

# *A 'Roller-coaster' Journey Since Early 1998*

***I'm really getting better!!!!***

**M**y eldest daughter, Ianthe, and I were sitting in the quiet, window-less waiting room in Sydney, for me to be seen by the neurologist for my yearly check up, to see how I was going with my Alzheimer's Disease, how the medications were affecting me, and whether there were any functional or mood changes that I had noticed in myself.

It was cool inside and there was very little noise, apart from the clack, clack, clack of the receptionists' keypads, and the rustling of magazine pages being idly turned. It was May 1998, and outside Sydney bustled busily in the sunshine of a warm autumn day.

I tried to focus on the article in the nature magazine before me, but inside I was bubbling over with excitement. I wanted to rush in and shout 'I'm better!' – but Ianthe, bless her soul, had been able to restrain me and suggest that perhaps if I did this the neurologist would definitely think I had 'lost it' and was declining further into my dementia.

We had talked about this in the car during the long three-hour drive on the highway from Canberra to Sydney, and she suggested that maybe I should try to stay calm and simply say, 'I think I'm beginning to feel a lot better at the moment'.

Calm?! I felt far from calm. This was hugely exciting, this was the most amazing thing that had ever happened in my life. This was something unheard of – in all of my reading about Alzheimer's I had never ever seen anything about people doing anything other than declining. Sure, they might stabilise for a while, especially on the new anti-dementia drugs. But feel better? No, that never happened.

### *1995–1998*

At first, after my diagnosis in May 1995, for a year or so I really did feel as though nothing was really wrong, and maybe it was all a mistake. But I enjoyed the time off work to be with my daughters and to rest with fewer weekly migraines. And in October 1995, the neurologist started me on Tacrine (Cognex), which was the first breakthrough drug for mild to moderate dementia, just on the Australian market. It was an anti-cholinesterase inhibitor.

These types of drug stop the breakdown of acetyl choline in the brain. So, what's so special about acetyl choline? Well, it's a chemical messenger in the brain making the neurones spark better and speak to each other more clearly. Basically you get better reception inside your head if you have more acetyl choline inside there. With diseases like Alzheimer's and other dementias, acetyl choline tends to be in short supply, so your brain gets very slow and 'foggy-feeling' inside. By taking one of these anti-cholinesterase inhibitors, you get to increase the level of chemical messenger, and so help what remains to function better. It's a bit like a staircase on the sinking ocean liner, the Titanic, taking me to a higher deck, so my feet won't get wet as soon! Not a cure, but what's called a symptomatic treatment.

But even with more of this stuff sloshing around inside my brain, by mid to late 1996, I began to notice real changes, difficulties in functioning, in remembering, in speaking, in all sorts of things. Before I

thought it was only a little problem, which could be excused due to stress. And even when faced with the awful picture of damage on the scans, I explained it all away by saying to myself that maybe I had always had this physical brain damage that showed on the scans, but had managed very well with what I had. I felt a bit of a fraud, to tell you the truth!

But by early 1997, there was no question that something was seriously wrong with me, and no amount of extra chemical messenger was going to really mask this. I had really deteriorated, changing as a person, losing the super-fast, super-smart me. I had become much slower in my speech, less able to make decisions, and more readily confused. As I slowed down further, it was as if the world was too fast for me. So much so that by mid 1997, I could not have given any talks, and I struggled to finish my first book. I was well into my journey with the disease, experiencing most of the cognitive, behavioural and neurological signs of mild to moderate dementia. I no longer drove, answered the phone or watched TV, but retreated into gardening and books, as well as very early bedtimes.

I was sinking into depression, believing the medical model of inexorable decline with dementia. And depression leads to pseudo-dementia, where you show more symptoms of dementia than might be expected from your brain damage. I was on a downward spiral of hopelessness and despair, as a result of which I was withdrawing into dysfunction. Alongside this depression were some very real symptoms of the dementia.

I began to experience hallucinations, which I found very scary, and finally asked three people at my church to pray for these to stop. I wrote briefly about this in my first book.<sup>5</sup> It's since writing that book that I have been told what really happened. Because I had closed my eyes dutifully while these three friends were praying, I had no idea that a whole bunch of my congregation had crowded round me – a bit like a rugby scrum – and prayed for me. And of course these wonderful people had no idea I had set limitations on what to pray for – simply that the hallucinations would stop – so they all prayed fervently for my complete healing. Apparently, so I learned a year or so later, there was

even someone visiting that day from the UK, who in the past had been gifted in praying for healing. What a coincidence – or should I say ‘God-incidence’?

The hallucinations stopped that day, and I have only had a few minor reminders of what they were like since – usually in the late evening, just as I lie down to sleep, and it seems to be if I am very tired or have started new tablets. I was happy enough to be free of hallucinations, but then over the next month or so, my head began to clear of the fuzzy ‘cotton-wool’ type of feeling that it felt like before. I could concentrate better, and found it easier to speak and listen. Was this the depression lifting, or was it more than that?

I hadn’t expected any more from the prayer than stopping the hallucinations, so it took me a while to realise that I was actually feeling better – definitely not something that was meant to be happening to me, nor what I had expected at all.

I began to speak on the phone again, and even to start driving again, despite the reservations of my eldest daughter, who was naturally quite alarmed at the thought of me in charge of a vehicle.<sup>6</sup> I speak of these improvements in my book, which was finished in February 1998.

But what I didn’t write about was that no one believed me when I said I was feeling better, and no longer declining as fast. It was hard enough for my three girls to adjust to the idea – and there was no proof, really. Well, not concrete proof anyway. I just seemed to be more of ‘my old self’ again. Maybe less depressed?

And given that it was my church friends who had prayed for me to get better, you’d think they would have been the first to believe me, but they weren’t. Somehow, everyone still treated me with ‘kid gloves’, assuming I couldn’t do things, so not asking me to.

But looking back now, in early 1998 was when my exciting ‘roller-coaster’ journey really started, when all sorts of things began to happen which I could never have dreamed were possible.

### *The neurologist's re-assessment in 1998*

But let's go back to the neurologist's office, in May 1998, and the beginning of my quest to prove that I really was feeling better, and battling to survive the decline of dementia by making sure I had a positive attitude. I wanted to hold onto my belief in overcoming the medical model, in allowing the unexpected to invade my life, and to allow my faith to carry me through this struggle to survive.

'Christine?' said the neurologist as he came out of his office, picking up my manila folder from the receptionist's desk, looking toward Ianthe and me with a welcoming smile. I stood up, barely able to contain my excitement, walked in, and said, before I even sat down, 'I'm *really* getting better,' in quite a firm voice, grinning widely. It was hardly something to look down in the mouth about or whisper!

'Well, that's good to hear. It seems as if you are really fighting this disease at the moment. Make the most of this temporary honeymoon,' he responded.

The neurologist's words weren't at all what I wanted to hear! Couldn't he *hear* what I was saying. Didn't he *believe* me? This was no mere stabilisation. This was no *temporary honeymoon!* I was feeling better each day. So I launched into a description of what had been happening to me over the last year.

What exactly had been happening? It had been a year of surprises, of trying to adjust to feeling better, and of then taking up this challenge to move on and make the most of the rest of my life. The words that best expressed how I felt were those said to the crippled man by Jesus, as he healed him: 'Take up your mat and walk'. That is what I felt I had done, take up my mat to start walking this journey of life in faith, to believe I was really able to do more than I had done before.

I thought back to my previous appointment the last August. 'No, I really am getting better. I drive locally again, I feel less confused and I finished the book and sent it to the publishers in January. I felt so much better, so much clearer in the head, that in February – just a few months ago – I enrolled to do a degree in Theology.' This is where Ianthe chipped in: 'Mum even got a High Distinction on one of her assignments!'

After talking with me for a little while longer, the neurologist asked me to sit up on his examination couch, and he got out his little hammer so he could check my reflexes. He also scraped my hand with something sharp, whilst peering intently at my face. What on earth did my face have to do with my hand? Ianthe asked what all these tests were. He replied, 'Your Mum had reverted to some primitive reflexes, which we see in newborn babies, and which are typical of the type of brain damage we see on her scans. This one (when he scraped the hand and looked at my face) is the pout palmar reflex, this one (when he scraped the inside of my hand and looked at my fingers curling up) the grasp one.'

'Hmm.' Then he peered into my eyes with a bright light. 'You do seem to be a bit better. Some of these reflexes are not as strong as they were. Would you mind if we did some more tests?' Would I mind? Of course not, I felt better and was sure that any test would prove it!

So off I went for all the tests again: more scans to check on how the brain damage was progressing, and more psychometric tests to test how my brain – my mind – was functioning.

The scans I had straight away, walking around St Vincent's Specialist Centre, finding all the relevant departments with Ianthe's help. The first was the computer-assisted tomography or CT scan, which would show how much of my brain was damaged. The second was the radio nuclide brain perfusion study, which looked at how what remained of my brain was actually functioning.

For this perfusion study, I was asked to lie quietly in a darkened room, with cotton wool in my ears for half an hour, then I was told a technician would come in and insert a needle in my arm, and that I was not to look at or speak to this person, as they wanted my brain to be 'resting'. Then someone would come in and take me to be scanned. It was a shock to be taken out into the corridor, after all this quiet rest, through into the noisy clatter of the brightly lit scanning room. I lay down onto a table, with a wheel-like scanner slowly clacking its way around my head making its own picture of what it saw inside.

Both the CT and the radio nuclide perfusion scans showed much the same picture – lots of damage, much more than you'd expect for a healthy 49-year-old. And this damage was in the middle, and around the front and sides of the brain. What did all this mean?

The neurologist had arranged for me to have psychometric tests in Canberra, after we got back. These tests involve sitting quietly with a clinical psychologist for two to four hours of questions and 'games'. I managed to see the same lady I had seen for my first diagnosis, and she welcomed me with a warm smile. Dark, short, neat hair, pleated skirt and simple blouse, she had a soft, kind voice. I felt very comfortable, not rushed or stressed, nor put under any sort of pressure.

But then the testing started. The psychologist slowly said numbers, long strings of them, and then asked me to repeat them backwards and forwards. How on earth was I supposed to remember these? Somehow only the last number or two she had said were ringing somewhere inside my head, obliterating any pictures or memories of a series of numbers. I repeated as quickly as I could those few numbers that were echoing loudly in my head, then made a guess as to what might have come next.

Then she told me little stories, asking me questions about them. At first she did this immediately, but then she asked me more questions about these stories after I had done other tests, and of course by then I had forgotten the details of where it had all happened, who had done what, and why and when it was!

She carefully spoke aloud a shopping list, but it was very odd, not like any you might write to go to the supermarket. It had furniture, vegetables, meat, clothes, all sorts of things mixed up together. It was impossible to hang onto the names of enough of the items as she spoke them all out, long enough to try to sort them into any category. All I could do was lamely try to recall as many of the objects as possible. There simply was not enough space inside my brain to do any sorting into types of objects, so that it would be easier to recall them later.

To sort, not only did I have to remember the objects, then label them as a category, but then I had to sort them into each category. It did not end there, because then I had to recall each category, and identify

and list what I had remembered in each category. You see, that all takes a huge amount of space up, and I was running out of space inside my head rapidly! As she spoke, I could almost feel bits of the list falling out again, so it was impossible to hold onto enough items to sort and recall.

I remember, too, being given puzzle shapes to put together in a pattern. 'Just take your time,' she said. But no amount of time would help me make sense of the shapes. They simply did not seem to make a pattern. 'It's OK,' she said, 'you still have more time.' But time was not what I needed, I needed something or someone to show me what this all meant. To me, these shapes and these story pictures had no connection to each other that I could see.

For most of these tests she used a stop-watch to record my time. I knew I was slow, so felt further demoralised in that it was being recorded for everyone – or at least her and my doctor – to see. 'Tick, tick, tick,' her watch loudly proclaimed, and my brain seemed even slower than the second hand on the stop watch, as I tried to make sense of all the puzzles laid out before me, the stories told to me, the lists of numbers to recall, the items to remember.

Thankfully, she decided *not* to do the maze test with me again, deciding there was little to be gained by showing that my skills (or lack of them) might have further declined from a previously recorded pretty low level. This was back in 1995. I had sat for what seemed a very long time, in front of a grey inanimate maze, and the psychologist asked me to use an electric rod to trace a path from the top to the bottom. This worked fine for what seemed like just a millisecond, until I made a wrong turn. An electronic buzzer sounded, loudly and insistently, feeling as if it had decimated what was left of my brain.

Carefully I traced the rod through another turn in the maze, but somehow my eyes could not 'see' a path through. There was the beginning, I could see that, and down there somewhere out of my vision was the end. But there was just a muddle of blockages, turns and twists in-between. The buzzer sounded many times, as I desperately sought to make my way from one end of the maze to the other. My score was pitifully low, a mere eighth percentile, and just confirmed

what I knew – that I had great difficulty finding my way along unfamiliar routes. It was a great relief not to have to repeat this awful experience again in 1998. After around four hours of testing, with numbers, patterns and stories, somehow she managed to gather all this together to make sense of what was wrong with me.

Her reports were sent to my neurologist, as part of his reassessment. She reported further mild decline, and indications of functional problems in the frontal and temporal areas. The neurologist decided to follow up with another scan, in July 1998, one that might be able to distinguish between the functional patterns of the various types of dementia, a positron emission tomography or PET scan. I knew what I was in for – I had already had a PET scan in 1995, and described this ordeal in my book.<sup>7</sup> You lie there with a mask on your face, your whole body laid out on a metal trolley and wheeled into this small tube. You have needles in each arm – one to put stuff in, the other to take stuff out. You have a blindfold on and ear plugs in, so that you are isolated from the world around you, and very quietly people glide in and out to take samples, or whatever, from the needles in your arms. It seems like hours that you are trapped like this, but in reality it's about 45 minutes.

The PET scanner was in Sydney, so I would need to travel back again from Canberra. It uses radioactive isotopes which have a very short half life, so need to be rushed across the road from the cyclotron to be injected into you, as you lie in a tunnel with a scanner noisily clunking around you, in the Royal Prince Alfred Hospital. Not something for the claustrophobic, I can assure you!

Finally I got the call to come to Sydney for the PET scan. But I will get ahead of myself if I tell you who took me to the bus station in Canberra that blustery July morning. Winter had set in, with early morning frosts and fogs over Canberra. But spring was on the horizon in more ways than I could imagine.

### **A new lease of life!**

The sand felt warm and finely grained between my toes and I squinted against the harsh sun in the glaringly blue sky. Shading my eyes with

my hand, I could just make out the dive boat out on the coral reef. One of those little stick figures just visible in the glare was my youngest daughter Micheline, snorkelling with a friend. This was my dream holiday, we had flown up to Gladstone, taken a helicopter out to Heron Island, and now we were relishing four days of sunshine, wildlife, and relaxation. This was a wonderful 1997 Christmas gift from my Grandma as she approached her 103rd birthday!

Micheline had made a friend, and been out with her and her family each day. I had done most of the walks around the Island, and enjoyed watching the turtles, birds and other coral reef sights immensely. But I felt very lonely – very excluded from the family groups around me and the young couples enjoying each other. For the first time in my life I began to feel the pains of loneliness. It was a real physical feeling of anguish and despair. I had always been so self sufficient, busy, focused and organised, pouring my energies into my girls and their lives, as well as my work. Now I felt empty, half of a person somehow. But I put it all behind me as we travelled back home.

‘Anyway,’ I kept telling myself, ‘it is silly to focus on my loneliness, as there is little I can do about it. After all, I’ve been diagnosed with a terminal illness, and the medical prognosis is at best for up to ten years of living at home with increasing levels of help, before needing to go into nursing home care.’

‘But surely if I am feeling better supposedly because of prayers for my healing, shouldn’t I really believe I am better and behave accordingly?’ I carried on this conversation with myself over the days and weeks ahead.

‘Well, maybe,’ I lukewarmly agreed, ‘and perhaps I should go out and socialise a bit more. But at the age of 49, where am I going to meet people?’

Church was the same group of friends, comfortable and secure. I was not meeting many new people, in a new environment. Maybe I needed to step out and challenge myself a bit more. But then, wasn’t this being silly? Who gets better with dementia? Who tries new things when they have this disease? Who’d want to make friends with me?

It was my friend Liz MacKinlay, the priest and gerontological nursing lecturer who had persuaded me to write my first book, who encouraged me to consider going to study at St Mark's Theological College. I mused at the possibilities here – I would meet people for sure, and it would be a supportive and positive environment. I felt really challenged now. How could I sign up for a degree, nine years part time, when I was declining every day with dementia?

Alzheimer's is meant to take away your ability to learn new things, like getting to new places, meeting new people, doing new things. And here I was thinking about a degree!!!! The conversation in my head began again! 'But didn't I really believe I was getting better?'

### *Embarking on studies*

One day in early February 1998, just a year after my surprising Heron Island experience of loneliness, I had dropped my daughter off at school, and was driving along a road in Canberra, one that leads across a bridge over the still grey waters of the lake. Just before the bridge, I realised that St Mark's College was just over the road.

It was a beautiful sunny day, I was in no hurry, and thought that maybe I would just pop in and find out about their courses. The lady at the desk gave me the information and then asked if I'd like to meet the registrar to find out more. 'OK,' I said, 'I'd like to know a bit more about how many units you have to do and in what areas, and how long it takes.' The registrar ushered me into her small, chaotic and paper-strewn office. I sat on the only chair that was not covered with papers.

She was enthusiastic, warm and welcoming. 'Courses are starting next week. Why don't you simply sign up now? I can get you in right away if you want. Here, take this form with you and you can drop it off later on today if you want to go ahead.' Looking at the form at home, I laughed out loud at the section that said 'Do you have any disabilities that might interfere with your studies?' Carefully I wrote in 'Alzheimer's Disease', thinking how ridiculous this would seem to the university administration. Maybe they would treat it as a student prank?

But I was worried. How would I cope trying to listen to lectures, absorbing new information, meeting new people, and doing essays on topics about which I knew nothing as yet? It was a great relief when each of the lecturers I met was kind, and asked what they could do to help me. They knew about my diagnosis, and about how I was trying to live positively each day, and to overcome my feelings of despair.

It was clear to them and to me that I could not hang onto new information for very long, but that I could interact with ideas, work on reading and taking notes, and try to prepare essays with lots of time. Many days I was simply not able to study – my brain was not focused, my head hurt, and my eyes somehow would not work properly. I needed clear lecture notes, time to read and absorb, and it was soon easy to see that I would cope better working in the distance education mode, with frequent visits to the College when I felt well enough to do so.

Meeting all these new people was wonderful, and I felt as if I was beginning to crawl out of my shell. It was stimulating to have new ideas, facts and issues being debated around me, to have challenges such as trying to write an essay, and to manage to get my increasingly limited brain space to absorb and process concepts that were totally new to me. I enjoyed the quiet of St Mark's library, with its smell of old paper, and its closely spaced high shelves full of tightly packed and catalogued books, which had been opened long ago by other students seeking information. I bought a new computer, and learnt how to use all its various functions. Searching the Internet became a passion, as did reading and discovering so much new information.

My studies went very well, and when my first essay was returned to me with a High Distinction I realised that the bits of my brain that were left were obviously still working very well indeed! Maybe my 'brain steroid' – my anti-dementia drug – was giving me an added advantage. It certainly was clearing the fog in my brain, and helping me to function, slowly but capably.

But still I had this medical diagnosis and prognosis hanging over me. I had been told the standard dementia script by the first neurologist I had seen: 'You have about five years till you become demented,

then a few years after that in a nursing home till you die.' It was so hard to shake off this dismal prognosis, and to just take each day at a time, as my current neurologist was encouraging me to do. How could I believe in a rosy future, in completing the entire post-graduate diploma course? I was doing this part time, and I was certain I could not last the distance.

Going to the neurologist with Ianthe in May 1998 for the check up, and for the follow-up scans and tests in July, was a 'circuit breaker' for me. Either I was really improving, or maybe I was staying on a plateau without getting any worse, or feeling better was just a figment of my imagination. The neurologist would be able to see whether the prognosis was still as bad as it was the year before. This would really help me to believe that I had a future, one in which the prospect of actually gaining a new qualification was a possibility. I was happy to do as many tests as he wanted.

While undergoing all the tests in Sydney, I began to think 'What if I will last a lot longer and not get so sick so soon?' But this happy prospect of good health brought with it feelings of sadness, as then as I would have years and years alone to experience the pain of loneliness that I had felt – an almost physical feeling – whilst on Heron Island.

### *Wishful thinking, or a vision of the future?*

I used to sit in my living room, teary and lonely. 'What a wimp!' I thought. 'How come this is the first time in my life that I have ever wanted a companion? What's wrong with me?' I think my girls sensed that I was not quite as content as usual with my own company, and for Mother's Day in 1998 they gave me a teddy bear. Certainly an improvement, but not quite the real thing!

That May/June, I was reading my daily bible study book.<sup>8</sup> I was astounded as before me was a series of meditations on loneliness. I sobbed my way through each of these, often praying passionately, and realising what fervent prayer really was. There I was, prone, weeping with the tissue box beside me. Thank goodness no one was at home to see me!

But then during one of these times of weeping and praying, I had this strange picture in my head, almost like a video clip, maybe some people might call it a vision. In this 'waking dream', I felt that I was in the passenger seat of my own car, with a pile of papers on my lap, the engine running and the driver's door open. Somehow I got the feeling that my life partner was going to get into the car, and that I had the maps on my lap, with which to help him in his ministry and our life together.

Well, I was sure this was just wishful thinking, of course. Maybe I had fallen asleep and had a dream. Wouldn't you? Anyway, I soon forgot all about this silly bit of fanciful thinking, and got on with my studies.

But the loneliness became stronger, the emptiness somehow more overwhelming, so I reviewed my life. Where was I going to make new friends, where was I going to meet people who might take me out for dinner or to the movies? Not at church, everyone was too busy and too protective of my health. Not at studies, everyone was focused on their work, and their very busy lives.

### *Meeting Paul*

I had been at St Mark's College for a few months and things were going well. Now Ianthe was driving me from Canberra to Sydney for my check up with the neurologist. We chatted about this and that as the tarmac road hurtled beneath, and the bush landscape rolled past. Finally I managed to pluck up courage to really open up and share with her my feelings of loneliness. Soon I was sobbing my way through several tissues. I said how I was so shy and would find it very hard to meet anyone, as I was too afraid even to ask someone to come for a cup of coffee with me.

'I can't believe you, Mum. You always seem so sure of yourself. So in control. Surely you could simply ask someone to have coffee with you?'

'I could if it were a woman, but I would be literally shaking if it were a man,' I confessed. I talked about the possibility of joining an

introductions agency, and wondered out loud if God could work through such an agency to find the right person for me.

Finally I was very bold, surprising myself and all my friends. Maybe it was really a sign of dementia to be this impulsive, to act this much out-of-character. But I managed to pluck up the courage to sign up to an introductions agency. In my prayers I made this deal with God, that if it was his will for me to be alone for the rest of this new life that I thought he had given me, then that was OK. However, if not, could he please work through this agency to find me the person he had chosen for me.

THE PHONE RANG loudly in the kitchen – it was the lady from the agency. 'We have a nice gentleman who we think you would like to meet. His name is Paul and he has been a diplomat for the Australian Government.' She told me he liked sailing, music, motorbikes and travelling. This sounded very intriguing. So I said 'OK, he can give me a ring on Friday evening.' The agency suggested we arrange a meeting somewhere in a public place for coffee or a walk.

I was so nervous on Friday evening, and when the phone rang, I picked it up hoping my fear could not be heard, as I said 'Hello, yes this is Christine.' We arranged to meet on the steps of the National Library for a walk by the lake, at 12 noon on Saturday.

The next day I felt ill with apprehension! I dressed in my purple trousers and silk jacket, woollen gloves and comfortable walking shoes. My hands were sticky and it felt difficult to breathe easily. It was a sunny but very chilly winter's day, with the sky a deep clear blue, as I drove into the Library car park wondering which car might be his.

I stood on the steps as this man about my age came towards me, smiling. He had blond reddish hair, glasses hiding his watery blue eyes, neatly trimmed beard, and a cord jacket and trousers. I was trying to take it all in. What was he like? Would he like me? Lots of thoughts filled my mind as he thrust a bunch of bright yellow daffodils into my hands. 'Hello,' he said, 'I'm Paul.'

I was overcome, not knowing whether to take off my gloves to shake his hand, where to put the flowers. Fumbling around in shyness, I thanked him for the flowers, stuffed my gloves in my pocket and shook his hand! Self-consciously we walked off together towards the still grey water of the lake, as I gripped tightly onto my bunch of flowers. We decided to lay the flowers on the nearby memorial to a girl who had recently been tragically killed in an accident there.

We started walking around the lake, talking about our lives, our children, our family life, where we had worked, where we had lived. Paul said he had a simple lunch in his backpack, and we decided to stop at a picnic spot just around the lake. He produced a blue seer-sucker table cloth from his backpack, laid it out on the picnic table and proceeded to lay out a magnificent spread of crusty bread, cheese, pickle, butter, plates, knives and even French wine and wine glasses! I was overcome.

Paul was so nice, that I felt terrible about *not* letting him know about my illness beforehand! I plucked up enough courage to tell him the whole truth about me, about my illness, expecting this to be the last time I would see this wonderful person. After all, who wants to date someone dying of a disease like Alzheimer's?

So sitting on the wooden bench in the chilly Canberra winter sun, I sipped my red wine, and told him all about my diagnosis with Alzheimer's Disease. I said that the doctors thought that I would need full nursing care in about five years, and would probably die a few years after that. Paul talked about his father dying of Alzheimer's, and did not seem at all put off by what I thought was bound to be the end of our relationship, when it had hardly begun.

We continued walking around the lake until the light started to dim, and the air became chilly and damp. Finally we decided to go back to our cars, realising that we both had sore feet and hoarse throats! As we dawdled at my car door, to say goodbye, I plucked up enough courage to ask Paul if he would like to see a movie I had wanted to see, but knew my girls did not want to go to. We arranged to meet again the next day and saw the movie.

As we sipped our hot coffee at a nearby café after the movie, I told Paul that I'd be away for a few days with my daughter, to visit my dear friend Leanne. I had spoken in my book about meeting Leanne every Friday evening for dinner, to commiserate and reflect on the past week.<sup>9</sup> She had now moved away to a farm south of Canberra, so the next day, Micheline and I boarded the bus for the six-hour trip. We had a wonderful time, sitting in front of a roaring log fire, walking in the beautiful countryside, tasting delicious red wines, and of course talking for hours, sharing all that had been happening in our lives. I told her about meeting Paul, about how lovely he was, and yet how I felt bewildered, bemused and perplexed, and wondered what to do.

When Micheline and I returned home, the answering machine was blinking insistently. I pushed the button and heard several messages from Paul, each one becoming more anxious as to when I might be coming home. Soon I plucked up courage to ring him, and he sounded delighted to hear my voice.

We saw each other a great deal those first few weeks, and of course now I can tell you that it was Paul, in his modest red car, who dropped me off at the bus station that cold day in early July to travel to Sydney for my tests.

A few weeks later we travelled together to Sydney to visit his family for his birthday. His mother greeted me warmly, and made me feel very welcome. We went with her to meet Paul's brother Ian and his wife, at a delightful Japanese restaurant nearby. I was so nervous. What would his brother think of me? But soon I felt right at home, as we chatted away over sushi and tempura. As we said our goodbyes in front of the restaurant, Ian gave me a big hug and said 'Welcome to the family.' I was overwhelmed. That night, before going to bed, I gave Paul his first big hug from me, and wished him a very happy birthday. My emotions were in turmoil!

But over the next few weeks I realised there was a large part of my life I could not really share wholeheartedly with Paul. I was a strong Christian, with a supportive church family. I went regularly to church and read my bible, and my faith had sustained me through so much.

Paul believed that God probably existed, and he went to church at Christmas and at Easter. His faith journey was very different.

Finally I suggested that Paul go back to the agency – much to the astonishment of my girls who knew how much I liked him! Ostensibly I said it was because I was only his first introduction, and there must be lots of lovely ladies waiting to meet him, so it did not seem fair to him to only meet me, someone who had Alzheimer's Disease. Paul and I had often joked about the agency being the Old Dog's Home, and that we were like a couple of lost old dogs who were looking for a good home. Back to the Old Dog's Home Paul went! He got a list of names from the agency, but never got to ring them!

Instead, my phone rang, insistently and loudly on the following Monday morning. It was Paul. 'I want to marry you, and take care of you, as I think I have been told to look after you.'

I gulped, this was all too much to take in, we had only known each other a few weeks! I said 'Perhaps you could come over for lunch and we could have a chat?' I put the phone down, my mind reeling. Yes, Paul was lovely, but this was so fast, so sudden, so unexpected. And just who was it who had been speaking to him about taking care of me?

He came rushing in that lunchtime, a big grin on his face, eyes shining, face beaming with delight. He started to tell me about the previous evening, when he had been sitting in his bed, ready to go to sleep. Suddenly the room was full of this vivid movie, perhaps like a waking dream. He was amazed as he saw us riding together on a motor bike, with a side car. We got off to look at the sunset, and a towering shimmering being got out of the side car. This shimmering being then calmly put me on the back of the bike, turned around and said to Paul, in a quiet, firm yet gentle voice, 'I will take care of her now', and rode off into the sunset with me.

Paul felt strongly that this vision, or whatever it was, meant that he had been told to look after me until I died, when I would be taken safely away. Medically that could be in a few years time. He became a Christian, joined me at church each Sunday and came to my bible study group, and began a rapid learning curve of living joyfully in faith

as part of the family of Christ. And the poet in him began to flow, to burst out of him like a release of love and joy!

First Paul wrote this poem about how it did not matter if we only had a few precious years together, before I declined and died with dementia.

### **How long**

How long do we have before our candle's out?  
 Forty, ten years, five, one?  
 Six months, a week, a day – too short sure!  
 But I'd not complain. Better one day than none.

Then he wrote this next poem about how he would be there for me until I died with dementia, and that when he in time died, we would be together again.

### **When you lie down to sleep**

When you lie down to sleep  
 I'll hold your hand.  
 Soft breathe, calm heart, content.  
 When you lie down last to sleep  
 Soft breathe your last on the Valley floor  
 I'll hold your hand  
 Not content until  
 My heart slow stops  
 Then content we're one once more.

Soon the muse and the poet were spending a lot of time together. Paul came round for breakfast, lunch and dinner, only going away to work and sleep. It was as if he didn't want to waste any time, a precious commodity for me. We packed a great deal of talking, of sharing, into just a few months.

It was a time during which my daughters needed to adjust to this new person, competing for this precious time with their mother who

was battling a terminal illness. It was not at all easy for them, especially for Micheline who was living with me at the time. We had become very close, just the two of us, after her sisters had left to go to university.

A few months after Paul and I had met, when Ianthe and Rhiannon were home, we all sat around the dining table, after eating our Sunday roast dinner. Paul stood up and gave a little speech to my girls, in which he promised that the only hand he would ever raise to me would be one to help. There were a few teary eyes around the table that day, as the girls and I realised his sincerity and willingness to begin this journey alongside us, the dance with dementia.

*Vision becomes reality!*

The phone rang, while Paul and I were busily preparing a meal together one evening in September 1998. I picked it up and it was the neurologist with the results of all those tests in May and in July.

'I've looked at the scans, and compared them with those that were taken three years ago now. I've also examined the psychometric follow-up tests.' He said, 'The pattern does not seem to be typical of Alzheimer's, and is more like a fronto-temporal dementia. Also from what I have seen in your functioning, and the differences in the various scans taken now and back in 1995, it does appear as if the deterioration is glacially slow.'

I was speechless! I managed to squeak 'Does this mean I might live long enough to see my girls graduate, to see any grandchildren? Could I last another 10 years or more?'

He quietly replied, 'I don't see why not, given the current rate of decline, and your ability to keep functioning.'

We danced around my kitchen at this news! We would have more time together that either of us had dreamed could be possible.

A FEW WEEKS later, I drove my little green car to Paul's house, as we planned to go together that evening to a sailing club meeting. We agreed to go together in my car, and as I was tired, Paul would drive.

Paul sat in the car, started the engine, and studied the maps to work out where the meeting was. But then he suddenly remembered that some papers were still in his house, so he gave me the maps, leapt out of the car, left the door open, and the engine running, and dashed off to his house.

I had forgotten my strange vision up until that time – but it certainly came back vividly at that moment. There I was, in the passenger seat of my car, engine running, driver's door open, and a pile of papers on my lap. I felt quite wobbly inside, with shivers down my spine. Tentatively, I shared this with Paul as we drove to the meeting.

IN JULY 1999, I was sitting in my counselling class at St Mark's, with my colleagues, wondering why Paul wanted to meet me there for lunch that day. Just an hour later, I walked back into my next class, with my world changed forever, and I started to tell them why I looked so radiant.

Paul had led me by the hand into the small, slate-floored chapel. We had sat quietly on the low wooden bench, gazing out of the beautiful glass window, with its frosted design of a cross. Beyond the glass pane was a swathe of moist green grass, dappled with the shadows of a large tree, where small birds chirped and flurried. In the distance was the calm water of the lake.

Paul dropped to his knees, took out a small box, and said 'Christine Eva Boden, will you marry me?' I was speechless and overcome. All I could manage was a breathless 'Yes'. I put on the ring, a large blue topaz that his mother had bought many years ago in Brazil, when she travelled there with his father to visit Paul. It was a very special gift to us, carrying memories of his father, and representing his mother's love and acceptance.

What followed was a frenetic time of organising by my church family, as we planned to get married just a month later. The love they showed us was amazing. All the organising, the flowers, the invitations, all the arrangements were taken care of, so a great weight of

worry and anxiety was lifted from me. All I had to do was organise my dress.

Why the rush? Not only were we both conscious of our time together being precious, but we had talked to my mum in England about arrangements. She was unable to come, because of her health, but she really wanted my brother-in-law, Ivor, to give me away on behalf of my father, who had died the year before I met Paul. And my sister and Ivor, who lived in Hong Kong, were able to come across to Australia with their boys only if we were able to set a date sometime in the last two weeks of August.

We managed to organise the wedding for 21 August 1999. It was a warm sunny winter's day, and the church was filled with family, friends and relatives for the celebration. As I got out of the car with Ivor, and arranged my gold dress, I tried to hold my creamy orchids steady despite my shaking hands. I was so nervous! All morning I had busied myself, getting fresh flowers in my hair, make-up on, and my dress. Flowers had arrived from friends, so the house was filled with their delicate scent. All too soon, Ivor was there with the white wedding car, with its white ribbons.

At the door of the church, Ivor took my shaking hand, speaking to me gently, and encouraging me. Then he led me slowly up the aisle, through the lines of people standing, and there was Paul waiting for me at the altar, grinning with his white silk jacket and gold cummerbund. Our minister guided us through a delightful celebration in which we exchanged our vows, and shared our joy, our faith and our hope with friends and family.

A very special moment in the wedding ceremony was when we washed each other's feet, using a thick new fluffy white towel, and a basin of warm water. We wanted to demonstrate how we would be caring for each other's needs in love, like the description of Jesus washing his friends' feet. It was deeply touching for our friends and family, knowing the journey that we were to make together, this journey with dementia.



Our wedding

My friends said 'We were all so overjoyed! Just four years ago we thought we would lose you to Alzheimer's Disease. Now you are still here, and getting married to such a lovely man. What a miracle!' Each day since that crisp sunny August afternoon does seem like a true miracle to me – not only am I better than I could have hoped for, but I now have a loving husband who shares my strong faith. Even just a few years ago, I could not have dreamed any of this was possible.