

# **Dangerous Journey**

**Living with cancer, surviving cancer: a personal memoir**

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Dangerous Journey

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Note: Some of the personal names in this book have been changed to protect identities.

**THE JOURNEY BEGINS**

Like most people, I feared cancer. Like most people, I called it 'the Big C', or something similar. Like most people, I pitied anyone who had cancer, thinking that it was like living in the shadow of death. And, like most people, I never really believed that cancer could strike at me. Perhaps I developed a sense of invulnerability when I survived an early scare at the age of 30 years after I found lumps in both of my breasts. The lumps were not only worrying but also very painful so I made an urgent appointment with my GP, who sent me off for a mammogram. To my relief, the scare turned out to be a false alarm: the problem was that my breast glands were retaining water, and a simple course of tablets soon cured me.

However, something good came of it because from then onwards I had a mammogram regularly. In a sense, I was hedging my bets: on the one hand, I believed that it wouldn't happen to me; on the other hand, I acknowledged that cancer was an ever-present possibility, depending on how the dice rolled. Still, nothing prepared me for my journey with cancer. Probably nothing can ever prepare anyone for such a journey.

My journey with cancer began during the first quarter of 2009 when I decided that it was time for my annual check up. My husband, Brian, and I migrated to Australia during mid-2007, and I was still not properly acquainted with the workings of the health system but, after asking around, I found that I could have the mammogram done free of charge as I was over 60 years of age. In fact, I felt a little foolish when I learned that the service that I required was located right across the road from our house! So I set the wheels in motion. First, I went for my regular check-up with my GP and was happy when no problems were detected. Next, I booked a mammogram at the clinic and a week later I was being probed and pushed by the radiographer, who said that it could take up to six weeks before the results were known. No problem -- I was quite happy to wait as I was confident that I was in the clear.

During this time, a close friend, Eloise, also went for her mammogram and was cleared within three weeks. However, I still hadn't got my result. Around about then, the first little cloud of doubt crossed my mind when I began to wonder why my results were taking so long. Then, after about seven weeks, I had the answer when I got a phone call to say that I needed to report to the clinic in Canberra for further tests. However, in spite of niggling doubts, I still wasn't particularly concerned, as I have no family history of cancer. I presumed that it would turn out to be no more than a small abnormality, as was the case many years earlier.

Eloise drove with me to Canberra, and we chatted happily during the trip. In fact, I never stopped thinking, 'It won't happen to me. There won't be a problem. If there is something, it has to be benign.' The staff members at the clinic were friendly and hospitable; in fact, they even provided tea and sandwiches for the patients and their companions. After a bit of a wait, I was subjected to another mammogram. Then there was a long wait before I had to undergo ultrasound procedure. Now, at last, I found out the reason for all the fuss and bother, when I was shown an image of the offending tumour.

I was told that the doctor would see me after lunch, so I got dressed, joined my patiently-waiting friend, and took her to lunch at a restaurant near the clinic. By this time, my senses were so much on the alert that I can even remember that we both ordered a soup of squash, pumpkin, cumin and orange, which was delicious.

Of course, by now I was beginning to worry. After 65 years, had my luck finally run out? Back at the clinic, with the doctor and two nurses in attendance, there was another ultrasound procedure followed by a biopsy. Now I was nervous and jumpy, and my state of

mind was exacerbated when they told me what they were going to do. In fact, the description was almost as bad as the procedure itself! They began by injecting a pain-killer and then did the first biopsy, which hurt so much that I jumped with both surprise and pain. That called for another pain killing injection. Next, they took three samples. Even at this stage, because the cancer was funnel-shaped, no one could locate a lump by manual inspection of my breasts.

I returned to the waiting room and after a while I was told that the results would only be available five days later, because the Easter weekend intervened. How would I like to be informed? I asked if they could tell me telephonically. No, I was told, I would have to report to the clinic in person or, alternatively, they could inform my local doctor of the results and he could let me know. I preferred to be told directly and sighed mentally, because that meant another round trip of 200 kilometres. Then I made an appointment for 2.30 p.m. on the Tuesday after the Easter weekend. The staff advised me to try not to worry and to enjoy the long weekend. Not worry? That would be difficult, because by this time my mood had changed and I was sure that I had breast cancer.

While we were driving back home, Brian called me on my cell phone. In fact, he had phoned a few times earlier but Eloise, who answered the phone while I was undergoing the procedures, was not able to tell him anything. Now I really could not make up my mind what to say. However, it hardly mattered what I actually said because Brian knows me so well that my tone of voice alone was enough to convey that something was wrong. It was no use trying to conceal the facts, so I told him exactly what had happened.

When we discussed the matter after I got home, Brian and I were not fully on the same wavelength because I wanted to talk about what might happen, but he did not. He said that he wanted the facts before he would talk about possibilities. I found this very frustrating. On the other hand, to be fair, he was willing to talk about what the doctor had told me. He just didn't want to speculate about possibilities that did not seem to tally with what we actually knew.

I really cannot remember what we did on Friday and Saturday; we got through the days somehow. On Easter Sunday, together with Eloise, we drove to Canberra to attend the National Folk Festival. Some of the performances were really good while others were uninspiring. However, on reflection, whatever the quality of the performances, on balance it was better to be busy instead of sitting at home enveloped in my concerns. It was a very full day because we left home at 7.30 a.m. and, after staying until almost the end of the last performance, only got home at about 11 p.m. However, even if I had managed to clear my mind completely of worry, I still had an ongoing reminder of my situation because, after the procedures to which it had been subjected, my breast was painful throughout the weekend and for about a week afterwards.

On Easter Monday we did very little except lounge around the house, reading and doing odd jobs. On Tuesday, the day on which Brian began a two-week vacation from work, we were due to drive to Canberra so that I could attend the clinic. We decided to extend our time in Canberra by having a walk around part of the lake but cancelled our plans when I got a phone call to say that the results would only be available on the following day. Could I come to Canberra then? No, I said, I couldn't, because we had appointments to see friends in the Hunter Valley as well as accommodation reservations there. When I said that, the receptionist at the clinic replied, 'OK, we will phone to give you the result and talk you through it.' So why did they refuse to give me the results telephonically earlier? But, whatever the reason, now I had to endure another 24 hours of unwelcome uncertainty. The

waiting had been almost unbearable, and now there was even more waiting to extend the tension almost to breaking point!

## **LIVING WITH THE KNOWLEDGE**

We were visiting our hosts at their home in the Hunter Valley when it was time to phone the clinic. I talked to a specialist, and it was a long phone call; by the time it ended I knew that I had a cancerous growth, that it was very small and slow-growing, that it looked as if it had been caught very early, and that as soon as I got home I should make an appointment with my GP to get a referral to a specialist. After the call ended, I had a quick chat with Brian, who advised me not to conceal the facts but rather to be open about my condition. So I told our hosts all about what the specialist had said, and I was pleased that I did so, because their down- to-earth approach helped to keep me emotionally stable and less stressed-out. In any case, knowing what I did, how could I have tried to act 'normal' for the rest of the afternoon and evening?

We had a pleasant visit, concluding with a meal at an elegant restaurant; however, the downside was that being with company meant that Brian and I could not discuss my condition. I don't remember much about those first hours after the phone call, except that I think that I was in denial. I couldn't believe – I really, really couldn't believe – that it had actually happened to me. While we were driving back to our hotel, I did try to talk about the results, and what they could mean for us, but once again Brian did not want to discuss possibilities until we had more to go on. On reflection, perhaps he was also experiencing his own form of denial.

Brian felt a bit hurt when I told him that I felt that he didn't want to talk about my condition. Later, when we discussed his attitude, he explained that he didn't want to discuss things that probably wouldn't happen, such as my losing a breast, and/or having a course of chemo and losing my hair, and/or spending a long time in hospital. He felt that all the signs were that the operation would entail a smallish incision rather than a mastectomy, that I would not have to undergo a course of chemo, and that I would spend less than 24 hours in hospital. The basic difference between us was that he thought that discussing extreme and unlikely possibilities was alarmist, whereas I wanted to explore all possibilities thoroughly.

Much later, discussing this period in our relationship, I said, 'My breasts have given you so much enjoyment in our sex life that I really wanted to know how you would feel about me if one was removed.'

Brian replied, 'But all the signs were that it wasn't going to happen!'

I responded, 'Yes, but we couldn't be certain about that. Sometimes women have gone in for what looked like a relatively minor operation but have come out of surgery without one or both of their breasts, because the surgeon found that things were much worse than they seemed to be. So, what if that happened?'

Brian said in exasperation, 'Well, then, I would deal with the situation as it developed.'

To which I responded, 'I know that you would. We both would. But, still, I wanted to know how you would feel, if it happened.'

In even greater exasperation, Brian replied, 'I just didn't know! I could have said that I would be fine – that would be easy. I probably would be fine. But I really couldn't say for certain exactly how I would feel or react and it was futile to pretend that I could.'

And that was that!

On the other hand, even if I felt that Brian wouldn't talk about my condition, I knew that he was very concerned. In fact, he was so concerned that he said that he wished that he could have undergone the experience in my place, if that had been possible.

I felt very randy during the next week, so much so that I wanted sex at least twice a day, and I wanted it in a variety of ways. Throughout our marriage of more than forty years we have had sex on average at least once every day, but this was a step-up in both frequency and intensity. Brian has always been a willing partner so my randiness was no burden to him – although it was a bit of a surprise. Later, he said that it was a welcome surprise, except that in future he would like to enjoy it without being overshadowed by a dark cloud of foreboding and uncertainty.

Not long ago, at a seminar for breast cancer survivors, I discussed my randy feelings with a nurse who was making a presentation on sex and cancer patients. She said that it was because I needed a lot more intimacy and comfort at that time. Perhaps it was – but, on the other hand, perhaps it was a symptom of human response to danger and uncertainty. Whatever the reason, my randiness lasted for about ten days.

The next day, still in the Hunter region, we visited an old friend from Southern Africa and I put thoughts about cancer on the back burner while we enjoyed a wonderful visit. Then we drove to Sydney where our oldest son and family live. Just before we arrived, Brian asked if I was going to tell our son about my condition. My response was, 'No, let's wait and see what the specialist says and then give him all the facts.' Brian agreed, although later he told me that he thought privately that it would be easier to be frank and upfront about things. Brian's attitude was that cancer was nothing to be ashamed about – after all, I wasn't a criminal or a malingerer, and nor had I brought it upon myself by my conduct – and I would feel less burdened and stressful if I didn't have to remember to watch my words.

My son does most of the cooking at home so I helped him in the kitchen. Suddenly, I was overwhelmed by a feeling that I had to tell him, so I said, 'Wayne, I have had some bad news and I think I should tell you about it. I have breast cancer. I wasn't going to tell you about it until I have seen the specialist but somehow I just felt that I had to tell you now'.

He gave me a startled look but replied in a steady voice, 'Mom, I'm pleased that you have told me. Please keep me informed about everything as it happens.' He looked quite shaken, and he was very pale; his next question was, 'How did Dad take it?'

I replied, 'Not so well. He won't talk about it; he says we must wait until we know more.'

Wayne gave me a big hug and said, 'Mom, it's going to be fine. It's a good thing that you are in Australia, because in Southern Africa they probably wouldn't have found it so early.'

The rest of the evening went as normal. We had dinner with Wayne and his family, watched some television, chatted a bit, went to bed, read for a while, and went to sleep. We didn't mention my condition and even now I don't know how, when, or even whether, Wayne told our daughter-in-law and grandchildren about it. The next morning we went to a camping and outdoors exhibition in Sydney where we bought a new tent – this was showing confidence in the future! Then we drove home. Once there, I phoned Eloise and told her the

results of the tests. Of course, she was concerned and wanted to come around immediately, but I said, 'No, I'm fine. I'll see you tomorrow as planned, but please don't tell anyone yet.'

I enjoyed our home worship group on Sunday. To give the parents a break, I usually look after the children who attend and in fact I was prepared to look after them. However, their mother said she would attend to them to give me a break. It was wonderful to join with the others for an hour. I really felt at peace.

On Monday, I walked down to the clinic to make an appointment with our GP. I waited for half an hour and then was able to see him. When I told him that I needed a referral to a specialist because I had breast cancer, he was very off-handed and just remarked brusquely, 'That's right, you have breast cancer.' He printed out a referral note, advised me to make an appointment, and told me where to find the specialist's clinic. Then he stood up and said, 'Well that's it.' As an afterthought, as he was walking towards the door, he asked 'Is that all?'

I only managed to say, 'Yes.' I was shocked. I thought, 'What's wrong with the man? I know he's not my ideal doctor, but, really, he has no bedside manner.' Not surprisingly, I changed doctors after that and was fortunate to find a sympathetic, female GP at the same clinic.

Still feeling upset, I walked over to the specialist's rooms. Not only was I shaken by the doctor's brusqueness, but I found the procedure awkward. I was used to the situation in Southern Africa, where doctors' receptionists make appointments like this and also explain the situation to the specialist. For instance, in Southern Africa a few years ago, when I broke a bone in my ankle and had to have surgery, my GP's receptionist made the appointment for me even although it was only a comparatively minor matter. 'Oh well', I thought as I walked the three or four blocks between the clinics, 'different strokes for different folks.'

My next shock wasn't long in coming. I handed the referral to the specialist's receptionist and said, 'I need to see the doctor as soon as possible because I have breast cancer.' She paged through the appointment book and said off-handedly, 'The next appointment is at the end of June.'

That meant a wait of two months – two months, and I had cancer! – so I protested, 'No, that's not good enough! The clinic in Canberra told me that it would take only two or three days for an appointment.'

Without showing much concern or sympathy, the receptionist replied, 'Sorry, the doctor is very busy. I can't do anything about it.' Trying to get a more favourable reaction, I handed her the pathology test report. However, she brushed it aside and said, 'That means nothing to me. Show it to the doctor.' However, she did say that she would speak to the doctor that afternoon to see what could be done.

I went home and waited, feeling angry and frustrated. Fortunately the doctor from Canberra phoned at about 4.30 p.m. and asked if I had an appointment. I told her what had happened and she said that, apart from arranging for the X-ray and ultrasound plates to be sent to my address, she would see what she could do. She also gave me the names of all the specialists in Canberra and said she would be sending some information for me to read. After this conversation, I felt a little better. Things improved even more half an hour later when she phoned with the news that I would soon have an appointment with the local specialist. She also said that the receptionist denied that she had told me that I would have to wait. This was a blatant lie and I thought uncharitably about the receptionist, 'Oh, well, I won't challenge your story if you feel that you have to cover your large ass.' (As indeed she had to!)

On Friday the receptionist, now oozing cooperation, phoned to say that I had an appointment for Monday. So I had to spend another weekend waiting in frustration! Saturday passed as usual with housework and gardening, and on Sunday we attended Quaker meeting in Canberra. While socializing over tea afterwards, I chatted with a couple who were returning to their home in the USA after spending a sabbatical in Canberra. Although I only intended to say goodbye and wish them bon voyage, suddenly I had a feeling that I should tell them about my condition. It turned out that Jane had gone through the same thing 20 years ago, and she shared her experiences with me. It really helped to talk to someone with first-hand information on the subject, and I was very pleased that I had responded to my urge to tell her about what was on my mind. I was learning just how important it was to speak to people who had been through the breast cancer experience and had not only survived but were living active and successful lives. It gave me courage and hope.

The visit to the specialist did not start well. I arrived just before 11 a.m. and was told to take a seat. Then the wait began. I could not concentrate to read. My stomach did flip-flops throughout the hour that I had to wait. However, when I did finally get to see the specialist, my apprehensions evaporated. I found that that I liked this slightly overweight woman with her professional but sympathetic air. She examined me, showed me the tumour on the ultrasound images, and confirmed that the cancer was very small and in the very early stages.

I said, 'But in spite of knowing that it's there, I can't feel it.'

Dr O'Connors explained, 'That's because it's not a lump, but tubular in shape.' She went on to reassure me by saying, 'This is quite rare, and it's good, if cancer can be good; also, because it's very slow-growing, I am sure that it hasn't spread.'

Of course, we discussed the fact that I would have an operation quite soon. Dr O'Connors explained that my breast would be injected with a blue dye to identify the lymph glands under the arm. The reason for this procedure is that with breast cancer, the lymph glands are usually removed as they are the first place to which the cancer spreads. She explained that I was fortunate, as it was likely that I would only need to have one gland removed. Then an incision would be made at the eleven o'clock position on the breast, after which the cancer and surrounding tissue would be removed. Next, an under-arm incision would be made to remove the lymph glands.

This was bad enough – all this cutting into my tender flesh! – but things got worse when she explained that, to mark the tumour, I would have to have a hook-wire inserted into my breast before going to hospital. Not only did it sound awkward and painful, which in fact it was, but it meant that I would have to endure a piece of wire in my breast for a number of hours before I had the actual operation.

Next, she discussed my options, which included the removal of the breast. She said that I would have to decide for myself which option to choose. I looked at her steadily and said, 'I know very little about cancer but I really don't want to lose a breast if it's not necessary. If it was you, what would you do?' She said that she would not have the breast removed, and, very relieved, I replied, 'That's what I want as well.'

What a relief! One of my greatest fears was that I would lose a breast and then would have to undergo chemo treatment. In fact, I had even had my hair cut short as I thought that chemo treatment was a real possibility. As I said, I had to deal with these fears on my own because when I tried to talk to Brian about it, he always said, 'Let's wait and see.'

I was not looking forward to the task of letting close family members, such as my younger son in Namibia, my sister in South Africa, and my cousin in Holland know that I

had breast cancer. However, during the same week that I saw Dr O'Connors, by coincidence my cousin emailed me to say that, as a result of cancer, her son's mother-in-law's breast had been removed. Somehow, that galvanized me and I knew that the time had come to tell the people who were closest to me. So, when Brian got home from work – he had phoned me earlier, so he already knew what Dr O'Connors had told me -- we discussed the matter and decided to let my niece in Sydney know first. This was a good move because she is a radiologist and, after a long phone conversation, I felt a lot clearer about many things.

I had also received literature from the clinic in Canberra, which I read before seeing Dr O'Connors. Frankly, it made me feel overwhelmed. Then Dr O'Connors gave me more literature. Did I really need to read everything? I skimmed through the literature and picked up two things that I thought might help. One was information about a breast cancer support group in Canberra. Thinking that practical information and support would be useful, I promptly completed the membership application form and mailed it along with a cheque for \$20. I have been receiving e-mails from them ever since, although I have not attended any of their functions, as they are usually held during the evening and Canberra is just too far away for an evening visit. I also found contact details for a breast cancer support group in our town. Being a smaller group, they were more informal. When I phoned, I got a friendly reception and was invited to attend their next meeting, which was scheduled for two days before my operation.

My sister was concerned when she heard my news but we could not have a long conversation because some of her friends had just arrived to take her on a long walk. I was pleased that she would be with friends as this would help her to deal with my news. Next I phoned our younger son, Aulden. It was a public holiday so he sounded half-asleep as he asked, 'Hi Mom, how's it going with you and Dad?'

I replied, 'Fine, but I have some bad news. I have breast cancer. But don't worry, it's very small and slow moving. The doctor does not think it's in the lymph glands but will only know after the operation.'

In a concerned voice, he asked, 'Are you going to lose your breast, Mom?'

I replied, 'No, just the growth and the surrounding tissues. It appears that I won't need chemo. But I have to wait to find out about that.'

There was a pause before he said slowly, 'Mom, since you moved to Australia, until now I haven't felt that you really are far away, but now it feels terribly far.'

I tried to reassure him by saying, 'Don't worry too much about me. Dad doesn't want to talk about it, but he has accepted it and is being supportive.'

Aulden said, 'Mom, I love you and I miss you.'

When he said that, I wanted to sit down and cry because Aulden usually does not show his feelings like this. His style is usually a quick hug and a few joking remarks. However, only three years earlier he and his wife did have a terrible experience with cancer, when her mother lost her nose, so perhaps he is getting used to dealing with cancer-crises!

Finally, I phoned my cousin in Holland. We are the same age and grew up together in the same town in South Africa, so she is like a second sister. We had a frank and open conversation, during which she said that she was very concerned and asked to be kept fully informed. As with the others, I knew that she meant it.

Cancer or no cancer, life still had to go on, even in regard to things medical. I had done my annual physical check-up and the mammogram but had still not had a pap smear.



With so much on my plate, I was tempted to put it off. I thought, 'What if there was another crisis? Could I face that as well?' However, taking the wiser course, I decided to get it over and done with before going into hospital. When I made the appointment, I found that the breast cancer nurse, Shirley, was also the women's health nurse. It was good to see a friendly face. We chatted for a while and when she phoned that afternoon to say that I should come in for the test the next day, she asked me to make time for a longer appointment so that we could also talk about my condition.

I find that pap smears are an awful ordeal. However, I must admit that this was one of the least unpleasant tests that I have ever had, even if I couldn't relax while undergoing it. Afterwards, Shirley gave me more literature to read and also offered me a free bra, which was part of the support package for breast cancer patients. Although I declined the bra because it wasn't made of cotton, I did accept a pink cushion that was shaped to fit under the arm. However, the main significance of my discussion with Shirley was that I realized that there was a lot of help and support available, both before and after the operation. For instance, when I told Shirley that I was going for the pre-admission discussion in one week's time, she said that she would see me there.

By this time I was beginning to worry that I was not having what the literature described as the usual reactions to breast cancer, such as anger, fear, self-pity, and 'Why me?' resentment. Was I different in some way? If so, should I be concerned? Finally, I shrugged and decided that, useful as the literature was, I had no choice but to deal with the situation in my own way and on my own terms. This did not mean that I was fearless: for instance, I was scared about having the operation and I was apprehensive about what I might have to go through in the treatment that followed. Also, I was worried about Brian. How was he really feeling and how would he cope with the stress of my operation, treatment, and post-treatment symptoms?

Although I was worried about how Brian was feeling, sex was still fun for both of us. For instance, we started to try positions that might be more comfortable after my operation. This was reassuringly normal for me because, as I said, throughout our married life we have enjoyed sex on a daily basis – sometimes even twice per day -- except for enforced abstinences such as after the birth of our two children or when we have been apart. So, not long before my operation, I wrote in my diary, 'We are hoping that this will continue. Let's wait and see.'

Life continued as normal in other ways as well. For instance, I continued giving cooking classes for U3A. I explained to the participants that although I might have to cancel some of the classes, I would make them up later.

## **THE OPERATION AND AFTERWARDS**

The hospital phoned to advance my appointment for the pre-admission session by one day and after I hung up, I started to shake with apprehension. I hate an agreed schedule being changed, especially as now Brian could not accompany me because of his work commitments. I would have to face the appointment on my own.

I arrived at the hospital on time but had to wait for nearly an hour. There was nothing worthwhile to read and I had left my own reading matter at home, so I had nothing to divert me while I sat there, consumed by anxiety. Finally, I was attended to. A nurse took my blood pressure, did an ECG, and asked a lot of questions about my health. In view of my state of

mind, I was not surprised to see that my blood pressure had risen from 130/80 to 165/85. Then, after a wait of 15 minutes, I was seen by an anaesthetist who took my blood pressure and told me what would happen on the day of the operation. We also had a long conversation about South Africa, where he had worked for some time. Finally, after another long wait, I was told that it was time to see the last doctor and have two more tests. However, by this time it was nearly 4.40 p.m., so I told the nurse that I couldn't stay because I had another appointment in 20 minutes time. She was understanding and said that I could come back on the following day.

I rushed home and then walked around the corner to the Multicultural Centre to keep my appointment to help the children with homework. There, I told two members of staff that I was going to have a breast cancer operation soon and might have to take a break from my work at the centre. By now, instead of concealing the facts and having to watch my words, I was finding it easier to speak freely about my condition.

During the time leading up to the operation, life went on as usual, with house work, voluntary work, relaxing with Brian after working hours, and talking to family members on the phone. Two days before the operation, I attended a meeting of a breast cancer support group at a nearby cafe. I really liked the members and felt that they were very supportive. However, Brian and I had still not really talked about the operation. I convinced him that he need not take off work on the day of the operation as I thought that he wouldn't worry so much if he was busy.

On the night before the operation, I hardly slept, surely because I was scared of the operation and apprehensive about the outcome. Also, my right shoulder and arm, which are usually troubled by arthritis, were very painful. But now the pain was much worse than usual, probably because of worry. At one time during the night I turned on the light to read, but then turned the light off because it woke Brian, who complained. Then he apologized, saying that he had not realized that I was reading. I apologized for waking him, waited until he was asleep again, and then turned the light on and went back to my book. I guess that neither of us was sleeping well that night. Whenever I did get to sleep, I would dream about the piece of wire being pushed into my breast, and that would wake me in a fright. Unfortunately daylight did not relieve my fear.

That morning the alarm went off at 5.20 a.m. We wanted to have time for an exercise session before Brian went to work as I felt that it might be my last opportunity for quite some time. Then, after arranging to visit me at the hospital as soon as I was accessible after the operation, Brian went to work while I did some house work and packed an overnight bag. All the time, my mind was preoccupied with the thought that my first stop would be at the clinic where the hook wire would be inserted into my breast. It was like living with the certainty of having to undergo inescapable torture at a fixed time and place. Also, I was a little upset that Wayne did not phone to wish me well. I thought, perhaps he'll phone this morning. He didn't, and that upset me some more. Aulden phoned a day before the operation, while my cousin phoned during the weekend as she would be away for three weeks. Also, I was cheered by e-mails from my sister and her younger daughter as well as one from a good friend. A couple of local people wished me luck; however, we are quite new to the town and don't have a wide circle of acquaintances, so I didn't expect to hear from a lot of people locally. Also, I hadn't told many people about my condition.

At 10 a.m., Eloise arrived and drove me to the clinic where, as usual, there was a long wait during which I got more and more apprehensive. At last I was summoned to the torture chamber, where one more ultrasound was done so that they could see where to put the wire into my breast. Although the doctor assured me that I would feel nothing because my

breast would be anaesthetized, at the first push I nearly went through the roof, so I was given another injection. Now, as the wire was inserted again, I could bear the pain even although the sensation was dreadful. By the time the doctors were finished, I also felt finished. In fact, I think that I was in a state of shock. For instance, when I had to get dressed I could not fasten my bra, so I had to ask the male nurse to help me. He did not look very happy, but did it anyway. At that stage, I was past caring.

To make matters worse, I had to go back to the reception room to wait for the ultrasound image to take with me to the hospital. By the time I left the clinic, I was shaking all over. Seeing my condition, when we got to the hospital Eloise asked if she could stay with me but the nurse would not allow her to do so. This was really harsh and unsympathetic, as I had to wait for more than three hours, as the operation was only due at 3 p.m. Next, I was taken to a ward, where I was directed to change into a hospital gown. I told the nurse that I was cold, so she covered me with a thin blanket and said that she would bring another. However, it never arrived and I was shaking all over when they brought me a tranquilizer at about 2.30 p.m.

At 2.45 p.m. the anaesthetist and the breast cancer nurse arrived and gave me two tranquilizer pills. My anxiety increased when, after questioning them, I found that the order in which the pills should have been given had been confused: in other words, I had been given an anti-acid pill earlier, and was given tranquilizers just before the operation, instead of vice versa. That partly explained why I had been shivering; it was caused by both cold and anxiety.

Fortunately, by this time I had calmed down and, once I was in the theatre, I was able to chat with Dr O'Connors, the surgeon. After that, I can only remember the big overhead light and the masked team, but nothing else.

When I came back to consciousness, I was back in the ward hooked up to a drip, with a tube under my arm. I no longer felt fear, and I also did not feel pain. I was drowsy and was not really aware of what was happening around me until the phone rang. It was Brian, who was making his second phone call. He made his first call an hour earlier when he was told that I was still in the operating theatre. He was relieved to hear my voice because he had been concerned that the operation was taking longer than expected. Was there a complication? Fortunately not -- everything had gone as expected, except that the procedure had taken a little longer than anticipated.

Brian arrived at my bedside within ten minutes of making the call -- our house is only about three blocks from the hospital -- and it was great having him there, even if I was still rather drowsy. While he was with me a meal arrived. But what a meal! It looked as if the kitchen had confused my dietary requests because the meal mainly consisted of foods that I had indicated that I didn't eat. I could only eat the green beans, which reminded me of the birth of my younger son in Canada, when the first meal that the hospital served after the birth was green beans and potatoes.

Brian left soon afterwards, with the understanding that he would return in the morning to drive me home. Although I missed him after he left, I was feeling very calm and collected, partly because of the anaesthetic but mainly because I had endured and survived the experiences that had caused me the most anxiety.

I needed to go to the toilet so I rang the bell and was given a bed pan. Although I was able to deal with it, I could not completely empty my bladder and needed to go again half an hour later. I asked if I could go to the bathroom and a nurse 'unplugged' me and helped me down the passage way. I felt very weak and woozy and had to be assisted whenever I needed

to go the bathroom. However, when the night staff came on duty, I had to manage on my own, which was fine except that I had difficulty extracting and re-inserting the drip in the plug behind the bed. At one stage, I accidentally rang the bell while I was trying to get the plug back in. A nurse answered the summons and was unhappy when I explained what had happened. However, she did not offer to help me.

It was a horrible night, mainly because of the noise. Although I had a private ward, I was not allowed to close the door, so all night I was disturbed by the sounds of patients groaning and crying out, nurses conversing with each other, and the sound of feet hurrying up and down the passage way. I have never been in such a noisy hospital! I was happy when morning arrived, even although by then I had a headache and a sore neck. I asked for a pain killer, which helped somewhat. Breakfast arrived and as with the earlier meal, the food was bland and unappealing.

Doctor O'Connors arrived, had a look at me, asked me a few questions, and said that I could go home at 10 a.m. However, when Brian arrived on time, we had to wait while a nurse changed the dressing under my arm and removed the tube and drip. Brian helped me to dress, after which a physiotherapist showed me the exercises that I should do for my arm. After that, finally, I was free to go, with Brian carrying my bag and the beautiful bunch of flowers that Wayne and family had sent me. As I left the hospital, I felt so relieved that it was like a heavy load being lifted from my shoulders.

When I arrived home, I was so hungry that Brian made me a big meal even although it was only 11 a.m. I spent the rest of the day either sleeping or watching television while Brian plied me with food and drink. I slept through most of the afternoon and was in bed and fast asleep by 7 p.m., waking at 6 o'clock next morning. Somewhat to my surprise, I felt so energetic that I wanted to attempt an exercise session. According to my medical advice, this was acceptable as long as I avoided putting pressure on my left side, the side on which I had been operated. Also to my surprise, although I could do the exercises as suggested by the physiotherapist very well on my left side, my right side was very stiff because the arthritis in my right shoulder was asserting itself. I used a Pilate's ball and, happily, I found that I could do quite a few exercises without any pain. Later, when Brian said that he was walking into town, I decided to go with him. I really enjoyed the walk, even although it was quite short; being outside, moving freely in the sunshine and fresh air, was like being liberated from a stultifying confinement.

Even although the operation was behind me and I was at home where I was able to exercise and move around, my physical condition was far from normal. For instance, the incision to remove the lymph gland made the adjacent under-arm and back areas feel as if they had been sunburned. Also, I felt tired all the time. This lasted for quite a while, as I found a few days later when I attended the monthly meeting of a club to which I belong and I was unable to stay for the full meeting because of weariness and discomfort.

Generally, my physical condition made me very fragile and sensitive; for instance, when Brian and I were sitting together on a couch watching television, his arm accidentally brushed against my back, and, at his touch, I cried out and broke into sobs. My back was sore and my right hand was very sore and swollen, and this additional jolt was just too much for me.

Another frustration was that I wanted to start doing the housework, but held back from doing so because of caution. In any case, Brian did as much as he could in the time available to him and wouldn't allow me to do anything around the house.

One week after the operation, I visited the Dr O'Connors and she removed the dressings. What a relief! I had been itching ever since the operation. In fact, based on past experience, I knew that I was probably allergic to the dressings and thus my wounds and adjacent areas were much itchier than they should have been. The worst part of the process was the removal of the dressing from my nipple, which was really painful. After that, I only had strips of dressing over the wound. However, it still itched. To allay the situation, Dr O'Connors gave me some cream, which only partially allayed the itchiness. That afternoon, as advised, I bought some cream and vitamin-E oil for the wounds.

All in all, in spite of the annoying itchiness, it had been a good day because Doctor O'Connors was satisfied both with the operation and my recovery to date. Saying that the doctor was 'satisfied' meant that, as far as she could tell and in lieu of further confirmation, all of the cancerous infection had been removed.

Within a few days, all of the dressings had come off in the shower. More relief! At last the itching stopped.

Finally, after a delay of a few days, Doctor O'Connors received the results of the operation. They showed that the areas of both the tumour, which was 4.5 mm in length, and the lymph glands, were clear. This was great news and, although we had been expecting it, Brian and I felt much happier.

## **RECOVERY**

Quite soon after my operation, the date for the annual Australia's Biggest Morning Tea, a fund-raiser for cancer research, came around. I was planning to make scones for the occasion but my right hand was too sore and swollen. This was ironical: I had been operated on my left breast and under-arm areas, but my right hand, which had no connection with those areas, was giving me the most trouble. After I put my hand into hot water and rubbed it with China Oil, which is a German product with a high concentration of peppermint, the pain and the swelling slowly subsided. On the following day, I made cup cakes for the tea.

The Biggest Morning Tea was held at the local public library and was organised by the local Breast Cancer Support Group. It was my first activity with the group and I enjoyed the camaraderie and sense of shared purpose. The tea was successful and we sold all of our food and snacks within the first hour. Brian took a break from work to visit me at the tea, and, arriving just over one hour after the start, was surprised to find that we were already clearing the tables and packing away our equipment.

After my consultation with Dr O'Connors, I had no fear about the cancer because I believed the evidence that showed that the infection had been completely excised. Instead, my troubles were more localized. For instance, my left arm was painful and seemed to get worse as time went on. Nevertheless, because I like to think of myself as determined and self-reliant, I tried to live life as normally as possible by doing all of the things that I usually did, in so far as they were physically possible, and by resuming all of my household, social, and volunteer activities.

After the operation, Brian and I experimented with sex and continued to have a satisfying sex life. Although, as I have said, I have always enjoyed plenty of sex, I feel that I am rather conventional. At this time, I relaxed my inhibitions a little, which was not easy even if the results were satisfying. Unfortunately, however, I still retained some inhibitions!

Within three weeks of the operation, I was feeling good. I exercised every day, mostly using our home gym equipment. My usual exercise routine, which is done to music with a rhythmic beat (1960s pop songs are the best!), consisted of loosening up movements, bouncing on a small trampoline, doing curls on an 'ab-machine', and doing a variety of exercises on a sliding board and a Pilates ball. Doing the exercises together with Brian helps to make them more enjoyable and less monotonous. Now, after the operation, I could still do many of the exercises, but had to eliminate or greatly reduce those that placed a strain on my arms and breasts.

I was pleased to see that my breast looked almost normal and I began to think that when the incision healed and the swelling subsided, it would look the way it always had. However, my under-arm and back were still painful and I had to be careful not to strain or bump those areas.

Dr O'Connors advised me that it might be prudent if I had a course of radiotherapy, so I phoned the clinic and was told that I would only be able to see the specialist in two weeks time when she made her monthly visit to our town. More waiting! Brian said, 'Maybe the specialist will advise that you don't need radiotherapy', but I was convinced that she would advise it and that I would act on her advice.

I felt so bored that I decided to do a bit of gardening, so I pulled on my gloves and, carrying a kitchen knife, went out and attacked the weeds in a flower bed. However, I only did this for about ten minutes because my left arm started to feel sore even although I did not use it. When I went to the Multicultural Centre, there were no children who needed help with their homework so I spent the time talking to another volunteer. After that conversation, I thought that sometimes when one listens to others, you learn how lucky you are. My encounter with cancer was almost insignificant compared to what this woman had suffered with her health.

While it was true that I was no longer concerned about cancer, I was still worrying about radiotherapy and about recurring pain and discomfort. One result was that I was eating too much, continually snacking on comfort food. Perhaps I would stop now that I realized what was happening.

By the fourth week after the operation, the pain and discomfort fluctuated. Sometimes I felt very uncomfortable and sometimes I was almost pain-free. For instance, during an evening in early June my breasts were really uncomfortable and I had to take pain killers. However, by the following morning I felt so good that I shampooed the lounge carpet and did some cooking. In my diary, I wrote, 'I hope that I stay feeling so good all day'. In fact, it was a good day, except that by the evening the itch was really intense and I had to stop myself from scratching. Apart from that, I felt great. To cap a good day, I received a batch of supportive emails from distant friends to whom Brian had written about my condition. Some of them wrote about their own experiences with cancer, including breast cancer, and some just expressed support and concern. Whatever the content, it was all very heartening!

In spite of having had a good day, I went to bed feeling that if my nipple did not stop itching, I would go mad. When I examined my breast in the mirror and discovered that a small piece of the dressing was still adhering to my nipple, I carefully removed it and, after a night of broken sleep, the itch was gone. Had I found the reason and the cure for the itch? I really hoped so. I felt good, and decided to write to a young friend who is a physiotherapist and ask about how much pressure I could put on my arm when exercising.

On 15th June I saw the oncology specialist. During a thorough consultation lasting one and a half hours, she examined my breast and asked a lot of questions. She told me more about the cancer and estimated that the chances of a recurrence were about 8% if I did not have radiotherapy. The choice was up to me. I hate having to make decisions like this because I never feel that I have enough information, so I asked what she would do if she were in my position. She replied that she would have the treatment, and I decided to follow her advice. She told me that the treatment would begin in about three weeks time and that I would have 16 doses, one per day on consecutive weekdays. The size of the dosage would be determined after I had a clinical test.

So that was decided – I would have radiation treatment. However, it was no surprise as I had been expecting the decision almost from the time that I came out of hospital.

At about that time, I was having heart palpitations. It was worrying. What could it mean? In spite of my concern, I did nothing about them and they gradually went away, so they must have been caused by stress.

After the appointment with the oncologist, I had my U3A cooking class and only one person attended. We had lunch after the class and enjoyed a friendly conversation. It was good to have someone outside of my everyday life to whom I could talk. In the evening, I went to a club meeting. Although the weather was very cold, the meeting room and the company were warm. However, the food was the worst that I had ever eaten at the hotel, which, in my opinion, is generally distinguished for its poor cuisine.

Now my mind was pre-occupied with thoughts about the radiation therapy. I was worrying about how I would react to it and what longer-term effects it would have on me. My tension began to affect my relationship with Brian, because I wanted to snap at him angrily no matter what he did or said. I had to struggle to restrain myself. To try to work off the tension, I used our 'step and twist' exercise machine for long spells. I also knew that, because of the tension, once again I was snacking more than I should. I began to look forward to the week that Brian had booked on the Sunshine Coast, thinking that it would be a welcome diversion before the treatment started. If only it was all over, I thought, then things would improve rapidly. It was just that I was no good at waiting for things to happen.

However, matters were improving in other ways. For instance, I found that my bras no longer hurt my underarm area and shoulder. What a relief! However, my lower back felt the strain if I did too much housework or gardening in one spell. This was a real nuisance because I was used to being fit and active, not partially disabled. When I felt like that, a hot water bottle and rest helped a lot.

On 23rd June, Eloise drove me to Canberra for the planning session. Once again, I had reason to be seriously worried about my good friend. En route, while driving at highway speed, she went blank and almost stopped the car. I had to touch her before she came back to full awareness. Then she was fine. This was not the first time this had happened when I was with her, and, after I discussed the matter with one of her friends, we both urged her to take medical advice. She had a number of tests to diagnose the cause of the problem, but not one of them yielded any useful information. Unfortunately she still has the attacks, so we continue to be concerned about her.

At the hospital in Canberra, I had to lie with my arms behind my head while the staff marked my breast and measured it. Unfortunately everything took twice as long as normal because it is a teaching hospital and the procedure was being observed and noted by medical students. By the time they were finished, my right arm was shaking and I could not bring it back to my side without assistance. That night my right shoulder was sore, but by the next

morning it was more or less normal. However, more than 24 hours later my left shoulder was still so sore and stiff that I had to take pain killers. I reckoned that the pain was caused by my having to hold my arms above my head. Anyway, I hoped that was all that it was.

I began to wonder if I would ever feel all right – I meant, all right, with nothing wrong anywhere – again. Although my left side, the side of the operation, had little discomfort, I had what felt like arthritis in my right wrist, chilblains on my left toe, and an itch that nothing seemed to help. When one has had an operation like this one, everything seems to be amplified.

Now it was time to leave for our vacation at the Sunshine Coast. Hooray – diversion and relaxation! After visiting my niece and then spending the night with our son and his family, we flew out of Sydney airport at lunch time. The Virgin Air flight was uncomfortable by any standards, with insufficient leg room and not enough seat space. So this is what a battery chicken experiences! Also, we were assailed by marketing messages and by attendants trying to sell us things, as if spending money would divert us from our discomfort. Thank goodness the flight lasted less than one and a half hours. Any longer, and I would have required chiropractic attention. By the time we reached our destination, both my arm and breast were a little painful, but not unbearably so. However, by the time we got to our holiday apartment, I was really feeling under the weather.

We needed a stock of food so we walked to a supermarket at the nearest mall, a stroll of about 25 minutes each way. I was walking so slowly that Brian asked if I was feeling all right. Normally I am a quick walker, able to match Brian's pace, but right then my hand and fingers were feeling heavy, as if afflicted with pins and needles, and generally I felt out of sorts. By the next day, I felt fine. However, I decided that on the flight back, I would wear a pressure sleeve, which the nurse had recommended but the doctor had said was unnecessary.

The holiday was relaxing and unstressful, and we did a lot of walking and sight-seeing. The only blemish was on the last night, when we went out to eat at a restaurant and had a disagreement over the menu. In the end, although I conceded to avoid a disagreement, I was not at all happy. Under normal circumstances, this would not have worried me, and I would have just gone ahead and ordered what I really wanted. However, at the time, I got upset easily and I felt that Brian was being stubborn for the sole reason of annoying me. Even at the time, paradoxically, I knew that this was not true; but my condition was such that I could not help feeling annoyed and irritable.

On the return flight, the elasticised sleeve helped to alleviate the discomfort and, in addition, Jet Star had more comfortable seats and more leg room. Finally, as always, it was great to be home.

On the day after we arrived home, I phoned my sister and told her that we planned to visit South Africa during December and would be with her for Christmas. When I said that, she broke down and cried, which was unlike her. I thought that she reacted like that because she had lost too many people from cancer, including the recent death of a close friend, and was worried about me. Perhaps she did not understand that the radiation treatment was only precautionary and not curative. I tried to calm her by reassuring her that I was fine and I hoped that I succeeded in doing so. However, the incident upset me and I got almost no sleep, spending most of the night reading. But was it only my sister's reaction that upset me? Was I also worrying about the 16 days of treatment? How would it feel and how would I react? I have to admit that these thoughts were on my mind, constantly.

I was a bit upset with Brian because, although I felt like making love, he just went to sleep. That happened two nights in a row. I thought resentfully, it seems that we only do it



when he wants it. He claims he was just tired. Oh, well, it wasn't worth worrying about, even although it was annoying at the time. That's how I felt at the time, when a lot of things were annoying me and adding to me feelings of stress.

## TREATMENT

Finally, the waiting was over and I had my first treatment session in Canberra. I found the procedure interesting, not at all threatening, and I was sure that I would have no problem sleeping now that the waiting was over. Back home, I got a welcome phone call from a member of the cancer support group, asking how I was and reminding me to be at the tea on the following day.

Next day, I had no reactions apart from my right under-arm being a little sore. I was still tired, but put it down to not sleeping for two nights and having only a fitful sleep the previous night. I attended the support group meeting during mid-morning and after most of the people had left, some of us stayed on, discussing our experiences with cancer. I think that it was a good encounter, because some of the members bottle up their feelings and need to have the opportunity to speak openly and freely. I mentioned that Brian and I were going to enter the Blackmores Sydney Running Festival, to be held during September, and would be inviting sponsors for Breast Cancer Network Australia. Some of the members were interested in the event, and one said that she would sponsor me.

My second treatment session lasted only about half an hour, if not less. Two hours travelling for a session of less than half an hour! That is the penalty for living in a country town. The alternative would be to stay in Canberra overnight, perhaps even stay for a number of nights. However, Brian and I rejected that possibility because both of us enjoy our home life.

That night, Brian and I had sex. It was really great, but unfortunately was interrupted when the phone rang. It was a friend, enquiring how I was. It was wonderful hearing from him and the interruption did not even spoil the quality of our love-making, which we continued at the same level of pleasure after the phone call. Life is great, I thought – but I just hope that I sleep better tonight.

As I adapted to the new routine, I was discovering that I felt good during the mornings, but that I tired later in the day after the travelling and the treatment. In fact, I always felt very sensitive after treatment. Today, because my muscles kept on jumping when they were fixing me for treatment, the session took a little longer than usual. However, that night I slept quite well and Brian and I had an enjoyable bout of sex after we awoke next morning. During our morning exercise session, I found that my bust was not as uncomfortable as it had been. Thank goodness for small mercies!

On Friday, the last day of my first week of treatment, I went shopping and ordered flowers for my niece in Sydney, who was having a birthday and an operation at the same time. I did a bit of other shopping as well. Throughout the morning, I thought with relief, 'Today is the end of my first week of treatment. It will be good not having to travel for two whole days.' Once again, thank goodness for small mercies!

The second week of treatment began. During the weekend, my left side was uncomfortable and my breast a little swollen. This began to dissipate during Monday and by Tuesday I was comfortable again. Brian started work after his vacation, so Eloise drove me

to Canberra this week, except for Friday, when Brian could arrange his work to suit my schedule.

On Monday evening, I attended the regular meeting of a club of which I am a member. Well before the end of the meeting, I could not wait to get home as I was really tired. However, a friend drove me home and we spent a while in the car talking about her husband. She has an unsatisfying marriage, as well as health problems, including a history of cancer. Listening to her, I realized how much she, like most people, needs a sympathetic circle of friends to listen and offer support, so I invited her to join Eloise and me during our mid-week tea appointment at a local café. I decided to try to make this a regular social get-together because I feel that there are a lot of people who need someone to talk to outside of their families. At the time of writing, the number has grown and now thirteen of us meet every week. We all enjoy the socialising, as well as the opportunity to talk about our problems to sympathetic listeners. Sometimes we even get around to discussing the problems of the world. From small things, big things grow!

For a long while, I had been worried about the condition of the skin on Brian's legs, as well as on other parts of his body, such as his chest. I was afraid that he might have melanoma. I had been urging him to make an appointment with a skin specialist and finally he agreed to do so. With a sense of relief, I made the appointment. I was even more relieved when, after examination, the specialist told Brian that the condition was just dry skin, which was mainly the result of ageing. Brian commented, 'I told you so! It's just one more case of things falling apart as we get older.' Perhaps so – but at least I know what it is, and that's one less thing to worry about.

The last week of radiation treatment was also the worst. My breast was red and very tender to the touch, while my under-arm and adjacent back areas were also painful. It was difficult to lift my arm. The nurse told me that the breast, under-arm, and back symptoms were 'normal' for treatment of this type, while the pain in my arm was a result of my arms being above my head during the treatment. I did not believe the latter diagnosis, as I used my arm freely throughout the treatment period. Instead, I thought that the main reason was that, ambitiously, I had started to use weights again during my home gym workouts. I decided to stop using weights and to cut down the number of repetitions on the arm exercises. I did that and the pain began to ease.

Monday 3rd August finally arrived, and I could hardly believe that I had reached the last day of my treatment. Throughout the day, I thought, happily, that this was the beginning of the last phase of my healing process. The staff at the clinic told me that it would take about two weeks before my body was back to normal and I couldn't wait to put those weeks behind me.

Symptoms or not, I was really enjoying life at that time. For instance, on Saturday evening we went to an engagement party for one of the members of the breast cancer support group, and we had a great time. The party was held at a local club and we would have gone dancing later, except that it was too late by the time the dining and the socialising ended. Gillian, the woman who was getting engaged, had both breasts removed because of breast cancer 20 years ago. There certainly is life after cancer! On Sunday, we did a bit of nest-building when Brian put up curtain rods in the family room – actually, it's our exercise room – and then we put up the curtains that I had made.

Although I was feeling quite good generally, I was not sleeping very well on at least four out of seven nights. I decided that I would speak to the doctor about this. Fortunately our sex life did not suffer at all, although I was not as randy as I was earlier. However, we

had to be careful that Brian did not put any weight on me, as that might not only be painful, but would also be dangerous for my weakened ribs. Because radiation reduces the thickness of the bones of the rib case, I will always have to be careful not to break or injure a rib, as they are much softer now than they were before I began the treatment. So, for instance, I have to be careful when exercising with weights. In fact, I have been advised that it would be preferable not to use them or, if I do, to 'listen to my body'.

After my last treatment session, I had a consultation with a specialist at the clinic in Canberra. She said that she was very happy with my progress and that I had not been unusually 'burned' (i.e. caused to have red skin) by the radiation. I asked her about the pain on the back of my arm but she did not know what could have caused it. Anyway, all the signs were that I had a clean bill of health, and that was very satisfying.

During the drive from Canberra – the last one for this particular purpose – I decided that I would try to change to a female GP, for general purposes as well as to get referrals to the specialist whom I had just seen, as I would be seeing her for another year at least.

## **POST-TREATMENT**

That evening, Brian and I had snacks with sparkling wine (we aren't allowed call it 'champagne', are we?) to celebrate the end of my treatment. The celebration was enjoyable, but didn't end as I had planned. I was so tired that, instead of having rousing sex, I was asleep by the time Brian came to bed. Another time, perhaps...

Next morning, we joined a women's breakfast group at which Brian was the invited speaker. In this post-treatment phase, I expected to be shedding symptoms rapidly but instead found that the muscles under my arm were very stiff and sore. What could be the matter? I managed to do some weeding, but then found that I was struggling to stay awake until Brian arrived home from work at 4 p.m. As the day went on, my muscles felt very tight and I had a minor headache. This was worrying. I had not felt so 'down' during the whole period of the treatment.

Wednesday, the second day after treatment ended, and I was feeling a lot better. I met with three friends for our weekly tea date. My idea was that we could enjoy each other's company and listen to each other's problems and it seemed to be working well. In fact, two more women would be joining us the following week. After that, I had a consultation with Dr O'Connors. She said that everything was fine and that the tenderness and discomfort would disappear in time. She also told me that the schedule with specialists would be that, for the next two years, I would see her every six months, and the other specialist every three months. After that, I would see just one specialist annually for the next 20 years. I asked Dr O'Connors whether the fact that I had cancer meant that members of my family had a greater risk of contracting the disease, but she assured me that they faced no more than a normal risk, which is 2% for the population over all.

On Thursday, the third day after treatment ended, Eloise and I did our Meals on Wheels deliveries. I was concerned to find that, whereas formerly I had no problems in finding the addresses for deliveries, now I was getting confused. I really did not know what was wrong. Was it a result of the treatment? If so, was it permanent, or would it disappear with time?

Another adverse result of the treatment was that the left side of my mouth was so uncomfortable that I could only eat soft food. When I saw my new G.P. to get a referral to

the oncology specialist, I also mentioned this condition. She said that it was a reaction to the treatment and gave me some mouth rinse. In addition, she advised me that my memory loss was caused by the treatment. Hopefully, it would only be temporary!

By the next week, my mouth was on the mend, and so was the ugly mark under my breast, which looked like a cross between sunburn and bad chafing. I wished that it would heal quickly because it caused me a lot of discomfort by chafing under my bra. Also, I realized that I would have to curb my natural tendency to be active and energetic, because I overdid things that morning when I spent 15 minutes cleaning the kitchen ceiling. The result was that I was tired and so sore that I had to take pain killers during the afternoon.

I attended a meeting of the cancer support group where I spoke about my own support group, which I was trying to get off the ground. A representative of the Cancer Council, who was a guest at the meeting, thought that it was a good idea. My intention was that we would not be a support group for any particular affliction or problem, but rather a support group for anyone who wanted to join. We would advise, talk with, and comfort each other, and would not have formal activities such as lectures or presentations.

Suddenly it was a month since the end of treatment. I still experienced pain in a few places, but did not tire so easily. In fact, life was almost back to normal. During this time, we had the excitement and pleasure of becoming Australians. About 25 friends and acquaintances were present at the local council chamber to witness the ceremony, at which the mayor presided with just the right mixture of friendliness and formality. Then almost everyone went back to our house for drinks and snacks. Wayne drove from Sydney for the occasion and that evening we went out to a restaurant for a pleasant dinner. All in all, it was an enjoyable occasion, and, for me, it was good to see friends from both my club and the cancer support group there.

A few weeks later, we went on a walk with the local bushwalking club. Near the end of the walk, I slipped and fell as I was walking down on a steep slope with a loose surface. While trying to protect my left side, I hurt my right arm and lower back, but by Wednesday both areas were feeling better. This was a good sign, because it suggested not only that my body was in good shape, but that it was healing quickly in spite of the operation and radiation therapy.

About one month after treatment ended, I began attending the cancer group that met regularly at the hospital. Part of the program involved aquatic exercises and I enjoyed the warm swimming pool even although, unlike most of the participants, I could do the exercises very easily. I also attended an Understanding Cancer course, which was run by the Cancer Council NSW once per week over three weeks.

## **FULLY ON THE ROAD TO RECOVERY**

During mid-September, seven weeks after my treatment ended, Brian and I participated in Blackmores Sydney Running Festival, an annual event which comprises a number of courses, ranging from a four-kilometre family walk/run to a full marathon. All of the events entailed participants setting off from the northern side of the Harbour Bridge, crossing the bridge (which was closed to traffic) and finishing in front of the Opera House. We chose the nine-kilometres Bridge Run. At the time that we registered, mid-way through my treatment, I didn't want to enter for a longer distance because I didn't know how I would be feeling by the time of the event. However, I was not too apprehensive about my ability to

handle the event as Brian and I maintain a reasonable level of fitness. Apart from working out on our home gym equipment, which I referred to earlier, we walk for an hour or more about twice every week. For longer walks, whenever possible we join the members of the local bushwalkers club on their monthly outings. In addition, we seldom use our car to get around town; I walk and Brian usually rides his bicycle.

There were other reasons for my decision to participate in the festival, namely that I felt that it was a way of showing friends and family that I was well on the way to full recovery, and that it offered an opportunity of showing appreciation for the care and support that I had received. So we submitted our entries and registered as sponsors of Breast Cancer Network Australia, using a joint sponsorship page. I must admit that I did not think that we would be able to raise much money, because, having lived in Australia for just over two years, our network of acquaintances was relatively small. Nothing daunted, I sent out e-mails to the clubs and societies of which I am a member, to our new friends, and to family members in Australia and Southern Africa. Aulden, our younger son, responded almost immediately with a donation of \$500. Our target amount was \$400, so we were off to a good start! By the day of the race, we had raised \$720, and almost \$1000 by the time that the sponsorship closed.

On the morning of Saturday 19th September, the day before the event, we went to the park next to Circular Quay and signed in for the race, getting our vest numbers and timing chips at the same time. After that, the weather being fine, we took the ferry to Manly and had a warm-up walk for about two hours. We were staying with Wayne and his family in northern Sydney, and that evening we took the whole family out for a meal in a restaurant. By the time that we got back to the house, I was ready for bed.

We awoke early on Sunday to find that the day was fine and warm. The only blemish was that there was a lot of smoke from back-burning in the Hornsby area. We left our car at Hornsby station and took the train to Milsons Point, hoping that the area around the bridge would not be affected by the smoke. However, there was no reason for concern as the sky over central Sydney was beautifully clear.

At every station between Hornsby and Milsons Point, more and more race participants joined the train. By the time the train left Chatswood, so many passengers were wearing vests and running shoes that it looked as if the train had been reserved exclusively for the event. However, the full magnitude of the event really came home to us when we looked out of the train as it drew into Milsons Point station and saw thousands of people walking and running up the approach road onto the bridge on the first phase of the family event. The multi-lane roadway was literally completely covered in people, wall to wall so to speak, as was the surface of the bridge for as far as we could see.

We began by heading for the Breast Cancer Network Australia stand, as I had been told that we could get free bandanas and pink lady emblems there to show that we were sponsoring BCNA. The attendants at the stand were very friendly and hospitable, and at their suggestion I bought the pink lady lapel pin that denotes cancer survivors. I wore it during the event, and I have been wearing it ever since. During the race, I wore the pink bandana on my head while Brian wore his over the crown of his bush hat. Both of us wore the pink lady cut-outs pinned to our backs. It was good to feel that we were doing this for a cause and that, by so doing, we were part of something much bigger than ourselves.

The atmosphere at the park was really friendly and cheerful. In spite of the crush, people were talking to each other and joking as we all slowly made our way towards the starting posts. There was such a crowd that, although our event began at 8.30 a.m., we only

crossed the starting line at 12 minutes to 9 a.m. So it took us, and the participants around us, almost 20 minutes just to make our way to the start-line!

The way was clear on the other side of the line and people began to run as soon as they crossed it. However, I couldn't have run even if I had wanted to do so, as it would have been too uncomfortable for my breast. Brian said that I should set the pace, which I did, knowing that I could keep it up for the whole walk. Sometimes it wasn't easy to maintain a consistent pace because of bottlenecks but generally we managed to keep going steadily.

At the one-kilometre point, in the middle of the bridge, a young woman had already collapsed and was lying on the roadway, probably suffering from cramp. I muttered, 'If someone that young can't do it, will I manage it?' Brian replied, 'Don't be silly! You are very fit. Of course you can do it.'

The walk across Harbour Bridge was really exciting, as up until then I had only ever crossed it by train. We enjoyed the experience so much that at a few points Brian had me walking backwards so that he could photograph me against the backdrop of the bridgework. Then, as we came off the bridge and turned left, we looked over the Opera House – always a stunning sight, especially in fine weather – and were amazed to see that the whole area was already packed with people.

Onwards we went, keeping up a steady pace of about nine and three-quarters of a minute per kilometre. The day was warm and there were only two water points along the route but fortunately we had our own supply, so it was not a problem. However, I did hear other participants complaining that there should have been more water points.

As we got near the end, we decided that we would improve our time by jogging for the last half kilometre. However, it was down hill all the way to the Opera House and I have a tendency to fall flat even on a slight slope, so we just kept up our steady pace. We crossed the finishing line in one hour and 25 minutes, which I felt was reasonably good going (for our ages, anyway – I was 65 years of age, and Brian was 64 going on 65!).

Would I participate in the event again? I was sure that I would, but probably not the following year, as I did not feel that I could ask friends and family to sponsor me again so soon.

In retrospect, participating in this event meant a lot to me, and I did achieve all of my goals. By completing the distance, and doing so at a decent pace, I demonstrated to myself, family members, and friends that I was fit and also well on the way to recovery. Secondly, I raised a reasonable amount of money for Breast Cancer Network Australia. This was not only a tangible way of saying 'thank you' for all of the care and support that I received, but also acknowledged how important support networks have been to me as complements to the technical and medical care. Thirdly, as Brian and I walked together with thousands of people who were raising money for various causes, many of them involved with cancer, we got a warm feeling for the generosity, both material and personal, of the citizens of our new country. This, surely, will be a factor in my recovery, as it has been already.

After I gave a written account of our walk to various organizations of which I am a member, my club sent it to the local newspaper with a foreword stating that they had sponsored me. The newspaper gave it full coverage, together with a photograph of me on the walk. In the past, the publicity might have embarrassed me, but now I was happy to have the coverage because it not only publicized the work that the club does for women's welfare but also might have given hope and courage to women who were dealing with breast cancer. After the article appeared, the amount donated increased. One woman, who made a donation

after reading the article, commented ‘Good on you’ on the web page. I say ‘Good on everyone’ who assisted and supported me throughout my journey with breast cancer.

## **LIFE GOES ON**

Less than two months after my treatment ended, we went on an excursion with the local bushwalkers club during a long weekend. The weather in the south-eastern part of the Snowy Mountains was cold and wet, but we had a great time. On every one of the three days, we did walks of about two hours each, the first two with damp boots in wet and muddy conditions. I handled the exercise well and felt that I was back on track, literally and figuratively.

After that, we spent one night at home and then went to a rural centre, where I had been asked to cook for 17 people who were attending a Quaker retreat. I agreed because the organizers were desperate, the location was attractive, and the company promised to be interesting. The deal was that we would receive free board and lodging for six nights in return for doing the cooking. Brian accompanied me to assist with the heavy work which I could not do, such as lifting big pots and cutting vegetables. In amused fashion, he referred to himself as the senior assistant to the senior cook.

Our work started at 6.30 a.m. each morning, when we cooked porridge, sliced fruit, and laid out the breakfast buffet. Directly after breakfast we would start preparing the lunch, which was usually a thick soup. We also spent quite a lot of time tidying and rearranging the kitchen and cold room, as at first it was very difficult to find what we needed. After lunch we would rest for an hour, then either read or go for a walk in the countryside around the centre. Then, at mid-afternoon, it was back to the kitchen to prepare the evening meal. This was a complicated affair, as we had to cater for a number of special requirements, such as gluten-free, sugar-free, and protein-rich dishes. We tried to satisfy everyone’s needs, and generally succeeded.

After the evening meal, we would join the group for a discussion followed by the epilogue. By this time I was tired out and sometimes I would go to sleep sitting in a chair. This could have been embarrassing, except that most people knew that I was recovering from an encounter with breast cancer. On our last evening there, which was also the farewell occasion for that group of course participants, everyone was requested to write to write positive and affirming comments about everyone else. Amongst the comments that I received were the following, which especially delighted and encouraged me:

\* ‘THANK YOU SO MUCH! Your care for me has been exemplary and I won’t forget it. I wish you a very healthy and happy future, and hope to meet you again.’

\* ‘I have been struck by your energy, terrific good humour, and confident engagement with all we are doing. It has stabilised this community wonderfully.’

\* ‘Your strength following your time of illness has been wonderful. Thank you for caring for us so ably. I hope our paths will cross again.’

\* ‘I admire your strength, courage and up-front attitude to life. A sense of humour always helps to see you through the hard times.’

These were encouraging and heartening comments!

## **ONE YEAR LATER**

About one year after my operation and treatment, I decided to end this book by writing some more about the journey.

Before I was diagnosed with cancer, we had told our family members in Southern Africa that we would be visiting them during December and January. After discussing my condition and prospects, we decided that it would be a good thing if we kept to our plans as it would be a decisive way of proving to our family and friends that I was doing well. So, soon after my operation, we booked return air tickets between Sydney and Johannesburg. Then, for good measure, we booked return tickets between Johannesburg and Amsterdam, as well as intra-European flights to France and the UK.

There was a small problem that had to be dealt with before I could take to the skies, namely that I had developed a mouth abscess before I was diagnosed with cancer but had been too frightened to have anything done about it. However, before the operation the anaesthetist said that I should not fly until the tooth had been taken out, as abscesses often flare up at high altitudes. So in November I summoned up my courage and went along to the dentist. 'Sorry, ' he said, 'I can't treat you because it is too soon since you had radiation treatment. There has to be a space of six months.' This meant that I would have to fly with the abscess untreated.

Fortunately, however, I had an appointment with the oncologist in mid-November so I thought that I would discuss the matter with her. But first I had to undergo the examination which, I must admit, was far from pleasant. An intern did the most of the work and I was in tears before the end of the examination. Seeing my distress, the doctor apologised and said that she should have asked how my breast was feeling before allowing a student to examine me. The doctor then had a look at me and, my distress apart, the good news was that there were no problems.

Before leaving, I took the opportunity to speak to the doctor about the abscess and told her what the dentist had said. She snorted in disbelief and commented, 'Where do all these myths come from? You didn't have radiation to the jaw!' Then she wrote a letter saying that the tooth could be taken out without any harm being done. So, two weeks before our overseas trip, the tooth was removed and it really was not as bad as I thought it would be. Within two days the abscess was gone and I was feeling much more comfortable. However, with one tooth missing -- the only one, I am happy to say! -- I must admit that I do not find eating as easy as it used to be, even now, six months after the extraction.

So, in mid-December we began our trip with a flight from Sydney to Singapore from where, after a short stop-over, we would take another flight to Johannesburg. Half-way between Sydney and Singapore, I had a strange turn. While watching a movie on the small screen in front of my seat, I started feeling ill and light-headed, and then passed out. Brian and the young woman in the seat next to me were very alarmed. In fact, Brian said that he wondered whether he would have been wise to arrange life insurance in addition to travel insurance. (I think that he was joking!) I was only unconscious for a few seconds and, when I revived, I heard Brian asking a flight attendant if there was any medical assistance on the flight. The reply was, 'Sorry, there's no assistance, but I can get her an aspirin.' These were duly delivered; I took them and then began to revive. I was fine for the rest of the flight and I



had no more fainting spells during the whole trip. Did this brief but alarming episode have something to do with my operation and treatment? I really don't know the answer.

After I revived, Brian grinned and said that, when he asked for medical assistance, he wondered if the flight attendant would reply, 'Yes, there is a Dr Harlech-Jones on board.' Brian is 'Dr Harlech-Jones', but he has a doctorate in the social sciences and knows almost nothing about medical matters. He says that if he put 'MD' after his name, it would stand for 'Medical Dunce'.

In the Eastern Cape region of South Africa, we spent time with my sister and with Brian's brother. We also contacted Brian's brother's estranged wife. (I will call her 'Susan'.) She had been diagnosed with cancer of the mouth and, at the time that we saw her, the treatment had not been as successful as planned. Things had not gone well for Susan, although the medical specialists had assured her that the cancer was gone. The symptoms and treatment were causing her pain and distress, and she looked and felt unhappy. Since then she has been back in hospital for four months and, thankfully, it appears that matters are improving.

When one has cancer and doesn't conceal the fact, you hear about many others who are worse off than yourself. Of course, there was Susan and her condition, as I have just said. Then an old friend told me about his youngest daughter, who has breast cancer. She is in her early 30's and had both breasts removed just after the birth of her youngest child. Another friend at the Christmas party was diagnosed with bowel cancer. He had had the operation but was waiting for further treatment.

The best part of a good Christmas visit was that our younger son and his wife took four days off their travels, when they were following the South Africa versus England cricket test series around the country, to visit us. We all had Christmas Day with my niece and family and then, a few days before New Year, we caught the flight to Amsterdam to visit my cousin and her husband who live in northern Holland. In spite of arriving in the midst of a great European freeze, which continued for most of the time that we were there, we had a great time. Actually, although it endangered some of our travel plans, all the snow, ice, blizzards, and cold weather added an extra dimension to our experience. In Holland, my cousin, June, and I went shopping at the New Year sales. We girls had a great time finding and buying clothing at reasonable prices, but I don't think that our husbands were all that impressed.

Next we went to the south of France to visit old friends who live quite close to the Riviera. This was slightly warmer with no snow, except on the surrounding mountains. Our friends took us on sight-seeing trips and every day we had lunch in a different restaurant: for instance, one day in central Nice, the next day on the coast near Cannes. It was a wonderful experience, except that I must admit that I was quite tired by 6 p.m. each day. However, in France, dinner is eaten at a late hour and our friend, Rachel, is an excellent cook, so there was no early to bed.

The freeze-up in Britain made us fear that we would not be able to fly from Nice to Gatwick Airport in time to catch other connections. However, by great good fortune, after three days of cancelled flights and with almost every other airport in France closed because of snow, our scheduled flight did take off. It was delayed for about three hours but, finally, it was in the air and heading for Britain.

I wish that I had sufficient words to describe the scene as our flight dropped under the clouds and cruised across the south of England towards Gatwick Airport. The countryside really looked like the proverbial fairy land. Fields, hills, trees, roads, roofs -- all were covered in thick, undisturbed snow. The fresh snow had no tracks on it. No vehicles

could be seen anywhere, except as white mounds, as they were covered by fresh-fallen snow. Then, while we waited for a train at snow-covered Gatwick station, the snow started to fall softly and fell all the way to Eastbourne, where our friends met us at the station. They apologised that we would have to walk to their home as their car was stuck in the snow. So, with the snow falling thick and wet, we dragged our suitcases along slippery sidewalks to their flat. It was a new experience and a great appetizer!

The next day, getting there by walking cautiously on snow-encrusted sidewalks, we attended a Quaker meeting in central Eastbourne. The three other people who were there apologised for the poor attendance, explaining that the blizzards and snow had kept everyone else at home.

On the Monday, we flew to Edinburgh. Once again, we stayed with an old friend. About four years earlier, David had lost his wife to cancer, so he was very pleased to see me looking so well. By this time the snow still had not melted, so we walked around the city in the cold and the snow, sight-seeing and recalling the time when we lived there for a year during the 1980s. Both of us enjoyed our visit greatly. One of my highlights was lunching at the Elephant House restaurant, which is where J. K. Rawlings wrote some parts of her Harry Potter books. Needless to say, I enjoy the books.

After Edinburgh, it was back to Holland for a long weekend with cousin June and her husband, Douwe, who took us to charming but still icy Dutch towns such as Edam, Vollenham, and Marken. Then, from frozen Europe we flew to warm South Africa for a week, thinking of sunshine and beaches. However, the best laid plans of mice and men often go awry: I got bronchitis, four days before we were due to return to Australia. I visited a doctor and was given medication, but my condition just got worse. We were due to leave on Monday and on the preceding Saturday I was so sick -- in fact, I was shaking, as if with a fever -- that Brian wanted to postpone our flights. I visited an emergency clinic where the doctor advised me to stop taking all of the medication that had been prescribed because I was having a bad reaction to one of the drugs. Within twenty-four hours I was feeling much better, and we were able to begin the return trip as scheduled.

It was a wonderful and memorable trip but, to be honest, we really should have restricted our visit to South Africa and perhaps neighbouring Namibia. My bronchitis and tiredness were messages from my body to tell me that I was doing too much across too many time zones and with too many severe changes of climate.

In the year since my operation and treatment, I have been living life to the full, and doing things that I want to. I have been motivated to get involved with cancer alleviation and care initiatives because I feel it is important for me to give back to the cancer community in recognition of what I have received. For instance, I have attended all of the Cancer Council meetings in our town, and I am thinking of joining the 'Live Well after Cancer' program. I have also been appointed to Cancer Australia's National Consumer Advisory Group, and, after attending a workshop in Canberra, I am looking forward to doing further work with the organisation. I also want to become involved in Can Assist as well as with Cancer Voices.

The Biggest Morning Tea has been another avenue of involvement. Recently, I attended a Biggest Morning Tea event arranged by my Thai Chi class after which, on the following day, the group of friends who I call 'The Wednesday Group' (that's when we meet for tea every week -- there are now 13 regular participants) hosted a Biggest Morning Tea at my home. I made a lot of the arrangements and really enjoyed doing so. Then, on the following day, the Breast Cancer Support Group had a tea at the library. It was my job to do

all of the advertising, and I also helped during the event. On that occasion, I realized that some of our group were feeling very depressed, and I began thinking about what I could do to help them to deal with their feelings.

I was also excited to have been awarded a short consultancy for a project in Uganda. In fact, I should have visited Uganda already, but the project has been delayed because of heavy rains and an outbreak of malaria.

I am writing this about one year after my operation and about ten months after my treatment ended. Of course, if I had a choice, I would not have chosen to have breast cancer. It has been a stressful, anxious, often painful, and always uncomfortable period. And yet, having said that, life is often ironical. Good sometimes comes out of misfortune, and often in unexpected ways. Now my social diary is fuller than ever, I have met new friends and acquaintances, I am wiser and more knowledgeable, and, although I am more aware of my fragility, I also feel stronger and more confident.

That, of course, is what often happens on a journey.

## **THE END**

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### **About the author**

Marie is an Australian citizen who was born in South Africa and has also lived in Canada, Namibia, the United Kingdom and Pakistan. She is married to Smashwords author Brian H. Jones and 'Dangerous Journey' is her second book.

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