

## Chapter 2

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# The first signs

I sipped my wine, savouring the flavour of the crisp dry white, my usual order, as well as the warmth and bustle around me. The restaurant was packed, as it usually was on Friday nights – each table of diners was noisily enjoying food and company, waiters were rushing by, laden with plates of steaming food – and the smells of delicious Italian food were tantalising.

After we had said grace, my friend Leanne offered me the plate of crunchy, buttery herb and garlic bread, and we sat quietly for a few moments, as the week's tension and busyness ebbed away. We came here almost every Friday, hurrying up the street from her house, to the welcome we knew awaited us.

It was mid-winter (August) 1994, and for a couple of years we had been sharing our Friday evenings, mostly over wine and pasta at her local Italian restaurant. We talked about some of our week's events, laughing and sympathising, offering advice, consoling, and then reflecting on a whole stream of experiences that had flowed through our lives over the past year or so.

I forked up my last heap of pasta, and said: 'You know, I seem to be living on a giant roller-coaster – "God's roller-coaster". Every time life seems to settle down, off I go on some other hair-raising loop or dip. It's been like a switchback ride this past year for me!'

Leanne agreed, 'My life is a bit like that, too, and somehow our faith keeps us going, no matter what.'

'Yes, it's a bit like the wheels of the roller-coaster cart, keeping us clinging onto the rails somehow.'

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I drained my glass, leant back, and thought about my experiences in 1993 and 1994. 'I think I've been on a fast and furious section of this particular roller-coaster for the last two years!'

If stress can begin to show up the symptoms of Alzheimer's, then 1993 and 1994 could have easily done it for me.

Life at work up to late 1992 had been stressful – but I still loved it, thriving on challenge. I headed up a division in the Prime Minister's department, of about 20–30 people. We advised the Prime Minister and his science minister on science and technology issues, we supported the chief scientist and his work, we managed the Cooperative Research Centre funding budget of around \$130 million per year, and we were responsible for bringing to the government's attention important science and technology issues for the country's future.

We had also coped in 1992 with a change of Prime Minister, from Bob Hawke to Paul Keating. This was followed by changes of the science minister and his staff, as old allegiances were punished and rewarded; then of our departmental head, making way for new blood; and of the chief scientist, as ill health and all the changes took their toll.

It had been a tumultuous year – of changes, of uncertainty – but also of some successes and achievements. Science now received more attention in our department and in the Prime Minister's office, and we had managed to achieve some important gains for industrial research in particular. My working hours easily topped 70–80 hours a week, with a bulging briefcase coming home with me each night. But work was exciting and challenging, and I felt a bright future lay ahead in 1993–1994.

But I could not have been more wrong.

It was just a week or so before Christmas 1992. I had come home exhausted from a long day, and wondered when Ianthe would be home from her cricket camp – was it today or

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tomorrow? I sank into bed, she was still not home – maybe it must have been tomorrow she was meant to be back.

I woke up to a whispered 'Mum, could we talk? Now?' Ianthe was kneeling by my side of the bed. I blearily looked at the glowing red numerals on the clock – it was two or three in the morning. It must be serious I thought, and my heart started thumping.

We crept into her room, and sat on her bed. Ianthe said that her friend from cricket was still in the living room and had refused to go home until she told me what had happened on camp. Ianthe had been found, by this friend, unconscious, bleeding profusely from her slashed wrist. She had been taken to hospital, but was OK now. Our family doctor had been informed of this attempted suicide.

I was shocked, speechless, terribly sad, and just didn't know what to say or do. I sat there quietly gathering my thoughts, carefully thinking over each word I would say – this was a critical moment in my life – I must not get it wrong. I began to share a little of the despair that had haunted my days as a teenager, and in my twenties, without God and without hope. I, too, had felt that life was not worth living. Now I tried to comfort Ianthe and sent her friend home, thanking her for her help.

The next day, we talked some more, and agreed that she would go to talk to a counsellor. We also agreed we would not tell her dad, because we thought he would belittle her, and make cruel fun of her in some way.

The counsellor, after one session with her, asked me to come for counselling too. It was clear why, on my first visit. The attempt at suicide was a cry for help, a cry of desperation – on my behalf too – because Ianthe and I had been, and still were being, physically abused by my husband.

I went two or three times, more than Ianthe, but I, too, needed to talk, and to listen.

These sessions made me realise the harm my marriage was doing to my daughters. The fears were that they, too, might marry violent men; that they could suffer hidden emotional

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trauma for the rest of their lives; that Ianthe could not – would not – ever come home again while I stayed with my husband; and that I was actually scared of being killed one day. Could I – should I – live like this?

My choice had become very clear – the precious lives of Ianthe, Rhiannon and Micheline, or carry on pretending that my marriage was OK, when it wasn't.

Ironically, both Ianthe and I were hit during these few weeks of counselling. I felt devalued, emotionally fragile, and very shaky.

This precipitated my final decision to leave, and I started to look for a house to rent. I had another week or so of holiday left to deal with this. Some holiday!

I was sleepily drinking a morning cup of tea a week later, when the phone rang. It was for Ianthe. She said little, put the phone down and rushed to her room.

I followed her in and found her crying. Unprecedented! Only the previous week I had got a letter from the counsellor saying that one problem that had not really been resolved was that Ianthe felt somehow that it was wrong to cry. Maybe this was because she needed to feel strong, not powerless, in the face of violence.

The call was from the army. They had reviewed her files, and she was not medically fit, due to her poor eyesight, to be admitted to the Australian Defence Force Academy to study for her engineering degree. But she was due to start at the Academy in nine days' time! We had bought her things, and were packing up her room.

What about other university choices? The very next day was the last day to make second round choices for university places!

The army had tested her eyes back in October – so why did they suddenly discover this problem now! But arguments were not going to help, action was needed, so she and I took off for Sydney to apply in person to the clearing house for second round offers – it was too late for the mail.

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It was a three-hour drive there and another three hours back. The summer heat was stifling – 40 degrees Celsius. Our eyes felt like fried eggs, our backs ran with sweat. Our emotions were a blank tangle of confusion, dismay, anger and frustration.

Over the next week or so we made the trip again, for medical reviews of the case, but the army would not be moved. There was no chance of organising a university place other than locally – there was no time to organise the upheaval of a move and so on. So she stayed in Canberra, and planned to do science/engineering at the Australian National University.

I went back to work in late January 1993, with my home life in turmoil. But at work, I was frenetically busy as usual. It retained a semblance of normality for me, even stability.

But then in March 1993, an election was called, and Keating – despite the pundits – won. ‘A win for the true believers,’ he called it. Yet again, it meant follow-on changes, even though the Prime Minister and his party retained government. Inevitably there were promotions, ‘rewards’, and reshuffles.

For my division, it meant a new science minister to work with. The previous minister had been a real sweetie, and was a delight to work with – polite, quiet, small stature and an alert and welcoming expression. He would ask questions, discuss issues, and always want to weigh up the pros and cons, and be willing to consider carefully any advice.

In the preparation for his Science Statement in mid-1992, I had often written up the minutes of a particular item from the Cabinet meeting, and then gone up to his office in the small hours, in the sure knowledge that he and his staff would be waiting to welcome me with a glass of white to sit back and review the success or otherwise of the proposals he had put to Cabinet.

We had worked well together, and shared a common hope of seeing science and technology gain more prominence on the national agenda. Tempered, of course, with the ever-present

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need to use any taxpayers’ money wisely and frugally, and to encourage business investment wherever possible.

The new science minister was a tall bear of a man. He towered over me, and my eyes were level with about the bottom of his tie. He abounded in energy, in determination, and in forcefulness. He was in charge, and his views would prevail. He was determined to make changes to Australia’s research institution, CSIRO – moving fisheries research out to form a new national marine institute, and moving the nuclear research body in to be managed by CSIRO. He was supported in these proposals by the chief scientist, who was a member of his office staff, although also working in our department supported by my division. A difficult situation, as it turned out.

I failed to see the logic in these proposals. It didn’t seem to save money for the taxpayer, indeed it would cost money, nor did it seem to promise any extra benefit to the nation from research. This set the scene for an ongoing and tense confrontation.

Much of my time was spent in many telephone calls and meetings, briefing papers and, euphemistically speaking, ‘full and frank’ discussions with the minister and his staff! Frequently I’d be summoned to his office, shouted at, and I’d have to repeat – quietly but firmly – for the umpteenth time why I didn’t think his plans were such a good idea.

People from the scientific and industrial community would ring me, complaining and giving their views and objections. The head of our department would call me into his office without notice to find out what on earth was happening. The Prime Minister’s Office would summon me, wanting to know the latest in the stand-off.

And, of course, there were difficult silences and circular arguments with the chief scientist, who was normally a charming and welcoming family man, whose office in our department was just a corridor away from mine. Repeatedly I’d ask for a rationale to support the dramatic nature of all the changes proposed, but whatever was offered always fell far short of justifying what was needed.

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In the end the proposals were dropped, but not before the science minister had rung my department complaining about me.

I peeked into Ianthe's room – her light was still on. It was the week after Easter and she was still struggling with glandular fever. But there she lay, with a huge book propped on her knees. I suggested she go to sleep. 'No, Mum, I've got exams and pracs all week – I *have* to study. But I don't know how I'll cope, I've got assignments due, too!'

Clearly the stress of doing a double science/engineering degree, with two faculties setting work independently of each other, made an almost impossible load. Together with her illness and the stress we were going through as a family, this was taking its toll.

'Why don't you just stop the course now?'

'But I'll fail if I stop now.'

'No, I mean withdraw, and take the rest of the year off.'

She was relieved, and amazed that I'd suggest that, but we agreed that next year she would try for Physiotherapy at Sydney University, with sports science at Canberra University as her second choice.

I said it would also be very helpful for me to have help at home while coping with the move to a new house – and it was indeed a real blessing to me for the rest of 1993, particularly the next few months.

It was a cold, bleakly grey Canberra autumn day, in May 1993, when I finally left my husband, taking with me 18-year-old Ianthe, 12-year-old Rhiannon and 8-year-old Micheline, as well as 16-year-old Buzz (our cat) and our recently acquired budgies.

We backed out of the driveway as the removal van was loading on our 'share' of the household goods. We had just experienced a weekend of trauma – arguments over each piece of cutlery, each item of furniture, each bed, each chair. I could have half, no more – so the girls could not even have each of their beds, nor their bed linen. I was wrung out and exhausted.

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But our new home was a haven of peace. For the first time in my life, I looked forward to coming home from work. Each of us relished the chance to live together as a family, rather than be isolated in our rooms, avoiding the source of our fears.

No-one at work, apart from Margaret, my personal assistant, knew anything more than that I had moved house.

In the Budget of 1993 the division heads in my department had been asked to propose as many ways to save money as possible. I had put forward a number of minor savings proposals, but felt that everything in science had already been cut to the bone. There was nothing left to take.

But Cabinet decided otherwise. Instead of minor savings to the Australian Science and Technology Council, it was to have its budget slashed by 45 per cent, and its staff would be moved from independent offices immediately into my division.

For months I reeled with exhaustion, talking to staff, endlessly reviewing figures, and meeting with the Council members. There was a great deal of anger, resentment, mistrust – and much of this was directed at me. I was seen as the devil, complete with horns and a tail, who had caused this to occur.

No-one at work seemed to notice anything wrong with my performance. I coped, and coped well, succeeding in bringing about the changes the government wanted.

But at home, I let my guard down.

I was sitting at the kitchen table we had borrowed from Leanne, sipping my mug of tea before starting my busy round of Saturday morning activities – shopping, washing, cooking, cleaning... Ianthe was sitting up on the counter, talking to me, explaining, expounding. But she finally exploded in exasperation, 'Mum, I just can't believe you hold down such a responsible job. You're simply such an airhead at home!'

I mumbled about just feeling burnt-out and stressed. I needed 'brain time out' at home. 'You make the decision – I have to make too many of them at work.'

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A few months later, Ianthe had just had a knee operation, so I was driving her to her regular tutoring session one evening. She directed me to the house, and I waited outside in the car with my 'in-tray'. I was never short of a huge pile of material to read, to comment on, and to make decisions upon.

Ianthe got back into the car. There was silence. 'Go on,' she said.

'Could you direct me?'

'But we only just came here! All right, just turn up here, left, up the hill.'

We reached the T-junction at the top. 'Well, you guess which way we go now!' she said jokingly, thinking anyone would know.

But I didn't, and guessed, and guessed wrong.

'I can't believe you just did that!' Ianthe said.

At work, I was suffering from thundering migraines. Each week they would set in by Monday afternoon/Tuesday morning, and only slowly lift at the weekend. Margaret would always know when I was sick – she'd see it in my eyes and say, 'You're looking a bit grey and pale. Are you OK? Shouldn't you go home? I could reorganise your schedule.'

But I always had far too many things to do, and would take handfuls of tablets to keep the pain and nausea under control, as well as reduce the migraine itself. I'd avoid eating in case I threw up, and would stand up slowly to avoid passing out from both the pain and all the tablets.

I sought permission from my departmental head to take extended leave from mid-November through to early February. He knew I had just had a gruesome year at work – with the CSIRO proposals and the new minister, and delivering a massive budget cut to an understandably unwilling and uncooperative body – and agreed. I think he also had an inkling that all was not well at home.

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I rang my mum and dad, and said I was planning to visit, with Rhiannon and Micheline, and could they possibly lend me the money until the property settlement came through. They were thrilled, but refused to lend the money – instead they insisted on giving it to me. This was actually a great relief, as financially I was really struggling. I was paying rent for our home, as well as the full mortgage payments on the family home where my husband was staying, meeting lawyers' bills for the property settlement, and paying all the usual bills, school fees and so on.

Rhiannon, Micheline and I boarded the jumbo at Sydney, and I sank back in my seat, sipping orange juice and delighting in the excitement and apprehension I saw in my girls as they experienced the thrill of this huge machine powering up for take-off.

Ianthe had waved us off at the airport, after teary farewells. She had been selected to play national representative cricket, and was to play in Perth – a once-in-a-lifetime opportunity for her.

The girls and I did all the tourist things in London, and came home each evening to my parents' welcoming and cosy house, to inviting meals and to soft warm beds. We each (even me!) got pocket money from my dad – he clearly delighted in treating us, and we were overwhelmed by his generosity. We then visited my aunt and grandma in Belgium, and then spent some time seeing a few sights in Belgium, Holland, Germany and France – with me driving a car on the 'wrong' (or right) side of the road. I managed – but only just!

It was freezing cold in the northern hemisphere January. Even Eurodisney was deserted – but the girls got to go fourteen times on the roller-coaster with no waits between! We made the most of our time, seeing castles, flooded rivers, and the changing cultural scenery of a land that has so much history.

We then started to turn back for Australia and the warmth. We stopped at Hong Kong to visit my sister, Denny, and her family, spending a few weeks thawing out, and having some family time together.

I sank back into Denny's leather couch at one stage and said: 'I still feel burnt-out and exhausted!'



*Overseas trip in 1993; Micheline and Rhiannon in Brussels eating waffles*

She took me for a new hairdo, a new outfit. I was much spruced up on the outside, but just as ragged and exhausted on the inside.

A nut-brown Ianthe met us at the airport, delighted to welcome us home in early February 1994. She was a little fragile, as my husband had been ringing her at all hours, embarking on some very strange conversations. So much so, that she had gone to stay with Leanne.

I'd only been back a few days when my husband started to come round, often very late at night, quite distraught, to talk.

The stress of my leaving him, and then going overseas for such a long period, clearly had been the trigger to a major breakdown. Also, the property settlement had just gone through, and even though he would get more than 60 per cent, the reality had hit home – he would now have to vacate the family home, sell up, and make moves to finding some way to support himself. But he was in no mental state to cope rationally with any of this.

The February summer nights were warm and balmy, so I would lock the security door, and if and when he arrived, we

would hold tense and very weird conversations through the wire mesh about things he accused me or others of doing, or things he believed he had done. Many times I would say, 'These incidents, I know, are very real for you, but I really don't remember them – they really didn't – couldn't have happened.'

I felt inadequate to deal with these problems.

It became quite serious after a week or so, so I rang Margaret and asked her to reorganise some meetings so that I could take much of the day off work in order to seek medical help for him.

Later in the day I went back to work, as if nothing had happened. 'A bit of a medical crisis at home,' I said.

Only a month or so later, the government decided to reshuffle ministerial responsibilities, and there would be a new science minister. Hooray! I thought – anything has got to be better than my ongoing difficulties with the current one.

But the government also decided that the current science minister would gain responsibility for the Cooperative Research Centres Program, and that its staff were to be moved from my division in the Prime Minister's Department, to his department. Maybe this was some kind of trade-off.

For me, it was a traumatic time. We were informed in the morning, and by that afternoon the staff would no longer be in my division. Also, the painstaking work we had just done to accommodate the extra Australian Science and Technology Council staff had been pointless, as there would now be plenty of room!

The office was in turmoil, staff were unhappy, confusion reigned.

Yet again, I felt as if I was rushing down another loop on my switchback roller-coaster.

I was still getting debilitating migraines, more and more frequently. I thought maybe what I needed was a change at work. So I went for a couple of interviews – and unlike any of my previous efforts to get a new job, I was unsuccessful each

time. The interviews were, for me, a source of panic as I kept 'losing the plot' in mid-sentence, or failing to grasp the essence of a question and answering capably.

My lack of success had Ianthe really worried. I had never failed to get a job I sought before, and she began to worry about whether – in her language – I was 'losing it'.

Well, as far as I was concerned everything was OK, but I was very stressed and all these problems were only too easy to write off as due to work pressures, combined with the difficulties I was going through at home.

Each night I'd stagger home after collecting Micheline from after-school care, with my in-tray under one arm, and a bulging briefcase dangling at the end of the other. I'd be greeted with: 'What's for dinner, Mum?' The cupboards were often empty, and my energy for cooking non-existent. Cheese toast was often the answer!

Looking back now, I can see that one early sign of the onset of Alzheimer's may well have been when I went for new glasses in July 1994.

The optometrist placed the awkward heavy metal frame on my nose and then started to slide round the lenses, each time asking what I could see. Each time, my answer was the same, 'Nothing yet. We'll have to wait until the fog clears.'

He was puzzled as to why my eyes took so long to adjust to each new lens.

But now I think that my reaction times were already slowing down, back then.

Two incidents in mid-1994 really shook me up, as they occurred in the true centre of my life – my girls.

Micheline had been complaining of a sore hip for a week or so, and finally I got her to a doctor one Saturday morning, in between the shopping, cleaning, washing and so on. He referred her for ultrasound on the Monday. The grainy, shifting, black and

white picture showed a caterpillar-like angry-looking appendix. I whisked her to the specialist and she was in hospital the next day.

That week I was an automaton – at home making lunches, cooking, tidying up, at the computer till the small hours – at the hospital, sitting by her bed before work, at lunch and after work, clacking away on my laptop – at work, chairing meetings, writing, making calls, negotiating. Bleary-eyed with exhaustion, I was delighted when her bite into a cheeseburger by the Friday signalled to the specialist that she was finally well enough to come home!

Life returned to normal – for a while.

Rhiannon had been given some money by her grandparents to buy a horse. She was looking at a few, and trying them out.

One bright Saturday morning I drove her to a paddock about half an hour away, where this stringy-looking grey Arab rolled its bloodshot eyes at us. After some pre-sales pitch about how wonderful he was, Rhiannon got on for a ride.

He was off, falling over his own legs like a clumsy, gangly schoolboy, but each time Rhiannon held on. Then he gathered speed, racing round and round the paddock, like a slingshot gaining speed to spin out to freedom beyond the fence. Rhiannon realised what the horse had in mind, and had the good sense to throw herself off before things got too much out of control.

I saw her in slow motion, sailing high up in the air like a puppet free of its strings, her arms and legs flailing. She hit the ground like a rag doll, bounced, bounced again with her head wobbling to and fro, and then crumpled into a heap. It took what felt like hours to reach her, lying there deathly still, her nose and mouth buried in the soft earth. I touched her, spoke to her, praying under my breath. After what seemed an age, she stirred, mumbled, spat out earth, and rolled onto her back. Slowly we got her up, and the rest of the day was spent in hospital, as she was monitored for concussion. Miraculously, she was unharmed.

In September 1994, I was presented with the Public Service Medal, for services to science and technology – but felt

embarrassed and inadequate for such an honour. I had received this award in the Queen's Birthday Honours List in June, but life had been so stressful, so busy, that it was hard to focus on what this meant.

I remember rushing back to Canberra from a meeting in Melbourne, with a thundering migraine, to participate in the medal-awarding ceremony at the Governor-General's house. It all seemed like a dream through a haze of pain. I rushed back to Melbourne that evening, as I had to chair an important meeting the very next day.

Little wonder I was suffering the symptoms of stress, or at least thought all my symptoms were from stress alone!

I took an hour off work later that same month, to pop down to the Family Court, to the hearing of the divorce case. It only took ten minutes, but it lifted a twenty-year burden from my shoulders.

The following month I finally received the money from the property settlement, and could at last pay all my debts – and think about looking for a small house to buy for me and the girls. At long last we could also stop worrying if there was enough money for the housekeeping!

At the end of 1994 I took a three-week break over Christmas. Things had settled down at work, and home life was peaceful and uneventful. As usual, I 'went on holiday' to my favourite location – home! To be a mum to my three daughters, and to potter around with them and go places with them in their holidays.

I really felt free of stress at last. We had just heard that Ianthe had finally got in to do Physiotherapy at Sydney University, after a year of sports science at Canberra University, and everything seemed to be falling into place. My ex-husband seemed to be quite stable, the girls were happy at school and at home. I felt everything at work was in good order, and I had exciting ideas

for new directions for our division. I felt able to cope easily, and wanted to enjoy life.

I spent my holiday buying terracotta pots for our rented house, and choosing plants. What a delight it was to run my fingers through the soil, looking carefully at each plant, and watering, feeding and generally taking the time to 'watch the plants grow'.

But when I had five migraines in that short but restful holiday break, it was the last straw. I had to get rid of these migraines somehow. I changed my family doctor and my new one was sympathetic, having been a migraine sufferer herself.

I'd already tried most migraine cures – changing my diet, vitamins and so on. Also people kept sending me articles on all sorts of treatments.

The new doctor was methodical in her approach, asking me to keep a headache diary, and then trying most combinations of tablets – both old and new migraine treatments – and still I got weekly migraine attacks. By Tuesday I'd be well into it, and only get well by Sunday, ready for another week at work. And now I was getting so sick that I had to go home more and more often – something I had never done before.

By early March 1995, I was feeling more and more stressed and confused.

Rhiannon, Micheline and I would pile into the car each morning, in a great rush. Lunches had been hastily made, bags packed and my briefcase and in-tray thrown into the back of the car. Turn left out of the driveway, right at the end of my street, and down to the T-junction. But which one was this? I had two T-junctions to negotiate. 'Do I turn left or right here?'

Rhiannon and Micheline could not believe what they were hearing. 'We always turn right here!' they chorused, with some amusement.

No-one knew at work that often I got lost on the way there – neither did my doctor. It was just stress, as far as I was concerned. I had too much on my mind, that's all.



In early April 1995, my doctor decided to send me for routine brain CT (computerised tomography). I fitted in these scans on a frenetic Thursday, between two stressful meetings. It was actually quite a treat to lie quietly for ten minutes while being scanned!

The CT was basically a total and detailed picture of my brain, built up from many X-rays, each of a thin slice (pictorially, not literally!) through the brain. The doctor wanted to make sure there was no physical cause – no tumours or anything like that – for my migraines.

I went back to the doctor on the 10th of April. She took out the scans from their large envelope, looked at them and the radiologist report carefully, and said that although there were no tumours, there was quite a surprise in that there appeared to be generalised atrophy (wasting away) of the brain. She insisted I go to see a specialist neurologist that very afternoon and arranged an appointment with the nearest and most readily available one in Canberra.

The specialist looked at the scans, checked my reflexes and general neurological status. Then he asked me about any other symptoms. I related how I was really quite stressed out and felt burnt-out and exhausted. He was the first outside my family to hear that I had sometimes taken the wrong turning on my usual route to work, that I occasionally 'blanked out' in mid-sentence, and I couldn't remember people's names – even those of my staff at work. To me these all seemed simply to be symptoms of stress, and what I felt I needed was a long restful break and then everything would be all right.

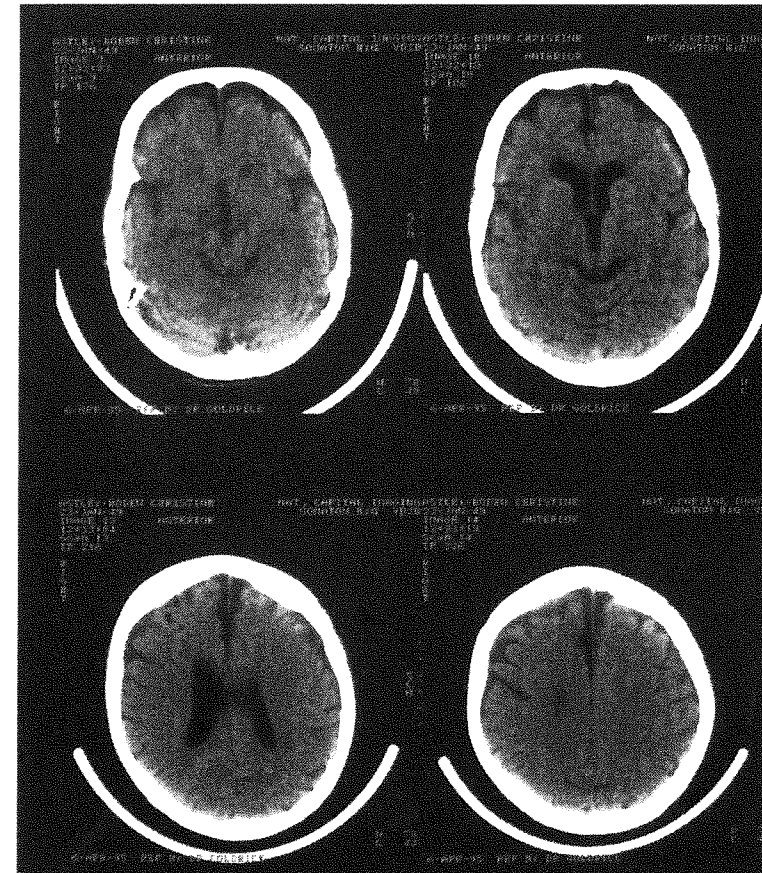
The specialist said very little, but referred me for more scans – this time MRI (magnetic resonance imaging).

Now I was getting concerned – maybe this was more than just stress. Even I could tell there was a big hole in the middle of my brain, and lots of space around it. The CT scan of my head looked like a black and white picture of a shrivelled walnut!

That very night, I had a large formal function to attend at Parliament House, the award of the Australia Prize for science and technology. I would have a chance to meet up with

colleagues from around Australia, catch up on news, swap ideas, and rekindle my excitement for a technological future. But my head was pounding and my mind was in turmoil. I went through the motions of circulating, talking to people, greeting former colleagues. It was all like a bad dream.

The migraine pursued me home, beleaguered me all night, and totally debilitated me the next day. It was the worst I had experienced in a long time, and I excused myself from a meeting that next morning, and went home to bed.



*Computerised Tomography (CT) scans taken in April 1995*

A few weeks later, on the 4th of May 1995, I had the MRI scan. This was an even more detailed picture of my brain, made by sensing the vibration-like response of all my minute brain atoms to a large electromagnet pulsing around my head. Totally painless but a bit claustrophobic – lying on a metal table and being slid into a very small, narrow tunnel around which the magnet made very noisy grinding sounds, clunks and clicks. And staying there for what seemed like hours, but in reality was probably only 15–20 minutes.

The resulting scans showed the ‘walnut’ of my brain just as shrivelled as ever, so I thought up all sorts of excuses as to why I couldn’t get back to the specialist with my scans for another week or so.

And of course you know the rest of the story, as far as that fateful visit to the first, Canberra-based specialist went, shocking me with the first diagnosis of Alzheimer’s disease.

And, yes, I was still convinced I was far too young, and that something else had to explain why my brain was wasting away.

## The second opinion

‘My wife’s a physio,’ the specialist said, having asked Ianthe what she was studying in Sydney. ‘What year are you in?’ Ianthe explained that she was in first year, but had just completed a year of sports science.

It was the 30th of May, just eight days after the first diagnosis, and we were in the second specialist’s office. This new specialist was clearly going to treat us very much as people, not just as medical cases, and to explain as much as possible at each step of the tests.

These tests were extensive. The first step took two days, and began with a complete gamut of blood tests, to rule out any infections that could have caused the damage to my brain, including AIDS, which can cause dementia. The blood tests also looked for hormone deficiencies, or the presence of any toxic substances. These can also cause dementia, and if corrected can be cured. Unfortunately nothing showed up.

I also had a SPECT (single photon emission computed tomography) scan. This was a bit like MRI, in that it relied on detecting changes in atoms around my brain, and like the X-ray CT in that it built up a detailed picture from a whole series of tiny ‘slices’ through my brain. But unlike both of these, which looked at structural changes in the brain, the SPECT would look at how my brain was actually functioning, specifically how it was using oxygen.

I was injected with a low-level radioactive substance, as a sort of label in my blood that could be seen by the scanner as the blood flowed around my brain. An hour or so after the injection,

# You look so well! – if only I had cancer!

I sat with a couple of friends in my garden, sharing a pot of tea and some biscuits.

'You look so well!' one friend said.

'Yes,' said the other, 'I don't think I've ever seen you looking so well.'

But how did they expect me to look? How are you meant to look to the outside world when you have Alzheimer's disease?

For younger sufferers, we don't *look* to you as if we have Alzheimer's – you know, white-haired, dodderly, frail. We don't look that old, we are often fit in our physical bodies, and so you don't know anything is wrong with us.

The time I now have at home, to rest, to eat, to garden, means that I look better than I have ever done before. I'm now quite normal in build rather than thin, and no longer appear pale, drawn and ill, as I was at work with continual migraines.

Unfortunately I have a disease of the brain, so you just can't see the diseased bit of me. My outer shell is fine, it's just my mental powerhouse that is on the blink! What's wrong with me is inside my head. I'll probably look well until shortly before I die, when my brain finally forgets how to run my body. Unlike other diseases, such as cancer, people who don't know I am dying will see me as a perfectly fit person who just behaves a bit oddly.

In early 1997 I had an unusual spot appear and grow larger on my leg. I joked – but more than half seriously – 'Maybe it's cancer, and if I do not get it treated, I could die as "me", not some

very altered person who is totally confused and not connecting with life around her!' It turned out to be a wart. Although it was large and malicious-looking, it was totally harmless. I was actually disappointed that it was not cancer, as I still sought some release from a death of my mind by slow degrees.

If I were to die of cancer, I would still be the real me, the one I know, the one my family and friends know – mother of my three girls and member of my church 'family'. When I die of Alzheimer's, who will I be when I die? Even though friends and family repeatedly reassure me that I will always retain the essential 'me' right to the end, only my head knows this, but my heart still does not accept it.

Alzheimer's disease is a terrible thing for us as a family to face up to – that slowly there might be less and less of 'the old me', as my brain slowly erodes away. The brain is, in a way, what defines us, gives us our sense of consciousness, of being in a world and able to interact with that world. It, too, I feel, is what gives us the ability to pray, to communicate with God.

I am scared of the prospect of eventually not recognising my surroundings and not knowing who my girls are, or being able to greet my friends. Surely that will be a lonely and frightening place to be – always somewhere unfamiliar, surrounded by strangers, and nothing you recognise to turn to. Will I still be able to hold onto my faith in God?

At least with cancer there is a chance, however small, of full recovery. Who has ever heard of someone getting better from properly diagnosed Alzheimer's? In the past all sorts of dementias (caused by depression, hormone deficiency or toxic substances) were all lumped together and called Alzheimer's. But many of those other causes of dementia can be cured. And that is why I had so many tests, to rule out all possible curable forms of dementia, and to find a cause for the brain damage that was so clearly visible on X-ray, let alone on the other more specialised forms of brain scan.

So Alzheimer's expected to be is a one-way street; true, it's relatively slow, but it is inexorable. Death by small steps. Friends

and relatives lose you by minute amounts each day, each week, each month, each year. So perhaps they will get used to this slowly evolving new person, until they have forgotten what you were really like before your brain started disappearing. That's why I'm glad we have bought a video camera. At least there will be some record of who I was when I was more or less really me, and not the diseased me.

And my very dear friend, Karen, has said she will always remember me at the various stages. She has travelled this road with her father. I trust her to be there for me until the end.

My daughters, too, will always remember, I know, but for them there will be so much pain and grief that this will be the hardest part for them – watching me disappear by small steps, becoming someone different each day.

The material I have read talks of being 'stripped to the core' with Alzheimer's, and so although the outer layers are gone, the essence of what makes the person an individual remains, and this includes their spirituality. Maybe this should reassure me.

Oliver Sacks said, in a recent *7.30 Report* interview, that Alzheimer's sufferers don't lose their essential selves. True, maybe, but I know that I have changed a lot already. I am more stretched out somehow, more linear, more step by step in my thoughts. I have lost that vibrancy, the buzz of interconnectedness, the excitement and focus I once had. I have lost the passion, the drive that once characterised me. I'm like a slow motion version of my old self – not physically, but mentally. It's not all bad, as I have more inner space in this linear mode to listen, to see, to appreciate clouds, leaves, flowers... I am less driven and less impatient. And Karen certainly prefers me this way!

But am I really still me?

We are each a kaleidoscope of personality, which makes up every facet of who we are. But often we are limited in our range of expression of this multi-faceted person, because of our busyness, the demands and constraints, the expectations of our lives. I believe that God knows us in our entirety, each and every part of this kaleidoscope of who we are. As I unfold before God,

as this disease unwraps me, opens up the treasures of what lies within my multifold personality, I can feel safe as each layer is gently opened out.



*Christine admiring her sunflowers in 1995; watching flowers grow  
– her new passion – in her slow-motion version of herself*

The fullness of who I once was will be seen in the simplicity of who I am within, surrounded by layer upon layer of memories. These memories form the kaleidoscopic perspectives of all the many expressions of my being over my lifetime: as a child, daughter, granddaughter and sister, as a student and young adult, as a wife and mother, as a friend, as a researcher, an editor, an information officer, policy manager and senior public servant, as a member of St George's church and a Cursillo team member, and as a writer of this book.

In each of these aspects of my life, the centre of my being was always there within, expressing itself in these many forms of me. This unique essence of 'me' is at my core, and this is what will remain with me to the end. I will be perhaps even more truly 'me' than I have ever been.

## A terminal illness – so why are we ashamed of it?

Alzheimer's is not a mental illness – I don't need a shrink. It is an organic disease of the brain, that eventually leads to death. I have outlined in Appendix I as best I can what I have gleaned from my investigations (personally motivated) over the year or so since being diagnosed with this disease.

Basically some cells of the brain become diseased and tangled, confused and no longer able to function. The cells affected are those making up our personality, our behaviour, our thinking, our memory. These cells are mainly at the front of the brain, around the temples and behind the eyes.

The disease has little effect on body movement and function, which are actually controlled by a relatively small area of the brain. The largest effect is on the 'higher order' brain cells – those that make us who we are. Eventually, so much is destroyed that the brain can no longer run the body (you forget, for example, how to swallow), and you fall into a coma and die. So people can't actually see much happening. We don't shake, we can walk...but our behaviour begins to change.

In its early stages it creeps up on you, subtly altering your behaviour and how you cope with life. Everything becomes more stressful, and that stress in itself can exacerbate the disease. In my case, I was lucky to be diagnosed in the early stages.