



## **Cancer Strategy Survey Part 2**

### **Results**

**October/November 2010**

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**Cancer Support Association**

*Environment, Wellnes & Healing*

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## **CANCER STRATEGY SURVEY**

### **RESEARCH BACKGROUND**

The “Cancer Strategy” survey is a joint project between the Cancer Support Association of WA and Wire Surveys.

This survey forms the second stage of a two-part survey aiming to develop a “Cancer Strategy” for newly diagnosed patients. The first stage (exploratory) of the project was conducted in June/July 2010 – the results of which were implemented in the development of questions/answer choices for this stage of the project.

The primary objective of the survey was to assist with the development of a “checklist” for new patients to serve as a guide upon diagnosis, and assist patients, carers and their families with decision-making, particularly during the early stages of diagnosis.

### **DATA COLLECTION METHOD**

The Cancer Support Association of WA directed its members to the [www.wiresurveys.com](http://www.wiresurveys.com) website to complete the self-administered questionnaire. The questionnaire consisted of 14 questions (excluding demographic information).

**Total number of participants in this survey: 169**

**Survey Period: 22 October – 29 November 2010**

### **ABOUT THIS REPORT**

The first section of this document summarises the most frequent responses for each of the surveyed questions.

The majority of the questions had an “Other” component for which some participants provided a written response – these are included with each respective question.

Additionally, the survey asked respondents for “Other Comments” at the very end of the survey form – these comments are provided from page 23 of this report. Not all participants provided a written comment.

## **LIST OF QUESTIONS**

### **Question 1**

Upon diagnosis, the most important information given by the GP, or questions to ask the GP, should relate to:

### **Question 2**

When choosing an oncologist, it is important to:

### **Question 3**

When dealing with the oncologist, the most important information to receive relates to:

### **Question 4**

Upon diagnosis, apart from referral to a surgeon or oncologist, it's essential to also be referred to the following health care practitioners:

### **Question 5**

I consider the following as important factors for newly diagnosed patients with regard to non-mainstream health care practitioners in relation to cancer treatment:

### **Question 6**

I believe the following are the most important factors when choosing a counsellor/psychologist to assist with the cancer journey:

### **Question 7**

With regard to treatment and options, I believe the most valuable information and support come from:

### **Question 8**

With regard to treatment and options, I believe the most valuable information and support come from:

### **Question 9**

Upon diagnosis, the most important behavioural changes to are:

### **Question 10**

I consider the best financial advice to give someone just diagnosed with cancer to be:

### **Question 11**

I consider the best financial advice to give a well individual before a possible cancer diagnosis to be:

### **Question 12**

Besides family and friends, the best sources of support during the cancer journey are:

### **Question 13**

For a successful patient-carer relationship, the most important factors are:

### **Question 14**

Ultimately, an effective cancer treatment strategy would involve:



**CANCER SUPPORT ASSOCIATION OF WA**

**CANCER STRATEGY SURVEY  
OCT/NOV 2010**

## **RESULTS**

**SUMMARY OF SURVEY RESULTS**  
**Key responses to questions**



**Cancer Support Association**

*Environment, Wellness & Healing*

## **DEMOGRAPHIC INFORMATION**

(based on 169 responses)

### **SEX**

21.4% **Male**

78.6% **Female**

### **AGE**

0.0% **Under 18**

0.0% **18-25**

4.1% **26-35**

17.8% **36-45**

34.9% **46-55**

27.2% **56-65**

16.0% **Over 65**

### **LOCATION**

82.8% **Western Australia**

4.1% **Victoria**

3.6% **New South Wales**

4.1% **Queensland**

0.6% **Australian Capital Territory**

0.0% **South Australia**

0.6% **Tasmania**

0.0% **Northern Territory**

4.1% **Outside Australia**

*(Canada, Christmas Island, New Zealand, USA, UK, Mexico)*

## **Introduction Question**

**I am a:**

28.4% Cancer patient

16.6% Carer

36.7% Survivor

18.3% Other?

*(All participants who chose "Other" were either family members of cancer patients or health care practitioners)*

## Question 1

Upon diagnosis, the most important information given by the GP, or questions to ask the GP, should relate to (choose as many as relevant):

- 13.9% All treatment options (including pros and cons)
- 12.8% Specific details about the cancer (including “in understandable terms”)
- 10.6% Information re coping with the effects of treatment/surgery
- 10.3% Information on how to deal with the emotional impact of cancer
- 9.4% Direction/information on support groups/counselling
- 9.2% Lifestyle improvement information (inc. diet/exercise)
- 8.8% Prognosis for cure vs. death
- 8.0% More direction regarding specialists to talk to
- 7.4% Direction/information on complimentary therapies
- 5.0% A referral for a second opinion
- 2.5% Information on diminished life expectancy
- 0.0% Don't know
- 2.1% **Other**

*How to talk to your children.*

*To answer questions truthfully - listening to the specific question.*

*A step-by-step handout about what to do next. We were left to leave a public hospital after being told my husband had 12 months at the most. We sat in the car and didn't know who to speak to next. Eventually we drove 30 kms through Perth traffic to a friend's house where we both collapsed very distressed. A person to speak to immediately leaving the Dr would have helped us sort through some sort of plan of what to do next.*

*Can your cancer be managed if no cure?*

*Telling me that there is an exact procedure of how the surgeon will approach things.*

*It is useful for the GP to write down all of the information that they are giving you about your diagnosis and treatment options.*

*More info for carers.*

*Maybe a referral agency that can deal with all the questions as they may be too much for a GP doctor, but let the patient know and let the appointment be quite immediate.*

### **Question 1 (cont.)**

Upon diagnosis, the most important information given by the GP, or questions to ask the GP, should relate to:

#### **“Other” responses, cont.**

*Emotional support is a very important issue and some doctors require a better bedside manner. Referral early on to a counsellor/psychologist is a must (first priority).*

*Which naturopath will he work with?*

*No single topic provided to choose from is more important than another. The GP unfortunately has to feel their way with each individual patient to support their individual needs. For me it was a high level summary of the specifics of the type of cancer (although at the time I thought there was only one type - that being terminal) prognosis vs cure, options, support groups, emotions, timing of getting help, then all the rest.*

*Information about the role and emotional trip for the carer, if relevant.*

*To let you know you have time to think this through. You are not going to die tomorrow so you do have time to gather and absorb information and then make decisions.*

*GP really only to referred to the specialist at beginning. Later would want other things from GP.*

*Much of this should be addressed by an oncologist - GP for follow up and support with late effects.*

*What to expect: loss of toenails, pubic hair, eye lashes. If relevant importantly what side effects of treatment will be permanent, eg bone loss. If I knew then, I would not have had chemo!*

## Question 2

When choosing an oncologist, it is important to (choose as many as relevant):

21.7% Choose one who explains everything simply, yet thoroughly and in detail

20.4% Choose someone with whom you feel comfortable and can talk freely

20.2% Find one who listens and respects your choices

15.9% Ask medical practitioners/friends/nurses for recommendations

14.2% Choose one who is "open" to complimentary therapies

5.2% Take your doctor's advice regarding the choice of oncologist

0.0% Don't know

2.2% **Other**

*Someone who gives you time at your appointments.*

*Choose one that doesn't become defensive when you ask tricky questions. Choose one that is compassionate and treats you as a person not someone with a weighty label.*

*"Traditional" doctors often 'bad-mouth' complimentary therapists without even bothering to listen to the patient. There is often an emotional element for the patient - it's their life they're fighting for. This disregard on the part of doctors can depress a positive attitude toward fighting the disease.*

*A doctor who understands both mainstream and natural therapy medicine.*

*Provides multidisciplinary psychosocial support.*

*Work in conjunction with your GP.*

*Radiation-oncologist or urologist?*

*Speak to other cancer patients and ask for their opinions of their oncologists.*

*The number of successful procedures carried out in a year.*

*The doctor's philosophy about healing/curing. It's important for me to know the truth, but I don't want doctors that play to be God and who give "death sentences" to patients who need hope.*

*If one is a disability pensioner choices are limited - the Cancer Support Association's advice is invaluable in negotiating the "system".*

### Question 3

When dealing with the oncologist, the most important information to receive relates to:

- 25.7% Honesty regarding all information
- 24.3% Information regarding side effects of treatment/treatment outcomes
- 13.4% Information regarding complimentary therapies/treatment alternatives
- 12.2% The time available before beginning treatment
- 11.6% Additional time to make decisions
- 11.1% Information regarding support groups
- 0.0% Don't know
- 1.7% **Other**

*My sister has a wonderful doctor, after meeting a few, who knows both conventional and complimentary medicine and is sympathetic to people who want the alternative route.*

*How the hospital can accommodate those living in the country who have to uproot for periods of time to undergo treatment.*

*Where to seek counseling for the patient and/or family members.*

*Acupuncture, exercise, meditation.*

*All treatment types available.*

*Firstly I should say that as important as an oncologist is they are only one part of a team. The most important member of my wife's team with the primary colon cancer was the surgeon. That said, I feel that the most important information relates to how they will attack the cancer, what the side effects will be and the probability of success.*

*Is the radiologist, oncologist or the urologist the person referred to as "oncologist"?*

*A range and choice of treatments.*

*Second opinions from alternative treatments or mainstream treatments.*

*Information that relates to you, not just a percentage of patients!*

#### Question 4

Upon diagnosis, apart from referral to a surgeon or oncologist, it's essential to also be referred to the following health care practitioners (choose as many as relevant):

23.2% A psychologist/counsellor

23.2% A support group

16.3% A nutritionist

11.1% A naturopath

17.8% All of the above

1.8% None of the above

6.6% **Other**

*A support person specific to the type of cancer.*

*A counselor should be available immediately after diagnosis.*

*Bill Giles Immunobiologist.*

*If possible, this could be the 'second wave'*

*Make people aware of what the Gawler Foundation offers.*

*Neurolink practitioner.*

*Acupuncture and exercise programme.*

*Social worker.*

*All of the above, if patient requests but not essential unless patient chooses any of them.*

*Breast care nurse.*

*It is not ESSENTIAL (your choice of words) however all of the support practitioners have a role to play. At diagnosis the person and their partner probably have too much on their minds to be referred to all the potential help. Later (weeks?) the GP needs to assess what help the person and their support needs and refer accordingly.*

*Doctor of Chinese medicine.*

*Home care groups - plus housekeeping.*

*Would be good if the GP would refer to all of the above, but does not happen.*

*Options and follow up at later appointments - at diagnosis you don't know what you want, but later options should be revisited.*

*Physio, if surgery is involved.*

*Integrative medicine-type practitioner.*

### Question 5

I consider the following as important factors for newly diagnosed patients with regard to non-mainstream health care practitioners in relation to cancer treatment (choose as many as relevant):

- 24.1% Do what feels comfortable/right for you
- 20.9% Conduct thorough research first
- 20.9% Take your time to make decisions
- 17.6% Do a combination of mainstream/non-mainstream treatments
- 11.4% Got to a support group for information first
- 2.7% Follow mainstream treatment only
- 0.5% Don't follow mainstream treatment at all
- 0.4% Don't know
- 1.6% **Other**

*Depending on type of cancer and wellness.*

*Ask your specialist to do research on the same subject as he/she will have a much wider research base to base an opinion on.*

*Time is not always an option - also don't know where to start looking for alternative information.*

*My sister went to a well known complimentary practitioner because of her research but it proved to be contradictory to her pathology (right descriptive word?) and caused her more sickness.*

*Acupuncture, exercise, meditation.*

*Ask lots of questions and check statements.*

*Consult openly with medical professional.*

*Find an integrative medicine-type practitioner.*

*Talk to people who have been there.*

## Question 6

I believe the following are the most important factors when choosing a counsellor/psychologist to assist with the cancer journey (choose as many as relevant):

- 20.8% Is open-minded/non-judgemental
- 20.6% Is empathetic/a good listener
- 18.5% Is experienced in cancer therapy
- 17.5% Has an understanding of cancer
- 17.5% Has a good reputation/comes recommended
- 2.9% Has had cancer themselves
- 1.3% Don't know
- 1.0% **Other**

*Please no new graduates - they need to understand the complexities of juggling multiple roles in life and relationships.*

*Has the ability to help people formulate a plan of action.*

*Can relate to the age and gender of the patient.*

*"Couple Counseling"*

*Not cbt*

*People who have been on the same journey and understand what you are feeling.*

## Question 7

With regard to treatment and options, I believe the most valuable information and support come from:

21.9% Cancer-related organisations

19.5% Other cancer patients

19.1% Oncologist

15.3% Books/Internet

11.4% Surgeon

9.4% GP

0.2% Don't know

3.3% **Other**

*Radiotherapist, support groups.*

*Silver Chain*

*Valuable information comes from various sources.*

*Affiliated staff working in the area: nurses.*

*Particularly cancer patients that have had positive results.*

*Bill Giles Immunobiologist.*

*Support group.*

*CANCERTUTOR.COM*

*Cancer nurses and clinic and/or hospital support staff/counselors*

*Specialist nurses.*

*Those who have healed themselves of cancer [non allopathic self-treatment].*

*Any health professional who is passionate about working in the field assisting patients with cancer related services.*

*Naturopaths and naturopath colleges.*

*Nurses in the cancer treatment field. They are practical, talk and relate to patients and their support and have seen it "a hundred times".*

*Other therapists.*

*Internet.*

*It varies depending on the viewpoint of your health care providers.*

## Question 8

Upon diagnosis, the most important lifestyle changes to are (choose as many as relevant):

- 24.6% Reduce stress
- 18.4% Increased meditation/relaxation techniques
- 17.3% Change diet
- 14.1% Increase exercise
- 11.8% Alter working habits
- 11.0% Attend support groups
- 0.3% None
- 2.4% **Other**

*Lifestyle assessment.*

*Address emotional issues.*

*Whatever makes you feel your most comfortable and happy.*

*With awareness - what do you choose?*

*I think that it can be overwhelming to try to change too much all at once - that can introduce even more stress - it is important to find out what you can do to help yourself heal but make the changes as you feel able to do so.*

*Attitude*

*Experience love from others.*

*Learn coping skills and help to deal with any anxiety.*

*Depends on your capacity.*

*Each individual does what feels right for that individual.*

*Alter mindset.*

*Keep body active in all normal activities but don't get exhausted - rest when the body needs it.*

*Keep healthy, fit and look after yourself.*

*Take offers of help. Get plenty of good quality sleep, even if it means getting sleeping tablets from GP for a while. If you become anxious, see the GP for anti stress tablets for a while.*

*Think positively!!!!*

### Question 9

Upon diagnosis, the most important behavioural changes to are (choose as many as relevant):

- 19.5% Appreciating what was important in life
- 18.9% Developing a positive attitude
- 17.5% Surrounding yourself with positive people, family and friends
- 13.6% Focusing on the present
- 12.8% Increasing meditation/relaxation techniques
- 8.6% Attending support groups
- 7.9% Using affirmations/imagery/visualisation techniques
- 0.0% None
- 1.2% **Other**

*Allow yourself and family to be aware that "down" days are okay.*

*Get in touch with spiritual side of self.*

*Putting yourself first.*

*Making a "Life Map" as the person going through it experiences why their life is worth fighting for and also gives them a sense of accomplishment and an album of love for the ones they might leave behind...also a motivational tool for why life is worth fighting for.*

*Long term goals and strategies.*

*Do what you feel is right at the time.*

*I would change my health care team if I had a PPO, but unfortunately I have an HMO.*

*Try to avoid the negative people. Try to still have a laugh.*

*Believe in yourself!!*

## Question 10

I consider the best financial advice to give someone just diagnosed with cancer to be:

- 29.0% Don't panic/take your time
- 25.1% Living well and healthily can be more important than money in the bank
- 13.7% Seek help from a financial planner so you can focus on your fight
- 11.6% Join a support group
- 7.9% Get private health cover
- 6.0% Be conservative with money/be prudent
- 2.6% Don't use the private health system
- 1.4% Don't know
- 2.8% **Other**

*Financial advice for spouse as well as children.*

*Put your priorities in the right order.*

*We have a great health system.*

*Centrelink.*

*Eat as healthily as the patient can but keep to a budget where possible.*

*Understand your super/income protection.*

*Fight is a harsh word to use.*

*Pre-pay your funeral, plan out all your wishes so you can be at peace.*

*Focus on your health and the rest falls into place.*

*Be aware that you can claim on your life insurance if terminal to assist with financial stress.*

*At the time of diagnosis we had top health cover and no financial worries so I could only guess what to answer this question with, and I will not do that.*

*Don't be too proud to seek help from charity if needed.*

### Question 11

I consider the best financial advice to give a well individual before a possible cancer diagnosis to be:

31.4% Eat as well as you can now (it's an investment)

22.3% Get top health cover/health insurance

22.3% Have income protection/insurance

17.5% Save your money

2.5% Don't know

4.0% **Other**

*Don't worry about anything but yourself and whatever else you need, and love.*

*Have a lifestyle assessment.*

*Have money/investment set aside just to cover an unplanned life emergency.*

*Exercise! Meditate!*

*I wouldn't give financial advice.*

*Remove stress and anxiety, it can kill you.*

*Income protection is probably more useful than private health insurance, because this will enable you to take time off work to cope with lifestyle changes and stress. Treatment will be covered adequately by the public health system.*

*You can't live your life as though you're going to die tomorrow.*

*Spend money on critical nutrients.*

*Make the most of everyday.*

*Live a balanced life and be happy.*

*Meditate and live in the present; de-stress.*

*Do not get into debt, insure mortgage for loss of income.*

## Question 12

Besides family and friends, the best sources of support during the cancer journey are:

22.9% Cancer-related organizations

20.3% Other cancer patients

15.0% Myself

14.4% Books/tapes/internet

12.4% GP/medical practitioners

11.9% Church/faith

0.4% Don't know

2.7% **Other**

*Silver Chain.*

*Support group related to my cancer type.*

*Alternative doctors.*

*The nurses.*

*Bill Giles Immunobiologist.*

*The Gawler Foundation and similar organisations that help you by empowering yourself and teaching you how you can help yourself.*

*Hospital staff/counselors, immediate family.*

*Internet.*

*Palliative care specialists in Perth.*

*Nurses involved with the treatment of cancer. They can relate to patients and their partners and help with the practical things. Frankly, I found them more believable than the doctors.*

*Friends and family.*

*Family and close friends.*

*Breast Care Nurses.*

*Family.*

### Question 13

For a successful patient-carer relationship, the most important factors are:

- 19.6% Honesty/complete sharing of information
- 19.2% Patience and understanding
- 16.2% Rapport
- 14.7% Show appreciation for the carer/nobody cares for the carer
- 14.6% Understand the carer needs time off
- 13.1% The carer must be a good listener
- 1.2% Don't know
- 1.5% **Other**

*Support group relevant to my cancer type.*

*Understand that it is common not to have any carer at all.*

*The carer must believe in you 100%, no negativity, no doubts. If so, they must take a break and stay away from you until they are back on track.*

*Money.*

*Enable carers to have ready access to medical support staff to keep abreast of all information.*

*Empathetic, fun carer.*

*Love one another.*

*A mutual positive mental attitude!*

*Carer needs to take care of him/herself as well, meditation, exercise, food, etc.*

*Be careful if relationship problems can put your life at risk.*

#### Question 14

Ultimately, an effective cancer treatment strategy would involve:

22.6% Focusing on a positive mental attitude

22.1% Decreasing stress

12.9% Not rushing into treatment

12.4% Investment in counselling

11.2% Seeking a second opinion

9.1% Regularly attending support groups

6.3% Changing work habits immediately

0.6% Don't know

2.8% **Other**

*A positive attitude.*

*Exercise, fresh air, good food.*

*Changing lifestyle habits - diet, exercise.*

*Use your intuition and believe in yourself.*

*Need to be mindful of not too many appointments.*

*Doing what feels right for you.*

*Taking control of treatments.*

*IV Sodium Ascorbate, MMS & other suppressed treatments.*

*A good GP/specialist communication.*

*Find a good medical support person/group/counselor to help you through it.*

*Nutritional support and naturopath/doctor relationship.*

*A GP and/or breast care nurse to give advice on all aspects of the journey.*

*Change diet, bring body back into balance, meditate. Exercise.*

*Once you have decided on what treatment, have it asap and maximize the treatment level.*

*Finding a good support group where you can talk to others who have been there and done that.*

*Setting boundaries and put distance between you and negative people.*

*Seek as many opinions as required to satisfy your questions.*

## OTHER COMMENTS

(Comments left on the survey by respondents)

*After the initial shock of diagnosis, particularly if you are partners, try to work together to get through the shock and then look at all the positives a diagnosis can bring. If done correctly, you can gain so much from this journey. Although our path did not turn out the way we were working so hard to achieve, we did not leave a stone unturned in the three years of the journey. Also, if it is a partnership, be aware of your abilities in what you can do and what your partner's wishes are. Not once have I had to ask myself what if? Did I do all I could? etc. I know, we worked together and did everything we could. I also know that I carried through to my husband's final wish: that he wanted to be at home if that time ever came. I therefore asked the oncologist to allow me to bring him home. I had two more days with him and our children were with us as a family when my husband took his final breath. He went peacefully, I know.*

*One-on-one quality time is important - whether it's a healing or beneficial conversation, comfort is needed.*

*I am a parent of a female child diagnosed at 5 years old - she is now a 16 year old survivor.*

*Sometimes organisations are not forthcoming with information, the 'system' waits for you to be in a situation and then provides information as to what help is available. You have to 'push' and fight for help/information, make sure you have a strong support system and advocates.*

*Advocacy from support groups as well - although charities/support groups are unable to do this if they have DGR from tax department. - Need to change Commonwealth legislation.*

*There are 2 stages to the journey - treatment and survivorship. Both have completely different sets of issues. Drop any preconceived beliefs about cancer - most of it is all totally wrong.*

*It is trickier living in country WA to access many of the options available through places such as the CSA and good, constructive support groups, choice of treatments etc. The focus when diagnosed with cancer should be on wellness. The system as it is at the moment holds people in fear and dread.*

*Everyone's journey is unique. So you must empower yourself with knowledge and then make decisions that are right for you. Then you must act on them. They will be forever changing as you move along your journey. Finally, you must remain focused and devoted to your decisions and your new way of life... believe me, it's a GOOD way. Simply put, the success of this journey involves WISDOM, ACTION AND DEVOTION. If you address these three you will find yourself on the path to wellness.*

*Opportunity to explore the implications of surgery involving pre-existing injuries would have been helpful particularly with experienced allied health. There does not seem to be anything that assists with determining the impact of breast reconstruction on shoulders and neck.*

*Our experience was traumatic - and we had a good outcome - no cancer. I am a clear thinker and found difficulty dealing with the immediate aftermath of the diagnosis. To have someone to talk to who could have helped us sort out some sort of plan to get us through the next couple of days would have been a Godsend. As it was we stumbled about in an emotional firestorm trying to make sense of what we had been told.*

*The person with cancer must do what feels right for them. Friends and family may not agree but they are the person having to cope with the cancer and must do what feels right for them.*

*Gyn cancers needs a higher profile.*

*The WA CSA would benefit from a discussion/interview from Bill Giles, an Immunobiologist who we have been consulting for the last 3 years when my husband was diagnosed with NSCLC and given 6 months to live. Bill is absolutely brilliant and knows the immune system like no-one else in Australia. He is based in the ACT. (Google him)*

*Difficult to answer from a general perspective. Everybody reacts differently and has different needs.*

*Everyone will have their own way of dealing with the diagnosis and treatment and should be given time to work out what that way is at the beginning.*

*I found that the belief that the best available treatment in the world is used in Australia was helpful and I still believe that to be the case.*

*Hey, the treatments aside from mainstream are complementary, NOT complimentary!!!!!!!!!!!!*

*It would be good to see treatments that have had many successes in the past but don't result in pharmaceutical companies making millions actually being investigated properly rather than continually suppressed or subject to ridicule by vested interests.*

*Concentrate on improving your own immune system first.*

*Some of the questions were relevant, and in my case having surgery was a good option, however there was not enough information from the medical profession or pastoral carers about the Wellness Centre in Cottesloe. A friend who is a cancer survivor introduced me to the Centre.*

*Do your lifestyle homework et.c while you still have time, ie prevention is better than cure!*

*Most importantly, a person who has been diagnosed with cancer should have a positive attitude in every aspects of their life and continue to be as active as possible.*

*When I was diagnosed I had already heard about the Gawler Foundation through a relative who had been there. It meant that I started off with a very positive attitude because I knew that there were other avenues for helping myself heal - this knowledge was a very valuable thing for me and had a tremendous effect on how I coped EVEN before I actually contacted the foundation or read Ian's books. I didn't 'discover' the CSA until a few months later. With hindsight it would have been good if my GP had told me about the value of a support group right from the start.*

*I had lung cancer. Surviving this particular cancer is only due to the excellent work done by the surgeon.*

*GP's and radiologists should not give out information to patients (especially under 18) without an adult and/or parent with them, and should not give out information without their specialist present. Results or comments should be given sensitively to the patient by their doctor or specialist.*

*As a healthcare professional in the area of cancer I had a good basis to build on when diagnosed with cancer. However no amount of knowledge prepared me for the level of anxiety and apprehension or the gruelling nature of chemotherapy. My most anxious time was from diagnosis and surgery to seeing my medical oncologist. The surgeon wouldn't talk about my prognosis and told me to talk to my medical oncologist. This appointment was 4 weeks after surgery and is too long to wait for information. Immediate follow-up and information is needed for those that want this type of information. The other area that is grossly over-looked is that of lymphodaema education. I have found mainly cancer patients with lymph clearance quite ignorant of the risks and necessary precautions. As a sufferer of lymphodaema I am very disappointed in the level of healthcare cover for treatment.... what do the poor people do!!*

*At diagnosis the treatment and type of cancer, GIST wasn't explained very well- a lot of our understanding came from the internet, we felt alone.*

*A lot more research needs to be undertaken in relation to the anxiety related to cancer diagnosis. There needs to be a lot more infrastructure and funding into making sure that people have access to good quality emotional support through qualified professionals, and the ability to be able to choose who you would like to have as your therapist, with a financial rebate system through such things as Medicare.*

*The chemo for prostate should be diluted at entry 50/50. This will greatly reduce the debilitating impact on the body and make life a lot better in those 8/10 days of the chemo adverse impact.*

*We found consulting with medical practitioners or therapists often difficult as we were aware their time is precious. Sometimes you can't or don't want to burden family and friends with your worries and fears, as you need them to stay positive to support you to continue living your life as normally as possible, so talking to people (usually strangers) who have been on the same journey, for us, was more therapeutic and provided answers to the questions you most need answered, especially about the emotions we were experiencing throughout the treatment.*

*Breast care nurse that you really trust and is empathetic to your needs is essential. Well-informed, interested GP to oversee every medical decision is essential. Being allowed time to make decisions about surgery and other treatments so you make the right decision for YOU and your future.*

*I am an engineer and approached my wife's diagnosis for colon cancer, treatment, remission, 2 secondaries in her brain, treatment, remission and final death from 4 secondaries in her brain with what I think was a logical and honest approach. I needed to know the likelihood of successful treatment and planned accordingly. As the cancer journey (4 yrs) progressed I became more experienced in sorting through the issues. I am happy to share this with you if you either call me or send me your email address. My details are (removed).*

*Not a well worded survey as no 'oncologist' is part of the prostate cancer regimen.*

*I survived cancer in 1991 -when I was not expected to survive by my oncologist (told me 5 years later I was his black cross at the start as it had spread ) and was the carer for my husband who died at home in June this year of glioma of the brain after 4 1/2 years of treatment- we had Silver Chain help which was limited and I had to go to our Federal Member to get more help but being at home was his choice and it was the best one for both of us.*

*Don't be afraid to ask for help - find buddies who understand because they've been there too like at Cancer Buddies Network. Be as positive as you can and know that you can do this! Take good care of yourself.*

*I have been on both sides of the fence. I am a radiographer, as well as a patient. Finding an alternative/complimentary practitioner with credentials is very difficult. I have the best oncologist in the world, but have experienced the very mainstream, inflexible, not able discuss alternatives, no information, no discussion, no rapport, no sensitivity version.*

*Most people don't get to choose their oncologist or any of their other medical specialists.*

*Check with patient how supportive their family is and what their home situation is. Some people's families can't deal with it.*

*Knowledge that it is not an immediate death sentence! Support from people who have been there before you.*

*Private health cover meant I had to spend another \$6,000 in gap fees which meant I had to keep working and was a source of stress. My oncologist had appalling interpersonal skills and I should have changed to another but didn't and I rushed into treatment recommended instead of thinking about it more.*

*Write your will then focus on living. Truly believe you are doing everything to survive. Have many people pray for you. Accept it's OK to have cancer in your body.*

*Courses like those run by the Gawler Foundation, retreats for cancer patients and their carers are all good options too.*