



# Cancer – What now?

*A guide for patients, families and carers.*

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## **Feedback for Cancer – What now? DVD**

**From – Louise Bond, Mannum S.A>**

This would have been a great DVD to have had about a year ago when I was diagnosed with cancer. Over the last 12 months I have learnt a lot about cancer, the practical issues and services available, but there is still information on this DVD that I didn't know and found useful.

### **Chapter 1 – You have been diagnosed with cancer, what now?**

Listening to other people's stories helps to validate your own feelings and reactions as 'normal' and helps to understand that you are not alone.

There is no right or wrong way to respond to a diagnosis of cancer and that feelings and emotions can change.

### **Chapter 2 – How do you tell people who are important to you?**

Good advice from counsellor and psychologist. It was reassuring to hear that the approach we had taken with our children was along the right track.

As a patient watching the DVD, I developed a greater awareness of the needs of carers, something that I hadn't given much thought to in the early part of the journey with cancer.

### **Chapter 3 - Learning about cancer.**

The good news in this chapter is reassuring.

Mention is made of asking for a second opinion. This is something that I had never done before and it was my naturopath that brought my attention of the need for me to do so. I wasn't really aware at the time that I needed to. My point here is that maybe there needs to be mention of when a second opinion is warranted and also how to go about getting one. (Asking your GP?) The thought of me telling a specialist that I didn't have confidence in him was daunting but thankfully my surgeon offered to tell him that I had changed oncologists. I was also lucky that my naturopath suggested another oncologist whom I found to be very positive and well respected. I'm not sure how I would have gone about finding another oncologist without a recommendation. Does getting a second opinion/changing specialist require private health cover? I'm guessing that would depend on who you go to for a second opinion. The oncologist I see now would be too expensive to see without private cover so does private cover expand the options of who you can request to treat you?

### **Chapter 4 – Choosing quality health care.**

Interdisciplinary care was explained very well. This is something I learnt about in the early days of my diagnosis. When I changed oncologists, I was a little concerned how this would affect communication between the three specialists I see. I didn't need to worry. Even though they don't all work at the same hospital, the communication between them is excellent.

There is discussion about public and private health care and that collaboration between the two systems is getting better. This hasn't been the case for me. I needed private cover to be able to have the oncologist of my choice and having chemo therapy at a regional centre close to home was not an option because I was a private patient.

### **Chapter 5 – Treatment options.**

Prognosis . This is an interesting one as I did ask my first oncologist but didn't like his answer. I wanted to hear something positive which he didn't offer. When I put the same question to one of my surgeons, he said the statistics are based on hundreds of people and that I was an individual. If he gave me a percentage of survival rate for my situation, this would have no bearing on me as an individual. This was something that I think I was aware of but it was good to hear it from the doctor and helped me to regain a positive attitude. Since this discussion, I've given considerable thought to 'statistics' and who they are intended/useful for. Do they take into consideration, age, general fitness and ways in which the patient is working to improve their own health (e.g. exercise, diet, complimentary treatments etc.)? Maybe there needs to be a chapter for doctors! I've never been offered false hope but doctors with positive attitudes help to make this journey a lot more hopeful, bearable and manageable.

Treatment options. I would love to have seen the footage of theatre before I my first surgery. I had never experienced either and was a little daunted by surgery initially, even though it had been well explained to me.

Listening to social workers, counsellors and psychologists talk about reactions and changes in thinking is reassuring when you've had similar experiences.

### **Chapter 6 – Complimentary therapies.**

As mentioned in the DVD, choosing to take on board complimentary therapy is a way on taking charge. How true. I found by going to a naturopath and the exercise physiologist that I had regained some control over my treatment and life, not to mention the health benefits.

The discussion on exercise I found to be very encouraging. I had been doing some exercise but this section gave me reason to not only continue exercising but also to increase the amount. Since the release of the DVD the web site for the Australian Association for Exercise and Sports Science (AAESS) has changed to <http://www.essa.org.au> (Exercise and Sports

Science Australia). I found this web site very useful to find a practitioner that specialised in cancer rehabilitation.

Finding a suitable naturopath was not so easy. Until we first spoke, I wasn't aware that there were naturopaths that specialised in cancer support, something I feel is very important. (Going to a generalist naturopath would be like going to a GP for cancer.) After first talking with you and then doing some Googling, I found Belle McCaleb. Googling terms such as 'naturopathic cancer care australia' can bring up some useful web sites but I found it difficult to find someone nearby that specialised in cancer support. The web site (I've mentioned to you before) - <http://www.cancersupportalliance.com.au> list practitioners for many different complimentary therapies and may be worthwhile including in the references. (This is a relatively new web site servicing South Australia.) As yet, I haven't been able to find a similar site that details other complimentary practitioners that have a special interest in cancer support.

Listening to the dietician, I heard some contradictions with what I've learnt from the naturopath regarding diet for cancer patients. With reference to cancer patients maintaining body weight and muscle strength, the dietician recommended increasing sugar (e.g. lollies) and adding extra fats and oils to the diet. My diet included eating enough protein and complex carbohydrates to maintain the body and energy levels. I cringe at the thought of being recommending sugary and fatty food to someone whose health is already compromised.

### **Chapter 7 – Who can help me?**

Great information for where to get information and emotional support and what the Cancer Council offers. What I also needed was practical support. More about this later.

### **Chapter 8 – Practical issues**

I've added 'Contact Centrelink' to my 'To Do' list.

### **Chapter 9 – Getting on with your life after cancer.**

Talking about the 'new normal' is something I'm beginning to appreciate and explain to family and friends some of whom seem to think that because I'm starting to do some of the normal things I used to and starting to look healthier, that the old me is just around the corner. This is a particularly important chapter for family and friends.

I plan on doing the 'Staying health after cancer' course later on. I hear from other patients that it is very worthwhile.

### **Chapter 10 – Palliative Care – When cancer won't go away.**

I finally took a look at this chapter and it wasn't as scary as I thought it might be. It gave me some insight to what palliative care is which no longer implies that you're at the end of the road.

### **General Comments and Suggestions**

The format of the DVD was great a good balance of introduction followed by interviews with practitioners, patients and carers. The detailed menu made it easy to revisit chapters or sections of particular interest.

#### **Fact Sheets and Web sites**

The lists of fact sheets available from the Cancer Council and the web addresses are most useful. However, since joining the ranks of the short-sighted, I can appreciate that some people (particularly elderly or unwell people) may find it difficult to copy the details from the TV screen, especially if it's a small screen. On some CDs and DVDs I have, there is also a CD ROM track which can be used in a computer. If fact sheet and web site information was also presented on a CD ROM track, then people could choose to print the information they require and links to web sites could be clicked on to provide immediate access to the site without having to worry about typos. I don't know about the technical details of how this is done, but it could be worth finding out about.

#### **Distribution of the DVD**

The Public Library System which also incorporates Community Libraries (joint use public and school libraries) in regional SA would be an effective way of providing wide spread access. I gather some copies have made it to libraries as a friend on the west coast borrowed it from her Community Library.

#### **Chapter for children.**

My eldest child (12 ½ years) I feel is looking for support and information. Maybe a chapter for children/teenagers would be useful. As you mentioned when we met, it could be difficult having children talk about their experiences (as a patient or as a sibling) on camera. I recently saw a short promotional video for Relay for Life in which a young girl talks about her experience with cancer. If you like, I'll try and get hold of a copy for you. I thought the segment was well done. However, a chapter for children could still be presented by without patients or siblings (as was done for the chapter on palliative care). A chapter for children would also be an opportunity to promote Canteen and other services available for children. E.g. school counsellors, counsellors at the Cancer Council, Headspace - <http://www.headspace.org.au> (a Government established National Youth Mental Health Foundation) and Kids Helpline Kids (Helpline is Australia's only free, private and confidential,

telephone and online counselling service specifically for young people aged between 5 and 25. [www.kidshelp.com.au](http://www.kidshelp.com.au) Like adults, children have to cope with telling their friends and imagining worse case scenarios. Dealing with school work, changes to routines at home and still wanting to do all the normal kid stuff can also be a worry.

### **Chapter for carers, friends and family.**

Some people have trouble coping with a friend or family member who is diagnosed with cancer. Maybe there could be discussion on how to deal with difficult emotions and support that the Cancer Council can offer these people.

I've been so fortunate with the practical support from friends and family. It was difficult to accept help initially but the most effective people in breaking down this barrier were those who offered specific help (as compared to those who said 'Let me know if I can help in any way'). Offers of doing the washing and ironing, cooking meals, making the kids lunches, transporting kids to school, doing my grocery shopping, house cleaning, lawn mowing, gardening were all so much appreciated.

Phone calls, emails, sms messages, cards and visits were also greatly appreciated. Some people said they didn't ring because they thought I'd be getting too many phone calls. I did get too many calls at times but when I needed to, I let the answering machine take the call. An answering machine could be a worthwhile acquisition for cancer patients, especially when first diagnosed and the news gets around or even when time is filled with appointments or just feeling unwell. It's still nice to know that people are thinking of you, even if you can't or don't want to talk to them at the time.