The Public Trustee prepares a will at no cost but will take 4% (approx) commission of the assets held in your name. They will also act as the executor of your will and do all the paper work and distribution of assets. For appointment with the Public Trustee, Ph 8226 9204 or 1800 673 119 (free call).

### **Getting Things in Order**

**Banking:** You may find it helpful to make sure you have your banking set up in a way that will make it easier for your partner to make the transition with your finances. A conversation with your bank manager should help you get this right.

**House maintenance:** Like me, a lot of men I know like to have things set up for their partner, this especially includes things like having the house and car in good repair, 'so she won't have things to worry about when I'm gone'. This is something you can start on early, like getting the house painted, gutters fixed, security arrangements in place or whatever it is that you feel would have 'things in order'.



**To have all these things in place can give you a feeling of confidence and you can be at peace with yourself. This enhances your quality of life. Worrying or just leaving things undone can only become a burden. Don't be afraid to ask for help from others. There are many people and organisations willing and competent to help you.**

## *The Grieving Process*

As a part of every culture in all of history there have been ways in which people have grieved for those who have completed their lives. These rituals and forms have varied greatly but they all have the same purpose. That purpose is to release the grief and sorrow so that those who are left can move on into the next part of their lives, knowing that they have given due respect and expression to their own feelings and emotions and due respect to their loved one as they have prepared them for the next world. When this does not happen there is a heavy burden that lays on the soul of the bereaved. This burden can turn into neurosis, sometimes so serious and debilitating that it does not allow people to move on. We have all seen people who have not been able to let go of their loved one in a healthy way.

**Some key elements in the grieving process are:**

**Acknowledge that death is death:** It is a final separation, a severing of the cord of this life. Sometimes we make efforts to suggest that death is not real. Some American undertakers have made a fetish of this, at great expense I might add, with elaborate make up on the deceased, more than elaborate coffins and graveside surroundings that suggest that the deceased is not buried in the raw soil, mother earth. Fortunately in Australia this is not generally so, tastefulness being the main concern.

**A time of celebration:** It is a time to celebrate the *life* of the one whom death has separated from us. A life that has been lived over many years, rich in experience, been full of highs and lows, gifts and non-gifts, a life that has touched our lives in profound ways. It is this unique life that we are celebrating and being thankful for. A funeral service should be an occasion for such a celebration.

**No shame in our tears:** The funeral service also gives opportunity for mourners to shed tears together, to be comforted by friends and those close to them. There is no shame in our tears, they are a sacrament of our love. There needs to be this letting go of the floodgates of our grief.

**The return:** With friends and loved ones there needs to be a time of reflection together. A time that eases us back into the normal. The cup of tea and sandwiches after the funeral is a very valuable part of this. As are friends dropping in to see how you are going or helping you sort things out.

## **Before**

A lot of the grieving process can happen together, before the time of death. With a terminal illness it can be helpful to together reflect on your life, to celebrate it together, to rejoice in the good and affirm your forgiveness for the times you may have hurt each other. There will be times you have struggled and together have come through, there will be times of high joy, fulfilment and satisfaction. Relive them together, celebrate them, so that in the end you can both say, 'My life has been full and I am thankful'. Then you can say your goodbyes with a glad heart, even though it may be a little tearful.

## **After**

As a carer you may have reactions which can be unpredictable and seem quite alien to you, even though you thought you were prepared. These can include anger, anxiety, depression and certainly relief, which can then be followed with a sense of guilt. They are all natural but can be quite frightening, especially if you think you shouldn't have them. It is important to have some way to express your feelings and it is an important time to have someone support you while you grieve, someone with whom you are not afraid to share these deepest feelings. It is likely that you will need to talk about these feelings and get them into perspective so you can understand them.

It is also an important time to look after yourself physically, making sure you have enough to eat and enough rest. You may only be able to cope with the basic things at first. Leave big decisions until later.

If you are a member of a palliative care service they will offer bereavement care in a variety of ways including counselling and a support group.

Remember, your feelings will be real and very important to you. Nevertheless there is a new reality present for you that you must accept with an open heart. In doing this you are honouring your loved one, honouring their love for you.

## **Funeral arrangements**

**Your own send-off:** One of the opportunities that a terminal illness gives is for you to plan your own 'send off', your own funeral. If you have a partner or family you are able to plan it together. Some may not care to think about it but there is a sense of satisfaction in being able to contemplate what will take place at your own funeral. The life celebration *you* want. I think it is also helpful to do this early. If you wait until the later stages it may become too emotional.

Things that can be talked through and planned are:

- Singing, if you want it, what hymns and/or songs you would like?
- What Scripture readings or other readings that may have meant a lot to you?
- Who would you like to take part in the service? Who to give the eulogy?
- How you would like to celebrate your completed life?
- You may even want to write something yourself, as a kind of last word to your family and friends and have it printed or read at the service.

*Talking these things through and making the appropriate plans is an excellent therapy and preparation for your 'great transition'.*

**Funeral directors:** Another aspect is to decide on the funeral directors. Most funeral directors are very sensitive and do an excellent job. They provide a form of counselling as they make the arrangements with you. They also pick up all the arrangements that have to be made, death notices, newspaper notices, flower arrangements; in fact all the things that need to be dealt with. On that score you will have little to worry about.

**Costs:** A simple funeral typically costs from \$2,500 to \$5,500. You may wish to arrange for a 'pre-paid' funeral. This can be arranged with any of the major funeral directors. You may wish to phone several to find the arrangements that suit you best. One thing to watch out for is those who advertise for cheap funerals. At first glance they may look to be considerably cheaper but I have found that what they quote is for the basics, coffin and service. When you add on the extras they are not so cheap. Suffice to say, you should check the details.

## ***Care for the carers***

### **Who is a carer?**

A carer is someone who provides care and support for their partner, someone who is very ill, frail or aged, has a chronic mental or physical illness or has a disability. The task may include bathing, dressing, toilet, medication, supervision, shopping and responsibility for financial matters.

There are 2.3 million carers in Australia which represents about one in every five households. Because it can be constant and taxing, carers often experience frustration, isolation and even ill-health. There are many organisations that can assist carers with financial help, Meals on Wheels, home help, home maintenance and modifications, home nursing, palliative care, counselling and respite care.



## **Financial support**

There are numerous ways in which carers can receive financial support, particularly if the carer is a wage earner or needs some of the help mentioned in the previous paragraph. For advice on your situation contact Carers Association of SA Inc on 8271 6288 or 1800 242 636 (free call).\*

## **Taking care of yourself**

It is of the most importance that you take good physical care of yourself, for your own sake and the sake of the one for whom you are caring. You will get very tired. It is important to eat well and regularly, take regular exercise and get plenty of rest and sleep. These three can very easily get put aside until later but the later never comes. It is also important to keep a regular check with your GP and talk to them about your caring role and the demands it is making upon you.

## **Caring for your inner self**

There will be times when you will not understand your moods. Times when you will get grumpy and angry; angry at why you have to cope with it all. Stress, anxiety and emotional tiredness will overwhelm you. You may become depressed from time to time and you may be overcome with guilt. You may feel afraid that you cannot cope. Feelings of sadness at the loss of a relationship may assail you. With the continual grind you may just feel numb. Even the happy times don't lift you and little tasks take too much energy. You may need to be prepared to learn some new coping skills.

There are many problems that you may have to deal with and are at the heart of why you need to take care of yourself. It is important, therefore, to find ways to regularly get some distance.

- Take a break - ask for help to do this - respite care is important and can be arranged through the Palliative Care Council or Carers Association.\*\*
- Have someone to confide in, things you can't raise with your family or friends, such as a pastor or counsellor.
- Learn to relax, meditate.\*\*\*
- Have interests outside your care responsibilities.

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\* I am indebted in this section to material from the 'Carers Association of SA'.

\*\* See list on 'Help for carers at home' page 47.

\*\*\* See section on 'Meditation' page 16.

# *A Carer's Story*

*The following story is from Margaret, my wife, a carer. It may seem a little dramatic in places, for the journey I had was not usual for a radical prostatectomy, in fact only about 1% of cases. The story, however, serves to give a human face to the role and the stress of being a carer. This took place in 1994. This is her story.*

'...cancer confirmed, what now? Things were moving quickly — we are both practical people — that helped as the medical conveyer belt started up. But we also called on our inner resources, our belief in a universal God, prayer and meditation were very helpful. We can handle this, I have known illness, we know how to make this a positive experience... desperation!

The lead time to the operation was short, less than a month. Six weeks from the first suspicion to operation day. Moving in the fast lane. The decision to go with surgery was made with the view of giving it our best shot. The conviction that we both needed to prepare our bodies, minds and spirits, was acted out in attention to diet, exercise, reading, learning and researching all that we could. This included incontinence, impotence and an understanding that life must go on. Our commitments to our congregations needed to continue — some of that was hard. Barry cared for three dear people who died of cancer during those six weeks... but we both found that the love we received through the folk of our churches we could recycle and give out where it was needed. That was a very important fact.

You might be saying that this is Barry's story. Yes, but it was very important for me to be there, at doctor's interviews, to read the books and to share in the prayer and meditation, to talk to some of the helpers. Only Barry could have the operation but I had to prepare myself also.

The day for admittance came, we were as prepared as we could be... it was time to allow the decision we had made to be acted out. Barry went into hospital, I was to spend three days with his sister, Peg, who lived near the hospital. It turned out to be three weeks! I sensed that the operation was big but successful. I could only visit, watch and pray and keep the family and friends informed.

My role as a carer was seriously tested. Barry had several complications following the operation. I needed to be at the hospital much more than I

had anticipated. He was out of high dependency (1-C) for the second time, having lost his catheter, when a nurse rang one morning to say that Barry had asked if I could go in all day. What a pleasant surprise, he must be feeling much better! I waltzed into the ward about 10.30 am with books and flowers. Barry was sitting out and I was thrilled, until I looked at him. He was grey, slumped in his chair and gasping. I called the nurse, she was right there making a bed. Immediately the medical machine went into action. Oxygen, doctors running, all kinds of technology wheeled in and out. I just sat on a chair out of the way. One asked, 'Who is she?' 'Wife! Oh! No!' I thought Barry had had a heart attack. A friend came in and we talked quietly in the hall watching Barry through the glass to see if he was still breathing, we thought that was important. Eventually I was told that they suspected a clot on the lung, Barry was taken away for X-rays.

I do not remember having lunch that day, but about 2.30 pm I decided I needed help. I phoned friend Maysie, she is never home, but she was. Can you come NOW? Yes. Then I phoned Dr Bruce, a friend, even though I knew he wouldn't be home I could speak to Helen. Well, he was, he had an infected thumb. I cried on his shoulder, over the public phone! He listened carefully, asked questions, then gently said, 'Margaret, what we have is some medical information. As soon as they can the doctors will tell you what it means for Barry. But I believe that as Barry is still with us he will pull through', and he patted me kindly on the shoulder, over the phone, and assured me of his love and prayers.

I raced back to check on Barry's breathing and found he was back in 1-C. Staff were very busy caring for him, apologies were made that there was no spare staff to care for me. Soon Maysie arrived, we sat for a while, walked for a while, drank coffee, and I shared that the resident urologist had told me in the midst of all the confusion that there was a pathological indication that the cancer had spread outside the prostate. I asked Maysie not to repeat this to anyone. I felt we didn't need to deal with that right now. I went back to Barry, he was on oxygen, he pulled the mask aside and gasped, 'Margaret, I think it's time to call out the troops.' Many people were called to prayer that night. By the time I left the hospital at about 9.30 pm I was reasonably confident that Barry would indeed pull through. But the doctor said, yes, I should call the children, they needed to know. That was hard. It was Kathy's birthday and she was devastated. Even though it had been a horrendous day — I had picked up a parking fine as well — I had a deep conviction that this was not Barry's time to leave us.

It was not at all plain sailing after that but there were no more major setbacks. Further pathology revealed that signs outside the prostate were minute, just a microscopic speck. Not to worry! But I had worried. In fact to a degree that almost made me physically sick. So gradually the adrenalin subsided and the decision to care through the healing process had to be made all over again. I was in for a few shocks. I was shocked by Barry's weakness, it went on for weeks, so tired in body, mind and spirit. It was draining. I was shocked at his ignorance of hospital procedures, things worried him that I had experienced 40 years ago. Having babies really robs you of modesty. And I was shocked because Barry was acting like an old man, worried, fearful, tentative. It took time for me to realise that these were normal recovery symptoms even for Barry. I kept expecting him to snap back to his old decisive self but he seemed to keep coming up with new things to be anxious about.

I was not a great carer, on the way home from hospital I hit every pothole in the road. Some weeks later we went for a drive and I took him over a very corrugated dirt track. He nearly lost his catheter again. Oh! How tired I got. I would sleep through all Barry's tossing and turning and groaning. But though I did have some reaction to all the above I did not get sick and I can now say this extra ordinary journey has been a blessing.

Some of the things I have learned through this time are:

- To leave my own anxieties outside the door when being a carer.
- To find ways to express encouragement and hope.
- To keep a peaceful atmosphere, especially when a new trauma erupts.
- To find my own space, you can't continually live in another's space.
- To have my own network of support, especially if the caring role goes on for an extended period.
- To rehearse that right now this is my job, my vocation. Anything else can wait.
- To rehearse, several times daily that God is with me continually, I am given the strength I need. And I was. And I am.'



# *Community Support\**

## *Caring organisations*

**The Cancer Council South Australia**  
(08) 8291 4111 or 1800 188 070  
(free call)

**Cancer Help Line 13 11 20**

**Cancer Care Centre**  
(08) 8272 2411

**Carers Association**  
(08) 8271 6288 or  
1800 242 636 (free call)

**Relationships Australia (SA) Inc**  
(08) 8223 4566 or 1800 182 325  
(free call for country callers)

**National Association for Loss & Grief**  
(08) 8411 3124 or 8300 0095

**Crisis Care 13 16 11**

## *Peer support*

**Prostate Support Awareness (PSA)**  
Adelaide: (08) 8333 2858  
(Gerry McCreanor)

Northeast: (08) 8261 1004  
Barossa Gawler: (08) 8564 2015  
Port Pirie: (08) 8638 4693  
Berri Barmera: (08) 8588 0420  
Onkaparinga: (08) 8382 6671

For other regional support groups  
contact: **The Cancer Council  
South Australia** on (08) 8291 4111  
or 1800 188 070 (free call)

**Cancer Support Fellowship Inc.**  
(08) 8271 6817

**Cancer Connect**  
(08) 8291 4111, or 1800 188 070  
(free call for country callers)

**YANA**  
an on-line prostate cancer support  
group: <[www.yananow.net](http://www.yananow.net)>

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\* Whilst the names and phone numbers in this section are for South Australia, the same names, or similar, can be found in each State phone book.

## ***Professional help***

Professional help should be available from each of the following. Be sure to have your lists (preferably written out) with all the questions you may have.

### **Your GP**

#### **Urologist**

A second or third opinion is quite in order.

#### **Department of Veterans' Affairs**

(08) 8290 0555

#### **Counsellors**

From Carers Association  
(08) 8271 6288 or 1800 242 636 (free call)

#### **Legal**

Your Solicitor  
Legal Services Commission:  
1300 366 424 (free advice)  
Public Advocate:  
(08) 8269 7575  
Public Trustee:  
(08) 8226 9200

#### **Consent to medical treatment and palliative care**

Department of Human Services: (08) 8226 6436

#### **Internet services**

The Lions Australian Prostate Cancer Website  
< [www.prostatehealth.org.au](http://www.prostatehealth.org.au) >

## ***Help for carers at home***

### **Meals On Wheels**

(08) 8271 8700

### **Domiciliary Care Services:**

Eastern (08) 8222 1796  
Northern (08) 8182 9277  
Southern (08) 8277 3366  
Noarlunga (08) 8384 9277  
Western (08) 8222 8000

### **Domiciliary Equipment Service**

(08) 8285 3266

### **Independent Living Aids**

(08) 8271 9251

### **Home help**

(ask at your local Council)

### **Palliative Care Council of SA**

(08) 8291 4137

### **Respite**

(call Palliative Care)

### **Royal District Nursing Service**

1300 364 264 (24 hours)

### **Carers Association**

(08) 8271 6288 or  
1800 242 636 (free call)

### **Transport**

Red Cross Transport  
Services: (08) 8267 7666



## About The Author

Barry Oakley, like many men, has had to face those words, 'You have cancer.' This prompted him to write '*There's Some Good Years Left Yet*' a story of hope for all those men and their partners who have also had to face those words. His second book, '*Life's In The Pink*' looks at how to maintain a quality of life while living with this chronic disease.

Barry was raised to be a Mallee farmer. He grew up knowing about droughts, rabbit plagues and dust storms, as well as the triumphs of 'bumper crops'. All through his life's journey of service he has retained the ability to speak easily as 'one bloke to another' and has used that ability in his writing.

His book is refreshingly honest, open and frank, dealing with those hidden fears and emotions that are most often skirted.

**'Your cancer never goes away, it's like it is on the end of a big long rope that is attached to the back of your head. It stretches way back and a lot of the time you don't even think about it, it's just there. But then, when you go for your PSA test or a new pain starts up, (as you get older they seem to become more frequent) it is like it is on a big spring and *wham!* There it is again, right up at the back of your head.'**