



*Woman
to Woman*



**Insights from
rural women
with breast cancer**

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This research was conducted as a collaborative partnership between the Department of Human Services (DHS - Hume region), Women's Health Goulburn North East (WHGNE) and Breast Services Enhancement Program (BSEP - Hume region).

The Department of Human Services, Hume region is a key human services agency with responsibility for the portfolio areas of health, housing, aged care and community services. It leads the delivery of the government's goal of high quality, accessible health and community services, and contributes to the building of cohesive communities and reducing inequalities across the region.

The Hume Breast Services Enhancement Program (BSEP) commenced in late 1999 and was funded by BreastCare Victoria, Department of Human Services (DHS) until June 2004. This program was one of nine quality improvement programs across the State and aimed to establish a model of breast care services in line with established best practice. Key priority areas for the program included increasing access to multidisciplinary care, breast care nurses and information, communication and support.

Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, WHGNE is the government funded specialist women's health service for the Goulburn Valley and North-East Victoria. The vision is to lead the Hume region in creating opportunities for women to experience a positive sense of self, health, safety and wellbeing.

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This book is a compilation of excerpts from interviews with 20 women from the Goulburn Valley and North- East Victoria to highlight particular aspects of the experience of having breast cancer. Where requested, names have been changed to preserve anonymity.

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Edited by Debra Parkinson, Claire Zara, Angela Verde and Kate Cuss.

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Introduction

Poignant, sad, inspired, refreshed, angry and deeply moved were just some of the emotions I experienced while working with the original interview transcripts and these ensuing stories of 20 women who opened their hearts to tell us of their journeys with breast cancer.

We've all been touched in some way in our lives by cancer – whether it be professionally, or a relative, colleague, or friend, and yet we can never really truly understand their experiences if it hasn't been us who has been told 'You have cancer'. Each of their journeys is unique to their personal situations, and yet they also share some common experiences.

This qualitative research project evolved as a partnership between one woman who experienced such a journey with breast cancer who was employed with the Department of Human Services Hume regional office, a colleague at Women's Health Goulburn North East, and a project within this rural region to improve services for women with breast disease, Hume Breast Services Enhancement Program. To Angela and Debra, it has truly been a privilege to learn and grow with you along this journey, and to know that the findings of this research will contribute to our vision of *'increased awareness of rural women's experiences of breast cancer, resulting in informed policy and improved services'*.

Between August and October 2003, Angela conducted in-depth semi-structured interviews with 20 women with breast cancer aged between 34 and 70. The unique benefit of a researcher who shares a common experience with the respondents is invaluable. Developing a rapport with the participants led to their increased commitment and willingness to participate and disclose. It is also imperative that processes be put in place to safeguard the credibility of the research, which we did.

All women lived in the rural Hume region of Victoria, in a variety of major regional centres, smaller towns and rural settings. By documenting and analysing these women's stories, we now better understand the effects of breast cancer and its treatment on women, and the particular implications for rural women of a breast cancer diagnosis. In addition to this book of stories, the research report has been published, "Woman to Woman: A Research Report on the Experience of a Breast Cancer Diagnosis on Rural Women and Implications for the Provision of Health Services", which features ideas from women about what would be useful in terms of service system redevelopment. The research also identified the strategies and supports that women found most useful in managing their lives with breast cancer.

A heartfelt thank you to the women who shared their stories and insights you are about to read.

Kate Cuss
Program Manager, Hume Breast Services Enhancement Program



Evelyn Margaret

It was from a regular check-up. It was 12 months since I'd had one. It was a grade three aggressive, 16 millimetre. Fourteen lymph nodes as well.

I decided to go against having chemotherapy. I was given the opportunity, with three to five per cent difference if I had it or if I didn't, and I'd just gone through my husband having chemotherapy, which affected him badly. I lost him in July. I'd have been living on my own if I had it, and I didn't think six months of chemo was worth it for a five percent difference. And because I possibly wouldn't have been able to drive myself under treatment.

About eight months before I got the breast cancer, I had back surgery and I was to have a total knee replacement, but the breast cancer came first. About three months after the breast cancer treatment I had a total knee replacement. I just got over each operation and tried to get going doing everything I could.

I was doing heated pool exercises at Numurkah, going with the Community Health bus. It was a long way to travel, but I'm sure it helped get back with the muscles and the different exercises for all my operations as well as the breast. And I went in between operations. But it's too far. It's an hour over to the pool, an hour back, and an hour there. It would be very good if they could get a heated pool here, because it helped get all my muscles going.

I've just decided to get on with my life and to push it out of the way. I haven't let it worry me.

When I had my back and knee operations, I had a problem in getting help from the Shire. In the end, I got my own home help lady, and I plated my own meals. When I knew I couldn't get help after my knee operation, I put my meals in the deep freeze before I went away. They just said, 'You're not entitled to it.' And I do know it wasn't offered to me before when I only had one hand to use. At the same time, I know a lady very well who had the same operation about a month before mine, and she went down and made arrangement to get home help and meals-on-wheels for a fortnight, and she got it without any problem because she was public.

Because I came from a private hospital I could not get a breast prosthesis. I had to pay for it at two hundred dollars, which I'd have got free if I had come from a public hospital. It's been a big problem. I was told I could get a prosthesis free - if I waited two years. I'm a pensioner and I've had private insurance since '72.

The 12-monthly check-up revealed that everything was clear. It was nice to get the all clear. And I'm quite sure it's gone now - I feel a lot better than I've felt for a long time.



Jessie

I have experienced other cancers since I was 37 - melanomas and my uterus was removed with cell change. I've had polyps in the second stage, basal cell cancers, so I've had all these types of cancers. But that was all...

I was at my aerobic class when I found this massive lump. I thought I'd pulled the little muscle in my left breast.

The next day I visited my GP and he said, 'Oh, my gosh. Why haven't you picked this up? It's massive.' Actually I had a lot of mastitis and I'd visit my doctor and have mammograms and that sort of thing. All your little lumps and bumps - you didn't take a lot of notice of them. So I had a few words with him.

I went to visit a specialist in Melbourne, as my doctor was unavailable. I wanted the best. I'd heard of him because quite a few women from Wangaratta had visited him for surgery.

He did a biopsy, and said, 'Well, there's no hurry, but can you be down here Friday to be operated on? We'll have to do an operation straight away'.

They removed all my nodes. It was advanced breast cancer - it was in ten of my twelve nodes. The surgeon came in and told me they'd got it all.

They all say that.

The oncologist was very kind. He sat down and held my hand; I was rather impressed by him. He said that I would need treatment. And rather than going backwards and forwards to Melbourne, he would send me to a colleague of his in Wodonga. I became his patient.

You're in a daze, you just think, 'This is not happening to me. It can't be happening to me. Yes, of course it's happening to me.'

I take everything in my stride, but this was a big stride.

It's the shock of it all, what your system has to go through. Even now, there's the numbness and the irritability from the prosthesis. And it falls out every now and then.

I went into a study group - a clinical trial. It was heavy stuff, a pretty big shock. You're nauseous and travelling backwards and forwards every week.

I think the biggest shock was the pain, and the discomfort of losing your hair. It happens so fast. I'd look in the mirror and I think, 'No, that's not happening to me.' I couldn't believe it.

When I was on Phenergan - I react to most drugs - if anyone met me coming out of the hospital they'd think, 'My God, he's taken her in to dry her out!' Like an alcoholic. I just went zonk! As soon as it hit my vein, off I went. It wiped me out. My husband would be nearly carrying me out - that was an embarrassment. You had embarrassing sides to it, like losing your hair, and having the drugs, and the depression that you go through, your body goes through, and it's just all part of it.

The toxins just pour through your body and it just bombs you out. You get so fed up with scans and scans and X-rays.

I can still see the doctor sitting there on his computer saying, 'You've got the worst possible cancer anyone can get. You've got two months to live'.

All I could say was, 'Oh, shit,' and stood up and put my hands on my head and sat down. It had gone to my lungs. Secondaries.

The doctor said, 'There's a drug, a new drug called Herceptin. It's going to cost a thousand dollars a week'. It wasn't on the list [PBS].

'We'll handle this, and we'll see what we can do for you,' he said. The next minute the Health Fund had their round table conference over it and I received 14 weeks of treatment for free.

In the meantime, I decided to write two letters to Dr Wooldridge, the Minister for Health at the time. He did not get the Herceptin passed through Parliament. So I wrote a letter, SOS right on top of the letter, to Mr Howard, and said that I felt that I've had a pretty good run in my life but there's a lot of young women with young children that need this drug, and how about instead of paying out big payments to your politicians you look after us.

As volunteers, we've volunteered our time - I know I have, for years and years in our community, how about looking after us? And I took the letters in to Ken Jasper, National Party, and Lou Lieberman, Liberal.

The girls were very good in their offices. They typed it up for me and knew what channel to send it off to. I received letters back from the Government over it. The next minute it was passed, so I presume that a lot of letters were sent in.

Herceptin has given us all a better quality of life. We can lead a reasonable life.

The only disappointment in my three years of treatment and communication with hospitals and everyone involved is the words, 'You have two months to live'.

I didn't need that.

The only other experience I had was with the breast care nurse. I think that it was in Melbourne. She came in and was telling me about crop tops and said, 'You'll need one of these.' Well, she threw this prosthesis at me! Have you felt a prosthesis? It was just like a big blob of fish or jelly. It landed in my hand I just threw it straight back at her face and said, 'Here, you can have it.'

So, that's not bad in three years.

On my days where I will have a down day, and I mean a down day, you stay there. You don't want to get up and fight it because you haven't got the energy to fight it. I can wake up in the morning and pull the sheet over my head, or I can step out and step into the shower.

I'm very close to God, I take my Communion each week and I feel I get the body and the blood that gives me the strength to keep on going on.

Faith has been very important to me, very important. It's number one.

Be patient and trust God and listen to the beat of your heart. If you live in a positive way and don't let negativity, stress and fear get on top of you, then I think luck comes your way. You probably make it yourself, but if you are doing something active to keep your mind in a good place then I think that's what helps. Those who trust in the Lord for help will find their strengths renewed and will rise on the wings of an angel. Never let your burden paralyse your progress. Reach out and help someone else.

Every day is so precious. We have no time to waste joy on misery. The secret is live on, one day at a time, because tomorrow is a new day. Pain - we can choose to be positive. We can avoid misery, the option is to choose joy, choose to smile rather than frown. You choose how to look at your illness. We can look at the flowers or the weeds. We can see the bright side or look at the clouds.

Remember you can be as happy as you decide to be. Pain is inevitable, but misery is optional. A beautiful day, isn't it? Go, go, go.

Now, I say that on my good days, and my good days are very good. But as I say, I don't want to look down the road to death because I believe that if I accept I'm going to die next month, I'll go down. We'd all go down. We withdraw into ourselves.

I get very upset with the Lord. Why me? And we all say it, 'Why me? Why me?' You know damn well that's just life. The luck of the draw.

My husband is very kind. He knows how I feel at times, so he'll just automatically do the vacuuming because after all these years married to a farmer, this is his way. He might say, 'Oh, I'll cook the meal tonight.'

I feel sometimes that a shield is there. It's very hard to put it into words. I can just feel that he doesn't want to know what is going to happen to me. He won't let it register in his mind.

I want him to sell. I want him to build a two-bedroom unit down the road. If we had done this three years ago I wouldn't have the worry of having to think, 'Oh, my God, I've got to start cleaning these cupboards out.'

So I go to do it and I think, 'Oh, blow this for a joke. I'm going to live on. I don't want to clean my cupboards out yet.'

My daughter came out one day and I was in the bathroom throwing things out. 'Mum, Mum, don't do it. Forget about it. We'll do it,' she said. 'Don't worry about it.'

I've got a very caring husband, but he doesn't want to see down the track. He's hiding; he's putting it away.

He's very reserved. He'll come in and give me a cuddle during the day. He doesn't worry me with sex. You feel dead inside, and half the time you've got vaginal itches anyway. We just cuddle each other and I've always thought that's more important than sex life, anyway. Except if you're over-sexed, which neither of us were.

I have a great interaction with my husband, family, my close friends (I call them my twelve apostles), hospital staff, doctors and fellow patients in the oncology ward. I know I can ring Women's Health at anytime ...

It's all organised, but it's not going to happen, you see. This is the problem. How do they say people learn to accept things? To me that's a lie. I don't think any of us accept death. We don't want to accept death because we're not going to see how the neighbours are behaving, or what your children are up to, or whether your husband's going to have a redhead or a blonde. Is someone going to sleep in your bed? You don't say that, but you know it's in the back of your mind. And I don't know whether that's wrong, or whether it's right. But to me, I think it's natural.



Anna

As English is not Anna's first language, she was offered an interpreter. Anna chose to have her daughter with her, whose comments are in italics.

I felt normal, like today. Everything working. Nothing. And then last year from Wangaratta they sent me a letter to come for a breast screen. Two days later I get a phone call from the hospital in Ringwood to go for an ultrasound, something like that.

They found a little spot is very, very deep in the breast and when coming back the doctor said, 'Better get the operation.' Anyway, this time we decide it's far away down to Melbourne and the doctor thinks go to Albury. Yes, and the doctor in Albury, he make a wonderful job. [They did a lumpectomy] and removed 18 lymph glands. Five (lymph glands) infected, the other ones removed is all clear.

I not expect three days in the hospital, you know. I expected probably to stay more. But anyway, they sent me home, and recovery very, very well, like the leg, you know [melanoma on the leg twelve months before]. Never taking any Panadol or aspro - nothing.

The chemo never affected me. Feel good. We go first chemo in through the hospital, chemotherapy just in the ward ... you know how you live with fright, you know? But walk out from the hospital like normal.

Then we finished chemo, work in the garden. When you get chemo, work in the garden not allowed, not allowed in the sun. A little bit boring because I've got nothing to do until the sun is...you know...

Then started radiotherapy. Up to Wodonga Monday to Friday, every day. Six weeks. I woke up early in the morning, mighty early. There and back. I get in my groceries after going, but never feel tired or something like this. I got home, no pain, nothing you know.

[It's the right side and she is right-handed.]

Yes. This one I use to chop, everything, more stronger. Never get an infection, nothing. I think today the specialists, the doctor, the sister, the staff, everyone is wonderful. It was fantastic. The district nurses, they look after very, very well. And I say thank you for everyone.

[Physically, she still does everything she did before.]

And still bright the memory, I remember all my dates. I write down the books the date. I remember all the dates, everything. So then when Linda says, 'You know next week, or in two weeks time...' you never forget the date. Memory's good.

I never been worried in my life. I sleep through the night. Yes, going good.

[She didn't want to go to cancer support groups, she'd rather stay home and garden. So she played her bocce, and did her gardening. That's why with radiation she came home and travelled every day because then she could do what she wanted to do. It didn't interfere. She just kept doing what she enjoyed doing.]

[It didn't bother her to lose her hair. She just wore a hat and she was happy.]

I lost my hair. I remember one time, I started to lose a little bit, and one night I came out from the shower and started to dry off my hair, and I started to lose it all at once. I called my husband and said, 'You come in, just take a look?' He said, 'What's happened? Oh, my God!' Better to lose my hair - is better than to lose my life. My husband is different to me. I am optimist, my husband is pessimist, you know, he's got more worry.

I was happy with everything. Yes, everything, making wonderful job for me.

When it first happened, I sat down and think about it, but, no, not very upset...a little bit, you know, for my husband.

[She was happier having to deal with it here than having to go to Melbourne because we don't have family in Melbourne either, so that would have been really hard. The thought of having to go to Melbourne stressed her out more. And Dad is not comfortable driving in cities and towns. I drove her each time. He had to stay here because they've got the chooks. That was good, though, because they kept him busy. Otherwise he drags her down because he's so negative. I think because she was here and he could see how well she coped, it was better.]

[She normally puts something in the Myrtleford Show every year. She was worried about missing out on entering. She wanted her chemo to work in with her being able to present at the Show. She was worried that she'd be sick on the Friday.]

Anyway, I bring my flowers inside overnight, and my vegies. Woke up in the morning, five o'clock in the morning, go through the garden picking up all the vegies, fresh vegies, you know picking nice ones ready for seven o'clock and driving them to the Show. I did win, yes.

So nothing stops you? No.

Not the melanoma, not the breast cancer? No.

[And I was always with her.]

Sue

I don't think my husband really understands. I think it's a bit frightening for them, actually. Sometimes he appeared to take things very lightly.

I suppose it depended on my mood. I couldn't deal with it. One day I had an early appointment at radiotherapy and I got up and went. He was still in bed. It was about eight o'clock.

I came home and I let him have it. I did. I said to him, 'I just sat there and I felt so alone.' He came every time after that.

He was a big help physically, but sometimes he drove me mad, too, because he was always so bubbly. I think he did it for me. Bubbly and bright, and he'd laugh and joke about a half a boob.

I think he was covering up his own fear in a way. He said to me afterwards, 'I didn't know how I was going to cope. I didn't know what I was going to do.' So I think a lot of it was cover up. I don't think he wanted me to see him worried. He probably felt I had enough to deal with.

I felt guilty if I wanted to cry.

[Even my best friend], I don't think she ever put her arms around me and let me cry or anything like that. It was just all this positive hype because she had a sister-in-law who died of cancer, but it wasn't breast cancer. She'd nursed her a bit towards the end. She believed a lot in the power of positive thinking.

I couldn't talk to people on the phone. My husband used to get cross with me when people would ring up to wish me well, and I'd say to him, 'I can't talk to them. I cannot. I just can't talk.' I'm not a great one for the phone, anyway. I just didn't want to go over it. That's what I felt - it's just going over the same story.

He got cross with me. He actually got cross with me! I hadn't been home from hospital that long, and my sister-in-law had called in. She was here when the other sister-in-law from Melbourne rang, and I said to Ian, 'I can't talk to her.' Ian said, 'It's Dorothy. You've got to talk to her. This is the second time she's rung.' His sister let him have it. She said, 'No, she doesn't. If she's not up to talking to them, she doesn't have to. You just tell Dorothy she's not up to talking.'

Maybe I had too many expectations that I'd bounce back. And I couldn't bounce back. I'm constantly tired and haven't a lot of enthusiasm. Now I enjoy just sitting quietly reading a book or something like that. I don't want to go out. ... I know I should make the effort and go out. Ian would say, 'Come on, let's go for a walk. Let's take the dog for a walk'. I'd [say] no. Even to pick Britt up from school, I let Ian go and pick her up. I probably would have, before. I had more enthusiasm. I just don't have a lot of enthusiasm and I think, if I'm completely honest, in the back of my head, I expect something to come back. I think I do.

I think because my father was my age when he died at 57, which is very young. He had this cancer of the kidney and about two years afterwards he got the secondaries come through. It was the only time in his life he had ever been sick.

I think, in the back of my mind, I expect something else to happen.

I don't dwell on it, but I sometimes wonder, because I don't feel as good as I think I should feel. ... But then maybe I'm talking myself into it. ... because I'm thinking about it all so much.

Janelle

Oh, it was very frightening. I'd recently separated from my husband a few months before, after stress and unhappiness. Funnily enough I was in the process of changing my will and I went that very day to the solicitor to change it all, and just before, the surgery rang and said, 'Can you come back to the doctor?' So I'm remaking my will thinking, 'I'm about to be diagnosed with breast cancer.'

The (GP) was very good, he just said, 'It's not good news, I'm afraid.' He explained what the process was, and where I would go, and he wrote it all down for me because he said, 'I know you won't remember all this when you're at home'. He made the appointment, and I was in about a week later.

I chose mastectomy because I had the option and I wanted the best result, and the best result was mastectomy. It was a hormonal cancer so we had to look at the early menopause aspect. Once again I was given the option of chemotherapy or a surgical, and me being me, chose the surgical. I had the ovaries out because it would also remove the chance of ovarian cancer.

They let me recover from the first one, then it was just overnight for the oophorectomy. That was quite painful just for a few days and then it was sudden menopause, just like that. But the surgeon had warned me of it, so then it was just coping with menopause, really.

The breast care nurse was really good. She was fantastic with the mastectomy. I think I grilled her on the phone for about half-an-hour before the operation. And she called in to see me afterwards which was good.

I had a breast reconstruction as well. In Melbourne you can have it done at the same time as a mastectomy, but up here you have to wait 12 months or so. I had the reconstruction over the course of two or three operations. The first operation was twelve months after the mastectomy and then it was about six months later they finished off. It was good. Definitely worth it. You don't have to worry about little cushions and pads and things.

I pushed out the fact that I've got cancer, because it had been dealt with. Okay? So I've dealt with it, and it's gone now. And that's how I see it in my head.

Initially, not knowing is the worst, whether you're going to live or die. After I came home, I sort of plunged into the depths. That night I'd worked out who all my pall bearers were going to be. I guess it's a natural reaction. Then I thought, 'I'll be so small, anyway, I'll probably only need about four people'.

It's probably just in my head. I'm quite sure I'm fine. But then the seeds come. You get a bit of a pain here, and you think, "What's that?"

I suppose that's common to everybody. I mentioned it to the surgeon last time. He was good, because surgeons aren't often people persons. He said, 'In my experience people who've come back to me like you have, if they do have a problem, the problems have been there from the beginning.'

That made me feel better. Until I got the next twinge or headache. And when you have your blood taken that always reminds you, again.

That seed of anxiety at the back - that's always there. It rises and falls with different intensities. If you feel a bit tired you think, 'Oh, is this how I felt before? You start thinking, 'No, I'm not even going to feel anything...in case I feel something, I'm not going to'.

It's changed my whole life, really. It changes what's important to you, outwardly and inwardly. You value your friends more, and your family.

It makes me look after myself more. Because I work hard at a part-time job, a small business, and I've just finished a degree as well, and I've got my son ... and the marriage break-up. So now I just slow right down. If I feel like doing nothing, I do nothing.

Now I am far more aware of eating healthily. My friend from Mansfield drove all the way up for a day, and she was researching on the Internet all the good foods and that kind of thing. Mum bought me a juicer. As a physical support my mother came over and stayed for a while and helped with cooking and cleaning and just doing things for me. I had home help, too, for the first week. But, even after a week when Mum left it was hard to cut vegetables and things. Later Mum kept following up, and a girlfriend would phone every day.

Being May, it was autumn, and the autumn sun would come, so I'd just sit out in the sun. It was lovely. And friends would call in, and work people would call in, and there were flowers everywhere. Lovely, lovely.

Bev

My grandson is seven, and he was five when I had my lung operated on for cancer. His parents didn't know what to tell him, so his mother told him that I had a little mushroom that grew that they had to cut out. Anyway, when I got the breast cancer, I said to him, 'Oh, you know that damn mushroom,' and he said, 'Yes, Mummy told me about it,' and I said, 'Another one's grown, I've got to go and have it out. It's grown in my boob.' 'Oh, no,' he said. And then he went to Show and Tell and told everyone that Nanna had to have another mushroom out!

I was in the shower one day and he came racing down to go to the toilet, and the downstairs shower hasn't got a screen around it, and of course I'm standing there in the shower. 'What happened to your boob?' All thought of going to the toilet was gone. I said, 'What do you mean, what happened to my boob? I told you about the mushroom.' He said, 'I know about the mushroom, but what happened to your boob?'

It's very hard to tell little kiddies.

After both of the cancers you see life just a little bit different. We've been to Melbourne, I reckon hundreds of times, but to go now to Melbourne you just look up to the sky and say, 'Look at that beautiful cloud formation,' or, 'I didn't notice that beautiful tree there.' You're much more aware.

I don't know how I found time to go to work. I worked full-time up until I had my lung cancer. I had my sick leave, and was just ready to go back to work when I got the breast cancer. So I used up the rest of my sick leave, and said, 'Time to get out of here. My life's not worth it'.

I used to say to myself that I would finish work at 60, but I don't know whether I would have. I was such a go go go person.

Now the kids reckon that I've completely lost it. 'No,' I said, 'I just don't let anything worry me.' And I don't. Before, two flies going up a wall would worry me. I would lay all night worrying about things that I could not change. Now I just say to myself, 'I can't change this. It's not my problem'.

It's had a big effect. It's taught me to appreciate life, really. I never used to garden and now the front garden's mine. Before, I didn't have time for it.

But I've put on a stone and that annoys me. That annoys me because I've been nine and a half to ten stone all my life and you've got a spare tyre here because there's no boob to pull the skin up. It could be related to the Tamoxifen, or it just could be related to the fact that I'm sitting down here watching the roses grow.

That's what the surgeon said to me. I said, 'Would these tablets make me put on weight?', and he said, 'Oh, go on. It's because you're so relaxed.'



Ann

A diagnosis of breast cancer makes you look at life a lot differently to the normal run of people who think they're immortal. No-one's immortal. It does really make you stop and look at life, and I've certainly done that.

My oncologist sat on the bed and said to me, 'Were you as sick as this last time?' I said, 'I'm too far away this time to go home, or go to someone else's house and be sick there. I want to be in hospital.' It's a long drive to get home from Melbourne.

I stayed in for the chemotherapy treatment. I went to hospital every time. The shortest time was four days so it was quite an arduous treatment. Sometimes I got to come home. Then I started six weeks of radiation at [Peter MacCallum Cancer Treatment Centre]. I lived at Peter Mac for six weeks and never came home.

Twice my husband came down to see me as it was impossible for him to stay with me - we run our own business which requires someone to be there 24 hours. My daughter came one weekend. An overseas student who used to live with us came in and out to visit.

It is a lonely time. At times it hurt me. I am a person who can exist by myself, but sometimes you just need someone. I had a very good friend who said, 'I'll be there for you.' And every time they did the chemo she was beside the bed. At Peter Mac it was the same. If she didn't ring me she was there every day. And she'd take me shopping or something like that. A great support. And then my sister would come and take me. She took me out one weekend - but sometimes you're so tired you don't want to be dragged around.

The distance from the treatment makes it hard, but it was my choice to go back to the doctors who had treated me before. I was there for a routine check-up, so I'm not going to walk out of his office and say, 'I don't want you. I'm going closer to home.' I would go back tomorrow if another situation arose. As I said to them, 'I don't know how brave I'd be if you confronted me a third time...' but I would certainly go back to those treating doctors. They know my history, they know me, and why would I change?

As for radiation, it's still a long journey to go to Albury every day. Barry couldn't have driven me to Albury every day and then back. It would be three hours and then it depends on what time you spend up there. You could have looked at four hours every day. It was far more feasible for me to live in Melbourne. The accommodation that I was given at Peter Mac, I couldn't have asked for a finer situation. It was just some days...

My daughter, eleven years ago, was an incredible guardian angel while my husband was away. The first time I had cancer he had a lot of difficulty in accepting what had happened to me, and when it happened the second time Monique got here on the Saturday morning and she doesn't cry very much, but I could see that she had been crying and she was upset. She gave me the biggest hug and said, 'Mum, I'll always be there for you, but Dad's going to do it this time. All right?' So I told him what she said. He said to her later on at lunch time, 'By the way, on Thursday when Mum needs to go to town, would you take her?' And she said, 'Yes, I would if I had to, but you're bloody well going to do it all this time.' She can talk to him like that, they just get on extremely well.

Even my husband's friend who'd been through a similar situation couldn't really get him to talk in-depth about it. All he would say to me is, 'You'll still be here when I'm dead and gone.' It was like he was in denial of the situation. Statistics do show that often the person closest to you is the hardest to talk to about it. You can often talk to someone away from the family better than you can talk to someone very close in the family.

I had four miscarriages, then we adopted Monique. I became pregnant just after her and was confined to bed for eight and a half months, and then [the baby] died four weeks later. So, yes, there's been patterns in my life that have probably been often, say, a little more traumatic than having cancer.

When Monique was four, we were given another little girl for adoption and we lost her after six months. They decided not to proceed because she was bordering on autism. I tried to fight the case, but I still couldn't win. I feel more cheated from that than I do from having had cancer.



Devi



I went back to work thinking, 'I'm all right'.



I lasted two or three weeks and that was it. Oh, it was tiring. I couldn't teach properly, memory loss was really bad. When you're teaching, you can't afford that. It was very difficult. I took six months off, and then started again in November 2001. I went full-time. Then in 2002 I did full-time for two terms and I couldn't cope because teaching is a job where you have to be on the go, and you can't relax. You can't go into a classroom and say, 'Look, I'm feeling tired, I want to sit down.' You can't do that.



They would play up, especially the junior kids. It was just impossible. I asked the school for part-time. They were supportive in the beginning, but when I came back... Some teachers helped me. I had to do yard duty. They gave me the full load, more than the full load because there was a shortage. Whenever I went out in the sun I used to get lumps on my arm. I told the Principal that I couldn't do yard duty but they didn't take any notice of me.



Then a couple of things like that happened. They had a swimming carnival. I said I just couldn't go but that I'd get my Year 12s and teach, because I was behind. My Principal said yes. A couple of teachers complained. I told my Principal, 'Look, it's not my problem, it's their problem. You sort it out with them. I'm not coming. This is what I'm going to do.'



He helped me a lot.



One day I did yard duty and when I came back I was drained, I was just sitting there, I couldn't say a word. A couple of other teachers, lady teachers, saw me and said, 'Don't worry about yard duty, we'll do it for you.'



I used to worry. I asked for part-time. The school refused because they didn't have enough teachers, so I kept on going. They pushed me to an extent where I got really angry. I rang up the Union and the lady there said, 'Look, why are you suffering? We'll deal with it and you can go on point six. Get a letter from the surgeon and the oncologist and send it to us and we'll look after it.'

The school didn't have any other choice, because the Superannuation Board came in and said, 'You pay point six and we'll pay the rest.' The school didn't help me in any way. They didn't have a clue what is available - I found out everything myself.

During that time also I ran out of leave, I didn't have anything left. I contacted the Union and they got in touch with the Superannuation Board. They gave me a pension. Just a little pension, not much, but something. All of a sudden, to lose one's salary, it's not easy.

The school still pushes me a lot. I had to change my attitude. I can't do perfect things. I told that to my Principal and he was quite happy. Nowadays if I can't do it, I can't do it. I just rest. That's how I'm coping.

It's made me think about my life. You become very philosophical.

I became more calm. Before, even a little problem was a big problem - but now even a big problem is a little problem. This pushed me into spirituality. I analyse things a different way.

It also made me accept. I haven't told the kids, but I've told my husband that if I get it again, no more treatment. I'm quite willing to accept that. I can't go through chemo again. I had a very hard time. My family finds it hard to accept me as a sick person. In the middle of the chemo treatment I had my twenty-fifth wedding anniversary. My daughter organised two parties. I had to get ready and go to those parties. They were surprise parties, so I didn't know. Things like that. I knew they cared, but at the same time I just wanted to be left alone. They didn't understand that.

My husband was very supportive. Without him I couldn't have gone through what I went through. But he doesn't like to see me like that. I had to go through with normal life, which I found very, very hard. I couldn't eat. Even now my tastebuds are gone. I try to cook and I get frustrated because I can't taste it. I don't seem to get over it. I deal with diabetes as well.

My sister came from London and stayed with me for about two months. Others also came around and visited me, or took me for chemo, and they bought me flowers. The teachers from school organised a once a month outing to one of the garden centres for coffee. They picked me up and brought me home. I had a lot of support. One of my friends even took a week off and came and stayed with me. Then my Head of the Department in London came and stayed with me for a week.

But sometimes you just want to be left alone. I wanted to be, but I couldn't. I felt I shouldn't say that, because lots of people haven't got the support.

My husband organised a holiday, too. That was half-way through chemo. I vomited all the way.

I've had it. I've had the treatment and if it is going to come again that means it is the end this time. Why extend your suffering by taking treatment again? You've tried once.

I'm not saying this because I'm bitter or anything like that. It is my decision and I just want the others to respect that.

Sonya

I went to the doctor's to get a medical check-up for superannuation.

I was sent off to meet a surgeon. I had no idea why, where, how.

I found a scribbled note in my post box with a date - two o'clock that day. I picked my mail up at six o'clock that night and had missed the appointment. I made contact with the regional hospital to find out who I had been referred to. At that stage I didn't know it was a surgeon. I had no idea who he was.

I explained my situation and they ended up giving me his mobile phone number which I rang at the cricket on Saturday afternoon. He responded and I met him at his surgery at nine o'clock on the Monday morning. He wanted to do a biopsy on my breast.

I was fighting him, because I didn't want to be cut for no reason. I couldn't understand why he'd want to do a biopsy when there wasn't an issue.

Apparently, my doctor had discovered burn marks on my arms. I work in a home economics room at the college. I still had burn marks on my arms in November. They were from hot cross buns back at Easter. The burn marks were still quite evident. He indicated that it was a sign of an abnormality in the blood. My argument was, why don't you do a blood test rather than a biopsy of the breast?

He virtually had to explain slightly what was going on. They sent me for a mammogram that morning, and that afternoon I was back in his surgery. He thought I had some form of breast cancer – I had to come back again in a couple of days and have it diagnosed.

They said 'It's definitely got to go. You've definitely got to have a mastectomy'. It was Paget's, which, at that stage, was in situ on the nipple. As a result I ended up having a mastectomy.

Eleven years later...

I was having problems sleeping, I took myself off to the doctor for some pills. As I was walking out the door I said to him, 'By the way, I've got some mozzie bites and some ant bites that I can't cure – they just won't settle down'.

It was just a little mozzie bite in the area on the mastectomy scar. He immediately sent me to the surgeon where a biopsy was conducted. It was grade three tumour. The rash, which I thought was ant bites, had nowhere to go and it had leached into the skin, so there was a skin cancer issue as well.

At that stage I didn't think it was very bad because it was only little – as you do – but by the time I was operated on, which was six weeks from finding it, it had grown to 30 mm in diameter.

I had day surgery to have the lump removed. I was very happy with day surgery. I didn't want to go through a prolonged anaesthetic. I didn't want to face drainage tubes that felt like you were having a varicose vein removed without an anaesthetic. I didn't like that feeling at all.

This way it was a lot quicker. A lot smaller operation, too, but it hasn't left me with much. There's no muscle left, the skin is very, very tight. I'm not too sure whether the elasticity in the skin will return. They used exactly the same scar line, so I don't have two different lines. It made getting my arm movement back a lot, lot harder because of the scar – it pulled terribly.

This is a completely different cancer to my original one. I've had many, many tests and they cannot find any traces of the original. They're watching an area on my spine and they're watching a kidney, and that's all I know at this stage.

I had chemotherapy, four treatments once every 21 days.

Basically the staff needs a course in PR skills. I have an issue with their attitude. As a result of no communication it took nine weeks before it was mentioned that my struggle to eat and drink could be relieved by rubbing cold water and ice over my nose and mouth and down the throat prior to and for a couple of days after chemotherapy. That way it didn't leach through the veins or leach out. And golly, it made a difference. I had already had three treatments and I have a top plate and couldn't use it because my mouth was so sore.

In the end, I did bring my own cold water, but because the room was warm - although I was freezing - it melted. They brought me some water from a machine that had cold water in it. They produced that only on the fourth time.

About half an hour after chemotherapy started, I would just freeze. I ended up with gloves on, and a coat on, and thank goodness, I had a beanie.

In fact, I was so concerned about the attitude of hospital staff, including doctors and nurses, that I was paranoid about getting the wrong treatment. They were so quick and fast, and in-and-out and in-and-out, that I actually made my daughters read exactly what was on the bags.

I had to have chemo and decided that rather than go to Melbourne for chemo I wanted to be at home, so I continued there despite how unpleasant it was. At first, I thought it might have been me being negative towards chemo. I wanted to get over that because I was there for cancer treatment, not to make best friends.

There were enormous problems with communication between medical oncologists, surgeons and other staff. My original diagnosis was that I would need an operation, I would need chemotherapy, and I would need radiation therapy. I asked for a referral to Melbourne. Reluctantly, that was given, but they asked – or demanded – that I go back to my regional hospital for chemo.

If I'd had to drive back from Melbourne after each treatment I wouldn't have been feeling very well at all. So after a hell of a lot of painstaking thought, I did it in the end. [I had my treatment locally.] I was quite happy just to get home and do my own thing. I had support here. I always had someone with me for the first five or six days.

It was really necessary for someone to be here just to get me through the worst days and just give my husband a bit of a break, and so I'd get back on my feet and get ready to go back. That's the reason why I had my treatment locally.

There was no communication when I started radiation. The staff communicated with you across the room. They didn't actually face you face-to-face. On my last day they were trying to work out when my next appointment was going to be. They opened my file and decided it was too hard for them – 'You get in touch with us. You sort it out and get in touch with us'. And that's how I left chemo.

I was to see the breast cancer nurse in chemotherapy. I did see her one day, talking to somebody else about her very ill father. That was it. There was no contact whatsoever.

I still, to this day, after 12 months, don't know what the role of a breast cancer nurse is.

I have a brother who works with the Cancer Council. Without him and his knowledge, I don't know where I would have been. My local treatment team didn't coordinate, changed their minds mid-stream, told me in the beginning I needed radiation therapy and then one of the visiting oncologists in the St Vincent's team decided I didn't need it because there was no evidence to prove it worked! That was in the middle of chemotherapy when I just did not know. I didn't **want** to be put in the position where I had to make those decisions.

I didn't make the decision easily. I searched the Net, I got my brother from the Cancer Council – I got on his back and put him in a pretty awkward position because it's personal. I used the Cancer Hotline many, many times.

It was the use of the Internet and the searching that made me decide to go through with the radiation and chemotherapy treatments. It was the statistics that I was provided with from the Cancer Council that convinced me.

I'm not very happy about the treatment. I have spoken to a lot of people who have had chemotherapy treatment at that regional hospital. Not only chemotherapy but oncology treatment. It's very awkward because you've got people – young, elderly, men, women – who are actually on chemotherapy while you're sitting around waiting to visit oncologists. I just don't think the environment is conducive to a confident treatment. I found that a worry. There's not enough seats. You've got all these people sitting around in a U having chemotherapy. You've got people around the outside with nowhere to sit. It's embarrassing for men having all these women walking past.

The services are different. When you're in a position like this, reassurance that you're going to have the best person for your cancer is really important. If they don't offer that rurally, then I think they must give patients choices. There was **no** contact. I just took myself off to radiation because I didn't know who to speak to, what to speak to. No contact from anybody.

I could have been six feet under and they wouldn't have known. They wouldn't have had a clue. If you don't give people choices to go to Melbourne, bring the services to the

country! Offer them the same services, the same facilities, so people can stay in their own homes.

It would have been very helpful to me to have some follow up. I had one oncologist saying, 'Take your time. Don't rush. Your cognitive responses are very low and your allergy reactions are severe. Don't rush yourself.' But I had another doctor saying, 'I don't know why it's taking you so long.' Conflicting advice.

If only there was somebody on the outside looking in who could say, 'Look, you're fine. Don't worry about it.' It was a concern because I didn't know which way I was going.

The Cancer Council line was terrific, but they're not 24 hours a day, or Saturdays or Sundays.

After my treatment the tiredness and everything just hit me like a ton of bricks. I just went down in a heap. I didn't feel sick by then, I just felt so unwell. Uncoordinated and physically no strength in my arms or legs. I couldn't function. I couldn't drive a car. They pulled a part out of my car so I couldn't drive because they were that worried about it.

I wasn't really conscious of how bad I was, but the family were desperate because I was forgetting meals. I just wasn't coping. Time meant absolutely nothing to me. I didn't care whether I ate or drank.

It took seven months before I could actually say I'm me again. I probably set goals that were too high, so I had to take myself back again. My concentration span was zero so I set myself a task of remembering to go outside with three things each day, and then I progressively built that up to five and went from there – to try and strengthen the memory.

My long-term memory was good. My short-term memory was just terrible. Finally, I built my concentration up by starting with half an hour and extending that, because I wanted to get back to work.

I am remembering names, and I remembered the school code phone number to get out the other day and that was a terrific feat. I was really excited about that!

I think there's a lot of changes that I've had to pick up over 12 months, but I'm back and I'm enjoying it. I love the students.

I have decided that I am not going to put off in life what I want to do. I've had some tasks that I'd put aside for retirement, and in case I don't make it, I've decided I'm going to take them on.

The first one is to research the chemicals in fruit and vegetables, what they are, and work on that. The second thing is to make time for tasks that I haven't been able to do because of time. Pleasurable tasks. Visiting friends and spending time with them. Spending more time with my granddaughter. Just things like that. One of the things I've noticed is that I enjoy doing tasks no matter what they are, whether they be mundane or fun, I'm going to enjoy whatever I do.

Make time. Make time for things for yourself; I think it is very important, really important.

Jane

I was over 55 and I'd been having mammograms every two years. I was called over to BreastScreen for what they call an assessment day because there was a small lump or something they weren't happy with. Or an 'unusual' lump, they said. I had a core biopsy. They were very, very good, the people at BreastScreen.

The results of the biopsy came back negative; it was benign. At that stage I didn't realise that the needle can sometimes miss the mark. When you have a core biopsy you've got to be very careful about those things.

I had a lovely old friend, Norma and she was dying – she had breast cancer. I thought, no, I don't want that lump in the breast, I want it gone.

So I went to my doctor and he said, 'Well, the results are back and it's benign,' and I said, 'I don't care about that. It's a lump in the breast and I want it gone.' So he wrote a referral. He said, 'Who would you like to go and see?' Which was a stupid thing for a doctor to ask because I didn't know anybody.

Because the girls were wonderful at the BreastScreen clinic I thought a surgeon that works there would have to be good. I went to see him. His name was Smith¹. I've since learned he's a very top surgeon.

He couldn't be bothered with a little lump in the breast, but if it had been a real gutsy stomach cancer or something like that, he would have been in there boots and all – that type of fellow. No regard for women at all.

¹ Not his real name.

I didn't know this at the time. The lady at the desk said to me, 'Doctor Smith has got a student doctor in with him today. Would you mind if she was in there?' They asked my permission and I thought, well, people have got to learn. So I went along with that and I said, 'Yes, that's fine.'

Smith came in and introduced me to this girl, and then he went out again. The girl sat there and asked me some stupid questions. I don't know why she was asking them. They were stupid, mundane questions.

I thought, 'God, I'm paying eighty bucks a minute for this' or whatever I was paying. Smith walked back in. He had a cup of tea or coffee in his hand. He said, 'Oh, there's hot water out there if you want to make yourself a cup.' This is to the girl sitting there.

He went behind the desk and just sat and looked at me and said, 'What are you here for?' 'I've got a lump in the breast'. 'Yeah, but it's benign,' he said. 'You've got other lumps. What do you want that one removed for?'

I have a lump on my face and he was obviously looking at that.

I explained to him that Norma was dying of breast cancer and I wanted that lump removed. And he had read the referral letter that my doctor had written, where he wrote, 'She is anxious to have it removed'. I **was** very anxious to have it removed. And he more or less treated me like a dill, a bit of a dope.

'What do you want that removed for? I'll have to go to that much trouble. I'll have to insert a wire with a coil on the end of it...' He made out that it was going to be too much trouble for him to go through this procedure for me.

Then he proceeded to talk to the P-plater (student doctor) beside me. His daughter was pregnant, and she had high blood pressure, and a blood pressure monitor. The little P-plater very quickly pronounced it and wrote it down. He said, 'Oh, I can pronounce it but I can't spell it.'

This was the rapport that was going on between the specialist and the P-plater. And here am I sitting here like a bump on a log.

He examined me, and very arrogantly I thought – he was not very professional. I didn't find him professional at all. He said to the student, 'I'll show you how to examine the axillia. You do it like you would an anus'.

It gets worse, it really does. He puts my arm down and he goes right up under the arm, then tells the girl to do the same. It was a dreadful examination.

Half of me wanted to believe him when he said, 'You don't need to have that removed. What are you worried about?' He could actually see by the look on my face that I wasn't real happy about it so he said to me, 'With breasts like yours, you'll just have to have a mammogram every 12 months'.

I really wasn't happy with that. 'Oh well, if it will make you happy we'll get it done in six months', he said.

I had the mammogram done because I could feel it [the lump] now. It was a bit uncomfortable by this stage.

He said, 'Well, I'm not happy with that. I want a core biopsy done.' He gave me an examination. I felt he was a bit of a male chauvinistic pig. I've never met that type before, because I don't know any pigs like that.

He rang up right there and then and got me into Imaging. When I had the first biopsy done at [another hospital] the technicians were very, very kind and very, very gentle. So going into Imaging locally didn't worry me. I thought, oh well, they'll do the same thing.

It was horrific. It was like being stabbed in the breast eight or nine times. I was in tears by the end of it. I don't think he even put an anaesthetic in there. Or if he did, he didn't wait for it to work.

The results of that biopsy went back to Smith. I was absolutely distraught. I really went to pieces and I went back to the hospital to talk to the counsellors because there was no way known I could go back to Smith. His attitude was very aggressive. It was disgusting. The counsellor, who was a young girl, said, 'Look, we've got a beautiful female doctor here, and I'd like you to see her'.

'What's the point?', I said.

The BreastScreen people at that hospital did get on to her [the doctor], and she phoned me and she said, 'I've got two appointments left on Monday and I'm saving one for you. Would you come in, please?'

There was no way known I was going back to Smith. I was absolutely distraught because I had nowhere to turn. At home here they're all male doctors and they've got a big waiting room –you just can't go in there as distressed as I was. You couldn't look at me. It was horrific. Only because of what he'd done. Had it been a normal type of diagnosis I would have coped all right. But because he was such a heartless mongrel...

I cried from Friday to Monday and then went to see the female doctor. She took me by the shoulders and said, 'Look, I'm going to help you. I'm going out on a limb for you because one doctor will never go against another doctor, but I am going to help you.'

She rang the local Imaging department and got the results. She looked at me and said, 'Well, it is malignant.' I'd cried as much as I was going to cry. Three days crying is enough for anyone. She rang another surgeon, and he saw me in his lunch hour. He was very, very kind.

He sent his secretary to get the tests. While I was in his rooms he got a phone call, and he looked at me and grinned and said, 'The patient has changed her mind.' So I knew what it was all about.

'You're entitled to do that. I'd do the same. If I didn't like someone that fixed my car I could change my garage. So you're allowed to do that with doctors.'

I had a lumpectomy within a week. It was a stage four. It was aggressive. It was large. And it had gone into the lymph nodes. Five were infected. It was 20 millimetres, maybe. He did say it was large.

That all happened that dreadful day. I rang my husband. He said, 'Yes, I've got a message on the answering machine'. He told me that Smith wanted to see me. He rang, himself, personally. He was all concerned then because it was something for him to get his hands on, and he was all ready to go.

I thought, 'Get lost, mate.'

On that dreadful Friday morning when I went back to the BreastScreen people, I said to them, 'Why didn't you tell me about Smith?' The girl said, 'We aren't allowed to.' He was a real pig. They knew. As soon as I mentioned his name, the look that came over that woman's face. I knew that I wasn't wrong in picking him for being a pig.

I said, 'Why didn't you tell me on the day?' and she said, 'We can't.'

What I'd really like to come out of this is that women know that they've got the right to get another opinion. That's a big thing. Governments spend millions and millions advertising every year. They should spend millions telling these doctors to remove the lump if a woman wants a lump removed. It's **your** right. He's **obliged** to do it.

Because you don't get too many second chances.

Marjorie

It certainly does affect your life.

It hangs over me like a black cloud all the time; it does affect you and it affects your kids and your husband.

Bruce [my husband] gets cross. He gets very cross about the whole deal. I accept this is my lot in life. But he just thinks it's so unfair. He says, 'Why is it happening to you?' He lost his mother with breast cancer. I think it probably affected him in some ways a lot more than it affected me.

I noticed when I first came home from hospital. You're not allowed to do any housework – and three people would come but their backs were bad. That sort of nonsense. I still hurt over that, I really do. The whole deal certainly sorted out your friends. People that I thought would stick by me let me down. Badly.

Sometimes you don't realise how close to the surface it is. I don't think I would have ever survived the whole deal without Bruce's sister, Margaret. She'd come out all the time. She was just wonderful. She'd been through it and I really think that's what made the difference.

Afterwards, when I'd finished the chemo and didn't have any hair, some of the cruel remarks were unbelievable. One was from my sister-in-law. It was summer and I was in my own house. I didn't have my hat on. She just walked in and said, 'Oh for God's sake get your hat back on, will you!'. That type of thing. It hurt like you wouldn't believe.

One girl who was supposed to be my very best friend ever said, 'Well I suppose you sit up now and think of all the conversations we've had about it coming back, don't you? Because you know it will.' You really sort your friends out.

I worked with this lady for about 16 years and we were good mates. I rang up and said, 'I've got to have my breast off,' and she said, 'Oh, you're lucky it's only small.' I didn't feel real lucky at the time.

They're still my friends but I have a totally different outlook on them. They let me down when I needed them most. I have drawn back from them. I don't ring them or visit them like I used to. I think, well damn you! I can't be bothered with you any more. My best buddies didn't turn out to be my best buddies when I needed them.

Up until now I haven't cried about it. I've just got a little bit angry about it. As time goes on you just feel disappointment.

I craved for my mum. Just someone that really understood.

My hair was just coming back and I very bravely went up the street without my hat. One old man looked and said, 'You're going to go and get your hair set now, are you?'

I was going to give him a piece of my mind. I just think cancer's so prevalent now that surely if you see someone with hardly any hair, especially a woman, that you'd know that they're coming out from treatment.

You just come home in shreds.

You go there trying to be brave and someone can tip you up real easy.

■ Lil

■ I was actually pregnant at the time.

■ During the latter stages of pregnancy is when I noticed there was something a little bit odd about my right breast.

■ I was a bit emotional; my mother had also had breast cancer. My doctor was away at the time so when I noticed something the thought was, 'Should I mention it to somebody? There could be something wrong, but I'm pregnant, this is my last baby...'

■ I did not mention anything to the doctor just in case there was something there. I wasn't ready to acknowledge that there could be.

■ My primary thought at the time was for my unborn baby. If there was something wrong, I didn't want anything intervening. I wanted to have her or him. I would deal with whatever after.

■ The other two were breastfed, and this was going to be the same. I thought if I could feed her for at least six months I'd be happy with that. I still hadn't been to see anybody. I kept looking in the mirror every now and then, my husband didn't know, nobody else knew, it was only me. Only me and the mirror.

■ Out of the blue, something said in my head, 'Oh you stupid thing. It doesn't have to be a lump,' – because I couldn't feel anything, 'but breast changes.' I went hunting for a book to make sure I was right in what I was thinking, and then I really did frighten myself that I could have breast cancer. I really scared myself. But I wasn't ready yet to go to the doctors.

I wanted to be as strong as I could be and I just wasn't feeling very strong. I was remembering what Mum had been like. I thought I would never be able to be as strong as her.

Then this voice in my head said, 'How stupid. You should at least have been getting a mammogram.' So I thought 'Oh, I'll have to go and see a doctor or something.'

But then Bruce [husband] had already arranged to have some wisdom teeth out. I thought we'll get his all fixed up first. That's one of the things I had in the back of my mind as well, we can't have two things going on in the family at once.

All at once it became quite urgent; I needed to know. I wanted to know for the peace of mind.

I had to go to Imaging for an ultrasound.

I was lying there and after a while he [technician] said, 'You know you're right, there is something there.'

All at once I felt all the things going out of my body and I was thinking, 'Thank God for that. I'm not paranoid'. I hadn't been imagining it. I felt relieved.

My husband and I – he decided he was coming too, we both went to the doctor's – and I was sitting there and he had the results back and he said those words, 'I'm sorry,' and whatever followed, like 'You've got breast cancer.' And I just sat there, nodding my head.

I didn't want to cry. All I was saying to myself, though, was to my husband sitting beside me, 'Don't you dare touch me.' I wasn't saying it out loud, I was saying it under my breath because I knew if he put his hand on my knee or touched me that'd be the end. I've always wanted to be in control.

Gail

My story began in July 2001. I was in the shower and found a lump, and I ignored it for a couple of days. I was having a lot of ear problems and went along to my doctor.

He said, 'Now that's why your ear could be playing up. It's telling us there's something else in your body that's wrong, because in a way it's gland related.'

He popped me on the table and said, 'Yes, there is a lump there, but it could be nothing to worry about. We'll book you in and we'll have your mammogram and ultrasound as soon as we can.'

They found six cysts in the other breast I didn't know I had, and eight in this one where I had the lump.

I could feel it was quite large.

My doctor rang me at the house. 'We'll book you in to the surgeon,' he said. That was when my cancer took over. I call it my journey.

I walked in thinking he was just going to say, 'Well, it's just a little nip and tuck,' or something similar, and the first thing he said, 'Looks like it may mean a mastectomy'. I said, 'I didn't come here for one of those'.

I walked out numb.

My initial reaction was: 'Off! Go! Get rid of it.' The surgeon said, 'Well, to be honest, you only need a lumpectomy. Women are very vain, and if you're going to have to look into the mirror every day of your life and see that something's gone that didn't have to...' and then he said, 'In this day and age we can be fairly accurate.'

So I was very lucky. I was put in by a very good specialist.

So I turned it over to them. I only had to attend. I had such a good medical team, they were my support. They were at the other end of the phone, even my specialist. My strategy was relying on them. Because you're having a whole team opinion you know you're taking the right course then, don't you?

I just found it was wonderful.

I'm sort of a nervy person inside. I think I surprised myself. I faced it. I've got breast cancer. I've got the best of people looking after me. I can only go in the right direction. So I left it to them, and I sort of copped out, I suppose.

I've got a husband who's very good, too. He worries for me. So he worried and I followed.

I was very lucky while I was in hospital. At the Private you're a person. The chemo nurse at the private hospital is just the most delightful person. Once I was having a down day, so they sent her in to see me. And at that stage I didn't have results, but she had. She's the person that always knows ahead of everyone else.

Without her it wouldn't have been as, well, a silly word, *easy*. Because she is such a caring person with a big smile. She doesn't call a shovel a spade, she calls a shovel a shovel. She's so down to earth, and she'll swear here and there just to comfort you.

You'd have to know her to understand it. She's just born for that job. She really was. It was an emotional time, it wasn't morbid or anything like that, it was just really, made easier by her caring, made lighter for us.

It was just two armchairs and a bed. If you weren't really well, you could have the bed. Often there was only myself, but if the others came in the oncology nurse was just such a character she'd say, 'Oh, not you back again!' Instead of dreading going in there, you felt like you were going home to family.

It was just wonderful.

My first chemotherapy felt like I had had an electric shock.

The waves went straight to the end of my hair and my crotch and I just screeched! My husband said, 'Gail, stop it!'

'Well, you didn't go through what just went through me', I said. There was an old lady in there and she had the exact same reaction. She said, 'Oh, I enjoyed that. Can I have another one?'

Radiotherapy was like a five-week holiday. The accommodation was so much like a motel we could just sit back and relax and there was so much support there from the other people in there for treatment as well.

I was very lucky with chemo, I didn't get sick. No vomiting, no diarrhoea.

The hair was gone. But that was the only side-effect. I did feel light headed with, mostly, morning sickness and chronic constipation.

The cancer made me stop and value my life. I'm at war with myself sometimes, that scares me. But I don't let it win. I still, at times, think, 'I've got it, it may come back'.

It's a fear.

I thought I'd won. Lately it's been hitting me a bit. I think I'm in the house too much and I'm worrying too much. Too much time to myself.

I don't feel I'm as serious as I was. I'm finding it's not worth it. Trivial things don't worry me. I feel we're very lucky people.

We're given the chance to get our lives in order, and we appreciate it so much.

I took six months leave from work and I was all set to go back then. I didn't have a lot of hair, and I decided I wasn't going back with a scarf or anything, but I was going back.

Then I realised I couldn't go back because my husband was made redundant. We had both been employed in the same store. Tom had been there for 16 years and it becomes a family, country living, which a lot of people don't realise. I was there eight years.

A lot of people looked on my husband as an uncle. There was a very good rapport.

And it wasn't just Tom's redundancy. When he was made redundant, a lot of the staff hadn't learned to cope with my problem.

I was the first ever to have cancer in the store.

I couldn't even go back there to shop. I wish I could have gone to the front of the shop and said, 'Hi, it's Gail. I'm well. I'm cured and I'm doing well.' But everywhere I went in the shop, every staff member, even customers – because I'd been there that long – they'd be asking, 'How are you?' and 'Where are you up to?' and you'd sort of want to hand out a newsletter.

With some people you're very friendly with there's tears, and there's more tears. They make you cry. I had trouble going into the store.

At work we used to be so flippant with each other. All the flippancy stopped. No more tricking or teasing, just, "Oh, hello. Isn't it a nice a day?" They were stand-offish. It took me a few days to realise why. They didn't know how to approach me, they didn't know what to say.

I went in and gave notice. I found it very, very hard because it was our life for so long. I wasn't able to face the staff with my situation, and no-one knew how to face me with Tom's situation. It was very, very complicated and it was just emotionally too much.

I was home for 22 years as a Mum and house-maker. Being back at work was just everything to me. I was running my own department. It was wonderful. I need that self-esteem back, of having employment.

Since the cancer my self-esteem isn't as good.

When I was first ill, with the surgery and chemo and radiation, I couldn't walk across the road on my own. There was no confidence. I knew health-wise I was right, but just something as silly as crossing a road was too bewildering.

After all my treatments, probably up to two to three months later, I was feeling as flat as flat.

I ran into the oncology nurse. 'I was waiting for you,' she said. 'I couldn't go to you. I had to wait.' I thought there would be follow-up. But that's part of the therapy, they tell you, you've got to reach out after being on the merry-go-round for the surgery, chemo and radiotherapy for four months. All of a sudden there's no appointment and you just feel deserted. She said, 'I knew you would feel this way. Most women do'.

I had all the paperwork of what was available, but you tell yourself you're well, you don't need it. You think, 'I'm just having a down day'.

She sent me to a counsellor.

It was wonderful.

I'd plateau-ed out. The journey had come to a halt. The counsellor gave me so many answers. I saw her three times. When I said to her, 'Do you want me to make another appointment?' she said, 'No, Gail, you've qualified now. You've graduated.'

Life becomes richer. But the answer is to move on, keep busy and enjoy life every day.

Cathy

I had a partial mastectomy and they took the lymph nodes out from under my left arm. They didn't do any radiation, it being so small, and they put me on Tamoxifen.

I was on Tamoxifen for five years and then it was a matter of whether they kept me on it or took me off it. It was like they flipped a coin whether you were kept on it or taken off it. I was taken off it because I had been clear for five years.

About six months after I stopped Tamoxifen the cancer was back. They decided that I was to have a mastectomy and chemotherapy.

I'm really sorry that I didn't have the other breast taken off as well. For some reason I had a real gut feeling that I should really have the other one taken off.

My surgeon said the risks weren't that high, but it was up to me. My daughter said, 'Oh that would be too traumatic, Mum,' Later on I thought, 'Hey, I'm going to be going through this for one, what difference would it make going through it for two?'

As far as I was concerned they'd served their purpose. I'm still very annoyed that I didn't go ahead. I should have.

People just keep telling me to be positive. I said, 'I was positive for six years and it didn't stop it coming back. I'm as positive as you can get. But I also deal in realities. I'm fully aware of what can happen.'

At the moment I've got a lump that has come up in that area and, of course, because there's no breast there you can see it as well as feel it. I asked my doctor about it and he just said, 'Oh you'll just have to keep an eye on that.'

Afterwards I thought, 'I'm not really happy with that.'

I popped in and saw the breast cancer nurse who is an absolute delight. She said, 'Would you mind if I had a look at that lump?' And I said, 'No, that's fine.' And she had a look and she said, 'Get it checked for peace of mind if nothing else'.

I was told by oncology that you do not assume anything. I was tending to assume that it could be scar tissue or something like that, and I thought, no, this might be developing a little bit different to scar tissue.

They tell me that I handled it really excellently.

I was actually feeling a bit proud of myself.

The last time I saw the oncologist he said, 'Now I want you to get back into your normal life.' I just looked at him and said, 'Excuse me, but I have hardly missed a beat through this.'

I got a lot of support from friends, especially these ones that were going through cancer themselves.

They were very, very supportive.

Sometimes they'd come around and sit, you know, they'd give me a couple of days... they'd ring up and talk to me the days that were really bad, where you know you're really not well. Other times they'd pop around.

Even the president of our bone marrow group, the bone marrow people, they kept ringing up all the time. They would remember when I was having chemo and they'd ring up and see how I was, did I want anything done. And they were very good.

Actually they were better than my family.

I still don't think my children fully understand, which I get very, very annoyed with. It's sort of like 'Mum's been through these operations...'. I mean I went through brain surgery back in about 1990, and I've had the two cancer operations.

I think it's a problem that 'Mum's a very strong lady, and she's on her feet, she's moving around, she's doing all this...'. And once I crossed back over the river to home, 'She's there, we're here, she's all right, she's okay.'

One of my boys rang me up last night and it's the first time I've heard from him for a long time. He's been moving house, he's moving into a new house and all this. He had all these excuses, you know, 'We've just got the phone on,' and all this. He said, 'I guess that's no excuse, is it Mum?' I said, 'No, I'm glad you realise that. It is no excuse – there are a lot of telephones around'.

I was getting very, very disappointed with him because he tends to do this.

He ... you know, they're off in their own little world. Whereas the youngest one in Melbourne, he rings me up about once a week. He's very gentle with his mum. He's tall, very tall, he's got curly hair like his mum, and it's so nice when I do see him, you know, and he just wraps his arms around me and gives my hair a little bit of a pull and says, 'Oh, Mum.'

It's lovely, you know, when they're nice and gentle like that.

I said to my daughter yesterday (and she's very hard to talk to) 'What I would like my kids to do is come and sit down with me and say, "Hey Mum, how do you really feel? Would you like to talk about it?" ' I would try to explain my innermost feelings about it.

I have already suggested to a couple of them to learn as much about it as possible.

They just don't think. And I think probably a lot of that may be the fact that I am very independent, a very strong person. I said to my daughter only recently, 'It's amazing what people want me to do'.

The first time the surgeon actually told me that it was cancer – it's just that word 'cancer', and you sort of feel as if you've had a hit in the stomach, you know.

I had learned a bit of meditation and relaxation many years ago which has got me through my operations and I just took a couple of deep breaths and I thought, 'Well it is only small, it will be all right. You can deal with this.'

And that's the way I was all the way through it.

I've known all about Ian Gawler for years. It's funny, I've always said to the kids if I ever got cancer I'd want to go and see Ian...I think he's out of my price range...but I have started to read his book *Peace of Mind* again, and the newsagent has located *You Can Conquer Cancer* by Ian for me.

I talk to myself a fair bit, talk myself out of bad moods and depression.

I'll even go into the bathroom and look myself straight in the eye and say, 'What is it with you? You know you can do this'. You've got to be able to hear it and if there's nobody else around to say it to you, you say it to yourself.

As long as I don't start answering myself I'll be all right.

This time around, to think that it came back and things were a bit more drastic now, I still maintained that fairly calm feeling. But I would be telling big lies if I said that I do not have my moments.

There are so many around me with it, and so many where the prognosis isn't very good. You do get that little touch of fear every now and then and I don't think anybody going through it could deny that you get that.

I do keep very busy. If you let yourself get a little bit down, that's the time when it sort of creeps in. But I try not to.

I've had lymphoedema in this arm since the first op and nothing was ever done about it. When I told my surgeon that my arm was getting bigger, he just said, 'Oh well you can get that after an operation like that'. My doctor gave me a pressure bandage to put on it for a while, and that was that. Anyway, the breast cancer nurse picked up on it. But when I was doing my pre-op stuff, I said to the anaesthetist, 'I've got lymphoedema in that arm. They don't do tests on it,' and she said, 'Oh I don't see any lymphoedema there'.

The breast care nurse understands that we don't get enough information about lymphoedema. She asked me, 'Do you elevate your arm at night?' and I said, 'Oh, I rest it on another pillow.' And she said, 'No, you've got to get it up, above your heart.'

Since I've been doing that...I mean that arm used to wake me up at night, I'd just about be in tears it was so sore, just about begging it to stop...and I get a full night's sleep now with that elevated the way I was shown.

I'm afraid I've become very disillusioned with the medical profession in a lot of ways. They seem to contradict one another, and they contradict themselves. They don't tell you enough.

And then on the other side of the coin they don't listen either.

I just tell myself I'll be all right.

And you'll be all right.



Glenys



My husband had commented a number of times leading up to this, that he felt I had a lump in my breast.



With great reluctance I went to the doctor and he said – to my utter astonishment and dismay – ‘You really need to have that checked out.’



So I had my first ever mammogram.



Then they noticed that something may be a little amiss so they took another lot from different angles. And then I had an ultrasound, and a little while later they came back and said, ‘We really need you to have a needle biopsy.’



And poor Don, my husband, is sitting out in the waiting room wondering what on earth’s going on.



I was probably there for about three hours. I went from sort of go to whoa in the space of the afternoon.



We waited three or four days for the results.



The doctor here at the local surgery said that it had been identified as a malignant tumour and we needed to get on with it straight away. I got the diagnosis on a Monday, the definite diagnosis, and I was in surgery the following Monday.



It was that quick.

The lymph nodes were all clear much to my joy and celebration. But the actual tumour was on the aggressive end of the spectrum. As soon as I finished healing I went onto chemo.

I was devastated by the fact I had to have chemotherapy.

I didn't like the idea at all.

I didn't like the idea of this toxic stuff coursing through my veins, and I'm sure I'm not alone in that.

I did in fact go through a little bit of a research project. I was presented with different forms of chemotherapy. I was recommended to have the most toxic which is the...AC? The red stuff. Tucked away in there somewhere amongst possible side-effects it said that this AC can cause heart problems.

Now, my mother has a heart condition so that's the one I latched on to, and I thought if I'm carrying some sort of genetic predisposition to heart problems I don't want that exacerbated by this particular treatment.

So that caused me a little bit of concern.

What I did was a lot of research on the Internet actually. I found that quite useful in that most of the time, in fact all of the time, it actually reaffirmed what I'd already been told by either the surgeon or the oncologist.

The other thing I did was ring the Cancer Helpline, just once. They suggested getting in touch with someone who'd had this particular treatment and that's in fact what happened. I spoke to someone who now lives in Sydney who had had the AC treatment, and so she was able to say, 'Well it was okay, and I survived'.

I raised these concerns with my oncologist and she said, 'Well there is another option, and it takes six months. It's a combination of tablets and drip and it's not quite as toxic but it's a longer process and you'll be six months before you can start your radiotherapy.'

So I guess I thought about it all and thought, 'Let's go for the three month hit and get it over with.' Then I went on to radiotherapy.

I took five months off work while having surgery and chemotherapy. I worked while I was having radiotherapy - I started back half time. I had been on long service leave and I was able to transfer across to sick leave.

I did pretty much isolate myself while I was having chemotherapy, and that was my choice.

I didn't want to exacerbate anything by catching any flu or colds. I did decide not to go to church for instance, because...among one hundred and twenty people, anything might be floating around. And as the chemo finished, well then I started recirculating a bit more. I don't know whether that was wise or not.

It was a choice that I made.

I did keep as good a health as was possible, given the treatment I was on. When I was feeling better between the doses, I'd potter in the garden, and I knitted my husband a jumper.

So I tried to have little projects on the go that I could have a sense of achievement about even though I wasn't working.

I started working on Sundays again during radiotherapy, so that I was working on the weekend, and I did a few little bits and pieces during the week but I didn't over-extend myself.

But I was able to attend meetings and be involved in planning, and a little bit of pastoral visiting, because I was past the toxic phase by then and felt that my immunity could cope.

You immediately link the word 'cancer' to potential death, I suppose.

And then you go through the surgery and the treatment and you start to realise that maybe they've got everything, that maybe it's physically been dealt with.

And gradually you start to think, well maybe I have got a life after all.

I never felt in any way stigmatised by having cancer. I felt that everyone gets something wrong, and for me it's breast cancer. For my husband it was a kidney stone at one stage. For someone else it's asthma. I mean, we can't expect to sail through life unimpeded by some sort of health issue.

Mind you, I'd been pretty healthy up until this point. In fact I almost prided myself on my health. I was feeling as fit as I had for a long time just before this all happened.

I was disappointed in a way that I felt healthy and I knew that this treatment was going to make me sick to make me better, and there's a bit of an irony in that. But then, as you get out the other end you realise that there is the potential to feel healthy again.

You do hear people say, 'Why me?' and I did say to myself when I heard the statistics, 'Why not me?'

If there's one in eleven people have the potential to have breast cancer, well okay, that's fairly short odds really, and I'm the one.

So I was fairly philosophical about that.

It's an affliction. I don't know why it particularly got to me. I haven't had children, that may be a reason.

It is something you can recover from. Nevertheless, I have to say that one also lives with this shadow hovering over one's head.

In retrospect, there were difficult moments, but I would say that my experience of breast cancer and its treatment has been, on the whole, on the positive side.

I'm grateful for the fact that I've been able to access the services in this region.

We just recognised that there would be a three-hour bite out of every day during radiotherapy.

So we took that into consideration and ordered the rest of our lives around that three-hour gap.

Somehow the news sort of spread through family and friends.

We were actually getting emails and phone calls and notes from all around Australia, from church people that, at some point on our journey, we'd interacted with.

I'm a Christian and I believe in the support and the power of prayer, and to know that there were people upholding me in prayer from all these places.

That was almost tangible in its support.

Maxine

My local doctor said, 'I'm sorry, but it has proved positive.' And I thought, 'What do I do here?' and I started to shed a bit of a tear, because we were going on this trip on the 18th of July. This was the end of June.

The specialist advised me not to delay the operation for the trip, but then he phoned and said, 'If you are in the private on Sunday night, we'll operate on Monday, and we'll have you on that plane.' And he did. We went around the world. We started off in Honolulu.

I'd had a full mastectomy on the right breast. Get rid of it quick, and let me go. The holiday was more important than a bosom.

And there's so many people say, you know, how brave she was going on the trip. Well, we reckon it was the best therapy out. I don't call it bravery, I call it... I just thought I was being dumb. Well, we drove from Vancouver in British Columbia right up the Alaska Highway up through Alaska, and back and around. We did around sixteen thousand Ks. And down through America, then we went across to England, Ireland, and back through Thailand.

I suppose I haven't got much in the way of brains, but I just feel that it hasn't affected me all that much anyway. I've just gone on living. I've got on with my life. I've played golf, I do all my gardening and I just don't worry about it.

The biggest problem is that we're an hour and a half away from the specialists. The travel is tricky. That's about the only thing, and I mean that's not really a problem. Well, we're still capable of driving down ourselves. It's not that you've got to get the community car, or

get one of the kids to take you, or anything like that. I'd rather John drive because I'm not all that confident.

I think I could claim travel assistance, but I'm not real sure. I've not worried about it because we do our shopping when we're down there, anyway.

I was a bit lagging on the prosthesis, but that was perhaps the only stumbling block. But that was my fault. The sister may have mentioned it in the hospital. I mean it's a long time ago now. I'm pretty sure she did mention about prosthesis but I sort of dismissed it. You know, I'm not going to be home so I don't want to know about it, and postponed it. Until I got back. And then I thought I could live without it. And found that I couldn't.

I didn't realise just how heavy it was, and a prosthesis certainly does help the balance.

I contacted the sister when I came back and she gave me every help I needed. I asked her about a prosthesis because I was getting awful back aches. She'd given me a wadding one for the time being and also a cushion for my arm to keep it open for a while, which was very good. And I left that in England because John's relative is a breast cancer nurse over there and she knew nothing about that sort of thing.

You've got to realise, too that [this small town] is a bit different to big centres, because everyone knows everybody, and word does get around. Well everyone knows. What does it matter? Actually I got a lot of support from a lot of people. You know, before you didn't think they were interested in you, and then they'd come forward and offer you support.

I think...well, with me, I just took it in my stride. I think when you've got a large family and that, you just take each catastrophe as it comes and try to weather it out or do the best you can. But I do think people should understand more about it and how it can creep up on you. And another thing is, too, as a little bit of a story, is that I did have HRT, the hormone replacement, which I totally agree with because honestly I was down and at the time...this is many years ago...I had a hysterectomy in '72 and I was sort of a bit drained and short of energy, and it certainly boosted my energy, and it made me feel so much better. I never regretted doing it, but we have a friend in Utah and she had HRT and she's very adamant that's what caused her breast cancer. And yet the lass in England said at the time that there was no proof of the link.

I'm not sorry that I did (take HRT). In fact, there are times now when I feel tired that I wish I still had it!



Lorna

'Oh,' you know, 'it doesn't feel anything to worry about.' He said, 'I wouldn't lose any sleep over that but we will get a little biopsy done'. There was an incident about four years ago where a little lump showed up in the mammogram, same breast, and they said, 'We'll just get in quick and take that one out', and they did everything on it, and it proved to be quite safe. And where I found this lump, I was sure it was where the scar tissue from that was. Now whether it's because the tissue has been cut or whatever, I don't know. Has it grown because it was all disturbed there? Has it grown because of the stress? I don't know.

I hadn't heard anything for about, oh, I suppose ten days, and of course being in the middle of summer and bushfires and everything, well it was the last thing on my mind. Because my surgeon said, 'Don't lose any sleep over it,' and the guy that did the needle thing, he said, 'Oh, I'd be very surprised if that's something'.

As I say, furtherest thing on my mind because the creek had stopped flowing at Christmas time so there were water issues, there were feed issues because of the drought, and then once the fire started it was like... But I was carrying the mobile on me and that's when I got this call to say, 'Could you come in and see me,' from the doctor. And I said, 'Well, look, it's not real convenient to get in at the moment because we're sort of, you know, bushfires all around, and I'm on the fire front, and...' He said, 'Well, I have to give you the news over the mobile because it's important and we need to be doing something about it.' So that sort of hit me a bit.

My brother was near me at the time, which was good, and he comforted me. I've got two brothers, one's here at the farmhouse where I grew up, and the other one's going to shift back into the area, which is great. And my sister's near, so we're all fairly close.

The surgeon briefly explained to me what was going to be done. What I really wasn't told about was how much your right arm can't do. I just wasn't prepared for that. Being ignorant to all that, I didn't realise that it meant this arm's not going to be able to do anything for quite some time.

The bushfires were still raging out of control and one was only three miles north as the crow flies, and I thought, 'If we get a hot north wind while I'm in hospital, I'm going to come home to nothing.' And I had quite a lot of animals still here, and so basically I had to call on as many friends as I could and evacuate as many animals as I could. My goats went down to a friend's place so they had a beaut holiday. The rest were drafted off into five different places and I organised for a cousin to come in and feed what animals were left.

The two days after the surgery...oh...look, I don't know about everyone else, but I just felt like there was a big watermelon stuffed under my arm, and it was just so uncomfortable. Yes, both lots of drainage tubes. And two days after I started to bleed, and I was filling those bottles quicker than they could change them.

So it was a case of major panic, and back into surgery again where they proceeded to cut it all open and try and find out where it was bleeding from. All I recall is them trying to tell me to lay down and someone saying, 'Get nine mls of morphine into her quick,' and someone else saying, 'Oh, there's a couple of doctors walking up. Grab them, we'll need them.' So there were people flying everywhere. Well, they phoned the surgeon who had to make a very fast trip to the hospital, and there were doctors rushing in everywhere. One lady kept pressing to try and stop it from bleeding, but she didn't realise the tube was still in there, and she's bruising it like crazy as you can imagine, so I was just about going through the roof. And then as they were wheeling me up to theatre someone said, 'Oh, we didn't get her to sign anything. Quick shake her awake and get her to sign this.' And I'm going, 'Oh, I can't see what I'm doing.' 'That's all right,' she said, 'just draw a cross.'

But on the emergency bleed, one nurse was screaming to the doctor, she said, 'Oh, don't put the bung in that arm,' and he said, 'Oh, well, we've got to, because we need our back-up.' Because, see, I'd already had the glands out. And he ended up putting it in. You know how you're not supposed to because of the possibility of lymphoedema.

I had all the papers and everything shoved at me too, you know, you'll get lymphoedema, and you're a good candidate, and don't do this with your hand, and don't do that, and put gloves on when you wash dishes and don't dig around in the soil, and I'm thinking, 'God, if all this scare factor works then you'll just be wrapped in cotton wool for the rest of your life.' And it frightened the hell out of me. That frightened me probably more than the surgery.

The day after the emergency bleed, the surgeon came back to tell me that they'd missed part of the lump. 'Oh, we'll give you a couple of weeks break and then do it again.' So I went back for another operation.

By then everyone was getting sick of feeding my animals because I spent most of February in the hospital.

One of the nurses gave me some written literature which said that Tamoxifen can cause a different type of cancer and that, and I'm thinking, 'This is good! Why am I taking it?'

You know, there's a big element of scare in there. They just scare the pants off you, and when you're on your own...I mean I know I've got family and that but it's not the same as having a partner to share it with at the end of the day.

A psychic lady introduced me to meditation, which has been fantastic for me. It's given me an inner peace through all this turmoil. It's been like my whole life was a whirlwind of chaos and, you know, where's it all going and why is this happening to me? All of a sudden there was this little peaceful thing happening in the middle with this meditation. It was just an incredible experience for me and it has helped me so much.

The doctors said, 'Wait a couple of weeks and then go and see the people [at a particular hospital]. I got up there and they made appointments and this and that, and a certain person started on me, 'You have to have chemo...' Well, I locked horns with him severely. He said, 'You have to have such and such,' and I said, 'Well, hang on a minute. I'd like a second opinion,' and he got quite narky about that when I said I wanted a second opinion.

So I went down to Melbourne and saw someone down there. I booked an appointment with her, and I said, 'Okay, look, I don't feel that chemo's going to be good for me,' and she said, 'Well, it won't be,' she said, 'you've had a heart procedure done.' And then when I explained to her how I'm allergic to band-aids or sticky tape or anything like that, she said, 'Oh, well, you will strike problems.' Anyway, I said to her, 'What else can we do instead of those treatments?' And she said, 'Well, because it's a hormone-based cancer,' she said, 'we really need to stop your monthly cycle from happening.'

She said, 'We've got several ways of doing that. They can either zap it with radiation,' which I didn't like the sound of because you can hit other parts down there and it cooks bits and pieces that don't need cooking, or they can surgically take them out, or you can have these Zoladex implants which stop them from functioning.' I had choices.

So I then went back to [that local hospital] again and said, 'Okay, I know what I'm doing. We're going to go ahead with the Zoladex implant. Let's get the radiation under way.'

And so they booked me for the following week, and I had my little appointment ticket for the radiation, and the appointment ticket to see the oncologist, went back the following week and they didn't know anything about the appointment. So that lost another week. I got a little bit annoyed. This is where they knew I'd already locked horns with the specialist over wanting to have a second opinion. I knew there was another oncologist there, and I said, 'Can I see that oncologist rather than him because obviously he and I aren't going to get along on anything'. He phoned me back and said, 'They don't want to take on any more patients.' And I said, 'Well, tough. I'll just stick with seeing him'.

So I saw him and I had six weeks of radiation which, going up there each day on your own, it does get to be a bit of a... It wasn't until the end of the third last treatment that one of my friends from meditation twigged to what was going on and she said, 'Why the hell didn't you tell us you were going up there?' So there were a couple of trips she drove me to. She came in and watched the procedure and she said, 'Oh, I don't know how you can handle this on your own. It's so intimidating'. And I said, 'Well, I've had to face quite a bit on my own.' And even just living out here in the bush on your own, I've had people say, 'How can you handle that?' They said, 'Come night time, I'd be freaking out.' And I said, 'Well, I love it here. I wouldn't be anywhere else.' If I could make it nicer for myself, well that's my aim, to make it a little bit more liveable - even just comforts like a flushing toilet. I don't have that yet but it doesn't worry me, you know.

The one thing that really hit me once I'd had the treatment was that I had to ask people for help. I was very overcome with feelings of 'I'm a burden to people' and that really worried

me but going to the meditation helped me through all those feelings. And I'm expressing myself through my paintings. What I'm painting now is very different to what I used to paint.

For me, the best medicine is doing things here, and the meditation, and the painting. If I focus on the word cancer and everything that goes with it, I start spiralling downhill.

I would be terrified to be in the likes of Melbourne, but out here in the sticks, if I have to face bushfires and whatever, that is my area. I'm at home in that. But Melbourne freaks me out.

A lot of people didn't make it known that you can get the bit of extra financial help. It wasn't until I was really fossicking around in the cupboard wondering how I was going to meet some payments that the breast care nurse said, 'Well, you might be eligible for a bit of...'. And there's a Cancer Council one-off payment, too, where they actually put some money towards something that wasn't medical, which was good. Because I'm finding that after the Zoladex, having to pay for that, financially it has been my biggest burden now. Trying to cope and get back up above water again. Because what really hits is that Medicare is not what it's cracked up to be. That safety net's a load of garbage. You know, they cover some, but... And because of the emergency and that, I've got so many doctors that, 'Oh, well, we were there, too. We were there, too, and where's our payment?' So all up I think there were something like 28 doctors involved in it. Quite a lot of it, I got bills for. Because it wasn't booked. I don't know why. Medicare - once people started talking about safety net, I thought that meant you got a hundred per cent back, but it's not so.

I know personally just trying to go through it on your own was terribly difficult.

Just for someone to hold you at the end of the day and say, 'Hey, you're going to be okay'. But I think I got a lot of that from my dogs, and my animals. Especially the dogs because they're very tuned to my emotions and if ever at any stage I showed any sign of tears, they'd be up and they'd put their little feet on my knee and look at me, you know, like 'Oh, come on, Mum. Don't get upset'.

I've found a new level of happiness and peace in amongst all the storm, I suppose. And if I find the perfect partner to be with me then that will be a bonus. If not, then I've still got my happiness here and my animals, so...



Robyn



I had a sandwich of treatment - three months of chemo, six weeks of radiotherapy, and another three months of chemo. Before this, I'd had a lumpectomy and axillary clearance. It was a very aggressive tumour.



Unfortunately a lump then appeared in my armpit and proved to be cancerous. The cancer was spreading. Further examination showed that I had some lumps in the lymph glands in my neck as well. They couldn't operate on those because it's very close to nerves and spinal cord and stuff, so they don't try.



I had to start weekly chemo again.



It was a while ago, and at the time it all seemed frightfully important and I could reel off all the details, but in the scheme of things, four years later, it's a bit hazy.



I remember going through the breast cancer book - the information book you get when you're in hospital - and there was a list of things which my friend has since spoken to the anti-cancer council about actually. The heading at the top says, 'If you have only two or three of these things in the list, then the chances of a recurrence are small.' And I went through and I had most of them. That was quite daunting. That's all very nice for people who do only have two or three, but then there are going to be a certain number of people there who have a big number on the list. And the book is supposed to be a reassuring little document, and it was a most un-reassuring little document.



The one positive thing was that I was able to have Herceptin. At that time, Herceptin wasn't available on the public list, but my oncologist said he was prepared to lobby my

health fund, and so my health fund paid for the first six months of my Herceptin. And it's \$25,000 worth of Herceptin.

I'm still on it. It's is an inhibitor – it's not going to cure anything, it's not even going to shrink anything, it just inhibits the action of the tumour. It slows the tumour growth.

After I had all my CTs and checks, a tumour was discovered in my liver, so obviously it was time for a change of chemo.

Then I had a sore spot on my back, so we did a bit of a test on that. There was a tumour on my spine.

I had only a one off big zap of radiotherapy, and that's been really good. It seems to have actually stopped that. I thought it was wonderful. An easy, painless way of having treatment. I wish they could do that to all of them, but they can't.

On my last CT scan there were some spots on my lung. But they may or may not be tumours, we're still trying to investigate that.

There was some good news with the scans in that the tumour in my liver had reduced, so the Taxotere was successful there. But my understanding is that cancer can then reinvent itself and change and go off and do something else somewhere else, and you've got to bring in another drug. Something different and eventually I'll run out of options, but, well, the oncologist said that there's about three hundred more up his sleeve!

My initial reaction was that most people I knew recovered from breast cancer, so it didn't actually affect me very much at all.

My sister had had it the year before. She had a recovery and no recurrence. I just thought, or assumed, everybody got better from breast cancer. So it was really some inconvenience that I had to get through. I had to do the treatment with the minimum of impact on my family, and it never really occurred to me that it would actually come back. I spent one day thinking...I remember Linda McCartney died from breast cancer and I remember thinking, 'Oh, what would happen if that happened?' And that thought occupied me for one day.

Just didn't occur to me that it would be back. However, since then, obviously when it comes back...um...

Cancer's a funny thing. You pick up bits of information along the way that nobody is ever going to tell you, and you just hear bits and you finally put the whole bits together.

One piece of information was from the radiotherapy people, and this was when I hadn't had advanced breast cancer. One of the doctors said to me, 'If someone's got advanced...once it's spread or something, then we treat people completely differently. We have to look at conserving life and quality of life because we aren't going to cure them'. And at that stage that didn't affect me, but then, of course, when you are in that situation you think back to that. I guess what I'm saying is that once it had moved I knew that you couldn't bring it back. You know, it couldn't be stopped.

When I discussed it with my oncologist, he said, 'Well, look, I have heard of people on Herceptin in America for 10 years'. So I was hoping I was in that category.

The thing is, once you actually realise that you might not be an 80-year-old grandmother in a nursing home, you do completely reprioritise your life. Well, just things that, you know, you put off...like you imagine you will do one day, you suddenly decide you have to do. I mean it can be very liberating, I'm not going to put up with shit any more. I'm not everybody's doormat, I'm not a dog's body. I'm not going to be around all that long. I'm going to not be bothered with activities that I don't need. The family are very important and I'll put time in with them. Family becomes more important because you realise you're

not going to have great amounts of time with them. And you very quickly weed out what you don't want, and that's actually a good thing. You also don't want to put up with pretences, and lots of people that you tolerated before you won't put time into, and that's a good aspect of it.

I've become a counselling junkie.

One of the first things I thought was that I was going to find out what services for counselling were available, because it's very stressing. So a counsellor lady came from the Shire, and because I'd requested some house help when I was having chemo I was actually enrolled with them with their palliative care. So I was able to access her, and she came to the house. I thought she came from the Shire, but in the end it turned out that she actually was funded by palliative care.

So I had some counselling and that was good.

In fact, I don't know how people survive without it. Because I do see people even my age who won't really discuss it with anyone. I mean not the...you know, not the real facing up to the fact that you're going to die, in any sort of a way. And I don't know how they cope.

At the same time as I finished my first lot of treatment, my daughter developed bi-polar, and I said to people, 'Look, having cancer's a piece of cake compared to coping with having your child with a mental illness'. And she was very sick. She still is very sick. She had several long hospitalisations. It was extremely traumatic. And my 16-year-old daughter was at home at the time and she was really traumatised by it, too, and actually went on to develop an anxiety disorder because of it.

There's not very much around for people with advanced breast cancer. Heaps for people with breast cancer, that's all very supportive and nice. But once you get advanced breast cancer, there's not much happening. And I'd rung the Anti-Cancer Council a couple of times and said, 'Are there any support groups for people with advanced breast cancer?' Yes, there was. They meet once a month in the city. They could put me in touch with someone, but the impression I got was that 'Think carefully about whether you want to get involved because people die, and people leave, and you may not want to know that a year down the track you're going to have tumours on your spine, liver, and lungs, and brain. Because that's what happens. So it's hard, and we don't know whether to recommend it or not, and we certainly don't promote it.'

I felt like I lived in a different world to a lot of other people at times. There are probably a lot of people around who are facing up to their early death, but nobody talks about it. People will see you in the street, and they know I'm having treatment, and one of the good things, one of the main supporting things is living in a small town and having most of the town keeping an eye on how you're going. And people may find that intimidating, but it's actually terribly supportive to me.

But people actually don't want to hear that you're sick, they want to hear that you're getting better.

So people will enquire and ring and speak to you, and 'How are you? Oh, you're looking well,' and it really isn't appropriate to tell them, 'Well, I'm not actually'. So, even though I said before I'm not very good with people who pretend, you do put up a pretence.

You don't even want to talk about the same things. You don't have a future. You actually face up to the fact that whatever you thought about as your future isn't going to happen, so you don't have a future. And you don't realise how much of your time you spend just thinking ahead. 'Well, one day I might go and see that film, or I might go to Italy one day. I will go to Ayers Rock one day. I will...' You know?

You spend a lot of time subconsciously planning what you're going to do in the next 20 years. And it even includes 'Well, I guess one day my daughter will get married. Wouldn't it be fun if it was in the garden?' I didn't realise until I faced up the fact that I didn't have a future, how that then removes you very much from people who are all the time talking about things that they're doing in the future.

So you also have this big unmentionable thing that you mustn't talk about. And it is very isolating, and it becomes very lonely.

I had a friend who had ovarian cancer. She was very up-front about the fact that she was going to die, and we used to have daily contact. You had someone on the road with you. But since she's gone, there isn't anyone on the road.

She would tell me what sort of coffin she was planning, and she'd found this person who hand-painted coffins and she was having horses all over hers. The really practical stuff of what was going to happen.

That's a big black, misty hole, when there's no-one there to talk with ...

I remember when I first had the recurrence diagnosed, because there were three things that I had, three bargains. I wanted first of all, I wanted my parents to die before me. Then I wanted my youngest daughter to have finished school. And I wanted my oldest daughter to have had her first baby. So yes, you do bargain. And then, of course, you have to give those things away. I mean, probably none of those are going to happen now. I actually faced up to my own anger and grief at the situation, and the loss of future.

I was always interested in photography so I booked myself in for a photography workshop for a weekend in June. I'd never been to Sydney, so we were going to go for a weekend in Sydney in July. In August, what happened in August?... Yes, we went. Well, it was something that I was going to do and I actually did it. Another time it was going to *Madame Butterfly* at the opera. I can't remember what we did in August, but September we took a beach house with my sister for a couple of days down at Apollo Bay, and all the girls came down. And this month it's the French family coming.

So it's planning something not too far ahead, so that you can't suddenly be too sick to do it. Well that's it, because you don't realise that half the fun of going to Italy is the year before when you spend imagining it. When you've got nothing nice to be planning for, life is fairly bleak. And look, it doesn't even have to be big things. One time, too, I thought, 'I just want to have a picnic with X, Y and Z, because I really like their company, and a picnic would be lovely'. It doesn't have to be expensive.

I said to my husband, 'There's another way I want to do this', because it was going to be my super that was paying for it. 'I'd rather you took some time off and we did some things at home that we always thought we'd do when you had time.' So he actually took off about five months, and we did some little trips. We spent a lot of time together and we put in a little work around the house. That was one of the things I was really cross about. I was never going to get the garden cleaned up. I was thinking, 'I'll never see it now. Yes, finish off some projects and just spend some time. So that was nice.

He's gone back to work now, though. But that's all right, and I mean, you need to eat. And he needs to keep his life, too.

Dee

I had a two-month old baby when I was rushed to Accident and Emergency where they diagnosed renal colic. I was in hospital overnight in order to get my pain under control.

A week or so after that I still was not feeling right. My GP , wanted to do some more investigations. It was at this stage that I asked her about my...it wasn't actually a breast lump that I felt, it was just more of a thickening of tissue. It just didn't feel right.

I had felt the change in my breast about six weeks prior to actually saying something. It was early days in my breast feeding and I thought it was just normal changes in my breast.

My GP was great. Although she could not feel the area, she felt my concern was enough to have it investigated. So my GP sent me off for a mammogram, a very unpleasant experience with lactating breasts!

Following the mammogram, I had an ultrasound which confirmed that there was something actually there. My GP rang me at home and said she wanted to see me and she also wanted me to make an appointment to see one of the local surgeons.

Being a nurse, I knew the surgeon I wanted.

I rang the surgeon but was unable to speak to him. The earliest appointment was two weeks away which was too long for me to wait. I asked a girlfriend who I had worked with

at the Private to leave a note in his pigeon hole, and he rang me back. He said that he would see me immediately. I think it was only a matter of a couple of days.

When I saw the surgeon, he could not feel the thickening either so he did not want to do a needle biopsy, he wanted a core biopsy. I had actually found another lump like a pea under the skin. He could feel that one.

I continued to breast feed my baby until I found out what it actually was.

We could not get an appointment for a core biopsy for about a fortnight and I was not happy to wait that long. So again, I rang a girlfriend in radiology and she organised everyone to be there to do the biopsy that week. It was a positive diagnosis of cancer.

I can remember being at work that Monday. When I arrived home, there was a message on my machine from the surgeon to give him a ring. I was home by myself when I returned the call. The surgeon read the whole histology report over the phone. He was reading it out to me because he knew that I would understand it.

It didn't sound too great. He then said, 'We need to get the lumps out and have a good look at them'.

In the next week, I had a lumpectomy.

The surgeon said to me, 'Just continue breast feeding'. I can remember going home that night and trying to feed my baby through the night. It was very painful - my breasts were still engorged because Sophie was feeding every three hours.

I can remember the surgeon had done the dressing without, obviously, giving it much thought, as he had just left my nipple sticking out of all this thick bandaging. I thought how am I going to get Sophie to attach with all this bandage in the way? So I can remember getting the scissors and cutting the bandaging away with my Mum saying, 'You can't cut that! Don't touch it'. But I knew it would be fine so I cut a bigger hole so that Sophie could actually attach to my breast.

I can remember sitting there in the dark crying as I was trying to feed her - it was very painful, but I had to persist.

The surgeon and the oncologist decided that the best action would be to start chemotherapy straight away and leave the major surgery for a little while. They felt that if I had the surgery it would be quite some time before I could commence the chemotherapy because of the healing aspect. So I actually started quite an aggressive regime of chemo which was not too bad probably for the first couple, but from there on it became fairly debilitating.

In addition to the chemotherapy infusions every three weeks, I would have a 24-hour pump on, which I used to wear around my waist, that would give me continuous chemotherapy over a 24-hour period.

It was decided that I would have to have some sort of line in and they tried to put lines in my arms.

The first attempt punctured my artery so I would not let them have another go. The breast care nurse came around as she knew that I was having the procedure. She found me in this dribbling mess. I was in tears, covered in blood, and she agreed this was enough.

A couple of days later they tried again in the other arm, and one of the anaesthetists did this attempt in theatre. The first attempt did not work, and the second only lasted 24 hours

before it became infected, so I ended up having antibiotics and had to have the line removed.

The day before I was to start my chemo they decided they'd put a Hickman's line in. It is a line that is inserted under the clavicle and into the artery that's going into the heart. It stays there permanently and has to be dressed every week. There is a high risk of infection and as it is close to the heart it is important to care for it.

These were all added pressures.

I had to stop breast feeding when I had my bone scan. I was going to have to wean anyway with the chemo so the decision was made for me. I had no realistic choice. Because Sophie was still feeding every three hours and I had healing wounds on my breast, I had to avoid a milk abscess.

I did a lot of ringing and talking with lactation consultants in Melbourne at the Women's and at Monash ... trying to get information on how I was going to wean without having an abscess. From all the information I had gathered, I decided to take a one-off tablet that they recommended. It did not work terribly well. I still had engorgement and had to use cold packs and express for comfort only so I could reduce and eventually cease my milk production.

I think this time was the worst part of my cancer diagnosis - actually having to give up breast feeding. I had breast fed my other girls and I was such a keen breast feeder. I suppose I was a bit angry at this stage because I had seen so many people just give up so easily, and I didn't have a choice. That choice wasn't mine.

I recall when I was at university and doing lectures about body image and people who had to lose body parts. I can vividly remember the lecture we did on breast cancer and on losing a breast, and what that meant to women and the impact on their body image. I can so vividly remember that.

I made a decision that day that if that ever happened to me that I would be okay with having a mastectomy. So my decision to have a mastectomy was not a hard decision for me.

The day I actually found out that the diagnosis was positive from the surgeon, the breast care nurse met my husband and I. It was very, very helpful because the surgeon had written and described all our options on paper and we had made a decision on which way we would go. It was just so confusing. It was good to talk to someone else. Someone with time. Andrew and I knew that the surgeon squeezed us into an appointment and we were very conscious of that, whereas we got the feeling that she was there to talk – no time limit.

So I commenced chemotherapy. I think every session of chemotherapy that I had was just awful, seeing that fluid go through. I just hated the look of it. It made you feel unusual. You did not feel right. You did not feel yourself. It is hard to explain.

The surgeon wanted to do a mastectomy and an axillary clearance, and at that stage my husband and I had been talking about having the other breast taken off as well. I think that was a decision I had made immediately when I first knew of my diagnosis.

But it took a little bit of talking to convince the surgeon that this was what I wanted. I suppose his issues were that I was young and that there was no need to take the other breast but he also said, 'That might be something that had to happen down the track'. And I just thought, I don't want to have to be in hospital unwell forever, I just want to get this over and done with and then deal with chemo and deal with whatever comes up. Finally he agreed to it. I would have a bilateral mastectomy.

My other issue, being a public patient, was who was going to do the surgery. Especially knowing that in public hospitals you often will get the registrar, and you don't know their level of experience.

I pleaded with my surgeon that he do the procedure. He assured me that he would. And he did. That made me feel a lot better because I had been given names of surgeons in Melbourne and surgeons that I knew of prior who that were very good in the area, but I opted for a local surgeon because I knew him personally, and I trusted him. The other thing was that I was close to my friends and my family and that was important to me at this time.

We needed help at home, and we did consider my husband leaving work and just spending 12 months at home and helping me and the girls, but financially we would have struggled with our commitments.

So Mum offered to move in. And she's basically reared Sophie. Mum had to go through putting her on the bottle, and that was a big thing. It took her two days before she would actually accept it. She was pretty stubborn.

So basically Mum just took over. She did everything. She did my housework, my cooking, my childcare, she got up through the night, she did not expect me to do a thing. She did not expect Andrew to do extra either. She was fantastic.

There was nothing out there to support her. She came to help us and we were trying to get her a Carers' Allowance. We applied for that but she was ineligible. She wasn't my carer, she was Sophie's carer, so they wouldn't give it to her. I actually went in to Centrelink several times and tried to get them to understand our unique situation, and they just could not understand. They just would not budge from their criteria.

Yet she was there.

She wasn't looking after me because I could shower myself and I could feed myself, but I had a three-month old child, a two year old child and a four year old child that I couldn't care for, and they just had no concept of that, so that was frustrating.

There was just no help there for young women with young children.

One service that we found helpful was our local childcare centre, where my girls were going at the time of my diagnosis. The office manager rang me and told me that there was assistance if I wanted to put my three girls into childcare full-time for 13 weeks. I did not want to do that. I did not want to have my girls in childcare full-time, especially Sophie, she was too little for that. I did put the girls into childcare one day a week, a full day just to give Mum a break, except for Sophie. Mum was not happy to leave Sophie either, she was so attached to her. We also tried post-acute care to see if we could get some childcare at home, and we could not because they needed to get a trained person.

The other experience which I found confronting was being treated by men. The day I had my mapping for radiation therapy, I felt so awkward lying there. I had three young men actually, doing the mapping. There was not one female. I found that very, very daunting as I was their age. I didn't find the radiation part so bad because there always seemed to be a female. If there was a male, there'd be a female as well. I think they need to be aware of that. I mean, not just because I'm a young person. I think an older person would feel exactly the same - uncomfortable.

I had to see my oncologist that day before the mapping...and he actually told me that I did not have a very good prognosis.

My tumour was quite small but it was very aggressive, and it had infiltrated into my blood vessels. I had seven of fifteen lymph nodes affected.

It certainly stopped my life in the sense that the goals that I had and what I had envisaged for the future has certainly changed dramatically. With lots of things.

I had career aspirations of where I wanted to be and those certainly won't be happening now, for probably a couple of reasons. The first reason being that I don't know whether I can handle that stress and pressure. I was under a lot of stress. I never left my work at work. So I just don't think that's going to be very good for me at the moment, or maybe ever. So I've been trying to think of something else I can do.

Secondly, my children are so small that I think, well it will be good just to stay home and spend that time with them.

Now I don't live too far into the future. It's more about living short-term, I suppose, and trying to forget about what we might be able to do next year or the year after. It's about what we are doing today and tomorrow.

It has certainly changed my life and at this stage I can not say that it has changed my life for the positive, because I'd love to have my life how it used to be.

I spoke to a grief counsellor who made such a difference to me. When I was first diagnosed, I thought I had breast cancer and I was going to die. The grief counsellor worked through the reality of it. I was not prepared to do anything at home, I did not want to plant trees, I didn't want to do anything because I thought, what's the point of it? And I suppose she changed my way of thinking.

I was having nightmares. I would write all night in my imagination. I'd be writing letters all night and I wouldn't be sleeping, or I'd wake up through the middle of the night and think, 'I've got to write that down,' mainly letters to my children. I wanted to write like a little speech that someone would read at my funeral. And at my children's twenty-firsts or their weddings. That consumed my whole night time and consequently I was just exhausted through the day.

I often think about my funeral, especially when just recently I've been to a few funerals of friends' parents. So I sit there and I analyse the whole funeral and think, 'Now I wouldn't do that,' 'Now I would do that,' 'Now that sounds nice.' and I just... I'm sort of planning, yes. I hear songs on the radio and I think, 'I must remember that song.' I mean, how ridiculous is it?

The counsellor just took away the scariness of dying - talking about it in a lighter way and she spoke to my children.

I've been interested in the spiritual side, ... and I've been right into alternative options and diet changes. I have been seeing a naturopath who does Mora therapy. And I also do emotional release kinesiology. I do yoga twice a week and I go away to an ashram twice a year.

We've changed to chemical free products. We try to keep the chemicals down, and we're putting in a veggie garden which we're weeding at the moment without Round-up, which is a bit of a challenge!

I have learned a lot through a support group. We go away once a year for a weekend and our facilitator does a lot of emotional work and meditation. We talk about what makes us angry. Some ladies have been diagnosed with secondaries. We do a lot of brainstorming and writing and drawing and walking.

I find a real connection with the facilitator. She was diagnosed with breast cancer 17 years ago. She was very young at that stage, and now she runs the group. She is an inspiration. She talks about how she changed her life. She's almost a mirror image of myself.



Julie

My youngest son bumped me one night on my right side and when my elbow hit my breast I found a lump. Now, prior to that my mother was diagnosed with breast cancer at 60 and died at 67, and we had known that her grandmother had also died from breast cancer. So they advised me that every five years I was to have a mammogram. Because I was only young. I was 31 at the time. And yearly checks with my doctor, and do my regular breast checks after my period, which I did.

I had a check that previous year by the doctor and he said everything was fine. He just said, 'You're very lumpy. You're an old lumpy old cow', and I thought... it was more than that.

Three years ago, and five months before finding the lump, I went onto a liver trial because I had chronic hepatitis C. I was due down to hospital in Melbourne for a check-up for my liver trial, and I said, 'I found a lump'. And so my nurse set up a system to go straight into the breast screening clinic at the same hospital. Within an hour I'd had the mammogram, a lump biopsy, and an ultrasound. After this, I went to the counsellor and the doctor came in, and said that it was breast cancer, and that the lump was about a two by four lump which was quite large, and that they suggested a lumpectomy. I said, 'No, I want a mastectomy, and I'd prefer it if you took both because I've had a history of relatives that have had breast cancer, and I want both off'. They saw that as quite radical, and that I needed time to think it through.

So they gave me the information, I had some counselling, then I came home. I got my ex-husband to pick me up because I couldn't drive, I was in a state of shock. He worked in Melbourne at the time and he drove me home. It was like being in a mist, a storm. There were mixed emotions.

There were a lot of decisions to make, but I knew what I wanted to do because I'd seen what my Mum had gone through. I'd had four years to think about if it came my way, what I would do, and I'd already made my mind up I'd have a mastectomy. Then friends got on the Internet, and my ex-husband got on the Internet, and found out more stuff, and you just don't want to read the information at the time.

The next week we went down to Melbourne. I took my ex-husband with me and my sister-in-law, who I'm very close to, and she took a tape recorder because I figured that I'd forget half the stuff. They didn't mind me taping the information.

At that time they were very, very certain that I just needed a lumpectomy, and I said no. I still wanted two off, but in the end I said, 'All right, take the right one off.' My right breast at that time was so painful.

And my ex-husband said, 'Well, why don't you have a rebuild at the same time?' and I said, 'Well, I probably don't want to do that.' Some plastic surgeons came in and said it was possible, and they laid it out. It sounded really good at the time, being young. I thought, 'Well, it sounds okay.' I think I did it just so that it was okay with my ex-husband, really, now I look back.

After the test results they said, 'We did the right thing,' and I thought, 'Well, I have done the right thing but I had to push for it.' Because if I'd had the lumpectomy I would have had to go straight back in and had the rest removed.

The rebuild went well for a month. [But some time later, I developed an abscess under the reconstructed breast] that was nearly as big as the breast put on. The only thing that was keeping it up was really the abscess, so, once it was drained, the breast just swung under my arm. And they sort of said...oh, well...you know...they sort of didn't say anything.

I had a holiday to get ready for the chemo. There was a hiccup with having chemo because of hepatitis C. All up I'd had - with chemo and the liver trial - 13 months of heavy drugs.

There were basically two surgeries and that triggered the lymphoedema. So with that then you have to wear a bandage which I have to buy every three years at one hundred and eighty dollars - and that's a bit of a drain, being in my position.

I've been through a lot of stress - the year 2001 - the year after I had the breast cancer diagnosed, operation, rebuild, the infection. I also had marriage problems, had deaths in the family and had deep concerns for my children.

You have to be a well mother to be a good Mum. You have to think of yourself so you become a priority. It's not being selfish, it's being kind to yourself. It's what's best for you and what's best for the family.

I really think there needs to be significant help for young women with breast cancer because they often have a young family. There's a great hole in the network for young women with breast cancer. There needs to be a support system there, and there's not. I had to seek out the Young Ones [support group] in Melbourne, and I can't go down to their meetings but I get their newsletter.

Younger women have got bigger issues, for Pete's sake. Some of them can't ever have children again. It's a bigger issue than a woman that's already gone through menopause

and has grandchildren. A young woman mightn't even see her grandchildren. She's still got young children. There's a big need there that's not being met, and that's what I see.

I really think there also needs to be something done for the children of people that suffer cancer and a lot of the young mothers that have breast cancer agree. Their kids do suffer the same symptoms as mine. They're angry, they're aggressive, their mood changes, they get upset, they think you're going to die.

Because I've got three children I could see their need and their pain. When I could see my children falling apart, I wanted family counselling for the whole family. It was too big a problem. You know, they can't cope. Because they're not ADHD, there's not a category to put them in. So there needs to be that for the base of the family. My marriage might still be together if we went and had counselling. I think a lot of marriages do fail in this situation.

Being one whose marriage has failed, I have to deal with the fact I'm only young. Do I live the rest of my life alone without a partner? Or do I have a partner and I've got to face the issue of telling that person I don't have breasts.

After breast cancer surgery, your body image isn't good and you'd look at yourself, you'd look at the rebuild and think, 'Oh, that's disgusting,' when you'd look in the mirror. And that's just a part of a normal day, you know? You'd get dressed and there you are. And everyone, when you've got clothes on, would say, 'You look so wonderfully well. You look healthy'. And you know, they say all these wonderful things but within you you're saying, 'You haven't got any idea of what the hell's going on in here and you don't know what this body's been through.'

Women do make the choice of either having a rebuild or having no breasts. And because I've done both, I'm happier with no breasts. There's a bit more liberty, I think. Boobless and fancy free. But I hate the fact that I can't go into a normal shop and buy a bra. And I look at those nice bras and I think, why can't they just have something a little bit easier that I can put my future prosthesis in? Why do I have to stick to these ones that look like my mother wore?

A year after the chemo, I thought, 'All right, then, I'm going to get genetically tested.' It took six months for all the test results to come back, which said I was genetically [at risk of] ovarian and breast cancer. I found out that not only did my mother, my grandmother and my great-grandmother, but her mother also died from breast cancer. And the oncologist said, 'We highly recommend you have your body parts removed', because of my history.

So those tissues, for the rest of their duration, will be researched. My family and cousins, aunts, uncles, can go in and get freely tested. Now my children and their children can be tested freely and helped. If there's a cure for genetics, they are a priority to get the needle before anyone else.

And that's the reason I did that.

I've had a lot of flak about even getting genetically tested, by family saying, 'Well, we really don't want to know'. But I've provided that for the family.

When I was diagnosed with breast cancer I didn't want to read anything about people who die - the statistics. We already know a large majority of women die. So I thought I want to read about someone who lived. Professor Jane Plant was a doctor who had breast cancer five times and studied diets.

I've been very health conscious because of my liver anyway. Now, I've based my diet around no dairy products, and only a little red meat.

I believe the bedside manner of doctors needs to change for women. When I had my first operation, the amount of specialists that came and viewed my body ... I felt like a lamb that was laid out to the slaughter. And when they told me, 'Oh, look, there's ten men coming to look at you', I said, 'No. I think I'll get up'. But I couldn't. These are specialists. I thought it was humiliating.

You just don't do what they want you to do. I saw Mum walked all over, and she thought the doctors were Gods, and they're not. This is my body, this is my life, and this is how I want to live, and they have to work around me as a person. Yes, you have to be assertive otherwise you could be dead, so to speak.

I've only had a few doctors who were sensitive. The others just stand at the end of the bed and say, 'Well that went well. Didn't I do a good job?' It's got to change. I think that every student doctor that comes my way, I'd tell them about that one. Always consider the patient is a person, not a number.

Researcher's concluding comments

My work to date on the project has been confronting at times. There certainly have been occasions where I've cried along with women, and I've known exactly what they're feeling, exactly what they're upset about, and I've joined with them. The majority of times I've just felt privileged to be able to listen to their very intimate stories, and I felt very close to them. I ensured that all of them knew that I had experienced breast cancer, and there's something about knowing that, I think, that has made them feel close to me and they have all been very open in the telling of their stories to me. And some of the stories have been very positive. I mean they've all been inspiring, but some stories have been happier than others, some have been very sad and, you know, it's hard when you're interviewing women with advanced breast cancer who know that they are actually dying.

But even those stories have been inspirational as well especially when you look at the strength of these women. And I have really appreciated their willingness and their openness to be involved in the project work. Occasionally, not often, there have been stories that have made me feel very angry and this was around the fact that I thought someone had been treated very unfairly. One particular woman, for example, had to assert herself quite strongly to get the service that she wanted, and she felt very dissatisfied with some of the services that she'd received. When I heard her tell her story I did feel quite angry afterwards and thought well I hope we can improve upon things there.

On the other hand, I've often felt heartened by women's positive experiences. Interviewing the women has been a really fascinating thing to do. I've interviewed most women in their own homes and that's been very interesting, too. It's brought me to all sorts of different places in the region that I never would have gone to before, and some in quite isolated bush settings, and across sand dunes, and across paddocks, and through pot holes....

I think it was something very special...to be a researcher and be able to share intimacy with the women. I didn't retell my story until they'd already given me their story, and even then it was only when they requested it of me. However, through the course of the interviews, if women expressed a particular emotion that I might have also felt, I have told them so they've known throughout the interview that I have at times, felt in a similar way to them.

I found that most of the women were very interested to hear about my experience and many of the women have actually contacted me to check on my progress. I've had calls from many of the women to thank me for their own copy of their story, to tell me how much of a positive experience it's been for them and to ask about my welfare. I feel indebted to the women who have told us their stories and we sincerely thank them for sharing their innermost thoughts with us.

Angela verde

