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Diagnosis of any life-threatening illness is a frightening experience for the diagnosed individual and their loved ones. Breast cancer represents the leading cause of malignant death for women within Australian society. Around one quarter of Australian women diagnosed with breast cancer will go on to develop advanced disease.

*A Life to Live* is a collection of stories from Tire T/111rn111)' Girl.<, a professional/vled, expressi, -e-support group for women with ad, -,mced breast cancer. Accurate reflections on the experience of cancer and its treatment arc conveyed through enlightened and often humorous stories of hardship, pain, suffering and loss, balanced with stories of lives well-lived and enjoyed to the full. Partners and children illustrate the impact of cancer on family membns through original poems, stories and humorous anecdotes. These stories illustrate the crucial role of psychosocial support as a central concern of any model of comprehensive cancer care, alongside al,1r111 ing and devastating revelations of medical mismanagement and neglect.

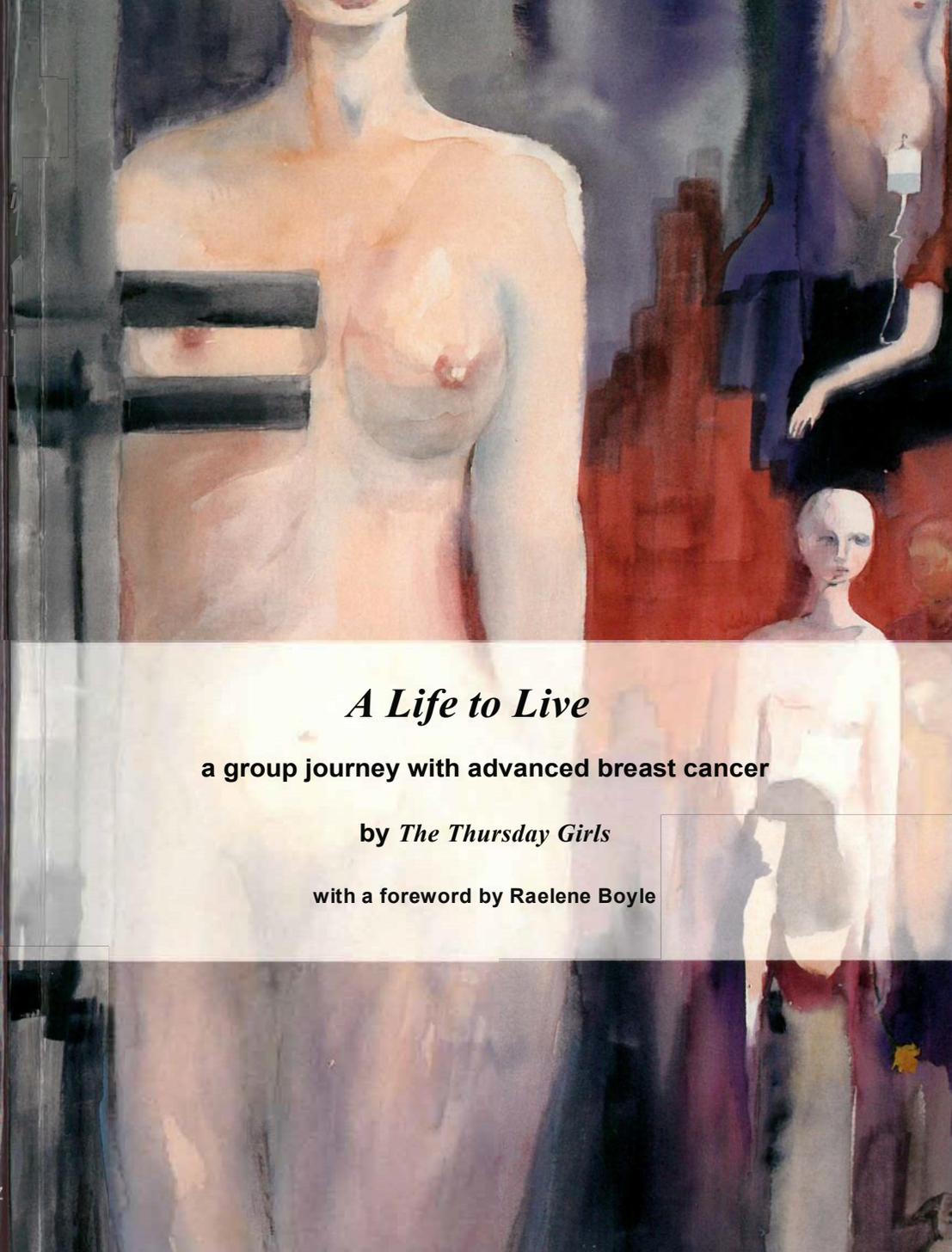
'l'irc r1111r,d'ly Girl.< began as an :Australian research project to explore the findings of origin,d research by Da, -id Spiegel l 1989) from Stanford Lniversity, who reported a significant extension to life from involvement with supportive-expressive group therapy. :Aot only does the group experience contribute to a better quality of lifr, researchers have observed that group members tend to accept initiation of cancer therapies and persevere longer with these treatments. Weekly sharing of information on health issues, treatment side effects and new drugs and approaches provides opportunities for women to better understand available cancer treatments, encourages more effective doctor-patient communication and enables women to feel more in control of their treatment.

Of interest to a wide variety of women, in particular, those diagnosed with breast cancer and their relatives, this book is also Valuable to any individual and their loved ones confronted with a diagnosis of life-threatening illness. It is essential reading for all professionals engaged in this field.

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PSYCHOZ



## *A Life to Live*

a group journey with advanced breast cancer

by *The Thursday Girls*

with a foreword by Raelene Boyle

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#### *Cover Painting*

The cover image, *My Journey with Cancer*, was painted by Gail Carnell and entered in the 2001 Daffodil Day Art Awards. The painting depicts the stages of her breast cancer, from the initial mammogram, the chemotherapy, the hair loss and weight loss to wearing wigs and dressing up once again. The background portrays a hospital building superimposed with fading images of her loved ones - her husband, three children and Johnny the dog (in the lower right-hand corner).

## **My Dancing Flame**

*To me you will always be a glistening candle  
Your glowing love fills me with warmth and a feeling of security  
I stare into the dancing flame, its movement is so unpredictable  
Yet despite its ever changing directions, it remains bright  
With sparks of optimistic images of what the future may hold*

*Your light radiates through my body, filling me with energy  
And a sense of hope and happiness  
This shining light guides me on my journey of life*

*Although this glistening candle cannot shine forever  
As the wick wears down, life itself drips slowly away  
I watch the burning wax melt away  
Each piece evidence of a fulfilled, beautiful existence*

*The flame has gone and I am mourning  
Tears flow down my pale white face  
I struggle amongst the dark and gloomy smoke  
Suffocating, I need the light, I need the warmth  
I feel I cannot get past this smoke, I cannot exist alone*

*Then the smoke has cleared, I finally begin to walk away  
I accept the challenge*

*I realise that this flame is still alight in my heart  
It will remain within my soul  
A dancing spirit, that I will love, I will admire, I will appreciate  
And I will treasure in the passing of today and the coming of tomorrow*

For Helen Sertori by her 15 y.o. daughter Andrea. Helen died in November 1997.

## ACKNOWLEDGMENTS

Many thanks to *The Thursday Girls*, past and present, who, when tired and receiving treatment, found the strength to write down their painful experiences and memories, their joys, laughter and the precious times spent with their families.

Special appreciation to Anne Carnell and her friends who raised funds for this book at a Moulin Rouge themed cocktail party, and Michael Carnell for bringing our stories to life through his cartoons.

Thanks to Kim Wormald and Meme McDonald for their kind instructions in the writing process; to Rosemary Tribe and Elaine Christie for preliminary editing; to Sue Flockhart and Lyn Muir for assistance in our search for a publisher.

Our heartfelt thanks to organizations involved in the life of our group: *The Kathleen Cunningham Foundation* and the *National Health and Medical Research Council* for funding this project through the *University of Melbourne* and *Centre for Palliative Care*; the *Box Hill Hospital* where our meetings took place; the *Box Hill Salvation Army* for car parking, and later for meeting space; the *Breast Cancer Network of Australia* for their interest and support; and the *Australian Association of Group Psychotherapists* for the on-going professional development of the participating group therapists. Many thanks to our oncologists for their dedication and encouragement for us to join this support group.

Special thanks to Daryl Boyd, who encouraged our efforts and generously volunteered editorial expertise, and to Jennifer Whitehead for her assistance to Daryl.

Finally, our thanks to the *School of Social Work* at the *University of Melbourne* for the provision of financial support that has enabled *The Thursday Girls* to continue working together.

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*by Raelene Boyle*

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## FOREWORD

Thanks to the efforts of many people over recent years, much has been said about the importance of screening and early detection for breast cancer. Several books have addressed the issues for women with early disease, such as the shock of diagnosis, the difficulties in telling family and friends, and the challenges of the treatment and recovery stages.

However, around one quarter of Australian women diagnosed with breast cancer will go on to develop advanced disease. Unfortunately, there is much less written about, and for, these women. I think this is mostly because the news is less positive, and the issues become far more complex and confronting for us all.

In my work with Breast Cancer Network Australia, I have met many women with advanced breast cancer and each one of them has touched my heart. Like *The Thursday Girls*, their daily lives are filled with heaps of challenges and yet they face each day with courage and determination. They appreciate that life is for living, and that is what they intend to do, for as long and as well as they possibly can.

I congratulate the women who have shared their private and poignant breast cancer journeys with us in this book. Their willingness to do this will help the community to understand their issues and also help other women with advanced disease to know that they are not alone.

*Raelene Boyle*

## INTRODUCTION

This book is the story of a group of women and their journey with advanced breast cancer. You may have found your way here because you or a loved one has been diagnosed with breast cancer or a life threatening illness. You may be a dedicated health professional seeking to provide the best care possible to such people, or an interested reader wanting to know how people manage when confronted with such challenges. It is the hope of *The Thursday Girls'* that these accounts will provide some support, encouragement, information and hope to everyone.

The stories found in these pages are not just testimony to the courage of these women, they are testimony to the capacity of the human spirit to survive in the face of enormous threat and confront what we most fear. They are also testimony to the strength that we can draw from each other. Life's most difficult circumstances can be better endured when the journey is shared.

Breast cancer is a significant cause of morbidity and mortality within Australian society. It is the leading cause of malignant death for women. To any woman, a diagnosis of breast cancer is a frightening and devastating experience. A diagnosis of advanced (metastatic) breast cancer is even more so. It is very difficult to accept that a supposed eradicated cancer has reappeared and spread. It raises stark issues of mortality and

loss of family and friends. Yet this ultimate confrontation can also be a positive and rewarding experience, as many of the inspiring stories in this book show.

Professor David Kissane and Christine Hill have led a study of group therapy with women suffering from advanced breast cancer. This group, known as *The Thursday Girls*, meets every Thursday morning. The aim of the study has been to explore the possibility that group meetings can improve quality of life and may even prolong survival. In the course of this study, these women have formed an extremely cohesive and supportive group.

The group has become a 'safe place' - a place where the members can share their pain, worries and confusion and know they will have immediate understanding and support. Through weekly sharing of information on different health issues, treatments, side effects and new drugs and approaches - they have come to feel more in control of their individual treatments and learned to question and explore a variety of medical options.

Of course, a journey with cancer has a huge impact on family members and family life. This group experience has provided support and inspiration for families who, in turn, have been able to nurture the group.

The support, friendship, knowledge, hope and inspiration *The Thursday Girls* have gained from the group have been very powerful. They now wish to share their experiences with others. In basing their account primarily on a series of personal stories, *The Thursday Girls* provide a rich and diverse range of experiences that serve as an indispensable guide to others. The stories tell of the joy and the grief, while reflecting accurately on the experiences of cancer and its treatment. These stories give a unique insight into the role of a professionally led supportive group and the contribution it makes to enriching quality of life.

We hope that other women and their loved ones will feel supported by the words of *The Thursday Girls*. We hope this book helps them come

to terms with a diagnosis nobody wants to hear, and gives valuable knowledge about seeking the best medical treatments. We hope it gives them strength to confront the fear of death and the grief. Above all, we hope they embrace the inevitable demand to live for the moment and make the most of what time they have with loved ones.

1

**GROUP  
EXPERIENCES**

**Pictured Right**  
The Thursday Girls  
meeting at Portsea (left to right):  
Linda, Jean, Shinta (standing),  
Gail, Mary K and Jeanne.  
*(Photo taken by Jeanette)*

### *The Thursday Girls*



No account of *The Thursday Girls* would be complete without remembering those who are no longer with us and whose stories are not included in this book. They have helped engender a spirit that has endured years later. Since the group first met in July 1997, women with diverse backgrounds have occupied the seats in our meeting room on a Thursday morning for group therapy.

*The Thursday Girls* is a professionally run, expressive-support group for women who have metastatic breast cancer. It is funded by the *National Health and Medical Research Council* and was facilitated by Professor David Kissane (psychiatrist) and Christine Hill (psychologist). As part of a research project, it is a trial to test whether patients who participate in such groups survive longer and have a better quality of life. Previous studies in the US indicate that patients in similar groups can live longer, and the study that we are involved with follows similar guidelines to this original research. Our sincere thanks to David and Chris for their care and commitment to the project and its participants. Following the recent departure of David Kissane to take up a position at the world-renowned Memorial Sloan-Kettering Cancer Centre in New York, Fiona McDermott has joined us as a co-facilitator.

Initial impressions at the first meeting of the group in July 1997 were somewhat negative: *What am I doing here? Do I really need this? How would I cope when someone died?* Now, sadly, none of the eight original

members are still with us. Most subsequent members have had initial doubts. Our fears about dying were to be realised only too soon, because Helen S died on 12 November 1997. We realised then that eventually we would all die of this insidious disease. It was very confronting.

The exchange of information has been an important aspect of the group experience. Newspaper cuttings, publications and Internet items are all shared with enthusiasm. It is beneficial to swap notes about various treatments and their side-effects, and reassuring to know that you are not alone in your concerns. Wigs, diets, prostheses and issues such as lymphedema are discussed. A contact list enables members to keep in touch by phone between weekly meetings, especially if someone is undergoing treatment or going through a rough patch. It is reassuring to have a chat with someone who understands. Sometimes members are in hospital, so a visit is always appreciated. We all try to offer support with family problems that surface inevitably. Cancer affects everyone around the person with the problem.

The idea of a publication about our experiences was suggested by one of our founding members. When finally under way it proved to be a rewarding experience for the group with its worthwhile focus and the valuable insight into people's lives before they had breast cancer. Gail's family held a Moulin Rouge fund-raising party for the book, and the group had a two day think-tank at Portsea.

The group is quite social with lunches, birthday celebrations and dinners that sometimes include partners. There have been trips to Portsea, where a member made her family holiday home available, with much discussion and sampling at local eateries. The term *The Thursday Girls* was used originally by a founding member, who also suggested celebration of birthdays, having lunches and other joint activities.

*The Thursday Girls* have become involved in consumer advocacy with participation at seminars, training and membership of a consumer committee. Our involvement with the *Victorian Government Breast Services*

*Enhancement Program* evolved from our letter to the Hon. John Thwaites, Minister of Health, and subsequent contact with Project Officers Sheila Hurst and Chris Scott. *The Thursday Girls* have also provided input to a book by Dr Fiona McDermott from the *University of Melbourne*, about groups generally, how people lead groups, and how people who participate in groups understand the experience. Some members and their families have participated in the annual *Daffodil Day Arts* award, conducted by the *Cancer Council of Victoria*, through submissions of poetry, prose and art work.

Group members come from diverse backgrounds with diverse beliefs and attitudes, so it is appropriate to reminisce on those friends no longer with us, who played such an important role in the success and development of *The Thursday Girls*. Helen S, Margaret, Jacquie, Brenda, Judy, Jean, Gail and Frankie were the original ladies when the group first met in July 1997. The individual stories of Jean, Gail and Frankie are included in Chapter 3. Of the other original members:

*Helen S* was articulate, well informed and died with dignity.

*Margaret* was articulate, immaculate and embraced life with enthusiasm. She was a voluntary worker for the *Cancer Council of Victoria* and a gallery guide. Who could forget her arrival at a group meeting with her oxygen on a trolley or her appearance one Thursday morning direct from the airport after an overseas trip?

*Jacquie* was a somewhat flamboyant character, who took rather desperate measures to search for a cure.

*Brenda* lived life to the full and adored her sons.

*Judy* threw herself into her work as a childcare nurse, developing a computer system in connection with the work.

Later ladies no longer with us but who made such a valuable contribution to the group success were:

*Joanne* was a gentle Earth mother, a vegan and involved with Neighbourhood House.

*Connie*, a sweet lady, was the bud of her close-knit Italian family.

*Caie* was larger than life and swept into our meeting one day, somewhat overwhelming us. She had certainly lived and told very funny stories of encounters with the medical profession.

*Julie* taught us how to accept dying and to die well. She was full of life and took videos of her last weeks with the family.

*Kath*, who with her husband were a devoted couple, a real love match.

*Ruth* was very quiet with a beautiful smile.

*Lesley* had held a responsible bank manager's job. She loved *The Thursday Girls* and enjoyed several social occasions with us.

*Jane* was a young woman who came once to the group and decided not to continue. Sadly, we heard she passed away the following year.

*The Thursday Girls* have been well represented at most of the funerals since the group began. Ranging from High Catholic to a garden setting in the Dandenong Ranges, each service has mirrored the person. Recently, a Salvation Army funeral proved to be inspiring, and *The Thursday Girls* felt very special being seated behind the family. Far from being a sad occasion, it was a joyous celebration.

We continue to derive much comfort and support from our group therapy involvement, with abundant love, humour, fun and enjoyment of life. Fortunately and unfortunately, we continue to welcome new members. Thus *The Thursday Girls* continues to evolve as a group. The dynamics may be different but the purpose remains the same.

## **Jean**

The group experience with *The Thursday Girls* has been interesting, rewarding and challenging for me. Our group has bonded well, and close friendships have developed. It isn't easy when members become ill and die - this is the ultimate confrontation, and one that I was unsure initially of how to handle. We have seen some truly inspirational women who have died

with great dignity and courage, and have helped those remaining behind to gain strength to face their own journeys. Attending funerals has proved an enlightening and saddening experience, often providing insight into a person's life that we had not been party to previously.

Cancer can be such an isolating and lonely illness, and the opportunity to share fears and concerns has been wonderful. There is always someone to talk to, express your deepest anxieties with, knowing that kindred spirits will understand. The sharing of knowledge and information is an important function of group therapy. It gives some sense of control over what is happening to you. At least you can ask the medicos reasonably intelligent questions.

Group activities have extended far beyond our Thursday morning meetings. We meet for coffee after group - wouldn't the researchers just love to tape our conversations! Lunches are numerous, and sometimes families are included in social gatherings. Birthdays are celebrated with yours truly in charge of purchasing presents (only because I am good at remembering dates), and there have been several forays down to Portsea, with much talking and sampling of local restaurants.

## **Gail**

I am the last of the original members of *The Thursday Girls* a confronting thought! Why have I survived while the others have not? Especially when my initial diagnosis was metastatic breast cancer, stage 4. The vagaries and insidious nature of the disease continue to amaze me. I have been witness to the demise of numerous women over the past six years (since 1997) and gone to most of the funerals. One might think that this would be too much to bear, but in fact it has helped me face my own mortality.

What is the secret of the group? What makes ill people turn up each Thursday when it would be so easy to stay in bed? Why have there never been altercations and power plays? We don't have a structured

committee - different people fall into positions because of their skills and willingness to do a job well. I would suggest that one of the reasons for the success of the group is because we have the same illness and understand the problems faced. Also there are always manners, mutual respect and acknowledgment of individual opinions and decisions even when they don't coincide with yours. Another important factor is humour sometimes it is very 'black' but we have all loved to laugh. David and Chris, our facilitators, are the lynch pin. Without trained leaders, groups easily could fall into disarray. I would love to see Breast Cancer Groups led by trained persons funded by the Government so all women could have the positive experience I have had.

### ***Susanne***

My journey has brought some special women into my life: *The Thursday Girls*, my therapy group, who like me are living with secondary breast cancer. Other people think it must be a morbid group, with us all facing our mortality and coping with doctors' visits, treatments and recurrences, but we spend a lot of time laughing, even when we recall embarrassing moments with wigs and breast prostheses. We celebrate our well-being and give support when things get tough. We also cry together when one of our group succumbs to this dreadful disease. These women have taught me a lot about hope and courage and how to live and die well.

### ***Jeanette***

I joined *The Thursday Girls* after my oncologist suggested I would benefit from being a member of such a therapy group. It was a research group studying whether this type of group experience could help to extend our life expectancy. At first I was not convinced that I could gain anything by joining the group, but I kept going every week anyhow.

After two years I have made firm friendships with other girls and have had lots of love, support and laughs - as the saying goes '*laughter is the best medicine*': Our morning tea or coffee after our group session has helped with our bonding. We discuss family, social occasions, and anything else that pops into our head. We also ring to check when a group member is having treatment or tests.

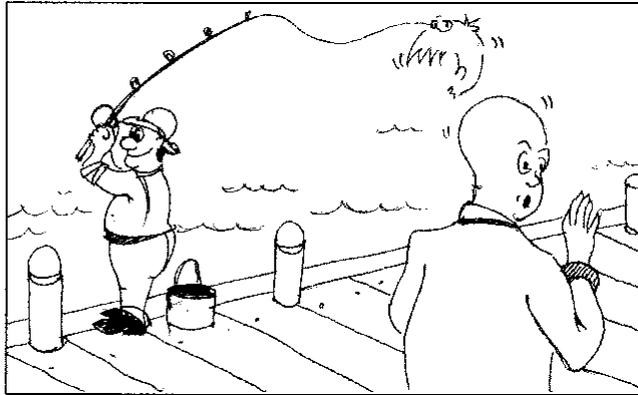
If we had been sitting at home and wondering we would have missed out on the knowledge that we have gained about treatments and types of cancers from other group members' experiences. We keep our eye on news articles of new treatments and take them along to group for discussion. We have gained confidence to make contact with policy makers in the government and medical profession and put forward our views about what might be helpful for people first diagnosed with cancer. We have had favourable responses to our suggestions.

On the emotional side of cancer, group members have been able to discuss how they feel about things that they might not be able to discuss with their families. This is because we share a mutual understanding of the feelings we are going through. This mutual support is invaluable.

The group experience has helped us to cope with the passing of group members and enabled us to provide support to each other at these sad times. Our group has been able to talk frankly with each other and provide the love and support (and hugs) that are so important in our medical situation. It is the aim of *The Thursday Girls* to continue to provide support and knowledge for people in the future.

During one of our days away at Gail's holiday house in Portsea to work on this book, we went for a walk along the Portsea pier. We strolled along chatting away to each other and propped near the end of the pier talking together (like women are wont to do!). It was windy and cool, but sunny. I looked around and saw that we had stopped behind a group of fishermen who were casting their lines. Most of the ladies were wearing wigs at the time, and a picture flashed before my eyes of a fisherman

flinging his line behind him and a wig, caught on the hook, disappearing out to sea (my wild imagination!). I suggested quickly that we all move further along. After pointing out the fishermen and describing my mental picture we had a good laugh.



Fishing can be a hair-raising experience'

### **Lois**

I joined *The Thursday Girls* group with extreme reluctance in November 1999. The first meeting was devastating. I learned of all manner of possible secondary cancers ahead of me, things I had never heard of or contemplated. Over the next few weeks I calmed down and realised I wasn't destined necessarily to get all of the secondaries. It was encouraging to see how some of the girls were going really well years down the track.

Now I believe that joining *The Thursday Girls* is the best thing I have ever done. The girls are so warm, friendly, concerned, supportive and knowledgeable. They have experienced or know about all the treatments and drugs, know the right questions to ask, and encourage me to stand up to the doctors. Contact with these brave, determined women has been enriching and inspiring for me.

### **Shinta**

I joined *The Thursday Girls* group shortly after being diagnosed with metastatic breast cancer. My reason for joining was to help this research to gather more information. Even on the first day, I felt comfortable for I knew that all of us were going along the same journey, although some have it harder than others. As each member introduced themselves and described their conditions and treatments, I was dismayed at what they had been through and the extent to which breast cancer can affect you. Although I have collected a lot of information about breast cancer by reading books and from the Internet, my interaction with women who are affected similarly has been a revelation to me.

Even though they are facing an incurable disease, they still manage to look wonderful, and their ability to cope gives me encouragement and hope. It is a frightening journey but I know the group will help me go forward with their practical examples, love and support, and very importantly, their humour. I look forward every week to find out how each member is coping with their compromised life and learning from each other. It has been a most rewarding and enriching experience for me.

### **Mary K**

When approached to join *The Thursday Girls* group, I wasn't at all keen. I had avoided groups of women and committees like the plague. I just didn't need all the mundane chatting and family talk. I already had a social environment through my work, and my attitude to cancer was one of living with it and getting on with things. I would also have to make time for this meeting, nominally 9-10.30 am (a joke really, as most group activity takes place *after* the meeting, and I never leave till 11.30-12.00). Small talk was never my forte. I guess I'm a serious person. It was only the promise, wrung from me by David Kissane, that I would try it for six

weeks. Having agreed I couldn't, in all good manners, back out.

When I joined the group I started to mellow. Here was a group of women, most of them worse off than I, who also were getting on with it. They were courageous! They had endured more treatment than I had and had come up smiling. Side-effects were discussed and commiserated with, and eventually rationalised and put away. The education process was continuous as treatments were discussed in detail. The feeling of empowerment and control that results ensures that a person is not just putty in the hands of the experts, but someone who can ask sensible questions when further treatments are considered. There was an ongoing exchange of information, handy hints and warm good humour. The group is very social, enjoying good company, lunches and holidays.

A genuine happiness is felt for the others in the group when things go well, and a genuine distress when there is bad news. Being a member of about twelve months, I have not witnessed the death of any of the girls I have come to love. When that happens it will be very hard.

As I have got to know *The Thursday Girls*, I have come to love and respect their individual attitudes of caring and kindness to each other, and their courage in the face of the uncertainty of life-threatening illness.

### ***Linda***

When I first attended *The Thursday Girls*, I found the group very welcoming but extremely confronting. I wasn't sure whether I wanted to talk about my cancer and meet others who had experienced worse symptoms and treatments than mine. It meant that I would have to deal with the reality of metastatic breast cancer on a weekly basis. During the first few weeks I returned home overwhelmed, very upset and often depressed. I had made a commitment to David to attend for at least four weeks and had adjusted my workdays to accommodate the group. When speaking to friends after group meetings, I was quite negative and really

needed cheering up. Friends often asked '*Is it really good for you to go to this group?*' Now they are surprised that I continue to go a year later!

At first it was the constant reminder of what could happen to me: symptoms, outcomes, treatments and so on. Everyone was friendly but I was reminded continually that conventional medicine could offer no cure. My participation was at first made easier due to the writing of this book. In the preliminary stages I was able to use my librarian skills, and access a variety of books at work to provide examples of similar works.

Work on the book turned out to be a real ice-breaker, and I participated in a weekend away and meetings after group to discuss the content and layout. It was interesting to learn more about each member through listening to the stories. Work on the book has been an intense, therapeutic and learning experience for me, as has been my attendance at the Thursday group. There is also the extra support and caring provided by group members, such as phone calls when you are in hospital or when the group knows you are having a bad day, discussions about treatment options, and support for each other in difficult times, as when a group member dies.

Since joining the group, two members have died and we have attended the celebration services for their lives. It is hard to accept the loss of a group member, but on both occasions *The Thursday Girls* received special mentions and seating, which in turn has made us feel very special.

The love, laughter, support, sharing of information and opportunity to talk about cancer encouraged me to stay. I continue to attend the group a year later and wouldn't miss it except for a very good reason!

### ***Helen B***

In March 2002 I joined the metastatic breast cancer research group. I was not thrilled about joining the group and agreed to take part in the project reluctantly. I didn't want to spend my precious time sitting around

with a bunch of 'sick people'. However, I quickly realised that this group did not regard themselves as 'sick people' and were a feisty determined bunch who shared experiences, encouragement and worries. It was a confronting year for the group, as several members died and progressively the group became smaller. Each death was an ongoing reminder that nothing is forever and that we all have only a limited time. This was brought home when people would be at meetings and then two or three weeks later they would die. The courage with which members faced their illness and death was inspiring.

My family members found the cancer group and the ongoing loss of its members very unsettling and they felt as though my being part of the group would hasten my end. In some ways I wondered if this was so if the continuing deaths would trigger a fatalistic attitude that the progress of the cancer was inevitable. I don't know, but I never accepted that it was for me. In fact I was very annoyed when the cancer returned, as I felt really well and strong and was getting on with my life.

Aside from the sadness of the deaths, *The Thursday Girls* group provided a wonderful vehicle for an exchange of knowledge and experiences. It was very useful to find out how treatments affected people and what different treatments did or did not do for people. Within the group we discussed issues about prognosis, worries about the return of symptoms, frustrations with what was happening, and other concerns without having to worry that we might upset others. The reactions of family and friends are an ongoing issue for us all. We want to keep people informed and yet are conscious that people want us to be doing well. The value of this group support and understanding cannot be overestimated.

### ***Robyn***

After my operation and radiotherapy, and during my blackest period, I met a gentle and insightful psychiatrist. He invited me to join a support

group that he was involved with. I was most reluctant to join because I have always been shy and more of a quiet observer than a participator, but with my family's encouragement and a feeling of trust in the psychiatrist/facilitator, I did join *The Thursday Girls*.

I feel helped by the love and generosity of the facilitator and each member of the group. They welcomed me unreservedly. At no stage did I feel 'on trial' before acceptance. I have learned a lot in the few weeks since I joined and I now look forward to each Thursday morning. I see the courage of people sicker than I and admire the humour, common sense and love that prevail. How thankful I am that my path through life has led me to be accepted and included as a *Thursday Girl*. And long may I be a member! I am feeling a slow but hopefully sure lift in spirits from my involvement with the group and the gentle patience and encouragement of the daughter with whom I live.

### ***Sally***

It must be fate: the 'Thursday Syndrome' has struck again! This time, however, I have been careful to schedule the not-so-pleasant side of things for the rest of the week and leave Thursdays for enjoyable experiences.

On a Thursday evening, late in August 1994, I discovered an enormous lump in my left breast. Everything seemed to happen on a Thursday - confirmation of my worst fears, the mastectomy, blood tests followed by chemotherapy. I did what I had to do to get well. I didn't feel brave, just scared and in survival mode.

An important part of my mental recovery took place on Thursday evenings in the Box Hill Hospital when I became part of a research study into group therapy. Here I met six wonderful, diverse, inspiring and supportive women. We laughed, we cried, we talked, and talked and talked. Even if we were not feeling well, all of us made an effort to be there. The opportunity to be able to discuss openly how you felt about

what was happening to you with other women who knew what you were going through was extremely beneficial. The chance to 'get things off your chest' so to speak was very helpful. It relieves the burden from family who, no matter how caring they are, must surely have a heavy enough load to carry without listening continuously to how the patient is feeling.

The remaining four ladies in this group are now firm friends and gather together regularly. We continue to support each other, sharing the good times and, most importantly, being there for the bad times.

Then on a Thursday in late July 2002, the dreaded cancer reared its ugly head in my upper spine along with two new tumours in the vicinity of the original problem. I was devastated. Emotionally, this was much harder to cope with than the first time. After all those years, I thought I had not only won the battle but was actually winning the war.

Being back on the medical merry-go-round is demanding on both my time and my body. My state of mind has caused me a reasonable amount of concern. I do not fear the actual act of dying, but the journey to that point upsets me greatly. My dear friends from my first group have been wonderful, but they cannot fully understand what I am currently going through. So I set out to find a support group specifically for women with advanced breast cancer, a more difficult task than I imagined. However, I eventually found another professionally led group.

*The Thursday Girls* have been meeting weekly for a number of years. Once again, I have met a group of wonderful, diverse women all of whom have been living with secondaries for longer than I have. They are my inspiration when things are not going so well. Once again, I have found a sanctuary where I can laugh when I can and cry when I have to, knowing they will understand. We share information and experiences that help put things into perspective. It is particularly helpful to have the professional facilitators, Chris and David, as they are able to answer our many questions, both medical and psychological.

Group therapy is not for everyone. It can be very confronting, especially

when one of the group is not in good health or passes away. To face your own mortality is not always easy. For me, to talk about my deepest thoughts and fears is often difficult at the time, but later in the day I look back and realise I feel a lot calmer about the whole thing. I know within myself that group therapy has helped me to adjust to my new circumstances and will continue to be very helpful as time goes on.

### ***Toni***

When I was first diagnosed with metastatic cancer in my liver I was, of course, devastated. I had little idea of what the implications of this may hold for myself and my family. My positive and helpful oncologist told me that the emphasis now was on control rather than cure which, he explained, would be very difficult from this point. I was still too shocked to absorb what he was saying: that all my struggles against this wretched disease had been in vain and that breast cancer would almost certainly be the end of me!

In the days and weeks that followed, I struggled to come to terms with my new situation. I sought counselling from the hospital social worker and rang the Cancer Council help-line. While both of these people were helpful in their separate ways, they were unable to put me in touch with a support group that could cater to my specific needs. There seemed to be a large network of potential support group options for women with newly diagnosed breast cancer but little for women in my situation, whose needs are equally, if not more, pressing. Traditional self-help support groups are not really designed for women with metastatic disease, as we represent the 'worst nightmare' of newly diagnosed members. It wasn't until I was seeing a different oncologist, this time at the Peter MacCallum Institute, that I was put in touch with *The Thursday Girls* group.

The group convenors, David Kissane and Christine Hill, are highly trained professionals whose guidance of discussion is subtle and unobtrusive

but encourages the group to confront their demons and ensures that each person has the opportunity to raise their feelings and concerns.

The other group members themselves are truly inspiring. They all have long histories of struggles with this disease and bring their own perspective to each meeting. They are a mine of information and share resources willingly. Best of all, they are welcoming and loving people who were on my wavelength and knew exactly what I was going through. They had all been through it too, and had emerged from the trauma and distress to be women with a lot of living still to do. Things were more difficult at times according to their state of health, but they were basically getting on with their lives.

When I first joined the group, a long-standing member had just died. In fact, they had lost several friends in the previous twelve months. This was confronting for me and I did wonder whether I wanted to put myself through this experience. However, the benefits I have gained since becoming part of this group far outweigh any concerns I have about the challenging issues that may arise.

Our own mortality is a reality that must be faced by whoever draws breath. The privilege of being with these women, as we all walk this road toward what is the inevitable end for everyone, takes the fear out of the situation and reduces it to what it is, a natural part of life. The stoicism and humour and plain, practical, helpful advice offered by the group is invaluable, and I feel lucky to have become one of them.

**THE THERAPISTS' PERSPECTIVE  
OF THE GROUP EXPERIENCE**

Christine Hill, David Kissane and Fiona McDermott

The idea for this book came from the women themselves and was nurtured by many group members as they wrote and shared their stories. It has been a wonderful privilege for us as therapists to know them and to share a part of their lives. They have been a group of courageous women whom we have held in the highest regard. This book is their story. It has been a rich journey of love and creativity, in which they have strived to live out their lives to the full. In the process, they have shared much love and joy. This book is addressed not only to fellow women sufferers of cancer and their families but also to professionals engaged in this field and the interested reader. It contains enlightened and often humorous stories of hardship, pain, suffering and loss, but also accounts of lives well lived and enjoyed to the fullest. In addition, it brings together stories, original poems and humorous anecdotes from partners and children who have journeyed together with the women. We would like to add something of our experiences as therapists who work with these women.

Within any model of comprehensive cancer care, psychosocial support represents one of the common goals of the treatment team. The threat to life that a diagnosis of cancer brings necessitates a major psychological adjustment for every patient. Yet within the flurry of activity involved with medical tests, surgery, chemotherapy, radiotherapy and a gamut of other medications, psychosocial support has tended historically to be relatively neglected. Patients have frequently lamented its absence.

The community has responded with an array of self-help groups, that are dispersed widely for women with early stage breast cancer. Advanced cancer brings further threats and challenges. The potential threat of death becomes a greater reality and the need for support an absolute imperative. The model of professionally led *supportive-expressive group therapy (SEGT)* emerges as a cost-efficient and proven strategy for effective delivery of psychological support. It is an essential component of care that should be offered routinely to all women caught up in this stressful health predicament.

In this chapter, a background perspective is provided about the nature and experience of facilitating a supportive-expressive model of group psychotherapy for these women with advanced breast cancer. This has formed part of a seven year Melbourne-based trial of SEGT, from 1997 to 2003 inclusive. It continues as an ongoing group. Our experience of these women is captured here in the hope that some of the mystique is lifted and the benefits of involvement are made plain for all to understand. Some patients who might think initially that they are 'not a group person' might reconsider in the light of the information about actual experiences presented in this book by the participants of our group.

### **WHY WOULD I JOIN A GROUP?**

*Do I really want to belong to a group for women with advanced breast cancer? That could be a distressing experience! I wonder if it might prove to be a bad experience for me.*

Such a concern was voiced often as each woman weighed up the advantages and disadvantages of group therapy for advanced breast cancer. A widespread fear was that the group would be a morbid place, where people were tearful, sick and frightened, and that had the potential to harm others with a highly contagious process. How could benefits possibly flow from such a risky and demoralizing experience?

Most women carry some of these concerns as they contemplate joining a group for the first time. Yet the real experience is widely different from these misconceptions. Few dream that it will generate such warm friendship, a committed sense of support and a feeling of being so well understood, and at the same time prove to be such fun and involve good humour. When women who have shared life-threatening trauma come together, the opportunity of relating their experiences to others, who genuinely understand, proves enriching. The group provides a safe and secure space to speak about things that matter to people who truly understand because they also are living through such comparable encounters.

Supportive-expressive group therapy started in California in the 1970s when Irvin Yalom, a psychiatrist at Stanford University, led a series of studies into group support. His conviction, grown from his understanding of existential philosophy, was that serious illness provides an opportunity for personal growth. Much of life involves periods in which people drift somewhat aimlessly, taking life for granted. Only when the preciousness of life is recognized, when death is faced as an inevitable possibility, does an authenticity emerge that brings with it the capacity to live life truly and fully. Existential thinkers such as Kierkegaard, Heidegger, Husserl and Sartre, grappled with the meaning of our lives and argued that only through consideration of our non-existence can we gain a genuine value of our existence. Death, so often a taboo subject in everyday life, needed recognition and by confronting the reality of death and fragility of human life we can enrich our lives all the more.

Yalom's groups discovered that, through confrontation and talking about dying, their fears lessened. Knowledge empowered a sense of control rather than powerlessness; mutual support countered a sense of lonely isolation. Sharing fears and concerns proved not only helpful but nurtured courage and confidence in the choices people made. Relationships improved, families felt supported and a conviction emerged that quality of life was increased. Indeed, a formal study of group therapy confirmed

that a significant improvement in quality of life was achieved for patients who met in professionally led groups for ninety minutes each week for one year. Supportive-expressive group therapy had been born.

### THE GOALS OF SEGT

The goals of supportive-expressive group therapy (SEGT) were later enunciated by one of Yalom's students and long-term exponents of the method, David Spiegel. These goals can be listed as follows:

- to build bonds
- to express emotions
- to detoxify death and dying
- to redefine life's priorities
- to increase the support of family and friends
- to improve the doctor-patient relationship
- to improve coping skills.

The *supportive* component of the method reflects the development of team-work and collaboration that strengthens into genuine and committed friendship, while the expressive part alludes to the role of an open exchange of thoughts and feelings so that deep trust in each other grows.

The SEGT technique generates support and understanding through open communication and can be applied to any relationship. Indeed, individual counselling could just as readily adopt the model of supportive-expressive therapy. The group environment therefore warrants special emphasis. How crucial is the group? The group creates a different setting in which to share comparable life experiences. Through this process the power of any single interaction is magnified as it brings to the fore what several have experienced. The diversity of group membership enriches discussions. Varied experiences bring together different understandings, and open up the range of coping options; in contrast, the similarity of what has happened helps to counter any sense of isolation in suffering from

this illness. Bringing together a dozen women diagnosed with advanced breast cancer creates a rich repository of human experience, of wisdom about life and of the range of treatments available for the breast cancer. The experiences that the women share in common, together with the differences in how these experiences have affected them, serve to enrich the group environment and give it the potential to be more powerful than any individual therapy experience.

Does attending a group imply that a person cannot cope? Far from it! In SEGT, high functioning women come together in trust and confidence to support each other and enrich their lives. Groups are not critical of their members, nor are they designed to 'teach' people how to live. Women choose to belong because they recognize the group as a safe place to share difficult life experiences. An illness that threatens death brings one of the most challenging of personal experiences. There is no implication that a new member is coping poorly.

However, in SEGT the word *therapy* is as important as the word *group* because it refers to the special tone and agenda that exists in the group room. A safe place is provided in which to discuss deeply personal issues, fears and challenges alongside joys and triumphs, but with dedicated goals to optimise quality of life and live it to the full. This group exists because of cancer, and this brings a specific agenda. The group seeks to create a special support network with others who are living through a similar experience and to harness the wisdom of these people to enrich the lives of all. The group doesn't shirk discussion of illness, hardship, loss, distress, disability and even death. Moreover the group is there to provide active support to any member whose illness draws them closer to death, to help them in frailty, visit them during hospitalisation and, indeed, love them while dying. The group reaches out to partners, family and friends, and cares for them all with courage and conviction. A further goal of the therapy is to improve doctor-patient relationships and support members to assert their needs with confidence. In discussion

of what matters in life, members choose what is important to them, so that their lives are lived with authenticity and purpose. The goals of the supportive-expressive group make it 'therapy' because within that term comes recognition of the important work of the group, a special agenda that the women commit to and respect.

### **IS THIS GROUP THERAPY SIMILAR TO OTHER GROUPS?**

Many worthwhile forms of self-help activity happen within the broad community, all to assist those in the journey with some form of cancer. Some social groups bring people together for free discussion of their experiences; others hold a range of educational activities and vary in their frequency of meetings. While there are self-help groups for women with early stage breast cancer, few have emerged for advanced breast cancer. Moreover, the combination of women with both early and advanced cancer meeting together presents challenges for those hoping to achieve a cure; there are considerable differences in the needs and discussion agendas of women at such different stages of the illness. There is a strong argument to respect the divergent needs between those who work towards cure and long-term survival, and those who strive to live with a chronic and progressive illness that will lead to their death. Self-help groups serve an important purpose in the community. However, special challenges come to the fore with advanced cancer, and these circumstances are best responded to by the development groups led by professionals. This view has received powerful endorsement from the women we have worked with over the years, and is expressed in their stories here.

The goals of SEGT are not modest, as the well-being and lives of members are at stake; issues discussed are sensitive, emotional, poignant, and critical to life's fulfilment and joy. SEGT aims not only to optimise the quality of life of each group member but also to accompany the member to their eventual death. A vital feature of 'group therapy'

(as opposed to a self-help group) is the professional leadership that facilitates each session and takes responsibility for the safe journey of the group together. This leadership also makes it 'therapy'. This courageous journey is not undertaken lightly or blindly, yet for many it traverses uncharted waters:

*Like a ship being steered out through the heads when seas are rough and currents potentially dangerous, experienced pilots prove a godsend. Use is made of their wisdom, knowledge, judgement and understanding of the journey to make it safe and worthwhile.*

As group facilitators, we bring training and experience into the group process to enrich the journey and guide the members to achieve their goals. We take responsibility for the conduct of the SEGT, and act as containers in the creation of a space to think about and express powerful feelings. This enables the women to come to terms with the unbearable prospects of pain, loss and impending death.

In future appropriate and responsible development of health resources the engagement of professional leadership of such groups should be the norm. As the seriousness of these neglected needs becomes better recognized and professional programs are developed to respond with more expert assistance, government funding of professional group facilitators is essential. Such programs should become routine over the coming decades. Formal funding provides surety about the continuation of the program throughout the remaining life of any potential new group member, a commitment vital to the important continuity of such care provision.

### **IS PREPARATION FOR SEGT IMPORTANT?**

Preparation is a vital component of beginning with an SEGT group. It is routine for group facilitators to meet with prospective members prior

to their attendance at the first group session. This allows new members to get to know us as the therapists. It is our responsibility to introduce new members and ensure appropriate consideration and response to their personal needs. If possible we incorporate new members in twos or threes rather than one at a time. This takes pressure away from any one individual and also sets a clear group agenda of getting to know new members. The timing for this introduction requires skilled judgement, as the transition is easier when the group membership is in a phase of relatively better health than at a point when one of its members is dying.

During the preparation session expectations of the group process, its style of operating, the range of its membership and potential goodness of fit with new members is discussed. Practical aspects such as start and finish times, parking arrangements, help with transport, holiday breaks across a year's program, and how to contact the therapists are considered. It is important to secure a commitment to confidentiality about the content of group discussions. The mutual respect and trust that makes the group a safe place for members to share any personal or private experiences they choose is dependent on this confidentiality. This is balanced with sound judgement about the openness of family relationships that evolve over time as genuine supportive friendships develop. Simple illustrations of what the group might consider to be confidential are given to new members to convey clear understandings and expectations.

All SEGT groups have norms or rules that govern the effective operation of the group. Group members worry about the well-being of absent members unless appropriate apologies are tendered with regard to planned absences such as holidays. When unanticipated absences occur through illness, some communication to a therapist or group member is necessary to keep the group well-informed. Each new member makes a commitment to give importance to the group over other social activities across the week. However, common sense must prevail. What does a member do when her oncologist books a scan or X-ray that corresponds with the

group time? Does the member negotiate assertively for an alternative appointment, or should avoidance of delays with such tests necessitate that she prioritize the test ahead of involvement with the group? Every member will miss occasional sessions for important medical or family reasons. However, members may need to educate their oncologist about the importance of the group to them and ensure that respect is given to the group in the overall care plan.

In recognition of the anxiety some new members carry when they first join a group, a commitment is sought from each person to attend at least four sessions before they make any decision about the suitability of the experience for them. Some women take to the group like a duck to water; others fear that they may be demoralised or harmed by the experience. Invariably the first session is the hardest and not the one to base a decisive judgement upon. Sometimes tears are shed in the opening session, but not seen again for several months. Members need to recognise that after a few sessions each person has a sound feel of how suitable the group experience is for them, but initial judgements may differ once they settle in and get to know other members. The ambivalence that arises as they witness some sadness in the opening session may be understood differently with the passage of time.

#### **WHAT HAPPENS IN THE LIFE OF OUR GROUP?**

This group has been a happy place where life has been pursued with authenticity and fervour, and friendships have been nurtured. Members exchange telephone numbers and addresses. They meet for coffee after the formal group session and call each other with queries, news of results from medical consultations, and for support at any time across the weeks. The women enjoy special lunches to celebrate birthdays and Christmas. Some have engaged as consumer advisers in group projects to raise funds for breast cancer research or other altruistic causes.

A typical session commences with reports from members on their current progress and recent test results. If a member is absent this arouses concerns and anxieties about a relapse. However, over time, the communication network ensures that members are kept informed of progress. Group time evolves around a variety of themes. As leaders we allow the group to raise issues and do not formulate tasks.

The group has become a place to discuss anything from traumatic aspects of illness and treatment, issues of assertion, new methods to deal with pain and discomfort, expression of feelings, through to seeking help with family difficulties. Members often express how they may look good on the outside, but feel rotten inside, and hesitate to talk with others in case they are seen as frauds. Comments highlight this, such as '*Cancer is a disease that laughs at you*'; or from one woman's son: '*Baldy - the problem is you look so good!*'

There is much discussion on how to protect families from the devastating effects of disfigurement as a result of breast surgery and hair loss, that leave them with a feeling of incomplete femininity and identity. The group provides an opportunity for open expression of such fears, and issues of sexuality and intimacy have been discussed at length.

A poignant area for discussion has been around death and dying. The women have confronted this with great courage and have been inspired by those who can discuss their pending death and its impact on family members, in particular, young children. An original group member declared it was '*a fight we have to develop*' and that fear of death was something that '*just creeps up... we have to confront it and take control*'. In dealing with issues about death, common elements have emerged. Often it has been stated that death is not what they fear but rather how they will die. It is important to maintain dignity and respect at the time of death. Another worrying aspect is '*slipping out of life on your own*'. Through the space provided for such sharing, the women have been able to think about ways of open discussion to prepare their family and friends for a

future without them. Over time these fears have dissipated and the women instead have found inspiration from the individual coping strategies.

On one occasion when the issue of death notices arose, a member declared that she did not want her notice to report that she had died after a long illness: '*My life has been much more than that*.' Other comments included '*Yes, we certainly don't want 'battle' put in*' and '*We have really been living*.' Most members of the group, including the therapists, attend funerals of those who die. Recently it has been common for partners and children of other deceased members to also attend, indicating a genuine connection to the wider family. As group therapists, we have been impressed by the development of this sense of cohesiveness within the members, that has extended beyond the life of the group.

The women frequently express the importance of the group to individual members. Identifying themselves as *The Thursday Girls* they declare how the group has become the highlight of their week. Learning to take control of their lives has developed as another major positive gain. This has many forms. One member made the decision to change her GP after twenty years. She had felt that she should remain with the original one even though there was little sense of empathy. A few women entering the group have felt negative about their medical treatment and their inability to engage with their doctors. Gradually, with the help of other members they have seen the benefits of trying new chemotherapy as well as other alternative treatments perceived as helpful. Knowledge acquired through group discussion and informed reading has led to more enlightened and assertive questions to oncologists and GPs.

Recognition has developed within the membership about the importance of the formal therapy conducted within session time versus the social support provided outside. Sessions are not for chit-chat, which is reserved for elsewhere, but are dedicated to the shared journey with advanced breast cancer and its treatment. Experienced group members differentiate issues of purely social relevance from important matters that affect members.

A comment might be introduced such as 'When you were telling me about 'X' the other day, it struck me that it was an important issue for us to share together here in the group.' This ensures reservation of group time for relevant agendas and involves facilitators in the optimisation of the coping and adjustments of members. Each member generally has time to provide updates on their health and progress, to raise important family issues and to explore other areas of concern.

### **IMPACT OF SEGT ON TREATMENT ADHERENCE**

Involvement in SEGT is about the optimisation of quality of life. High-level evidence has confirmed the capacity for and efficacy of quality of life gained through membership and weekly attendance at SEGT. This is the primary reason for any woman to join such a group.

Group members compare models of care with regard to the use of pathology tests, monitoring tumour markers, choice of treatment regimens and even dose levels proportional to side-effects for some of these regimens. Knowledge of the illness and its treatment is enhanced through group membership and there is a consequent direct impact on the actual anti-cancer treatment received. This has led to better doctor-patient relationships. Several factors influential in this development include:

- greater clarity in the women's minds with regard to their needs
- the appropriateness of their assertiveness to have these needs met
- the value of preparation for each consultation
- the development of satisfaction with the doctor that provides a reciprocal feedback loop with further consolidation of the relationship
- beneficial effects for doctors who appreciate this open and fruitful communication.

Since doctor-patient relationships are so significant to not only the health, but also the emotional and psychological well-being of the women, considerable time is devoted to the optimisation of the communication

involved in these relationships. Sharing such experiences proves most informative. On occasions, members will seek out second opinions with regard to their care as a result of encouragement from other group members. Group support can prove empowering, as having the courage to seek a second opinion is quite difficult for some members. Gradually a group-as-a-whole confidence has emerged about what is legitimate to expect from each medical consultation. When an issue of delayed diagnosis, false reassurance or simply a poor standard of care has occurred, patients do well to establish a new relationship with a different professional.

Much scientific debate has occurred since 1989 when David Spiegel and his colleagues from Stanford University reported a significant extension to life from involvement with SEGT in the *Lancet*. Was this a chance finding? One scholar pointed out that the overall survival of the control arm was unusually poor in that study, with the group arm achieving standard care. A replication study conducted as a multi-site randomised controlled trial across ten provinces in Canada (reported in 2001 in the *New England Journal of Medicine*) did not show any increased survival. However, many variables could affect this result, such as the training and experience of the group therapists. It is hoped that the large survival benefit of nearly eighteen months extension to life found in the Spiegel study will prove to be the norm in future studies.

Our study in Melbourne has also been a replication study to explore the hypothesis of whether SEGT might increase survival. An observation that has impressed our team is the tendency for group members to accept initiation of anti-cancer therapies and to persevere longer with these treatments. This process is often termed *treatment adherence*. An illustration of *treatment adherence* is found in women who join the group and express a dislike of chemotherapy. One woman recalled an unhappy experience with her adjuvant chemotherapy during initial treatment some years before for early stage breast cancer. With the development of secondaries in her lungs, her oncologist had recommended the reintroduction of

chemotherapy. She had flatly refused. This woman was breathless in walking across the room for her introductory session. The group listened to her story and sympathised with her difficult past experiences. She was welcomed and accepted by the other group members. As a few weeks went by, she heard others talk of their chemotherapy, and began to learn more about the aims and side-effects that they tolerated. She seemed inspired by the courage of the women, who also challenged her attitudes quietly and emphasised the value of her life. Over a few sessions, her attitudes to chemotherapy became less emphatic. She asked more questions of her oncologist and accepted a trial of a regimen. The group support increased her awareness of her options, including the option to change her mind about what she chose to do. She did not appear to feel pressured at any stage, and we marvelled at this change that the group induced and that her oncologist was unable to do.

What emerges from the group experience is a determination by members to get maximum benefits out of any medical or alternative treatment regimen because they better understand its intent. As a result, group members often complete nine cycles of a chemotherapy regimen while many clinical counterparts who are not in the group study stop after six. We have a strong clinical impression, now to be tested by formal research, that group members receive more anti-cancer therapy than other patients with comparable disease, who lack the endurance empowered by the group.

While we don't want to encourage false optimism about the 'mind over matter' power of group therapy to enhance survival, we acknowledge that there may be more simple mechanisms in operation. If women can better understand and make use of the anti-cancer treatments that medicine has to offer, improved outcomes for all may be achieved. It could also be part of the bigger picture in which these women take control of their own treatment, whether this be conventional medical therapy or alternative medicines. This is but one positive achievement of group participation.

## LONG-TERM BENEFITS FOR FAMILIES OF THE DECEASED

Before we conclude our reflections on the experience of SEGT, some mention of the support from surviving family members is important. Spouses become well-connected with group members and their relatives over time. This becomes a source of tremendous support during bereavement. The group maintains an interest in the activities and well-being of the bereaved, and reaches out with sympathy and concern to ensure that grief is coped with over time. This reassures the women, who realize that, when their turn comes to die, their family will receive support and consolation.

Group members enjoy hearing from the relatives of deceased members for several years after the death of a member. This serves not only as a happy commemoration of the lost member, but also as welcome news of how relatives cope beyond the life of a loved family member. Groups are not only generous and supportive during the last illness, death and funeral of a group member, but they communicate concern for relatives when times are hard. Such altruism is an example of the wonderful spirit that is perpetuated through the group experience. Spouses and children of deceased members continue to attend funeral services of other members and are invited to extended family celebrations at Christmas.

## THE WOMEN SPEAK FOR THEMSELVES

This book grew out of ideas from the women. It tells of their life experiences with both humour and pain, as together with their families they draw on their courage and endurance in their journeys with cancer. We commend their stories to you and know they will speak for themselves. We hope you will be touched and inspired by their lives as we have.

## CONCLUDING NOTE

*The Thursday Girls* group has had one new co-therapist and an additional three new members since the stories in this book have been told. David Kissane departed in July 2003 to take up a position as Head of Psychiatry and Behavioural Science at Memorial Sloane-Kettering Cancer Center, New York. Fiona McDermott, who was co-facilitator of a similar group with Christine in another hospital setting, has now replaced David. The two remaining women in our other group, Barbara and Mary, transferred to *The Thursday Girls* group and another new member Chris D. has joined recently. Should any readers be invited to join such a group to accompany them through their final years, we hope that this report of SEGT, and the courageous human stories narrated here, will inform and guide their choice.

*Christine Hill* RGN, MAPS is a clinical psychologist and psychotherapist and President of the Australian Association of Group Psychotherapists.

*David Kissane* MBBS, FRANZCP, is Head of Psychiatry and Behavioural Science at Memorial Sloane-Kettering Cancer Center, New York. He was the previous Director of Palliative Care, University of Melbourne.

*Fiona McDermott* PhD: is a Senior Lecturer in the School of Social Work, University of Melbourne and a member of the Australian Association of Group Psychotherapists.

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## 3

## INDIVIDUAL JOURNEYS

*Jean's story*



My name is Jean Brown. In June 1990 my life changed forever. A diagnosis of breast cancer was to have a profound effect on my very existence.

I was born on 30 September 1936 in Stretford just outside Manchester, England, which makes me a 'Lancashire Lass'. My brother, Donald, is eight years my junior. I have happy memories of bicycle rides and picnics in the Cheshire countryside with my family. Manchester, in spite of its grimy industrial exterior, always had its share of culture. I enjoyed theatre and musical treats such as the Halle Orchestra conducted by Sir John Babirolli, and visiting world class artists. Musical shows were often tried out first on Manchester audiences, reputed to be unforgiving. If they got past us they would go on to London and other less down-to-earth venues.

After leaving high school I worked in the local public library and studied for a librarianship qualification. The travel bug hit and after holidays in Italy and Switzerland I took the plunge and came to Australia in 1960 as a migrant on the £10 assisted-passage scheme. I travelled with a girlfriend who also settled in Melbourne and remains a dear friend to this day. In 1970 I met my future husband Bill and we married in 1973, settling in Melbourne.

Life was pleasant until that awful day in 1990 when I discovered a lump in my left breast. I did nothing for two weeks, hoping the lump would go away or was a figment of my imagination. But it wasn't! I underwent a mastectomy and recovered well physically but was changed emotionally.

For someone who hardly had been ill all her life and hadn't been in hospital, it was devastating. Suddenly I faced my own mortality and felt vulnerable, scared of the future and what it might bring. As someone once said *'It's not so much the dying, we all have to die, but it's how.'*

However, the cancer didn't appear to have spread and life for the next six years returned to almost normal. I found a greater appreciation of life, friends and everyday pleasures, and experienced a heightened awareness of the world around me. The loss of a breast was not as traumatic as I had thought - I was grateful to be alive! There were lighter moments too, such as the day my prosthesis slipped its moorings and fell into the vegetable patch, sitting like a surrealist slug amongst the foliage. Thank goodness for a sense of humour!



However, fate did not let me escape so easily and I suffered a great deal of leg pain following a car accident in 1996. Eventually an MRI showed a tumour on the lumber spine that was treated with radiotherapy followed by Tamoxifen. This involved a stay in the Peter MacCallum Institute to control the pain as I underwent radiotherapy. I can't emphasise enough how wonderful the 'Peter Mac' staff were. Of course the bottom line is that all the patients have cancer and I found it all very

depressing and confronting. There was no way anyone could get me to join the therapy group to paint plaster gnomes. I stuck to my book and was given up as a lost cause on the gnome front at least!

Confronting secondary breast cancer was much more of a challenge

than the initial diagnosis, as hopes for a cure now receded and I fell into a deep depression, losing interest in everything. Fortunately I had an understanding and perceptive radiation oncologist, who suggested I have some counselling. This proved to be a turning point and I decided to join a cancer support group to provide a boost to my emotional well-being.

In July 1997 I turned up one Thursday morning at Box Hill Hospital for the first meeting of the group, feeling nervous, wondering what I was doing there and what to expect (like everyone else). Little did I know that over four years later I would still make my weekly journey, through good and bad times, to group meetings. As part of a research project, the group was planned originally for twelve months, so I guess everyone including the researchers are amazed it has lasted so long!

It did take a while to settle into the group and feel comfortable baring one's soul to almost complete strangers. I didn't say much for a while, but I listened carefully and absorbed all this new-found information. Members of the group have been a constant source of companionship, comfort and loving support.

Meanwhile in 1998 a tumour was discovered on my thoracic spine and so began another round of radiotherapy followed by Arimidex, a hormone therapy. Unfortunately spots appeared on my liver, and it was then into the unknown realms of chemotherapy and Adriamycin. Thank heavens for the ladies of the group who had been through 'chemo' and could offer advice and support on side-effects, such as hair loss and where to obtain a flattering wig.

Losing your hair is such a blow to your femininity. At least when losing a breast you can hide the fact with a good prosthesis and no one, apart from your nearest and dearest, is any the wiser unless of course you lose it in the vegie patch! The purchase of a wig was made more bearable, and even amusing, by shopping with a good friend who always gave an honest opinion. There was no chance of a radical transformation to redhead or brassy blonde, or even a 'Morticia look-alike' - my own rather faded

ash blond was the choice. It worked brilliantly and most people didn't even realise I had lost my hair. The same friend also helped me with a wig update. My wig also has been the subject of an after-dinner incident when it was almost removed by some errant chopsticks.

My journey continued with a recurrence in the lumbar spine in 1999, followed by more radiotherapy and Femara, another hormone therapy. My condition stabilised and my husband and I took a trip to Canada and the USA in July-August 2000. I had no problems and regained my confidence to travel further afield. My advice is: enjoy the experience and sense of achievement in spite of frustrations, such as being unable to obtain full travel insurance - you can always catch a plane home.

Late 2000 brought the news that the spots on my liver had increased, so in February 2001 I joined an 'Improved Access Program' for Herceptin that involved treatment every three weeks with Tascol, a chemotherapy drug. The initial response was good with my high tumour markers plummeting, but by September the Herceptin was no longer controlling the problem so it was on to Aromasin, another hormone therapy. I was so disappointed and depressed that after seven months of treatment I seemed to be back to square one; but I guess I would have been worse off if I had no treatment at all. Now I find that the Aromasin is not working, liver tumours are growing and markers are going up. We are trying another chemo, Navelbine.

The uncertain, unpredictable and insidious nature of this disease goes on. Constant visits to hospitals and interminable waits in consulting rooms take their toll and almost take over your life. Should one have the mail redirected to the hospital? Frustrations such as fatigue, being unable to walk so far or to do as much gardening as before are upsetting. In particular, I have found it difficult to be feeling well and then have to face up to a course of debilitating chemotherapy with all its side-effects, not knowing if the treatment will have a positive response.

Suitable veins, or lack of them, proved a real problem for me, but

life has been made easier with an infusion port tucked away near my remaining breast. At least treatment and blood collection can be made via the port, much to my relief and I'm sure the relief of oncology staff.

An aspect that has surprised me most in my journey is that many good and positive things have emerged. My marriage has been a happy one and I am blessed with a caring and supportive husband who must also find the journey difficult. Our relationship has become stronger. He shares visits to the oncologist and for treatment, and is always ready with a supportive hug. Through my journey I feel that I have developed as a person, becoming more tolerant with a better understanding of myself and a greater awareness of the joy of life. What a pity it takes a life-threatening illness to make us appreciate life!

Friends are a great support and I am grateful for this. Neighbours are concerned for my welfare, and work colleagues before I retired in 1999 helped me through some difficult periods of treatment, including when I was about to shed my hair for the first time. My Manager suggested that all the staff should shave their heads in support. After treatment when it was time 'to come out', I plucked up the courage to appear in the office sporting a 'Judy Dench' hairdo. The younger members of staff reacted with '*cool*'; so I retired to my office feeling really 'with it' for the day. There are some great and caring people out there and most of the medical fraternity involved with cancer care seem to be hand-picked for their care and compassion. I feel I have made friends with some of them and value their friendship as well as their professional expertise.

My experience as a member of *The Thursday Girls* group has been interesting and rewarding. I have enjoyed my involvement with consumer affairs, including participation in a consumer affairs committee and Cancer Council of Victoria seminars, in addition to the provision of suggestions for improvements to the Breast Cancer Enhancement Program of the Victorian Government. My library background has stood me in good stead, and I have been able to do Internet searches and pass on information

to the group. My role as *The Thursday Girls* 'secretary' is enjoyable and gives me a focus and a chance to use my library skills.

Facing up to the death of members of *The Thursday Girls* who had become dear friends was something I didn't think I could cope with. But I did. We have lost five members of the group this year (2002). They dealt with their illness with great fortitude, and helped us all with the concept of death and dying.

The next chemotherapy tried was Navelbine in October 2001. Unfortunately this stopped working, so I suggested another hormone therapy, Megace. The next treatment was another chemotherapy, Xeloda, which is given in tablet form. This treatment started off to be quite worrying as the liver was getting out of control, but I have gone through three cycles now and blood tests seem to indicate that the Xeloda is bringing calcium down to more normal levels and shrinking the liver tumours. Palliative care has been outstanding in their assistance to me with all sorts of aids. We have been surrounded by people installing equipment, offering Reiki sessions and massages and anything else that may assist us. Talk about five-star service!

I have tried to keep my quirky sense of humour throughout this journey and am fortunate to share it with a friend who started a 'bat' theme in 1990 when I was having the mastectomy. A bat card arrived at the hospital with the inscription 'hang on you old bat!' We have kept up this somewhat bizarre theme with bat cards and balloons and even a bat birthday cake.

Who knows where my journey will take me? It will be a challenge, but I know I have the love and support of many caring people around me. Thank you all.

### ***Reflections from Jean's companion***

My name is Bill Brown. My wife Jean was diagnosed with breast

cancer in June 1990. To say it was a bolt from the blue is an exaggeration. These things happened to other people, not us! Within a couple of weeks everything had changed. Jean had her operation and I, as the onlooker, was introduced to a new world that has now become familiar, more a way of life. No after-treatment was prescribed and Jean made good progress, resuming her life, work and various activities with only periodic checks. She had been lucky with her health and used to have shots at me, the '*old hypo*'; as over the years I had problems such as sinus and kidney stones. However, the Nineties changed her life with a vengeance.

In 1991 Jean had a fall on route to work, breaking both wrists. She had no more problems with the cancer until 1996, which was a bad year for us. In the February we had a serious car accident that Jean got the worst of with a broken ankle as a result. After being in plaster for six weeks, she had physiotherapy. When she suffered extreme pain in her leg, all the medicos assumed it was linked to the accident. However, X-rays and ultimately an MRI showed that there was a tumour on her spine. She had a spell in the Peter MacCallum Institute where she had radiation therapy. This seemed to do the trick and after a period of recuperation she resumed work three days a week until she retired in 1999. Her work involvement was very therapeutic for her, and no praise is too much for her understanding boss who remains one of our dear friends.

At the time of the return of Jean's suffering I must admit my own state of mind was fraught. When I heard that her back problem was indeed cancer, I broke down. It was all so unjust. Jean, who was in great pain and taking morphine, seemed almost relieved, thinking at least now the problem was revealed it could be treated, and some solace was in sight. In contrast, my view was that, as Jean had been subjected to so much pain and angst since the car accident, this return after six years of what we thought we had beaten was a devastating body blow.

Jean soldiered on, and in 1997 a great event happened. Jean joined a therapy group of ladies who all had secondary breast cancer. Initially

there were a lot of misgivings: *Was this a good idea? Do we really want to listen to other people's moans and depressing problems?* ... Anyway, the group seemed to take off. Now four years later it is still going. Originally eight strong, there are now ten of *The Thursday Girls*, a formidable team that only the courageous would dare cross. Of course, a few have passed on in the four-year period and those doughty characters remain in our thoughts. If there is an afterlife I am sure they will look down and nod their approval each week. I am happy to say that I have met all of them past and present. If Jean's treatment coincides with the Thursday meeting, I often join them for morning tea. Recently I was accorded the title of 'Thursday Boy', so that accolade can't be bad can it? I have met some of the husbands, partners and carers. I certainly know, like Gilbert and Sullivan's policeman, the lot of a carer is not necessarily a happy one.

The Cancer Council seminars I have attended give a good perspective on the problem of cancer, from the folk who live with it to the staff who dedicate their days to helping and understanding the emotional side-effects of the illness. Jean battles on and *The Thursday Girls* are her great inspiration - those eccentric, feisty and caring, lovely ladies. May they be immortal and, like that famous brand of paint, keep on keeping on!

#### CONCLUDING NOTE

Sadly, Jean passed away on 29 January 2003. One of the original women to join *The Thursday Girls* in 1997, she was secretary, gift buyer, consumer representative, friend and confidante. She was very involved with the book and a great believer in our group. She was our lynch pin, a positive person whose favourite saying was *I'm not about to fall off the twig just yet!* We miss her impish humour, her goodness and her love.

#### *Gail's story*



My name is Gail Carnell (a Picasso wannabe). I was born in Innisfail, North Queensland in 1940. With warning of an imminent bombing attack on Darwin in 1942, my family evacuated to Melbourne and settled in Frankston, a seaside township (now a city) about 45 km south of Melbourne. I remember a happy childhood with loving parents and siblings. At seventeen, I enrolled in an SRN course at Bethesda Hospital and took to nursing like a duck to water, even managing a couple of prizes.

After four years at Bethesda, I travelled with a friend overseas. We spent three weeks at sea on the *Fairstar*, a popular ship of the time. As we sailed out of Melbourne we gobbled a box of chocolates we had been given. Needless to say we were both seasick and spent the next three days in our cabin. After one year away I returned to Melbourne and commenced a Theatre course at the Royal Children's Hospital, which I loved. It was there I met my husband Alan at a dinner dance for the visiting West Australian hockey teams. Nurses were often called upon to be partners for visiting teams.

Within a couple of years Alan and I were engaged and we married in 1966. We have been married for thirty-five years and have three beautiful children: Anne, Michael and Richard. My hobbies and loves are my family, pets, painting (especially watercolour), the theatre and art galleries.

The start of my journey with breast cancer was a little different from the norm. Instead of having stage 1 and progressing to stage 4, I

had stage 4 and proceeded to go backwards. In November 1993 a small lump in my left breast and a larger lump in my neck were investigated. The result was lobular cancer with metastases. All sixteen auxiliary nodes taken were affected, as was the node in my neck. I had a modified radical mastectomy and a couple of days after the surgery the surgeon noticed I was extremely pale and ordered a blood test; my haemoglobin was 6, the normal being around 13. Back to theatre I went and had a five-stab biopsy done on my right breast and a bone marrow biopsy. The results weren't good: I had lobular cancer in the right breast as well and a 98% invasion of my bone marrow. This equates to stage 4 lobular cancer - not a good stage, as the next stage is 'pushing up daisies'!

I was discharged from hospital on Christmas Day. A moving gift from my family that day was a framed letter expressing their love and support for me. Of course I burst into tears, I was so touched.

Next were the treatments. In my case the tumour relies on oestrogen so the oncologists tried me on Tamoxifen, a hormonal treatment aimed at blocking the production of oestrogen. After eleven weeks I hadn't responded and was very ill. They started me on chemotherapy, a mix of Adriamycin and Cyclophosphamide plus blood transfusions for the low blood counts. After the second dose of 'chemo', Alan was convinced that the treatment was working. It was, and I went into remission for approximately three years. Before this time my feelings are best summarised by what I wrote in my diary (August 1994):

In a daze not a lot of emotion

Guilt - disrupting our family life, obstructing my daughter's career (She had flown home from overseas the minute she heard of my plight and was looking after me.)

No motivation

Feeling isolated - a prisoner in one's own body

Desolate feelings

Cried to the depths of my soul - felt better afterwards

On a roller coaster

Rolling with the punches, just to survive

i Anger, mainly at one oncologist who asked if I had my house in order. I wrote: *'I'll show him!'* I didn't want to hear those words. I saw it as taking away hope and without hope what have you got?)

Love for my husband and children and my wonderful friends. (I must say there were a couple of hurtful disappointments in my friendships, but time allows more understanding of some people's behaviour and enables you to move on.)

My daughter resumed her work in occupational therapy and I was delighted. However, I was alone then each day until Alan came home in the evening. These were often lonely and thought-provoking days. I couldn't work, as tiredness was awful after 'chemo'. I had to search my soul for what to do. I decided to throw myself into my art that I had neglected. I found a new world for myself. When you are fully absorbed in an activity, you don't think so much about other problems. This was a wonderful therapy for me, but I still felt the need to express my worries and fears to someone. Most would agree that you try to protect your family and friends as much as possible from pain and suffering.

One day I heard a lady by the name of Jen Rusden on the radio talking about starting a breast cancer group called *'The Daffodils'*: I thought *'that's what I need'* and I rang her and joined. Jen was a wonderful and inspiring lady who was a ground-breaker of her times. It was the first breast-cancer-only group formed, and it was great to be able to discuss our special problems without having to burden family and friends - problems such as: wigs and where to purchase them; tiredness and how to combat it; the loss of eyelashes and eyebrows. The group runs a program that is free to cancer patients entitled *'Look Good, Feel Better'*: They show you how to apply make-up, how to choose wigs, how to tie scarves in nifty ways and the best type of hats. They also show you how to relax/meditate and explore alternative ways to enhance the spirits. You are advised on

diet, because a lot of women suffer with nausea and diarrhoea whilst on medication and a good diet and supplements are required. Different treatments are discussed - who's on what and for how long and what are the side-effects. Through this type of communication with other women in similar circumstances, we learn to have more empathy for others and to know when to let go of the 'rubbish' that often takes over our lives. When in treatment, feelings of depression, tiredness, sorrow, and anxiety about results and what lies ahead can often take over (similar I imagine to Damocles with the sword hanging over his head by a hair!). Fortunately you don't always feel like this.

The next recurrence of cancer was in my right pelvic area, near my femur, that made weight-bearing very painful. I had ten sessions of radiotherapy, which worked well except for a burnt anus and diarrhoea.

I am forever grateful for an ointment called Xyloproct that gave much needed relief. A hormone treatment was prescribed called Arimidex. This is an oestrogen inhibitor and usually prescribed for women who have an oestrogen receptor-positive tumour. This treatment was effective for about eighteen months. During this time I enjoyed reasonable health, and did many things. I became a volunteer at Yooralla, going once a week to help in the schoolroom. I figured if you help someone less fortunate, you end up helping yourself. The kids were wonderful. I became especially fond of Leo, who was blind as well as having cerebral palsy. His hands were his eyes and this could be a challenge at times. And there was dear sweet Anna, who had severe cerebral palsy and laughed at all my corny jokes. I recommenced art classes and worked two days a week at our furniture business, where I did sales and gave decorating advice. Each week my friend Patty and I visited an art gallery, and of course had an enjoyable luncheon as well. These visits had an amazing effect on my art. The knowledge one gains by looking, inquiring and educating oneself has a flow-on effect, and my paintings have become larger and bolder since.

At this time another wonderful gift came in the form of a small Jack

Russell x Fox Terrier called *Johnny*. My daughter Annie lured me to the Blue Cross animal shelter after our darling fifteen year old poodle, *Bindy* had passed away. *Johnny* leapt into my arms, put his paws around my neck and was declared by all and sundry to be the dog for me. We love him intensely and I give him a lot of credit for my amazing survival, simply because of the good feelings evoked when love is returned.

Around this time I joined *The Thursday Girls*. I had lost confidence in my GP and felt that he had been remiss in his treatment of my cancer. For six months he had dismissed the lumps in my breast and neck as just swollen glands. He had not even inspected the breast lump. Having been trained as a nurse in the 1950s, I had been taught to almost revere doctors as gods who were always right. So I thought I should remain loyal. However, in discussion with the group, my peers strongly encouraged and assisted me to construct a letter about my treatment. The letter was to the point but still a nice letter, explaining that I was now moving on.

In 1999 I experienced bloating and sudden diarrhoea at the most inopportune times, as well as headaches and visual disturbances. The day before my husband and I were to leave on a holiday to Darwin I had a CT scan and an MRI brain scan. Nothing showed up on the scans, so off we went. It was not a successful holiday, as I didn't feel at all well. My abdomen was swelling daily, to the extent that I had to buy clothing two sizes larger to camouflage it. I arrived back to Melbourne winter wearing white elastic waist shorts and an XXL T-shirt, the only clothes that fitted me! When I rang my oncologist to tell him about my 39 inch waistline he instructed me to go to hospital straight away where they drained three litres of fluid from my abdomen.

After further CT scans it was discovered that my cancer had set up in the omentum (an apron-like structure that envelops the bowel to hold it in place). I was put back on 'chemo', the treatment being Taxotere with an IV infusion every three weeks for eight doses. While I didn't go into remission, the cancer was described as being 'under control'.

There is a blood test used for breast cancer that shows a number (markers CEA and CA153) that represent the cancer growth and activity. As I understand it, the markers are a measure of a protein expelled by the cancer cells. A few months after completing my chemotherapy, these markers went up indicating further cancer activity. I was sick and tired of treatment, with the accompanying lethargy, hair loss, lack of eyelashes and eyebrows, not to mention libido, and diarrhoea. Was I to be on treatment for the rest of my life? It is times like this when you need a loving husband/companion and family together with a few really good friends. I am so lucky to have all these. The lives of families affected with cancer are different, and prolonged treatment puts enormous stress and strain on relationships. My advice is to seek help - I did!

So yet another treatment, this time Xeloda, an oral chemotherapy that at least avoids the interminable injections. I tolerated the treatment well although I felt a bit lethargic, with some peeling skin on the soles of my feet and around my fingernails. After eighteen months those wretched markers started their march up again. More scans showed the problem this time was in my left pelvic area (in the bone) and multiple bony areas in the skull, spine and ribs. The pelvic area is painful because of its weight-bearing significance, but I was assured that ten sessions of radiotherapy would do the trick. When told that I had metastases in the skull, I had the scary vision of them eating their way through to the brain. I have been reassured that it doesn't happen in this way.

My oncologist is terrific. He informs me promptly of the test results, and I feel he has my best interests at heart. The nurses and medical staff are special people, so friendly and empathetic. It's important to have caring, friendly and fun-loving people around you through this journey with cancer. It is a tough call for anyone, and in the end it is the people around you who count, not your wealth or material possessions.

Over the last few years I used to pick up Susanne (a past member) each Thursday morning on the way to the group meeting and we became firm

friends. We even joined a watercolour painting class and often painted together. The only problem was that we did more talking than painting. Susanne was much younger than me, but we hit it off and I miss her enormously. She passed away in March 2002 but I still expect to see her at the group each Thursday.

When my daughter Anne noticed that we were self-funding gifts and outings she set up a committee to raise funds for the group. They organised a cocktail party with a 'Moulin Rouge' theme, fresh in people's minds after the Australian premiere of the movie. The party was held at the trendy 'Smit Bar' in St Kilda, Melbourne and they decorated the bar as a Parisian nightclub. The committee dressed in little black numbers, scarlet feather boas and head dressing, all in keeping with the theme. The event was a huge success and raised \$6500 for the group.

We are indebted to the committee for their cheerful and loving support. As the amount raised far exceeded our expectations, we wondered how to best use it and decided to write a book about our experiences in the hope that it might help and inform others. None of us were professional writers but it was amazing how many contacts we had in this field. The project has been an enormous challenge and the excitement generated has made us bond even more.

#### **CONCLUDING NOTE**

Sadly, Gail passed away on Monday 4 August 2003.

#### ***Reflections from Gail's companions***

#### **WINTON KNOP**

This is an extract of reflections made by Susanne's husband Winton Knop at the Celebration Ceremony for Gail on Friday 8 August 2003.

Alan and I now share something we were not looking for in life: we join a growing demographic group in society called 'widower'. We also have a unique connection through the special relationships that our wives shared in that infamous *Thursday Girls* group. This is a Celebration Ceremony because, in addition to celebrating Gail's life, we can also celebrate our association with *The Thursday Girls*. This band of courageous women fight not only to make a difference in their own lives but in the lives of others. Yes, we celebrate that.

We also celebrate the good work and guidance of David Kissane and Christine Hill, with whom valuable research has been done on the power of sharing in the unique journey of breast cancer, with its treatments, personal struggles, wavering emotions and valued relationships.

We celebrate all that *The Thursday Girls* research group has accomplished. Aside from the clinical outcomes that aid medical science in better understanding the physical, emotional, mental, spiritual and medical needs of the clients, the group has provided and continues to provide deep and enduring friendships, support, love, encouragement, laughter, understanding, accountability, celebration, empathy... the list goes on. These are invaluable intangibles, essential for such a challenging journey. We thank all those associated and hope the group may be allowed to continue to provide this essential place in breast cancer research and care.

We also celebrate all those professionals and their agencies such as St Vincents Hospital, the Peter MacCallum Institute, the Blood Bank, Imaging Departments, palliative carers, and the Cancer Council of Victoria. We would have been lost without their professional ethic and practice in providing the best service and care for our loved ones.

There is one other celebration left for Alan and I: Although we no longer have our wives with us, their beauty, unique vibrant personalities, capacity to love, gifted creativity, and energetic influence lives on in our families and in our hearts. We see them in our children and miss them so deeply - the grief and loss is heart wrenching. I know it is not quite

the same, only a glimmer really, but nevertheless they live on in the next generation and in our hearts.

#### **MICHAEL CARNELL**

I am honoured to make this tribute to my mother Gail in memory of the life of a wonderful lady. As Gail would have preferred, she passed away quickly and peacefully on the Monday morning of 4 August 2003, after first being diagnosed with breast cancer in November 1993. The last decade was a hard struggle at times, but her happiness far outweighed the pain in a wonderful period of self development. Mum often said she had developed as a person due to her illness and, as everyone who knew her would agree, she maintained a healthy 'joy for life'.

Gail trained as a nurse at Bethesda Hospital. An early hiccup in her nursing career was when she was found nervously taking the temperature of a patient who had been dead for a couple of hours! But she carried on and blossomed into a fantastic nurse. Gail moved on from Bethesda to the Royal Children's Hospital where she gained extra qualifications as a theatre sister. She loved nursing and was incredibly proud of her profession. Whenever we debated anything medical in the Carnell household, Mum's signature line was to say *'I am a nurse you know!'*

In 1962 Gail and her close friend Betty headed off to see the world. Leaving as a naive Frankston girl, she returned a year later as a sophisticated and street-wise world traveller. However, this new-found confidence wasn't much help later when she became a sucker for the wise-cracking Alan Carnell. The Camberwell hockey club was hosting an interstate ball and needed local nurses to partner their guests. Gail turned up, Al chatted her up and the rest is history.

The relationship between Gail and Al plodded along for a couple of years until Gail announced that she was going on another overseas trip. But Al said *'No you're not. You're going to marry me!'* She settled well

into family life, becoming a wife and mother who will be loved forever by her family. Mum's life was all about family and friends, all of whom had their own special relationships:

Some of us made a connection with her cheeky sense of humour

Some of us were the victims of her practical jokes

Some of us were witness to her more serious side.

Whatever our relationship with Gail was, we can be sure that when we weren't around she loved to gossip about every one of us!

Possessing a natural ability to make people laugh, Mum told a thousand jokes throughout her life, but couldn't remember the punch line to one of them! Nevertheless, her humour was appreciated for the attempted delivery rather than the content.

One of our fondest memories is of family dinners at the Donvale home. You always knew that Mum would be ready with a glass of champagne and her favorite CD playing in the background - usually *Memories* from the *Cats* sound track played repeatedly through the evening, and every night thereafter for the rest of the year. Thanks to Gail, the Carnell family has little appreciation for the progressive music scene, but we can all recite the words to every song from *Phantom of the Opera!* She was happiest at these family gatherings on the patio by the pool. Her family, her devoted companion and pet dog Johnny, and the view over the pool made her as content as anyone could be.

Our house was always open to our friends and our friends were always Gail's friends. Her bubbly personality, striking good looks and great ability to interact with people of all ages attracted a steady stream of people to our home over the years. We know for sure that it was Gail they came to see, and certainly didn't call in for her cooking! Mum was not always the life of the party. She had many sad times and a temper that would put the fear of God into us. But that is best left for another time.

Art and theatre were a huge part of Gail's life. She had a good appreciation for it and was a terrific drawer and water-colourist in her

own right. This wasn't a skill she kept to herself, but one that she brought into our home. The Donvale house was always filled with creative art and she had a small studio space for her own works in progress. Being able to paint at a high level, she relished the chance to create her pictures as a present or to paint for a chosen charity.

After being diagnosed with cancer, Gail became more intent on beating the odds and tackled her problem with a huge determination. With the help of two terrific oncologists, she made the most of the next ten years. She orchestrated fortnightly family dinners, cherished her outings to the theatre with Jen, attended galleries with Patty, and dined out for lunch with Lillian. Later she joined a well-run cancer support group called *The Thursday Girls*. All suffering similar ailments, the women confront their situations with determination.

To talk of Gail is to talk of the people she touched. She brought light and laughter into the lives of all. My family thanks all her friends and relations for giving the same to her. My final acknowledgment is to Al, our Dad. Easily Gail's biggest inspiration was her marriage to Al. She was so proud of him as a husband and father.

#### ANNE CARNELL

The last Saturday before I left the hospital, Mum stopped me to say that she would like to make a tape recording for us. She wanted to say what a lucky life she has led, how happy she was to have a wonderful husband, three beautiful children and a wonderful daughter-in-law. She didn't get time to make the tape.

She was unlucky to get cancer. But to Mum the glass was always half full. For the last ten years she cherished every happy moment with her family, her friends, her pets and her beautiful world. I know she felt blessed in her life. I feel lucky to have had a Mum who has shown me how to love and be happy and to treasure all of the good things in life.

**RICHARD CARNELL**

**Gail's View**

*We will not stand at a grave and weep  
We will not deprive the salvation of sleep  
Champagne in hand and a view to you and me  
We will scatter her ashes from London Bridge and out to sea*

*Nervous hearts and trembling hands  
Together we will admire this part of the land  
Mum will be a thousand winds that blow  
Or a diamond glint in the snow*

*She will be the sunlight on ripened grain  
And the subtle warmth of autumn rain  
When we awake in the morning's hush  
Mum's memories will be our uplifting rush*

*For Gail's sake we can embrace this future mile  
And turn to life and give back that same cheeky smile  
Love won't end with dying or leave with her last breath  
For someone we loved so deeply, this won't end with death*

*Courage, willingness and strength may have given ten extra years  
How are we to know, let's ask her peers?  
Thursday Girls as we all know, what do they say?  
'Only one person knows!'  
'She is a nurse you know!'*

**Frankie's story**



My name is Frankie Brennan. In May 1983 I discovered the first lump in my left breast. I was in England with my husband John, a university lecturer, who was studying in the UK on a Commonwealth Teachers' Exchange. I took myself to a hospital in Cambridge where the Registrar performed a needle aspiration and drew out 15 ml of straw-coloured fluid. The result, one week later, was mammary dysplasia. It was suggested that I have a mammogram on my return to Australia since it wasn't possible for me to have one in the UK as I was not a resident.

At the beginning of 1984 we returned to Australia. I fell pregnant and instead of having a mammogram, I checked my breasts regularly and thought that all was in order. My daughter, Sarah, was born in January 1985. I breast-fed her for nineteen months; somewhere in my mind was the theory that if you breast-fed your baby you were immune to cancer.

In August 1986, as I travelled to hospital with Sarah who had suspected pneumonia, I was involved in a serious car accident. This brought about an abrupt weaning of Sarah as I required several X-rays and did not want to contaminate my milk with radiation. Now in a major public hospital in Melbourne, I remembered the cancer issue from back in Cambridge. The doctor did a mammogram and widespread calcification was discovered in my left breast. It was not malignant and I was recommended to see a doctor every six months to a year for check-ups, which I did at the Medical Centre of a major teaching university hospital.

In October 1988 I noticed that the other quadrant of the left breast had a small hard pea-like lump. I requested a needle aspiration and biopsy and a frozen section. The doctor I had seen at the public hospital, who was now at the University Medical Centre, refused saying that if every woman made this type of request the theatres would be overflowing. I was told to come back in six months. It is important to know that mammograms are not suitable for women under the age of fifty years because of the density of breast tissue - 10% fail to give an accurate diagnosis and come up negative, showing a non-malignant lump.

I returned in March 1989 to the University Medical Centre. The same doctor greeted me in an off-hand manner, saying *'Why are you back again?'* I was given a poke and a prod, but no mammogram, and reassured that it was *'a superficial node; it'll go away'* and to come back in two years. I knew something far more serious was going on - at night I could feel an electrical impulse going zing inside me from the pea-sized lump.

A month later I went to my family doctor with a sore throat that would not clear up. The fact that I am alive today is due to him asking *'Any other concerns?'* I told him about the breast lump and the treatment I had had to date. He was upset and angry about the gross medical negligence I had suffered. With some drama he referred me to a surgeon, saying *'No woman in her 40s should have a breast lump: A surgeon at a large public hospital performed a needle aspiration and expressed amazement that the University Medical Centre had failed to do so. In May the pathology report showed apocrine cells and recommended further investigation. However, the surgeon was lackadaisical about the report saying that this pathologist was 'a bit of a fuddy-duddy when it comes to cancer: In July 1989 I had to put the hard word on him.*

On Wednesday 5 July the surgeon performed a biopsy and a frozen section. When I woke up in the recovery room he said *'It's cancer'* and walked away. I was shocked. It felt like a death sentence. With a drainage bag at my side, my body was shaking with fear and anxiety. It was now

nine months down the track since I discovered the lump. I requested the surgeon see John and I that night. He spoke coldly about my breast having to be removed as if it were a dental extraction.

On Monday 10 July 1989 I had a modified radical mastectomy and the pathology report came through on the Thursday. The surgeon told reported no lymph node involvement and said there would be no follow-up treatment. What he neglected to inform me was that the report also stated that the cancer was stage 2, with ductile infiltration of the left breast and multifocal carcinomas.

A year to eighteen months later my nursing friends asked me why hadn't received any follow-up treatment. My sister, a nurse, suggested I get a second opinion regarding follow-up treatment, which I did with a general surgeon at another central Melbourne hospital. He protected the surgeon who had performed the mastectomy, saying *'He did the right thing: I was in and out in a few minutes. He wasn't interested in someone else's surgery. The pathology report was given back to me and on reading it I was alarmed. I transferred to yet another surgeon; these two men knew each other and were the top research men in the field of breast cancer in Melbourne. While my sister was saying I should be having follow-up treatment in the form of radiation, chemotherapy or Tamoxifen, this new surgeon was now reading the pathology report that had been in the hands of three of his colleagues. He was a fast worker, commuting between doors to two patients at a time. I could hear his conversation with the patient in the other room while I waited for him. A poke and a prod, 'You'll be right; you've got five years behind you already.'* Out the door, *'See you in six months:*

For the next four years I had six-monthly check-ups and a mammograph of the right breast once a year. At the five-year mark, one's case is ready to be dismissed. In January 1995 I saw the surgeon and had the mammograph. I felt fine. Then in February 1995 I was at work when I felt a horrendous pain going through my hip like a searing red-hot poker. The thought

crossed my mind - secondaries! I rang the surgeon, but all he suggested was that I drop in on my GP on my way home. I was given a diagnosis of rheumatoid arthritis. A bone scan showed degenerative changes with no tumours present, but my condition continued to degenerate.

In April 1995 I was in Ireland for the wedding of my youngest brother. My eldest sister, a nurse with thirty-six years experience of pain management, observed that my degree of pain was not compatible with rheumatoid arthritis. On my return to Australia in June, with the pain creeping up my body, I was referred to a rheumatologist. I took his prescribed drugs for a few weeks but the pain was getting worse. This practitioner, with his alarm bells ringing, booked me in for a bone scan.

At 11 pm on 29 June 1995, I was diagnosed with secondaries: 'extensive bony metastases'. I was admitted to hospital and referred to a medical oncologist who began three weeks of intensive pain control with morphine and an implant to arrest the growth of the tumours. This was a two-year endocrine chemotherapy implant. The pain was horrendous and I was very ill. I had ten treatments of radiotherapy to the lower spine over two weeks. Most of that time I was frozen with shock and lay curled up in the foetal position, with severe back pain. If I tried to get out of bed I had to use a walking frame or a wheel chair. I suffered severe constipation and bowel impaction, as well as vomiting from the radiation treatment. My sister came over from the US to look after my daughter. On discharge my sister continued to look after us until she had to return home. My condition started to improve, but I continued to have a lot of pain. In 1996 I experienced a horrendous back spasm. A bone scan diagnosed that I was in remission and after this followed a period when I was pain free.

In 1997 my health deteriorated again. The tumour on the left thoracic vertebrae flared up and I was admitted to hospital for another ten radiation treatments. In July 1997, I was nauseated and vomiting, and was admitted to hospital for intravenous therapy. No reason could be discovered despite blood-urine tests and scans as well as X-rays. My haemoglobin result

came back with a reading of 8 and I was given three units of blood.

My house was put on the market and my sister came over from Ireland to look after me for three months. I was discharged on a Friday in August and had to pack up by Wednesday the following week. We stayed with friends for two months, as the unit was not ready. Again I was readmitted to hospital with impacted bowels and vomiting. The MEPCA nurses started visiting. By September my iron count was down again. My family doctor gave me a full blood examination and my haemoglobin was 6. Back to hospital again and a further four units of blood. With the impacted bowel, I had to go to theatre to have a perianal abscess excised. The platelets were very low: 30,000, when normal is around 150,000. This low clotting factor made me anxious about theatre - I was shaking like a leaf wondering if I would recover. CMF chemotherapy was commenced as well as Aredia, a drug to strengthen the bones destroyed by cancer.

In November 1997 I moved into my unit and two weeks later my sister had to return to Ireland. I coped until June 1998 when I had severe pain in my right rib cage and was hospitalised to bring the pain under control. I was too distressed to receive radiation. On the Thursday afternoon I was given a large dose of morphine (120 mg) and only remember coming to on Saturday morning. I had been hallucinating and could not account for one and a half days. Lying flat in bed I had developed a chest infection due to the effect of the morphine on the respiratory system. By Tuesday the infection was bordering on pneumonia and that took ages to get over.

A week later I was re-admitted with severe vomiting and diarrhoea. I couldn't keep anything down and was severely dehydrated. I was given intravenous therapy again; my haemoglobin was down to 6 and I needed another four units of blood. My appetite was, and continues to be, poor. A month later I developed tachycardia (a thumping heart) and my colour was bad. Anaemia was suspected and I had a full blood examination; my haemoglobin was 6 again and I had another four units of blood.

From May 1983 until September 1998 I have lost everything through

pain and illness: my marriage, job, income, home and health. Should I let these fellows off the hook for their gross mismanagement and negligence of my case? I cringe every time I hear them say *'We've got all the cancer, dear:* What was the point of finding the lump early if I was going to be dismissed? Is that another myth, that early detection will mean early and successful intervention of the disease? I phoned these medical practitioners and gave them a blast, but with arrogance they replied *'We stand by our decision'*. Are they not prepared to learn from their mistakes? I have paid a high price indeed for medical mismanagement.

In the UK no woman is dismissed after surgery - there is always follow-up treatment. Australian women are compromised; the surgeons fail women by not keeping up with world treatments. There is an arrogance amongst doctors regarding non-referral to medical oncologists. Why aren't the medical oncologists asking questions about non-referrals? There is a conspiracy of silence. A four-pronged approach is needed that includes the surgeon, medical pathologist, medical oncologist and medical radiation oncologist, with all four working together. It is a myth that Australia leads the world in the treatment of breast cancer. I hope my experience informs and alerts other women and their daughters to the dangerous minefield to be traversed on the journey of treatment with breast cancer.

#### **CONCLUDING NOTE**

Sadly, Frankie passed away on 14 October 1998. This story was recorded by Cynthia Parker, MEPCA Volunteer. *The Thursday Girls* remember Frankie fondly. She would have us almost falling off our seats with her Irish humour. She regaled us with stories, such as the time when she took her dog to the vet and he referred to the 'bitch', to which Frankie retorted *'Who - me or the dog?'* Her favourite bedtime reading when unable to sleep was 'The Rise and Fall of the Third Reich!' Who said group therapy was all gloom and doom?

#### ***Susanne's story***



*Born at Bethesda Hospital on 4 July 1956 to Don and Dawn McCoy, Susanne was the second of six children, three girls and three boys. After secondary education at McLeod High School she trained in primary teaching at Melbourne Teachers College. She was an outstanding netball player, chosen as a state representative within the Salvation Army interstate competition. During this period she met and married Winton Knop in November 1977 and began her teaching career at the Preston East Primary School, where she taught until the birth of Ashley in April 1981.*

*In March 1982 Susanne and Winton entered the Salvation Army Officer Training College in Parkville to train for ministry as full-time officers within the Salvation Army. They served together over the next eighteen years in three church appointments: Emerald (where Benjamin was born in June 1984), Bairnsdale (where Christopher was born in October 1988) and Warragul. Then followed four years as training officers at the Salvation Army Training College, and six years in Youth and Children's Ministry. Susanne always took a full and active part in all aspects of ministry during these years, and was well respected for her teaching, preaching, and pastoral care for people.*

*Susanne had many artistic talents including painting, ceramics, many forms of handicrafts and calligraphy, as well as having a delightful singing voice, used constantly during her life within the Salvation Army. A love of reading and journaling has left us with a rich account of Susanne's journey with cancer. Please read on.*

For Christmas 1996 my eldest son Ashley gave me a lovely large notebook. I wasn't sure what to use it for but a purpose soon came to light. In February 1997 I was diagnosed with breast cancer and decided to record my experiences.

Because of my optimistic outlook on life I expected my doctor to tell me that the lump in my right breast was nothing. When he sent me for an immediate mammogram and ultrasound I was taken aback. *'It is difficult to know how to react to the possibilities'*, I wrote in my notebook. *'I feel fidgety - wanting the time to pass so that I can get on with life.'* As expected, my husband Winton and our families were concerned and reassured me of their love and support. Soon after a needle biopsy my surgeon confirmed that I had breast cancer. We talked about treatment, shed some tears and talked about faith. Through it all I was conscious of God being in control. It was an amazing sensation. *'One has to pinch oneself to realise it is not a dream,'* I wrote, *'yet there is a great sense of calm due to the knowledge that God is in control.'*

Winton and I told our three boys as much as they needed to know; they shed a few tears, gave me cuddles and told me they loved me. The hardest thing was to think about anything else, such as practical home matters like what to have for dinner. I prepared to go to hospital and went shopping for suitable nighties. As I handed over the credit card, the tears welled up.

We went to church the next Sunday morning and I was assured again of God's wonderful grace and care. We took the philosophy of 'one step at a time', knowing that if we looked at all the possibilities it would be truly overwhelming.

The plan was to remove the 2 cm tumour along with a small amount of healthy tissue and some lymph nodes, but as I was coming out of the anaesthesia I vaguely heard the surgeon saying that they had found more than they anticipated. The tumour had spread and instead of having breast conservation surgery I would need a mastectomy, followed by chemotherapy

and radiation treatment. Coming out from the anaesthetic I felt like I had an elephant sitting on my chest. I was told that although surgeons had removed the tumour, it had already spread into the lymph nodes.

I had to choose between a six-month course of treatment or a more intensive, three-month course. Words such as 'serious', 'advanced' and 'invasive' made me aware (again) that I was not on any Sunday school picnic. One night the enormity of it all got to me and I was in tears. I didn't think it was fair that I had to make such a decision. But, fair or not, it had to be made. I chose the intensive course of treatment, so from March through to the end of May I had the 'chemo', and I thank God that I only experienced minor side-effects. Tiredness was the hardest thing to cope with; some days I didn't even get out of bed.

I guess I've forgotten the main side effect: hair loss. Forgotten is not actually correct, as there was no hope of forgetting; every glance in the mirror or cold breeze around the ears was a reminder. About two weeks after the treatment began, the odd hair fell out as I washed and brushed it. Then one day I had to clean my brush after each stroke. I didn't want my hair falling into my dinner so I told Winton I was ready for him to shave it off. As he did I cried like a baby. I know the most important part of a person is inside, but self-image takes a few brutal knocks when the outside is attacked so fiercely. One look in the mirror at my new self was earth-shattering, but our boys joined me and had their heads shaved too.

After the treatment finished my hair started to grow back. *'Red and curly please, God'* had been my order, but it was dark blonde, straight and just like baby fluff. At the rate it was growing it would be ages before I would have a good cover. At least the treatment was over and throughout it all I was reminded constantly of God's amazing grace, of being aware of his love and control over all that was happening in my life.

When my journey with cancer began in 1997 I believed I would be one of the many women who, once treated for early-stage breast cancer,

would go on to live a long and fruitful life. However, the journey I have been on has resembled a roller-coaster ride physically, mentally and emotionally.

In November 1997, four months after completing chemotherapy and radiation treatment, I found the cancer had returned. Nodes under my left arm were removed in April 1998. More chemotherapy and radiation followed, plus a second mastectomy later in the year. With little time to recover, April 1999 saw the discovery of cancer in my spine and hips. A course of high-dose chemotherapy put me into a short period of remission. But in May 2000 I found that I had secondary cancer in the brain, which meant more surgery and radiation. Later that year I had another small tumour excised from my chest wall.

This record cannot begin to express the feelings and emotions that accompanied each procedure. My self-image continues to take a beating. The scars on my body remind me of the train tracks at Flinders Street Station and my hair has fallen out for the fourth year in a row. In the past it has returned soft, thick and curly but this time, due to total head radiation, it is struggling to break through. Prayer and a daily head massage form my current course of action.

One of the worst side-effects was an infected throat during high-dose chemo that meant my food had to be vitamised before I could swallow. I remember lifting the lid of my hospital dinner tray to find blobs of green (peas), orange (carrot), white (potato) and brown (meat), which together reminded me of an artist's palette. It took half a litre of gravy just to help it slide painfully down my sore throat.

Experience tells me that the future will be a series of bridges to cross. I ask God daily for the strength and courage to face them and not to spend every day living in their shadow. There is no way to anticipate the course of the disease or the speed with which it might progress. I choose not to look too far ahead because there is too much to live for and so much to experience. I don't want to waste time on things I can't

change or are not important to the eternal scheme of things. Support on this journey has come from many people. I am truly blessed, as I know people pray for me daily. My husband Winton and my sons Ashley, Ben and Chris surround me with love and don't mind that I am often in bed when they leave for work and school, or that I might still be there when they come home. We have had to rely on many other people to cope and I thank God for them all.

Throughout this roller-coaster ride one thing has remained steadfast - the love of God, who has journeyed with me. He often surprises me with reminders of his goodness. The night I entered Peter MacCallum Cancer Institute to face the first of many weeks in hospital, I was given a single room. These are kept generally for those who require extra privacy and the nurse showed her surprise when it was allocated to me. As soon as I sat on the bed I knew why, as I looked out the window to a glorious view of the floodlit spire of St Patrick's Cathedral. It was God simply saying *'Trust me I'm in control'*: I continue to do so because with His presence comes peace, hope and love. I have experienced these in abundance.

#### **CONCLUDING NOTE**

Susanne was diagnosed with more brain tumours and had more radiation treatment. This had devastating side-effects with her memory and balance. Sadly, Susanne passed away on 1 March 2002.

#### ***Reflections from Susanne's companions***

#### **ASHLEY AND THE FAMILY**

I write this tribute in the middle of a crowded room full of McCoys doing what they do best - talk! For those who don't know, the ability to talk wasn't just a unique gift given to Mum amongst her family of three

boys and three girls, mother Dawn and father Don, but rather a family quality. Keeping this family tribute to within the limited space here has been hard. Almost as hard as putting into words how much Mum meant to all of us as a mother, wife, daughter, sister and friend.

Your brother Michael speaks of the McCoy family as a team: each person a special and unique individual bringing different qualities, but sharing the same vibrancy for life. He says that the McCoy team has now lost its captain. This is so for many of the groups that you were involved in, Mum, including our family.

Your niece Madeline said she thought that you liked helping people. She wanted to thank you for your friendship, and says she will miss you very much.

Dad has always admired you, Mum, as the special woman that God had planned as his partner for life - a beautiful person and stunningly attractive. You were the epitome of the 'brilliant blonde'. No amount of camels offered for you during our Israel tour were going to tempt a sale!

Susie, you were blessed with a myriad of qualities:

articulate - never lost for a word, yet always a word worth hearing  
discerning - with a wisdom that grew with your love for God's Word

love for learning and literature - your insatiable love of reading was a testament to your active and instructed mind

decisive - with an eye for the obvious ('why couldn't I see that!')  
determined - just ask those who witnessed your courageously fought battle with cancer. (Dad wants to acknowledge the support of Mum's Thursday Girls group and how much they meant to her.)

creative and clever - such hands God gave you Susie, soft and subtle

compassionate yet challenging - she loved her boys dearly, but would never let them get away with too much

spontaneous and thoughtful, tender and tough - no one could hug you as Susie could!

Dad finished by noting *'To say that I will miss you is such an understatement; yet you will live on in us, in our hearts, in our thoughts and in our actions. Enjoy the delights of heaven my darling Susie.'*

Ben tells me that the positive attitude and the way he has coped with things over the last five years have been recognised and complemented by others. This he believes reflects wholly on you Mum. He says *'I'll never forget how happy you always were, and how much you smiled even though life was tough. Thank you for giving me the ability to be happy with what I have, and to always look at the positives of life.'* His prayer is that through your life many may be influenced to seek the joy of the Lord in their hearts.

Chris's words are few but heartfelt. He says *'It will be different without you, but I know that we will cope because we realise that you're happy now and that you will never be sick again.'*

Mum, thank you for giving to me and loving me as much as you possibly could. I thank you for all the wonderful school assignments you allowed me to put my name on and for the times you saved me from the wrath of Dad, when I fully deserved what Dad had in mind. Thank you for the hours you poured into making the amazing Hawthorn bed cover that I still sleep warmly and safely under today. Thank you Mum for the great example you have been to us all, particularly your sons. Not once have we heard you complain over the last five years. It seems that the longer your journey with this disease went, the less you thought of yourself and the more you thought of others. In the words of your mother: *'It's been a privilege to have spent time with you through your journey of cancer, and to see you use the disease to deepen your relationship with God.'* No one would have complained if you had spent some time in self pity after the beating your body received, but instead of asking God *'Why me?'* you determined to use your suffering to glorify God and asked *'Why not me?'*

I don't know how we will cope without you Mum. I thank God that Dad's cooking is getting better. Nothing anyone could do or offer will ever replace who you were and what you did in our lives. I praise God that right now you are perfectly healed, and I am glad that the image I will hold on to forever is that of an angel. You were an angel Mum and you deserve to be where you are in heaven with your fathers.

#### THE THURSDAY GIRLS

*The Thursday Girls* were privileged to be at Susanne's Salvation Army funeral. Nearly 1000 people attended, an indication of how she was loved and admired. Her inner and outer beauty shone through, and she was an inspiration to all. Such a bubbly person, she could *'talk the lid off an iron pot'*. A member's husband commented *'Susanne can talk faster than I can listen!'* Her love of life and people and her huge commitment to God and church were evident every day of her life, and her hugs were legendary. She has left an immeasurable void in our group. We loved her dearly and miss her so much.

#### *Jeanette's story*



I was born on 24 June 1936, the youngest of six children, and grew up in Thornbury, Victoria. I have fond memories of Sunday evenings, when all the family members and their girlfriends and boyfriends (later to become wives and husbands) would gather for dinner and enjoy the delicious food prepared by my mother. Later we would join in a singsong around the piano, played by my father. I remember the wonderful times I had with my friend across the road; her mother always included me in outings to pantomimes, pictures and later church dances. My friend and her family have remained close to me over the years and we now have grandchildren.

After a happy childhood, with daily piano lessons after school, I left school at fourteen years and worked for the Postmaster General's Department in the accounts branch, progressing up the levels to become the boss's secretary. I had a great group of friends at work and we still meet every two months, and have done so for the past forty-five years. We have had 'just girls' holidays and have been through all of our ups and downs in life together. We call ourselves 'the Post Office girls' and are always there for each other.

When I was twenty years old I married my husband Cecil, who worked in a bank. I was teased a lot by the post office staff, with remarks such as '*Are you knitting a singlet for Cecil?*' I continued to work for five years after my marriage before leaving to have our first daughter, Annette.

Seven years later we had our second daughter, Simone.

While Annette was a toddler I cared for my elderly parents and when Annette was about four years old they died eleven months apart. I took it hard when my mother died. I was only thirty-three years old and thought it unfair that I should lose my mother at such a young age. Later I had a big sadness when my brother, who was two years older than me, died of cancer at forty-three. We had been very close and I felt his loss deeply. I have lovely memories of when we were teenagers and he took me to parties and dances with his friends. We both enjoyed jazz and swing music.

Another trauma in my life occurred in 1988 while driving with my husband through the high country. I had a chicken dinner at Bright and felt sick on the next day of our travels. After stopping the car, I stepped out and fainted head-first into a ditch beside the road. Cecil drove me back to Omeo Hospital where I was cleaned up and diagnosed with food poisoning. Next morning I felt ill and fainted again, hitting the back of my head on a doorjamb and splitting my head open. Cecil rushed me back to the hospital where I was taken straight into surgery. The doctor inserted stitches inside and outside of the wound and I spent the next four days very ill in hospital. We then drove home slowly.

Unfortunately, that was not the end of my trauma. For the next four months I had severe pain in my jaw and face. After visits to different specialists, I found that I had pierced the cartilage in my jaw when I fell out of the car. The prosthodontist put a splint on my denture plate to keep the jaw open enough for the cartilage to heal and I had to eat soft food for twelve months.

During all these difficulties, I had another health worry: my eyes went blurry. The eye specialist diagnosed 'iritis', probably caused from the knock on my head at Omeo. After cortisone treatment, a cataract formed over my only good eye and left me virtually blind. (I lost the sight in my other eye after being struck with a tennis ball when I was two years old.) Following a scan of *my* head I had an operation immediately

to have a new lens implant. It was devastating to lose my sight and it took my confidence away.

In 1991 I had a hysterectomy; the specialist removed my uterus but left my ovaries, which were healthy. He put me on hormone replacement therapy (HRT) until I was diagnosed with breast cancer in 1997. After finding out that my breast cancer was oestrogen receptor-positive, I realised I had been getting a double dose of oestrogen. With healthy ovaries, I was producing enough oestrogen and did not have any change of life symptoms. I now wonder, after being diagnosed with cancer, whether it was this extra oestrogen from the HRT, or the hit on the head and fall from the car at Omeo that might have set it going. As the youngest of six children, another factor could be that my father and adult brothers and sisters smoked around me when I was young and going through puberty.

After the girls went to school, I worked part-time with Avon, Tupperware and the World Book. I was involved in the World Record Club for two years where I made some good friends and indulged my love of music, especially jazz. When the Club closed, I worked at the local newsagency until retiring nine years later.

I am fortunate to have had forty-five years of a happy marriage and wonderful holidays over the years when the children were young. Cecil and I have had several overseas trips since retiring. We have travelled in most parts of Australia by four-wheel drive - fantastic!

I am a social person who loves people and keeping busy. I enjoy holidays, giving dinner parties and having lunches with friends. I love to cook, am keen on our garden and like adventurous things too, such as bush walking and climbing hills, and have tried hang-gliding and hot-air ballooning. I have loved my experience of several light aeroplane flights.

My daughters now have four lovely grandchildren that I adore and have lots of fun with - which keeps me young. My eldest grandchild Isobel used to stay with me some days when she was a toddler. At bath time, I

would get in the bath with her and splash and have fun, which she loved. After I had my breast removed she would say *'Come on grandma, hop in!'* and I would have to say *'Oh darling, I have just had a shower before and don't want to get all wet again.'* After a few times of hearing that excuse, she stopped asking. We didn't mention to the children that I had cancer because my granddaughter had heard about people at church who had died of cancer. I was keeping well and having fun with them and did not want to worry them. I certainly didn't want them to think I was too sick to play with them.

## DIAGNOSIS

In October 1997 I was sick with bronchitis and my GP sent me for an X-ray. The result was not good: I did not have pneumonia but there was a shadow. A subsequent scan showed a small lump in my right breast and a swollen thyroid. I was told I would need an urgent operation, because eventually the thyroid would choke me. I was sent to a general surgeon to first remove the breast lump. After a lumpectomy he advised that I would need more tissue taken around the lump or the whole breast removed.

After thinking about it for three weeks, and a second opinion from an oncologist, I went ahead with surgery to have my breast removed. Afterwards I was put on Tamoxifen because I was oestrogen receptor-positive. I bounced back and felt that I was home free - it was only a small lump and, after all, it was better to lose a breast than lose my life!

After two months of recovery over Christmas, I was admitted to hospital in January to have my thyroid operation by the same surgeon. He did a good job, only taking half of it and so avoiding the need for me to take tablets. However, instead of handing me over to an oncologist for further check of my breast, he said *'No, just come and see me every six months.'* That was in March. The following September, while on holiday in Sydney with 'the Post Office girls', I had an awful persistent pain in

my neck and shoulder. I was due for my checkup with the surgeon in November and, when I told him about my shoulder, he just said *'Have a massage, Jeanette.'* I thought that was a bit too flippant.

I worried about my shoulder for a day before ringing the oncologist who had given me the second opinion on my breast removal. She did a bone scan, but it came back clear. When I told her that the pain was driving me mad she ordered an MRI scan. On the same day in December, she told me the bad news. I had a tumour in my spine at the base of my skull. I told her that I did not want chemotherapy if it could be avoided, so I had ten sessions of radiotherapy. In the middle of the treatments I got sick and was sent to the Peter MacCallum Institute where I spent Christmas while finishing the treatments, as well as lots of tests and a spinal tap. My daughter had booked tickets for a stage comedy show called *Mums the Word* but it coincided with the evening of my spinal tap. However, I felt good after the spinal tap and the oncologist said it would do me good to go to the show. An hour before my daughter was due to pick me up at the hospital I started to vomit. The nurses were great and gave me a basin and a plastic bag to take with me. I could not stop vomiting and could not laugh at the show (although it was very funny), so one of my daughters took me back to the hospital at intermission. I went home on New Years Eve. Subsequently I was handed over to a medical oncologist for my ongoing treatment. I was then put on Arimidex, a hormone tablet, as obviously the Tamoxifen had not worked.

## REACTIONS

All of us were in shock at the diagnosis of my cancer, and it took a long while for it to sink in. The oncologist was marvellous and ordered radiotherapy treatment immediately. My husband and two daughters were devastated, but I took the view after the initial shock: *'it's no good crying over spilt milk; it's happened and we will fight it and get on with life:*

After discussion with our girls a meeting was arranged for all members of the family to meet with the oncologist to discuss the results and the on-going treatment. The girls found this very helpful. I think it is most important to have a positive outlook and not let things beat you.

I did not have a problem with losing my breast and the support nurses at Waverley Hospital were great. I left hospital with a cotton wool pouch that sat in my bra and heaps of information from the Anti-Cancer Council. When I got my prosthesis and looked normal in my clothes (which was important to me), I looked great. While in hospital a good friend came to visit. She had a mastectomy some fifteen years earlier, followed by chemotherapy, and has been free of cancer since. She said *'You will be OK. When I had my breast off, my husband was happy as he still had one to play with.'* We had a good laugh.

When I got home from hospital, I needed my husband to help bathe me. While he was washing my back he did not know where to look and was obviously uncomfortable. I noticed and said *'Oh, for goodness sake, so I am flat chested on one side! Men have flat chests and we don't go Oh, Ah!'* We burst out laughing which cleared the air. He realised that I was the same loving person, in need of hugs and reassurance. After a while my husband got used to the prosthesis and life then went on as usual.

#### **FRIENDS AND FAMILY**

It is amazing how you quickly find out who your real friends are when you are diagnosed with cancer. Some friends did not want to know about it and abandoned me, and others were supportive and treated me the same as usual. After the initial treatments and rest times, I have had a good three years of normal life on Arimidex, with no more secondaries or ill effects. Life must go on, and I believe that you have to be positive and, when you are feeling OK, go and do things instead of putting them off. I have enjoyed holidays and outings with friends and family. I went

overseas for five weeks with my sister-in-law, in between four-weekly drips of Aredia. We had a great trip through England, Scotland and Ireland. I have had wonderful times with my grandchildren, who are now eight, six, five and four years old. You have to always have something to look forward to and plans to make. You also have to try to look your best, so you can then feel good. And plenty of laughs with friends is always good medicine. Good nutrition is also very important to keep your immune system strong. Getting cancer has been an ordeal but I still think the temporary loss of my sight was worse.

I have been blessed with a caring and loving husband, who has always given me freedom to pursue the things I have been interested in. Since my diagnosis of secondary cancer, he has juiced six vegetables one day and six fruits the next, which I drink for lunch. To my Cecil, I thank him for everything.

#### ***Reflections from Jeanette's companions***

##### **CECIL**

The initial diagnosis of my wife Jeanette's breast cancer was a time of great shock to myself and our daughters. It is difficult to describe your personal and emotional feelings when you are confronted with a situation you are totally unprepared for. However, I have learnt that the lack of knowledge of the various types of cancer and the available treatments contributes to the anxiety and possibly an inability to provide adequate support at the time. I am fortunate because Jeanette is a positive person and after her surgery our lifestyle continued much as before.

Obviously the discovery of Jeanette's secondary cancer was very difficult to accept. We had been confident there would be no further problems. Again Jeanette's great spirit and the wonderful support of various medical professionals enabled me to overcome another difficult

time more easily. Publications from the Cancer Council and other sources have been beneficial and a positive attitude and the ability to share your feelings are important in coping with the journey of cancer.

#### **ANNETTE**

My name is Annette Muir. In the first months after the diagnosis of Mum's secondary cancer, I felt overwhelmed with emotions. I would lie on the floor some nights sobbing in despair. I experienced times of disbelief. Half a day would go by, and then I would have the shock of remembering. I had a sensation of panic, of waiting for the worst, and feelings of intense sadness. How would I explain Mum's death to my young son Scott, who was only eighteen months old and adored his Grandma? How would I get over him not remembering what a loving and involved Grandma she was, and her never seeing any of the milestones in his life, such as birthdays, kindergarten and school? I could not enjoy a family occasion together any more, because I was always thinking it might be the last. I would see old women in the street and ask why should they be alive, when my young, vibrant, loving mother was going to die? And I was angry. If Mum had received better medical advice at the time of the initial breast cancer she would not have been robbed of years we could have had together. I was frustrated by not being able to talk to the doctors about Mum's condition and only able to get information second-hand.

After three years, those first emotions are no longer overwhelming and have been overlaid by more positive thoughts mostly due to Mum's attitude: her strength and determination to live to the full. A lot of the time now, because Mum's health is so good and the cancer is not active, I almost forget she has it. Now, instead of thinking about dying, it's more like living with an ongoing disease, especially with the new treatments emerging. In a way it's better than when someone you love dies suddenly, because you have time to say and do the things you need to do. I now

enjoy the time we have, rather than thinking it may be the last.

An oncologist who spoke to the family told us that Mum could live for between six months and ten years - and we're planning for the latter! It was such a relief to talk directly with the doctor, and I believe a meeting with the oncologist is vital for families struggling to cope with cancer.

Scott is older now, and has had so many wonderful times with his adored grandparents that I'm sure he will remember them. I'm hopeful that Mum will be around next year to see him to school. I'm so glad she's here to get to know my little son. It's reminded both of us of my childhood and strengthened the bond between us.

*The Thursday Girls* cancer support group has become an important network of friends for Mum. We wondered at first whether it would be too upsetting or depressing for her, but she can say things to them that she can't say to us, and it is an important source of information.

I can't believe that this woman who plays hide and seek and imaginary games with her grandchildren, who worries about and helps her daughters, who gives so much love and is always interested in learning and doing new things, will really die. I don't want to lose her, or my wonderful Dad, but I guess this is a preparation for what we all have to face.

#### **SIMONE**

My name is Simone Brewster and I am the younger daughter of Jeanette. Going on this journey with Mum has been a painful, scary, yet life-enhancing experience. The diagnosis of primary cancer was unreal, but because Mum coped with the mastectomy so well, and was so positive, we all moved on quite quickly. However, the diagnosis of secondary cancer was something else altogether! My journal entry for Wednesday, 9 December reads: *'Mum has cancer in her bones. I feel sick. Exhausted. Stomach ache. Headache. Hot. Feverish. Dull pain. Nauseous. Want to vomit. Can I cry any more?'* I was in shock and the pain of possibly

losing Mum was too horrible to contemplate. I was at a loss. I remember feeling that my heart was being ripped out of my chest.

For many years Mum and I had a tenuous relationship: an underlying passionate love for each other had been marred by misunderstanding and conflict. However, in the last few years we had reached a beautiful place of knowing; so many past hurts had been healed and laid to rest. She had become one of my dearest friends, supporter and confidante, so much so that I could have her as a birth-support partner when our beautiful Amy Jean (named after Mum) arrived in July 1998. How could she be close to death, when we were finally so close! I cry now remembering the pain of this time.

The following weeks were difficult as we witnessed Mum having treatment, being in hospital over the Christmas period, being sick with an assorted cocktail of drugs and feeling down. It was a strange time. In one sense I coped well and my faith in God sustained me. On the other hand, the stress, which I didn't know how to express, was taking its toll. I remember 'losing the plot' around this time. I was crying and screaming hysterically, and begged my husband Tim to call a doctor to come and sedate me. It was a weekend and the locum took ages to come. I'd calmed down by that time, but he was kind and listened to how I was feeling. I suppressed a lot of emotion during this period because I was in survival mode with three little kids. Mum was one of my main confidantes, but also the person suffering, and I couldn't burden her more by talking about my feelings. My overwhelming thought was: *'Be strong, you need to be strong and be there for her. You are not the one going through this, and facing death yourself'* It felt selfish to express my own feelings. I realise now that this was pretty unhealthy. However, I didn't realise how suppressed my feelings were until I came to write these reflections. I couldn't write, I couldn't explain; all I could do was cry.

I am thankful to God that Mum is still here with us, and I treasure each day we have with her.

### *Jeanne's story*



My name is Jeanne Denise Pettersson. Today is a big day: I have just used shampoo in my hair! A small thing you might say, but I have been waiting for my hair to return for seven months. I feel so good at the moment, that I can almost forget the unsettled nagging stomach that I fear signals the return of a tumour. I haven't plucked up the courage to call my oncologist and launch myself into another barrage of tests and treatment. It's peaceful at home at the moment, being the Christmas break. I have examined and balanced out my life in terms of its quality and longevity for a few years now.

I first found a lump in my breast in April 1992 and the next day I went to see my local doctor, who is a surgeon. He looked at me with a serious face and said *'This needs to come out:* He sent me for an ultrasound and an X-ray, and told me to make an appointment to see a specialist surgeon that he recommended. I was concerned because I had a lot of trust in my doctor and he seemed to know that it was serious just by feeling the lump. When I saw the specialist a few days later, he read the reports of the ultrasound and the X-ray and did a needle aspiration, but wasn't able to tell me if it was cancerous or not. He gave me the ultrasound report to read, but I wasn't settled enough in my mind to understand it. He said *'This lump could turn nasty and needs to come out. I will make an appointment for surgery at the Maroondah Hospital.'*

I was confused: *What was the diagnosis? Was it cancer or not? It could*

*turn nasty?* Time went by. I had a new job as a computer orders clerk and everything was going well. I had learnt a lot and it blended nicely with my responsibilities as a single parent. However, there was still the nagging worry: *'this lump could turn nasty'*: Finally I phoned the hospital to find out when my lumpectomy was scheduled. To my surprise they had not heard of me and had no paperwork! When I called my surgeon's rooms I was told *'he has gone on holidays for two weeks and taken the paperwork with him'!*

After the surgeon returned from holiday, an appointment was made for surgery but was cancelled again and again for more urgent cases and because of equipment failure. Time was moving on and the lump was growing bigger. It was difficult for me to follow up the surgeon or the hospital as I was unable to make phone calls from my job. I remember calling from a pay phone in Croydon with just enough time to call the surgeon's office before picking the girls up from school. His receptionist was abrupt: *'No, you can't talk to the doctor, you are a public patient. You will have to wait and see him at the hospital.'*

There was no speeding up this lumpectomy! I tried the surgeon's other office with the same negative response. I was becoming frantic. My parents offered to pay for me to have the operation privately. I made the appointment at the surgeon's private rooms and paid for it myself. It was not a pleasant consultation and he seemed uncomfortable. He did three needle aspirations, although I don't think they were successful because he threw them into the bin, seemingly in disgust. He said he would book me in as soon as possible. I was reluctant to believe him and we argued the point in the doorway as I was ushered out. I hated this man who brushed me aside so nonchalantly. I was falling apart inside.

I recall the advertising campaign on television that encouraged women to check their breasts for lumps. Well, I had checked my breasts and found a lump. But for me there had been no proper follow-up procedure. I went home and cried. I didn't show the kids. How did I get to this point? In my

naive way I had thought that if you did all the right things and worked hard you could be organised and not let your life get off track. But maybe you can't control other people's failings especially people you put your trust in who let you down.

I underwent surgery seven weeks after the initial finding. Three days later I was told by an assistant doctor that my whole breast needed to come off. I had surgery to remove my breast and eight cancerous lymph nodes. Twenty-three days after the mastectomy, I was informed over the phone that I had a secondary in the spine. Yet again, my surgeon was nowhere to be found.

I was in shock. I had been agitating for attention for so long and now everything had happened at once. I didn't have time to be angry with the surgeon; I was just concerned with surviving for the present. I suffered from the shock of losing my breast, the ugliness of my body and all those tubes. How I was going to look after my girls while I was ill? Not having a partner, I needed to rely upon friends and family to take the girls to school and ballet and to keep things as normal as possible.

I got through the chemotherapy all right, although the treatment itself was scary. However, I had a terrible reaction of anxiety that caused me to be impatient with people. It got to the point where I couldn't cope talking to anyone. I remember a time when my father drove me home and I abused him because we had to wait for a traffic light. To cope with the anxiety attacks, I isolated myself in my bedroom, where I would curl into the foetal position and try to sleep it off while my girls, fourteen and nine, looked after me and made dinner.

The girls at oncology couldn't figure out why I was having the bad reaction to the chemotherapy. It wasn't until my second last treatment that I felt the anxiety coming over me as the Maxalon was being added to the intravenous injection. It turned out that I had an allergic reaction to Maxalon. When it was left out of my last treatment, I had no side effect whatsoever, and no nausea either. I have learned since that my bad

reaction to the treatment could have been discovered earlier, as many people are allergic to Maxalon.

My next round of treatment commenced, with more chemotherapy and a course of radiotherapy. Again I had to rely on friends and family to help out. I can recall the long, lonely evenings and sleepless nights where thoughts ran wildly away from any logic. I missed not having a partner to confide in or to cry with. The best I could do was to take a few Valium tablets and wait until morning for the daily routine to enclose me.

I looked terrible - a skeleton with no hair. I impressed upon my family that it was the 'chemo', not the cancer, that made me look like this: after the treatment I would be my normal self. It's hard for those supporting a cancer patient to keep this in mind. I certainly know, as a patient, it is hard to distinguish between the side-effects of the treatment and the effects of the cancer that will still be with you when you recover.

The chemotherapy brought an overwhelming sense of loss. I suppose the most obvious one was the loss of my breast: I felt a loss of femininity and hated to look at my body. Of course my hair was lost too, but that would return. I also felt a huge loss of lifestyle. I needed an income to have any reasonable standard of living, and I had just secured a job of three months after a long period of training. This was to be my career and I was excited about it. It was also to be my independence and meant security for us as a family. But I lost my job as soon as I asked for six weeks off for treatment.

Looking back, it took a lot longer than six weeks to recover from my mastectomy, and with the six months of 'chemo' I don't know where I would have found the energy anyhow to hold down a job as well as recover. I was tired constantly and suffered hot flushes that would arrive every twenty minutes and last for about four minutes. They would leave me wet and sticky and I would lose my train of thought. I felt that I was losing my peace of mind. And I was. The flushes were caused by the oestrogen- blocker drug that I was now taking because my cancer was

oestrogen dependent. So it was necessary for my survival to put up with these disturbing side-effects. Eventually I found myself at a naturopath whose Bach flower remedies eased the severity and frequency of the hot flushes. This made life a little more bearable. He also told me to avoid certain foods, along with tea, coffee and wine. At least now I had some knowledge to make helpful choices, something that western medicine hadn't offered me.

A year later I started to recover and adjust. I decided to have my breast reconstructed come hell or high water. It would happen one day. I noticed that my skin was aging quickly and my once slim and fit figure was changing shape - changing to no shape! All of this was due to the lack of oestrogen, which couldn't be helped if I was to overcome the cancer. As time went by I began to think that I had survived this ordeal. For five years I was fortunate to live without drugs and to be cancer free. I believed I had survived. I never regained my same fitness as in pre-cancer, and I was always tired. Little did I know that the cancer had returned!

During those five years I was very busy. I met a lovely man and we were married. Life couldn't be better. My life was falling into some sort of order again and I was really happy. I had the three operations necessary for my breast reconstruction, and in a way this made me feel physically compensated. To some degree I was able to pass on from the awful initial experience of shock and anguish at the negligent treatment I received in my first diagnosis. Once again I was able to enjoy life. I helped out in the family business and we built our own house - a beautiful, light and happy house. My girls took a while to adjust to the new family situation. My husband's teenage daughter came to live with us, and the blending process of the new family had its moments. This was to be expected, and the memories of the good times from this period are very precious to me. I now have three wonderful daughters.

## CONCLUDING NOTE

Jeanne passed away on 30 August 2002. A warm and gentle person with a beautiful smile and a steely resolve. She was the centre of her family, an earth mother and a true free spirit who embraced a natural lifestyle. Her lovely home in the hills on the outskirts of Melbourne enabled her to indulge her love of the outdoors.

### *Reflections from Jeanne's companions*

#### AMANDA

Mum was re-diagnosed with cancer in November 1998, one month after she married my step-dad. I was overseas at the time. When I told Mum that I may not make it home for Christmas, she made me speak to my sister. Laura sounded desperate on the phone. All that long flight home, I thought there must be something seriously wrong with Laura, like leukemia. Mum met me at the airport. Her face seemed a lot bigger than a year ago, and she looked fatter and a little more tired. I just put it down to her living a fuller lifestyle - food, beverage and holidays.

I waited for Mum to tell me that she had something like the flu. Three days after I was home she sat me down and told me that the cancer was back. I just started crying - sitting and crying, and asked her what it meant, knowing all the time exactly what she was talking about. She had been re-diagnosed with secondary breast cancer after I left to go to Europe. She didn't tell me because she didn't want to ruin my trip.

For the next three months I stayed in bed. Quite selfish really! I just cried, cried all the time: about losing a mum, losing a mum too early, not having a mother of the bride for my wedding, a grandma for my children or a best friend to talk to. Life wasn't fair, so I stayed in bed and only got out when Mum needed me, for cooking or cleaning or taking Laura

to school or ballet. Otherwise, I remained depressed. As time went by, so did my savings and I applied for a job. I was a total mess socially but I managed to earn some dollars.

Mum went through different treatments, western and alternative. When she was re-diagnosed she was given five months to live and she lasted almost four years longer. I saw my Mum go through all the treatments to prolong her life. I was there through all the side-effects and operations and hospital visits. Along the way she preserved a quality of life. No matter her situation, she made the best of it. Her positive thinking no doubt extended her life sentence. I made her laugh till she cried, keeping her life jovial. I gave her chocolates bought by the rich and famous just so she could taste the experience and took her for drives in the mountains.

I hate the doctor who 'lost' Mum's paperwork, who wouldn't take Mum's phone calls because she was just a 'public patient' and who put back her surgery for 'more important' cases. Mum's gone now. She left us in the early hours of the morning. It's hard to not have her around any more. Sometimes I go into her bedroom just to smell her clothes. It was strange and terrible to see my Mum progress from extra healthy to terminally ill. One of her diary entries reads *'I can't help thinking I would have had a longer life if I had received prompt attention when I needed it. This insidious disease has cheated me from a long and loving life with my family and friends, and the initial lack of medical treatment, and the nonchalant attitude taken by my surgeon of the time, has exacerbated this.'*

#### LAURA

It was Wednesday night, about 9 pm. Just back from ballet and on my usual high, I was filling in time before I wound down for sleep. Mum said *'Perhaps you should sit down Laura. Let's have a chat.'* Oh oh, she had that tone in her voice! I didn't want to sit down; it was easy to tell something was up. She told me: *'The cancer is back. It's in the bone.'* After she had

discussed the problem for a while, I went into a state of shock. Once I finally realised what this *bone* thing actually meant, I started crying. I'm just that kind of person.

The next day in Drama class we improvised a scene at a dinner party. Our teacher walked in as her character, sat down at our fake dinner table, and said '*I have cancer and, as you are all my friends, how would you feel if I decided to opt for euthanasia?*' I could have died! What a coincidence! We all said '*Of course we'll help you out in any way you want*'. My friend looked at me in amazement. How could I contain my tears when it was less than twenty-four hours since I had found out that I probably wouldn't have a mum in three years? The terrible news hadn't sunk in.

Our acceptance in class of the option of euthanasia for a sufferer seemed a natural reaction for us all. The idea of quality of life is very important and, even as young as we were (year 11), we appreciated the fact. Mum was a master in this regard. She had a massively positive attitude, even before her initial diagnosis. After being diagnosed as terminal, her attitude didn't change. She always managed to laugh. Once we were Christmas shopping and I was pushing her around in the wheelchair when all the bra and underwear hangers caught in between the spokes of the wheels. We proceeded to do 'wheelies' around the Myer store. She had a fit at us, but was laughing at the same time. Mum definitely did not fit into the category of a poor feeble wheelchair person. When sales assistants would lean over and call Mum things like 'dear' in a sympathetic patronising tone, she might have been expected to feel frustrated. However, little things like that didn't seem to get to her. She lived for the moment with the attitude of someone about to conquer Everest. All the fat books about healthy living and cancer-free diets take up most of the bookshelf in our house. Hers was definitely a fighting spirit.

Mum started to have counselling as part of *The Thursday Girls* group. I remember thinking '*Mum doesn't need counselling; she always has had everything so together.*' Now having read what she wrote, I realise that

she did this to protect us, as we were too young and perhaps too naive to understand how she was feeling. If Mum didn't have herself together, how were we supposed to cope with our own feelings? This thought helps us to understand why she went for nine months knowing of her terminal disease, but not telling Amanda or I. She was protecting us. By waiting that time, she was able to educate us with a positive attitude, and tell us exactly where she stood with the diagnosis.

As time went on, I learned and understood more about the ways in which Mum's problem affected the family. Mum was lucky enough to be part of *The Thursday Girls* group, which was a bit of a mothers' club meeting minus the Nutrimetics, but with helpful discussions of life-changing issues that even doctors couldn't supply. When you go through hard stages in your life, your peers can give the best support. All of a sudden in our family the roles were changed: I was now driving Mum to her support group, trying to dodge all the pot-holes in the road to avoid jolting her frail spine. *And* I was now able to drive her V6 Fairmont there's always a positive aspect to every negative, as Mum taught us! I'd fill in time while she had coffee with fellow group members. However, one day I had coffee with them. This day was a huge eye opener for me. Everyone was having their coffee, some wearing wigs or scarves, some frail, weak and pale, and yet all were laughing and having a good time. *And* so they should, they were still living.

As time went on, Mum became interested in alternative therapies and the philosophy of Buddhism. There'd be alternative therapy books around the house, along with some Buddha statues. She'd get up early for daily meditation and, together with her reflexology and yoga (in the early stages), she really helped to extend her life. Having seen the results at first hand, it is amazing how much value and quality of life Mum gained from her alternative therapies.

Mum was able to teach Amanda and I so much, being the wise and intelligent person that she was. In mothering our own mother, it has

definitely helped us to mature faster. With Mum now gone, everything seems so empty. Even with all those years of preparation and anticipatory grief, the realisation didn't fully sink in for a couple of months. However, we never felt the guilt that comes with having a good laugh just after you've lost someone. Mum was such a true spirit. It has felt good to laugh every now and then, because that's how she would have dealt with the situation. Always find the positive from the negative.

The undertakers walked across our floor with their shoes squeaking. It was a sound I will never forget. The sight of the undertakers' empty bag that her body was to be put in made me angry: *'Mum deserves better than that. You can't just put her in a bag!'* That was when I realised that her body was lifeless. Now the most important things to keep are the memories of our Mum who was always able to laugh and is now in a place we will never know until we get there ourselves one day. Maybe she was flying peacefully through the double rainbow that appeared on the morning after her passing. Either way, Mum will always be there, as she always was in the past.

### *Lois's story*



My name is Lois Fynmore. I was born on Friday 13 August 1937 (a bad start?). My father in his dotage said '*We passed a funeral on the way to the hospital - I don't suppose you remember that!*' I was the second of three girls. My father was a GP; my mother was a pharmacist.

I had a happy childhood in a loving, close family. My elder sister Kate is not quite two years older than me and we played together and went to the pictures, on bike rides and to sporting events together. Sport has always been a great interest of mine. I was coached at tennis from eight years old and played in schoolgirl tournaments, school teams and later in pennant for Melbourne University. I have always enjoyed watching sport too, following the Essendon football team since 1947. Kate and I never missed a test match or interstate cricket match at the MCG, or any tennis tournament at Kooyong. Since my marriage in 1988 I have taken up golf, which is now my only active sport.

On New Year's day in 1954 my life was shattered when my mother was killed in a car accident. My sisters were badly injured, my father less so, and I had concussion and some cracked vertebrae. I have never got over losing my mother. Our lives were changed in many ways. As my father's practice was at home, the house could never be left empty, so we had a succession of resident housekeepers over the years, some good and some not so good. My father retired in 1963 and I looked after him until his death in 1973.

I completed my education with a Bachelor of Commerce from the University of Melbourne. I worked briefly as the first employee of the Committee for Economic Development of Australia with Sir Douglas Copeland, and then some seven years at the Petroleum Information Bureau, initially as statistician. In 1968 I went to BHP, initially into the oil and gas division public affairs and then in 1983 moved to their corporate public affairs until 1988 when I retired to marry my boss, Russell Fynmore. I had an interesting career, in what was largely a man's world, and was often the only woman present, or the first woman to do something.

Russell's first wife had breast cancer in her late twenties, just after the birth of her third child. More than twenty years later she had further cancer, in her upper arm, which was thought to be a consequence of the heavy radiation treatment she had at the time of the breast cancer. Her arm was amputated, but she died of secondaries some seven months later. Russ has three wonderful children, Sharon, Stephen and Robyn, who have been supportive and kind to me.

My family history of cancer is very bad. My mother was one of six girls, five of whom had cancer. She had breast cancer, but was killed in the car accident within about six years. Two of my cousins have had cancer. One died from it: she had breast cancer and then some other form twenty plus years later. My younger sister had a melanoma and died from secondaries ten years later, on the day I had my second dose of chemotherapy.

In 1992 a mammogram detected a small lump in my right breast. It was a shock when my GP rang with the news, but not exactly a surprise given my family history. It was a non-invasive breast cancer and was removed in the day hospital. I saw the surgeon every three months until the beginning of 1994, when he said I only needed to see him every four months. At that time I had a mammogram. At my next appointment he found a lump and attempted a needle biopsy without success. My husband and I had arranged to go to a conference in Kuala Lumpur, so the surgeon

said to have a good trip and see him on my return.

When I got back I went into the day hospital and it was confirmed that the lump was malignant. The surgeon recommended a radical mastectomy. My surgery was trouble free and the nursing care at the hospital was excellent. From the size of the lump, about 2.5 cm, it must have been missed by the mammogram and the surgeon at the beginning of the year. The first time I saw what used to be my right breast was the only time I wept throughout my cancer experience. While I was in hospital I was shown a collection of breast prostheses and given a couple of wig catalogues, but was not told about government funding for a prosthesis, or about '*Look Good, Feel Better*'.

As many lymph nodes were affected by the cancer I had chemotherapy, four cycles of Adriamycin and Cyclophosphamide. Two days after the treatment I vomited for a couple of days and then had violent indigestion as soon as I swallowed anything. When I had the second course of chemotherapy, I saw a young trainee oncologist who just gave me more sedative, so the consequences of the treatment were the same. Next time, on the advice of some paramedical friends, I asked to see one of the senior oncologists and he gave me a collection of pills which solved the nausea problem. After I finished the chemotherapy I went on Tamoxifen for the next five years. I recovered the use of my right arm before too long and was able to play tennis and golf again, and generally resume a normal lifestyle.

Five years after the mastectomy I was diagnosed with secondaries, nodes on the outside of my right lung. I took Arimidex for a time, then a high dose of Provera. I felt really well on the Provera. It even cured a chronic problem I have with my neck and shoulder while I was on it, though no one knows why.

In November 1999 I joined *The Thursday Girls*. I was reluctant to do so and initially found it very confronting. However, it didn't take long for me to settle in and realise the great benefits of the support, comradeship,

caring and information sharing from the group. Now I'd say it was about the best thing I've ever done.

Around May 2000 I had an increasing problem with shortness of breath, and had two litres of fluid drained from my chest cavity. It was obvious that Provera was not really effective so, after returning from holidays in mid-year, I started another chemotherapy, Xeloda. I had a couple of episodes of vomiting, and after the second my oncologist told me to stop taking the Xeloda. He was going away for two weeks and would review the situation on his return. Unfortunately, I continued to take the anti-nausea medication Maxolon that I had been given, and I kept vomiting and could not really eat anything for about eight days. I lost 20 kg. I am sure now that it was the Maxolon that made me sick and, on the suggestion of *The Thursday Girls*, I checked and discovered that indeed I had Maxolon with the initial chemotherapy in 1994. I went back on the Xeloda, with Dexamethasone as the anti- nausea drug. I don't believe that Xeloda caused me any nausea. However, I had one bad side effect from Xeloda inflammation of the palms of my hands and the soles of my feet. They kept peeling, my hands about twelve times and my feet about six. My hands were swollen and made me clumsy, and my feet felt as though I was walking on needles. Also all my toenails came off.

After about eight months on Xeloda it did not seem to be helping so in April 2001 I switched to a new drug Aromasin. This also proved to be ineffective. Then in August I started on another chemotherapy, Taxotere. My hands and feet had not recovered totally from Xeloda, although I had been off it for some three months. The Taxotere also affects my hands and feet, I am losing my fingernails, my eyes water all the time and I have had mouth ulcers.

In losing weight I have lost a lot of muscle and, as a consequence, strength. I have had to give up tennis because I am not able to run and am not steady enough on my feet, but I can still play golf. Virtually all my problems so far have been caused by the treatment, not the disease.

Had I not lost weight I believe I would have been going along doing everything I was doing before, including tennis. I also got a cataract from the Dexamethasone. Losing my hair the first time was traumatic and I was reluctant to lose it again, but more due to the inconvenience and disruption it causes to my lifestyle, like no swimming.

My family and friends have been kind and supportive, and I really appreciate that and know how fortunate I am. My husband has been fantastic kind, supportive, helpful - everything one could wish for. I hate to think how I would have coped without him. We enjoy sports, music, dining and travel, and have had some wonderful holidays, before and after my cancer. The best trip of all was to Antarctica, six months after my mastectomy.

I am pragmatic about having cancer. With my family history it was not unexpected, though I must say I thought I was all right after being clear for five years. My basic attitude is to ignore the cancer. I don't want to be asked how I am all the time, or to discuss it. I simply try to behave normally: Russ and I do whatever we are interested in, and do not put things off.

### ***Reflections from Lois's companion***

My name is Russell and these are some thoughts about my wife Lois's battle with breast cancer and its impact on me. Having been through the experience once before with my first wife, you might expect that I would have all the answers this time. But each case is different and so it is with Lois.

Because of Lois's strength our life has not been impacted seriously as far as what we do and what we talk about. Lois does not wish to dwell on her condition, and so we don't. One can't dismiss the problem, but to the best of our ability we do not let it consume us or our lives together. We recognise that it's probable that I will outlive Lois and in her own way

she is trying to prepare me for that time, but I do not plan for it. One must just take things one day at a time and that is what we are doing.

Lois is admired greatly by my friends and relations for how she conducts her life. I am very proud of her, particularly when I am told what people think of the fight she puts up. Being a rather selfish person, I can honestly say that my lifestyle with Lois has not been affected much. But I am ready to support her when the time comes and she needs more help than she does now.

Isometimes wonder how life deals your hand, as I have been personally involved with breast cancer for nearly forty years. Frankly, I am a better person for the experience, because I know you should not plan too far ahead and try to get as much out of life along the way. I am now of an age when I attend more funerals than weddings, lose friends who were well only a few months ago, and realise that one must accept one's lot in life. I continue to be proud to be Lois's husband, friend and lover, and I trust I will be for some time to come.

#### CONCLUDING NOTE

Sadly, Lois passed away on 11 June 2002. She was such a 'spunky' person, never giving up. Her attributes are best summed up from the Thanksgiving Service: a special friend to many, a loving and devoted wife to Russell, a caring independent person, a successful career woman with quiet confidence, an able sportswoman, and a life-long Essendon supporter (Long Live the Bombers!). She was playing golf three weeks before she died, and at one stage during her illness had a hole-in-one. We presented her with a golf socks embossed with a hole-in-one for her birthday. She will be sadly missed by her friends at *The Thursday Girls*.

#### *Shinta's story*



I was born in Indonesia in 1956, the eldest of five children, two girls and three boys. My father left mainland China as a young man to avoid political persecution. My mother was born in Indonesia, of Chinese descent. We had a happy and comfortable childhood and, as my grandmother and two aunts lived with us, we had lots of tender loving care. Father and I shared the same principles in life and we both loved history and the old traditions. I learned from my mother to be self sufficient. She raised us single handedly as my father had his business in Jakarta and only came home to see us at weekends.

My father did not hold with the Chinese way of thinking that only boys required an education. He believed the best legacy he could leave his children was to provide us with a good education to ensure our independence and freedom to pursue our own happiness. It was not easy for Indonesians of Chinese descent to study at government universities. Although we could study at a private university, we would still have to sit for government exams. So in February 1975 I came to Australia to study. I was looking forward to the freedom to make my own decisions without parental involvement. My sister followed a year later.

I graduated from Melbourne University with a Bachelor of Science degree. During this time I married and had my first beautiful son, Kemal. He was looked after by my mother in Indonesia for three years while I completed my degree. Unfortunately, after eight years my marriage ended

in divorce. I was lucky to have my mother with me in Australia to help as I worked full time as an analyst programmer and studied part time for a Bachelor of Business in Banking and Finance at Monash University.

In 1987 I remarried and had a second beautiful son, Gregory. At first the marriage was filled with many adjustments for each member of the family. In 1997, I lost a considerable amount of weight but I put it down to stress and dealing with family problems. I also found a lump on the outside perimeter of my right breast. I was not too worried about it as it was not *in* my breast. I had an ultra scan and was assured by my general practitioner that it was not cancer, although he suggested an operation to remove the lump. I decided not to as I do not like unnecessary operations. Six months later, however, the lump was getting bigger.

My doctor referred me to a surgeon who organised a biopsy straight away and the diagnosis was cancer. It was a shock to have my worst fears confirmed, but deep down I knew. So many 'if only' scenarios went through my mind: if only I had it removed earlier; if only I had coped better. But the fact was that I had stage 2 breast cancer with lymph node involvement. Although I have never gone through the phase of asking the question '*why me?*'; I would never wish this on anyone. I felt I could deal with the problem and find a solution if I tried hard enough.

A lumpectomy was carried out after Christmas 1997, a procedure suggested by my surgeon. At that time I only wanted him to do something to solve the immediate problem. I did not know anything about breast cancer and it never occurred to me to worry about the loss of my breast. I have always believed that my worth is in my whole person, not just in how I look. My small breasts have been part of my body and have served me well in caring for my children. I was discharged from the hospital on my birthday, with a bag hanging from my side to drain fluid from the wound. What a birthday! I was only forty-two years old.

The surgeon advised a course of radiotherapy but I was told to see an oncologist before making the decision. After reviewing all the pathology

results, the oncologist recommended more surgery to remove any leftover cancer cells. I chose to have a mastectomy to avoid radiotherapy. So it was back to the surgeon and 'the bag', but this time I was not so lucky because an infection set in that put me back in hospital for antibiotic treatment. I was also to begin chemotherapy treatments.

I chose Adriamycin and Cyclophosphamide and had four cycles of treatments. My oncologist also suggested CMF but I preferred shorter and stronger doses rather than taking tablets for two weeks and perhaps enduring a longer period of suffering side-effects of nausea and tiredness. My knowledge of chemotherapy's side-effects had been gained only from the media and second-hand stories. It was hard, emotionally and physically, to get ready to undergo these treatments and their possible side-effects. I promised myself I would be prepared and would face them with courage. My mother and family's tender loving care was an important part of this preparation.

I am a practical person so I handled the treatments the way I handle other problems - find ways to cope and live with them. Life goes on with or without my participation. I was lucky the side-effects were minimal, although my mother 'wrapped me in cotton wool' during this period. She would not allow me to do any housework or to go out into crowded places where I might be exposed to infection. She prepared all kinds of Chinese concoctions to strengthen my body, hoping these would help me recover quickly and get rid of all the cancer cells. Fruit juices and sometimes vegetable juices are now part of my daily intake, although I would rather have steamed vegetables. Multivitamins and food supplements (which my mother gets whenever she hears about them working wonders on other peoples' cancers) are part of my life. My mother's love and devoted caring for me make my life so much easier.

I started losing my hair after the second treatment and was completely bald. I wore something to cover my head when I went out, but this was for other people's sake rather than mine. I was comfortable being bald

so at home I did not cover my head unless it was cold. I didn't wear a wig as I didn't like it. I had a black turban with a nice gold buckle made by the volunteers from the Peter MacCallum Institute and people always admired it.

Life went on as usual after finishing these treatments. I went back to work part-time and made a gradual commitment to full-time as I became stronger. I didn't feel that I was treated differently by my colleagues as I continued to work on my current tasks and participate in new projects. They knew my ability and dedication to work, and I was glad for the support they showed me. But it also meant working as before, with long hours and pressures to meet project deadlines and bottom lines.

Physically, I was fine but uncertainty that the cancer would strike again created an uneasy state of mind. I always felt that the 'beast' was lurking, waiting to attack unexpectedly, but I hoped I would have a long time before I had to face it once more. I wanted to be able to guide my younger son through his teenage years and be there to celebrate his twenty-first birthday, at least.

My hopes were dashed. Eighteen months after the treatments, at my six-monthly checkup, my oncologist found lumps in my left and right clavicular lymph nodes. A biopsy was done and cancer was confirmed. What a blow! The sternum and the lining of the lung were the sites now affected. It was decided that I should undergo a course of CMF treatment, to begin after Easter, when I would be baptised. I had postponed this decision since high school, when I was not ready to take the step of being a committed Christian. When I choose to do something worthwhile I have to make sure I can participate to the best of my ability. For me, duty and responsibility are serious matters.

The CMF treatments began and I had hardly any side-effects because I was careful in managing my lifestyle. I made sure I had enough rest when I needed, without feeling guilty. I ate balanced meals and avoided activities that could cause infections. The CMF treatments ceased to be effective

and were discontinued after six months. I had a two months break and went to see my family overseas before starting another treatment.

It is always difficult for nurses to find my blood vessels so I had an infusaport inserted to deliver the chemotherapy before starting the new treatments, thus reducing damage to the veins that are still needed for scans and other tests. That was the best decision I have ever made.

In February 2001 a drug called Taxotere was chosen to 'hold the fort' and attack the cancer cells if possible. But success is not always the outcome. I began to suffer from nerve-end damage, causing tingling in my feet and fingertips. My leg muscles were weakened and I was always tired. Household tasks had to be done in between rests. I wanted to stop these treatments and have hormone tablets instead, thinking I could go back to Taxotere in the future, but I have oestrogen negative cancer so hormone tablets would not work for me as well as chemotherapy.

Cancer treatments seem mostly to be hit and miss, and success and side-effects are dependent on individual responses. It is not always wise to stop a particular treatment without good reason. Consequently I had much indecision about stopping the Taxotere treatments because I was frightened of the consequences. Many health conditions can be controlled or completely cured with medication, but cancer is not like other illnesses. The oncologists are always doing their best to find available treatments that will help to give patients a longer and more comfortable life.

In the end the Taxotere treatment was stopped because my cancer cells were active again and the drug would not have been effective. I was quite relieved that I didn't have to live with the consequences of my choice to stop the treatment earlier. On the other hand I was disappointed that I was not going to be in remission.

Luckily there was a new vaccine that fights breast cancer with over-expressed HER-2 protein to slow down cell growth. I was given these treatments weekly for ten weeks and did not suffer any side-effects, but the cancer marker kept going up. Navelbine, was added to the weekly

treatments and I continued to take vitamins, food supplements and fruit juices.

During this period I lost the hearing in my right ear. The sudden discovery that I could only faintly hear a voice during a phone conversation, when my hearing had been fine the day before, was frightening. I was referred to a head and neck specialist and had a hearing test. The specialist suggested an MRI scan to find if the hearing loss had been caused by the cancer. Luckily this was not the case and, although the specialist said that I may not get hearing back, miraculously my hearing recovered 100 percent within two months.

When Navelbine was found to be no longer effective, I asked for a six week break from chemotherapy before starting a new regime. During this time my voice started to disappear. I felt like there was a lump in my throat and I coughed a lot. Back I went to the head and neck specialist. I was told that my left voice box was paralysed because of nerve damage caused by the cancer. They said they could help me with an injection technique or with surgery. The injection technique inserts an inert Teflon paste into the paralysed vocal chord through the mouth or the neck. The paste fills the vocal chord and pushes it to the midline to help with voice quality and swallowing. It was preferred to do the injection when I was not having chemotherapy, however, this was difficult because I require constant treatment. I decided to live with my funny hoarse voice as long as others can still hear me (albeit with difficulty) and understand what I say. I look upon it as just another price I have to pay to deal with the cancer. My voice problem reduces my social life because I feel awkward in large gatherings. I try to find quiet eating places to meet my friends.

One of the soft tissues in my chest kept getting bigger and the oncologist decided to try radiotherapy for the first time. It reduced the size of the lump and I was lucky not to have much of a problem with it.

I decided to go overseas before Christmas 2002 to visit my family. I tried alternative healing methods suggested by my family, in the hope

that they would help me to live longer or cope better. The cancer marker went down during this period, due to the radiotherapy or the other healing methods; I am not sure why. But I still had to go on to the next treatment, Xeloda, in tablet form for a two week period with the third week off.

Xeloda alone did not do the job, so weekly Herceptin was added to my treatment in June 2003 in the hope that it would increase the effectiveness of the control of the cancer. However, both treatments had to be discontinued three months later. Unfortunately I have an allergic reaction to the contrast used in CT scans, which means that no more contrast can be used. In a way, I am glad because I don't have good veins left. I was given three further choices: to have radiotherapy for my neck, as CT scans showed that the lymph nodes were getting larger; to repeat previous chemotherapy treatments, as the oncologist was running out of new approved treatments; or to join a trial which involved biopsies. I chose radiotherapy. At least my body can recover before the next chemotherapy.

I started taking Bonafos, a treatment for bone cancer, in November 2003, but I developed constant shoulder and arm pain that could not be relieved with Panadol. The next cycle of treatment suggested by my oncologist has been weekly Taxol chemotherapy and Herceptin, as well as monthly Zometa to replace the Bonafos. I am still on these treatments. Perhaps a new treatment will become available. The longer I stay alive the more chance I have of spending time with my family.

Feeling tired is part of my daily existence. Household tasks seem much bigger than they actually are. I have to stop and rest while vacuuming the house. I decided I would rather do the cleaning than do exercises. The house stays reasonably clean and tidy and my muscles get a workout. I try not to feel disappointed when I have to change my plans for the day because I need to nap. I always try to rest before I go out, so that I can last as long as possible without looking like death warmed up, and keep life going on and being enjoyable.

My breast cancer has given me the chance to stay home with my son, and participate more in his daily life than I would have if I had continued to work. I am lucky I have not suffered financially, even though I have to face a lot of hurdles and uncertainty in other aspects of my life. My faith has helped me to have peace within myself. This is my golden opportunity to give back as much as I can to my family and society for all the happy times in my life. I want to live as long as possible without suffering and lead as normal a life as possible, both for myself and my family. I don't want them to suffer with me.

I am now more comfortable with myself. I don't have to prove that I can do everything and I give myself permission to do what I want to do. By looking after myself, I can look after others more and also learn to let others look after me.

My husband Graham is a great support and lets me do whatever I think is important. It is not easy for my younger son to cope with his mother feeling unwell. He tries so hard to avoid doing anything that would make my life more difficult. I am so glad to have my sister with me especially now. She has been a tower of strength and a wonderful person to have on this journey. It is hard for the family to know the cancer may shorten my life. Death is a fact of life but it is heart wrenching to lose your loved ones even if you are ready for it. I am so grateful to them all for their love and care.

### *Mary K's story*



My name is Mary Keenan. My story could be suitably titled: 'hatched, matched but not yet dispatched'!

### **HATCHED**

Mum and Dad met at Edenhope, a small place near the South Australian border. Mum was a pharmacist as was her eldest sister, brother and father, and her siblings owned the local chemist shop. Dad, who had been a jackeroo and station hand since age sixteen, worked for a local stock and station agent, after discharge from the Army due to blindness in one eye. He had been a PE Instructor in the Army and used to wow us with a push-up where he clapped his hands and feet together as he was suspended above the ground. He was always a very fit and strong man.

Dad regarded Mum as a great catch because she was attractive, with lovely figure, great legs and beautiful hands. She was well educated and (not so much of a plus) a Catholic. Dad was a tall, dark, handsome gentleman with a sense of fair play, and was Church of England. Before the curtain closed on World War II, they married at St Patricks Cathedral, after Dad promised to raise any children as Catholics.

I was the first to be hatched, some twenty months later in November 1946. Later came Liz 1948, Jim 1950, Tom 1952 and Andy 1954. In 1953 a property near Wangaratta in NE Victoria (the Trig farm) was purchased.

This is where we were all raised and Dad still lives, aged eighty-six. Mum died at eighty-three.

My final two years at school were spent at Kilbreda in Mentone. It was a happy time, as I fitted in well and was a better than average student. Although I won a studentship to take up teaching, I went into the Public Service instead. Mum was dismayed that I did not want to teach and so insisted that I sit the Public Service exam. I was packed off to Melbourne for the interview where I was asked if I would like to work for the PMG (Telstra), Navy or Australian Taxation Office (ATO). I had no idea, but being a country girl I dismissed the PMG (linesmen always enjoying smokes on the side of the road). And the Navy offices were at Albert Park, that is, not in the city. A boy I knew 'was doing well in the Tax Office'. If he could do well, so could I! On arriving at the ATO I told that if I wanted to 'get on here' I must study accountancy. I had no idea what accountancy was but, being ever obliging, asked *'Where do I enrol?'*

#### **MATCHED**

Geoff and I met when I was still at boarding school. He was in Wangaratta studying electrical engineering and I was in my final year at school in Melbourne. We saw each other at the Wangaratta Town Hall dances on the odd weekends that I was home. When I finished school and was working at the Tax Office, he was in Melbourne continuing his engineering. We used to go to the pictures (Peter Sellers movies were a favourite), or to dances at the Hawthorn Town Hall or ice-skating at St Moritz - he was a much better skater than I was but it was fun. There were balls, dinner dances and friends. We were both studying and went home often to see our families. We married in February 1969.

Our first child Russell was born in July 1970 followed by James in 1973 and Emily in 1976. My aunt Pol lived with us and helped me with the children and house from James's birth until Emily started school, about

seven years. She has been a wonderful support to our family even still in 2002 when she is ninety-eight years old. She still does my ironing - claims it is good exercise! During all this time, I began to build an accounting practice and over the years have come to know many wonderful clients. It helped pay for some of the family extras like private school education, holidays and a year on exchange in Denmark for Emily.

#### **NOT YET DISPATCHED**

At Easter 1994 we were at my parents farm with some friends. We had been to a winery and on walks around the hills. After a shower, I glanced in the mirror and my eyes fixed on a puckering in my left breast. I knew immediately what it was and showed Geoff. On returning home, my GP was away so I had a few days wait. Once I saw him, he referred me immediately to a breast cancer surgeon and organised a mammogram.

My specialist was kind, but definite: it was a cancerous lump and I could have a lumpectomy but, because my breast was small, a full mastectomy would be more appropriate. He tried to take an aspiration but the sample had too much blood. He explained that I needed further tests: an X-ray and bone scans to confirm the extent of the disease. I was matter-of-fact as I left his room, but the tears welled up as I reached reception. The nurse gave me a tissue and let me into a spare room where I could compose myself. Although I knew it was breast cancer, the full realisation was just starting to penetrate. I went home, told my Aunt Pol and had a good cry. She was shocked, as I had always been the healthy one, strong and never sick.

The mastectomy was set for the end of April. If the lump was cancer, as we were almost certain it was, it was agreed that I would have an immediate reconstruction. A saline sac would be implanted and existing skin stretched over. At a later stage, more saline would be pumped in and gradually the reconstructed breast would reach the size of the remaining

breast. There would be no nipple, but I would have some cleavage, which would be more attractive in bras and bathers (from this viewpoint, it has been a great success!).

My operation went well and the scar healed quickly. My staff were kind and supportive, and sent a large modern arrangement, some flowers but also decorative cabbages, vegetables and fruits. It was the talk of the floor, and nurses and staff came to inspect it. Some of the comments were very funny!

I had no psychological difficulties with losing a breast. They had always been small and 'undernourished'. I had breastfed two children with mixed success. My breasts were sensitive but not usually the focus of my partner's attention (he was more of a 'leg' man!). As a consequence my breasts were not a big thing (pardon the pun) in our relationship, and for once I was grateful for this. There was no stress from my husband.

#### **TELLING MUM AND DAD**

Following my discharge from hospital we travelled north to tell my parents. I was nervous as they were nearly eighty and I had no idea how they would accept the news. Both were upset, but Mum later pointed out women in the district who had mastectomies and were thriving many years on. I was relieved and inspired!

Three of sixteen lymph nodes were infected and follow-up treatment was 'light' chemotherapy for six months. This involved an injection followed by two weeks of tablets and then two weeks break. My hair thinned, but was OK and I suffered some nausea and fatigue. I continued to work full-time, but was fortunate with staff. My new staff member, Jenny, an accountant, was wonderful. I believe that she was 'sent'. Together with my secretary Katrina, she kept things running well.

Because of my business and the goodwill associated with maintaining fees, only a small number of friends, relatives and staff, knew of my

connection to breast cancer. At that time, as now, I had two businesses: my accounting practice and a soft-furnishing import business. The import business was difficult and not financially sound, but my accounting practice was a joy and profitable.

During that 'chemo' period, there was a Trade Show in London that I wanted to visit. A friend was able to travel with me for the two weeks and I asked my specialist. The reply was: '*No worries, chemo should not control your life; you should control the chemo*'. We had a wonderful trip and I had my last period of the thirty-five years total, in London!

Menopause had commenced! I was able to ignore most of the problems of menopause. However, I did suffer from awful night sweats and it was hard to ignore the perspiration dripping from upper lip and brow during perfectly mild weather with clients sitting opposite, as we discussed the tax deductibility of their latest car, home office or weekend jaunt to Sydney. Over time I also noticed the effect on my skin. I started to look older and felt that I did look my age. This was rather sobering. I could understand why many women embrace HRT if only to maintain that youthful bloom.

Two months after the mastectomy, Geoff arranged a holiday in Vanuatu. It was a new experience and an interesting place - very relaxing where time did not matter. It was not until we were there, six weeks after my operation, that I was able to look at my scar in the mirror. Prior to that I felt that a mutilation had taken place.

Another blip: In the New Year following my mastectomy the saline sac of my reconstruction started to leak. By the time I was able to see my surgeon it was urgent to get to hospital to have a permanent prosthesis inserted. It was always smaller than intended but was reasonably okay. (Ironically, at this time of writing I am quite skinny and my reconstructed breast stands out rather humorously, but what can you do?)

For the next three years I was well and able to work hard. Cancer was not on my thoughts continuously, but I did take measures to reduce

the stress in my life, with yoga, meditation and exercise, and to savour the day, enjoy life and love my family and friends. Life was normal and enjoyable. Geoff and I even managed five weeks in Europe.

The yoga group, organised with the Cancer Council, was run by an inspirational woman who had regained excellent health after two mastectomies, and bone and liver secondaries some ten years prior. She had great respect for Ian Gawler's ideas on meditation, relaxation and diet, and was open-minded on natural therapies. This was my first experience of the benefits gained from sharing similar problems. Although the group has dispersed some of us meet occasionally to check up on each other.

I have been helped and influenced greatly by Ian Gawler's book *'You Can Conquer Cancer'* and also *'Mending the Mind and Minding the Body'* by Joan Borysenko. Prior to my diagnosis, because I had never been sick I had little interest in the ailments of others. As a consequence, I was ignorant about all cancer and breast cancer in particular. These books gave me something to clutch at and believe in. They gave me some solutions about how I could help myself and opened up many possibilities relating to natural therapies and improved lifestyle.

During 1998, I developed a soreness in the groin. It felt muscular but was puzzling because I couldn't seem to get rid of it. I tried all sorts of anti-inflammatories, but eventually became 'fed-up' and visited my GP to complain. I told him that I wanted to go to London next week, but realised that in my present state I would not be able to manage the steps of the Underground and the walking that such a trip entailed. Blood tests were ordered, another specialist arranged an X-ray and the nasty news was clear: the breast cancer cells had gone to the bone! The pain that had caused me to limp for months was the result of the muscles pulling on the bone tumours in the pelvic region. The cancer's progression was hard to accept, as I thought I had been doing all the right things. In retrospect, had I been aware of the statistics relating to lymph involvement and the likely return of the cancer, I might not have been so surprised. Fortunately

I did respond well to the hormone drugs Tamoxifen and later Femara but only for about nine months each time.

Bone pain has been the biggest problem, but I have learnt a lot about pain management and it rarely gets the better of me. It also comes and goes, so there is always respite. It has been necessary to have some radiotherapy on my spine and one hip and I can foresee further trips down that road in the future. In each case, the radiotherapy has been extremely successful.

My latest challenge is some liver tumours, but once again I have been fortunate. Any symptoms are minimal. For the past two and a half years I have followed a vegan diet with fish added. This diet has given me great energy, and the exclusion of dairy products was a positive move for me. I have lost weight, and this has been exacerbated by eating difficulties caused by mouth ulcers, which in turn are a side effect of the chemotherapy.

In August 2001, I commenced chemotherapy (Adriamycin) to attack the liver spots. During the treatment, however, I required some radiotherapy (hip) and then I had the misfortune to fracture my thigh. The bone had been weakened by tumours and fractured when I jarred it twice by tripping on the garden hose. This necessitated ten days in hospital where a titanium 'nail' was hammered inside the femur from hip to knee. Pegs hold the bone in place. Everything has healed well and I can walk quite well unaided, though with a slight limp.

In March 2002, with the liver tumours on the increase something needed to be done. My oncologist suggested Xeloda and Taxotere. I looked at him in horror - not Taxotere so soon after Adriamycin! He relented and said that maybe we could start with Xeloda and see if it was effective. Being a tablet form of chemo it is easy to take and fortunately the side-effects were minimal although cumulative. Over the course of the treatment my feet became slightly numb and peeled, and my fingertips lost some feeling and caused me to be rather clumsy. Also the skin on both thumbs split and did not want to heal - minor matters in the scheme of things.

The blood tests improved immediately, and continued to do so through the six cycles, and my general well-being was obvious to all my friends. So much more energy for work and play!

My family have been a great support and I sometimes wonder to what extent they have been affected by my illness. When I race around normally, working, shopping, cooking and enjoying life, they are able to forget this dagger hanging over my head. When I am not well, they respond in different ways: they become more helpful but I see the stresses starting to mount. Like me, they begin to think about death and me not being around. I then wish they would consider some counselling.

I find it hard to reconcile that my will alone is not sufficient to keep me alive. I think of those I have known who have not wanted to die 'just yet', but they do anyway. To what extent can our minds dominate our bodies? Can our will not keep us alive until we are ready to go? Sadly, I see a happier path if we accept the inevitable when it does in fact become so. In the meantime, a positive attitude, optimism and remaining open to new treatments is an important way to help yourself and still enjoy what life offers. To stay 'well' continues to be my aim.

Fortunately I have always had a very optimistic nature and expect that things will work out well for me. This positive outlook has allowed me to keep working full time in my accountancy practice, which I regard as great therapy. An obligation to staff and clients makes you get out of bed in the morning, and we all know how things improve after a cup of tea, shower, breakfast and a trip in the car to the office. It becomes another day of looking outwards not inwards: no time for depression or sad thoughts.

Cancer has been a huge learning experience for me and has taught me a healthy respect for my body, that it is not a machine. It has made me more empathic to others who endure illness and disease. It has made me appreciate kindness, an underrated virtue. I know that I am less judgemental and more tolerant of human failings. I really enjoy my life.

Life is so precious and so short. We only have one chance to make the most of it and hope that some good will evolve from our brief time. One can only do one's best and hope that it is good enough.

#### CONCLUDING NOTE

Sadly, Mary passed away on 13 March 2003. Mary rejected the idea that cancer was going to interfere with her busy fulfilled life and she was so determined that she succeeded. Mary not only ran a family, but also two businesses and attended to these commitments until two weeks before she died. She even had a business trip to Europe in January 2003 - amazing! With all this she still made time for *The Thursday Girls* and rarely missed a group meeting. That was our Mary- gracious, proud and determined to the end.

#### *Reflections from Mary K's companion*

My name is Geoff Keenan and Mary was my wife. We have been blessed with three healthy and wonderful children.

It is sometimes said that there are three conditions for a good life: an active life, an inquiring mind and a peaceful death. Mary had all three, but she went one better. She believed that one should always try to obtain the best under the circumstances. She would draw her boundaries and set out to get the best outcome. Anyone who knew Mary soon learnt that there was a difference between 'good enough' and the best available. Mary would not compromise - second best was never an option. She had an eye for quality, taste and value.

Every minute was important to Mary, and she would often stop, close her eyes and breathe in the experience. She battled her cancer with great vigour, never prepared to give even an inch. She read extensively on diet and its effect on her body, and she followed the guidelines without

exception. When the pain built up she resisted the advice to simply dose up on painkillers. She would take only the minimum painkillers so she could be aware of her body and any change in her condition.

After Mary was diagnosed with secondary cancer she was invited to join a group of women who had similar problems and experiences. Her initial reaction was to decline, fearing the group might not be suitable for her. After agreeing to attend one or two meetings she realised the purpose and value in the group, and became an enthusiastic member. It became important to her and she looked forward to each meeting.

I am convinced the group had a positive and beneficial effect on Mary.

Eighteen months ago Mary complained about difficulty in walking. An X-ray did not show any problems, but the pain increased over the next week. She insisted on a second X-ray and the doctor finally agreed. It showed that her leg was broken almost right through. She was hospitalised and a steel pin was driven down the middle of her leg and pinned to the bone. For over a week she had endured much pain, but barely showed it.

I took her to the hospital for chemotherapy treatment on the Tuesday before she died. The doctors advised that they would stop the current treatment as it was not improving, and was possibly aggravating, her condition. She was to stay in hospital for two nights for a minor procedure, but her condition deteriorated very quickly. By Wednesday evening she had lapsed into a coma. She died peacefully and without pain at midnight on the following night.

Mary would discuss her plight openly and with pragmatism. She was a brave and stoic person, yet calm in accepting her position. Medical professionals were amazed at her attitude and in her belief that she could make a difference. She fought bravely but in the end the odds were against her.

We will all miss her dearly and we will not forget her.

### *Mary C's story*



My name is Mary Cooper. I was born in March 1934 in a small town on the banks of the Missouri River, USA. My birth was followed within a few minutes by the birth of a twin brother. We joined an older brother to complete the family. Early life in a small town revolved around family and friends. My father worked in a local business and was an important part of the community. As children, our lives were simple and involved church groups and other social and sporting activities through school. The community was one in which you knew most of the town and they knew you, which had advantages and disadvantages!

In 1956 I graduated from university and began training at a large teaching hospital as a medical scientist. In September 1969 I decided to accept a job in Australia and see the world. The job was for two years and then I planned to travel and see what the future held. However, I married Ian in 1972 and in the next few years had two children. Life was busy- I had to make new friends and establish a life without close family. The children were a great way to make friends via playgroups and school. We were fortunate to travel several times to the States, and this gave my children and my family a chance to get to know each other.

It was a morning in late November of 1986, with school about to finish and Christmas very close. As I was showering I felt a lump in my right breast. I told myself it was probably nothing but knew it would have to be investigated. The day was filled with pre-Christmas shopping and passed

quickly. In the evening I told my husband and as he examined the lump his concern was apparent. After a few phone calls, an appointment was organized with a surgeon. When I saw the surgeon the needle biopsy was negative but to make a definitive diagnosis a surgical biopsy was required. This should have been a routine procedure but the nurses were on strike and hospital beds were at a premium. The next few weeks passed slowly as I tried to stay focused on getting organized for Christmas. As I returned home one afternoon the phone was ringing to inform me that there was a bed. In the evening Ian and our two children Sarah and Mark came in to see me. Mark who was ten asked how much the room cost and when told questioned '*Can we afford it?*' We all burst into laughter for the first time in a few weeks. I had a long wait the next day, as surgery was in the late afternoon. When I awoke after the surgery, Ian told me that I'd had to have a mastectomy. This was devastating news and I prayed that I had the courage to face whatever the future held. We decided that Ian should go home and tell the children the news and spend some time with them. In ten days I was home and we had Christmas at home as planned.

In January I started chemotherapy with CMF. At the time of surgery, a prosthesis was inserted that was to be injected with saline each time I had 'chemo' to prepare the site for a permanent prosthesis. During the chemo I had a lot of nausea and the anti-nausea drugs gave me little relief. We spent time at the beach and tried to maintain as many normal activities as possible.

Before the drama of my breast cancer, Ian had been planning to take some much needed long service leave. As the end of the chemo was drawing near, we decided to pack our bags and headed for London. We had been in London only a few days when I received word that my father had died. Although he had been ill for some time, his death was a great loss for me and one that seemed magnified by being so far away from my mother and brothers. It was at this time I realised that Ian, who had been under a lot stress at work and had suffered some mild bouts

of depression with the worry of my illness, was not well. We journeyed to Paris, but soon returned to London for medical help where Ian was hospitalised. After a few days of sitting in airline offices, I managed to send the children to my family in the States. In three weeks we were able to join them, but after a brief period Ian required more hospitalisation. It was wonderful at last for me to have the support of family at a difficult time. Six weeks later we were all winging our way back to Australia, hoping the difficult times were behind us. Sarah and Mark resumed school and Ian resumed work.

Unfortunately once more life was to be interrupted. I developed a high temperature and a lot of pain over the area of the prosthesis. When I spoke to the surgeon he said to take some Amoxil and I would be all right. However, my temperature increased and my husband, realising I needed urgent medical attention, arranged for a physician friend to see me. I was hospitalised for two weeks with a very resistant organism infection and needed to have the prosthesis removed. The infection left me a bit battered and it took a few weeks to regain my strength.

Over the next eight years I was always greeted with good news from the oncologist and for this I was grateful. I was fortunate because Ian had several episodes of ill health, with two admissions to intensive care and another severe bout of depression that required hospitalisation.

In September 1995 Ian retired and we left for France with friends where we had a wonderful time living in small villages and enjoying the country. After six weeks we returned to Australia with great plans for other trips and more time together in retirement. However, in early February Ian suffered a cardiac arrest while playing golf and died a week later. It was a devastating time for the three of us. The support of family and friends was incredible and my brothers arrived to stay with us for several weeks. Eventually life resumed some pattern of normality. Sarah and Mark returned to university and I resumed some of my former activities.

In order to have something to look forward to, we decided to plan a

trip to the USA for Christmas. The bookings were made and we all looked forward to a winter Christmas. However, a few months before we were to leave I developed swelling in my right arm and a loss of feeling. When this was investigated I was found to have a lesion in the brachial plexus that would require six weeks of radiotherapy. Travel plans would have to be changed. The three of us were very depressed. It seemed as if nothing was going as we wished. After a little clear thinking it was decided that Sarah and Mark would travel as planned and I would join them a few days before Christmas. They enjoyed the activities of being with many cousins while I sailed through the radiotherapy. However, I awoke one night with severe abdominal pain. I had an acute gallbladder problem that required surgery as soon as possible. I was discharged two days before Christmas Day and the children and I spent our first Christmas without Ian on opposite sides of the world.

Over the next few years Sarah and Mark finished their university courses and took overseas trips. I also travelled to the States to spend time with my American family. Upon returning from overseas, Mark decided to return to university, only this time it would involve a move to Sydney. He left in early 1999. In 2000 Sarah decided it was her turn to travel and she headed overseas in June. While Sarah was away I was told that the markers for my cancer were going up and it was time to switch my medication from Tamoxifen to Femara. This was devastating news for me, as after fourteen years I thought I had been able to put the breast cancer behind me. However, scans revealed that I had the disease in my liver, lungs and bones. More bad news followed, as the Femara had no effect and more chemotherapy was needed. I found this news very distressing and was referred to Dr David Kissane. He reassured me that I was not depressed, but distressed and that this was a normal reaction, and told me about the group sessions he ran for women with metastatic breast cancer. I began the CMF treatment. The side-effects involved hair loss and proved debilitating for me. After four cycles of the treatment

the scans showed improvement. I was feeling well and looking forward to enjoying life.

November arrived and plans of Christmas began to circulate in my head, pushing everything to the side. I had not had any chemotherapy since May and had been able to lead a full and busy life. However, I had to face the fact that the breast cancer had recurred. I felt well but the scan showed that the liver had active disease and the markers were rising. I was shocked. The oncologist agreed to wait until after Christmas before further treatment, as it was an important festival for the family to enjoy together. A few days before Christmas I had a lot of pain in a rib. I agreed to have radiotherapy and one dose eased the pain.

In early January I was to see the oncologist and begin chemo, but my left hip became very painful and made walking very difficult. The radiotherapist started treatment immediately and a few weeks later I was ready to start chemo. The chemo began and Adriamycin was chosen. After the first dose of chemo I began vomiting and no anti-emetic was successful. The next morning I rang the hospital and was admitted to the Day Ward. With help from IV fluid and anti-nausea drugs the vomiting subsided. To play safe I was kept in hospital overnight. At home the next day all seemed to be going well, but in the middle of the night I woke up very short of breath and needed to sit up to be comfortable. So back to the hospital for me, and in the morning I was diagnosed with left-sided failure although the reasons were not clear. I have a leaky valve so this would have contributed to the problem. After two nights in hospital, I was back home at last with enough drama for a while. My daughter and I agreed that the car seemed to know the way to the hospital automatically! When I arrived home, one of *The Thursday Girls* came with a lovely bunch of flowers and lots of messages of support from the group.

Finally in February, after weeks of leukopenia from Adriamycin, I was started on weekly Taxotere. This would be a challenge although the doses were to be very weak. At this time I was encouraged by the arrival

of my brother and sister-in-law from overseas, who would be a great source of support for me over the next few weeks. We had a lovely time although my activity was restricted by lethargy.

In April my twin brother and his wife arrived - another boost for our morale. The Taxotere was taking its toll, with lethargy, muscle aches and a drop in haemoglobin. My fingernails turned purple and fell off and a significant peripheral neuropathy developed in my fingers. However, I had good news: the liver scan showed marked improvement and the markers were down. The chemotherapy was stopped and life began again.

It was great to resume some activities and be involved with family and friends. However, after two months the marker activity increased and a CAT scan showed active disease once more. Medical options were getting fewer. Xeloda was suggested. From *The Thursday Girls* I knew that those who had it seemed to cope quite well. I was started on Xeloda but severe nausea began on day three. I was tried on Anzemet, but had the same problem. My frustration is high and I cannot understand why I have these problems. I was tried next on Navelbine. The first dose caused the vein to spasm and a PICC line was needed. This procedure needed three goes and I was nearly in meltdown. In the third week I had a 30% reduced dose of Navelbine, and was sure all would be well. But my platelet count was too low - what next, who knows?

At last Navelbine has been stopped and I am coping with an enlarged liver and lots of discomfort. It is difficult to do anything. I am encouraged by the constant support of *The Thursday Girls* who ring regularly.

#### **CONCLUDING NOTE**

Sadly, Mary passed away on 20 November 2002. Chemotherapy didn't work well for Mary but she always tried. She was a wonderful mother and a generous friend to all. Her fine intelligence, dignity and courage saw her cope with the difficulties that life threw her way.

#### *Linda's story*



My name is Linda Evans-Lindupp. I entered the world in November 1958, my sister Carol had arrived two years earlier and we waited seven more years for my sister Alison. My family immigrated to Australia from Warwickshire, England in 1966. Our family life has been challenging and interesting. My older sister Carol trained as a missionary and taught for eight years in Tanzania. While Carol was in Africa, Alison was diagnosed with multiple sclerosis. It was a heart-rending time for our family. Since my own diagnosis, I understand how Alison felt, and she has been a fantastic support for me throughout my treatments.

I completed study as a librarian at RMIT and met my husband Craig in 1984. We were together for nine years before we decided to marry and our daughter Melanie arrived fourteen months later. Mum and Dad doted on Melanie, their first grandchild. Dad was diagnosed with Parkinson's disease fourteen months earlier, and Melanie provided a focal point for them. Dad loved to play with her and take her places. Dad became more disabled with the disease and the time arrived when he had to go to a nursing home. It was a difficult time for all the family, but especially for Mum and Dad. We felt a sense of helplessness and uselessness.

Not long after, I discovered that I needed an urgent visit to a doctor. I had reached down and placed my hand on my chest, for no particular reason - maybe indigestion, I don't remember. I felt a small lump on my right breast. A million thoughts crossed my mind, but I didn't tell

Craig, who sat beside me watching television. The earliest appointment with the doctor was Friday - two days to wait! I resolved not to worry until I needed to, but found my hand feeling the lump all too often. I had plenty to keep me busy - my daughter was turning five in a few days with a party at McDonalds planned for Saturday, a family party at home for Sunday, and cakes for creche and kinder. Busy, busy, busy!

Friday came around quickly- I still hadn't told Craig about the lump; I just told him I was going to the doctor's for an overdue pap smear. The doctor decided I required a mammogram that day. How did I feel? Just tired. I hadn't been sleeping well. I was convinced I didn't have cancer. The mammogram was over in minutes. When I got back home the message on the answering machine was short: *'Please ring the doctor as soon as possible: I turned to Craig and said 'It must be cancer!'*

The receptionist entertained Melanie while we talked to the doctor. We were devastated and drove over to tell Mum. Tears, tears and more tears. Poor Melanie didn't really know what was happening - she turned five in two days! What do we tell her? The next week passed in a blur of birthday parties, doctors' appointments, tests and biopsies. I told my family at the end of Melanie's family birthday party. I was greeted with silence, disbelief and promises of help. After a talk with Craig's mum, I convinced myself everything would be okay. She had a lumpectomy a few months before followed by six weeks of radiotherapy and was pronounced 'clear'. And a friend of hers who had been told that she needed a mastectomy had only had a lumpectomy. Things were sounding good and I was confident, if a little nervous, when I visited the specialist.

The specialist explained everything carefully. We looked at the mammogram and discussed breast cancer scenarios, but then the crunch came - mastectomy! I was devastated and the tears flowed freely. The specialist explained why a mastectomy was recommended. It didn't really help, but I appreciated the time taken to explain everything. It makes a huge difference when you can communicate with your doctors! She

recommended a biopsy the next day and that we return to discuss the results on Thursday. I don't remember much about the rest of the day.

Wednesday was the biopsy. The nurses were really nice I was given a towelling gown embroidered with the initials VSG - Very Special Girl. It was an interesting experience as I wasn't used to baring my breasts to such a number of people! The radiologist explained what he was doing and the nurse wished me good luck as I left - it's the little things that help you feel better; not just another patient on the way through the line. It was a beautiful day and we decided to go to the beach and enjoy the sunshine. It was hard to believe that less than a week had passed since the mammogram.

Back to the specialist the next day. We talked for a long time, and considered the possibility of taking a holiday before the operation; I joked that I could *'take my boobs on holiday'* for the last time, however, we decided to go ahead with the operation on Monday.

I had kept it together until the Sunday afternoon when I couldn't stop crying and said that I'd rather die. Craig talked me around and we went to bed very late. I thought about it all night. I wasn't frightened by the operation, or about cancer, but I hated the idea of losing a breast.

I was so upset on Monday morning that Craig rang the doctor. She spoke to me and then telephoned the specialist who said *'I don't want to make you do something that you don't want to do, but I believe that this is definitely the best option for you.'* She said she would ring back in ten minutes to know my decision, as the hospital would have to be notified if I wasn't going to be there. I looked at my daughter, now used to seeing her mum crying, and decided to have the operation I had to be around as long as I could for her. As Mum drove off with Melanie she asked why she was being so funny and silly (Melanie had a net bag over her head and was pulling funny faces). She said *'to make Mummy and Daddy happy:'*

We headed off with my new feeling of resolve - now I had made the decision I was okay. The hospital staff and anaesthetist were caring and

gentle. The operation was delayed three hours and Craig stayed with me. We talked and joked and I spent time looking at a photo of Melanie in a fairy costume. Her smile reminded me why I was having the operation. I wanted to stay in hospital as long as I could because I did not relish the idea of caring for the wound, plus having drainage tubes to deal with at home. I was very upset when the morning after my operation, I was shown a video on caring for the drainage bag at home, as I would be going home soon. Less than forty-eight hours after the operation I was told *'You can't hide in hospital forever'*, which made me angry. I didn't feel emotionally or physically ready to leave hospital and I was not going home with my drainage bag in if I had anything to do with it!

I was shown the different prostheses and given a soft shape with polyester filling to wear when I left for home. It felt odd - my polyester boob kept riding up because it wasn't heavy enough. I thought that everyone knew that I didn't have a breast and I felt very vulnerable. I remember going to work with the bottom of my bra safety-pinned to the waistband of my jeans to keep my breast and prosthesis looking level until I received funding from the PADP. I feel strongly that patients should be able to purchase prostheses straight after the operation and be reimbursed by the PADP later. It would make such a difference to the restoration of confidence. My specialist visited every day to offer reassurance. The results of the pathology were not so reassuring, with fourteen lymph nodes affected. I was told that the prognosis was not good.

My family and friends were great throughout the whole experience: they visited, phoned and helped with housework and cooking when I returned from hospital. I felt very loved. It was difficult for us to know what and how much to tell Melanie. We told her that I had an operation to remove cancer. Two weeks after the operation she asked to see what I looked like and declared that my scar was not very big (I thought it was huge!). Many friends offered to have her over to play at their place to give me a rest - I was very tired and boring to be with for a five year

old. However, this soon had to change when we heard Melanie playing in the bath one night, saying to her toys that they had to go over to their friend's house because Mummy was dying. We told Melanie that I was having strong medicine to kill the cancer and I did not intend to die. We decided to have more friends over to play with her when I was up to it and when Craig was home.

There was no rest from the medical tests. It was at this time that the reality hit - I had cancer. I started the medical merry-go-round: CT scans, bone scans, blood tests, referrals and visits to an oncologist and radiotherapist, as well as checkups with the specialist. Good news! The bone scan and CT scan were clear! Chemotherapy and radiotherapy were still recommended because of the lymph node involvement, so I was referred to an oncologist. The seriousness of my disease was made clear as she recommended a couple of trials in addition to the usual course of chemotherapy. Craig and I were asked if we wanted more children, as the chemotherapy could make me sterile.

One trial involved the use of Taxotere in conjunction with Adriamycin to destroy any microscopic cancer cells that may have travelled through my lymphatic system. The other involved high dose chemotherapy (so high that most white blood cells were destroyed) and stem cells had to be removed prior to chemotherapy so that they could be replaced later. The latter had not yielded any positive results, but the Taxotere was achieving some good results in advanced breast cancer.

We anguished over the various decisions, but opted for the Taxotere trial. My oncologist agreed this was her preference. The day came around too soon. I was randomised into the combined Taxotere and Adriamycin trial, and was happy because it involved the shortest duration of chemotherapy. I experienced side-effects with the Taxotere and needed a very slow infusion and my chemotherapy visits could take four to six hours.

My veins were not great for intravenous drugs. On the three occasions I was hospitalised during chemotherapy as a result of low blood counts,

my veins refused to cooperate. I was persuaded to have a surgically implanted infuser port. Hello again to my surgeon!

I hadn't realized the need to avoid 'germs' until I was hospitalised after the first dose of chemotherapy - it is difficult to avoid sniffing children when you have a daughter at kinder! Feverish and hot, I was very ill. Melanie had a friend over to play so I didn't phone my oncologist until late in the day. My blood test showed a neutrophil count of 0.03. Off to hospital for six days and on to an antibiotic drip. I was told my hair would fall out ten to fourteen days after the chemotherapy. True to the advice my hair started 'aching' while I was in hospital and began to fall out. My face was covered in an itchy red rash, another side effect. Two days later my hair all came out in the shower, and as I looked in the mirror I cried: one breast, no hair and an extremely blotchy face. I was due to start work on Monday - how could I face anyone?

Out with a wig and on with makeup! I attended a 'Look Good, Feel Better' session for women with cancer. It was great fun and I learnt things I could have used years ago. I felt ready to face the world. It was a fantastic opportunity to change my image! Craig fancied a long, brassy blonde wig



and I liked short and red. Melanie looked carefully through the book and chose one that looked exactly like my own hair - she wanted me to look like Mummy, and asked 'When your hair falls out, can I take some to kinder in a bag for show and tell?' I explained I was getting a wig so people wouldn't know I had lost my hair!

Needless to say I ended up with Melanie's choice of wig. My daughter's feelings were important.

A different look would draw more attention and I didn't want to fend off too many questions. I was fragile enough as it was. People assured me that the wig looked great, but on bad days I felt that people just said that to reassure me! It felt odd, rode up and I was convinced it was going to come off, but I couldn't go out without it despite the hot weather. I didn't look stylish in scarves and turbans like some people and kept my velour beanie for home and bed. On my return to work, a customer commented 'the short hair really suits you!' I thought 'if only you knew how short it was!'

Having people over for tea was interesting, as the wig went frizzy if subjected to heat. At these times I would substitute the velour beanie for my wig. A friend of Melanie demanded to know what had happened to my hair (it had been on my head five minutes before and I now had my beanie on to cook tea). I explained that I was on some medicine that made my hair fall out. The next time I saw the friend I had hair again. I explained again that it was a wig. She wanted me to take it off, put it on, and take it off, much to the embarrassment of her mother!

Chemotherapy lasted for six months (three months on Taxotere with Adriamycin and three months on CMF) followed by a four-week break, then six weeks of radiotherapy. I was generally well, considering the strength of the two drugs. I remember having no appetite for four days immediately after the infusion and my sense of taste and smell would only return two days before the next dose. I was very tired and always came home to sleep for at least six hours after the infusion. Mum was fantastic: she drove me to chemotherapy and looked after Melanie so that I could sleep it off (I was completely out of it when I left the hospital despite my 'pensioner nap'). My aunt was great too - she actually enjoys ironing!

During this time I visited a psychiatrist to discuss how I felt about my situation. I still go to counselling with a different counsellor and find it very useful. Craig found it hard to cope with the chemotherapy. He had taken me to the first session when I had a reaction and was very

uncomfortable. He was happy when Mum offered to drop me off and collect me.

I resumed some fundraising duties at the kindergarten and found the energy to attend the pre-prep transition program with Melanie. I attended two days at work with a few interruptions for hospital stays or if I was feeling unwell. Gradually, life returned to normal, interrupted by the various cancer treatments. I also attended the Gawler Foundation. I found it inspiring and felt that this was one way I could help myself. It was important to feel that maybe I could have some control over my disease, and the dietary advice helped me through chemotherapy. At the same time it was confusing. Conventional medicine accepted that once you had cancer, diet was not an effective treatment. I resolved to do both - I felt better eating lighter foods and enjoyed the meditation and the sharing of information and stories. It was a long drive to Yarra Junction, but well worth it!

The last phase of my treatment involved six weeks of radiotherapy. Monday to Friday for six weeks was inconvenient, but on the whole the treatment was easier to handle than the chemotherapy. I again felt very vulnerable. All my previous doctors had been female, and now for the first time I had to bear my scar and naked chest to male radiotherapists. A mirror above the radiotherapy table reminded me constantly of what my new body looked like. I was still dealing with accepting my new body image!

The treatment started and was fine until the end of the fifth week. Plans were afoot for a big 'end of treatment' celebration, when my radiotherapist (another caring person) advised that treatment would have to be suspended for two weeks as my skin was being affected by the therapy, and it would burn badly if the treatment did not cease. I had to cover the affected area in Solugel and light bandage for two weeks to allow the skin to heal and could not wear my bra (and no prosthesis) for nearly five days more time off work. I was declared fit after two

weeks and resumed the last week of treatment. I was finished and the scans showed no cancer!

It was celebration time! We planned a trip to Magnetic Island with friends. I had my three centimetres of hair styled and coloured - I wasn't wearing the hated wig on a tropical island! It was a beautiful island and the holiday provided a much-needed change from the cancer therapy routine. I'm sure my hair grew a couple of centimetres while I was away!

I continued my oncology visits in accordance with strict guidelines set down in the trial. I was still tired, presumably the after effects of treatment. I decided to apply for a short stint of full-time work and looked forward to the challenge (and the income). In late February I started getting pain and nausea again. People at work assured me they were suffering the same symptoms. It was as if I had an attack and then three weeks to recuperate followed by another attack. I was reassured that my workmates were again suffering the same symptoms. After the fourth attack I decided to go to the doctor. A blood test revealed that my cancer count was on the way up and scans revealed spots on my liver but my bone scan was clear. The results did not reflect the pain I was feeling in my back. An MRI was ordered and revealed cancer in my spine.

My oncologist suggested chemotherapy again. I decided to change my diet and see if I had any results before I started on chemotherapy. Unfortunately the pain in my back became unbearable. I was uncomfortable doing anything except walking fast around the house and was admitted to hospital and dosed on morphine. At least I could lie down and rest. After some X-rays, a course of radiotherapy was prescribed. I spent most of the time in hospital, as I was exhausted and not coping well with the re-diagnosis of cancer, especially the long-term implications of metastatic breast cancer. I needed time to get my head around it all.

Mum was fantastic during this time. Melanie stayed with Mum most nights and was ferried to school and very much loved. Craig had lots of work on and staying with Mum provided Melanie with much needed

security. Her teacher commented that Melanie was handling the situation well compared to most children her age. Friends and family rallied around to help, and when I returned home several people delivered meals and a couple of friends cleaned the house. I felt very weak and tired and had to accept that the next step was chemotherapy. The cancer merry-go-round of tests and treatments had started again!

My oncologist recommended a course of Navelbine combined with SFU. The Navelbine consisted of weekly infusions for three weeks with the fourth week off, combined with a continuous infusion of SFU via an attached pump pack. This idea of continual chemotherapy was not appealing, but was there any alternative? I tried to find alternative options, including hyperthermic and microwave treatments and a cancer vaccine offered by a series of alternative health providers. The treatments were expensive and none offered a cure. Back to my oncologist! An oral chemotherapy Xeloda was achieving good results. I decided that Xeloda was my preferred option and started in May. I ended up in hospital with a low blood count and required intravenous antibiotics. The year before I had my infuser port removed, with the declaration that I had no intention of ever going back on chemotherapy. Needless to say my veins proved difficult to access and became infected again. I was having Aredia (a bone strengthening medication) infused on a monthly basis, so another trip to the surgeon was required, this time to have a more conventional port inserted. The Xeloda yielded some positive results. Although my tumours did not shrink, they did not enlarge. My liver function test returned to normal. The cancer count indicated started to decrease. Xeloda made me feel tired and had some effect on my sense of taste and my skin and nails, but my hair stayed put! My bowels were taking a long time to recover from the radiotherapy and were now being assaulted by chemotherapy. My periods returned several months after my first treatment of chemotherapy in 1999, but now appear to have ceased permanently as a result of the radiotherapy. I was plunged into

menopause yet again and was suffering loss of libido, hot flushes and mood swings with a vengeance.

It was around this time that I started to attend *The Thursday Girls*. I found the group welcoming, but extremely confronting. I had resisted attending because I was unable to arrive on time due to dropping Melanie off at school. It was important to me that continued to do this while she wanted me to, as she had to endure a lot because of my illness. Also I wasn't sure whether I wanted to talk about my cancer and meet others who had experienced worse than me and have to deal with the reality of metastatic breast cancer on a weekly basis.

I had found a wealth of information on the Internet and at times I was overwhelmed and upset. I wanted to think about the cancer when I wanted to, if I wanted to. It was important to remain positive despite test results. David Kissane had asked that I come to *The Thursday Girls* for four weeks before I made any decision about continuing to attend. It was hard and I would return home feeling depressed. Everyone was friendly and approachable, but I was reminded continually that conventional medicine could offer no cure. The love, laughter, support, sharing of information and an opportunity to talk about cancer provided by the group encouraged me to stay.

I was extremely disappointed when my cancer count started to increase again and scans showed tumour increase in the liver. I had been feeling unwell and my oncologist recommended I stop the Xeloda, as it was no longer effective. I had a break for six weeks but ended up in hospital with pain in my left arm. A bone scan revealed that the cancer in my bones had now extended to most of my upper body. I commenced my fifth lot of chemotherapy (Navelbine) to help restore my liver function and reduce the metastatic bone cancer that could be causing the pain in my arms.

Navelbine caused me a few problems with side-effects and I ended up in hospital just after Christmas 2001. My oncologist decided that we should stop using Navelbine after two infusions, as it had no effect on

my liver function or cancer count. We considered a Phase One trial at the Austin Hospital. This antibody trial works to attack tumours that have the Lewis Y indicator on them. Test results had shown that my cancer did have the Lewis Y indicator. I had to wait four weeks to start, as I had to be chemotherapy-free and not have received radiation. During this time, I had bone pain but was determined not to have radiotherapy so I could participate in the trial, as it offered a less invasive form of treatment.

A series of exhaustive tests were undertaken before the trial could begin. CT scans, blood tests and PET scans consumed an entire week and I was exhausted driving back and forth from Ferntree Gully to the Austin Hospital in Heidelberg. Friends and family offered to take me but I felt that if I could drive myself I should, because each test involved hours of waiting. During the six weeks of the trial both my mother-in-law and my father passed away, adding to my extreme tiredness. By the end of the trial I was asking people to drive me to the hospital and often stayed overnight with my sister who lives in Ivanhoe. The trial was exhausting and I often fell asleep during the tests. It was discovered that my haemoglobin levels were very low, and I felt much better after a blood transfusion.

The trial infusions did have an impact on my cancer. The cancer count halved and a large lump in my neck, and other cancers that were not so visible, reduced in size considerably. Unfortunately my liver function was affected badly and I was unable to receive the fourth infusion. The liver function did not improve sufficiently in the set time frame and I was unable to continue on the trial. Back to my oncologist!

My oncologist was concerned about the effect of the trial on my liver function and suggested a few days in hospital. The cancer was beginning to impact more on my lifestyle. I had to take stronger painkillers, was unable to drive and was very tired. I couldn't take my daughter to school or to her regular after-school activities. My husband, family and friends rallied around and life proceeded as normally as possible. I felt good when I left hospital with my medication under control, but was told this

was the best I may feel for a while if my liver did not improve. We took a wonderful Queensland holiday. With perfect weather it was meant to be! We came back tanned and relaxed, but not ready for more treatment.

I am debating whether or not to have chemotherapy again. As my liver function improved slightly while I was away, I am tempted to wait. However, my cancer count is nearly back to its pre-trial level.

I am booked in for a liver scan and hope it will show sufficient improvement so the chemotherapy decision can be left a little longer. Hope is important in cancer treatment. It is hard to achieve a realistic level of hope, but without it there isn't much! I know I will be on some form of treatment for the rest of my life just to keep the cancer to an acceptable level. But there is always that ray of hope for maybe three, six or even twelve months without treatment, or maybe even a cure! I need hope to keep going. Some probably think I'm in denial, but that's the way I need to be.

The liver scan results are worse and the blood test is slightly worse than my post-holiday results. After a long talk to the naturopath I have decided to leave chemotherapy for a while and try homeopathics in the hope that they will be more gentle on my body. My toenails have not recovered from my last chemotherapy and I continue to get the skin rashes that commenced with the chemotherapy. I feel very tired, am often nauseous and wish for even one day with no symptoms!

#### **CONCLUDING NOTE**

Sadly, Linda passed away on 3 September 2002. She tried so hard to stay with us, especially for her seven year old daughter, whom she adored. A spiritual person she embraced a healthy and natural lifestyle. She left instructions for her funeral to be a celebration of her life, toasting it with her favourite champagne.

## *Reflections from Linda's companions*

### **CAROL**

Linda and I were born almost two years apart to the day. I don't remember much about our childhood together but my parents told me stories, and there are many photos that show two little girls on various holidays and at weddings, parties and family gatherings.

We will never forget the day Linda told us that she had been diagnosed with breast cancer. I was struck dumb with shock but I gave her a hug and told her she was going to be all right and not to worry. It turned out not to be true. Although after surgery and massive doses of chemotherapy she got the okay and was told that the cancer had gone, it returned with a vengeance about twelve months later.

I was too scared to ask how long she might have left, for fear I might upset her, but she told me in her usual matter-of-fact way that two years was the average. I counted up two years in my diary and decided we would still have her around in April 2003 and began to count off the months. As she deteriorated I reluctantly revised my calculations.

Linda faced terrible pain, horrible medical procedures, her loss of independence and the sadness of not seeing her daughter Melanie grow up, with great courage and dignity. If it has been difficult for us, it must have been a nightmare for Linda.

Thank you Linda for your life and allowing us to be part of it. We mourn your passing but celebrate a life that was lived to the full, with enthusiasm and energy, lots of jokes and laughter and an amazing capacity to be positive in the face of adversity. We miss you terribly and will never forget you.

### *Helen B's story*



My name is Helen Breen. On this particular day I knew I was in serious trouble when I saw a large group of doctors coming towards me there seemed to be at least eight or more! It was certainly more than the two or three doctors who visit other patients during the rounds. And I knew that they weren't just students practising their diagnosis techniques; I had endured several of those over the last few days.

It was Friday morning 31 August 2001. The day was bright and sunny as it had been every day since Tuesday such fateful days in my life. This weird journey started on the Monday when I had gone to see a doctor. As I hadn't been to a doctor in about eight years, my decision involved finding someone to consult. I had experienced three weeks of 'the flu' and my constant exhaustion and inability to move around without dizziness and nausea had convinced me that my ailment had progressed to anaemia. The doctor sent me off for a battery of tests and said he would see me on Friday with all the results. But on Tuesday morning my husband received a call from the doctor. The results of my blood test were serious and I needed to see a specialist and be admitted to hospital. This cracked me up: nobody gets into a hospital that quickly! However, that afternoon I was tucked up in a hospital bed, waiting for the required blood and platelet transfusion.

I needed five units of blood and this made an immediate difference to the way I felt. Once the transfusion was over I felt quite energetic

and was ready to go home. Instead I had another range of tests: a bone marrow biopsy on Wednesday and a CAT scan, pelvic ultrasound, breast mammogram, and ultrasound and biopsy on Thursday. Now here it was Friday and the messengers of doom had arrived!

The scenario I had run with since I entered the hospital was that after the battery of tests they were going to say something like: *'Oh yes, it is anaemia and you can have iron injections and go home now'*. But it was not to be. Instead, the opening words were: *'We didn't find leukaemic cells in the bone marrow biopsy. But we did find carcinogens that are attacking the bone marrow. The carcinogens are coming from an advanced breast cancer, and there are areas in your stomach that we don't like.'* Well, from that description I wasn't too keen on them myself either, but worst of all the diagnosis was mine! Lots of words followed: *aggressive chemo-therapy, advanced breast cancer*. It was all very surreal.

The thought of aggressive chemotherapy stunned me. Having watched close relatives on their journeys with cancer, I had always felt that I would look for other treatments if I was ever diagnosed, but now this didn't appear possible. I had spent the past twelve months growing my hair from very short to shoulder length and now I was being told it was about to fall out and I would have to start over! The diagnosis of breast cancer was surprising because I had no breast lumps or anything else to warn me. I was told to go home and come back the following Tuesday for the first of my chemotherapy treatments.

Going home had been my focus since I entered the hospital but was now coloured by having to tell family and friends of the diagnosis. Telling my husband Rod and my two children Mike, nineteen, and Bee, seventeen, was the first hurdle, and then breaking the news to my wider circle of family and friends. It certainly was not news anyone had expected, but they all rallied wonderfully and hid their worries under a layer of laughter and jokes. It was such a relief to be out of hospital that we celebrated that night with close friends and family.

Throughout this journey I have been overwhelmed by the generosity of friends and relatives who have appeared from everywhere to help and support us. Faced with all this caring and love, I have felt and still feel today like a 'walking, talking fraud'. I just haven't felt that bad.

Although the chemotherapy knocked me around a bit and I wanted to sleep for about three days after a treatment, I never felt sick. I had no pain and, with no operation to recover from, I found it hard to relate to the seriousness of the diagnosis. While I was on chemotherapy, life took on a routine of two good weeks and one not so good. As a result I could work and enjoy life's little pleasures, in particular, a glass of champagne.

Although I continued with the chemotherapy treatment, I was determined to investigate whatever could ensure my well being. In the first week I went back to talk with my doctor about the other things I could do to help my body cope with the effects of the chemotherapy. We discussed a range of different treatments and remedies and I opted for those I thought I could cope with, such as vitamins and eating healthily. After I had finished the chemotherapy treatment and was feeling well, I looked more closely at other options. I decided to try Iscador, a treatment of extracts from mistletoe plants, believed to help reduce tumors and stimulate the immune system. I always feel great when I am using it and it fits with my personal philosophy, as it is of spiritual and physical benefit.

After the first round of chemotherapy my hair started falling out in large clumps. As I have thick hair there was an awful lot to fall. Eventually Rod claimed that I was shedding more than Maggie our Golden Retriever. Although we joked about this, the constant shedding was difficult, in particular, for my daughter to see. Rod took to my head with the trimmers and cropped my hair back to an inch all over. It continued to fall out from there, but it wasn't so distressing for others. After the second round of chemotherapy my hair fell out even more and great bald spots appeared until I was completely bald. I wasn't conscious of my lack of hair and initially, when out shopping I would notice people staring and would

check that my buttons were all done up. My son commented that it was good to walk into a crowded room with me because he knew nobody was looking at him. I had always worn my hair short so being bald never worried me too much. Hats don't suit me and I can't be bothered with a wig. As I always looked very healthy, most people were unsure whether my bald look was a deliberate choice or not. A friend who hadn't seen me for some time said *'What's with the 'do' Helen?'* He had wondered about chemotherapy but wasn't sure because of my rosy cheeks.

For the first few chemotherapy treatments I had blood transfusions, but the day came when my bone marrow was back in operation and transfusions were no longer necessary. Such a relief! Trips to the oncology centre were shortened considerably. Chemotherapy week was always fun as my sister would come over from Adelaide to be with me. When she wasn't able to, a friend would come with me. Company made the wait a pleasant experience, and staff at the Day Centre were always full of fun.

After three rounds of chemotherapy my test results were good, and after six rounds the test revealed a huge improvement, with all the initial spots disappearing. My HB count was stable at about 10.5 without transfusions. My form of breast cancer is receptive to oestrogen. I was given a maintenance treatment of monthly injections of Zoladex, a hormone blocker designed to block the production of oestrogen. I can't say I enjoyed them. I can still see the face of the young registrar when I asked how long I would have to be on Zoladex. He was shocked and explained that with metastatic cancer there is never any guarantee that it has been eradicated, and so I would be on Zoladex or some such treatment for the rest of my life. His gravity amused me. I understood the seriousness of my disease, but was determined to do everything to ensure the rest of my life was a very long time!

*'Tigers above - tigers below'* became my key phrase for dealing with chemotherapy and my cancer diagnosis. This phrase comes from a Buddhist story that has always appealed to me. A woman is running away from

tigers, but the faster she runs the closer the tigers are behind her. She comes to a cliff edge, sees some vines and starts to climb down them. As she is holding onto the vines she looks down and sees that there are more tigers at the bottom of the cliff, and then she notices that a mouse is chewing away at the vines. However, she also sees a bunch of beautiful strawberries close by. She looks up, looks down, looks at the mouse and then takes a strawberry, eats it and enjoys it thoroughly. The moral is that whatever the situation we may as well decide to enjoy it as much as we can. I decided to enjoy the treatment process as much as I was able to and to look for the good stuff wherever I could.

The end of my treatment and the gradual return to feeling healthy - better than I had for a couple of years - brought new pressures. It was too easy to slip into the old rush and busy workload and let go of the things I knew were important. I tried consciously to avoid this by attending weekly meditations, always trying to watch what was happening in the world around me. Throughout this process I was sustained and inspired by two close friends, also affected by life-changing illnesses. We met weekly while I was in Melbourne and were able to share openly and safely how we were feeling and coping with the changes in lifestyle, hopes and dreams that the illnesses had wrought on our lives. A surprising aspect of being ill is how suddenly all your dreams and hopes change. Some things are simply no longer possible and some dreams simply seem unimportant, while others become a focus for getting better. One thing I realised after my diagnosis was that the world went on happily without me, and all those tasks that I just *had* to finish were unimportant. There was always someone else who could do the job, not necessarily the same way and maybe even better!

I remain grateful for the benefits cancer has given to my life. I would prefer not to have the spectre of death hovering over my shoulder, and yet this wakeup call that time is precious and there isn't forever to do all the things I want has been a huge blessing. Rod and I had always

dreamed that once the children finished school we would move somewhere near the beach, raise hens and grow vegetables. We spent many holidays searching for an ideal place. We probably would have left that as a dream for another five years, but now we have done it. We have bought a lovely place at Pambula on five acres, nestled in the trees on a hillside with the beach only a five minute drive away. Life here is idyllic, peaceful, relaxed, low-key and very therapeutic....That was supposed to be my final statement!

But life often turns up the unexpected! We enjoyed two months of the idyllic lifestyle, slowly settled in and started to relax after all the frantic pace of packing, moving and unpacking. Then I began to feel nauseous all the time. Rod and I both knew it was something serious but kept hoping that it was just 'the flu' or a reaction to something I was eating. However, as soon as my stomach started to balloon up we were fairly sure the cancer had returned. I headed back to Melbourne for a checkup. My daughter Rebecca came up on the Saturday and drove me down on the Sunday. Throughout all this she kept a smiling chirpy face, only showing how worried she was by soundly berating her brother for not being at the house to greet us when we reached Melbourne. My son Mike looked at me and asked the question everyone else avoided: *'What do you think it is?'* I replied *'stomach cancer: 'Yep,'* he said, *'I think so too.'*

Once again things moved quickly on the hospital front. I saw the oncologist on Tuesday morning and was in a hospital bed that afternoon. After more tests my stomach was drained: 8.5 litres of fluid gone! What a relief! The tests revealed what everyone suspected. The cancer in the peritoneal lining had flared up again. On Thursday chemotherapy started again. This time the nausea struck immediately and I was shaky and unwell the following day. After a couple of days my son drove me back to Pambula, and coped magnificently with me throwing up as he drove through the narrow winding roads close to home. I doubt at twenty-one that I would coped so calmly.

This time my experience of chemotherapy was different. I had constant nausea and at times could not even keep water down. I also suffered with indigestion and heartburn as my stomach filled up with fluid all the time. Moving around became difficult because I had constant dizziness and became weak quickly. Poor Rod found it difficult to keep work going while doing everything for me. It was a struggle to get out of bed. Just raising my head off the pillow often brought on a vomiting fit. I could still manage to shower myself, but needed to lie down for an hour or so after a shower. Food became a huge difficulty. I was hungry, but could eat little and only if it was pureed. At one stage my rule for food was that I would only eat things that didn't hurt on the way back up. Rod, who loves cooking and is a fabulous cook, found his creativity challenged. Often he would find something I liked and then I would have a vomiting fit and not be able to face that again. My sister came to stay with me for ten days and she was marvellous. I realised that things were not going too well when she came into the room and burst into tears. I hadn't thought I was that bad! The problem for me was that the cancer symptoms, nausea and constant vomiting, were exactly the same as the side-effects from the chemotherapy.

Life came to have a very narrow focus. Anything that required me to concentrate, like talking on the phone or reading, would exhaust me and induce vomiting. I spent large amounts of time propped up in bed; lying down was impossible because of the fluid retention in my stomach. From my window I could watch the birds, wrens, robins and honey-eaters flitting through the bushes. I couldn't concentrate on anything for long and wasn't able to meditate because I was in such a hazy state. So I just sat, with my mind going nowhere. Once again the tiger story kept me on track and I enjoyed what I could: watching the progress of the sun across the sky, watching the birds, realising how unimportant so many worries were. I have always been active and those three months of inactivity and weakness were a whole new experience. So too was having to rely on others

for everything. I found this difficult and would often push on stubbornly past my limits in order to be self-sufficient. This made life very difficult for Rod, as he could see that this stubbornness only made me weaker and did not help at all. It was hard to find a line between acceptance that I needed help and the fight to maintain my independence.

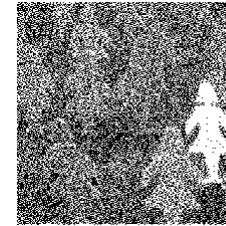
In the middle of all this I reached another milestone - I turned fifty. This was a great time, with visits from my brother from New Zealand and my sister from Adelaide. I even managed a glass of champagne.

I had three cycles of chemotherapy from April to June and, although it seemed to be working, the toll on my health was too much and it was stopped. I am now on Navelbine and the difference is huge. I have no nausea, I am able to eat normally and I am starting to be able to do things again. Although I am still weak and tire easily, I do feel that each day I can do more. Most important, I am enjoying coffee again. As a coffee addict, it is wonderful to be able to enjoy the taste of a coffee once more.

#### **CONCLUDING NOTE**

Sadly, Helen passed away on 15/07/2004. She offered her time and expertise generously to make sure our book was published. Even though she moved to Pambula, NSW and enjoyed the peaceful life of the country, we kept in contact. She remained a loved member of *The Thursday Girls*.

#### ***Robyn's story***



I was born in 1937 in a tiny saw-milling town eighty miles from Perth. My father was a glorious Irish man whom I adored. He was Mum's second husband. Dad had a wonderful Irish sense of humour and the sweetest singing voice. Some of my favourite memories are driving in his utility without its hood, both of us singing the Irish songs he had taught me at the tops of our voices, with the wind blowing our hair. What bliss!

After five years, and the arrival of two brothers in quick succession, we moved 'to town', a place fifteen miles from Perth. My father was killed in a motorbike accident when I was eight years old and I grieved secretly for forty years. I did so adore him. Mum loved him too, but could never bring herself to mention him for many years.

In due course I grew up, fell in love, married, moved to Melbourne, produced five children, fell out of love and became divorced. Some time after I developed breast cancer with lymph node involvement; a mastectomy and chemotherapy followed. By this time, three of my children had left the nest and our household consisted of my seventeen year old twin sons and me. This event had a mammoth impact on my family, and demonstrated how much love surrounded me. It was quite overwhelming. Perhaps the twins who were living with me were affected the most. They were in an important phase of their schooling and an intense phase emotionally. I became very proud of them. For the entire six months of chemotherapy they took on most of the cooking, all of

the dishes, hanging out and bringing in the washing, food shopping and trying to make lots of funnies to lighten the atmosphere. This was on top of their heavy load of schoolwork and homework. My loyal daughter would come from the other end of town to hold my hand every time I had chemotherapy at the Peter MacCallum Institute. She was responsible for making an appointment for me with a breathtakingly beautiful naturopath, who referred me to a wise and compassionate yoga teacher. These two helpers did so much for my healing process.

I became, what they call at the Ian Gawler Foundation, a 'one hundred percenter'. My diet was impeccable: vegetarian, all organic, freshly made juices and so on. I did yoga exercises twice a day and meditated three times a day. Gradually I became fit, healthy and happy.

It was at this point that I began to slip backwards, too busy to do yoga or meditate, and enjoying all-too-frequent junk food. Thus I carried on for fourteen years until I was no longer getting any relief from the chiropractor for pain in my back. Rather than spasmodic episodes of pain, it was constant. Still it never dawned on me that there was a flare up of the cancer. Eventually, after I had tried many healing modalities and was at my wits' end, I conceded defeat and sought medical help. My general practitioner sent me off for a bone scan and I learned the bad news that I had metastatic bone cancer in my spine. Radiotherapy thankfully relieved the pain for a good while.

My daughter and I bought a house together in Seaford, but when I started to deteriorate further we put tenants in our house and rented a house in Box Hill North. This was for several reasons, the main one being that we would be closer to three of my sons and hopefully they could be more supportive. A few weeks before we moved from Seaford I began vomiting and could keep nothing down, and this continued in the Box Hill North house. I had no food for five weeks, which caused dramatic weight loss. The district nurse suggested I go to hospital to try find out the cause of the vomiting and to stabilise me. One doctor asked if I had

headaches. When I told him that I did he recommended a full MRI scan instead of just from the neck down. This appalled me, as an MRI scan was an unknown bogey of which I had only heard horror stories. To my aggravation the doctor insisted, and just as well because the results showed two small accessible brain tumours in very early stages.

The feelings I experienced when trying to absorb this information are indescribable. I overlooked the good news that my bone cancers had not changed since the last bone scans, against the horror of having my skull opened and someone cutting my brain. The prospect of *not* having the operation and allowing the tumours to grow and cause who knows what havoc and pain was even more scary, so a few days later I was operated on.

Physically the operation was a breeze, but I sank into the deepest depression of my life for several months. Radiotherapy on my spine for the pain and on my brain as a precaution has made me very ill. I don't have the motivation I had the first time around to get my act in gear, and I have no energy whatsoever. My medication is: Aredia once a month as a day procedure, Zyprexa for depression, Fentanyl patches for pain, Dexamethasone in a very small dose, and Losee to counteract the cortisone side-effects that seem endless.

My first experience with cancer was a great shock, but I had more motivation to get well. I had two dependent sons, a mortgage and a full-time job. I felt that my life's work was not finished. Now, at sixty-five years of age, my sons are married with good jobs and families of their own, and my mortgage is paid off. I gave up work because of the pain. I sold my car for the same reason, but this cost me a huge chunk of my independence and confidence.

During my black days I felt dependent and useless, and wallowed in depression and self-pity. I felt there was no purpose in my life and for the first time in many years my previous role of caretaker for my family and helper in a myriad of ways was now obsolete. How thankful I am to

be part of *The Thursday Girls* group. Since I feel better physically and am able to be of more help to my daughter I don't feel so useless and I am becoming more positive.

#### **CONCLUDING NOTE**

Sadly, Robin passed away on 3 October 2002. She won her first battle with breast cancer for fourteen years. Not an easy life and secondary cancer was the last straw. Sweet and gentle, Robin wasn't with the group for long, but we felt she gained a lot of love and support from it. She died as she wanted in peace surrounded by her family.

#### *Sally's story*



My name is Sally Walker. I was born in Alice Springs on 18 June 1957, eighteen months after my brother Alan. My mother, Agnes, was in Australia for a two-year working holiday when she met and married my father, Tony, who migrated from London just after the end of the Second World War.

We left the Northern Territory when I was about a year old as Alan suffered badly in the heat, and already our parents were thinking of the future and our education. My father worked for the PMG and managed to get a transfer to Mt. Barker in the Adelaide Hills. Alan started school and, much to my dismay, I was bundled off to kindergarten. I was a small, shy child and the bigger boys used to make fun of me. I did my best to avoid going, and more than one day was spent playing happily on the front verandah by myself when my mother thought I was at kindy.

Just before I started school we moved again, this time to the northern suburbs of Adelaide. Primary school was much better than kindergarten and I enjoyed high school. I played competition netball for four seasons, my team winning the premiership in the last two years. Looking back, we had a fairly sheltered childhood. Our parents rarely argued in front of us, never discussed money and told us amazing stories to protect us, such as when our dog had to go because he was wreaking havoc with the chooks next door! My mother's word was final and we did not ever think about questioning her decisions. At least we knew exactly where we stood.

Alan moved out of the family home when he started university and I was married at age twenty-one. I had just completed my apprenticeship as a commercial cook and my first husband worked as a barman in the same restaurant. The marriage lasted less than four years. My ex-husband introduced me to a pastime that I still pursue touring motorcycling. It is one of life's pleasures to pack the camping gear on the bike and explore our beautiful country.

I had all the usual childhood illnesses, such as measles and chickenpox, and also a broken arm as a result of falling off a friend's pushbike. My first stay in hospital came about after going over the handlebars of my motorbike. The doctor had to dig out bits of gravel, sock, dirt and leather from my left ankle. That was the last time I went out on the bike without the correct riding gear, boots and all!

After about five or six years of cooking for a living, a change was necessary. We all need a social life and mine was almost non-existent as I was always at work. So I joined Australia Post for what was to become a long and rewarding career. I was lucky enough to have experienced all the facets that make up this organisation, from delivering telegrams and parcels, sorting and delivering mail, and working behind the counter to managerial duties.

In 1988 country living beckoned me and I transferred to Bendigo where I boarded with my brother and his wife for a couple of months before I found a place of my own. At this stage I was spending a lot of time with Chris, a friend I had met through my motorcycling interest. Chris lived in Melbourne, and on Australia Day 1991, just after I landed a job in the Box Hill Post Office, we moved in together.

My relationship with Chris was well established by 1994. Unfortunately this year turned out to be our '*annus horribilis*': Chris's father was revived on the operating table, his mother died after a short battle with cancer, my grandfather died about two months after being told he had bowel cancer, and on the day of his funeral I was diagnosed with breast

cancer. All through these hard times Chris was my rock. He came to all my appointments, was there holding my hand as I was wheeled away to have a mastectomy, was the first person to visit when I returned to the ward and, most important, he helped me keep my sense of humour. I took part in many cancer research trials including group therapy, which I recommend highly.

Chris and I had a lovely, casual, relaxed lifestyle. We loved motorcycle travel, camping, good food and the occasional glass of champagne. We wandered along happily for several years, acquiring a little dog, a few more motorbikes and hundreds of photographs from our many trips around our beautiful country. We rarely discussed marriage; it just wasn't that important to either of us.

Every two years we load up the sidecar and, along with a group of friends, head into outback Australia. Our sidecar has been built to withstand the rugged conditions, with good suspension, a fridge, and extra racks for fuel and water. We can be self-sufficient for five days. Over the years we have seen a large part of our wonderful country including Tasmania, the Birdsville Track, the magnificent Kimberleys, the Victorian High Country, Innamincka, Lawn Hill National Park, and across the Simpson Desert. The enjoyment of a quiet evening away from the city gazing at the stars is something very special. In 2000 we spent ten weeks overseas, including the best part of a month motorcycling through the West Coast of the USA. We avoided all the usual tourist places except the Grand Canyon. It was the first time Chris had been out of Australia. I had spent three months in Britain in 1979 visiting relatives.

In 1999, I accepted a voluntary redundancy from Australia Post. After three months of retirement I was bored and started work in a small family business that was a newsagency, Tattsлото agent and Post Office. I was very happy there for three years until the business changed hands. Unfortunately there was a definite personality clash between the new owners and myself, and we parted company. Currently, I am employed

on a part-time basis at the post office at Monash University, Clayton.

In late July 2002, our world turned upside down again. The cursed cancer reappeared after eight years. It had spread to my upper spine and there were two new tumours in the original area. All of one and most of the other tumour were removed surgically. Once again, Chris showed his true colours and, with the help of his warped sense of humour, we got through the first six months, which I found pretty rough going, especially the side-effects of radiotherapy.

In the middle of my problems, Chris sprang a huge surprise on me: he proposed! This happened on a Sunday evening while we were away on one of our outback adventures. We had enjoyed a few cold beers during the afternoon so I didn't think he was serious. However, the next morning he asked me the question again in front of our motorcycling friends, who all cheered loudly when they heard me say 'Yes'. We celebrated our marriage on Australia Day 2003, twelve years to the day after moving in together. It was a lovely, happy, casual day shared with family and friends, accompanied by much champagne and laughter.

### *Toni's story*



My name is Toni Gartside. I was born in 1957 in Oakleigh, Victoria, and was the last child and only daughter of my parents. My two brothers were much older. Brian was eighteen when I was born and Peter was ten. My poor mother was forty-three when I was born and had a very difficult time with a baby who threw up on everything! Nevertheless I survived various childhood illnesses and accidents without giving my parents too many extra grey hairs. The worst of my accidents was a broken leg in a fall from a ladder at two years. Primary school was a happy time for me, and many carefree days were spent in the company of neighbourhood friends. Holidays consisted of camping at Noogee or at the family holiday house on the Mornington peninsula at Tootgarook.

The first cloud on my personal horizon arrived when my father died when I was twelve years old. I was devastated and at the same time relieved by his death. A series of strokes left my vigorous, fun loving father almost completely disabled over a period of two years. It was a slow and terrible way to die. My mother was, of course, very lonely and relied on me for company more than my developing sense of independence was happy to provide at times.

I had the usual adolescent joys and problems through the politically volatile Whitlam years. I met my husband Michael at an ice skating rink when I was fourteen and he was twenty. We were more or less an 'item' from that time. I was a keen student at high school and enjoyed science

subjects, in particular, biology. When I left school I worked at Monash University and studied part-time towards a science degree at RMIT in the evenings.

I married my long time boyfriend and life partner Michael at nineteen. We bought our first house and got on with creating a home, along with acquiring a plethora of pets. Our eldest son Paul was born in 1980, a beautiful and normal baby who grew into a delightful little boy, then a high-achieving student and now a magnificent young man. Paul has always been a mature person for his years. In many ways he has been a third 'parent' to his younger siblings. He is a creative person who, after completing his arts degree and an extended overseas trip, has decided to try his hand at writing a musical, while working part-time to support himself. He is our pride and joy and Michael and I love him very much.

Our second son Ben was born in 1983. Ben's birth was three months premature and extremely traumatic. I had severe pre-eclampsia and Ben had to be induced at twenty- eight weeks gestation. He showed signs of foetal distress and it was believed he had died *in utero*. He was born alive twelve hours later but, not having been monitored in that time, had suffered significant brain damage due to oxygen asphyxia. For several weeks his life hung in the balance, and we lived on an emotional roller coaster. Neonatal intensive care became our second home. Gradually Ben won his battle and we brought him home triumphantly just before Christmas 1983.

I thought I had coped well up to this point, but I suffered a crushing post-natal depression that resulted in a brief hospitalisation and continued for many months. By this time it was obvious that all was not right with our baby, and significant developmental delays were apparent. Over the next few years we embarked on a path familiar to all those who have been parents of a 'special needs' child. We sought out every therapy and service we thought would be of any benefit to help minimise the effects of our child's disability. Parents in this situation are driven by the hope that the

next technique or program will be the one that will 'cure' their child. Of course this is a vain hope and it didn't come to pass in our case.

Ben, intellectually disabled and autistic, attended a special school for and thrived, achieving the best academic outcome of which he was capable. He gained a wide range of personal development, independent living and social skills. He can read and write to grade two level and is virtually self sufficient in self-care. Ben is now a happy and fulfilled teenager, living with several other teenage boys in a supported community residential unit and working part-time (again in a supported setting).

My own life was put on hold to some extent for many years, and it wasn't until 1992 that I finished my science honours degree, now at Monash University. In my late thirties, I found myself unexpectedly pregnant again and gave birth to a normal and beautiful baby girl. She was such a joy to us after the trials and tribulations that we had experienced with our second son. Our whole family are besotted with her.

The years flew and our daughter Caitlin was at kindergarten before we knew it. After a weekend at our family holiday home at Jamieson I noticed a lump in my right breast. It was quite central and had not been obvious during my rather cursory self-examinations under the shower. Besides, I smugly assured myself, I had a perfectly clear mammogram twelve months previous. Nevertheless, I made an appointment with the doctor. Forty-eight hours later I had another mammogram followed by needle and core biopsies of some nodes found in my axilla. I was given an immediate diagnosis of breast cancer with lymph node involvement. We were devastated but, on the advice of my doctors, hopeful that all would be well. My reaction was the now familiar *'if I just go through this operation with treatment and therapy then all will be well and I can have my own life back'*.

Several rounds of pre-surgery chemotherapy to shrink the tumour followed. I was part of a drug trial that involved evaluation of the effect of a bone-marrow stimulant in the maintenance of blood counts.

I was luckier than many with regard to side-effects, having just a couple of flat days after each treatment and a little nausea. I lost my hair, but my wig looked great and I received many compliments about my new hairstyle. I had a lumpectomy with excision of lymph nodes four months after starting the 'chemo'. This was more painful than I expected and I hated the drainage bag with a passion. Body image questions were not such an issue for me: I was focused (and still am!) on whatever gave me my best chance for long term survival. There followed more 'chemo' and six weeks of radiotherapy before I was ejected from the end of the treatment regime, as I hoped, free and clear.

For about eighteen months, I thought I was clear. I believed I had more than likely 'beaten it'. I felt fantastic and had gone back to work full time and had resumed my life much as it had been before diagnosis. Then, despite the Tamoxifen I had been taking, I had a local recurrence along the scar line in my breast and a mastectomy was the result, followed, at my own request, by more 'chemo' as a preventative measure against metastatic recurrence. Once again I thought if I can just get through this treatment I can have my life back. At the end of the treatment, I begged my oncologist to perform a CT and bone scan just to be sure that I was clear. To both his and my amazement, the CT scan showed cancerous spots in my liver, the metastatic growths I so dreaded. I felt perfectly well and yet this insidious thing was growing within me once again.

Like everyone faced with this situation, I felt that I was looking down the barrel of a gun. As the oncologist explained patiently to my overloaded brain, cure was now a remote possibility and control was the major focus of treatment. My tumour, which had previously been oestrogen -receptor positive, was now only weakly positive but my oncologist wanted to try one more hormonal therapy, this time Letrozole. I started my hormonal treatment with the belief that I was wasting my time. Possibly this negative attitude was partly to blame for the lack of success I had with this treatment.

I am a firm believer in a strong mind-body connection in the disease process and that there is much people can do to improve their chances of a good quality of life or even healing. Being a proactive person, I sought as much information on complementary therapies as I could. As a trained scientist my natural scepticism was activated on many occasions. Nevertheless I have adopted a range of dietary and lifestyle changes, along with the more conventional medical treatments that I still pursue. I have taken up daily meditation, in two-three half-hour sessions. This was difficult for me initially and it took many weeks of perseverance before I was able to still my brain. I have found this practice to be invaluable and now have a much calmer attitude to life. I have also taken up two yoga-based exercise classes each week, which is wonderful for coping with the muscle stiffness and bone pain that often accompanies 'chemo'. I have adopted a largely vegan diet, omitting all dairy products, but with the occasion inclusion of fish, eggs and free-range chicken. I attribute my still normal liver function tests to this diet and believe it may assist my good energy levels and lack of nausea. I take a good multivitamin and a limited range of other dietary supplements. However, I try to minimise these as I believe people can go to extremes and spend large sums of money to little effect. I attended a twelve week self-help course with the Gawler Foundation, that has been of great benefit. Their advice is designed to complement conventional treatment and is supportive and positive at practical and psychological levels. Meeting other people who are also making their own cancer journeys has been inspiring in much the same way as with *The Thursday Girls* support group. I have reduced my workload to half time and arranged to step down from my supervisory role to that of a laboratory assistant, thereby reducing my stress levels. I can now pick up my daughter from school on most days, which she loves.

Following my lack of success with Femara, I took part in a drug trial at the Peter MacCallum Institute with a drug called Iressa, which has been used extensively in lung cancer, but was a complete unknown in breast

cancer. Unfortunately the drug proved of no benefit to me. My tumours had progressed a bit after two months but the news wasn't all bad. My liver was still coping well and the cancer hadn't spread outside my liver. Back to the drawing board! It was decided to revisit one of the drugs I had been given when first diagnosed, Taxotere, to be administered weekly for three weeks followed by a week break. This is my current treatment and so far all seems to be going well. Again I have few side-effects and have a good quality of life.

My life continues to be happy and fulfilling. I have my share of days when I feel miserable, but I try to pick myself up and get on with it as soon as I can. Life *is* too short, as the saying goes! I have a lot of living to do before I'm done. Naturally I hope that will be many years into the future. However, in the spirit of 'covering all bases', I am writing a journal, organising photo albums, taking videos of myself with the family and writing family letters, especially for my daughter who is almost eight years old.

We have reassessed our priorities as a family. We spend more 'quality' time with one another. Saving for a future I may not have is less of a priority. Within reason, I am no longer willing to 'make do' unless it is unavoidable. We are spending money on much-discussed renovations around the home and take more frequent holidays together. Having cancer is not a wholly negative thing. My life is more focused and I feel closer to my husband, family and the things that are important to me. I am no longer distracted easily by things over which I can have no control or are really no longer important to me, such as a future career. My life is for living to the full, right now.

### ***Beth's story***



What a gift of life to sit in the sun on the porch of my home on a cold but sunny winter's day in Melbourne! Twenty years ago, my breast cancer with lymphatic involvement was diagnosed. I would not have thought that today would be possible. But here I am, less robust and touching sixty. I would like to share some of my journey.

Growing up in Echuca was my youthful world with memories of baking hot summers and cold and frosty winters with sunny days. At seventeen, I began a career in nursing at Echuca and Bendigo, and later at the Royal Women's Hospital in Melbourne as a midwife. My career continued until I was fifty-five and I experienced all facets of nursing, with its care and compassion for others, its sadness and supportive requirements, and its fostering of wonderful friendships that have lasted to this day.

I married my husband Peter thirty-three years ago. We were touching twenty-seven years old and moved to his home state of Western Australia. He had left his job in the Post Office to commence training for the Methodist ministry, now part of the Uniting Church. We have three children who have shared our lives with their wonderful personalities. Elise is a thirty-two year old teacher of English and writing. She is married to Rob, who is a doctor of medicine. At present, they are travelling around Australia and we follow their journey as we share the highs and lows from afar. Our second daughter Margaret is thirty and is studying for her librarianship. Marg works close to home and lives with us. The constancy of her care

and concern is unswerving. Our son Justin is twenty-seven and an actor who supports himself with cafe and bar work in the city. His gifts are numerous and his light shines in all he does. He is still finding his way, but hopes for improved acting opportunities. Peter continues as a Uniting Church minister and has been a school chaplain and teacher for the past twenty years. He is my tower, and the encouragement, love and support I have received from him and our children have carried me through all the various processes that have allowed me to keep going.

This year 2003 has been on the tough side. The specialist came in the late evening as I was being treated for the latest emergency. To prevent me having a stroke, he was going to insert stents into major blood vessels that had closed down due to the pressure of tumours. The doctors worked all day in preparation with tests and other necessary procedures. My doctor walked in and greeted me as 'Elizabeth'. He spoke softly and calmly as he proceeded to insert the stents carefully from my leg to the major heart vessels. He explained what he was doing. Then he commented *'Elizabeth, you have gone to sleep on me.'* Wow, what a peace! At such times of vulnerability, my right hand is always open to receive the peace of God or the kind hand of a staff member. I have always looked upon cancer as 'my friend'. At times I am able to use my personal strength and understanding to deal with it. However, there are times when I am angry with 'my friend'. Nowadays I seem to need resources beyond myself to deal with things that are present and appear inevitable.

Justin was only six when I was diagnosed with breast cancer in 1983. This was just six weeks prior to us moving from Perth to Melbourne for Peter to take up a new position. My surgery and chemotherapy started in Western Australia. The second round of 'chemo' was at the Alfred Hospital in Melbourne just before Christmas 1983. People took many photographs of me that Christmas but I assured them not to worry, as I would be around for a good while yet. The chemo was tough in 1983, as the aftermath was almost unbearable. I survived the treatment and after

six months felt able to get on with my career and care for my family. The renewal of friendships and association with my extended family in Victoria was a bonus after the deep sadness of leaving the close bonds we had in Western Australia. I stabilised on my treatment of anti-oestrogen hormone tablets. I seem to have been on all the latest drugs that science has delivered, Tamoxifen being hailed as the first real success.

Nine years later, a recurrence of the cancer necessitated my first treatment of radiotherapy to deal with localised secondaries. Full-time and part-time work as a midwife was accompanied now with the revisit of 'my friend'. However, life was good, as only annual visits to the Alfred Hospital were required.

Then came the Port Arthur tragedy and Peter and I felt the pull to Tasmania where a job had been advertised at Scotch Oakburn College in Launceston. From 1997 we spent five and a half years in that beautiful place, residing in a delightful cottage in central Launceston. I made friends in the Breast Cancer Network of Australia and worked for a while at the local hospital.

In 1998 I experienced further difficulties, this time involving the heart and breathing problems. After chemotherapy and radiotherapy I was better for a while, but then required more treatment. This pattern continued off and on until 2002 when we returned to Victoria. We had a wonderful time getting to know 'Tassie' and her people: the history of the roots of Australia, the job satisfaction and the great people. I was able to walk the Overland Track and enjoyed swimming until the disease restricted my breathing and prevented me taking heavier exercise.

In Tasmania I worked for, and was helped by, the Breast Cancer Network where I was able to offer my experiences as a consumer of breast cancer services in written submissions to help frame Government policy. The *'Living with Cancer'* program of the Tasmanian Cancer Council was very helpful. I was honoured to walk beside some wonderful brave women, in particular, those with families younger than mine. The bonds of group

## *Reflections from Beth's companions*

### ELISE

Perched on a deep red dune, I look eastwards where the Simpson Desert dawn begins to sing. Through a wash of streaky cloud emerges the first hint of sun fire, burning over the horizon as the arc of a gold ring catching light. Silence would ensue, were it not for the morning groans of camels far from the eye. Their conversation gives life and hope to what is so often known as a barren place.

I think of Melbourne further east. And the journey. Not simply the outback ventured by this young wife and her husband, but the journey of that other young wife and her husband as they took their children through place and time to forge life, together, through emotional and physical spaces where hope might, at times, seemed a most desolate desert.

Sun still rising, another image of soft pink and light rises in my mind from an old family photo. It is Perth summer in late 1983. There's a formality to the picture and the details are vague; dad's in a suit, my younger brother and sister stand fuzzily in front, I stand to the side. Mum, however, is clear. A kind, assured smile, her stance suggests composure and contentment. Maybe it's the soft pink and white stripes of the dress, the slightly puffed sleeves, the belted waist and smooth cotton, reflect a seeming calm on mum's face. A woman in her thirties at her best with her family.

The morning desert light brushes the landscape with a magic glow, but belies the potential suffering of beast, plant or human within. So too, that old photo draws on a wisp of truth, for my mother had just discovered she had breast cancer. 2003 marks Beth's twentieth year living with breast cancer.

It wasn't until a year ago that I came to the realization that life isn't fair. It's not 'fair' that movie stars make millions when aid workers volunteer their time; that we live with the relative luxuries of health,

support are invaluable. Dealing with the different stages of the disease is much easier when the life and death issues can be talked about in the total freedom of knowing that you are among friends who understand. In Melbourne I became a member of *The Thursday Girls*. In the early stage of my disease my attitude was 'get on with life'. I still try to maintain this but, when darker shadows loom, the group helps me not to slip into the fear of the reality of my situation. These groups, including more recently the Eastern Palliative Care Service in Melbourne, have been a great support for me.

After our return to Victoria, in mid 2002 we took a trip to central Australia. Peter used part of his long service leave to travel to the USA. During his absence I had two stays in the Alfred Hospital. At this time our darling dog Ebony had a splenectomy to remove tumours and died in the following February. We kept in close touch with Peter through this difficult time. After his return we worked to establish him in his new role as teaching Chaplain at Penleigh and Essendon Grammar School.

Over the last five years I have experienced various forms of breathlessness and had many radiotherapy and chemotherapy sessions, with the problem returning regularly. Dealing with the progress of the disease and the accompanying surgical interventions and other treatments over the past eight months has been difficult. I have had to deal with intense fear and the realities of death more than ever before. Psychological and spiritual help from professionals, family and friends has been my mainstay. I still enjoy the fun things of life and try to maintain a positive outlook.

I went to a healing session years ago where I asked for peace and strength to deal with my journey and to see my children grow to independence. I will not ask for more. All my life now is a bonus with the help of medical science. Living for the moment each day is a blessing. To all of those who know who they are, thank you from the depth of my being for all your continuous love and support on my journey through breast cancer to the advanced stage now and whatever the future holds.

hygiene and peace, when many nations suffer the absence of democracy or the violations of war; that women's rights are scant in many places; or education, sanitation, freedom. And it's not 'fair' that people you love get sick. It's less fair when it is those who love you the most. And it heads off the 'unfairness' scale when the sickness tries to trample them, not just once, but over, and over.

This epiphany came as one of my most productive life discoveries. To view the world as intrinsically unfair can be defeatist or fatalistic. However, with an acceptance that the world *will* often be unfair, you can bypass complaining or worrying over its imperfections, frustrations and cruelties. To whinge about yourself or a situation never dissolves problems, never makes the world fair. Rather, it can be productive to simply 'get on with it', with a spirit of hope.

That's been Beth so often, over twenty years of sunrises. Cruelties have aimed to dry out hope at times, but Beth carries a determined spirit that it is a blessing to her and so many. To Beth, cancer has never been about 'unfairness'. It has not succeeded in trampling her, physically or spiritually, and in all its 'unfairness' has remained an entity Beth has called her 'friend', with each of its visits and mutations. Beth's ability to inhale life by just 'getting on with it' has filled many lives by her unintended example - to embrace what might be unfair and take action for the most productive and happy outcome.

In the near silence of the Simpson Desert, this young wife sees a pathless and frightening world. Yet there is colour from the road in the distance and the camels chortle. There is Beth who, as I hesitated to venture into the wilderness, said '*Just get out there. Get on with it.*' That other young wife in a soft pink striped dress. She is sunrise through darkness. She is the saltbush, giving and living...with cancer, determination and a full heart.

('Saltbush' received a Commended award in the 2003 Cancer Council *Daffodil Day* arts awards - this is an edited version)

## CONCLUDING NOTE

Beth passed away on 1/4/2004. She made such a fantastic contribution to the fight against breast cancer. Beth offered her experiences to the Breast Cancer Network as a Consumer of Breast Cancer services and helped as a volunteer with their various activities. Beth loved to say '*Out of the strain of doing, into the peace of done.*' Now it is done.

4

GROUP HUMOUR AND  
OTHER CONTRIBUTIONS

### ***Poor Fred Award***

The *Poor Fred Award* originated one day in a group session. Gail was bemoaning the fact that Alan was annoying her. Jean responded with '*Poor Alan!*' A few weeks later Jean was berating Bill because of his habit of crossing his legs in a manner unacceptable to her. Gail countered '*Poor Bill!*' Then at our Xmas party Jeanette came into the restaurant with smoke coming from her ears, saying that Cecil had gone up the wrong street and had not listened to her directions. We all said '*Poor Cecil!*' In due course Bill suggested that we should have an award for the most maligned husband and call it the *Poor Fred Award*.

One day at morning coffee after our Thursday meeting, we were having a good laugh about the idea and promptly purchased three chocolate Freddo frogs in individual paper bags, inscribed them and sent them home to the respective husbands. At this stage there was no stand-out winner for this award, so the contestants (all partners qualify) were asked to submit a poem in support of their attempt to win the prized Golden Freddo Frog and become the holder of the *Poor Fred Award*.

**CONTRIBUTION FROM ALAN (*Gail's husband*)**

*Poor Fred is an award of some repute  
I'm a contender, there is no dispute  
Others lay claim to this prestigious event  
But few can match the huge extent  
To which I am harassed, confused and twisted  
Shaken and harangued and sometimes resisted  
Life is a saga of rights and wrongs  
Guess who's there when they hand out the gongs*

*Copping some lashings is the bane of my life  
Some are even dished out by my wife  
Many a time I bow in shame  
But the question is am I really to blame?  
My wife in a car knows north not from south  
But in the passenger seat can be quite a mouth  
'Go right here, no left, put your foot on the brake'  
'Hurry up, don't go slow, we are running so late!'*

*My push for this prize is no 'poor me' conception  
It's an unwanted product of nature's intervention  
Healthy cells are maybe a memory of last year  
Breast cancer has entered the lives of us here  
Some now have departed life in this place  
To be sadly replaced with another face  
Chemo and hair loss, tests and intrigue  
Combine with cat scans and therapies to produce this fatigue*

*The Thursday Girls have thought up this prize  
It is an attack on Freds in subtle disguise*

*They meet once a week on the aforesaid day  
When they dream up schemes for their innocent prey  
Poor Fred of course is the collective term  
For all we partners who seek and yearn  
To provide our partners with love, hope and cheer  
For many an hour, a day and a year  
It is much more than that, a commitment of note  
The Thursday Girls get our first vote*

**CONTRIBUTION FROM BILL (*Jean's husband*)**

*He also serves who stands and waits  
an old saying there's no debate  
To stand by in ready pose  
giving care and support if need arose  
Who are they, this faithful breed  
a silent shadowy creed?  
A collective league, enough said  
Let's call them Fred*

*Freds vary in shape, size and age  
no mould was cast or weight or gauge  
Formed as they are, nearby they hover  
ready to attend their partner, mate, lover  
Knowing about chemo, pills, is the drill  
the carer's manual, now that's a thrill  
Life goes on, sometimes on its head  
but that's the story of a Fred*

*Now on Thursday the girls converse  
are the Freds mentioned, anything perverse?*

*On that day a few male ears glowed  
but their shoulders can carry the load  
They give us chocolate frogs, such a delight  
this makes it worthwhile, everything right  
Freds are resilient, made of tough stuff  
fearless and hopeful when the going is tough*

*So the Freds continue what they know best  
giving support, comfort and the rest  
Hospital rooms are second home  
X-rays, scans, they could write a tome  
What was life like before? Who can recall?  
from their true path they'll never fall  
Would they seek solace in some other bed?  
not on your life, because they are a Fred*

**CONTRIBUTION FROM CECIL (Jeanette's husband)**

*Pills, pills all in a line  
They do make her feel fine  
Did she take them yesterday?  
Has she taken them today?*

*Poor Fred has to pause  
Senior moment perhaps the cause  
The steel trap mind is no more  
His ego has been cut to the core*

*Some say love is blind  
Others think a state of mind  
However we poor Freds are inspired*

*By loved ones so much admired*

*For dear ones departed we shed a tear  
Your courage helps us cope with fear  
We poor Freds have a privilege indeed  
To feel wanted in times of need*

*As we travel along life's passage  
To all poor Freds I leave this message  
Nil desperandum, omnia nondum perdita  
'Do not despair, all is not lost'*

***Other contributions***

**LINDA**

**It's Only a Breast**

*Breast cancer...tears  
I greet my daughter's birthday guests  
Brave-faced, red-eyed, exhausted*

*I tell my family...  
Silence, disbelief, tears, hugs...  
We'll support you*

*I convince myself it will be okay  
Then...mastectomy!  
Tears, more tears*

*Husband: 'It's only a breast'*

*Support, love, tears, hugs...  
We'll fight this*

*Friends: 'It's only a breast'  
Gifts, flowers, notes, calls...  
We'll help you*

*It's my breast! I'd rather die!  
Selfish...foolish  
It's only a breast...tears*

*It's time. It's my breast  
I call my doctor, my surgeon  
I can't do this...! have to  
Tears, tears. More tears  
My daughter, my family, my life  
I decide...it's only a breast*

## **GAIL**

*The Thursday Girls* agreed it was important to show that there is a lot of humour and laughter between us, and to tell of funny incidences that have occurred. The following was one of mine!

I had joined a relaxation yoga class and the instructor was a shy young man. We were told to assume an A-frame position that involves bending from the waist and touching the floor in front. On returning to the sitting position, I felt a lump in my



T-shirt around my waist. To my dismay my prosthesis had fallen out of my bra during the exercise! Being in the front row, I couldn't just pop it back in the bra so I held it in place and inferred to our shy instructor that I had a stomach ache and needed to go to the toilets. Phew! I don't think anyone noticed but I was a nervous wreck. I dedicate this story to all the caring people out there. They are the world's unsung heroes.

## **MARY K**

### **Oncology Day Ward**

*O gentle hands, so sure and kind  
Blue gowns rustling quietly by  
Voices soft, reassuring  
Certain of the role required*

*A joke, a smile, laughter and fun  
The patients all ill, all brave  
Some quiet, some laugh  
All enduring  
But watchful, seeing others  
Wondering, hoping  
That the road still to travel be not too short  
Not too straight  
That life has a few more wondrous times for love and joy*

*To leave a mark, a legacy  
Some small earthly dot  
Thoughts drift as the gentle hands  
Move with touch so smooth and sure*

## ***Epilogue***

*The Thursday Girls* group began with eight women in July 1997 and continues to this day. Over the past seven years, thirty-two women have spent time in the group and of these twenty-five have died. Of the sixteen whose stories appear, four continue to live full lives. They have been joined by six new members who have their journeys ahead of them.

Contrary to the morbid images conjured up when one thinks of a group of women with advanced breast cancer meeting together, these stories show that life goes on after diagnosis. For many of these women there was an initial reluctance to meet with others in the same predicament. However, they found that the bonding and connections formed gave them strength at times when strength was hard to find. Where else could they tell of their fears and anxieties without the need to protect loved ones and family? They have shared the shock of diagnosis and their fears of death. How will they die and how will they be cared for during this time? How do we leave loved ones and prepare them for the eventuality of death - particularly young children? They have faced the knowledge that they may not see their children grow up, or to be there for the 'big events' of their children's lives - graduations, weddings, and grandchildren. And together they have shared the anxiety and helplessness that arises from not knowing how much time they have left.

The central role of the group is reflected in how women come to the group until the time they die. When members are so sick that they are

unable to come to the group, the group has met around their bed or in their home. Over time they have learnt to see that everyone has to die. Far from being morbid, these women not just share tears, but many good times and lots of laughter. In fact, like all groups confronted with difficult and stressful circumstances, they have had their fair share of delightful black humour.

Many women, partners and families have drawn enormous benefit from being part of *The Thursday Girls* in the later part of their lives. A huge comfort for the women is to observe the ongoing support for partners and families after the death of members.

Within any model of comprehensive cancer care, psychosocial support is fundamental to a treatment plan. Since the research funding finished in December 2003 *The Thursday Girls* have struggled to continue. Without funding its future remains uncertain. The continuing referrals made to the group indicate a real demand. It is time for health service planners to recognise the essential and cost-effective role that such services provide in ensuring the quality of life for women with advanced breast cancer and their families.

How many of us know when we will die? What confronts these women is knowing they will not live to a ripe old age. As many of the women have said here, the diagnosis can be a 'wake up call in a life'. They show how, in the process of coming to terms with their situation, the best option for us all is to live for the moment - to enjoy what time we do have.