

. Please forgive you

A TRAJECTORY OF HOPE

CHARLEY BARBER

Publishers Info

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FOREWORD

One of the most chilling experiences a person and their family can have is to be told, "You have a brain tumour." Not all brain tumours lead to a fatal or a devastating outcome, but a significant proportion of them do. The treatment of such a tumour depends predominantly on what sort of tumour it is and may include many alternatives from merely watching the tumour to the use of surgery, radiotherapy and drug therapy (chemotherapy).

To read Charley Barber's account is to be humbled by the grace and dignity displayed by Julie. It is also a telling insight into the difficulties that such a horrible tumour creates within the family and the stresses that are brought to bear on loved ones.

To be involved with the intimacies of medical care for a person is an incredible privilege. The delivery of bad news to an individual can be stressful to the doctor as well as being stressful to the individual and their family. Different medical personnel handle this in different ways and sometimes individuals cope with the situation by being cold and remote. This does not necessarily mean that they're not caring, but may be that individual's way of dealing with an unpleasant but recurring experience. It would be difficult to continue in medicine without developing a coping mechanism and, sadly, this sometimes produces an uncaring or remote persona.

Brain tumours are relatively uncommon tumours, but the primary brain tumours, those that arise in the brain rather than spreading from elsewhere in the body, may be curable; but in many instances are not. The most important determinant of outcome is the type of tumour which is determined by examining it under a microscope as well as undertaking ancillary investigations including gene studies. The most aggressive brain tumours are the *glioblastoma multiforme* (GBM) which was the variety Julie Barber experienced. While they are not as common as tumours affecting other organs such as prostate or breast, they have a devastating effect because they often strike young and middle-aged adults. They are the greatest cancer cause of loss of working life according to information from the Australian Bureau of Statistics. It is therefore clear, that while they are less common, they are amongst the most devastating forms of cancer.

The first major conference devoted to these aggressive brain tumours was held in Sydney in 1985. The most recent of these multi-specialty meetings devoted to brain tumour was held in Sydney in 2007. In 1985 we had high hopes that immunological techniques would lead to the breakthrough with these tumours that have been achieved in so many other forms of cancer. As yet, that has not been achieved and in 2007 we were able to describe a longer period of survival, but no coherent report of long term success in treating these tumours.

Molecular biology and our understanding of genetic alterations which lead to the development of the tumours have suggested a significant number of possible chemotherapeutics, but very few get to the point of clinical trials, much less open availability, because the incentive to develop such a drug is not present for the commercial manufacturers of drugs. It presently costs about \$1 billion to bring a new drug to the marketplace and commercial imperative is lacking for business to do this. The only realistic prospect for advancement is for governments and their agencies to fund the development of such medication.

The ability of the neurosurgeon to safely remove a tumour depends above all else on the underlying nature of the tumour, but also depends upon its anatomical position within the brain or on the surface of the brain. The more aggressive cannot be cured with surgery, but surgery will provide the opportunity for the pathologist to identify the precise characteristics of the tumour and will reduce the amount of material inside the skull which may gain time for other measures such as radiotherapy and chemotherapy to take effect. The ability to remove the tumour also depends on exactly where it is situated within the brain. It may be possible to completely remove the identifiable tumour in some places, but in others it can only be done at the expense of function, such as paralysis or loss of speech. The cure of brain tumours remains one of the challenges for the 21st century. The more comforting news is that not all brain tumours are at the aggressive end of the scale like that experienced by Julie Barber and some can be removed totally with an expectation of cure and others can be treated successfully with an expectation of a long period of survival.

The personal and intimate story drawn by Charley Barber gives us a meaningful and dramatic insight into the problems encountered in dealing with this monster which devastates those who love and care for the person with the cancer and leaves them behind to struggle with the consequences.

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First, last and always this book is dedicated to Julie.

This book is also dedicated to the families, friends and support networks of all brain tumour patients. And to the medical profession who battle heroically against this ailment.

“Even his griefs are a joy long after to one that remembers all that he wrought and endured.”

Homer, *The Odyssey*

PROLOGUE: WITNESS

The dog knew. Usually Rosie would greet people by raising her head from her paws and appraising the situation. Quizzical look, dismissive look, interested look. Strangers required investigation. I didn't. Some visitors provoked excitement; others were avoided through crafty canine intuition. But I was too much of a familiar face to provoke anything but a look and a raise of the head with pricked ears.

But today was different. Rosie was mad with joy. She cavorted and capered about like a puppy rather than a whippet teetering on the edge of being elderly. The stereo was off. I thought it would be on. The vacuum was where I had left it for Julie to use, but it was untouched.

I looked for Julie, but somehow failed to grasp the whole scene. I will never know why. Then I saw her and started to scream.

An hour later, I was sitting with Lloyd, one of the paramedics who had responded to my 000 emergency call. Lloyd and his partner, Chris, had steered me outside on to the verandah with imperceptible manipulative gestures and signals. I sagged down on the top step and sat there. I would spend most of the rest of the day sitting on the top step. Lloyd sat with me while Chris went to ring the police. Palliative Care had told me that if I called an ambulance when Julie died, they were bound by law to call the police.

I was sitting with Lloyd in the warm autumn sun when Ruth, Julie's doctor, arrived. She told me afterwards that when she saw the ambulance and no activity, she concluded that Julie had died. Lloyd and I were chatting amiably about the property, the horses, the good Bannister farm country, whatever. He had been here before with grieving relatives. Not to Bannister, but Lloyd was familiar with the psychic territory of shock and grief. Those weary eyes had seen a great deal, and I have no doubt he was as tough mentally as an SAS commando. But there was compassion and gentle kindness in his soul that I needed and appreciated.

Ruth parked away from the house and I told Lloyd who she was and that she and her husband, Justin, had been coming for lunch. Ruth's knees buckled when Chris told her what had happened. She pulled herself together and made a beeline for me on the front steps. Lloyd got up and Ruth sat down on my right, put her arms around me and began to talk. I was beginning to go into shock and

would remain traumatised for the next couple of days. The rest of the day was viewed through a miasma of grief, shock and then enormous weariness.

I only remember two things that Ruth said. They stand out in stark contrast to the rest of the conversation.

Ruth said, "You mustn't blame yourself."

I realised that she was right. Julie was the most determined individual I had ever met. Once she made up her mind to do something; that was it.

Later in the day I perceived a sense of disquiet in Ruth. She was uncomfortable about something and I thought I knew what it was.

I turned to her and said, "Don't worry, Ruth. I'm not going to do anything."

She looked awkwardly embarrassed and said, "Do what?"

I gave a grim half smile, "I'm not going to snuff myself, Ruth."

Her eyes widened with incredulity and then narrowed, "How did you know that's what I was thinking?" She had apparently asked the police to do a quick search of the house for firearms and they were checking on their computers whether or not I had a gun licence.

I shook my head and smiled again. "Ruth, I've spent my entire career as a teacher living by my instincts, knowing what the kid in the back row is thinking. If it wasn't Saturday, I could tell you if there was a fight on the playground at my school. I live by reacting to how I think people are thinking and feeling."

Ruth asked me again, "How are you going to be?"

"Fucked up. Really fucked up. And I think I will be for a long time."

She nodded in silent agreement and put her arm around my slumped shoulders in silent communion.

I'll never know what happened that day or why. Only Rosie was witness when Julie died. And now, she's dead, too.

CHAPTER ONE: DIAGNOSIS

“OK, I’ll go.”

Like most big things, it started small; and this was the start. It was about 3am on 7 December 2003. Julie was experiencing memory problems but it seemed to be more than that. Calling it “problems with my words”, Julie was having trouble functioning in her job as an English teacher and had been for about two months. Virtually unable to write her semester reports, having difficulty performing her duties and now admitting to cognitive difficulties, she was at last agreeing to go to the doctor. It hadn’t been easy to get this agreement.

Describing the antipathy Julie had for doctors is as difficult as describing Julie herself. Any description would be dismissed as fanciful. She was a walking contradiction. She meant so many things to so many people that a *Rashômon*-like story would emerge. However, there would be some points of commonality. Julie was not a beautiful woman, she was a beautiful person. Slender, slight and small breasted, she felt that she was personally cursed with heavy legs and a big arse that did not look good in jodhpurs when she rode the scores of horses we owned over the years. Born with blonde hair, this gradually darkened with age to light brown. She had terrible eyesight and wore thick glasses, but she had luminous blue eyes, which radiated enthusiasm and bubbly good humour. This people occasionally misinterpreted as insincerity. Nobody could be that chirpy all the time. Nothing could be further from the truth. Incapable of duplicity; her honesty was disarming, and her smile and peeling laugh infectious. Julie invariably ambushed people with her enthusiasm and charm. She swept them up in a tidal wave of affectionate chatter, good will and gusto. But she was so innocent and guileless that apparently in Year Nine, when girls are a predatory species, she had no adolescent enemies. She had achieved Willy Loman’s goal of being “well-liked”.

I was Julie’s husband, but the love of her life was horses. The farm, our band of 31 horses and Julie’s riding expertise were testament to our complete involvement with matters equine. Horses were Julie’s first and last love. I knew my place.

But she didn’t like doctors...not personally. There were very few people she didn’t like. Julie didn’t like going to the doctor and hated going to hospitals.

Julie was a farm girl and hated any fuss being made over her. Going to the doctor was a fuss and only sick people need go. Julie's definition of sick was hard to classify. There were a few definite rules. You weren't sick if a horse kicked you and you could get up. You were sick if you couldn't get up, but you didn't call the doctor to come to you. That would be making a fuss and inconvenient to the doctor. These rules only applied to Julie and me. I was being a "wuss" one time when a horse jumped on me and I could not stop limping. I finally went to the doctor and had the foot x-rayed. It was broken and I had to stay off it for a week. My initial visit to the doctor to have the foot x-rayed was a definite sign of frailty and the unspoken censure I received from Julie implied I should have just been more stoical. After all, what did the doctor recommend? Just staying off it and allowing it to heal. Of course, if I had stayed off it without the visit to the doctor that would have been sloth on my part.

Confused? Most of the time I was too.

These regulations regarding medical intervention seemed to shift like the dictates of a whimsical sheik. They seemed perfectly logical to Julie. The reasoning was hers and based on a rigid moral imperative that drove Julie constantly.

You must always do your best, you must never complain, you must achieve and succeed. Softening this was the innate charity that emanated from the very soul of her being. She was the gentlest and kindest person I have ever met. Yet, no one ever drove another the way Julie drove herself; not the toughest drill sergeant, the most ruthless coach, the most callous dictator. Julie would set herself impossible and unattainable goals and then would upbraid and chastise herself for not achieving them. Her legendary patience with children and horses never extended to herself.

This was not an easy person to get to the doctor. And when you did, it had to be serious.

The memory problems had persisted for so long that obviously Julie thought this was serious and so did I.

We had built our dream home and moved into it six months before.

Everyone fantasises about one. Everyone wants one. We had built one.

We had spent the previous two and a half years renovating and selling our other property and developing this property: the ultimate destination of Peoria Arabians, the place where our vision of what an Arabian horse should be would be brought to fruition. The new property, Bannister Springs, located in the rolling hills northwest of Goulburn and high on the Great Dividing Range, was a reflection of a draining exertion of will. We had fenced, built, dug, dragged,

planted, lifted and, most of all, sweated.

Five kilometres of fencing had been done by the two of us. Sheds, stables, yards and a riding arena were standing testaments of our drive and effort. But the house was the centrepiece of our dreams.

We had fallen in love with homes that a company based in the New South Wales Blue Mountains produced, crafted entirely with cypress pine, a native Australian species, *callitris columellaris* or *callitris glauca*. Cypress pine is technically a softwood, which looked like ordinary radiata pine, but is durable and tough. Naturally termite resistant and inordinately heavy, the houses the company produced had an almost palpable patina of comfort; they seemed to glow with an aura that radiated a rich luxurious reassurance. We loved them. Everything in the house was cypress: walls, floors, ceiling lining. The walls were hewn and milled out of whole cypress pine logs that fitted together like a giant Meccano™ set. We imagined the logs being fitted together, the tongues of the bottom log slotting into the groove of the one on top, the joints meshing together with a satisfying clunk and the redolent, pungent smell of the cypress pervading the house, the building site and our lives. We could not wait to order one.

The director of the company arranged a visit to one of the homes they had built in Leura in the Blue Mountains. We entered it with the reverence and restraint of pilgrims filing into the grotto at Lourdes. Julie held my hand and her eyes glowed with wonder. This was it. This was going to make the farm perfect. I remembered one of my professors at Notre Dame calling one of Keats' poems "the pristine apotheosis of spiritual realisation". I didn't have a clue what he meant till I went back to my room and looked it up and was I impressed then. The house was like that.

Like Kubla Khan, we would build this house and our fragile vision would be wedded to this dream home and, like some metaphysical equation, our happiness would be exponentially enhanced.

Meanwhile we lived in one 3.5 metre by 7 metre bay of a shed on the property and slept in a similar sized bay at the other end with four open bays in between. We were living like hillbillies and for 16 months, this was our home. All our earthly possessions were in boxes. Furniture stacked, lounges covered and bookcases enclosed and protected by old drapes. I thought of Tutankhamen's burial chamber with all the possessions and mementoes of his life stacked near to him. There was enough space for our bed next to the roller door and for us to get in and out of bed. There was a windstorm one night early in our stay and the shed was shaking and groaning. My side of the bed was under the cylinder of the roller door. It was like being under some B&D sword of Damocles, and the first time the wind blew I imagined it crashing down on me. I thought it would make *Ripley's* for a novel way to die. The fucking thing was making so much noise;

it just could not stay up there.

We were lying there one day after what had become a ritual: going shopping for fittings for the new house. Julie's enthusiasm was exhausting. Tiles, tubs, toilets, light fittings and fixtures, doors, vanities and mirrors. Expense was a minor consideration. But, bargains were sought and pursued. We always haggled and negotiated. Julie, despite the largeness of her heart, would not allow anything that looked cheap and synthetic in the house. She would snort with derision at a tap and gently fondle another, testing its weight in her hand, imagining its ergonomics, thinking what it would be like to wash under it, enjoying it and either nodding with slow and satisfied approval or sadly shaking her head and moving on. No vintner in Bordeaux ever put more careful consideration into the colour, bouquet, flavour and aftertaste of any wine than Julie did into the selection of furnishings for the house.

With the shed shaking, groaning and roaring like the Ancient Mariner's ship being driven before the blasting storm in Antarctica, Julie reached over, squeezed my hand and said, "I've never been happier".

The home was built, slowly. The builders broke ground ironically on the shortest day of the year, the winter solstice, 2002. We moved in from the shed, by degrees, in May of 2003. It was an odyssey and an exercise in patience and perseverance. Everyone we knew said that building would test our marriage and us, and it did. My standard joke was that there were only three phrases in a builder's vocabulary: "Gunna", "Tomorrow" and "Pay me". Our builder came and went without a pattern but always promised more than he delivered. Our tiler went walkabout, our plumber went to New Zealand and then tried to rip us off. Our electrician did a sterling job. One phone line did not work, but the painters did.

When we were finally in the house we would sit in the living room with a glass of wine gazing at the ceiling, contemplating the veritable galaxy of knots, the intertwining network of capillaries that were grain patterns in the walls and floors and ceiling and feel that we were not in a house, but in some benign and benevolent universe somehow separate from the hostile and indifferent world which began at the front gate. We had 270° views of the verdant pasture at Bannister, the bush and our beloved Arabian horses.

There were no curtains in the house. There was no driveway to the house or footpaths around it. There was no garden and probably would not be for a year. We were \$60,000 over budget, but we didn't care. When we made love in the bedroom, it was either fiercely with an atavistic need to possess each other, or gently feeling that we were somehow in rhythm and harmony with an elusive undertone and current which pervaded the house, and our lives. We felt enhanced and complete and that the house, the horses and our marriage were all moving to

a level that we had dreamed of but to which we had dared not aspire.

Then Julie developed these memory problems and she finally agreed to go to the doctor.

On the morning of Sunday, 7 December 2003 we rang Julie's doctor, who we both called "Dr Ruth", and left a message on the answering machine that Julie would need an urgent and immediate appointment. I had worked so hard to convince Julie she needed to go to the doctor that I didn't want it put off any longer.

Julie dropped me at school the next day and headed off to Ruth's office to be there when the surgery opened at 9am for her appointment. Through the course of the day, I wondered how Julie was going and wondered why she had not called me on my mobile to let me know what Ruth had said.

Julie wandered into my classroom at about 2.15pm looking apologetic and bemused. Ruth was not happy that Julie had put off seeing her so long. Ruth wanted some tests and also wanted to see me. She had scheduled the tests for the following morning and an appointment for us to review them at about noon. Julie left immediately. I finished my work and went to see my boss, the principal of Mulwaree High School, to arrange leave.

Tom Coll is a tall, thin, lanky Scot with a lean, angular face. He had been promoted to the principal's position at Mulwaree in 2001. He had a gentle manner about him that the staff found reassuring and the school had become imbued with a spirit of reassuring calm in which we were gradually finding a new identity in the community.

I had a fifteen-minute chat with Tom and briefly told him of Julie's memory problems. He discreetly enquired as to what our suspicions were and I went through my layman's insights: medication for Julie's depression, early menopause, metabolic problems and, what I thought was my worst nightmare, the early onset of Alzheimer's. I told him that Ruth's usual *modus operandi* was extensive testing and I thought we would be off to Canberra, or wherever, for the rest of the week. Tom said, "OK" in his usual friendly and laconic manner and I told my staff that I would be away for the rest of the week and I was not really prepared to explain why.

Julie picked me up at 3.15pm and we went over her appointment with Ruth, who would be calling late afternoon to speak with me. When she called at 5.30pm, she was critical of me that I had not somehow compelled Julie to see her earlier. She was upset that, first of all, Julie had not seen her earlier and, secondly, that Julie was so casual and dismissive of any possible problem. The doctor thing.

She wasn't sick.

"Are you concerned?" That was the question Ruth put to me.

Of course I was. I could not explain to Ruth that Julie and I had been arguing about this for days and weeks. Ruth wanted us to sit down and try to make up a chronology of when these memory problems had started. When? Where? How severe?

I didn't want to point out to Ruth that someone with memory problems was probably not well equipped to analyse and reflect on the nature of her problems.

We sat down that evening with the farm diary and Julie's daybook from school. We were able to compile a chronology in point form as well as our concerns regarding changes in mood and behaviour.

When I typed it out for Ruth I didn't know whether or not to be shocked or pleased about what it told us. I had absolutely no idea whether what we recalled indicated a major or minor problem; whether or not her mind was degenerating, or if this was only a minor hormonally driven issue that therapy and some adjustments to medication would rectify.

The morning of 9 December was glorious. It was one of those early summer days before the heat kicked in. Temperatures in the low to mid-twenties, not much wind, a touch of high fluffy cloud. We went straight to the CT Unit at the Goulburn Base Hospital. CT stands for Computerised Tomography. The unit would essentially divide Julie's skull into photographic x-ray slices and identify any organic problems that might be affecting her memory. We killed time in a waiting room that was hospital dingy and infested with the standard number of out of date *Women's Weekly* and *New Idea* magazines trumpeting the latest tacky headlines about soapies, celebrities, sports stars and wannabes. I think I found an ancient National Geographic and was reading about the virginal sacrificial rites of the Mayans or the Aztecs, who I always tended to confuse, and vaguely thought that this was a culture that knew how to keep Year Nine girls in line. Julie emerged from the scan, smiling as always. I asked her if the technician had said anything. Julie replied that he only asked her if she had been having headaches. I assumed that this was a standard question the techie probably asked everyone who was having a cranial scan.

We had about two hours to kill before our noon appointment with Ruth. We went to the Post Office and for a browse around the shops. We stopped in the kebab shop on the main street and had an early lunch. Julie had been required to fast for the scan. We assumed Ruth would run late. She always did and Julie wanted to do some work on the farm in the afternoon. It was an unexpected bonus that I was going to have a few days off. She was planning on how to get the tests over with as soon as possible to utilise as much of the next few days she could "being productive".

We now had the stables, the riding arena, the yards, the time and benign weather. The prospect of six weeks off stretched in front of her: a summer of promise and fulfilment during which the last two years of drudgery would evolve into the infinitely more satisfying work of riding and training. Julie chatted pleasantly about the great things we would accomplish over the next few weeks: weaning the fillies, starting on a new horse, getting a couple of young ones ready for the show season in autumn, breaking in Biscuit who had an endearing, quirky personality, like the Biscuit on the TV show, *Ally McBeal*. However, he was short in the neck, did not move particularly well and was smaller than we had expected from the mating. But he had that knowing personality, like he had been here before. We had to sell a couple of the youngsters and start another youngster, Psychic, under saddle.

Julie loved to work. Her life was an endless series of plans, projects and commitments. Her patience and her ability to focus were sensational. What she could not do was time schedule. She lived her life in a time warp, perpetually late for everything because there were only two types of jobs: “big jobs”, like fencing the new farm, building the new riding arena and planting 3000 trees in the laneways and windbreaks on the new property, and “little jobs”. These ranged in duration from five minutes to no more than a couple of hours. She would assess the nature of the task at hand, smile and snort with irrepressibly buoyant optimism, “That won’t take long”. She would then turn to me for confirmation and confidently ask me for an assessment of duration. I always gave the same downbeat answer, “It depends on what goes wrong”. Julie would variously interpret my response as caution, affirmation or me stalling to be able to listen to the races or watch the cricket. When we ran into a problem she would seethe and wail with an almost metaphysical indignation, “Why is this taking so long?” This sanguine optimism, this surety of purpose, led Julie to attempt huge tasks blithely confident that it was “a little job”.

I wondered how many of her latest list for the summer were “big jobs” and how many were “little jobs”. It was a familiar story. A reassuring template of what our lives had been like for the past 10 years, only this time the horses would be better – the stallion was breeding far beyond our expectations; the house was beautiful and comfortable; she had better horses and better facilities than ever before. I loved to hear Julie talk like this. She was so incredibly optimistic and positive. Julie ignored, as I always did too, the fact that six people could not accomplish in six months what she planned for the two of us to do in six weeks. I didn’t care. Julie would bemoan our lack of industry and accomplishment and make grander plans for the autumn, Easter Holidays and the winter. Life was good.

Both of us trusted Dr Ruth. We thought she was a sharp operator, a good doctor, and very caring and sympathetic. When you went and talked, she listened – to everything. A tall slender woman with an infectious smile and the ability to think laterally, her firm belief in the spiritual as well as the physical aspect of healing endeared Ruth to both of us. My days in the 60s counter culture and Julie's affinity with the spiritual and ephemeral made her something more than the run of the mill quack to us. A friend referred to her as "the hippie doctor". Not a bad analogy.

Ruth ran on time. That should have set off alarm bells. She usually ran to what we called Ruth Standard Time, a half-hour late. We went into her office after the usual pleasantries. I can't recall Ruth looking grim or shocked or steeling herself to deliver bad news.

We sat down and Ruth simply said, "Julie has a brain tumour".

I don't know how doctors rehearse or practice to give the kind of news she had just delivered. Ruth wasn't dissociative or detached. She was trying desperately to walk the fine line between accurate clinician and sympathetic friend.

I can't remember feeling shocked. Later, I remembered reading a description of Socrates' death in the *Phaedo* when I was at Notre Dame. How the hemlock gradually numbed his limbs; as if life in his extremities was an entity, which gradually lost the battle with the poison and retreated to his torso and heart like the medieval defenders in a besieged castle gradually surrendering the outer walls and retreating to the castle keep for a last stand.

I knew one thing, Ruth wasn't joking. Her manner had always been friendly, precise and detached; she was involved and personable but professionally direct. Julie and I remained calm. There was no bursting into tears, no screams, no wailing.

I asked Ruth one question: "How bad?"

Ruth gently replied, "The worst."

Ruth then explained that the scan had revealed a brain tumour called an *astrocytoma*. I waited for an explanation while the numbness began to take over. It started in my feet.

Ruth said *astrocytomas* were particularly difficult brain tumours: very fast growing, aggressive, comparatively rare and almost impossible to treat.

The numbness began in my fingers.

"Do you mean Julie is terminally ill?" I asked, trying to maintain control.

Ruth became evasive, or perhaps that is incorrect and unjust. The diagnosis needed confirmation. They would perform more tests, an MRI this time, which would be more precise than the CT scans. Surgery would be initiated to biopsy the mass of the tumour. The neurosurgeon would remove as much of the tumour as possible, radiation therapy and chemotherapy would follow.

Ruth looked at me intently. “You will have some time together, time to...” She seemed to be searching for words to accurately reflect what she wanted to communicate. This had to be exact. There could be no room for ambiguity. There could be no slips.

Then it struck me, she was looking for something like the standard, “Time to get your affairs in order”. “Time to say goodbye.” “Time to contemplate slow death.” No time at all.

The numbness hit my knees. Ruth reverted to being efficient. We had a neurological consultation with Professor Noel Dan, the professor of neurosurgery at Sydney University. He was a long ball hitter, as good as there was in Australia. His rooms were in the Eastern Suburbs of Sydney, in Edgecliff, very up-market, with real estate costs that resembled phone numbers. We were going to one of the best.

Ruth became more business-like. She was outlining our program. We would need to prepare for an extended stay in Sydney. How long? Six weeks. That hit me harder than the diagnosis. Immediate and familiar problems are always more compelling than the alien and unknown. We had young horses in the stables, two yearlings that barely led. We had a full agenda of work, horses to be weaned, young stock to be handled, horses to be broken in.

Not anymore.

The numbness had been transformed into something surreal. Through this, strange as it may sound, I had not looked at Julie. I don’t know why. I suppose it was because Ruth was speaking and what she had to say was so profoundly compelling that she had my total focus: a shock-driven, attention-grabbing imperative that centred all my awareness on Ruth. I looked at Julie now and instinctively took her hand. I mouthed the words, “Are you OK?” She smiled, squeezed my hand and mouthed back, “Fine.” We had always held hands a lot even in our 40s and 50s. She had a bemused, almost disconnected expression on her face, as if she were hearing a very interesting story, but one that did not involve her. She squeezed my hand again twice. Our unspoken code for, “everything is OK, I’m not worried”. She was amazingly calm. I don’t know what I was like.

By this time my hands were numb. I had a faint taste of bile and garlic in my throat, as if the kebab and my gut were having an argument. As my body slowed down and my shoulders felt heavy and weary, my mind seemed to become hyperactive: the critic in me came to life and began to analyse the incredible tale I was being told. This, quite simply, could not be real.

It was sometime during the consultation that the phone rang. It was Professor Dan’s office, giving Ruth the details of what would be happening the next day. Julie would have a bed at Concord on the afternoon of Wednesday, 9 December, “if necessary”. The tone of her voice indicated that it would be. I wanted to ask

Ruth a million questions. I wanted to pick her brain for evidence of a redemptive cure or therapy but I realised that this would be fruitless. Ruth was a GP and a good one. The brain guy was in Edgecliff. Ruth would not know.

Ruth told me one thing. Professor Dan had a patient who had survived for seven years with an *astrocytoma*, however, there were no hard and fast rules regarding diagnosis, therapy or survival times. We would hear that a lot. *Astrocytomas* were tumours that behaved like individuals and the patients reacted to them individually.

Ruth gave us both a hug and asked that we stay in touch. She gave me her home phone number and her mobile number, something she did not hand out lightly. She had once had a problem with a stalker, and I imagine that kind of experience would make her guard her privacy jealously and her security warily. I felt that it was a great trust.

We walked out to the car holding hands and sat there for a minute. Julie tried to reassure me. She was OK. She would be fine. We needed to go shopping, there were things that she needed. After that, we must hasten home to Bannister and prepare as well as we could for the trip to Sydney. Ruth had given me one final caution: wait for a diagnosis from Professor Dan; don't get on the Internet and scare the shit out of myself by searching "*astrocytoma*". I resolved to get on the Net after Julie went to bed.

We needed nightgowns, toiletries, new underwear, slippers and, I thought, a Diskman for Julie to listen to in the hospital. When our vet, Ian Nielsen, was hospitalised with a heart attack a few years previously, he had told me that his little portable CD player was a refuge: music and audio books had sustained him. I wanted to buy one for Julie. I wanted to do something that showed her that I loved her that I was trying to do something – something conspicuous and prominent. Something that would reassure Julie that I was there, that my care for her would be devoted, genuine, authentic and indisputable. Ridiculously, with my mind swirling with confusion, all I could think to do was buy a Diskman.

Julie had always been a shopper. So off we went, and she assiduously went through the rack of size 10 nighties at K-Mart to find something she liked. At home she slept in pyjamas or sometimes, when the weather was hot, just her panties. She looked for something purple or lilac, her favourite colour. She could not find anything and bought three size 10s which were pale blue with a teddy bear on the front. On any 43-year-old woman other than Julie, they would look juvenile. On Julie, with her air of innocence and simplicity, they would look nice.

Julie next went to buy new undies, which was a big concern for her. It is said that men who are having an affair immediately buy new underwear. Old, stained, frayed, stretched "Y" fronts will not do when enjoying forbidden carnal pleasures, even though they are probably not on for very long. I suppose women

that are going into the hospital feel the same way. That people will assess the worth of their character and personality on the forensics of their underwear. My opinion was not required for the purchase of the unmentionables. I went off to buy the Diskman. It gave me something to do. It was a gadget, a gizmo, a boy's toy. It was audio related and I loved audio equipment. I ran through the choices from the no-name *yum cha* alternatives to the TEACS, Samsungs and Sonys. Somehow this made a difference, to me, inexplicably, this was important. It would comfort Julie. I bought a Sony.

One of life's little ironies.

She loved it. She gushed with approval and thanks and for a minute, the weight was lifted. In the end, she only used it once. She preferred to have me read to her, which over the ensuing weeks and months, I would do endlessly. The cheapest gift of all became the most valued.

Despite Ruth's admonition not to check the Internet, as soon as Julie went to bed, I went on line. What I found was sobering. *Astrocytomas*, *anaplastic astrocytomas* or *glioblastoma multiforme* (heretofore to be referred to as GBM) is a particularly aggressive and pernicious form of malignancy. They are fast growing and although treatment takes the usual medical alternatives that are used to treat most cancers, surgery, radiation therapy and chemotherapy, the overall prognosis was grim.

Called such because they grow from star shaped cells in the brain called astrocytes, this is a malady that provokes fear, loathing and reverential awe from the medical profession. Think of an invulnerable perfect alien machine of destruction; much like the extraterrestrial brute that Ripley battled in the *Alien* movies: pristine, implacable, relentless, indestructible.

The causes of an *astrocytoma* are unknown. Every medical practitioner knows the results of one. There is no cure. If radical surgery was to be performed on a patient and an entire hemisphere of the brain removed (rendering the patient either dead or a vegetable), the *astrocytoma* would recur in the opposite hemisphere. Pernicious and virulent, it is virtually the perfect cancer. It can double in size with breathtaking rapidity, making other cancers seem indolent and lacking in ambition. Spreading through the ventricles of the brain in a characteristic "starfish" pattern it destroys the brain. It's that simple. Motor skills, intellectual capacity and emotional responses become aberrant. People fall down with the "stumbles" and drop things. Attendant swelling and oedema in the brain cause crippling nausea and paralysing headaches. Words patients have used all their lives become meaningless. One patient could not grasp the concept of a dolphin any more. Patients are afflicted with dementia. The meek become aggressive. The brave fearful. The docile rage.

The tumours are graded by the World Health Organisation on a universally

accepted scale from Grade I to Grade IV. Grades I and II invariably occur in juvenile and adolescents.

Bad luck, kid.

Grades III and IV are adult illnesses. The statistics for a Grade IV *astrocytoma* make for sobering reflection. Median survival time from diagnosis: 8.7 months. Survival percentage of patients with a Grade IV *astrocytoma* after 24 months: zero. No one lives. Any therapy only buys time, and the inevitability of the patient's fate is as certain as the cessation of life on earth in several billion years. With an *astrocytoma*, it just happens very quickly.

I trawled around a variety of cancer sites: the National Brain Tumour Foundation in the USA, Filipino faith healing sites, Chinese medicine sites, clinics in Mexico with revolutionary treatments that were outlawed in the US because they were curing too many patients. The National Brain Tumour Foundation's website described Grade IV *astrocytomas* or *glioblastoma multiforme* as "the most common and devastating brain tumour that affects adults". The word devastating left me no room to manoeuvre, no ambiguity about what the outcomes were for Julie. Another site gave me the most chilling phrase of them all: the stark ambiguity of "universal morbidity". I'm an English teacher and it took me a moment. It meant "everybody dies" in bureaucratic newspeak that was as frighteningly bland as "terminate with extreme prejudice" for murder and "extraordinary rendition" for torturing someone till they spilled the beans. I felt ill. If Julie had a Grade IV *astrocytoma*, she was dying. And sooner rather than later.

Then I read what the tumour would do to her. It would slowly dissolve her brain. She would progressively lose body function, and what functions she would lose would just be a matter of what centres in her brain were being invaded by the tumour. Paralysis, lack of coordination, convulsions, vision problems, loss of hearing, loss of sight, loss of speech, incontinence, emotional problems, hallucinations, dementia and psychosis. There was no predictability to the nature, severity and sequence to the symptoms. Some lucky people had a survival time of zero. That is, they dropped dead without warning, and when the post mortem was performed, a brain tumour was found to be the predisposing cause of the stroke. I don't mean the word "lucky" to be interpreted ironically. Not in the least. They were lucky.

I was devastated, shocked, overwhelmed, confused and desolate. I could not believe this could be happening. Julie was a fit, vigorous, active woman who ate well, lived a conservative and healthy lifestyle and never smoked in her life. We had just built a new home; we had finally started to achieve our dreams with the horses. We had worked thousands of hours on three farms, building, working, fencing, shovelling shit for years in stables, Julie had ridden thousands of miles

around riding arenas honing and polishing her riding and training skills. We were poised to finally actualise those dreams. Years of work were going to end tomorrow in Sydney when our fragile vision would crash into the hard reality of the diagnosis Professor Dan would give to us. Julie had a tumour. That was indisputable. Even as laymen we could see the shadow and smear of it on the CT scan. We had to wait for him to arbitrate and decide our fate. It wasn't fair.

Our only hope was that the tumour was not an *astrocytoma*, that it was some other form of tumour, hopefully benign. I knew I was chasing rainbows. The implacable nature of the information I had been reading compelled me to fantasise, to dream, to try to find alternatives, possibilities other than the horrible, slowly sinking morbidity that awaited Julie otherwise. The kindest, gentlest, most compassionate person I had ever known had contracted one of the most vicious and aggressive tumours known to man. One from which everybody died. I sat upstairs and my share in our dreams died that night. I knew then that from the next day our lives would be irrevocably different. The unsympathetic biological reality of mitosis and cellular division, of chromosomal abnormalities in cells, were about to destroy Julie's life and change mine. I didn't know what to do. So I went to bed.

I felt like I had been working for weeks and all I had done was go to the doctor's and go shopping. I crept into the bedroom and slipped into bed in a state of confused anaesthetised numbness, taking as much care as possible not to wake Julie. Tomorrow would be a big day. We had packed that afternoon and into the evening and Julie was her usual industrious self, a whirlwind of activity making sure she had everything she needed for the next six weeks.

We had both felt the sense of nervous dread as we had packed our respective bags.

Where would I stay?

How long would she be at Concord?

How would we be able to look after the horses?

Everything was so confusing.

As I settled into bed, Julie rolled over and found my hand, squeezed it and whispered, "How did you go?"

"OK," I replied.

"What did you find?"

I tried to be vague; there was no point in telling her what I did find. "Lots of stuff, a lot of it contradictory and confusing. You know, the usual crap from the Net, some of it positive and some doom and gloom."

Another squeeze, "It'll be OK."

Julie rolled over and either pretended to be asleep or genuinely went to sleep. At any rate, we spent the last night of our old life in fitful sleep as we tried to avoid thinking about the future and our consult with Professor Dan.

Restlessness would pervade my sleep and continues to do so. A vague, indefinable unease would keep me on the edge of consciousness in some sort of twitchy limbo. I became ultra-sensitive to the patterns of Julie's breathing and the other cadences of her being. I woke up if she rolled over. I woke up if she got up to go to the toilet and asked the same question, "You OK?" I woke up if she coughed, and sometimes I just woke up because my overactive imagination had manufactured an event. Then I would lie there and wait, scanning the dark for the pattern and tempo of Julie's breathing and vital signs, and then gradually drifting off into the same light and fitful sleep.

But I think I went to sleep that night. I really do.

The next day was perfect, a tranquil, warm early summer's day. And we were going to Sydney to see if Julie was dying. We had not called anyone or told family or friends. We would wait for Professor Dan's diagnosis and then let people know what was going on. I woke up early despite daylight savings, and the only thing that we had to do on the farm was move two young colts, who we had just finished weaning and handling, from the stables to the paddock. We would need to spend a few minutes with them, lead them around and then take them out into the wide world and hope that they didn't freak out. But Murphy had his way, the job was already done, they were out and in a paddock, but not the right one. The two lads had played with the chain on the gate of the yard, opened the gate, had a good run around and managed to cause havoc because they were in the paddock with two rather indignant broodmares with their two fillies all of whom were absolutely appalled at the two hoboes who had knocked down the fence to get into the paddock. They were now expecting to be fed and looked at me with that mixture of expectation and contrived innocence, as if to say, "It wasn't us. We don't know nuthin' about that fence."

Julie fed the horses and I fixed the fence in record time. We moved the boys, who were well-behaved and cooperative, to their new paddock and I ate breakfast driving out the gate. Julie had to fast for the MRI.

We drove to Sydney, a trip we had made many, many times and we had some idea where we were going since Edgecliff was fairly close to Paddington where the old Sydney Showground was. We had been to the old showground countless times for shows. We both loved the place with its old world ambience. We would have to drive past it up Lang Road to get to Edgecliff. Making light of why we were driving to Sydney by ignoring it, we both knew that the news was probably bad and that we would have to deal with that later. We chatted about the weather, how good the two boys were and, of course, Julie started making

big plans for them, disregarding the fact that we would, in all probability, not be there. We planned who we would breed that season. We talked about the lack of rain, how lucky we were to live at Bannister because we had received more rain than Goulburn. We talked about how nice it was to have a couple of days off to spend the time together. We told beautiful lies we could live in and closed our eyes to what might happen in Edgecliff.

We wandered around the Eastern Suburbs taking the occasional wrong turn and frustrated by the ubiquitous No Right Turn signs. We parked on Ocean Avenue, in Double Bay, the suburb adjacent to Edgecliff. We would cross New South Head Road and be in Edgecliff. We found the medical centre that Professor Dan's rooms were in and found his office. One of his secretaries, a vibrantly chirpy and athletic looking young woman named Peta, directed us to Sydney MRI where she had booked an appointment for us. We went to Sydney MRI, which was, conveniently enough, located in the same complex as Professor Dan's rooms. It was a strangely industrial setting. There was a shopfront and you walked down a long flight of stairs to what I can still only think of as an underground bunker. I couldn't help thinking that if Hitler had this; the Russians would still be trying to roust him out. We filled in the appropriate forms and finally convinced the receptionist that Julie had never worked in the metal trades. Apparently metal in the body reacts very badly with the equipment. I tried to imagine what would happen if you had metal in your body. Did you explode, or did the machine? Images flashed through my mind of a bemused techie wandering out and saying, "Bugger, another housewife just detonated".

We waited for Julie's name to be called after filling in all the forms, releases and disclaimers that stated if she did detonate they would not be responsible, and I would have to clean up the resultant mess and pay for all damages. Waiting was to become one of the characteristics of our situation. I had not yet become accustomed to waiting. I tended to fidget and twitch. I thought constantly of that delightful passage in *Huck Finn* where Huck has to stand perfectly still but begins to fidget, and his whole body begins to itch, cramp, ache and otherwise make him want to move, scratch or stretch. I needed something to read and would eventually bring books with me. This time there were only the same copies of the same rags that had been in the CT waiting room. I wondered how they got them here before we did. They had inconveniently removed the National Geographic that I had not yet finished reading, and I was left with the dregs unable to round out my knowledge of how the Aztecs (or the Mayans) completed their adolescent virginal sacrifices. I wanted to get this over with and get back to Bannister. I even wanted to get back to work. I tried to pretend the CT scan was a mistake and the MRI would give the all clear. Later, I would learn to wait with an almost Zen-like calm. I tried to imagine that I was a goldfish swimming

around the bowl. One lap of the bowl and I would forget what happened to me. The world would be constantly new. I needed to be able to suspend imagination, knowledge, belief – just exist in the here and now and pretend there were no such things as brain tumours.

Julie emerged from her MRI and we went upstairs to a conveniently located food fair. Julie had been required to fast again. Grocery shops, specialty food hawkers, fish shops, delicatessens, noodle emporiums, cafés and bakeries competed for our attention. Medical downstairs, food upstairs. There seemed to be this almost ironic contrast I couldn't work out. Why shouldn't they coexist? No reason why. We bought coffee, tea and toast and talked about the MRI. What had it been like? Noisy. Earplugs, the sound of a construction site and lie still. I kidded her and said it sounded like rough sex. She, blushed, giggled and told me I was impossible.

We went back to Sydney MRI and asked when Julie's MRI would be ready. Not for a while, like afternoon, but we needed it immediately. Given a time and enduring the arch and condescending scolding by the receptionist about proper and organised procedures about MRIs and how irregular this was, we had the necessary oversized envelope. The envelope seemed appropriately weighty and substantial for either the dire news or the endless relief contained there.

We took the scans back to Professor Dan's rooms. And we waited. But not for long. We were escorted into one of Professor Dan's consultation rooms and he came in. Professor Dan was a short, stocky man with an almost courtly manner about him. He had lush hair elegantly combed back. My first impression was that he was a clone of my Uncle Joe, a huge man from Malta who had spent his life in New York City speaking in an English public school accent. For some absurd reason, in addition to my Uncle Joe, Professor Dan reminded me of a mafia don. He had small muscular hands, with what looked like short stubby fingers. I somehow imagined that a surgeon would have hands as refined and sculpted as a concert pianist. He was gently economical in his manner and infinitely reassuring to Julie. However, he too was going to make her an offer she couldn't refuse. She was immediately comforted by this grandfatherly figure with his gentle ways and soft-spoken manner. Despite his low-key approach, Professor Dan radiated proficiency and competence. Julie tended to make instant judgements about character. I could tell that within seconds of meeting him, she trusted him implicitly. And so did I.

Professor Dan shoved both the CT scans and the MRI scans into one of those white wall-mounted glowing panels for viewing x-rays. We had looked at the CT scan at home and saw a large lump or mass in what we would find out was the left temporal lobe. It looked alien and invasive, marring the structural pattern of Julie's brain. The MRI showed the same mass, the same obvious anomaly from

the otherwise evenly ordered structures of the tissue in her brain. You didn't need to be a brain surgeon to figure out it didn't belong there.

Professor Dan stood in front of the panel and the inscrutable MRI. He alternately changed views. You got your money's worth with the MRI. There were at least eight different sheets with views of Julie's skull and brain that he could inspect and up to twenty x-ray cross sections on each sheet. He rubbed his chin and squinted the way a farmer does at a distant rogue sheep that is separated from the main mob in the next paddock. He was trying to work something out, just like the cockie would try and think how to bring the ewe back to the main group in the shortest time with minimal effort. The mass didn't look as vicious as the various descriptions of *astrocytomas* had. I intuitively reached over and felt for Julie's hand, the way I always did. Her grip was strong. She was worried but her hand was only warm, not sweaty, not slippery. The minutes ticked by while Professor Dan shuffled the scans in and out of the viewer with the cool practised efficiency of a baccarat dealer snapping playing cards out of the shoe. I cleared my throat and broke the silence. This became almost a pattern. I tended to speak for Julie in some of the medical appointments. However much she already liked and trusted him, she was intimidated by the ambience of this office and the aura of professional competence of Professor Dan.

"Is it an *astrocytoma*?" I enquired. I already knew it was. Don't ask me how.

Professor Dan avoided eye contact and busied himself with rearranging the scans. He found something quite interesting on the surface of his desk and gazed at it in studied contemplation rather than looking at us. I looked at the desk as well and was mildly shocked that a patient of Professor Dan's had apparently vandalised it. I can't remember what it was now. I think they had pulled a handle off or something. I was scandalised. How could someone do that to this nice man? Perhaps, it was just rage. A lot of bad news was communicated in this office.

"Yes," he replied slowly. "I'm afraid that it is."

He wasn't afraid. We were. Julie's grip tightened.

"What do we do?" My question seemed vague and lame but it was the best I could do. The numbness from the day before was gone. We needed to react as if we had a horse tangled and thrashing in a fence. We needed a plan and we needed it now. We needed a commander to organise a brilliant and decisive campaign against the alien in Julie's brain, and we were both hoping that this serene and dignified authoritarian figure could do the job.

Now Professor Dan was on safer ground. He immediately perceived that there was going to be no wailing and screaming. We were not going to beat our breasts and howl with metaphysical outrage or pull more handles off his grand desk. He was going to tell us what to do and we were going to do it. He still contemplated

the desk.

“I’ve arranged for a bed at Concord this afternoon. And I can operate tomorrow.” He looked at us for the first time since we had introduced ourselves. “You will be having surgery?”

I looked at Julie, she nodded. Professor Dan nodded as well. We were all in agreement. “Not to do so would be...” His voice trailed off as he searched for the proper adjective. “...catastrophic.” He decided and nodded again in agreement with himself.

He became more businesslike. He told us that a bed would be available at 3pm. He had already arranged it. So, he knew too, even before seeing the MRI. He discussed getting to Concord, gave us directions via a back way through Five Dock that, surprisingly, we would negotiate without a problem. His manner had not changed. The same slow, studied and gentle approach charged with a civil humanity that a lot of other doctors we would meet lacked. This was a good man. A man who knew what was in front of us. A man who would treat us with decency, sympathy and compassion. We would need it.

We were done. Surgery would be in the morning. One of his associates would see us that afternoon. He would see us in the morning. Had we had lunch? No. Plenty of places to eat in the centre. We paid the account and found our way out.

We ate lunch while Julie chatted and I tried to grasp what was happening. We were sitting in an overpriced café in the Eastern Suburbs of Sydney amongst stylishly maintained and elegantly coiffed Jewish matrons, power dressed career girls, slick executives trying to hit on the latter, and prosperously bored housewives with strollers which looked like they should have a Benz star on the front of them. The lunch bills for this group would probably exceed both our combined weekly incomes. Julie was in a simple gingham sundress and I was in discount jeans. We were eating \$12 focaccias and getting ready to go to Concord Hospital to have neurosurgery for a malignant brain tumour of unimaginable viciousness. I was barely coping. Julie seemed fine and fretted about spending \$30 on lunch for what were basically two crusty sandwiches with a juice and a Diet Coke. Background conversation revolved around real estate, nappies, home renovations, a husband’s hernia and an aunt with Alzheimer’s. Kafka would have felt at home.

We went back to the Outback and started to drive. Somehow, the intricate instructions Professor Dan had given us to Concord jelled into coherence. Julie and I weaved our way through afternoon traffic while Julie made sense of the hieroglyphs of street names and suburbs in the street directory. A couple of “bear

to the rights”, “go straights” and I saw a green sign saying “Concord”. Julie told me to “turn right” and we were on Concord Road. Somewhere, in the welter of streets, turns and suburbs, between William Street and Five Dock, Julie said something that has stayed with me. We were stopped at a set of lights for a long time. She looked at me with that disarming honesty which looked right through you and touched my arm. “It’s OK,” she said. “I’ve got a brain tumour and if I die, I die. I’m not afraid of that. I thought I was losing my mind, it will be OK.”

Only Julie could be glad she had a brain tumour.

CHAPTER TWO: HOSPITAL

We were going to a hospital and Julie hated hospitals. Even more than doctors. I've checked and better writers than me don't know an antonym for *hypochondriac*. Stumps the thesaurus compilers as well. But whatever it is, Julie was one. I had taken Julie to the hospital a number of times for horse-related injuries – potential fractured skull, suspected broken pelvis, back injuries and possible broken ribs. These were separate incidents. For most of them, initially she refused to go.

A brain tumour would get her to the hospital. Just.

I presumed Julie's disregard for her symptoms, which is why we had been arguing in the first place about her going to the doctor. But like her "big job/little job" concept, this was "big stuff" as opposed to "little stuff", like getting kicked by a horse.

Old joke – epitaph for a hypochondriac: "I told you I was sick." Julie wouldn't tell you. Not a word. Never mention it.

I remember reading Michael Herr's magnificent book about the Vietnam War, *Dispatches*, in which he mentioned one contradiction of the many that he came across in his time in Vietnam. That was the sound of the helicopters – the Hueys, the Chinooks – was both sharp and dull at the same time. So it was with Concord Hospital; it looked both squat and bland as well as tall and imposing. Built of brick into a less than attractive Neoclassical Pillbox it gave the impression of a short, blocky, football player with a bullet head and no neck. A no-nonsense building, all efficiency, all business, a factory of healing. At the same time it towered over the surrounding suburban homes like a ziggurat, a cenotaph that had been plunked down in the middle of suburbia crushing to elemental grit the houses under it. We parked, a problem as always in Sydney, and found our way to the admissions desk.

I presented Julie's referral and her admission to the hospital began. We sat down and waited for our names to be called. I had always wondered how Buddhist monks and samurai warriors achieved that contemplative dissociative serenity – the merging of the one with everything, the state of being and nothingness. It was easy. They must have practised in hospital waiting rooms.

Julie's name was called and we met Robert, a jolly stocky smiling Pacific

Islander. Robert possessed a radiant smile that embraced and welcomed like a jovial and cheery Micronesian medical concierge. His huge smile and perfect teeth were set in a teak coloured pockmarked face fissured with laugh lines. It was as if life's misfortunes had cratered and creased it with minor cares and worries. Robert was the first to let us know this impersonal building was full of charitable and benevolent people who just happened also to be crackerjack doctors and nurses. Julie beamed back at Robert and relaxed. This was a guy she could trust.

However, there was an unspoken tension in the air. Julie was worried sick about money. Driving over to Concord, she asked me, "Can we afford this?" I didn't even answer and later, another kilometre further on, "Let's go home and forget about it."

I said, "You'll die."

Julie just smiled faintly and said, "I don't care, it doesn't matter."

We were broke, and she would rather die than be a burden and run up another bill. We had spent a fortune on vets over the years but her health needs and wants were neglected.

Robert marshalled and massaged us through the paperwork. He gently asked us for the details of Julie's admission while he regaled us with details of his home life where he was as henpecked and downtrodden as Basil Fawlty. He confided to us that it was not only at home. Secretaries passed his desk and Robert teased them with gentle taunts that they returned in spades. Grinning at us in confirmation of his martyr's yoke, he filled in the next line on the form.

Julie giggled, laughed and joked with Robert while maintaining a death grip on my hand out of sight in front of the desk. Robert had not yet mentioned payment and how the account was to be settled. We both hoped that it would not be mentioned and that it would somehow pass or vanish, just like we both hoped Julie's tumour would also just magically go away.

Robert looked up and asked the question which we dreaded, "Are you a public or private patient?" Julie's grip tightened further.

I just replied, "Julie has a brain tumour. She needs immediate surgery."

Robert frowned; his furrowed and pockmarked brow became even more deeply wrinkled.

"Ah, she's an emergency patient!" He boomed. "Of course she's a public patient!" his facial landscape smoothed, Robert's enormous grin returned, Julie's grip relaxed as the spectre of indigence passed.

"You have your Medicare card, don't you?" Robert's smile went up a couple of hundred watts. I handed it to him and he confirmed that we were indeed Charles E and Julie A Barber. That little innocuous piece of green plastic was our passport out of impecunious poverty. I had already wondered how much money

I could borrow to pay for Julie's treatment.

I gently changed the subject and asked Robert about motel accommodation close to the hospital. I didn't think it was possible, but his smile increased in intensity yet again.

"For you?" he chorused.

I nodded.

"You can stay in the relatives' accommodation, right here, on the hospital grounds," he proclaimed. He leaned forward and gently repeated, "There's accommodation here at the hospital, for relatives."

This time, more quietly as if it were a secret and if it were let out, the place would be overrun with squatters. He mentally checked the distance from Goulburn to Concord and told us happily, "You live far enough away." He leaned forward apologetically, "It's not much, but it's cheap." Robert leaped to his feet and we nearly fell over ourselves trying to follow suit. He pointed to another office where I could check into the system and my admission procedures would be completed.

We went up to the fifth floor of Concord on a silently efficient elevator. Broad expanses of grey granite and grey hospital walls greeted us. Julie and I had debated whether or not to get her things or to scope out the situation and then go back for bags, toiletries and clothes. We tentatively enquired at the desk located strategically in the middle of the floor, and we were ushered down a central hallway to a sunny room with two hospital beds. Julie chose the one by the window and gushed about the view. On the broad expanses of the Parramatta River sailboats, yachts, powerboats, cruisers, dinghies, all facing one way, bobbed gaily, all in a seemingly orderly formation, synchronised and organised by the currents and the tides. The foreshore looked like a park. Later I would be told there were numerous walking trails up and down the river, which would afford breathing space from the hospital, if I so desired. I never saw them. I would spend almost all my time with Julie.

Julie and I went down to the car and brought up her bag and her things. She perched them on the bed and began to unpack them with the same meticulous determined purpose that she brought to preparing for a holiday jaunt, chatting cheerfully about the view, Robert, how nice everyone was, our little victory in being declared a public patient. It might as well have been the Novatel in Broome or some other holiday resort if our conversation had been taped.

I left Julie to fuss about her things and told her I was going to check out the relatives' accommodation. I found the appropriate office, and rather than Robert's booming joviality, I was attended to by a glumly efficient Asian lady who gave me a key to Room 15 and some vague directions. I took the elevator to the basement, wandered out the back of Concord, past the canteen and cafeteria

and various rooms bristling with machinery whirring away down in the nether parts of the hospital. This was obviously the engine room where the stokers fuelled up large engines of healing to keep the wards above humming along effectively. I tried to look as if I belonged while simultaneously emitting signals, which said I needed help, and direction.

I meandered down a drive past the hospital chapel. The day was hot now, it was late afternoon and our day had started at 4.30am and I was beginning to fade. Twenty or 30 metres past the chapel, I saw a smiling placid woman of about 60 sitting on the small abbreviated verandah of a barracks-like building idly fanning herself in the afternoon heat. Built out of weatherboard with a corrugated asbestos roof, it looked like the prison barracks out of *The Great Escape* or *Hogan's Heroes*. The only thing, which made it distinctive, was its rather diminutive and unimposing appearance next to the squat presence of the hospital with its machinery and hushed and humming efficiency.

"Is this the relatives' accommodation?" I asked.

"Yes, love. Do you have a key?"

I nodded and she languidly pointed over her left shoulder through a doorway and up a darkened hallway. I didn't know if I would run into Hogan or Sergeant Schultz or see Hilts on the way to the cooler. The building reflected the dilapidation of a century or so of half-hearted maintenance. The building was beyond the skills of *Renovation Rescue*. There was no former glory to restore, it had never had any.

I found Room 15 halfway up the hallway on the left and I knew exactly what to expect. It was a narrow dormitory room containing a lumpy single bed with a chipped brown iron bed head. The painting was as old as the Mona Lisa. Some nondescript vinyl-covered chipboard furniture completed the furnishings. The mirror on the dressing table was eroded and worn at the edges and was becoming mottled with age. The silver flaking off the back giving the impression that it had acquired middle-aged rather than adolescent acne. The room was stifling hot having been closed up for an indeterminate period and stank of ratty carpet, too many sleepless nights and the musty, pervasive odour of despair. But it was cheap and it was close to Julie. There was no proudly attentive concierge to whom I could turn and say, "I'll take it".

I went back up to the fifth floor on what would become a well-established route. After a day or so, I was sure I could do it blindfolded, guided by the changes in the texture of the pavement, the sound of the ever-present machinery and the smells from the cafeteria and the lobby. I saw doctors by the score, some talking animatedly with colleagues, still in their baby blue coloured scrubs from the operating theatre. They looked vaguely like motorbike mechanics on a break, except for the disposable caps, which most of them had forgotten to

take off. Mechanics with paper and gossamer shower caps and the disposable slippers as well. Other doctors and nurses looked on the edge of exhaustion, fatigue hanging off them like a cloak. I was struck by the number of doctors and nurses who smoked. They swilled or inhaled cups of coffee along with vigorously puffing away, dosing themselves with caffeine and nicotine, battling weariness and strain. I wanted to go up to them and grab their cigarettes and rail at them about the injustice of Julie, who had never smoked in her life, getting cancer and to upbraid them for their foolishness, indifference and bad example. Naturally, I didn't. Instead, I smiled at them with grateful thanks and respect.

Julie was in bed resting when I walked in. I had stopped in the lobby and bought a can of Diet Coke. I too needed a caffeine hit. She had raised the bed and was half sitting up, with her eyes closed. She had on one of the new blue nightgowns and looked composed and serene. I had checked myself out in the slowly degenerating mirror in Room 15. Both the mirror and I looked like shit. I had a hunted, harried look, and my face was thin and drawn. I was flushed and sweating but my eyes looked bloodshot. I was to lose nine kilos in five days while still making sure I ate three times a day. It was my first instructive lesson in what stress can do to the human body.

Julie opened her eyes and looked at me with a vague weary smile, eyes droopy. "How's the room, Sweet?"

Sometime in the previous four years, that had become her pet name for me, "Sweet". I didn't mind, I kind of liked it. I couldn't imagine how kids at Mulwaree would react to that. Hoot with laughter, point fingers in derision, scream with glee at this unanticipated secret. Same with my colleagues. Steve Allen would have particularly enjoyed that little secret. His usual greeting of a morning was profane abuse. A fine fellow, Steve became my contact for passing on information to the staff and the school.

I had called Julie, "Babe" for a while. Like her name for me, I can't identify any distinct period of time that this started. I think she liked it. It made her feel desirable and feminine. If she didn't appreciate it, she never mentioned it to me. Sometime in the next 24 hours "Babe" metamorphosed into "Baby". I don't know why. Perhaps it was because Julie looked so innocent and vulnerable in the hospital context. Perhaps it was because her manner after the surgery became more childlike. It was not a conscious decision. It was like wandering around a hardware store and finding yourself in the electrical section when you were after screws.

I remembered afterwards that "Baby" was Bogie's nickname for Lauren Becall. If it was good enough for Bogie, it was good enough for me.

Julie's calm and serenity I found to be disconcerting. Later, the doctors would find it nothing short of astounding. She was usually more nervous and edgy at

a horse show snapping off requests for grooming gear, horse makeup and the ring schedule. Twenty-nine hours ago she had been told she was dying and she was so tranquil and composed, even peaceful about it, that it unsettled me. I didn't know how either of us was supposed to react. I felt on stage, like a first year teacher in front of a hostile class waiting for the surly kid with the furtive eyes in the third row to misbehave and challenge authority. I felt that everyone I met, who would know of Julie's condition, was waiting to pass judgement about our behaviour and attitude. There was no handbook or instruction manual. I was trying to react how the people reacted on medical shows. I respected and liked the stoical even-tempered characters and viewed the hysterical, whining ones with disdain, disrespect and disappointment. I thought we would get better treatment and I would understand what was transpiring more precisely if I managed to stay calm and focused. It wasn't easy.

I tried to sum up Room 15. "It's pretty shit ass".

Her eyes widened. "Is it?"

I nodded.

She sat bolt upright, full of energy and purpose. "Take me and show me."

Julie clambered out of bed, found her slippers and robe and we held hands while I walked her down to the elevator, through the lobby, past the engine room and on to the understated luxury of Room 15. She asked me all the way down about the various departments in the hospital, presuming because I had ambled past here once or twice that I would naturally know about the purpose and function of everything.

She peeked apprehensively into Room 15 and tut-tutted my previous assessment. "This isn't so bad!"

I knew what she meant was: "It's so cheap and it's so close." But that was OK.

We strolled back in the general direction of the main hospital building. We stopped at the cafeteria and I bought her a juice and myself another Diet Coke. We sat at one of the outdoor plastic tables with plastic umbrellas. The heat of the day was passing or at least here it was shaded and a bit cooler. We had nothing to say. There were no words of condolence or false promise I could conjure up. I reached across and squeezed her hand and she smiled with that same serenity. We sat and gazed at the first of the evening bugs dancing in the late afternoon sun and watched our lives change as the summer dusk slowly descended.

Dr Tilman Rust was Professor Noel Dan's registrar and we met with him Wednesday evening for him to inform us about the nature and possible consequences of Julie's surgery. Dr Rust was about medium height with a thin, slightly

Slavic appearance and an indeterminate Scandinavian accent. At least that's what I thought. He sounded Swedish or Norwegian and had the controlled manner of a monkish ascetic. For some reason he reminded me of Tom Courtenay playing the Bolshevik revolutionary, Strelnikov, in *Doctor Zhivago* but without the shifting tides of fanaticism which so animated Courtenay's performance. While Strelnikov vibrated with revolutionary fervour and zeal, Dr Rust strived for control, composure and a kind of sympathetic detachment. He looked like a Mormon, however, his speech had a Slavic cadence to it, like some Swedish Sergeant Joe Friday saying, "Just the diagnosis, ma'am".

Julie seemed to be approaching her predicament with a strange blend of enthusiasm and chirpiness, tinged with the previously mentioned serenity and composure. When the doctors spoke with her, she listened like the obedient child she had always been and then responded with energetic vivacity to what they told her.

There was to be an operation.

"Wonderful", she trilled. Beaming smile.

"It would be dangerous."

Julie gazed at Dr Rust with the benign trust of a five year old at a smiling kindergarten teacher.

"There could be vision impairment, hearing loss and possible paralysis of the right side."

Julie radiated confidence that two men such as Professor Dan and Dr Rust would not permit this to happen.

Dr Rust began to find her enthusiasm disconcerting. People always did.

There would be radiotherapy and chemotherapy afterwards. It could possibly be painful and distressing. Julie nodded, smiling brightly, with the same positive acceptance she had when she was told a horse was impossible to catch. It would be painful and distressing for other people, not for her. Dr Rust did not realise he was being listened to but not heard.

I looked at Julie and knew what she was thinking: *Other people might find the operation and the therapy was all those things. I won't.* Dr Rust didn't realise he was being dismissed, not contradicted. He just did not understand how hard she would try, how brave she would be; he had no knowledge of how this bright, chirpy and girlish woman with a teddy bear on her blue nightgown was as tough and as resilient as an old work boot. I knew she was already planning to get better. Somebody just had to tell her how to do it.

I began to realise Dr Rust was telling us that Julie was terminally ill. That information was beginning to seep through his catalogue of procedures and therapies. All would be for the purpose of "buying time". What I had read on the Internet the night before was gospel – it was just not some pessimistic naysayers

who were utilising the great democracy of the Net to put forward their opinions. *Astrocytomas* were the cancerous conquistadors of the brain. They conquered everyone and everything, subjugated everyone, killed everyone. The water was going to surge over the bulkheads in the *Titanic* and Julie, sailing along normally now, was merely an illusion. The gash was in the hull of her brain. Disaster was looming and Dr Rust was the polite and detached herald who was quietly and gently giving us the message.

We were sitting in the lounge of the fifth floor with a Coke machine, a snack machine and a television to keep us company. Some inane game show was babbling in the background. It was offering prizes to change the lives of energetically sweating contestants who were being publicly foolish to win a plasma, a new car, a holiday or some booby prize, the proverbial bag of shit, if they selected imprudently or played poorly. Our lives were being changed by the projected inevitability of the consequences, which Dr Rust was outlining for us while someone was agonising over choosing the right price.

This was really bad shit. I was crumbling on the inside. I struggled to maintain my phlegmatic manner, a type of impassivity that I hoped would be interpreted as my being brave. I tried to imagine how McQueen, Bogie, Nicholson would act.

What would they do?

What would they say?

How would they sit?

I had this duality going on. I tried to focus on Dr Rust's litany of outcomes and procedures and wondered if he was judging me as I was judging him. I suppose I subconsciously remembered innumerable situations in dramas and tried to mimic that behaviour which I had perceived as admirable and worthy.

I would not cry.

I would not break down.

This was demonstrating strength and composure.

Julie would draw reassurance from my calm and confident courage.

Julie's bright blue eyes transfixed Tilman Rust. He did not know how to react to Julie. He was, I supposed, used to hysterics, grim and stoical acceptance or raging comprehension. Julie's exuberant and radiant enthusiasm for her new project unsettled him.

I knew the modes of behaviour all too well. Julie was internally steeling herself for the ordeal. She would betray not a whit of fear, utter not a syllable of complaint, permit not a flash of anxiety to warp her smile. She could hold two mutually exclusive concepts with a non-contradictory singularity. First, she was hearing Dr Rust. She knew he was telling the truth. Julie had not lapsed into fantastical denial. She had an "astro". She accepted that. Second, she routinely attempted tasks which conventional wisdom and philosophy told her could not be

accomplished. And then, she nailed it, did it, performed the business, completed the hot trick. She would carry this off. She would prevail. She did not know how. Dr Rust knew his business, knew brains, knew tumours. He didn't know Julie.

Dr Rust's catalogue of catastrophic outcomes and consequences finished. The anaesthetic could kill her. She could have a stroke on the operating table. She could be paralysed. There could be some unpredictable "bin Laden" like event, which he could not anticipate. So, of course, Julie gave him a hug. It's what she always did – to me, to her family, to her students, even big thuggy boys who smelled bad. So why not to Tilman Rust who froze as if he'd stepped in hot cowshit barefoot. He was now totally flummoxed and as disconcerted as I felt. He had just told this woman she was dying, and he had scored a cuddle. He reddened and his hands flapped about his sides like a beached fish's fins while Julie bubbled gratitude and thanks.

I think it was then he realised that this was no ordinary patient.

Julie's dinner was brought to her. She picked her way through the vegetables and grabbed the dessert. She gave me the roll and the mystery meat. We had nothing to say. We were all talked out. I sat quietly by her bed. I knew that I would have to start calling people soon. Her family, her friends, her school. What would I tell them? How would I tell them?

I told Julie I would start to call people from the pay phone down by the elevator. I told her it would serve two purposes. I would be able to keep the phone calls short and we would know how much money we were spending. We were both worried about money. Our mobile plan was the cheapest that Telstra offered, however, when you made calls, they were charged at a prohibitive rate. The next hour or so was a muddle. I called her mother and father. I don't remember what I said. I tried to keep all the phone calls to the facts. Julie had a brain tumour. It was an *astrocytoma*. It was very serious and could be fatal. We would know more after surgery.

I rang Steve, her older brother but younger than Julie. He crumbled. I rang Jason. He remained calm. They both adored their older sister. I told him that he would have to be the strong one in the family. I didn't know how his parents would react and I thought that Steve would be a mess. I rang her best friend, Vicki. She started to cry. I rang her principal, Joe Steyns. He kept repeating, "You poor bastard." I can't remember who else I rang. I think I rang my best friend, Bede and I think it was the only time I lost my composure. I remember saying, "My life has turned to shit," while trying to hold back tears.

It was only weeks and months later that I became practised in delivering the bad news about Julie's ailment. I learned how to craft my delivery according to my audience. I never minimised the grim and grave nature of her illness and our predicament. No stand-up comedian ever crafted his shtick or carefully structured his routine as meticulously as I moulded and modulated what I would say to whom. It was early on that I started to repeat the stark cliché, "It is what it is..."

I was fucked. I couldn't call anyone else. I was exhausted. The morning, fixing the fence, driving to Sydney seemed like an age, an eon, a geological era ago. It was fifteen hours. Julie was spent and drained as well. The same Buddha-like inscrutable composure descended over her again. She dozed. I told her I was going to bed. She asked me to stay and so I did. I sat in the chair and catnapped. Julie would do the same. Occasionally, she would look over at me and smile. I know. I saw her do it.

At 9pm, she told me to go to bed. I kissed her goodnight and made my way to my room, anticipating what sleep would be like in my little hothouse cell. I had previously opened all the windows and was hoping that the faint evening breeze had cooled the room somewhat.

I heard a television playing at the end of the hallway and followed the sound down to a closed-in verandah that served as a common room. An ancient Rank television sat precariously on a rickety table that was probably a hall table in a previous life, one the Beverly Hillbillies had discarded when Jeb became a millionaire. It was painted puke green that furniture about to be discarded was painted as a kind of last rite prior to disposal. And it was here I met Doris and Shirley.

At least that's what I'm going to call them. I don't remember their names. The time that Julie and I spent down at Concord remains a strange and fragmented mixture of blurred half remembrances. Vignettes were burned into my memory with such crystalline clarity that there is every chance they did not happen but are impressions, masquerading as facts, that were snap-frozen, and with the passing of time, emerge somewhat transformed. Much like the steak you put in the freezer several years ago. When it finally emerges, it doesn't even vaguely resemble meat.

The atmosphere was so alien and removed from the isolated bucolic tranquility of Bannister that I might as well have been in another dimension, in another being's novel. Doris and Shirley existed, and they helped me cope, and that is what I needed most. They would be the start of the help we would receive, sometimes from unexpected quarters. They gave me mechanisms, strategies and routines that worked. They got me through the next few days.

Doris was the languid fanner from the verandah earlier in the day. She was grey haired and slightly stout, with the laid back laconic manner of country folk all across Australia. Her speech, manner and movements were measured and deliberate. Life, whether kind or cruel, had proceeded at a leisurely and unhurried pace and she had adapted to that gentle rhythm. Her brother had throat cancer. His prognosis was bleak and grim. She accepted that. Doris was here to provide what meagre comfort and support she could for her brother.

Shirley was different. She was bed-slat thin and crackled with edgy energy. Everything was viewed with a sort of peremptory impatience. Her teenage son, four years earlier, had been horrifically burned in a petrol explosion in the Hunter Valley. Teenage boys, can of fuel, motorbikes, you can do the algebra. Her role was the same as Doris'. However, her methodology was polar opposite. She had dedicated her life to restoring her son to normalcy. The medical establishment and the social fabric of Australia only existed for her to obtain this singular goal. Every doctor, social worker, government agency was analysed and then exploited as ruthlessly as any Soviet peasant in the Gulags was used, manipulated and sucked dry. Shirley was singular, selfish and obsessed. She had been at Concord on and off for the past four years, sometimes for months on end, staying in these same dingy and decrepit rooms. Her stay this time, she informed me, was for surgery to free up tendons in her son's ruined arm, which had been welded together by his burns, so he could flex it at the elbow. The operation was to be on Friday and she expected to be here for about three weeks, this time.

We exchanged pleasantries and she cut straight to the chase.

Why was I here?

My wife had a brain tumour.

They exchanged meaningful glances.

What room was I in?

15.

Right.

Shirley was on her feet.

Did I know my way around? I shook my head. I would shortly.

Kitchen, here. Lights went on. Communal fridge. Do your washing up immediately. Shirley would not tolerate dirty dishes.

Laundry, here. Buy your own detergent. You needed dollar coins for the washing machine and the dryer.

Showers, here. The lights went on again and a cockroach the size of my little finger waved its antennae in startled indignation. I was impressed. I would later swear I could see the segmented divisions of his antennae from across the room. He looked as if his legs were the size of chicken haunches. This was a mastodon, a bull, a stud cockroach. He didn't luxuriate in our appreciation, he promptly

scurried for cover. He probably knew Shirley.

“I shower during the day,” she stated pragmatically. I nodded in mute agreement at this wisdom. She thought that I was repulsed. She had no idea about some of the country showgrounds on which I had showered, shaved and slept travelling with the horses. This was OK. The facilities had at least been cleaned this month and not a decade ago. Broken glass, vomit, exposed nails, condoms, old mouldy underwear, even ancient turds were the obstacles I had worked my way round in the past. I had brought a pair of thongs with me, just for this eventuality. This was OK.

“Have you eaten?”

I nodded again. I seemed mute in the presence of this dynamo.

“Are you sure?” she asked with narrowed eyes.

I continued to nod like an obedient adolescent after a scolding.

“Eat your main meal at lunch. The cafeteria closes early.” She stated dogmatically. “If you stay with your wife, you’ll miss dinner.”

I almost asked her who would give a shit if I missed dinner. It would have been a huge mistake, huge.

“Go shopping tomorrow. Buy breakfast things and lunch things. Eat before you visit your wife. Eat your main meal while she is having her afternoon nap. Have lunch when you get back here at night.” She rattled off these instructions with an electric emphasis as if she were reciting a familiar mantra. Shirley knew: the system, the facilities, the routine.

“Keep your wife’s bread if she doesn’t eat it. That will be your toast the following day. You’ll need breakfast tomorrow. This bread is mine. So’s the mayonnaise. Eat what you need tomorrow, then buy (or steal, I thought) your own.”

Shirley’s tone was so measured, so clinical and so calculating that I was awed. She had thought through every aspect of the system for ease, for economy and for the benefit of herself. She then fixed me with a detached, level and inquisitorial gaze. She had absolutely no interest in me as a person, something far more important was at stake. I had just been inducted into the Fraternal Order of Carers and she was there to perform the initiation rites, administer the oath of office and to make me realise the duties involved.

My wife needed me now. That was my job, my only purpose. That was, now, my only reason for existing, for her bothering to take the trouble to explain all this to me.

“Don’t miss meals.” She didn’t scold. Shirley might as well have been telling me to put petrol in an ambulance. It wouldn’t run without it. “You’re going to lose weight. You can’t afford to get sick. Your wife is going to depend on you. You must eat, you must sleep, you must tend to her...”

Shirley was one of the most inspirational and terrifying human beings I had

ever met. I could not imagine how she treated the medical, administrative and custodial staff at Concord. Crossed she would be as unpredictable and unstable as nitro-glycerine. Her mission was as simple as it was impressive and comprehensive – nurse and care for her son and damn all who should interfere with her. She barely spoke to me again in the rest of the time I was there. Our schedules of care did not intersect much.

I heeded her advice. I hardly dared not to. And she was right about everything. It was advice tempered by hostile experience, the horrifying injuries and hideous nature of her son's accident. Shirley was a great help and you may think this portrait of her is less than flattering. I thought about the great racing writer, Les Carlyon, asking rhetorically if you wanted a cautious jockey when your rent money was on a horse. Shirley was a phenomenon. If I was to go back to Concord and wander through the relatives' accommodation again, I would expect to see her there, as implacable and irresistible as a glacier advancing to the sea. She was a great lady.

I returned to Cell 15. I was fucked. I only thought I was before. Now, I was. It was one of the longest days I could remember. Today, 10 December 2003 was my introduction to the fluid nature of time. I thought I knew that time could be a negotiable item. That the clock and the calendar could lie. That like in *Catch-22*, Dunbar loved boring people because he believed that it made time go more slowly. If time went more slowly, he would live longer. Over the next few days, weeks and months certain days would drag with a tedious monotony that compressed them into a drab linear sameness. The introduction I had to waiting over the previous day would expand into an extended seminar on the art of waiting. I would learn how to put myself into a psychological stasis, a type of cerebral limbo in which events washed over Julie and me. Like some latter day Buddhist I had to learn to become one with vinyl furniture, nylon rugs and ancient tattered copies of *Woman's Day*. I didn't practise a mantra. I didn't count backwards from a thousand. I had to learn not to think. To push all expectations, worries, anticipations and priorities out of my mind. To just be. It was not an easy learning curve.

Today was different. Today was overload. Too much had happened to process and a different kind of acceptance was required. I had to be at one with the events. Like Shirley I had to endure, ignore and then transcend to accomplish what had become my reason for being – to comfort and care for Julie. That was all. I had not learned yet to do that. A million discordant thoughts descended on me once I was back in Cell 15 and alone.

What was I going to do about money?

How much would I need?

What about the horses?

What about the house?

What about our jobs?

And one overwhelming completely selfish thought kept raising its ugly head no matter how much I tried to push it from my consciousness: What was going to happen?

If Julie really had this hideous tumour (and I knew she did), what was my life going to be like without her?

What would happen to her?

To me?

To us?

What would I do with the horses?

The farm?

My life?

Some of the young horses had not been weaned or taught how to lead. How could I cope on my own?

And then I was swamped with guilt. Julie was lying up on the fifth floor worrying about how her ailment would affect others and all I could think about was myself. I felt like a shit, subhuman, selfish and inconsequential. And somewhere in there, I went to sleep with a phrase from an old movie echoing through my consciousness: "Toto, I don't think we're in Kansas any more."

CHAPTER THREE: OPERATION

I would get up the next morning, December 11, at about 5.00am to go for a long walk with only one purpose in mind: to sweat out some of the torpor that had accumulated from the previous day. I walked from Concord Hospital down Hospital Road to Concord Road and turned left to walk to North Strathfield. I walked quickly wanting my feet to hurt, my legs to ache and pushing myself to get a stitch because it felt real and meaningful.

This became my morning routine: to walk, to watch and to look and to listen. I tried to absorb the cadence and tempo of life around me and craved that a discernable and meaningful pattern would emerge that I could somehow embroider onto present madness.

What did I see? Everything and nothing. I usually saw people on their way to work. It was too early for the cross section of society that Concord probably was. Reluctant apprentices and wannabe junior executives in Armani knock offs looked at me with the same indifference with which I wondered about them. I envied and resented them. They were annoyed and bored with the normalcy of their mundane, middle class mediocrity. I casually hated them for their lack of perspective.

Over the next few days I would get up, walk, shower, eat, go to Julie.

Later, Julie would ask me about my walks, and I tried to provide a narrative about the houses, the people, how some had built granny flats out the back, how the school at North Strathfield looked, what the shops along the way sold; anything, everything and nothing.

When I returned to Sweatbox 15, I ate a joyless breakfast of toast and tea, showered while keeping an eye out for the stud cockroach, and then walked over to the main hospital building where I would wait with Julie, hold her hand, doze, read and learn not to think. That was the routine. However, on 11 December, Julie was to have neurosurgery. Professor Dan would drill into her skull and we would find out what kind of a hand we had been dealt.

The morning was difficult. Mother and Father, Jason and Jane, Steve and Lisa, as well as Steve's kids, had called in. Ironically, they were on their way to Julie's ancient great aunt's funeral. She had been a grand old lady: vibrant, funny, and occasionally full of Scotch, who had spent most of her life in the affluent Eastern Suburbs. As she aged, her vitality slipped away, both her temper and being wearing away, growing thinner as her existence ran down like the Duracel Bunny's opposition in the commercials. I don't think she died, her body just stopped. There would be less than a dozen people at the funeral as she had outlived most of her peers and friends.

And the past came back not only in the hovering presence of Auntie Eileen, but from 13 years ago.

Back then on Julie's 30th birthday one of our stallions, Apparition, reared and struck her in the face. If he had been wearing horseshoes he would have killed her. Her nose was badly broken and was literally hanging off her face, with the tip gently touching her right cheek. Her scalp was peeled back and standing up like a rooster's comb.

This had previously held the record for the worst trip to the hospital. That record was now broken.

I had skipped into town on some pretext to finalise the arrangements for Julie's surprise party, which I knew would embarrass her to the core of her being, yet bring the people she loved most into one room at one time solely for her. It was going to be night to remember.

Kathy, one of our clients who had become a friend, worked at the hospital as a theatre nurse, and had rushed Julie to the hospital. She had stopped me on the road by flashing her lights.

When I had arrived at the Goulburn Base Hospital that day, Julie was sitting on the treatment table joking with the triage nurses who were staunching the blood, giving her painkillers and trying to keep her calm. Kathy had taken charge; she was issuing orders with precise authority, radiating an energetic efficiency that was both reassuring yet commanding. The other nurses scurried to do her bidding. Kathy was an implacable, irresistible dynamo. She organised technicians, anaesthetist, surgeon and everything else. This was her friend, Julie – only the best would do and she would make the best readily available.

Two hours later, I was playing guard dog at the door of Julie's room while chaos was occurring inside while we waited for the surgeon, the anaesthetist and the operating room to be readied.

"But what are you going to do?" I asked Julie's Aunt Jenny. I had stopped Aunt Jenny at the door of Julie's room. She had been called about Julie's injury and had dashed up to the hospital without pause or reflection. Jenny was almost beyond reason and logic. She was trembling and her eyes were darting about seeking

reassurance and also, Julie.

“I’m going to... I’m going to go to her...I’m going...to...” Aunt Jenny’s thin, pinched face was contorted with doubt and panic. Jenny had a fragile, brittle prettiness about her, like a porcelain doll. In her middle age, this prettiness was fading and her angst, which was almost constant, was appearing in a fine network of wrinkles. Jenny’s words didn’t so much trail off as crash into a barrier of incomprehension. She was there, that was what she was doing, that was how she would help. She would crowd into the hospital room and add her cooing reassurance to the chorus of non-stop crooning comfort that was being directed at Julie by her family.

I could not get near the bed. The main players were Julie’s mother who was holding her hand and prattling softly non-stop, Julie’s father, who was next to the bed ignoring her and talking to Steve, Julie’s brother, who was trying to console and calm her. Lisa, Steve’s wife, was trying to keep her infant son quiet, and talk to Julie and to Steve. Jason, her teenage brother, was there and probably felt a combination of adolescent angst and boredom. There were others there, too. I just can’t remember who. There was a hushed, gentle cacophony of all pervading solace.

The nurses in the room were trying to ready Julie for the operating theatre and they were gently manipulating the bevy of relatives around the bed with little apologies of interference. Julie was slowly slipping into shock from pain, blood loss and trauma and was, as usual, trying to put on that façade of bright happiness that characterised her public face. She was also loaded to the eyeballs on pethidine. Kathy had seen to that.

I didn’t realise it then, but this incident would provide a template for the future – a pattern of behaviour and insight into what was to follow 13½ years later. And as Yogi Berra had said, here in Concord, I now had *déjà vu* all over again.

Back then, I tried to gently make myself heard over the soothing din.

“Everybody out,” I flatly ordered. Everyone ignored me and the hushed, fragmented hubbub of misplaced philanthropy and sympathy continued. At least I had managed to keep Jenny outside the door.

I raised my voice, “Everybody out!” with an air of authority that Kathy would have been proud of.

The nurses began to shepherd the crowd from the room like a publican at closing time. I had given them the authority they needed to do what they had wanted done for the previous half hour. Steve turned on me with deadly intent and whispered, “You’re fucking dead.” Mother was stunned, but all obeyed with the passivity that years of good citizenship had made automatic. These were people who followed directions, paid their taxes and did their civic duty. If the

sign said to keep off the grass, they did. They were no match for the nurses.

These were good, decent, sober and upright people. The battering to Julie's face had upset their ordered hierarchical universe. The damage was profound and shocking, it was as if their Norman Rockwell perspective of life had been substituted by a grotesque vision of the world. Steve never touched me. He was far too gentle a soul to carry out his threat. Julie's face healed. She had a faint, almost imperceptible scar that ran across the bridge of her nose and down her cheek till it petered out, much like the source of a major river when you follow it upstream on a map. Julie returned to work in 10 days. The doctors had given her a month off.

The *déjà vu* part was what happened after I threw everyone out. Mother and Father confronted me outside the hospital room when the nurses asked me to go to the main desk and sign release forms permitting the surgery to proceed.

"You had no right to ask us to leave," Mother said.

Her face was drawn with worry and shared pain.

I shrugged my shoulders. "Julie needed to rest," I mumbled. "I thought I was doing the right thing. There was too much going on. She needed quiet..." I let my words trail off. To them, these were lame unjustifiable evasions. Their place was in the room. No matter what. I was precluding their perceived rights as parents. What I did was unpardonable.

Father said nothing; he never did during times of crisis.

The nurses repeated that the releases needed to be signed for treatment to proceed. Mother instinctively started for the main desk. The nurse said that mine was the signature required. The next of kin had to sign the release forms. That was me, it wasn't them.

Mother had the last word. "You will never come between us and our daughter again. Never." The last was a fierce maternal whisper that would suffer no contradiction.

I shrugged and murmured, "I was only trying to help Julie..."

They ignored me and walked out of the hospital.

I walked to the desk, signed wherever the finger of medical bureaucracy directed me, and like the good citizen I was, I asked permission of the nurse to see Julie again. Her face was buried under a pile of towels and makeshift bandages, which had been applied to control or ameliorate the bleeding. I reached under the covers and found her hand. I remember the temperature was different from what I expected and I found that mildly shocking.

"Everything's OK," I whispered. It patently was not.

"Everything will be OK," I whispered, which I hoped would be true.

"You were going to have a party tonight. Everyone was coming. I've called and cancelled everything." I paused. "You didn't have to do this to get out of going."

She gave a faint squeeze to my hand at my feeble joke, whispered back a thank you, and we waited for the call to surgery.

The family had come on this day for the same reason. They had to be there. Mother held Julie's hand in a trembling grip and talked incessantly. It would be easy to portray Mother pejoratively. She was sweet, gentle and well-intentioned. Charity and kindness were at the core of her being. However, over the years she had become indiscriminate with her conversation. Silence and pauses filled her with doubt and her defence mechanism was to speak – about anything. Her conversations tumbled along without interruption and she, in my less charitable moments, reminded me of Mrs Bennett from *Pride and Prejudice* with 20 milligrams of crystal methedrine on board. Her conversations were as fragmented and non-linear and, of course, Julie loved her unconditionally. She forgave the constant prattling by saying Mother was nervous.

Father, I don't think, listened at all. Mother's incessant chatter was the soundtrack of his life. It was the background noise in the foundry. The clatter of dishes in the restaurant. He had become accustomed to it and it was only when a dish broke that he paid attention. The matter was dealt with, the broken dish swept up and the caravan moved on.

After being introduced to the rest of the family Professor Dan and the enigmatic Dr Rust explained about the surgery again. I could tell they seemed to have the same confidence in Professor Dan that I did. The risks were reiterated, the possible outcomes highlighted again, and the family was left standing mute with shock, except for Mother's perpetual crooning.

Steve was visibly shaken. He apologised to me for hanging up. I dismissed his apology as unnecessary. Like me, he had scoured the Internet looking for solace, hope and a Get Out of Jail Free card. Like me, he had found none.

The conversation ground to a halt. There was nothing to say and chatter would neither generate more hope than we had, nor allay our fears. The funeral party departed. The anaesthetist called in and saw Julie. She was in her mid-30s and tall, with a thin, attractive face, and an amiable, gregarious manner. The most distinctive thing about her was that she had a lovely paisley patterned scarf as a type of turban. We both called her "The Turban Lady" after that because of her style and bearing, yet we never saw her again.

She sat down, grinned from ear to ear and took Julie's hand. "I've given you the most terrible haircut."

Julie's head had been partially shaved that morning in preparation for the surgery.

Julie laughed dismissively, "It'll be fine!"

The Turban Lady squeezed Julie's hand and explained that she was the anaesthetist. Had we been told about the possible risks? We nodded simultaneously. With that, she spontaneously threw her arms around Julie and gave her a hug. "They'll come to pick you up in a few minutes," she advised, smiled and left.

"Do a good job!" I called after her.

She stopped, turned and smiled at me. "Your wife is very special." And she left.

The Turban Lady was just one minor character in our drama and she was typical of the professionalism, the kindness and the compassion we both felt and experienced from almost all the doctors and professionals. They were great.

When the attendant came I accompanied Julie to the surgical departure lounge, kissed her goodbye, vaguely wondered if I would ever see her again and went to the Burwood Shopping Centre to do as I had been told by Shirley – to buy food for lunches that were really dinner and to purchase a new mobile phone. We would need it. We weren't going to be home for six weeks.

I made it back to Concord and took the groceries to the relatives' accommodation. It hadn't been easy to maintain focus on buying the right mayonnaise while trying to imagine what was happening to Julie in an operating theatre a few kilometres away. I was slowly learning to control fear and not to think too much along the way.

Doris thoughtfully asked after Julie. She had assumed her usual vantage point on the small verandah. I told her we would know more after surgery. She nodded with wise sympathy.

I made my accustomed way to the fifth floor and waited in the television lounge. I kept enquiring at the main desk about Julie's operation and condition, but they either couldn't or wouldn't tell me anything. Julie had gone into pre-op at 9.30 am. It was now just after 2 pm. Mother and Father appeared and I told them that I'd found out she was out of surgery and was in post-op but that was all I knew. They asked the usual questions about the success of the operation, the size of the tumour, the prognosis. All I could do was shake my head and say that no one had spoken with me. I think they thought that I was holding something back, to protect them I'd imagine.

Somewhere between *Days of Our Lives* and *Y&R*, Julie came out of post-op, grinning broadly and clenching and unclenching her right fist.

"See!" she bubbled. "I can use it! My right rein will be OK, Sweet!"

Her main concern had been that she would lose mobility in her right hand and would not be able to "feel the rein" when she rode, not that she would die.

We stood by the hospital gurney, the three of us. Mother took one hand, I took the other. I had the hand with the drip and tried to focus on not going anywhere near the cannula. She was fine, she felt fine, they had kept her there for ages. Her hand was fine, all would be well. The doctors were lovely, fabulous and amazing. Her head didn't hurt and was swathed in bandages. A catheter had been inserted and she had a drip. But she felt fine, got it? She wanted to get up and hug mother, her father and me. The attendant gently restrained her and told her to stay there and we contented ourselves with recumbent hugs. Dr Rust materialised and I asked him about the surgery.

Mother asked if she could stay for the conversation in a voice that brooked no disagreement. In fact, she proceeded to appropriate the conversation.

It was "a high grade glioma."

"What grade?" I asked.

"Grade IV."

"How long?" was all Mother asked.

Dr Rust shrugged his shoulders and dropped his eyes. He let his hands trail off the gurney and turned them outwards in a gesture of futile prognostication and gave a little shrug. "Four months to two years."

It was the textbook. I knew that, Mother didn't.

I don't know how I felt. The preceding two days had been like a tsunami. The wave had now receded and the tumult and trauma of the flood had stopped. We were now left with the chaos, the wreckage and the consequences. I had been steeling myself for this.

Dr Rust and Mother continued the conversation. I had been excluded. At the time, I was indifferent. Later, I would feel resentful at the intrusion and the presumption. The conversation was brief. In summary, Dr Rust told us, radiotherapy usually gave a good result. The remnants of the tumour would probably shrink down to nothing and would, in all likelihood, disappear off the radar of the MRI and Julie's brain would appear normal, except for the scarring caused by the surgery. Her progress would be monitored and we could consider chemotherapy when the inevitable recurrence of the tumour took place. This second part was not stated. Dr Rust knew that I knew that these things recurred with the inevitability of the tides. The only questions were: How quickly? How soon? Where? We would, as Ruth had promised, have time. We just didn't know how much.

Father betrayed not a whit of emotion. Dr Rust left and Mother resumed her ricocheting narrative. I stood there, holding Julie's hand and looking at her. She was smiling. She was glowing with good cheer. She kept reassuring Mother that she was fine, that all would be well. Father made the tiny, almost imperceptible signs that he wanted to leave. He shifted his feet, fussed about, looked at the

hallway. Mother knew, it was time to go, so they left.

I asked Julie how she really was.

“Tired.”

“Had it hurt? Did it hurt?”

“No.” To both. I think she was lying. She always did when it came to pain.

I expected her to be moved back into the room at the end of the hallway with the spectacular view. She was moved to an intensive care bed directly adjacent to the nurses’ station in what was, more or less, geographically the centre of the floor. She assumed the same peaceful resting pose as before – lying on her back with her head elevated about 30 degrees in what I would later learn was “the brain injury position”. She folded her hands, closed her eyes, lay there with the same faint trace of a wise smile on her face and dozed. The only difference was the surgical bandage covering 16 surgical staples arranged in a cruel inverted smiley two inches above her left ear and trailing down to be level with the top of her ear. She also had the drip in the back of her hand (which she would sometimes either tentatively touch or accidentally brush and grimace with a twinge of pain) and the catheter tube snaking coily under the bed.

So, we spent the afternoon and evening. Julie would doze fitfully. The nurses would check her monitors. I kept expecting the machines to go “ping”. Every hour or so, the nurses would come and wake her and ask her routine questions to assess her mental functions.

“Where are you?”

“What month is it?”

“Who is that next to you?”

“Why are you here?”

“Who is the Prime Minister?”

I had a foretaste of what was to come when Julie could not remember the name of the Prime Minister. The question confused her. She knew she did know and it was hovering there, on the brink of remembrance. It disturbed her faintly that the mechanisms weren’t operating that would allow this piece of knowledge to be retrieved.

The next two days I can only remember through the same muddled stultifying fog clouding my memory of that time. It was a hospital. Julie was on her back in the brain injury position. Her inactivity and relatively silent repose, punctuated by short bursts of vivacious conversation, contrasted with the perpetual activity of the hospital.

Her bed had no privacy, except for the scanty discretion afforded by the curtains. I suppose the situation was so stressful we did not notice. We retreated into our own world. I idled away the hours with the Herald, with the pay TV (which I watched with the sound off) while Julie dozed or felt headachy. We spoke of whatever popped into our heads. The topics became random and varied and trivial or profound.

We talked constantly of the farm and the new house. Of what we would do when we returned home. I planned on returning to Bannister on the Sunday. I would check the farm, the horses, the electric fences, the water tanks in the paddocks. Julie asked me to make a checklist and I read her the list repeatedly till I could recite it. She would periodically add to it or include little corollaries to make my inventory and survey more complete. I would repeatedly ask her if there was anything else that I could bring down for her. I would just need to do some washing. She would dwell on her needs for a while, but nothing seemed to come to her. She was content with what she had and we would return to my list of duties to check the horses and the farm.

Directly across from Julie was Mr McNally, an affable fellow in his early 60s. He was a big man without being intimidating. Like Julie, he spent most of the day lying down, which diminished any impression of his bulk. He smiled a lot, and his manner was much like a hearty, smiling farmer at the Cowra Show. However, he was a city chap, and had worked for Qantas or some other airline, and he had only recently retired. He was here because he had been out driving with his family when he had a neurological episode and lost control of the right side of his body and, therefore, the car. His right foot had buried the accelerator to the floorboards and he could neither lift his foot nor use his right hand to turn off the key.

There was a "shadow" on his MRI, which was either a tumour or the after-effects of a stroke. The medicos did not know; he was there for tests until they did. He was in IC because his condition was considered to be unstable.

Mr McNally's wife told me all of this, and as she confided in me she slowly disintegrated and was reduced to weeping. Their retirement was not supposed to be like this. Her life was in limbo and their fate was at the mercy of the shadow on the MRI.

Next to Julie was a small, dried up, contorted and comatose Vietnamese man. He was connected to a respirator, which filled his ancient chest with a relentless regularity punctuated by the odd gurgle and the occasional snorting choke as mucus accumulated in his plumbing, or the machine's. The process was interrupted only to resume a moment later, the pulmonary or mechanical hiccup overcome. Julie and I thought he would die at any moment and every choke or momentary blockage, at first, caused us to involuntarily hold our breaths waiting

for an ER type response from a crisis team who would shock or coax him back into his parody of life.

Two alternately twittering or silently weeping daughters or granddaughters would appear at his bedside to talk and minister gently to him. They hovered over him like two hummingbirds looking elegant and ageless. They would whisper to one another and flit over to the nurses' station and a conference between both of them and whichever nurses were on duty would take place. They would then bow their heads and return to their vigil, consulting with one another endlessly speaking in whispers or just seeming to incline their heads towards one another and commune in some manner beyond words. Every pause, cough, gasp or snort would bring them to reflexive attention and when he started to breathe regularly again, so would they.

The sun went down. The longest day of the year was less than a fortnight away. Jason and his wife, Jane, visited. He had bought a carton of Pepsi Max in cans for me. It would keep me going, I hoped. Jason only stayed a couple of minutes. I repeated what the doctors had diagnosed and what Julie's bleak prognosis was. I told him that I was worried about the family. Father appeared to have become a grim, emotionally drained zombie who had convinced himself if he showed no emotion then everything was under control. Mother, I thought, was becoming erratic. Jason nodded agreement with both descriptions. Steve was shattered. My assessment fitted with what Jason thought. Julie chatted with Jane while I told him he might have to be the strong one in the family. Again, he nodded. He was the coolest and the most logical on the phone. He adored Julie no less than the others, however, he seemed more in control of his emotions. He asked after me. He was the first one to do so.

Fucked, that's how I was.

Again, he nodded. That said it all. I imagine I looked that way as well. It was a description I was to repeat constantly for the next year. It covered a multiplicity of mental and physical conditions and those who were not offended invariably nodded with the same silent agreement and comprehension as Jason. Ruth later told me it should be classified as a distinct and identifiable medical syndrome.

The next two days passed much as the afternoon after Julie's operation. Events were tinged with a dark melancholy sameness. Nurses and doctors would stick their heads into our little cocoon. Beds would be made; meals served to Julie. Jason and Jane visited; they lived in the western suburbs of Sydney, only 15 minutes away. Julie's monitoring occurred with structured frequency, the intervals gradually increasing.

Each time one of these little intrusions occurred, Julie would gather her resources and smile and attempt to animate herself. She always succeeded. Dr Rust's reserve melted in the face of her relentless good cheer. The nurses

adored her. All the medical staff regarded her vivacity and sparky nature as a miracle. They seemed to make excuses to talk to her. They tried to spoil her and Julie would not allow it.

The rest of the time we retreated into that nether world. When there was no show to be put on, Julie would relax and settle back into that eerie repose that I found reassuring and disconcerting. Reassuring because I knew how strong she was and this was her way of marshalling her strength. Disconcerting because she looked for all the world to be dead; like one of those medieval knights fully arrayed in their armour with their sword on their breast or their duchess arrayed in her finest garb lying in state waiting for respects to be paid before the funeral.

There was just one significant part of my consciousness that watched Julie; that without thinking monitored every breath, sigh, groan, fart. Each was analysed. It became my permanent state of mind. A kind of heightened vigilance took over, which I began to unconsciously maintain.

I don't have many memories of what happened except for a few incidents that punctuated the next few days like flares over a battlefield at night.

Dr Tin visited us. She was Malaysian, I think, and an oncologist who would supervise Julie's radiotherapy. Dr Tin was stylishly dressed, organised and efficient. Like many doctors, as we would discover, she was direct to the point of being almost brusquely rude. She had as much tact as a ham. They would not allow themselves to see their patients as people, the protective dissociative behaviour routine. Perversely, I began to see them as being all the more human because of it.

Dr Tin explained the procedure. We would go to Royal Prince Alfred Hospital, hereafter known as RPA, for a preliminary visit. There would be exactly 30 treatments over six weeks, commencing in early January, after the Christmas holidays. We would get information about the management of Julie's therapy there.

Would there be any side effects?

Nausea, irritability, minor burns, dried skin, hair loss.

Long-term effects?

She avoided looking at me for a moment and laid her cards on the table.

She gave me a blank look. This was a glioma. No one lives long enough to suffer long-term side effects.

It was a cheery visit.

A nurse came to see me and quietly informed me that one of the doctors wished to see me. I went to the office I was directed to, and an unsmiling and sober Scandinavian neurosurgeon interrogated me. She had been periodically examining Julie when Dr Rust was off duty. The neurosurgeon was pregnant. I teased Julie that it had been done blindfolded or by artificial insemination. She was so cold, distant and detached it was hard to imagine pregnancy was the result of an act of passion. Under Julie's repeated and determined affability and warmth, she disclosed that it was her second child. I joked with Julie that her partner had obviously managed to get drunk at least twice.

She was probably lovely. Like most of the doctors, she had decided not to let the patients into the front door of her vulnerability.

Without introduction or explanation she began to grill me. "Is your wife always like this?"

"Like what?" What I wanted to say, dripping with sarcasm was, "Yeah, she has a fucking glioma every 28 days. Makes her a little irritable and I stay out of her way. Little neurosurgery and she's as right as rain."

She eyed me with deep-seated Swedish suspicion. "So happy," she hissed.

Not believing I was having this conversation, I replied, "Yes, of course."

Regarding me with obvious disdain as I was evidently telling porkies, quite big porkies, she sceptically pursued the point. "Are you sure?"

"Yup." I said. "She's always like this. Julie is a very cheerful and chirpy person."

Doubt suffused her being. She slumped a little. "We never have patients like this. We thought she was having an hysterical reaction to the operation."

With that and without adieu or how's your father, she turned her back on me in silent dismissal, sat down at her computer and went back to work. Dr Congeniality.

I managed to control myself, walked halfway up the hall, leaned against the wall and laughed. Not great gales of cathartic laughter, more like a choked giggle. It was great though. It was the first time I had laughed in four days. Julie had been laughing and joking constantly.

Mr McNally almost died one night. His answers to the nurses' hourly mundane questions sheared off into nonsense, the words recognisable, but just barely, the context without meaning or structure.

The curtains were pulled around him and the only evidence I had as to what was happening was the soundtrack from behind the drapes. The disjointed words became guttural grunting and then a kind of frustrated roaring, a choking ululating howling. I knew he was dying. Julie seemed unaware. I hoped she was

asleep.

Amidst his strangled bellowing, the nurses and doctors worked calmly. Their tones were measured and clipped. Everyone had their job. They worked with deliberation and care, or at least that's the impression I gleaned while I sat frozen five metres away in my darkened chair.

Mr McNally's cries gradually diminished. I thought he was gone.

Instead, he was resting comfortably. The doctors moved on, the drapes opened and the nurses changed Mr McNally's soiled sheets, something they always leave out of the TV dramas.

They cleaned him, removed his soiled gown and sheets and pragmatically wrapped him in clear cellophane about the waist before they put another gown on him. The cellophane was one of the most dehumanising things I had ever witnessed, but eminently practical. If they had to clean up his shit again, it would be easier.

I didn't think he would survive the night.

The next morning Mr McNally asked if he could borrow a section of my newspaper. We didn't think he could read any more. However, I think it made him feel like he was back in his old life with his reading glasses perched on his nose looking authoritatively at the Sydney Morning Herald, although I'm sure the symbols on the pages were as indecipherable as hieroglyphics.

The next night last rites were given to the comatose Vietnamese man. The two fluttering ladies appeared with a tall spare ascetic looking man. Dressed in a pale beige suit, which was Eastern rather than Western, he moved with a sinuous assured grace. The suit looked to be silk, but the rich, creamy beige fabric lacked its sheen. His face was lean and his cheeks were hollow with high cheekbones and deep set piercing eyes. He radiated an impressive austere presence.

The two twittering women had escorted the shaman, as I came to think of him, to the side of the bed with great ceremony, all the while whispering animatedly in their secret language to him and to one another. He ignored their comments and imprecations and approached the bed with accustomed confidence and conviction. He spread his arms with his palms up and began to intone, chant, harangue, shout, exhort and thunder in Vietnamese.

I got up out of my chair, bowed my head, smiled with deference, and slid the drape into place between Julie's bed and the ceremony thinking that they would appreciate privacy with their ritual. The shaman merely looked through me with the conviction of faith and magisterial command of dismissal that the chosen reserve for all infidels.

While the shaman paused for breath the patient maintained his own regular rhythm on the respirator while the two fluttering women held their breaths, investing their faith and will through his ceremonial mien.

However, if these were the last rites, when we left the hospital, the little man was still there hooked up to his respirator maintaining his rhythmic chant. Mr McNally was also still there. Both in limbo.

We were going home. Dr Rust told us on Friday morning that we could leave on Saturday, 13 December. I was shocked. Then I became suspicious. I wondered if they were sending Julie home to die. Dr Rust reassured me that one of the worst places for patients to get well was a hospital. Ruth could take out Julie's surgical staples in about a week. Julie was doing great. Julie was radiant. She glowed and bubbled. She twitched in anticipation. She told everyone. The nurses, the cleaners. Mr McNally and the Vietnamese man next door. She was going home, but she didn't want to wait till Saturday.

Julie had me pack. Dr Rust told her at 10am She was ready to go at 10.20am. Then she started to fret. The serenity evaporated. I was an easy target. I was ready to throttle Dr Rust. He was the hero who gave the good news and then bolted, leaving me to deal with the mess. Better to tell me and I could surprise her Saturday morning. "We're going home, Baby!"

She wanted to go home. Immediately. Without delay. Posthaste.

Who could Julie see?

Why couldn't she go home now?

Julie felt fine. She could take out the catheter and the drip, change her clothes and she was out of here. *Adios. Hasta la vista, baby. Vamoose. Cisco, let's went!*

I now had two rhythmic chants going on from the Vietnamese guy and Julie.

When the nurses came around (now on two-hour intervals) for the "name, address, serial number, what year is it" routine, Julie now greeted them with the same joyous ebullience, dutifully answered her questions and then shyly asked if she could go home ... now ... please? They responded as they thought they should, laughed heartily, pooh poohed her request and continued on their rounds.

Julie would then turn to me and start her mantra all over again. After a while, it modified. This was obviously my fault. I wanted to keep her here so I wouldn't have to look after her. Well, by crikey, she was capable of looking after herself and would tell the medicos that.

This went on till mid afternoon when a bruiser of a nurse appeared, stood over Julie, literally, and announced that if there was any more of this whinging

about going home or coming out of this bed, she would personally see that the said whinger would not be released until Wednesday and how did she like them apples?

Julie looked up at her shyly and promised to behave. I was so grateful I could have kissed her, but she was too imposing.

There were certain hurdles to be cleared. Julie had to prove to the Occupational Therapist that her motor skills had not been affected by surgery, and that she could walk unaided and perform certain basic tasks to indicate that these faculties were unimpaired. She raced the therapist up the hall holding on to her pee bag with all the nurses holding their breaths that, first of all, she could walk and, secondly, she didn't drop the bag. She then offered to arm wrestle the OT, with either hand.

She had to have the catheter removed. She offered to do it. The doctors politely declined and did it themselves.

Back in bed, she looked carefully around and whispered, "I still think I can go now."

I smiled and kissed her. She smiled back and went to sleep.

When I arrived at her bed early Saturday morning, there was a visitor. It was Brother John Henry Thornber, one of Julie's previous principals at St Patrick's College. Julie loved and admired John Henry. He was the first to recognise that Julie's enthusiasm could be channelled into an executive position. He'd urged her to upgrade her qualifications and get her degree, which she did. He'd cajoled her into applying for a coordinator's position at St Patrick's, and she became the first female year coordinator and then proceeded to set new standards for pastoral involvement, parental participation, information and welfare management.

John Henry was holding Julie's hand and speaking earnestly. She was concentrating and listening with avid interest. I felt like I was intruding. He saw me and greeted me heartily. We chatted amiably. He begged his leave with Julie and insisted that we must have lunch and catch up while we were in Sydney for Julie's therapy. I offered to walk him out and we strolled out into the hallway.

What is the real story? He wanted to know. Julie was, as usual, optimistic and full of enthusiasm about her recovery.

I told him that there would be no recovery. Just a period of remission of indeterminate length – maybe relatively brief, maybe as long as a couple of years. It was virtually the most aggressive and malignant brain tumour that the body could generate.

John Henry was pragmatic.

What were we going to do for money? I told him I had no idea.

Apply for TPD.

What was that?

Total Permanent Disability. Julie was insured for this through her employer. John Henry was the first to tell me this. I might not have found out otherwise. It was not a lot of money, but it would help to make her period of remission at least free of money worries. Call the superannuation companies, get the information, start to prepare for her treatment and illness and get some help for myself. I looked like shit; except for the bandages, Julie looked fine.

There was one more thing left. They would not let Julie leave until she had a crap. I couldn't believe it. They would not sanction her release until she had a bowel movement. Julie became the closest she would to anger at the hospital staff at this latest piece of bureaucratic involvement in her internal workings. She was fine. She could walk. She could touch her nose with her eyes closed. She could jog up the hallway. She was ready. The nurses were adamant. No way, Jose, until she made potty.

Julie was quietly furious. They thought she was just as chirpy as ever. She looked at me and I had seen that look many times, clenched her jaw and walked into the toilet and through sheer force of will had a crap. She came to the door and peeked out and demurely asked them if she could flush or did they want to inspect the turd to see if it passed inspection. Suppressing giggles, they told her she could flush.

Ten minutes later we were on Concord Road heading south for the M5 on what would become an all too familiar drive over the next few months. We were back at Bannister by 2.30pm. She dozed all the way home but woke up with shining eyes when we drove in the front gate and she saw the horses. Psychic, Julie's special boy, chased the car along the driveway. Julie made me roll down the car window on the driver's side so she could call to him.

It was important that she see Psychic. He symbolised all her equine hopes, and he validated all our efforts in our breeding program over the last 20 years.

I only realised later that Julie must have thought she would never see any of them again when I said goodbye and they wheeled her into pre-op for her neurosurgery.

CHAPTER FOUR:

RESPIRE

We were home. At least we were home. By unspoken agreement we did not talk about Julie's condition. Instead, we focused on short-term things like rain, water, grass, paddocks, young horses, fixing fences and avoided the metaphysical, the spiritual and the profound. The events of the previous five days were so blindingly devastating that we had not even begun to process what had transpired.

Julie proposed that she would just continue doing all the things she would normally do. Dr Rust had set the parameter of three weeks – and then she could ride. I knew that after two she would be looking to mount up. I had resolved to put up cursory resistance. Dr Rust's prognosis was definite – four months to two years.

I did not know it then but Julie's tumour was quite large. It was a cracker. She never did anything by half. I pragmatically thought there was little point in preventing Julie from doing anything. The quote, "A life lived in fear is a life half-lived" kept running through my mind. Warren Zevon, when asked what he planned to do when he was diagnosed with the incredibly aggressive form of lung cancer, mesothelioma, replied "Enjoy every sandwich".

Julie needed to enjoy every moment with the horses. Every breath of fresh air, every small victory with Biscuit. Every sandwich. She was going to die. We knew that. I was going to die. We knew that as well. The difference was that the first domino had been tipped with Julie, and a rapid and inevitable chain reaction had begun. And I was going to make it my primary focus that every moment was to be lived.

We planned to make Christmas 2003 as ordinary as possible. Not that we wouldn't have the usual brouhaha. I had opened my doors to Julie's parents and told them "our house was their house". I expected to clash with them about Julie working horses, insisting on working on the farm and pushing herself. I was tickled that there were no side effects and, so far, we had been spared the dreaded fits – *grand mal* epileptic seizures that occurred in many brain tumour patients. The thought of Julie being overcome by a rictus of thrashing convulsions frightened me deeply.

The faulty mechanism of memory comes into play here. My recollection is

that from the operation Julie had trouble reading and writing. That those skills and faculties were now greatly diminished. But the diary tells a different story: a record in her clear, rounded childlike printing which is precise and strong of the work on the farm and her strict medical regime.

Her primary medication was *dexamethasone*, or cortisone. And she hated it. It is basically a steroid; one of the most commonly used drugs with brain tumour patients. It is a potent anti-inflammatory that suppresses swelling in the brain. In a lot of cases, it keeps tumour patients alive.

Dexamethasone is a two edged sword. It is used as an immune suppressant. That means it inhibits the defence mechanisms in the body and, therefore, it was very useful in keeping the body from reacting to the tumour and the damage from the surgery in Julie's cortex. There are some quite unpleasant side effects: mood swings (including both euphoria and depression), fatigue, blurred vision and easy bruising, among others.

The most annoying is weight gain and increased fluid retention.

The "dex" as we called it was the curse of her life. We both hated the side effects over which she had no control and were no fun at all.

From December 14 on, I began the slow and painful process of informing people about Julie's illness. If you think it's hard getting bad news, try giving it. Over and over again. I tried to make the messages brief, optimistic and upbeat because that's how Julie felt. I didn't write, "by the way, Julie's dying and have a Merry Christmas".

One of my e-mails, much like Clancy, brought an unexpected reply. Cindy Reich was an overseas colleague from the USA branch of our horse world and her brother, Dan, had an astrocytoma and was surviving. Actually, he was thriving.

Cindy replied with copies of some e-mails that Dan had circulated to his family, friends and associates in his various networks, wryly calling them *What's Up With Dan?* And they had been collected and posted on his website. I took the first of the e-mails down from my office upstairs and read them to Julie. They fired her imagination and gave her the first positive outcome of anyone who had dealt with an astrocytoma and whose health was actually improving.

I sat upstairs and crafted an e-mail to Dan. No envoy ever worked on a diplomatic communiqué as carefully as I did on that e-mail. It needed to appeal to Dan's humanity by demonstrating our own; it needed to appeal to his better nature by reflecting ours.

I seized upon one quote of Dan's:

It is my sincere hope that, should I regain my life for years to come, that I will be able to help others by sharing what I have learned, thus enriching my own life and bestowing upon it a sense of purpose. It feels good to be where I am now (although the stand-up comedian in me wants to add "it

feels good to be anywhere”) and I’m looking forward to discovering where my path will lead.

Dan replied with the humour and grace that I read in his bulletins. He would help us; he would do what he could. I was pathetically grateful.

His therapy basically revolved around diet. He avoided red meat, alcohol, dairy and processed sugars. He practiced a Chinese exercise regime called Chi Gung daily. He consulted with a Chinese herbalist and consumed a concoction of herbal medicines and, above all, he stayed positive and optimistic.

Part of me wanted to scream out that this was nonsense, folderol, claptrap. Being a medicine man was amongst the oldest con in the business. We had consulted with kind and wise men of science and now some mucky tea, eating sensibly and some Chinese gyrations were going to make Julie well? What the fuck could I be thinking?

The other part of me said that Cindy was a sensible woman. She worked in one of the most disillusioning businesses – breeding horses – where large and expensive beasts of great beauty and little or no sense came to grief with sickening regularity. Old joke: do you know how to make a small fortune with horses? Start with a large fortune.

We decided to try what Dan was doing simply because we had nothing to lose. We started to put out feelers for a Chinese herbalist and modified our diet. I began to scour the Internet and phone books for courses in Chi Gung or Qi Gong. At last, we had a plan; at last we had something positive, some respite.

There were details to be attended to. We both had to make arrangements for leave from work. Julie cleared her desk and was her usual buoyant and bubbly self about her prospects of going back. Knock over the radiation. Beginning of Term 2. If Tilman Rust were correct, she would never go back.

I returned to work for two days that week. I had dwelt for a long time on how I could manage my work and leave situation and care for Julie. The strategy that I had hit upon was that I would take leave during the entire duration of Julie’s therapy while we were in Sydney. Then, naively, I thought that I could take leave on a “needs” basis. That is, when Julie “needed” me, I would dash home like some knight errant and provide succour and support. Right.

I cleaned off my desk, tidied up the last of my paperwork, tried to prepare my replacement for the coming school year and had meetings with the principal and with my staff. I laid it on the line with the details of Julie’s ailment, prognosis and my plans to care for her. I made it quite clear that she came first and the school came second, I didn’t pull any punches.

Some of the teachers had tears in their eyes. I avoided eye contact with them and if I looked at them, I focused on their hairlines or noses. No one said anything. Some tried for sympathetic and compassionate looks. Some looked at their knees.

No one said a word when I told them my priorities.

I had checked with the Department of Education and Training (DET) and I had a total of four months long service leave, plus some family leave and sick leave that I could convert to carer's leave. I thought that by opting for working and attending to Julie when she needed it, I could spin my leave out. I fully expected Julie to be quite healthy for substantial periods of time. Dr Rust had told me that after her radiotherapy, the tumour would probably disappear. I didn't think there was any reason why I could not work during this time. The financial imperatives of the mortgage, eating, feeding horses, of maintaining the farm would not change because of a growth in Julie's head.

My dream was that there could be an extended period of remission. That Julie could carry on for the seven years that Professor Dan had mentioned to Ruth that his other patient had survived for. And if she carried on for seven years, why not 17, why not till she was 70? I suppose at this point I needed to ignore the realities of what I had read on the Net about the merciless mathematics of survival rates from *glioblastoma multiforme*. That's probably wrong. I still knew them, the odds and the statistics. I just preferred the dreamy alternative. Self-delusion is a wonderful thing.

Just like Julie, I cleaned off my desk and emptied my desk drawer. One of my younger teachers, Stephanie, would act in my place. My older more experienced battle scarred veterans did not want the job. They had done it before and they hated it.

My two days of work were essentially a joke. It was the last time I was in a school in my role as head teacher. I never went back.

Going to Sydney the following day, 18 December, for Julie's first consult for her radiotherapy; she pored over the e-mails from Dan. They inspired her, and Dan's tone, wise, witty, sympathetic and positive, served as further motivation that something could be done.

Royal Prince Alfred Hospital is located in Newtown an inner city suburb of Sydney. Situated cheek-by-jowl next to Sydney University, Newtown vibrated with bohemian resonances. It was as alternative as Woodstock and Greenwich Village, as arty as The Left Bank and Berkley, as sordid as The Moulin Rouge and old Berlin. Walking past four shopfronts would have you rubbing shoulders

with gesticulating Greeks in singlets haranguing one another about soccer; drugged out and dreadlocked black tee shirted refugees from cloned Nirvana tribute bands; earnest tree-huggers from Greenpeace; power dressed career girls disdainful of all except the Brad Pitt knockoff who really might own the BMW he was lounging in, and scores of black clad waitresses who swarmed in the cafés raffishly named Stromboli and The Green Iguana. Two hicks like us both clashed and blended into the melange that trooped aimlessly or with vibrant purpose up and down King Street.

The Radiation and Oncology Department was located off Missenden Road in the Royal Prince Alfred Hospital complex. We felt our way around till we found the proper location and Julie's consult began.

I sat briefly in one of the treatment rooms and realised that I was sitting on a treatment table underneath a massive and businesslike nuclear particle accelerator. I figured out that there were a series of lasers in the corners of the room, which somehow triangulated on this treatment table. The revelation was both impressive and shocking. I found out later that the beam was capable of being aimed with not just millimetres but fine fractions of it. This was serious science and heavy shit. Julie and I had brought her MRI and CT scans, and I was escorted from the room while she was fitted with her mask. Julie was later vague about the details of what happened while I was out of the room. She thought further x-rays or some other type of imaging was done to help aim the radiation with microscopic precision.

Processing for the day was completed and we would return on New Years Eve for a final check of her "mask." The mask was used to precisely aim the radiation beam and only irradiate the tumour. A frame with mesh that reminded me of a tennis racket was treated with a solvent, and then pushed down over Julie's face till it almost completely encased her head. When the frame of the "racket" was even with the back of her skull, they stopped pushing. It was removed and left to dry or baked like a chocolate chip cookie till crisp.

Every day this mask was fitted to Julie's face on the treatment table and bolted to the table to hold her head immobile while the radiation worked its mojo. You wouldn't want to be a claustrophobe. Julie would emerge sometimes with a fine mesh pattern subtly stamped on her face. The waffle imprint would fade within minutes, and she never complained if there was any discomfort physically from the treatment or psychically from the restraint.

If one of your friends ever gets cancer, do what friends do in Australia. Buy them a book. Julie had a tumour. We bought books. People gave us books. Friends

recommended books. We went from knowing nothing about cancer to knowing too much. I read about diet, meditation, exercise, mind-body-spirit interfaces, boundaries and unions. We read about miracle cures. We read about hideous ailments overcome with it seems nothing more than willpower, some mantric chanting and carrot juice. There were books about the power of medicine and others about the impotence of scientific remedy. There were books obviously written by charlatans about scientists and scientists about charlatans.

I read, annotated, underlined, noted, dog eared pages, made observations, put post-its in important pages, read whole passages verbatim to Julie, paraphrased, summarised, interpreted, restated and repeated. We went Christmas shopping and came back with both presents and wisdom.

In addition to the men of science we were seeking alternatives. Dan used a Chinese herbalist; so would we.

I located one through a friend. He heard our tale and recommended we consult with Henry Liang, who proved to be an elusive figure, much in demand. He was not only an herbalist but also a medical doctor whose specialty was oncology, so he was Dr Henry as well as Chinese-Herb-Henry.

Our second appointment at Royal Prince Alfred Hospital was on the same day as our first appointment with Henry. The clinic, where Henry practised, was quite a few kilometres and galaxies away from Royal Prince Alfred Hospital. But not really. I found a pamphlet in the waiting room of the Radiation and Oncology Department at Royal Prince Alfred Hospital advertising a seminar that Henry presented on the oncology of Chinese herbs for medical practitioners at the hospital. Henry was obviously well regarded and respected by the men of science who practised on the fringes of bohemia as well as being *au fait* with ancient Chinese practices.

Henry practised on the fringes of suburban desolation in Western Sydney. His waiting room was an Olympic Opening Ceremony of cultures, costumes and languages. And we country folk were the outsiders.

Henry, as always, ran late and we, as always, were on time. We spent a long time in the waiting room. I read, Julie either dozed, or if she had a horse magazine, enjoyed the pictures and attempted to rediscover her reading skills. When we finally saw Henry, he was a slight, perpetually smiling, nearsighted Chinese man who was almost a caricature of the cheerily attentive Chinese manservant from scores of B Grade Hollywood three reelers. His uncertainty with English had nothing to do with his acuity. He ran a practised eye over the MRI, the radiographer's report and Professor Dan's report to Ruth Edwards. He was cheerfully frank. *Glioblastoma multiforme* was "very difficult, very dangerous". His strategy was to give Julie herbal support through the radiotherapy and then, after radiotherapy, give her further medication to activate and strengthen her immune

system. He examined her eyes and took her pulse, in both wrists. He made notes in Chinese and I followed the swoop and twirl of the Chinese characters on the page and wondered what they meant.

After Henry finished his consult he would repair to upstairs in the clinic where, like some Oriental Hagrid, he put in the eye of newt and toe of frog, wool of bat and tongue of dog. There were no guarantees with Henry. *Glioblastoma multiforme*. Very difficult. He did guarantee us one thing. It would taste awful.

So began my morning ritual. I bought a Chinese pot. It was a dark blue ceramic tea pot about 20 cm in diameter with a single handle and spout. I was to start with the herbs, soak them in three cups of cold water for half an hour and then cook them for an hour until the three cups cooked down to one.

Later I would say to Julie that I was going to cook “Henry” which provoked some sideways looks later on in Sydney.

The smell was a combination of the organic and the industrial. The tea looked as thick and vile as crude oil with vague, woody turpentine aroma. Julie would let it cool down for about 20 minutes and while it was still warm, drink it down in great glugging slurps, straining not to spit, choke or splutter out Henry’s brewed wisdom. I would then add two cups of cold water at night and recook the same herbs for Julie’s evening potion. I would ask Julie for confirmation about its vileness. I tasted it a couple of times. It tasted like peat moss smelled. Julie never complained or criticised Henry’s chemistry or my cooking. She would swig it down, suppress a grimace and pronounce it, “Wonderful”.

Dealing with people was not easy, but most reacted with compassion and sympathy. There was a *tsunami* of get-well cards, letters and phone calls from people. I filtered the phone calls from colleagues, acquaintances in the horse industry, students and friends and put Julie on if she wished to speak or was feeling either sufficiently confident or well enough to chat. Ghouls who wanted to hear what someone with brain cancer sounded like didn’t make it past me.

The other notable fact is that I started an e-mail bulletin similar to Dan Reich’s *What’s Up With Dan?* I called it *Julie’s Journey* because it was alliterative and because Dan kept referring to what we were going to experience as a “journey” with elements of the physical, psychic and spiritual. What had always impressed me deeply about Dan’s missives is that they reflected his physical condition and discussed his most intimate thoughts about himself, his mortality, fears and triumphs. It made his battle both personal and universal. They radiated a humanity in which you felt joined to his struggle and I sensed that his bulletins contributed to his healing in that the collective soul of mankind joined with

him. I have long believed that the majority of people will do that which is good, kind and decent in most situations. Dan's courage, honesty and grace enlarged us all.

I was hoping some of the positive karma that Julie had dispensed for so many years might flow back to her and make her healthy and strong again. That such goodness would have to triumph over her malady and that the more people who knew of her struggle, the more would join in wishing her well and making her well. I know, it was naïve but I'm glad I did it. I wrote the first one and sent it out on the 21st of December. It was how this book started.

Julie's Journey 1

I am starting this occasional bulletin, e-mail, missive in response to all the queries we are constantly receiving about Julie. For those of you I have not contacted personally, Julie was diagnosed recently with a malignant brain tumor in the left temporal lobe. Touch the tip of your left ear, go up two fingers and that is where the tumor is located. I will give you the approximate chronology of event.

I summarised the events of early December: Julie's memory problems, Ruth's diagnosis, Concord and our plan to fight this thing.

So we are embarking on a journey. If you don't want to know about it – that you would find it too depressing and adolescent, hit the ignore button in your e-mail. If you believe in the almighty, include Julie in your prayers. Her spirit, will power and resolve are amazing. She refuses to become depressed about the whole thing and intends to do exactly what she would normally do. In the hospital the doctors initially thought that her good cheer and chirpiness was a manifestation of some type of hysteria. Her first question to the doctors was about when she could ride again. Two weeks...

Think of us at Christmas and hold your family and friends close to you. We will commence the radiation therapy on January 5 and the plan is that we will be in Sydney Monday through to Friday and drive back to the farm on Friday afternoons for the six week period. I am worried about the nausea that seems to attend the radiation therapy but regardless, Julie wants to come home.

I will send periodic updates. Feel free to pass this on to our friends and anyone who would possibly be interested.

– Cheers Charley

The flood of responses astonished me. I was pretty good at writing deconstructive essays on Shakespeare, Faulkner or Keats, but I never saw myself as an inspirational writer who could rouse the soul. Apparently these e-mails did. Friends sent them to other friends and people who did not know Julie followed her journey with compassion and empathy.

I was later told I owed it to Julie to write this book. I don't know about that, but I still think writing the e-mails was one of the best things I ever did.

It was on 23 December that I started to keep a journal. My intention was to make daily entries about Julie's progress – physically and mentally – with her illness. I thought that it would be a useful document for both the medicos and me. I would be able to identify the day and date of symptoms, improvements, sudden declines, diet changes, the start and finish of therapies, the details and trivia of managing a major illness. Practically all of the books we acquired on managing cancer stated this was a virtuous thing to do.

Julie had always kept the diary. She recorded the significant and the inconsequential: which horses were trained; the work that was performed on the farm; the date the farrier was booked to come and which horses he needed to shoe or trim; phone calls, visitors, arbitrary events – whatever popped into her head. Most of what is written in my journal is fairly mundane. However, it forced me to review the day's events, to consider, reflect and draw conclusions. I tended to write either early in the morning when Henry's vile concoction was burbling away on the stove or at night after Julie went to bed. I wondered if certain events would assume consequence in retrospect. I was, in a muddled way, trying to take more responsibility. I thought if I could chronicle our path that our destinations would be more predictable and less frightening.

Birthdays and Christmas were special events in Julie's family and, previously, we had always had Christmas Eve at Mother and Father's in Goulburn and exchanged presents. We would return home, do the chores, tend to the horses and then go back in to town on Christmas Day for the big family dinner. When Julie and I were first married, it was always the traditional turkey dinner, regardless of the weather. I remember vividly one year watching the sweat drip off the end of my nose in sweltering heat to add a little more flavour to my mashed spuds and gravy. Like a great many Australians, cold chicken, prawns, turkey and ham with

salad had replaced the hot potatoes, pumpkin, peas and beans of earlier Noëls.

The cold Christmas dinner was a culinary leap forward. However, plain foods were the order of the day. Spices were *verboden*. Father apparently had a most delicate digestive tract. He could eat Mother's unpalatable meals (she was a lousy cook); but garlic, cumin, marjoram, parsley, sage, rosemary or thyme would give him colic or indigestion.

Christmas this year was to be at Bannister. Mother and Father now lived on the far South Coast of New South Wales and it was too far for us to travel. Jason would spend Christmas Eve with us and we would all go into Steve's in town on Christmas Day.

Mother and Father arrived on Christmas Eve. We exchanged gifts. I can't remember what I gave Julie. What gifts we exchanged that Christmas remain a mystery. Even though I have my journal, I have difficulty remembering what that Christmas was like. Julie and I had bought a digital camera earlier in the year to take photos of the horses as part of our push to make the stud more commercial.

Father dressed up as Santa to try and create a jolly atmosphere. It didn't really work. I've looked at the photographs of us with Santa and tried to glean something of the mood from smiles, postures, attitudes. I can discern nothing. Julie looks as she always did when she knew a camera was pointed at her, vague self-conscious embarrassment. She hated having her picture taken. Like everyone across the world having Christmas photographs taken, we glued on what looked like celebratory smiles and said "Cheese". There was no hint that there was another unseen guest in Julie's skull. But we all knew it was there.

There was an attempt to follow the template of Christmas past, but after the traditional big breakfast and lunch, Julie ran out of steam. We tried to retain the façade of normalcy and forced gaiety, but we had to head home.

We spent the time between Christmas and 5 January maintaining this fiction of the regular and the familiar. Julie pushed herself relentlessly. I knew there were times she was in pain. She ignored it. I knew there were times she was tired. She drove herself on. She was as implacable as the tumour. We were treading water and trying to make it meaningful at the same time.

My journal and the farm diary recorded what we did. Julie cleaned out stables, handled horses, moved portable horse yards, started to break in Biscuit, had visitors, went to the doctor, drove the ride-on mower, tended to the horses – feeding, moving them. This was what she always called "puttering".

She became more irritable with me. The only reason I can identify is that she could relax with me. Julie felt herself constantly on show. There was a duality

to her character that even I could not penetrate. And this is the enigma of her character, the paradox of her personality. There was not a whit of artifice about her actions. All of her actions down at the hospital were sincere and authentic. When she hugged Tilman Rust it was with heartfelt thanks and affection. Her effusive gratitude to the medical staff was as genuine, earnest and truthful as a novena from Mother Theresa. The only way I can explain this conundrum is by analogy.

Andre Schwarz-Bart wrote *The Last of the Just*, which is an attempt to spiritualise The Holocaust. The book is about Ernie Levy, a child in Auschwitz who is the last of the “just men”, the Lamed Vov. In every generation, according to Jewish folklore in the novel, 36 just men, the Lamed Vov, are born to take the burden of the world’s suffering upon themselves. When one of these unknown just dies, presumably after immense suffering, his soul is so cold that God must hold him in his fingers for 1000 years so that he can open paradise.

Ernie Levy was the last of the just men. A thousand years of history, 2000 years of suffering are all concentrated in the story of one boy, the movement of a family from Poland, to Germany, to France, to extermination. The implication is that the Holocaust was so depraved and so horrible that all justice and goodness in the world died with Ernie Levy.

Unlike Ernie Levy, whose job it was to absorb and expiate suffering, Julie seemed to think that it was her role to radiate happiness and joy. Like the sober Swedish sceptic at Concord Hospital, one should believe that there was a whiff of hypocrisy, of pretence, of contrivance about her, that no rational soul could be that happy all the time. The answer is no, she was that happy. However, occasionally, amongst those she loved and trusted intimately – me and her closest friends Sandra and Vicki – she would relax. The non-stop bubbling exuberance that was her public face would fade. The relentless good cheer would stop.

She wouldn’t transform herself from Cordelia to Lady Macbeth; rather, the fears, the doubts, the anxieties and the angst that we all feel daily would come to the surface fleetingly and momentarily. These anxieties would manifest themselves as misgivings about her worth as a human being. I could never soothe these fears, she never saw herself as others saw her. Where her students and peers saw an inspiring and dedicated teacher, she would doubt her own competence. Where her vivacity and kindness indicated her true nature, she saw herself as unworthy. Where we all loved her, she frequently viewed herself as unlovable.

What motivated and drove her is beyond my comprehension. It’s the way she was, it’s the constancy of her spirit that I can only present as evidence and say, go figure, because I haven’t been able to do it.

My journal records there were problems with Julie’s behaviour. The reading problems and cognition difficulties she was experiencing were identifiable and

there were easily recognisable changes in her physical and psychological makeup. The behavioural changes were a lot harder to define. Julie would become fixated with certain ideas and refuse to discuss them with me. This is what she wanted to do and we had to do it there and then. There was no dialogue or negotiation.

We had an old purebred Arab gelding, Dunwingeri Ibn Farhan, a quiet and gentle old soul. He was one of our more imprudent purchases. I had seen him up in Queensland as a three year old and recommended that Julie buy him as her next serious horse. She bought the love of her life Clive, instead. Two years later, she saw Ibn and talked me into buying him, saying that he would be “her backup horse”, in case anything ever went amiss with Clive. I was an easy mark.

She rode Ibn sporadically every holidays. He was kept rugged, shod, fed, drenched and pampered. Our equine chiropractor, Gary, kept saying that Ibn had the best job in Australia; he did virtually no work and lived in luxury. By the time Clive had to be retired, Ibn was too old to consider as a serious prospect.

“I want to put Ibn in the laneway for a pick,” Julie announced on 29 December.

“What for? He’s too fat now,” was my answer. I didn’t know the problems this would precipitate.

“Why do you want to do that?” I persisted.

“I want him to have a pick, he’ll enjoy it.”

“How are you going to block off the laneway?”

She ignored the question, “He’ll be fine.”

“What are you going to use to block the laneways?”

“Just the lunge leads.”

I became exasperated. “It won’t work, Julie. He’ll go right through them. He’ll get really stirred up when we move him and it’ll be a mess.” Two pieces of lead made out of webbing two centimetres wide and eight metres long tied across a laneway at chest height were not going to stop an excited 500 kg horse. I thought he might tangle himself in the leads, panic and take himself and about four fences out.

Julie was on the edge of tears. “I want him to have a pick. Why don’t you want to do what I want to do?” She was red-faced and quivering with angst. Seconds before she had been fine – joking and smiling.

Tears were now flowing. “I just want him to have a pick,” she sobbed.

“OK, OK, you grab him, Baby. I’ll get the lunge leads.”

As quickly as she had cried, she stopped. She went out the back and caught the ever-compliant Ibn. I had set up both leads.

The horses in the paddock beside him revved up at a strange new horse in the laneway. Julie walked him to the front lead, let him go and ducked underneath. Ibn charged off in the opposite direction, galloped for about 50 metres, chucked a wheelie and headed back towards us. He never broke stride and just charged

through the lunge lead. The fence snapped with a ping and Ibn charged up the driveway.

I hoped the front gate would stop him.

Julie screamed and kept screaming, "Ibbie, Ibbie!"

I grabbed the lead and head stall and headed up the driveway. Ibn was trotting around by the front gate. I caught the old gentleman and he followed me back to Julie. Only one wire was broken on the fence, Ibn had a little hair off his chest and Julie was inconsolable.

We fussed over him, made sure he was fine. Julie went inside and laid down for a nap while I trudged up the paddock to put Ibn away and fix the fence.

I let her nap and used the time to prepare dinner.

Later that evening as we were chatting amiably, I said to her, "Ibn's OK, he didn't hurt himself."

Julie looked at me, a little perplexed, "Who's Ibn?" She asked.

The tumour and the surgery had left these gaps. I would not realise it until later that the precision of care and treatment I had accorded to Professor Dan and Royal Prince Alfred Hospital were essentially illusions. The surgery was a blunt instrument. Professor Dan was as good as you get. The level of fluidity, elegance and grace required to remove any kind of growth from the brain is probably beyond human dexterity, proficiency and current science. It was as coarse and heavy handed as John Henry pounding in 10 inch spikes with a hammer in each mitt.

When we injure ourselves, our immune system reacts for us. There is swelling, oedema, trauma. Surgery is a wound. We don't give a polite request to our leucocytes, antibodies and T cells telling them to be good chaps and ignore the surgery and keep the swelling and the oedema down as it's not really needed or wanted in this case. There was damage in there, and as brave as Julie was, as sweet as her nature was, no matter how hard she tried, she had changed and we were trying to control and manage those changes.

Julie and I had a huge fight about Dottie. She was an exotically bred, very expensive purebred Arabian mare that we had leased, officially named, Greengrove Dotchka. We were originally going to put her in the Artificial Insemination program to try to breed our next stallion. Julie had long loved "Russian Arabians." Dottie's dam, a mare called Vnuchka, was imported by wealthy media moguls from Sydney from the Tersk Stud in Russia, the official Soviet state Arabian stud. Dottie was very beautiful and worth a lot of dough.

"I want to put Dottie to Legacy of Gold while we're in Sydney," Julie said.

We were working over by the stables, pattering with Biscuit.

I had been dreading this. I didn't want to breed anything this year. We couldn't afford the veterinary expense for artificial insemination, and I had no idea what

our situation was going to be in the next month, let alone in a year.

“Don’t know if that’s a good idea, don’t think we can afford it.” I tried to be noncommittal.

“We can afford it, Sweet. It’ll be OK. If we get a boy, it could be what we need, and if it’s a filly, just think what it will be worth.”

I just laughed, “You’ll never sell it, doesn’t matter what it’s worth.”

She laughed back and looked happy. “Will you call Ian and find out when we can take her out?”

I shook my head slowly while we both groomed Biscuit as he ripped at the lucerne in the hay net. The boy sure could eat.

“Might be best not to, we won’t know what we’re going to be up to with money.”

I was trying to evade the issue that if Julie was dying, I didn’t want another horse.

I felt like shit, guilty and lonely.

But I thought I was doing the responsible thing. I was a teacher, though. I was used to lying. And I was doing a selfish thing. I was looking out for myself as well.

The switch in Julie flipped. The chirpy banter was gone. She was shaking with rage while the tears mustered in her eyes.

I pursued this argument lamely, “We’ve got all the therapy in Sydney, we don’t know how much it’s going to cost to live down there, money’s going to be tight...” I sounded evasive and duplicitous and I hated myself for it.

“You don’t care about me, you want me dead. If you loved me, you’d do this.” Her voice rose to a shrieking crescendo. “You just want me dead and I hate you.”

She stormed off in the December heat back to the house from the stables. I finished with Biscuit and walked him back to his paddock. I went into the house and found Julie was in bed sobbing, rhythmically. I sat on the bed next to her, and she rolled over and curled up foetally, back to me.

I tried to speak with her. Julie ignored me. I tried for soothing half-truths.

Julie wasn’t buying it. She rolled over facing me and spat out, “It’s just like Peso.” And then rolled over away from me again.

Part of our marriage contract was that we always had to agree on the major purchase of a horse. The Peso Incident had for the last six years been wheeled out on occasion. We had gone to see him and I thought him lovely and crazy. The owner brought the horse up and when I put a hand on his shoulder, he ran back 10 metres dragging the owner like a rag doll. He was a warmblood and a big, rangy bay gelding of about 16 hands. I said “No” there and then and did not back away from that position. I will go to my grave believing that he was the wrong horse.

We later found out that a notable trainer *cum* horse breaker had him and could not even catch him to do anything with him. Later someone else told us that

he was “winning everything up in Queensland”. I didn’t see a single result in print and this story was anecdotal. Later we even contacted the original owner/breeder, whose marriage had broken up, and Peso was part of the detritus from that incident and she couldn’t tell us what had happened to him, that his fate was unknown. I tried to use this as evidence that he had not been much good. I was wasting my breath.

Peso had become for Julie the ideal horse and she had synthesised in him all her hopes and ambitions, much like a callow pimply seventeen-year-old boy will idealise the gorgeous unattainable blonde in his History class. Peso had been it for Julie. She told me that many times. And if he was crazy and fated to kill her then, by God, I should have let nature take its course because she wanted him. I think it was the only thing she never forgave me for. This day was no different but the argument about Dottie had triggered her residual anger about Peso yet again.

We had ruined a tyre on the Outback the day before. I needed to go into town to get new tyres. I would go alone. Julie was ignoring me, I whispered quietly that I was going back into town for the tyres and her back was rigid with dismissal. She was exhausted and drained after crying, let alone after the work we did that morning. When I returned home she was fine – her normal chirpy self. She asked how everything went, calling me “Sweet,” as she normally did, and admired the new tyres.

Julie’s radiotherapy was due to begin on 5 January, 2004. We had discussed staying in Sydney the entire time, but Julie desperately wanted to come home weekends. The regime was for 30 treatments, five days a week over a six-week period. She said that she wanted to come home weekends to see the horses, to walk around the farm, and, I suppose, to try and convince herself that this is why she wanted to live – for the farm, the horses and for me. I didn’t see a problem. There would be a lot of driving for me, about three hours on Monday mornings and three hours on Friday afternoon; I thought that a small price to pay.

We had secured accommodation at a cancer patient’s hostel in the elegant, leafy suburb of Double Bay but that accommodation could not be accessed until the second week in January. For the first week, we would stay with Jason and Jane in the western Sydney suburb of Telopea.

We packed with a mixture of anticipation, eagerness and dread. We read as much support material as possible regarding the effects of radiation, the services and facilities available at Royal Prince Alfred Hospital, and precautions we had to observe. Professor Dan had been adamant that her therapy had to start as

soon as possible and I think he was less than enraptured that there would be a four-week hiatus between surgery and treatment. However, everything stops for Christmas in Australia. Tumours have a great work ethic. They don't take holidays.

CHAPTER FIVE: THERAPY

Cancer therapy is all about monsters and metaphors. We don't understand the science so we resort to imagining the cancer as a monster. It can't be controlled. It needs to be destroyed if we are to live. It's invasive, life threatening, alien; its behaviour is random. We picture the malignancy as a thing unconnected to us, a mistake, and it is. It's the one monster we don't romanticise.

Science, we hoped, would kill our beast. Easy, but we knew there was a catch. The tumour would regrow and science had not yet figured out why. I had an illuminating conversation with Professor Dan later. Apparently in some American city, Washington DC, I believe, nine neurosurgeons were diagnosed with *astrocytomas* and *glioblastoma multiforme* in a period of months. Nine medicos that usually give the bad news got it instead. It scared the shit out of them. Sent the ancient visceral horror surging through their nervous systems. Guts must have churned. Ulcers blossomed. Sphincters loosened and contracted. Migraines must have broken out like crocuses in the Spring causing many brain guys to probably think they were dying there and then ("Oh my God, I have a headache!") and I wonder how many neuros booked themselves in for MRIs that day to see if they were next. Just like Ripley getting a chest X-ray in one of the *Alien* movies. If "It" was in there, they wanted to know.

And every neurosurgeon thought the same thing, *The fucking thing is catching*. Some virus, bacteria, microbe, germ, bug, organism caused the genetic and chromosomal alteration in the astrocytes and they were catching it from their patients. Some cough, cold, chill, twinge, headache, stomachache, neuritis, neuralgia, scabies or rabies would be the precursor to glioma and an ugly death.

The nine neurosurgeons died, horribly, as is the way with *glioblastoma multiforme*. And nothing like it ever happened again. It remains one of those events that are as random and as appalling as Krakatoa exploding. It defied logic and explanation and caused doctors and statisticians to give a low respectful sigh of incomprehension and leave it as a particularly bizarre footnote in the history of epidemiology.

Julie knew she would lose a lot of hair and while we drove to treatment she developed the ritual of gently brushing her hair, wistfully look at what accumulated on the brush and discreetly letting it go out the window. There would be superficial burns. She would have to watch what she used for soaps and shampoos due to chemicals that could react with the radiation. She would feel tired. The destruction of the cancer cells could cause headaches because the healthy cells in surrounding tissue would be affected as well.

Mother and Father would look after the farm and Rosie, our whippet, some of the time while we were in Sydney, and they would do a power of work on the farm. Cut grass, clean windows, sweep, dust, mop, clean out troughs, organise tools and sheds. They were wonderful. Bradley, our nephew, came out and worked for a day. He helped make and paint a pump cover. Bannister Springs was a hive of productive activity. It gave Mother and Father an outlet for their restless energy.

Our first appointment was a piece of cake. We walked in, we waited, I read a magazine. I would later swear the same greasy and battered gossip rags would follow us around to every medical establishment. Like alien drones in *Star Wars*, they all looked the same to me. They called Julie's name and she leaped to her feet and just about dashed across the room to the technician. They went in and I festered, resolving to bring my book or buy a paper.

Julie emerged about 10 minutes later, smiling.

"Had it hurt?" Dismissive snort.

"Did it burn?"

"Nope."

"Was it uncomfortable?" Negative head shake.

We were on our way to our temporary home in Telopea – one of the anonymous Western suburbs about an hour's drive from the CBD of Sydney. Telopea was bricks, mortar, fibro cement and sweat. Originally working class, these suburbs were the aspirational heart of Australia. They housed the workers, who wanted to move to east or north and up, but needed to start somewhere. And Jason and Jane were workers.

Julie and I still thought of them as newlyweds even though they had been married for three years. They seemed to be perpetual sweethearts and treated one another with the circumspect grace of a couple going steady in Year 12 and looking forward to the Formal. Jason was an IT consultant doing some esoteric database programming for inventory control. Or that's as near as I could figure out what he was doing. Jane was a teacher at Castle Hill Primary School. A step up the suburban food chain.

Jason worked and travelled a lot for his job. At first, it had been exhilarating to fly to Perth, Brisbane, Melbourne, to drive to Newcastle for a week. That romance

had faded. He worked a lot of weekends when computer systems were shut down to renovate or revitalize software systems. He wanted to be home with his wife. Jane did what teachers had done for thousands of years: her best.

Jason and Jane had a townhouse in Telopea. Tiny lounge area, smaller dining area, a cramped kitchen downstairs. Upstairs were two small bedrooms, one with their bed and the other containing Jason's sprawling array of computer equipment. There was a narrow crapper downstairs and a full bath and shower upstairs. Two people filled it up. Four would be a struggle.

Julie and I did some shopping on the way home. We bought some fresh fish. I would cook, and we would have dinner on the table for when Jason arrived home. Jane, on holidays with the summer school vacation, had left and gone to visit with her parents down in the Riverina. By the time we arrived at Jason's it was as hot as a steelworker's armpit. The Western Suburbs of Sydney are a virtual hellhole in high summer. Large expanses of asphalt and brick absorb the heat and radiate it with evil intent. I watched the outside temperature climb on the dash of the Outback as we navigated what would become a familiar route through the Inner West of Sydney to Telopea.

Julie was feeling the effects of the long drive down and the busy morning. I put her on the lounge, turned on the fan, opened all the doors and windows and moved our luggage and groceries inside. She stripped down to a bra and panties and let the slightly cooler air from the fan play over her. I organised a couple of cool drinks and we sat there and contemplated our dwelling. I ventured upstairs to check out where we would be sleeping and wondered how we would sleep in that kind of heat. The outside temperature was 37 degrees Celsius, just under the hundred Fahrenheit. I knew some days would be hotter, and not many cooler. Julie had wanted to exercise, walk, do things to maintain her fitness. Dan emphasised that keeping active was important during radiotherapy. An evening walk was a possibility, no afternoon walk today.

Therapy only took 10 to 12 minutes. We always arrived 10 to 15 minutes early to allow for traffic. Julie would sit and doze and I would read. We kept to ourselves. Julie felt shy, and we were both getting used to this new situation. Back in the car for the drive home and maybe some shopping on the way. We would go for a walk in what passed for the cool of the evening, when the furnace-like heat moderated to a sauna level, around the tranquil streets of Telopea where the little gardens were neat, the lawns kept trim and tidy, the houses shipshape. There was a nature reserve next to Jason's townhouse, which I think was no more than a giant storm drain for two suburbs, and we walked in there as well. The reserve wasn't really pleasant. After Bannister, Telopea's natural charms were limited. Jason had chivalrously given up the marriage bed and we slept with a slowly grinding overhead fan providing some relief from the heat although it tended to

keep me awake. Julie could sleep through virtually everything.

We read, watched pay TV, ate, read, walked and slept.

It was Thursday 8 January and we were having problems. Julie was feeling off colour, and I wondered if she had picked up some sort of stomach bug. She was feeling nauseous and had trouble eating dinner on Thursday evening. She felt listless and her language problems were becoming worse. I wondered if it was the heat and the stress from the travelling. She had also been pushing herself, going for walks in sizzling conditions to stay fit. I wondered if it was having the opposite effect. We had also missed a doctor's appointment. I hadn't sussed out the routine. We had a regular doctor's appointment every Wednesday. They would interview Julie and give her an once-over every week. Our first appointment had been on the Wednesday. Why had we missed it? No one had told me. They had told Julie. She had forgotten, or could not communicate it to me.

I made a big mistake. I told her we had missed the appointment and she blamed me. Of course she remembered the appointment, why hadn't I? She clearly remembered telling me. Of course she did. What she remembered and what she communicated were sometimes different. Julie was really angry and I could understand why. I was supposed to care for her, support her, we were doing this together and I had fucked up big time.

The next day, she went in for therapy. I went to the main desk in the treatment centre and took a deep breath. I told them that they needed to communicate everything with me. Julie had a brain tumour. She had memory lapses, and she was suffering from speech problems. They could not just inform her. They felt I was criticising them. I apologised and said that we were all in this together, I was still figuring out how to care properly for Julie and this was just another aspect of her care. They primly made a note in her file; I thanked them and hated myself for having to treat Julie this way.

I asked Julie if she wanted to grab a quick bite at a café, she snapped we couldn't afford it and I drove her back to Jason's. She didn't speak to me the rest of the afternoon. I put a movie on pay TV, some dreadful teen flick with lots of fart and masturbation jokes, and moved next to her to watch it. She had slept and wanted to watch TV. She moved over next to me and, despite the heat, reclined against me, took my hand, put it on her thigh possessively and we watched pubescent gross out jokes. It meant she loved me, it meant we were OK.

Jason left for work early on Friday 9 January and I had some tea and toast and made the same for Julie. She couldn't touch it and only had a bit of the tea. Minutes later she was in the toilet, throwing up copiously. I dashed upstairs and

found a face washer and soaked it in cool water and mopped her brow and I held on to her hair to keep her from puking through it. The vomit was yellowish brown, evil looking and stunk of bile. She was so retchingly sick that she puked on herself, convulsing backwards despite holding on to the toilet grimly. The bout of gagging and retching exhausted her, I had to help her up and she told me that she felt better. We were both convinced that it was the heat, something that she had eaten or a bug.

I cleaned her up, and with a few minutes rest she said she felt better and was ready to go. We were on Parramatta Road in heavy traffic when the second bout of vomiting hit her. She had no choice but to gather her blouse up and spew into that rather than foul the inside of the car. I hit the electric window and told her to puke down the side of the car. She either did not hear me or refused to be so publicly humiliated. The third bout hit her when I was parking the car and she fouled herself further. Traffic was hurtling around me and I was trying to comfort her, get to RPA and keep from having an accident. Thankfully, there was a parking place right in front of the door of the oncology clinic. I put her on a bench under a struggling plane tree and dashed inside.

I alerted the doctors and I helped Julie in. They took her clothes off, put them in a bag and gave them back to me, got a gown on her and told me that she was having a reaction to the radiation, sort of. The cause of the vomiting was probably cranial oedema and swelling. Four days of radiation along with the resultant damage from the surgery and swelling were the cause.

They put her on a gurney, took her into an area away from the waiting room and put her on an IV drip. They put a couple of injections into the drip – an anti nausea drug, *Stemetil*TM and *dexamethasone* for the cranial swelling. They re-scheduled her radiotherapy and the nurses told me she should improve quickly, it was a common reaction. The swelling was irritating the nausea centres in her brain and the nausea centres were doing their job, making her vomit. The effects of the *dexamethasone* and *Stemetil*TM were nothing short of astonishing: she went from a puking, quivering, babbling shell to feeling great in 25 minutes. Her stomach was fine, in fact she was ravenous.

They also asked me how she had been feeling and I told them tired and nauseous and her language problems were worse. I learned a new word, “*dysphasia*”, a disorder of language caused by a brain lesion. She would become dysphasic with the cranial swelling. Her language skills would degenerate and she might become disoriented and bewildered. The vomiting would follow hard upon or start suddenly. Ruth had told me about *dysphasia* but that morning bridged the gap between comprehension and understanding.

The doctors recommended a regular dose of the *dexamethasone* morning and evening and *Stemetil*TM on a “needs” basis. If she felt sick, she needed to take

it. She would have to stay on the *dexamethasone* for the duration of her treatment and we had to balance the dosage of the *dexamethasone* and the use of the *Stemetil*TM. The dosage of the *dexamethasone* was largely a matter of trial and error. There needed to be a weaning period with the *dexamethasone* when she ceased to take it, carefully managed to coincide with the finish of her treatment. It was all a balancing game. We were learning. Julie developed a grudge against the *dexamethasone* and she was always at the doctors to reduce the dosage.

And so ended our first week of treatment. I went out to the car and retrieved a change of clothes for her from our bags and she sponged herself down in one of the toilets with the nurses supplying some towels. We drove back to Goulburn without further incident.

Dan had sailed through his six weeks of radiotherapy without a single problem. We were wrung out and discouraged. But we didn't tell anyone that.

We arrived home mid afternoon. Mother and Father had no inkling about Julie's distress. I tried to be low-key about the problems and said that setbacks, to a certain extent, had to be expected. It was in the brochures, in the warnings. I suppose we had not expected it to happen. You could see their faces falling; it was almost like they were physically affected by the story of Julie's episode. She downplayed it and I tried to treat it as routine, one of the little speed humps on the brain tumour highway. They would always have trouble concealing their emotions. Father tried to by imitating a Botox junkie. You could see him steeling himself and hardening his will not to show anything. Consequently, he showed everything. Mother became more nervous and agitated. I can't remember if they left that night or the following morning. We were very grateful for the work that they had done.

By the evening, Julie was amazingly bright. Almost too bright. Restlessness and anxiety were also side effects of the *dexamethasone*. She had trouble sleeping that night.

We went to the Goulburn Base Hospital the next day on the Saturday, 10 January. The doctors at RPA had been appalled at the condition of Julie's leg. While Julie had been in Concord in early December, one of the older mares had been injured. Our first filly, Peoria Castagne (pronounced "Cas ton' ya" meaning chestnut in Italian) but known to us as Cassie, had a severe wound. We first found Cassie on Sunday, 21 December with a flyblown fist sized hole in her left (near) foreleg. It was dripping maggots and although it looked nasty, wounds like that would probably heal up nicely with antibiotics and bandaging. We both felt guilty that the injury was about 10 days old. What was worrying was the fact

that she kept falling over. When I put a headstall on her to bring her down for the vet, she hit the deck. I let the vet know that she had done this and he didn't pay any attention, vets and doctors do that.

She kept falling over. The next day when I went to give her the antibiotics in her neck, she fell over and just missed pinning me against the wall of the stable, which would have been a disaster. Being underneath 450 kilos of falling body and flailing legs is no joke. Poor old Cassie did this a number of times and twice she fell on Julie who was trying to hold her up and soothe her into staying vertical. The bruising on Julie's legs was severe, but since she got up she hadn't gone to the hospital.

Julie's Rules.

The nurses at both Concord Hospital and the Goulburn Base Hospital looked at me as if I was a negligent idiot. I didn't bother to explain that Julie would not have the leg checked.

We euthanised Cassie a week later, on 28 December. A second vet speculated that she had some sort of neurological problem. She had been struck by lightning 20 years earlier and had suffered a cerebral haemorrhage in the incident. The effects of it might have finally been catching up with her in old age.

The *dexamethasone* caused "easy bruising" so the bruising on Julie's leg looked worse than it was. She was X-rayed. The only damage was extensive bruising. I knew that because after Cassie got up, Julie did too. I could tell the nurses at RPA that the legs were OK and they would just think I was a moron.

All of this just makes what Julie accomplished that weekend all the more amazing. This is what the diary recorded for Saturday:

Went to hospital, legs

Started on fly screens, Charley cut, painted

Checked all horses

Watered trees

Sunday

Moved Tilly, Grace and foals to new paddock

Drenched out horses (all 31 of them)

Moved Biscuit and Dottie to paddock 10

Fixed fence, Cassie broke

She was amazing.

We returned to Sydney on 12 January and started our stay at Ecclesbourne House, an old Gothic style home in Double Bay built in the 19th Century. It originally had a ballroom as well as a library. It could house 26 "guests", read

patients, and their carers courtesy of the Cancer Patients Assistance Society of New South Wales. We had our own room on the first floor and the décor was very much in the spirit of Room 15 at Concord. Cheap beds, chipboard furniture, worn carpet, better smell. We had a side room and some type of flowering trees provided a view. The rooms had very high ceilings and were airy and large. We had two single beds.

We had mixed feelings about Ecclesbourne and it is difficult to recount my reservations without sounding churlish and ungrateful. It was only 15 minutes from RPA. After Julie's therapy, we would return to Ecclesbourne and fill in our days. We would walk endlessly around the neighbouring suburbs – Paddington, Vaucluse, Rose Bay, Bellevue Hill, Edgecliff, admiring the mansions and the more restrained cottages that oozed demure opulence. Double Bay was a harbour-side suburb, so the temperatures were more moderate than the baking furnace of the Western suburbs. The people were a never-ending theatrical cavalcade. Whereas Newtown was bohemian, Double Bay was right wing, cutting edge meretricious materialism. The display of ostentatious wealth was the norm and considered to be not only a God-given right but a virtue. People had worked hard at earning that money, or had been born into the right gene pool to inherit it, and it didn't matter much how they got it, they were going to enjoy it.

We went swimming a lot at a beach called Red Leaf Pool behind the council chambers. It was a tiny little indent of Sydney Harbour, surrounded by elegant apartment houses. The beach was shark netted and maintained by the council. There was a little kiosk, freshwater showers to rinse the salt out of your hair and a quiet ambience. We would change into our swimmers and walk the 20 minutes up New South Head Road up the hill and to the Pool. We would leave our sneakers, hats and tee shirts on a bench and swim, chat and paddle idly for an hour or so. We would then walk back through the shopping and restaurant centre of Double Bay past *Cherrijam*, *Luminello Ristorante* and *Arte e Cucina*. All the floors were polished bare wood, the furniture minimalist, the portions bird sized and the cuisine nouveau exotic. There was as much collagen and silicon as there was bling on slick looking Richard Gere types who might even own the Guccis they were wearing or, more likely, were bought for them by a fabulously maintained matron who had them on a leash. It wasn't as much fun as Newtown, but it was much more amusing because these people were *poseurs* personified.

There were enough fake tans to paint the town beige and the air was thick with pretence, pomposity and Perrier bubbles. We walked past them in our old sneakers and tee shirts with our baseball caps on. Darling, it was fantastic.

At Ecclesbourne, we killed time. I read, Julie slept, we went to the movies at the Double Bay Cinema. I cooked and made lunch and dinner – curries, stir-fries, salads and grilled fish. We were eating better than we had at any time in

our lives. Soy ice cream provided a guilty pleasure. We were close enough to the water that cooling sea breezes moderated the heat and we slept better. However, there was something unsettling about Ecclesbourne.

The atmosphere was laden with doom. There was a resigned fatalistic inevitability about the patients. They were, like the Townes Van Zandt song, "Waitin' 'Round to Die". Their therapy was being performed with a kind of perfunctory sense of duty, which said, "We'd better do something..." There was no sense of joy, no sense of optimism, no sense of hope, no sense of pleasure in the promise of life. The atmosphere was thick with the bored ennui of hopelessness. There were patients with ovarian cancer, breast cancer, throat cancer, leukaemia, lung cancer and another brain tumour patient. It was depressing.

There were people with bowel cancer that consumed huge slabs of thick tough steaks despite the link between bowel cancer and red meat. One couple, the wife was being treated for breast cancer, had their nightly four or five cigarettes out in the garden before retiring. And there was an unfocused aggression amongst some of the patients who quietly seethed with anger and resentment about their condition, demanding an answer as to why they had cancer. Why, indeed? Why anyone?

The hostel was supposed to be a place of life. It had a dead heart. It was as if their souls had shrivelled. Julie was her usual ebullient, outgoing and chirpy self. Everyone remarked at her cheerful nature. She hugged and tried to laugh with them. Their lives were already over. Dead men and women walking.

We would make love occasionally, afternoons, when a lot of them were out shopping, after our swim and walk. Sex was important. Julie needed proof that I loved her that I still found her attractive, feminine and appealing. We made love as quietly as possible clinging to one another, Julie sometimes giggling and telling me not to make too much noise.

I wanted everyone in the building to hear us. I wanted some sounds of life in this moribund atmosphere. I wanted them to hear springs creaking, heavy breathing and Meg Ryan having lunch and be envious that we could do something affirming and life-giving amidst their gloom. I wanted them to hear us, smell us, envision what we were doing, I didn't care if they came and watched us. I wanted everyone to know that I still loved Julie in every possible way and that would never change. I'm sure that Julie knew what I was thinking and told me to be quieter still.

I became used to the life. Therapy for five days, farm for two days. I found the waiting less frustrating. I was used to the routine of RPA. I was used to living out of a suitcase. I was getting used to Julie's condition.

We still had problems, lots and lots of problems. I had a delicate balancing act to maintain. I started to speak for Julie. She began to rely on me to communicate with her doctors and therapists. We would make up a list of questions before we went in for a consultation and I would ask the questions. I would keep one eye on the medico and one eye on Julie and she would nod, smile or tilt her head to let me know that I was asking the right questions or pushing the right buttons.

Occasionally Julie thought that I was overstepping my role as mouthpiece. I could speak for her. I wasn't allowed to think for her. And it's important to realise that intellectually Julie was unimpaired. She would routinely remind me of things we had to do. Items we needed for our trip and our stay. I walked out the door regularly without our mobile and we needed that badly. Her language could be fragmented and halting. There was heaps wrong with her brain, there was nothing wrong with her mind. We had long discussions as we walked along the sun-drenched esplanades of Rose Bay and Watsons Bay. Julie talked endlessly of the farm and the horses. What we would do, what we would accomplish when she was better, when she was well and whole again. She planned work programs for Biscuit and Psychic. She wanted to start handling and working with Windchimes. She planned breeding programs for the rest of the mares. Surprisingly, the house did not figure much in our talks. The house was done. It was beautiful and she loved it. However, it had its place and its function was to provide us with a place to eat, sleep and live. Occasionally, she would see a tablecloth or a coffee table or a painting in the window of an opulent gallery or quaint shop. "Wouldn't that look nice?" I would look, agree or comment, or sometimes disagree. She would smile and say, "But we can't afford it." And then go back to spending thousands on the horses.

Julie's reading skills degenerated to the point where she could not understand street signs. We would amble up the intricate laneways of Paddington and she would ask me "Sweet, what does that say?"

I would reply "Antiques" or "Gallery" or "No entry". It had gone that far.

If it distressed her, she didn't say. She could not pronounce or remember "Ecclesbourne". We stood in front of the little council street sign in front of the steep drive that went up to the tiny parking area and I would pronounce it for her and she would sound it out and try with all her might to link the syllables to the alphabetic symbols to make sense of the hieroglyphs of English which were her profession. When she chatted with her parents, with Vicki, with Viv on the phone she would stammer and laugh and then call over to me, "Sweet, what's the name of this place?" "Ecclesbourne!" I'd call out. She would repeat it with a

trill of laughter and say, “Just a problem with my words”. Physically, Julie seemed to be becoming stronger after the bout of *dysphasia* but we followed a weekly pattern. She would gather her strength on the weekend, work really hard on the farm (which actually enhanced her vitality) and then battle through to the end of the week of therapy. The radiation got to her by the end of the week and she was laden with weariness by Friday.

We began to see Dr Christina on Wednesdays, starting on 21 January. She was Greek and beautiful. Slender, warm and smiling with a gentle nature, her beauty was patrician without being forbidding. When Julie gave her a hug of thanks she responded with cordial and sincere affection. The therapy was going well. In the last five treatments, they would give Julie a boost dose of radiation. I took this to mean they would increase the intensity of the therapy at the end of treatment and the side effects might be that severe. Julie gently pestered Christina to further reduce the *dexamethasone*. Christina worked out what she thought would be an appropriate weaning schedule for ceasing the medication and Julie was pleased.

Looking back at my journal, the two most constant phrases are “a good day” and “a bad day” in about equal proportion. Julie would have a difficult or stressful day – the drives back and forth to Sydney really knocked her around, even though she rested and dozed all the way. The work on the farm invigorated her. By Friday, 23 January, we were half way. Julie had finished 15 of the 30 treatments. “Over the hump, Baby,” I told her. She nodded, tired but happy. We had a celebratory drink with Father and Mother and the wine knocked the shit out of Julie. After Mother and Father left, her cognition and vocabulary skills were at an all time low. The whole weekend was an up and down affair. It rained on the Saturday and there was a message from Ruth Edwards. She wanted to see me, not Julie. Me. I didn’t know when I could fit her in. I would see her when Julie’s therapy finished. I had a schedule from Monday to Friday and Ruth didn’t work weekends.

I think she wanted me to come clean that I wasn’t coping with my role as sole carer. It was hard – the mood swings, the cognition problems, the constant monitoring. I was learning to live in the here and now. Forestall despair. Don’t plan any further than lunchtime, then for dinner, then for breakfast the next day, and so on like Jan Johnson. Assess, react, plan the day, stay patient, stay focused, don’t get angry, don’t get down.

In the movie *The Thin Red Line*, Sean Penn plays a psychotic sergeant on Guadalcanal who says to one of his equally deranged soldiers, “I want to get to that point where I don’t feel anything...” I began to understand that.

I adored Julie. I loved her more than I ever had. Her bravery, her toughness, her uncompromising will to get better were moving, affecting and roused me to keep up with her. I wanted to be the man that she thought I was. Julie would look at me with such complete trust and dependency. I cooked but I always had cooked all the meals. I tried to do more housework, I tried to be productive the way she tried to be productive. I tried to anticipate her needs. I tried to make little surprises for her – smoothies, a nice piece of fruit, read something from the paper, find stories on the Internet, write the e-mail bulletins. I knew everything I was doing might be completely futile. That she would die and this relentless aberrant disease would destroy her body and her mind. I couldn't think about it. I had to think of everything and nothing. I had to think of details and not consequences. It became second nature to me after a while.

It was around this same time that I realised that there had to be two of me.

On Monday, January 26, Australia Day, 2004 Julie became ill again. The vomiting, the nausea, the *dysphasia*. I went immediately to the *maxalon*. Didn't work, Julie puked it back up after 45 minutes. Years of training with the horses kicked in. I started to write down what I gave her and the time frames. I rang Ruth. She advised that I give Julie just a bit of fluid with the *maxalon*, no food. No go, she vomited that back up.

Ruth told me to come in. She met me at her surgery and told me she was going to prescribe a potent anti-nausea drug called *ondanzatron* marketed under the brand name of *Zafron*[®]. This was heavy-duty shit. It was a controlled substance and she had to call and get clearance for the script from some government authority. She told me the *Zafron*[®] was in the form of a wafer that should be put under Julie's tongue. Ruth asked me about the *dysphasia* and I told her Julie was somewhat affected but not as severely as the time down at RPA. Julie was vague but "with me". I took the script and Ruth asked me how I was doing. I just looked at her and said, "As well as I can expect, but I'm not the one who's sick".

There was a problem with the *Zafron*[®]. No one in town had it. One chemist had the drug, but in the wrong dosage. I couldn't contact Ruth and the duty pharmacist wanted to follow orders. Eventually the owner intervened and I had the drugs – wrong dosage, but I could just double it and avoid going to Canberra to pick it up and be away for four hours.

If Julie had been sick in the intervening period, she didn't tell me. I gave her the *Zafron*[®], two 4mg wafers, and they appeared to work. The nausea passed. My journal has this notation, "stressful and mystifying day". No shit. Julie had a restless night and her communication skills were at an all-time low. She was crying and depressed about what was happening. A couple of times Julie just gave up on what she was trying to say. If she wanted a cup of tea, she pointed. I couldn't imagine how it was affecting her.

I rang RPA and told them that the weekend had been difficult and that Julie would need a consult when we arrived. It would happen. She had therapy and Dr Christina ramped up the *dexamethasone*, as I expected. Julie's level of activity was greatly reduced. Her walk was only as far as the shops on New South Head Road.

We had thought about a movie, but she told me, "I don't think I can sit through it, Sweet". She told me to go and she would just "putter" back to Ecclesbourne, which she, of course, couldn't pronounce.

The crying and depression of the previous day had passed. She was more resigned to her reduced level of activity. We had problems with little things, picking out ice cream in the shops, cold drinks, in which direction she wanted to walk, telling me she needed her hat or her scarf. I refused to become embarrassed by her inarticulate grasping for words. I just waited. She would laugh at herself and I could see the pity in some people's eyes.

I fucking hated them for it.

Julie didn't need their pity. She needed help, understanding and consideration. She was so brave and cheerful most of the time, laughing at her own disability and making jokes out of her mistakes that she became even more special to me. I didn't care about anything but her getting better.

And that's where the two of me came in. The weekend had, in Shakespeare's language, "amazed" me. I was baffled, confused, distressed, bewitched, bothered and bewildered. Later, I would explain it to people in this way. "There needs to be two people to take care of Julie. There needs to be the kind, considerate and compassionate husband. And there needs to be someone who is detached and clinical to make objective decisions about her care, sometimes instantly. Sometimes the roles are mutually exclusive."

I had quickly learned that, in dealing with medical bureaucracy, quiet, insistent, repetitive patience usually succeeded. They were trained to deal with the hysterical, the angry, the lunatic. At Concord and at RPA I had seen examples of petty rages from dissatisfied clients and had seen the shutters of co-operation close in the eyes of the medical staff. I knew that wasn't the way to go. If I wanted something, I just kept quietly restating my case, repeating what I perceived as Julie's needs, like a mantra.

This duality I would maintain all through Julie's illness. It served me well. My counsellor told me later about dissociative behaviour and I understood then how doctors coped. It was all they could do to keep from running screaming out of their office with the misery and suffering that queued up each day at their door. Most of them were brilliant.

The days passed at Ecclesbourne. We were into the fourth week of therapy. Julie was feeling more and more fatigued although the drug therapy helped a lot.

As much as she hated the *dexamethasone*, it worked. It controlled the nausea, it gave her more energy, she felt better. However, she had the side effects: weight gain, fatigue, but also insomnia. Julie had bouts of twitchy energy where we went for long walks up through Paddington or Edgecliff, even all the way into the CBD of Sydney to the Quay and Pitt Street Mall. Then, that night, she would be exhausted but have “running legs”. I’d massage her legs and give her back rubs and read to her. I found *Bridget Jones’ Diary* on the public bookshelf at Ecclesbourne and read parts of it to her.

We had a huge fight once when I handed her dinner and she immediately asked me if I had washed up. Without thinking, I said, “Do you mind if I eat first?”. She started to cry and I realised that her prioritising problems and the fidgety energy she felt were manifesting themselves. We worked it out as we worked everything out, but this became one of her fixations. The washing up had to be done instantaneously. I then thought she had probably heard one of the malcontent hags complaining about a stray glass, plate or fork left in the sink and that they weren’t going to do someone else’s dirty work. Sometimes, Julie made us wash up before we ate and dinner would be cold. You couldn’t reason with her, it was easier to do it.

We spent a lot of time on her vocabulary. I would prompt her with words and she would attempt to repeat them; sometimes she succeeded and sometimes she didn’t. Her writing was becoming unsteady and tremulous in the diary. Instead of the clear, strong, rounded strokes of her printing, it was wavering and looked shaky. “Rosie” (the whippet) would be spelled “Rozzie”; the famous “Biscuit” would end up “Busuit”. Consequently, she asked me to write more in the diary and so I did. She would tell me what to write: questions for the oncologist, appointments with the doctors, what movies we saw, horses to be trimmed by the farrier on the weekend and all the bits and pieces of our lives which she had so meticulously recorded for years.

When I saw her write and cross things out and try again I would be in agony of indecision. Do it for her? Help her out? Ignore the mistakes and errors? Prompt her? I never knew what the right or the wrong decision was. Sometimes she lit up like a Christmas tree and her thanks were effusive. Other times, she would squeeze the pen till her knuckles were white and her hand shook.

It was week five, Tuesday 27 January and we were leaving Ecclesbourne. Julie could not stand it any more. The pessimistic and gloomy atmosphere had affected us both. Julie said to me on the Sunday night, “I can’t go back there”. I didn’t argue. I immediately rang Jason and made arrangements for us to stay

there. No, it wasn't a problem. His sister needed him, he would help. Jane seemed to have problems with the arrangements. They were both young. I didn't know if Julie's ailment affected her; that the spectre of a possible terminal illness in her flat filled her with some kind of metaphysical heebie-jeebies. Jane seemed to make excuses for them to be out. The flat was so cramped; maybe they just wanted to give us space.

To a certain extent, I didn't care. I was becoming as ruthless as Shirley. I didn't know if Julie was being affected by the therapy or if she was degenerating. The *dexamethasone* was becoming a saviour and a curse. You didn't need to be Einstein to work out that when her dosage of the *dexamethasone* fell to a certain level the *dysphasia*, vomiting and nausea would kick in. Simultaneously you didn't need to be Einstein's brother to work out that the drug was really ravaging her body and her mind. We had to keep up her dosage. She was in the boost state of her therapy. Sometimes she walked out of the treatment room with the mesh pattern of the mask more deeply embroidered on her face.

One of the attendants, Gavin, had taken a particular shine to Julie. He seemed to always be there to escort Julie in to the treatment room. We saw a lot of familiar faces in the reception room. There was the same morose air of doom that pervaded Ecclesbourne. Some days, Julie sat in her chair, eyes closed, holding my hand as she gathered herself for treatment. If it hurt or caused her any discomfort, she said nothing about it. Not a murmur, not a single syllable of complaint.

The staff were "Lovely, amazing, fabulous!"

Gavin was "Lovely, amazing, fabulous!"

Dr Christina was "Lovely, amazing, fabulous!"

Sue, who had some sort of supervisory role, and who looked a real tough cookie, always juggled our treatment appointments so that we could leave early on Fridays and come back late on Mondays. She was "Lovely, amazing, fabulous!"

People seemed to think Julie was special and they were right. She went around the waiting room when she felt up to it and struck up conversations. One poor old duck who looked as if her nose was rotting off from melanoma adored Julie. She would glow when Julie came over and seem to wonder why this young woman wanted to talk to her. Her elderly husband would brighten up as well. They were "Lovely, amazing, fabulous!"

Omar was a squat, balding, fiftyish patient of indeterminate Middle Eastern origin who came with an attendant and never spoke. He was developmentally delayed and when he walked, it was with a pronounced shuffling forward lean. The lean allowed gravity to do its work and he got to where he was going with a minimum of effort just by maintaining a sort of balance. He never seemed to stop instantly, even when he only walked a few steps, he seemed to slow down,

change gears and apply his brakes. Julie passed Omar a few times in the waiting room and always brightly said “Hi, Omar!” He always looked at Julie with a blank stare and a faint smile, not a whit of puzzlement on his brow and not a syllable in reply, just the benign, passive amiable stare that he always had. Julie always chortled a greeting and gave him a big smile.

One day, some flicker of recognition or some memory of camaraderie or friendship must have flipped on with Omar as the involved process of him stopping kicked in. He stood in front of Julie who gave a bright “How are you today, Omar?” and stuck out a hand to shake hands and wish him well. That didn’t quite slot home with Omar. Julie stood for a moment with her hand out and murmured a shy “Hope your treatment goes well”. And moved on to greet someone else.

The convoluted processes of Omar’s brain must have kicked in. As Julie left him his fixed, faint smile broadened and his hand came up to shake Julie’s hand. By this time she had turned away and was greeting someone else. Omar leaned, his feet followed, his attendant, who had remained mute, followed and Omar followed Julie with his hand stuck out. Hot pursuit wasn’t Omar’s strong suit. He tracked Julie around the waiting room in his curious leaning gait before the old melanoma lady tugged Julie’s arm and pointed out the dogged Omar. She, of course, gave Omar a cuddle with his hand still extended in supplication. She always said hello to Omar after that.

The heat was enfilading and constant that week. Most days the thermometer in the Subaru drifted between 36 and 40 degrees Celsius. We sat around Jason’s flat watching dreadful movies on pay TV, dozing in front of the fan. Nights were spent under the persistent coffee grinder crunch of the faulty ceiling fan in their room. Jason and Jane insisted that we use their bed. I wasn’t going to argue. Julie would rally when they arrived home and put on her usual brave front. We were in our last days of therapy and Julie was feeling the pinch – heat, radiation, travelling, stress, brain tumour – I felt so sorry for her but there was nothing more that I could do. I couldn’t get angry at the inconsistencies of her behaviour, I tried my best not to be irritable, I talked to her as much as possible although I heard a thousand times, “You never talk to me”. Every husband does.

An oppositional relationship was developing between Mother and Father and me about Julie’s care. Mother and Father were discontented with what was happening with Julie but I thought their dissatisfaction had other levels. They were unhappy with where they were living, but could find neither a community nor a location, which suited their stringent social and budgetary constraints.

They wandered a lot; taking long meandering trips seeking the right community, with the right weather, populated by the right people and costing the right price.

They couldn't find it and this restless gloom had become a state of being for them.

Julie's illness finally gave them a focus for their restive disenchantment. I didn't realise it at the time, but they quite simply could not accept that Julie was ill.

They could see the hideous alien mass on the MRI, but that was just a picture. It wasn't real to them. They could see the image, but it was outside their belief system, which meant that because they didn't believe in it, Julie couldn't possibly die from it.

The obvious level of disapproval they had for managing Julie's care aligned with this level of denial. I was in a full tilt disaster oriented and death-haunted mindset of hoping for a karmic miracle in proportion to Julie's goodness.

They were in a state of denial that she was ill and, if she did die, someone had to be responsible. And that someone was going to be me. They couldn't find the right place to live, but could stop their daughter from dying simply because they didn't believe her to be sick.

Julie didn't get her attitude to doctors from the fresh air. She got it from them.

Deny you are sick, and you're not. Deny the brain tumour exists, and it doesn't. Deny that Julie really isn't married and has a husband, and I don't matter.

They were meddling, and it really annoyed me. I suppose it was tied up with the politics and dynamics of their family. They could not seem to get a handle on the fact that I was perfectly willing to discuss any aspect of Julie's care. I was wide open for ideas, but their engrained habits of clannish mistrust took over. Mother and Father didn't discuss and they didn't negotiate. At least not with me.

I couldn't engage with them about alternatives or suggestions about her care. It was all very vague and given to me in subtle hints and suggestions.

"Have you seen the dietician at the hospital?" Mother would ask.

"Why?"

"I don't know. It might be something you should look into."

I had reviewed our diet changes with Ruth who heartily endorsed them as any vegetarian doctor would: avoiding red meat, dairy, processed sugars and alcohol. But we needed to see the dietician.

I told Mother that we had assessed the changes in diet with Ruth and she thought them fine.

"Is Ruth a dietician?"

"No, she's a doctor." And a doctor that they disapproved of. There was an unspoken censure about Ruth. Father disapproved of her because she was a 21st century woman – motivated, independent and freethinking. Father had certain prejudices about women who seemed to appropriate what he viewed as male roles.

Julie and I ate well; we always did. Lots of fresh fruit and vegetables. Not much fried food, with the exception of stir-fries. Not much take away or junk food. We ate better than Mother and Father did but until we had the validation of a dietician, there would be no peace in the house about Julie's diet.

I finally made the appointment at Royal Prince Alfred during Julie's therapy. The dietician reviewed Julie's diet. Her diet was fine; maybe a bit more calcium to counteract the effect of the *dexamethesone*. Ruth had recommended the same thing. More soy milk with a calcium supplement had been my solution.

Mother greeted this news with fanfare. "Wasn't that worthwhile?"

"No, we had to wait for over an extra hour at the hospital."

"Well, I think it's good," said Mother with an air of finality.

They would not tell me directly what to do but appeared unhappy with what was done. I tried to discuss with them what they wanted, what they thought best; but these discussions were always vague and fruitless. I was constantly trying to do what I thought best for Julie and provoked unspoken censure from them. I didn't know what to do to settle this so we could all start to row with the same oar.

It came to a new plateau down at RPA on 11 February, towards the end of Julie's therapy. It didn't come to a crisis; that would come later. A wan, thin looking man in his late 20s came up to me in the waiting room. He asked me, "Are you Charley Barber?" He looked like a typical Newtown, inner city, quasi New Age alternative semi-professional. He had on jeans and a shirt with no collar. I thought they had gone out in the 70s, maybe they were back in? He looked to weigh only about 50kg despite being taller than me, and wore an intricately carved silver ring on his thumb. He looked bookish or cultivated that image, wore glasses so narrow I wonder why he bothered, he didn't get his money's worth from the optometrist and his hair was stylishly spiked to cover the fact that it was probably thinning.

I looked up.

He patiently repeated, "Are you Charley Barber?"

I nodded.

He looked at me again. "My name is David Hardke."

I tried to look as if I was pleased for him.

"I'm the Social Worker at RPA. Your mother-in-law made an appointment for you."

I was pissed. Mother had gotten it into her head that we needed to see a social worker. I told her that we had seen the social worker at Ecclesbourne. Regular interviews with medical staff and the social worker were part of the terms and conditions of your residence there. Didn't matter. Mother wanted me to see a social worker. Again, just like the dietician, I could get no definite reason.

I didn't know whether or not they thought we needed to get our dollar value out of all the relevant government agencies. A social worker is available just like free champagne at a wedding; you drank it even if you didn't like champagne.

I always used to think about Father's approach in much the same way that I did with Ozymandias. Shelley wrote about the fictional ancient king that his "frown / and wrinkled lip and sneer of cold command" reflected his penchant for his orders being followed without demur. Father expected the same, without the malicious spite of old Oz, but just as directly. In most matters, I didn't argue with them. I exploded my party favour and put on my funny hat at Christmas because they expected it and that was fine. That they wanted to go to bed at 8pm when they were staying here (which meant that I went to bed at 8pm as well) was fine too. I was adaptable. However, they didn't make appointments for me. They didn't peremptorily and, I thought, rather imperiously, decide what I was doing.

David knew I was furious. It crossed my mind to smile sweetly and say, "Fuck off and have a nice day." But, hey, he was in the middle. I followed him to his office and listened to what he had to say. I knew about IPTAAS. I knew about the Carers Allowance, which I reminded him I could not collect since, even though Julie was my full time concern, technically she was on leave and getting paid her full salary and would continue to do so for about a year. We chatted, I cooled down, we finished and I returned to the waiting room.

Julie was waiting for me. I told her that Mother had made an appointment for me to see the social worker. Julie said nothing. She knew I was livid. Later, I would broach the subject with them.

"Was the social worker a nice man?" Mother enquired when we returned home two days later.

"Yes." The tension in the air was palpable and Julie had obviously told them that I was angry about it.

Yes, it was pleasant and he was pleasant. No, he didn't tell me anything that I didn't already know. I thought with spiteful irony that neither of them would have listened to a word he said based on his appearance and their innate distrust of anyone that far from their conservatively staid social boundaries.

They knew I was angry and resentful. If that annoyed them, I didn't care. I doubt if they felt apologetic for their interference. They couldn't help themselves. They were suspicious and mistrustful of people and tended to take no one's counsel but their own.

They were not handling what was happening to Julie because they didn't believe it was. If any kind of remission was going to happen it was going to be on the tumour's terms, independent of their notions. Julie was going to be changed and altered by the disease, the drugs and the therapy. What was happening to her was brutal and uncompromising. They focused on details like dieticians and

social workers quite simply because they didn't accept the reality of the MRI.

The spectre of Julie's death had been hanging over me since noon of 9 December. If she survived it was going to be an arduous and difficult process. They had read Dan's e-mails about his grand mal epileptic fits, about his trials; but they read and didn't comprehend or accept. Mother coped through her constant activity. Father through stoicism.

Denial isn't just the longest river in Egypt.

It was Monday, 16 February, and we had almost finished therapy. We were changing accommodation again. Virginia, one of Julie's old high school friends, had made contact. I had run into Virginia's parents while shopping and told them of Julie's malady. Julie and Virginia had lost contact. Gin had married straight out of Uni and, by her own admission, the marriage was over before it began. She had two lovely daughters, one in second year of Uni and another in Year 12. Virginia had worked all her life in finance and investment and now had a lucrative job with a large multinational investment and finance firm.

Julie, Sandra and Virginia had been inseparable in Years 11 and 12 at high school. They called themselves "The Three Musketeers" and vowed eternal friendship. Virginia called in during Uni occasionally and she briefly lived back in Goulburn after her marriage disintegrated. However, they drifted apart over the years in much the same way I lost contact with my friends, first from Notre Dame, then from New York, and even people with whom I taught and socialised with before I was married.

Virginia herself had not changed. She was brilliant, brittle and beautiful. She was petite, and radiated sophisticated charm and elegance, although like most fortyish women in Sydney, she could swear like a fettler. A size six would have flapped on her like a gunnysack, living on adrenalin, vivacity and diluted fruit juice. Then she would pack down a Veal Scaloppine that might have pulled up a wharfie. Her professional, social and family lives were lived at a staggering pace. Every hour of every day was full. I teased her that she needed 28 hours in the day and no sleep and then she would get everything done.

Our penultimate day of therapy went much like the others had. We drove down mid-morning on Monday. Instead of turning west to drive to Telopea or East to drive to Double Bay, we turned north and headed over the bridge to Mosman. Virginia had a luxury apartment at Mosman. And it was on the beach.

We only got lost once driving to Mosman and parked outside her unit. Virginia had left a key for us and we held hands as we found the unit. We let ourselves in and both of us let out a collective gasp and sigh of relief.

“Oh, Sweet. This is heaven.”

There was nothing between Virginia’s windows, the sand and the sea except thin air. The views were panoramic, 180-degree views of the Sydney Heads.

We walked to the picture window in the lounge room and the groomed beach of Middle Harbour was at our feet. Preschool children were building sand castles. Ambitious career girls were jogging in svelte Lycra, and someone too ripped for words was paddling a solitary kayak with singular resolve.

I immediately rang Virginia. “We’re here, I’d speak to your landlord about your shitty views and try for a cut in rent.”

Raucously cordial laughter echoed down the line from Virginia. “I just need to tidy up my desk and I’ll be straight home.”

“Julie and I bought something for tea at the Fish Markets. You’ll join us, of course.”

“Dying to see you.”

Julie was all smiles. Her eyes were glowing with wonder. “And Julie sends her love,” I added unnecessarily.

“And mine to her, see you soon.”

Julie and I walked to the window and admired the view again. It was something out of the lives of *The Rich and Famous*. People in Sydney would kill and bury the bodies for a view and a location like that. And we were going to stay with her for the last days of Julie’s therapy.

Virginia had rung me two weeks previously in tears about Julie. I was used to that. I gave Virginia an account of Julie’s diagnosis, operation and treatment. Virginia invited us to stay. I discussed it with Julie and we took her up on it. We had two days of treatment and then a neurosurgeon’s consultation on the day after treatment finished.

If Ecclesbourne was a long way from Telopea, Mosman was a universe away. This wasn’t a place, it was a statement. This wasn’t a phase, it was a destination.

“Let’s go swimming, Sweet.”

I didn’t see a problem with that. The beach was the most enticing sight we’d seen in weeks and we were in our suits in seconds. Julie had slept on the lounge the night before at home. The *dexamethasone* was making her restless and my snoring was keeping her awake. She crept out in the middle of the night and I didn’t realise she was out there until the early morning hours. The swim and stroll on the beach might revive her physically and psychically.

We made our way down to Balmoral Beach, but the reality of the swim was not as seductive as the postcard view. There was a chill offshore breeze and the water was several degrees colder than the sheltered harbour at Red Leaf Pool. Julie only went in the water for 10 minutes. We paddled about and pretended how enjoyable it was and Julie insisted on staying on the beach for a half an hour.

She curled up on her towel and looked very frail and sick. We went up to Gin's unit and she showered and went to bed for a nap.

I was reading, keeping the idyllic view in my line of sight. It was like therapy for the soul.

Virginia let herself in at about 6pm. She gave me a hug and a peck on the cheek. "Charley, you look exactly the same."

"How about I lie and say the same about you."

We laughed and sat down on the lounge.

"How is Julie?"

"She's all in. This therapy can't end soon enough. It's really knocking the shit out of her. But you know Julie, laughs about it, says how much good it's doing her and won't complain about anything."

Virginia nodded.

"I really don't know how she is doing, Gin. That friend of ours, Dan, is doing well. He didn't have any of the fucking problems we've had." I ignored Dan's multiple *grand mal* epileptic seizures to focus on our own problems. "I hope that when this is over, she'll pick up, you know, and then maybe we'll have some time with remission. But she's very weak and a bit fragile now."

Virginia's brow was furrowed with concern, which faded when Julie roused herself and got up for dinner. Virginia and Julie were thrilled. It was just like old times however; Julie's energy levels were so low that, an hour after dinner, she was in bed, which is where she spent most of her time there. Still, the outlook was gorgeous, it was far roomier than Telopea, cooler and the ambience, I hoped, was healing.

We had our first consultation with Professor Dan since he operated on her the day after her therapy ended, Wednesday, 18 February. We had the worst day we had since the diagnosis on 9 December. And that included our day of perking on Parramatta Road.

I had tried to manage things carefully. I had called Ecclesbourne and asked if I could park there for Julie's consultation and they, of course, agreed. I further asked if we could spend a little time there waiting for her MRI to be processed for Professor Dan; again, they agreed. We had lunch at the Fish Markets and then drove to Edgecliff for our appointment.

I lost Julie.

I came as close as I did to panicking during her whole bout with the disease. I dropped Julie off at the corner of Ocean Avenue and New South Head Road because I didn't want her to have to climb the steep hill to Professor Dan's surgery. She agreed to meet me in the Food Fair, where there were a couple of benches she could rest on until I parked the car back at Ecclesbourne. I parked, rushed back up the steep hill and, out of breath, went to the Food Fair. She wasn't there.

I went back down to Sydney MRI, not there. I went back to the Food Fair, thinking she might have used the toilet. Not there. I went down to Professor Dan's rooms teetering on the edge of panic. She was sitting there, leaning back resting with her head against the wall.

"Are you OK, Baby?"

She smiled wanly, "Just tired, Sweet."

I said gently, "How come you didn't wait for me in the Food Fair?"

She looked temporarily perplexed. "I forgot."

She had forgotten where she had to go between getting out of the car and crossing the street. It was a little epiphany as to how sick she really was and what an enormous cost it was to her to put on the brave and cheerful front.

It had been a long day and we were on edge waiting for Professor Dan to give us the news. I had brought the MRIs from December, just prior to surgery, and he compared them to the pictures taken two hours previously. The news could hardly have been worse. The report stated: "Comparison with previous examination performed in December 2003 showed that the lesion has increased in size and its mass effect and oedema effect have worsened."

Julie's tumour had grown. Despite surgery, despite radiation, it was larger. There was "midline shift compressing the lateral ventricle" and "The brain stem is displaced towards the right hand side." Further, "The midline shift was hardly noticeable previously but is now significant." The reason she was so sick was that there was pressure on her brain stem. The brain stem controls your most basic functions, plays a vital role in basic attention, arousal, and consciousness. All information to and from our body passes through the brain stem on the way to or from the brain. Frogs have one, and it isn't much different to ours. Sufficient pressure on the brain stem would kill Julie as quickly and as surely as a bullet in the back of her head.

Professor Dan's disappointment was palpable. I could see his concern, his frustration and I saw him feeling for the phrases to explain what was happening. There were two possible explanations:

One, the tumour was resistant to radiation and was growing apace despite the "debulking" of the tumour and the six weeks of therapy.

Two, the tumour was reacting to the radiation and was undergoing a process of expansion before collapsing back on to itself like a burst balloon. This occurred with some tumours.

He recommended that we consider immediate chemotherapy. I tried to ask all the right questions. I asked him about some of the chemo treatments I had read about. *Tamoxifen*, *Temodar*, *Temozolomide*. Professor Dan said that there was no "preferred treatment". Some tumours reacted quite strongly to some drugs, others stayed the same, others grew more strongly. Dan Reich had said

that chemotherapy had only served to annoy his tumour and make it angry. I took that to mean it had actually grown rather than shrunk during chemo. Professor Dan strongly recommended that we go through with the consult we had booked the following week at RPA to explore the chemotherapy options.

We walked back to the car at Ecclesbourne in silence. It was downhill, Julie could do it, and I didn't want to leave her alone again. I unlocked the car, let Julie in and went and thanked the staff for allowing us to park. The duty nurse, Veronica, asked how the consult went. I just shook my head. She nodded in understanding and murmured something about being sorry.

On the trip home, Julie slept most of the way but we talked our way through the Sydney traffic and on past Campbelltown.

I didn't know what to say. I felt like a football coach down 30-0 at halftime with five starting players injured. There was no positive spin I could put on this.

"Maybe we just need the radiation to do its stuff."

"I'm tired, Sweet. I'm really, really tired."

"I know, it's been tough with all the travelling and staying in such shit holes, except for Virginia's."

"It's not the travelling. I'm just tired of being sick. I'm tired of the drugs." Julie let her words trail off. "I don't know if I can do chemo..."

We knew the nausea and the side effects of chemotherapy were going to make the radiation look like a doddle.

The stop and go traffic around Liverpool was giving way to suburban traffic around Campbelltown. She lowered the seatback as far as it would go and closed her eyes.

"I don't know if I can do this any more. We might be better to just go back to Bannister and ..."

I knew what "and" meant. "And" meant her dying.

I reached over and squeezed her hand. She gave two faint squeezes back and drifted off to fitful rest. We drove most of the way home in silence.

I thought about chemo. It was said the side effects could be quite dramatic and debilitating. I thought Julie's implication was that if she were dying, she didn't want to be fighting nausea, vomiting and debilitation. All of those would probably come of their own accord.

We broke the news to Mother and Father about Professor Dan, but said nothing of our discussion on the way home. Their faces fell and Father, in particular, seemed quite downcast. What I told them could hardly be cause for celebration.

CHAPTER SIX: CRISIS

The vomiting started at about 3am on Saturday, 21 February 2004. With no warning, Julie just sat upright and puked all over herself and the bed. It sounded like a torrent, and the stench was nauseating. By the time I asked her if she was OK, I had already gotten up and turned on the light.

Julie was sitting up and appeared to be dazed. She had spewed down the front of her nightie and all over the doona. She looked dishevelled and stunned; there was vomit on her face and in her hair. I got her up and managed to half drag, half help her to the bathroom before the next spasm of vomiting.

I spent the next 20 minutes with her in the bathroom, holding her hair back, wiping her face, trying to soothe her while she was gripped with repeated waves of violent retching. Her face was a mottled combination of red blotches yet she was deathly pale. What concerned me the most was the lack of comprehension about what was happening. She was almost somnolent. Everything she did was in slow motion, and she was unresponsive and bewildered.

I took off her nightie and washed her with a damp facecloth to clean off the sweat and bile and helped put on another nightgown. She sat on the toilet and kept telling me she was OK. She looked dreadful. I helped her to the lounge room, grabbed some towels from the linen closet and arranged these on the sofa for her to sit on. I draped two of them over her in case she started vomiting again. I went back to the laundry and snatched a bucket. I didn't think she would make it to the toilet in time.

I didn't have to wait long. She began to vomit within seconds of my returning. Great retching, heaving spasms convulsed her. I needed to start her on her medication.

When this bout of retching passed, I asked her if she was up to taking her medication. She just nodded at me, looking for all the world like a punch-drunk fighter: her face was puffy and covered with a slick sheen of sweat, her eyes were bloodshot and watering fiercely from the strain, her speech was coming slowly, she was wagging her head from side to side as if to clear it from a punch, her hair was matted and straggly.

She kept telling me she was all right, that she wanted to go back to bed. I went into the bedroom and stripped the sheets and shoved them in the laundry sink.

Julie began to nag me to go back to bed. She kept insisting she was better.

I didn't attempt to make the bed. We could sleep on the mattress cover for the next few hours and I would wash the sheets and make up the bed again in the morning. I left the bedside lamp on and helped her back to bed. I sat her up in bed and grabbed two tablets of the *maxalon* and a glass of water. I told her to take the tablets one at a time and to only drink small slow sips of water. The water hit her stomach and she immediately regurgitated the concoction. This episode seemed far worse than what we had experienced in Sydney and on Australia Day. It was not only the severity of the vomiting, there was no spark, no trace of the vivacity and chirpiness that was Julie's normal demeanour. There was just this dopey slow-moving dissociative manner. I was frightened for her.

I had swathed her in towels sitting up in bed. I added these to the mound in the laundry sink and moved her back out to the lounge. I let her rest for a moment and started to make notes.

I went to the cupboard and found the *maxalon* suppositories. I popped one out of the foil packet and carried the waxy capsule over to Julie. I handed it to her and she obediently took it from me and looked at it.

"It's a suppository, you know what to do with it."

I turned around to give her some privacy, to allow her to insert the suppository and she began to move to pop it into her mouth. I grabbed her wrist and stopped her gently.

"It's a suppository." I repeated. "Do you know what to do with it?"

Again, she tried to eat it.

Again, I gently stopped her.

"Do you know how to take it?" I asked.

She shook her head. This was serious, she was becoming worse and worse. When she shook her head it was like the slow shaking I had seen in the patients at Kenmore Psychiatric Hospital in Goulburn. When we had played hockey on their beautifully manicured fields, the patients sat on the sidelines wagging their heads back and forth to an inaccessible interior tempo.

I told her to lie down, rolled her over on her stomach and inserted the suppository. She lay there compliant and uncomplaining. I asked her if she wanted to go back to bed or sit up here. She pointed to the bedroom and I took her back there along with an armload of towels. I began to worry that Julie might be having a stroke. The surgery and the radiation had made the tumour even more unstable than it could be on its own. I had read the radiologist's report with the MRI on the Wednesday. There was necrotic tissue associated with the tumour, which meant that part of the tumour was dying from the radiation.

I helped Julie back to bed, sat with her and tried to talk with her. I would not let her lie down. She sat at about a forty-degree angle propped up on pillows in

the brain injury position. She appeared to be more comfortable and I was hoping that the *maxalon* suppository was beginning to work. We chatted amiably. She was drowsy and fatigued.

No such luck. At 4.20am she was overcome with another bout of vomiting. Just like Lady Macbeth I wondered how she could have so much fluid in her. I managed to get her to the bathroom again and we went through our routine of holding her hair back and swabbing her face. I had virtually tied the towels around her so that she didn't foul herself and added the towels to the heap in the laundry sink. The linen closet had almost been cleaned out of towels.

There was only one alternative left. I helped her back to bed and sat her up again swathed in towels, went to our drug cupboard and broke out two of the *Zafron*® wafers. I took them in and she held out her hand to take them. I tried as carefully as I could to explain to Julie that she should not swallow them. They needed to dissolve under her tongue. She didn't seem to understand. I asked her to open her mouth and lift her tongue and, feeling vaguely like a priest administering Communion, I put one on each side of her mouth under her tongue.

Again, she seemed to be resting quietly and I nursed the hope that the *Zafron*® had done its stuff. She started puking again at 4.45am and this time there was virtually no co-operation on her part to get to the bathroom. Julie was in some sort of stasis where she just let the forces of her illness and vomiting and my efforts and ministrations dictate. She was in a state of total passivity and quiescence.

When I cleaned her up for the umpteenth time, I told her we needed to go to the hospital. She looked at me blankly.

I asked her, "Do you know where you have to go?"

She shook her head.

"Do you know what the hospital is?" I asked, dreading the answer.

She mumbled back, "No."

"Do you know my name?" I asked, beginning to feel very, very afraid.

"No." She whispered.

"Do you know your name?"

"No."

The image of what went on behind Mr McNally's curtain came to me. How far away was that? I realised that she might be dying and I was giving her anti-emetics rather than immediately rushing her to the hospital.

I tried to take a minute to think. I was about 40km (or 24 miles) from Goulburn Hospital and about 18km (or 11 miles) from Crookwell Hospital. Did I call for an ambulance or should I try to take her myself? I wondered how long I had before her passivity would become unconsciousness. I thought an ambulance would take about an hour to get to Bannister by the time I called

them and they drove out from Goulburn.

I bundled her into the car after putting another nightie on her and slippers on her feet. I kept talking to her. She was responding, but only in monosyllables. I kept asking if she knew things: What was the dog's name?

Which horse was on the wall in her favourite painting?

What was her brother's name?

What was my name?

All the questions were met with the headshake or a mumbled, "I don't know."

Pulling on to Prices Lane at 4.55am, I still hadn't decided whether or not to take her to Crookwell or to Goulburn Hospital. Outside the front gate, sitting gazing at me stupidly were two kangaroos. It is hard to explain to overseas visitors just how transcendently stupid a kangaroo is. You don't hit them – they bound into you. I had to crawl the 2km up Prices Lane while the two kangas hopped ahead of me, following the road. At the end of Prices Lane I needed to turn right onto Bannister Lane whether or not I was going to either Crookwell or Goulburn. I was hoping that the two roos would either go straight down Learys Lane or left on to Bannister Lane. They knew where they were going. They turned right. I didn't try to overtake them. They could do something especially moronic like crashing through my windscreen. They hopped up Bannister Lane without deviating from the road. I followed behind them at about 10km an hour cursing fiercely to myself that this had to happen now. They stayed in front of me down the hill to the Bannister Hall and then abruptly bounded to the left over the fence and left the road clear.

I still had not decided whether to go to Crookwell or Goulburn. I had to choose when I arrived at the intersection of Bannister Lane and Walkoms Lane. Straight to Goulburn, left to Crookwell. I made up my mind to stay straight. However, I still could not step on it. Kangaroos were commonly all over the road between dusk and dawn. If we had to drive back to Bannister at night or into Goulburn in the dark we always drove sedately, at about 70km per hour. At that speed you had some chance of seeing the roos before you smacked into them. If you hit one at speed it was thousands of dollars damage to the car as well as having that collision become the prelude to a major accident. Grinding my teeth, I made myself drive at the required 70km per hour.

All the way into town I kept talking with Julie. She seemed to brighten up. I only drove with one hand, holding her hand with my left hand to which she clung; letting it go reluctantly when I had to change gears or put two hands on the steering wheel. She had no idea who I was. It was very disconcerting. She didn't know her mother's name or her father's.

I pulled into the Emergency Entrance of the Goulburn Base Hospital, ignoring the No Parking, No Stopping, No Way, Stay Away signs. I hustled her in

the door and rang the Emergency button. I had not rung or called the hospital. The thought had not crossed my mind. It probably would have been a good idea. The triage nurses were used to drunks, drug addicts, victims of fights or domestic violence or sick kids. They never knew who or what was going to press that button.

We were lucky. The nurse was a parent from Trinity. She recognised Julie. She knew about Julie's illness. I didn't have to explain a thing other than that she was *dysphasic*, vomiting and I was following Ruth Edward's protocol in bringing her in from Bannister.

Julie was put on a treatment bed, hooked up to the monitoring equipment and told that a doctor would attend to her immediately. I asked the nurse to stay with her for a moment; I had to move the car and retrieve the MRIs. When I moved the car I could already feel the heat in the day. It was going to be a bastard of a day, in more ways than one.

I walked back in and the nurse was talking cheerily with Julie, who had roused herself from her almost anaesthetised state. The nurse was chatting about her daughter and her friends up at Trinity. If she knew none of it meant anything to Julie, she didn't give that away. Julie was listening and nodding enthusiastically and trying to respond appropriately.

A young intern examined Julie. He did not do much more than take her blood pressure, heart rate and listen to her breathe. I informed him about the nature of Julie's condition and he looked at the MRIs without interest. I suppose he looked because I had bothered to bring them. Nothing happened. I was told "the specialist physician" would attend to Julie.

I lost track of time. I had been scrupulous about keeping track of time with regard to Julie's medication and the bouts of vomiting. I was reminded of the leisurely pace which attended Mr McNally's crisis; the almost slow-motion response to his public uncomprehending agony. I was hoping that the Base Hospital staff would be as efficient as the Concord staff had been in rallying to treat Mr McNally.

I still worried about Julie lapsing into a coma.

The nurses kept an eye on Julie and had a kind word for her sporadically and I could see that they would occasionally convene in some sort of informal huddle and whisper among themselves about what was happening.

About 45 minutes passed before the specialist physician appeared.

Dr Wickramasuriya was a middle-aged woman from the subcontinent, thin, with a look of permanent discontent furrowing her brow as if she had shoes

which were too tight or as my father used to say “a hair across her ass”.

The doctor wanted Julie gone, out of Goulburn, off her shift, out of her sphere of concern. I didn't know this. I only knew that Dr Wickramasuriya was the specialist physician who would decide how the hospital would deal with Julie. I just assumed that Julie would be admitted and treated. If my worst case scenario was unfolding she would advise as to how Julie's dying would be managed.

Some instant judgements on her part were made walking into the treatment room. I had not had time to dress for dinner or the ball. I was in old, stained work trousers. I had on a work shirt, which probably had a frayed collar. I had on my current pair of Redback elastic sided work boots. I wore them until the uppers gave out and my toes started to leak out the sides.

I was probably holding on to an old baseball cap, which would have been sweat stained, bleached and dirty. I might have even had it on. I had a bald patch. I put a hat on going outside to avoid sunburn as routinely as I put shoes on.

I didn't think about it until later but Dr Wickramasuriya probably thought I was a dirty, dishevelled hillbilly who smelled of horses, sweat from the work clothes, and, most likely, vomit. I radiated wild-eyed desperation and twitchy, edgy nervous energy. Julie, Dr Wickramasuriya knew, had a brain tumour. She probably assumed that I had lice. The fact that I was intelligent, literate and articulate would have been obvious to anyone after I uttered two sentences. Nevertheless, Dr Wickramasuriya had made a judgement.

Her opening gambit was that Julie needed to be treated by “her doctors”. I asked which one – her neurosurgeon, her oncologist or her GP? Dr Wickramasuriya asked where she had been treated. I told her that Julie's neurosurgery had been performed at Concord, that her radiotherapy had been at Royal Prince Alfred and that Ruth Edwards was her GP. Dr Wickramasuriya told me that she practised occasionally at Concord and that these were the doctors with whom I must consult and who must manage Julie's care. I informed Dr Wickramasuriya that Professor Dan had seen Julie only on the Wednesday previous, had reviewed these MRIs and that we had a chemotherapy consultation coming up on Monday, 23 February. Dr Wickramasuriya insisted that she would arrange for Julie's immediate transfer to Concord. She reviewed Julie's MRIs without comment and informed me that she would need to contact Professor Dan to confirm the transfer.

I was bewildered by her approach. I didn't know why some sort of treatment had not been started here in Goulburn. Dr Wickramasuriya departed without so much as examining Julie, only consulting with the chart in which the intern had made some notes.

I started to call people. I rang Steve and told him that Julie was gravely ill. I implied that she might be dying without stating it directly. He asked if he

wanted me to come to the hospital. I told him not to. I asked him to go out and check the property. I told him to grab Rosie and bring her into town. The dog might need to go into the kennel at Whispering Pines while Julie was in Concord.

I rang Mother and Father and told them to get ready to travel. I didn't even know where they were. I assumed they had gone home on the Friday to the far South Coast. I told them that Julie might be transferred to Concord and that decisions were being made about that now. They always went to Sydney from the South Coast through Goulburn and I told them as soon as I knew anything, I would call them.

I rang Vicki and told her the same story. Julie was gravely ill. She might be going to Concord. Vicki asked me if, "This was it?" I replied that it might be, I didn't know but Julie was very, very bad. Vicki started to cry, but still had the presence of mind to ask if there was anything I needed to have done. I had a flash of inspiration. I told her to ring Kathy Hill and explain the situation and ask her to come to the hospital. I needed a support person and a translator. There had been too much medical jargon thrown at me since December and I needed someone to explain to me in plain English what was happening.

If Julie was dying, I needed to know that in simple terms. I needed someone to explain her condition and her prognosis in simple declarative sentences. I remembered how great Kathy had been when Julie was kicked in the face by the stallion. I gave Vicki two versions of Kathy's number and told her if it wasn't one number, it was the other. Kathy's last four digits were two consecutive two-digit numbers, like 2223 or 2322. Vicki said she would keep trying Kathy until she talked with her. I told Vicki not to minimise the situation. Kathy knew that Julie had an *astrocytoma*. I was sure that if she were available, she would come.

I rang Julie's boss, Joe Steyns. If Julie died this weekend, Joe needed to be prepared for the monsoon of grief that would hit his school and his two campuses. Truth would not matter, rumours would circulate wildly and Joe would have an uproar to quell.

While I was making my calls Dr Wickramasuriya was making hers. She rang Concord without success. She could not raise Professor Dan or Dr Rust. She managed to have Concord agree to contact Professor Dan at home and they gave her the news that Professor Dan was in Melbourne. With that, Dr Wickramasuriya told me that she wanted the names of Julie's doctors at RPA. I obediently gave her Dr Tin's name and Dr Christina's name. A faint suspicion began to tap dance at the edge of my awareness that Dr Wickramasuriya wasn't the least bit concerned with Julie's welfare; she was more concerned with her own, with keeping her batting average up and her paperwork down by not having a brain tumour patient die on her shift. She had been adamant that the doctors at Concord were best able to serve Julie's interests, but now she was changing hospitals, suburbs

and specialities looking for validation, unconcerned as to who gave it.

Dr Wickramasuriya returned to me and said that RPA was unable to track down Dr Tin and Dr Christina, she sniffed haughtily, “was only a registrar”. It was now almost 8am and Julie had still not been treated. She was lying patiently on the treatment table in the emergency ward not vomiting, bright enough but still *dysphasic*. I asked her repeatedly if she knew who I was. At one point she looked at me and said, “I don’t know, but I know I love you.”

I was beginning to feel the pressure from Dr Wickramasuriya, the situation and from my own sense of helplessness. When the doctor returned, I caved in. She asked about transferring Julie to Concord again and I agreed. I didn’t really want to subject Julie to the trip to Concord but almost five hours had passed since her first vomiting attack and, except for my blundering and ineffectual efforts, she had received no treatment. I thought that she would receive care either in the ambulance or on the medivac. I was getting desperate.

Kathy came in sometime around then. She took charge again, as much as was possible, and asked me if I needed a cup of tea. I told her I was dying for one. She made the cup of tea and reconnoitred the landscape with the nurses on duty.

I was a man who lived by my wits and instincts as a schoolteacher. I could tell more from how a kid was sitting than I could from what he was saying. And the nurses were unhappy. The natives were restless and I knew it wasn’t with me; it was with Dr Wickramasuriya.

I asked Kathy, “Is she (meaning the doctor) trying to piss off a problem?”

Kathy replied, “That seems to be what everyone thinks.”

Dr Wickramasuriya returned. She told me, rather grandiosely, “Since you have decided to transfer your wife to Concord...”

I decided that like Popeye, enough was enough. I told her, “I have not decided to transfer my wife to Concord. You have. You’re trying to shoehorn me into a decision I don’t want to make. I won’t let her go to Concord until you give me a valid reason, and I don’t want to hear that her doctors are there.”

Dr Wickramasuriya looked at me as if I were a worm. With all the disdain she could muster she replied, “I am the doctor here and I think that is the best decision.”

I looked at her and with all the scorn and contempt I could raise I said, “You’re just trying to unload a problem. Until one of our doctors speaks to me personally, my wife isn’t going anywhere. I don’t understand why you’re not treating her.”

Dr Wickramasuriya repeated what had become her mantra, “Your wife’s doctors are at Concord.”

“What can they do for her that can’t be done here?”

“Your wife’s doctors are at Concord.”

I tried another approach. “Further surgery is out of the question. Professor Dan

ruled that out. She can have no more radiotherapy; she has reached her limit on that. What can be done there that cannot be done here? Tell me: I want to know.”

“I’m the doctor. Your wife’s doctors are at Concord.”

“We’re not going anywhere until I speak with one of our doctors. I’m an educated, literate, well-read man. I work in an executive position in middle management at Mulwaree High School. You need to explain to me what will be done for her at Concord. You just can’t keep repeating that nonsense about her doctors, her doctors are not available. Tell me what will happen at Concord that can’t or won’t happen here.”

She tried another tack. We were both angry. During this exchange she had been alternately domineering, brittle, haughty and then wheedling. After my initial anger, I had calmed down. By the time I had rattled off my last speech, I was calm. I remained calm for the rest of Julie’s stay in Goulburn Base Hospital.

Who was Julie’s GP?

Ruth Edwards. She was out of the country. Chris Harmon was her locum while she was overseas. There was a hurried conference, which was apparently to determine whether or not Chris Harmon had “visiting rights” to the hospital. No one seemed to know. I just said that he didn’t need to examine Julie, I just needed to have him validate Dr Wickramasuriya’s decision to transfer her to Concord. There was a burst of activity as resources were scrambled to locate Chris’ home number.

The hospital rang Chris. They could not find him.

I told Dr Wickramasuriya I would walk down to the surgery and see if he was there. It was only two blocks away. I asked Kathy to stay with Julie, who seemed to recognize Kathy. Julie could not recall Kathy’s name, only that her face was familiar and that she was a friend. She held Kathy’s hand with the same need for reassurance with which she gripped mine on the trip into town. I was back in 10 minutes. The surgery was deserted.

While Dr Wickramasuriya was out of the emergency ward, one of the nurses came over to me and whispered fiercely, “Don’t give up. She’s wrong.”

Dr Wickramasuriya returned and asked to see Kathy. When Kathy returned, she told me that Dr Wickramasuriya had informed her that an official complaint for some type of professional misconduct would be filed against Kathy by her. Kathy had responded by telling her that she was here only as a “family friend” and “support person” for me. Kathy also told me that Dr Wickramasuriya was withdrawing from Julie’s care. This ridiculous charade had been going on for about an hour and a half.

A very nice, smiling and well groomed middle aged lady came to the bedside with some forms to fill in for Julie’s admission. I signed wherever she pointed

and she informed me that Dr Renton would be taking over Julie's case. He had ordered that a drip of the familiar *dexamethesone* be administered and that she would be transferred to the second floor. I almost wept with relief.

Dr Wickramasuriya came back and rather pompously announced that she was "withdrawing" from Julie's "case." I restrained myself from ironically asking how could she withdraw when she had done nothing? I instead searched for a bland comment and simply said, "I think that might be the best for all concerned."

She looked at me with scathing contempt and, with as much venom as she could muster, spat, "I don't really care what you think." With that she turned on her heel and marched out.

I looked fondly at her departing back. I was already drafting the letter I would send to whoever was in charge of the Base Hospital sometime that week. Always dangerous to cross an English teacher. They know how to write letters, and working for the State Government, I knew exactly how to push the right buttons with the bureaucrats who ran this joint. She would keep. She was going to have a real bad day sometime the following week.

I rang Mother and Father again. Come to Goulburn, Julie was being admitted to the Base Hospital. By this time they were about an hour away and would ring me when they were closer. I told them I would meet them downstairs. It would be easier for me to meet them downstairs than for them to try and find where she was.

I accompanied Julie upstairs. She was already on the drip. Dr Renton would examine her when he arrived within the next hour or so. I asked Kathy about Dr Renton. She said he was a good man. Julie would like and trust him.

Mother and Father arrived. I took them up to Julie's room. It was a two-bed ward with Julie in the bed by the window. The other bed was empty. Dr Renton was interviewing Julie and talking with her. She was responding brightly, but, it was clear to him that she had no idea why she was there and no idea of the circumstances that had led to her admission. I gave Dr Renton a brief summary of the morning's events. After just 15 minutes on the drip, Julie was responding. It really was a miracle drug.

Mother and Father exchanged pleasantries with Dr Renton. He had treated Mother's elderly mother in the past. She liked and respected him. I handed Dr Renton Julie's MRIs and gave him the quick flyover of her diagnosis, treatment and therapy since early December. He told Julie she was doing well and motioned with a nod for us to move outside the room.

Warwick Renton was a big man. He had full head of sandy, reddish hair that

was combed back like Beaver Cleaver. He looked like the big jolly kid everybody liked in Year 10 in 1964 that had never changed his hairstyle and had become a doctor. His manners were overtly polite and his manner was deferential. I mentioned him to Professor Dan, who characterised him as being an excellent doctor.

Dr Renton held the MRIs up to the bright light coming in through the hospital windows and saw the mass in the left temporal lobe. He turned to me and asked, "You're aware of how serious this is?"

I knew that at some point in time I would have to tell some doctor somewhere what Julie and I had discussed about her condition. Every couple watches the news, some documentary or a film about some incredibly adaptive and courageous quadriplegic, amputee or sightless person who overcomes their handicap through perseverance and pluck. We all wonder how we would cope with some handicap, some malady, some terminal illness. I knew somewhere along the line I would have to see a doctor or a palliative nurse or a technician and tell them to do no more, if Julie's ailment went the way it was predicted to go by the website I had consulted, by Dr Tilman Rust, by Professor Dan, by Dr Tin...by everyone with whom we had so far consulted.

Julie and I had discussed this. Not since she had been ill, but before, in the endless conversations intimate couples have over two and a half decades of marriage. Julie would rather die than be a paraplegic; she would prefer not to live than live in a world without sight. She would prefer nothingness to a world of madness and had said on more than one occasion that if she ever went mad, she would kill herself. Deafness was OK: she wouldn't have to listen to me. If she badly injured a leg, as long as she could get on a horse, she would be fine.

When his question "You're aware of how serious this is?" was posed to me, I was ready sort of, kind of, maybe...

I told him I was well informed about the nature of *astrocytomas*, *glioblastoma multiforme*, the median survival times of glioma patients and the likely outcome of Julie's illness.

He nodded. "Your wife is critically ill."

I nodded. "I know."

I went into the speech I had thought about late at night and was hoping that I would never have to make.

"Julie and I have discussed this."

"Julie has expressed the wish..."

I cleared my throat.

"Julie has expressed the wish, and I agree with it, that if she is crashing, that if she is dying...that no heroic or desperate measures be taken. She doesn't want to live if what's done to keep her alive leaves her severely disabled..."

I felt my words trail off as Dr Renton imperceptibly nodded with understanding. Mother went nuts.

In a shrill voice she almost shrieked, "Well I don't agree with it! It's not what I want! We have rights here!"

Mother shouldered her way between Dr Renton and me and, teary with fury, began to threaten – me, Warwick Renton, the hospital system.

"What do I have to do? We have rights! I'll get my solicitor! Nothing matters except Julie must live!"

Mother turned on me and with possibly more fury than I've ever had directed at me – not by raging Year Nines, not by irate parents, not even by the cops that beat the shit out of me at an antiwar demonstration in 1969, spat out what she had probably long believed: a deeply held yet suppressed belief that was probably only secondary to her love of Julie.

"Don't pay any attention to Charley. He's not in this family. We've never liked him. He has nothing to do with this!"

I wasn't surprised by her reaction.

Mother and Father had disapproved of the relationship in 1978. Julie had moved out of home rather than stop seeing me. We had married in 1979. When we had gone on a trip to the USA, Julie later told me that Mother believed that I was somehow kidnapping her daughter away from her Antipodean homeland like some pillaging Arab brigand would take a concubine by force.

Over 24 years of marriage had failed to make an impression that Julie, rather than ceasing to be their daughter, had become an autonomous woman, an inspiring teacher, a committed rider and my life's partner. They had a concept of Julie in which their relationship to her was the primary relationship in her life. I was something of an aberration and an inconvenience. I held her horses; I built the fences to keep them in; I slept in the same bed as her for 24 years.

If I had become more important to Julie than them, their parenthood was somehow inferior and untrue. If Julie had admitted someone else into the embrace of her love, somehow they had been excluded. I was an interloper, someone who needed to be accommodated but not regarded as essential or important; an accoutrement of Julie's life but not an elemental part of it; part of her life but not of her spirit; her lover but not her love. They had lived their lives believing in the insular and restricted nature of their family, and membership was limited by blood and birth.

Kathy was thunderstruck. I think she would have had an easier day if Julie had been in cardiac arrest.

I said nothing.

Dr Renton seemed to sweep Mother and Father along in his burly arms and with a subtly authoritative lift of his chin dragged Kathy along and left me

standing stunned and silent outside Julie's room.

It was only 10am.

I immediately walked into Julie's room. She had been blissfully unaware of the emotional firestorm only six metres away. She was brighter. She seemed more coherent. She still didn't know who I was.

About an hour later I asked her, "What's my name?"

She replied, "Charley Barber...Does that make you happy?"

I almost wept with relief. I howled with laughter instead, sarcasm and irony were foreign languages to Julie.

Kathy came back into the room and Julie greeted her with a cheerful hello. I prompted Julie with, "Kathy came to help, like the time Apparition kicked you."

Julie thought about this and it seemed to strike a chord with her. For the rest of the day, when visitors arrived, I did the same: used their name and gave some excuse for their visit to give her a context. There would be a lot of visitors.

Kathy told me that Dr Renton wanted to see me. On the way out of the room she commented that Warwick had told Mother and Father "a few home truths". He was waiting for me down by the nurse's station. Mother and Father were sitting glumly on the dilapidated and stained lounges strewn by the nurse's station.

I had made my speech. Now Dr Renton made his.

Julie was dying. Not today. Her future would probably be measured in weeks and a few months. Quality of life needed to be our priority as carers. Julie needed to be viewed as a short-term, palliative care patient.

Further therapy, especially chemotherapy, was out of the question. It could kill her, and would make what remaining time was left to her a misery. A fairly intensive regime of drug support and therapy was what he was recommending – an industrial strength cocktail of steroids, nausea drugs, antacids, analgesics, sedatives and anticonvulsants to make what little time Julie had left bearable.

Dr Renton was also referring Julie's case to Palliative Care. A representative of Palliative Care would contact me and introduce herself to Julie. They would later visit us at home to analyse the home situation and determine how best to manage Julie and also to make some type of recommendation as to when she should be moved to hospice care.

I told Dr Renton I wanted to keep Julie at home. I didn't want her to die in an anonymous sterile room. Even if she were *non compos mentis*, I wanted her to leave this world from Bannister, in the home in which she had invested so much of her spirit and being.

Dr Renton just nodded in agreement, probably thinking I was being naïve

and would later come to my senses.

Julie would die at home in the house we loved. I promised myself that.

That was basically it. Did I have any questions?

Only one: what do we tell Julie?

He let me answer that one.

I asked him if it would be proper if we didn't tell her anything; that we tell her that this crisis was serious and that she would be a considerable period of time recovering from it. That she was still dangerously ill and her condition would be subject to peaks and troughs that we would have to ride out.

That by the time she was so ill that anyone could see the inevitability of her death, her cognitive ability would have slipped to the point at which she could no longer comprehend her own situation.

I told Dr Renton that Julie was the most cheerful and optimistic person that I had ever met. If she were told of her imminent death it could plunge her into severe depression. I mentioned to him that she had periodically suffered from depression, but he already knew that. The medication was on her chart. The depression could be the same type of blight on her remaining time psychically as the chemotherapy could be physically. He concurred with that. The other aspect was that Julie was a compulsive organiser. I didn't think I could deal with her organising her own death.

My father had died in the early 1980s from prostate cancer. My mother had made the decision not to tell him that he was terminally ill when he was recovering from his initial surgery. They had almost 18 months and my mother maintained that it was one of the happiest times of their lives. It was only in the last month that my father realised he was dying. I hoped Julie and I could have a similar time of tranquillity. I knew it would not be as long as the time my mother and father had together. I would be grateful for anything.

I told my father-in-law of my decision. He looked at me solemnly and said, "I agree with that." I didn't give a shit whether they agreed with me or not. I only cared about Julie. I honestly didn't know what they perceived was going to happen. At this time, my goals were very modest indeed. Just a little time.

Mother and I came back to Bannister Springs to pack a bag for Julie. I took mother with me deliberately. I thought that if I left her there she would spend all the time talking to Julie, who would have trouble processing the constant stream of disconnected thoughts. It was among the strangest two hours of my life. The strain of the morning was telling on Mother. I really don't know what she said; I don't think she did either. I think she was afraid of silence. A period of quiet

would give form and substance to the shadows of fear and doubt hovering on the edge of her consciousness.

When we arrived at Bannister, I went over to the shed to check on Rosie and I fed the horses, even though they didn't need it. It gave me some respite. I felt sorry for Mother. I thought that she might be heading for a breakdown. I didn't know how to help and, to a certain extent, I didn't want to. What she had said earlier in the day would never leave me.

On the return trip to the Base, Mother gave me a virtual blow-by-blow description of every step she took through the house and a detailed rationale as to why she packed nighties, hairbrushes, toothbrushes and toiletries. I knew she had no idea that for all intents and purposes she was sounding like a madwoman. I realised later that I probably looked like a madman: sweat stained with bloodshot puffy eyes, a hunted and probably suspiciously furtive expression on my face, dressed in clothes more befitting a refugee than a farmer, haggard, careworn and depressed.

We made a great pair. I barely spoke on the way back to the hospital except for the odd grunt or single word response while Mother paused for breath, her chaotic narrative filling the strained and oppressive silence. I never spoke to Julie's parents directly about my thoughts on their confrontation with me outside the hospital door. There was nothing to say. They believed that it was an accident of law that made me Julie's primary carer and next of kin. In a just world, I would be ripped out of the world, and they would deal with the situation unencumbered by their bad dream of my marriage.

Visitors took up the rest of the day. A stream of visitors appeared continuously at the door of Julie's hospital room: Vicki, Sandra, Virginia (who was travelling through town on her way to Canberra), colleagues and relatives. I gave the same pep talk:

Cry on your own.

You must be positive and upbeat with Julie.

The news was dire and awful. You deal with it.

The remaining time Julie has must be filled with love and laughter.

If you feel devastated, keep it to yourself.

If people needed to cry I reminded them that there would be enough time to cry later.

I left Julie at about 9.30pm. I came back to Bannister Springs and the cacophony of disjointed ideas that were churning around in my consciousness did not ease. I was developing a perspective where I didn't think about the big issues, rather I concentrated on the mundane, the trivial and the inconsequential. I could manage things like shopping, dinner and feeding the horses or the dog. I could cut grass, fix fences and clean up puke. I couldn't manage to put what

had happened, what was happening and what would happen to my wife, my marriage and my life into any coherent perspective or framework. I knew on some subjective and objective level Julie was dying, but I didn't yet try and deal with that, even though we had been told weeks before what the reality of our situation was. Dissociative behaviour, it protects your humanity by divorcing you from it.

I sat up in bed with the bedside light on, too tired to make the bed and half wondering if I was lying in puke. I was too weary to smell let alone do housework. That would wait for the morning.

I woke up the next morning out of a fitful sleep still feeling wired, edgy and tense. I had become used to the half-waking restlessness that passed for sleep these days. I cleaned up the bedroom, washed sheets, towels and hung them out to dry. I was into the hospital early on Sunday.

The transformation in Julie was complete. She was essentially back to normal: bright, chirpy and full of beans. She was being treated with intravenous *dexamethasone*, was eating normally and was nagging me about going home. We again had the endless stream of visitors and I tried to monitor their visiting time with Julie. I would tell them that she was recovering from a "crisis" or an "episode". When they asked about her prognosis, I would just say evasively that it was unchanged. I felt like a weaselly Parliamentarian in Question Time who, when asked a direct question, would, with great sincerity, answer another one. The only change that had taken place was that we were putting chemotherapy on hold because she had been severely weakened by this episode. Everyone accepted this explanation. Everyone knew it was not good news that we were in the hospital.

I tried very hard to identify my feelings. I was going to have to manage the decline of the person who I loved most in the world. I was going to have to maintain a façade of confident positivism – that we were dealing with it, that we were fighting the good fight and that we were full of hope, plans and self-belief.

Did I feel like a hypocrite?

That is a very hard question to answer. I felt that I was doing the best thing for Julie. I didn't care about myself. I had thought a lot about the alternatives while I was alone, while I was holding Julie's hand, while I was waiting for this episode of *dysphasia* to pass. This was the worst news I had ever received. Dr Renton's prognosis had brought an immediacy to our situation. Ruth had promised us we would have time. Apparently that time was to be short.

And then I learned a new word, "coning". I thought that I had seen the worst, read about all the horror, been through all the symptoms with all the

permutations of pain ...and then I read about coning.

“Coning” was the non-medical terminology that referred to “transtentorial herniation”. This was a bit of medical jargon for explaining a very simple phenomenon. Eventually, Julie’s tumour would become so large that it would kill her: simple. However, the manner of her death was not that the tumour would “consume” her brain, “eat” it, so to speak. It would destroy some of the tissue adjacent to its immediate area by compromising the circulation. Parts of Julie’s brain would die because they were not receiving sufficient oxygen. This would not kill her. It would lead to loss of function – blindness, deafness, paralysis, personality disorders, emotional instability, incontinence – but not death. Julie would die because the mass of the tumour in the brain would become so dominant, or the oedema that was part and parcel of it would begin to displace Julie’s brain and force it out the only exit hole in the skull, the “foramen magnum”, the opening at the base of the skull where the spinal column connects with the brain.

Pressure on the brain stem would become so great that the vital and primary functions controlled by the brain stem would cease. Julie would stop breathing, her heart would stop beating and she would be dead. Think in terms of the skull being like a sink and the tumour forcing the brain down the plug hole.

It is said that the pain associated with coning is excruciating. That is, before the patient lapses into the inevitable and pain-relieving coma.

I felt like Edgar in *King Lear* who, when he thinks that there can be no further horror, hideousness or depravity, finds his blind father.

And worse I may be yet: the worst is not
So long as we can say ‘This is the worst’.

Mother and Father spent a great deal of time with Julie and me. I tried to stay in the background sitting quietly in a chair while they chatted. As with all of Julie’s visitors that day there was a sense of forced bonhomie and good cheer. If Julie noticed this she didn’t say anything to me. The only real problem on the day was with her recalling a troublesome interview with Warwick Renton at a Parent Teacher Evening at St Pat’s. Julie had cried during the course of the interview and was quite disturbed that she might have somehow upset Dr Renton or that there was some unresolved issue regarding the interview. Dr Renton reassured her continuously that Peter, his son, had very much liked her as a teacher; that, as parents, they were satisfied with Julie’s instruction and management of the class. Her memory was such that she could not recall the details of the interview, only the tears. I finally called in one of Julie’s colleagues, a staff aide, who assisted Julie in the classroom and the matter was put to rest. It seemed to colour the rest of her

relationship with Dr Renton over the next few months. She tried to please him and somehow show through her diligence in being a good patient that she was also a good person. He was great with her.

On Monday, 23 February, Julie was released from the hospital. It was a big day in a lot of ways. I had an interview I had arranged before all this came down with representatives from the Department of Education and Training (DET) to sort out my leave situation. The events of the previous week had changed everything. I had thought that after Julie's return home, I could take leave on a needs basis. This was not going to happen. Julie, I realised, needed constant care.

My appointment was in the morning and I was scheduled to meet with Kim Smith and Clive Woodward who was a staff liaison officer with the DET. My previous meetings with DET officials had usually been oppositional. I was not overly optimistic about the meeting. I would be telling them I needed to be off work for the foreseeable future, and I had no way of knowing how long it would be before Julie's situation would resolve itself. Grimly, I thought, I knew what the resolution would be.

The interview took place in Tom Coll's office. Tom asked how things were going and I gave the three of them a brief chronology of the weekend's events and the likely outcome for Julie. They had apparently anticipated the possibility I wouldn't return to work. By staying away from work for an extended period of time I could access "Special Concessional Leave" which was leave accrued at some hideously slow rate – something like 22 days for every 10 years of service – but it would give me an extra nine weeks of leave. The problem was that I could not access this leave till I was away from work for six weeks and then it could be converted from medical leave to carer's leave. After the concessional leave ran out, I could begin to access my long service leave. I had about three months of that. What they were saying was that I could essentially have the rest of the year away from school. My leave would run out sometime in October or November... and after that...

I had another interview that morning. It was on the phone before I went into town: I called Professor Dan. I briefly gave him the same chronology I would later give to Kim and Clive. I could feel him sagging and mentally sighing on the end of the phone.

He told me what I already knew; that he was very disheartened by the MRI and his examination of Julie the previous Wednesday. The tumour was obviously resistant to the radiation and his postulating the balloon theory was more in hope than in expectation. He still expected to get some reduction of the mass

of the tumour, but not much. He said with a wistful sadness that he hoped that patients whose tumours were as advanced as Julie's would lapse into a coma and not suffer.

I told Professor Dan that Julie was tough, determined and resilient. He told me that it was both her greatest ally and her worst enemy. Her sturdiness and resolve would only serve to prolong the process. He said, almost hopefully, that she could have a bleed into the brain, stroke and die almost instantaneously. Otherwise, the symptoms I had read about would gradually manifest themselves. He said at the end of the conversation that she would almost certainly be partially or completely paralysed and that incontinence would be a given. Julie would require constant palliative care.

Professor Dan confirmed one other thing. I had sent out the next instalment of Julie's Journey #4 on Friday, 20 February. In it I had paraphrased Churchill's resonant quote about the difference between the end of the beginning and the beginning of the end. I had hoped that Julie's completion of her radiotherapy was the former; Professor Dan confirmed it was the latter. I knew Julie's time would now be measured in weeks and possibly a few months but that was all.

We drove back to Bannister for the second time in a week from a hospital setting. Julie was as bright as the proverbial button. She was already planning our week and what we could do to be 'productive'. About five kilometres from town she asked me solemnly, "Am I dying?" and I lied to her. It is a fragment of conversation frozen in time. I knew how I answered would dictate our immediate future. It was a lie and it wasn't. "Not today," I replied dismissively. The topic was never mentioned again.

CHAPTER SEVEN: PALLIATION

We were falling back on palliation like a besieged lost battalion. We would alleviate the symptoms of Julie's illness while the tumour did its thing. Its resistance to the radiation, and the fact that so much had grown back despite the radiation, were potent demonstrations of its intractability. The tumour would not be cured and the symptoms we were already dealing with would become worse: Julie's memory would further deteriorate; the occasional trembling in her hands would become quaking palsy; headaches would begin; the "emotional instability" which the various Internet sites had described would intensify.

Dr Renton knew the syndrome, and Dr Renton knew oncology and palliation; he didn't know Julie. Strength and fortitude permeated her being. She would not give up. Julie would fight with all her will and being to live and it was this, her greatest asset, which could be her worst enemy. She would die hard and it would be ugly.

Another colleague of mine at school watched her sister die of a different category of brain tumour. When her sister had been diagnosed, she refused to get out of bed and wept for days on end. When the doctors and family would try to discuss treatment or therapy with her; she became hysterical. Julie, to my knowledge, had not shed a tear in public. She had cried with frustration and anger in private with me, but never cried for herself, refusing, of course to complain. One of her first acts when she was diagnosed was to start a folder called "Getting Better". In that folder she put little bits and pieces of what she perceived was helpful information, medical insights, spiritual reinforcement – a grab bag of spiritual and medical wishes and wisdom. Julie was inspired by Dan. Every day in Sydney when we discussed the farm, the horses or the future, she would focus on that rather than on her illness. She was assuming that she would somehow overcome this hideous disorder and would move on. Julie would go back to work, would ride and do all the things that defined her being and her life. Dying from *glioblastoma multiforme* was not in the game plan.

I didn't see myself working at cross-purposes with Julie. I was hoping against hope that the other alternative therapies we were trying were going to make a difference. I rationalised it in this way:

- Dan had been told he was dying. So had Julie.
- Dan had been through radiotherapy. So had Julie.
- Dan had changed his diet. So had Julie.
- Dan had sought out a Chinese herbalist for oncological treatment. So had Julie.
- Dan had pursued a course of Chi Gung. So would we.

The last weekend of Julie's treatment we had begun our study of Chi Gung. It was something that we had followed up on relentlessly in Sydney without success. I had tried to track through the Chinese community – no dice anywhere. Some of the martial arts centres were closed for the Christmas and summer holidays: even aspiring Bruce Lees like to go to the beach. Other establishments wanted to know if I wanted my Chi Gung with rice or noodles. The closest I was able to come was to find two books on Chi Gung on Amazon.com – and ordered them. Any plans to try to learn Chi Gung at home were thwarted by arguments over the way Julie and I interpreted the diagrams and instructions depicting the various exercises and movements.

I had been diligently surfing the Net for days trying to find references to Chi Gung in Australia. It didn't help that it was also called Qi Gong (or Qigong). At the end of Julie's second week of therapy in Sydney I had found The Tai Chi Academy in Canberra. This academy was conducting a 10-week course in Chi Gung on Saturday mornings at the Woden campus of the University of Canberra.

The course began on Saturday, 7 February, and when we arrived at Woden, there was a whole gymnasium full of eager acolytes. With some tinkling ambient music in the background we went through a series of warm up exercises in which we waved our arms, windmilled them about, rotated our legs, flexed our waists and tried not to look self conscious. There were about 90-100 people in the gym in two groups: a Tai Chi class and the other, smaller group for Chi Gung.

Most of the members of the group were older than 30. A few, like me, were in their 50s so we felt comfortable.

The head instructor, Brett put us through 45 minutes of easy and simple exercises that neither one of us had trouble following. Brett didn't look like a martial arts instructor, which he obviously was. He was a little podgy and had a rather elegant and elaborately constructed coiffure that looked as if he was hiding a bald patch, not quite a Donald Trump combover, but he could head that way in his 50s.

Brett led us through the weekly exercises with gentle good humour and a plethora of stories about various mystical Oriental masters who performed astonishing physical, psychic and metaphysical feats of flexibility, endurance and spiritual elevation. Their strength of spirit, physical prowess and purity of

character left me feeling unwashed and daggy. Like Mark Twain when remarking about Jane Austen, I felt like a barkeeper in the kingdom of heaven. Julie hung on his every word. It became my unspoken duty to check Julie's performance against the template of Brett's example and make minor corrections in foot placement, arm movement and the angle of her bending. I would nod silently or emphasise my own movements till she got the hang of it. She loved going.

Being a cynic, I used to tease friends who asked what we did by holding my palms out in front of me even with my chest facing out and ask them to do the same. When they did, I just rotated them in alternate circles saying, "Wax on, wax off." Couldn't resist that. And Brett never called anyone 'Grasshopper'.

This became our Saturday routine. We would get up early and feed horses and be in the car by 7.30am, and heading to Canberra. Julie would doze in the car while I made the familiar drive from Bannister, through Gurrundah, to Walwa, down to Breadalbane and then on to Collector via the meandering back roads of the district. At Collector we would pick up the Federal Highway and follow that to Canberra and on into Woden. After class, we would then change out of our daggy Chi Gung outfits and do some shopping, either in Woden or at the Canberra Markets over in Fyshwick for cheap vegetables and fruit.

After about three weeks of class, we felt confident enough and familiar enough with the exercises to do our own routine. That became part of our day. We would face one another in the great room of the house and we would do our exercises for about 40 minutes. Julie claimed that if she woke up feeling "woolly" or with a slight headache, "wax on, wax off," as we called it, made her feel better and cured her headache. I too felt better practising Chi Gung.

Hemingway once said that the one indispensable characteristic that a writer required was to: "Develop a built-in bullshit detector." So this might test yours. What followed in the months of February, March and into April was, to a certain extent, one of the happiest times of our lives. Most people to whom I tell that look at me with profound understanding while their mouths make sympathetic sounds and their eyes scream "Bullshit". I try and imagine what it would be like to surf a tidal wave, to reach the top of Everest knowing that you're about to freeze to death, to feel that moment of ecstasy of achieving the lifelong quest full knowing that the quest will end with your extinction. I have always thought that type of fulfilment to be bullshit. Without life there was nothing.

Julie's tumour did not make us feel liberated like a sky diver who realises both chutes are not going to open so he might as well enjoy the view. Rather, the tumour removed the constraints of work. The pressing needs of social conformity

faded because society lurched out of focus, and our society narrowed to the two of us. It was cathartic because it was so dramatic and traumatic.

We returned to Bannister with one plan: do what we normally did and get better by doing it. And that we did, at least the first half. The diary for the months of February, March and April chronicles a hive of productive activity. Julie's activity in this phase of her journey was splendid. What could be more splendid than demonstrating, through doing what you normally did, how significant your life was? That's what Julie did – nothing out of the ordinary and everything out of the ordinary.

Biscuit became Julie's *raison d'être*. She became obsessive about working him. It was the top of the list of things to do every day. What process she used to justify working him I didn't know or didn't care. She required my help, of course. She always did even before she had become ill. I didn't mind then. I wanted her to work and break him in now.

We had started on Biscuit in December, after the operation and prior to radiotherapy. Julie had taught him how to lunge. Every weekend we were home from RPA, Biscuit was lunged, his feet picked up and he was groomed. On February 6, we became serious. He was going to learn how to get on and off a float.

Getting a horse on a float can be one of the easiest and hardest things to do. Big things like lions and tigers and little things like hawks and foxes are predators. Big things like horses and mountain goats and little things like rabbits and mice are prey. Predators hunt, prey escape. Some escape by flight, some by hiding. Horses are flight creatures, they don't like to go into little spaces like horse floats.

Rule one of getting a horse on a float – once you start, you don't stop. Ever. Otherwise the lesson learned that day is that you will give up before they do. Horses are dumb, they're not stupid.

So once we started on Biscuit, we wouldn't stop. The record was just over four hours and we have had some interesting antics. One mare threw herself down on the ramp of the float chucking an equine tantrum like a three year old in Woolworths. Every one of her progeny did the same thing. Then every one of them gave up, walked on and never created a fuss.

Some just walked on like they'd been doing it all their lives. One sat down like a dog and refused to budge. Neither would we. It budged, Julie didn't.

Biscuit followed the template of most of the good ones.

A little forward and then ease off the pressure.

Let them have a look and a smell. Give them a handful of feed. Not as a bribe, chewing releases endorphins in an equine brain.

Put a little pressure on, back off. Get them moving forward. Don't let them move back. Reward for forward, censure for back.

Julie was marvellous. She had a gift of thinking like a horse. She always took the head, I got the end I deserved. Julie had done a lot of work with the boy. He knew forward, he knew back. He responded to Julie.

Biscuit smelled the ramp and didn't mind that. The first part was getting his front tootsies on and we knew all the tricks for that. We didn't need them. The hard part is always conning them into getting their back feet on the ramp. Once you do that, they don't seem to mind. A tap with a piece of poly pipe here, a pat there, a handful of feed and lots of praise.

Biscuit was on.

It took about an hour and, at the end, he'd been on three times. The third time he just walked up the ramp and straight in. He had been easy. We could have gone faster, but like always, Julie did the job right rather than quickly and was in her element.

It was one of her best days.

Biscuit became the marker of time and a reason to live. But things didn't always run that smoothly. We only ever had one other fight where her mortality was mentioned. The first week in March the stallion, Sy had lingering colic: off his feed, listless and lying down constantly. It wasn't thrashing colic, which might indicate a twisted bowel – a death sentence. He wasn't gravely ill, he just wasn't well. The vet came and administered standard treatments – analgesics – and gave us standard advice – monitoring and bland feeds.

Maybe Sy being ill tripped a switch in Julie's consciousness. Maybe she could see her own mortality in his. Perhaps the stress of potentially losing the horse to which our future as a stud was tied was too much for her.

I had slept in as I had been up checking the stallion for most of the night. Julie was cleaning when I finally got up and that was the start of it. She was in a bad mood and as we did the chores (which included fumigating the stables) she couldn't control her irritability. She snapped at me for a lot of small things. I tried to be patient. On the way over to the vet in Crookwell to pick up some drugs, her anger overcame her.

I wanted her dead. She wanted to die. I hated her and always had. She said some terrible things and worked herself up so that she was weeping hysterically. I just kept driving to the vet while the storm beside me raged. Julie cried herself out and when we returned to Bannister, she took to her bed.

I didn't know whether or not the drugs drove her rage. Steroid rage is real and Julie's dosage was now industrial strength. I thought the most likely cause was the anxiety and stress, which she largely kept to herself. Pressure needs to

go somewhere. It needs to find an outlet and I was a proximate and constant presence so an easy target.

We talked a long time that night in bed. She cuddled up to me. A lot of what was said was non-specific – just the usual business of the property: Sy's health, how much to feed the horses, the weather (there had been little rain in February and none so far in March), what we needed to do in the morning. I think we were trying to recreate our intimacy.

The fight had damaged us; destructive angry fights like that always do. We weren't trying to reinvent our connection, just re-establish normal service. As we sat up in bed Julie snuggled down in the crook of my arm and put her arm across my stomach. It was non-sexual but as intimate and warm as any act of passion. Julie was trying to find the emotional centre of her world and I was trying to let her know that I would always be there, that I was not angry (I was hurt, but that didn't matter), that she had to feel a sense of belonging, security, a guarantee of unconditional love and acceptance. I could only hope that she would feel it. She drifted off to sleep, spent by the day.

Julie had a relatively robust period from about the beginning of March until the beginning of May. The massive doses of cortisone had the desired effect. The drug suppressed the swelling and the oedema in the brain and Julie began to function with the firebrand enthusiasm of the Julie of old.

We fed horses, drenched them, and shuffled them to different paddocks about the place, congratulating ourselves on the well-executed layout of the stud. No horse spent too long in one place, thus allowing the grass to regrow and freshen the paddock. The plan was successful. The farm was a success. What we had so ardently planned was coming to pass.

Julie continued to plan the further development of the place without even considering her own fate. The place had to go on. One of our projects was to plant trees around the sheds and stables and we spent many good days doing just that. Both Julie and I loved to plant trees. I used to tease her that I preferred trees to horses.

The trees brought us closer. Julie watered. The trees and me. I swung the mattock, ran the dripper line, put the drippers in and we both planted. I couldn't resist spraying Julie with the hose when I could as well.

We planted about 80 trees and some ground covers to hide the ugly scar of the bank behind the machinery shed. By the end of the day our hands were blistered and cut from the quartz shards in the basalt soil. Our legs ached from balancing on the slope of the bank and we looked like mud-spattered veterans

of the Western Front. But the trees were in. We could see the neat rows of white cartons from the house and they would remind us of our diligence, industry and environmental good sense. Within a couple of weeks they were sprouting like weeds. It was lovely.

Trees meant a lot to the both of us. We had planted 2000 trees on the Southern and Western boundaries in October of 2003 and these were growing beautifully. Julie had wanted to turn Bannister Springs into a garden and wouldn't be deterred from this, tumour or no tumour.

There was enthusiasm, joy and satisfaction in getting things into shape on the farm. The house was a dream house. The property was meant to be a show place, a functional and safe working horse stud. Julie needed that dream. Hope was the one thing we had.

My faint hope was that somehow all this activity, our new regime and love would combine to magically neutralise Julie's tumour. Deep within myself, I knew that all of this was futile. The ironclad calculus of the merciless statistics of *glioblastoma multiforme* said there was no hope, no respite, the tumour would march on with the inexorable surety inherent in mitosis. Emily Dickinson's words kept resonating in my head:

*“Hope” is the thing with feathers –
That perches in the soul –
And sings the tune without the words –
And never stops – at all –*

The soundtrack of hope became the background music to the harsh reality we were trying to avoid and master. Hope was all we had left, and we were seeking a path, a way, a trajectory of hope to restore Julie's health.

If Dan could do it, so could Julie. Simple premise.

On 6 March Brett told us of the “power” of Chi Gung in that one hospital in China only uses alternative medicine, meditation and Chi Gung for their patients. The sick who go there have usually been told that their cases are hopeless and they resort to this particular hospital for their one last throw of the dice to cure themselves. According to Brett the cure rate for these hopelessly incurable

cases was about 90%.

Everyone was nodding with deep appreciation of the obvious efficacy of Chi Gung for the terminally ill when Julie piped up, "That's what they told me, but you just ignore it."

With that 25 heads swivelled and looked at Julie with new interest and a sharp and collective intake of breath and a mental "Whoa!" Julie blushed bright red and the other 25 people and Brett looked at Julie who had been, up till now, just a silent smiling participant in their midst.

I said quietly, "Julie has a brain tumour."

That really floored them.

She had spunk that girl.

The next step with Biscuit was to back him, to sit on his back. With some horses, this was the first step. Julie wanted Biscuit going on the lunge before she sat on him, but sit on him she would.

We put him in the yard on Friday, 27 February, for Julie "to have a little sit" as she put it. The routine was always the same and we both knew our roles. Julie stood at his near side. I held the head.

"Good boy," Julie crooned and rubbed down the side of the neck, the back and over the hindquarter. "Very good boy." She eased an arm over his back, rubbed him down the ribcage and half leaned over him. Julie kept the rubbing down the off side and leaned on Biscuit, who tried to step away. That was my job. I turned his head toward his off side and when he couldn't move away, he stood.

Julie kept up the rubbing, leaning as far as she could across Biscuit's back. "Atta boy. He's a good boy. Get used to me here."

I already had the bucket ready for Julie. Keeping up the incessant rubbing, she stepped up on to the feed bucket and continued to pet, stroke and scratch Biscuit. I held him steady.

"What's he looking to do?" Julie asked.

"Nothing, he's fine."

"OK, hold him steady, don't let him walk on the bucket and scare himself."

Still standing up on the bucket, Julie eased herself down on Biscuit by leaning completely across him. He had seen this before. The different angle didn't worry him. He was fine. Julie rubbed down the ribcage and gradually let her weight settle on to his back. She was still on the bucket but was resting on Biscuit. He stood like a rock.

"Walk him off a step." She ordered.

This was delicate. He wasn't used to weight on his back. I had to make sure

that he didn't blunder into the bucket and send us all flying.

Biscuit walked forward two steps, Julie eased her feet off the bucket and let Biscuit take her full weight and then stopped. Julie almost curled herself around his neck, stroking the neck and talking non-stop.

"Another step." We went forward another two. "Good, good boy." And he was.

We did five more steps and Julie allowed her weight to take her to the ground.

We repeated the procedure three more times: Julie leaning across his back, letting him take the weight and then walking five or six steps.

"I'll get on him."

"Do you think you're rushing him, Julie?"

"He'll be fine."

I retrieved the bucket but, instead of standing at Biscuit's head, I stood at his shoulder. Julie leaned across him and let the weight go on to him. I kept the tension on the lead in case he anticipated and tried to walk off. He stood. Julie already had her left leg cocked back like a soccer striker. I grabbed her calf and shin and half lifted and half pushed her up on to Biscuit, all the while talking to him and keeping the tension on the lead. We had done this many times together. Julie neatly swung her right leg to the off side and, keeping her head even with Biscuit's neck, rubbed and talked to him.

"Good, good boy. Give him a handful."

I had the feed ready.

While he was focused on that, Julie slowly sat up. She was on him. She was astride and he hadn't moved.

Julie grabbed a handful or mane for balance and kept stroking with the other hand. "One step, please."

Biscuit calmly walked a stride or two. He was lurching a bit with the unaccustomed extra weight on his back, but he didn't mind.

"Another handful."

"I need to watch him. I'm out of feed."

"Another couple of steps."

I walked him about four steps, keeping him well away from the rails of the yard.

"Get a handful."

I moved a metre away and grabbed another handful of feed out of the dipper. Biscuit greedily inhaled the feed.

"Take me for a pony ride."

This had been a family joke for a number of years. I would lead Julie around on them bareback. Julie had ridden *Grand Prix* dressage movements but started young horses with a pony ride. Not one horse over 20 years had ever done a thing

wrong teaching them this way. Biscuit was no different. Just quieter and easier. I took him for a lap of the yard, gently one step at a time. Julie was over the moon with him. He was doing really well and so was she. We were going to see Viv the next day. Julie couldn't wait to tell her about Biscuit.

Our friend Vivienne wasn't so much a person as a natural phenomenon. We had met Viv though Sylvia Archer back in the early 80s. Syl and her mother, Edna, had commented on a number of occasions how much Julie and Vivienne were alike. Viv was as irrepressible as a whirlwind. She radiated a buoyant enthusiasm and an urgent energy that made a hyperactive child seem listless and dormant. I would swear on various occasions that she could talk underwater. And she was mad about horses – especially Arabian horses – and dressage. I was only Julie's husband. Viv was her equine soul mate.

Viv had cost us a fortune over the years in phone calls and riding lessons which involved discussions about lateral movement, flying changes, seat bones, hands, *piaffe* and *passage*, bits, reins, boots, riding helmets and the million other things that comprise the science and mystery of dressage. Julie and Viv would spend hours in earnest conversation about esoteric trivia. Julie would periodically recoil in horror at the phone bill and then find several phone calls to Viv of over an hour. I couldn't get angry. Somehow one couldn't at Viv. At a show Viv once asked me to hold a horse for a few minutes and was gone for two hours. I didn't get angry, I just never held another horse for her no matter how she cajoled and wheedled. Julie and Viv adored one another, and I thought both Viv and her husband Chris, to be wonderful friends – the kind you don't make too often in life – although Julie had more of a talent for finding such treasures than me.

Viv was in Canberra for the Canberra Royal Show. She wasn't showing, just helping a friend. She met us in Dickson for lunch.

I had rung a number of Julie's close friends the weekend she had been in the hospital. I told them Julie was definitely terminally ill and would be dying in the short term – possibly weeks and, at most, a few months. They were people who lived some distance away – Victoria or Queensland or distant parts of New South Wales. I told them to visit Julie in the short term. There would be no long term.

Viv was making sure that she saw Julie.

We had a wonderful lunch. Vivienne was, as usual, an explosion of news, views and enthusiasm. I had cautioned her to speak slowly so that Julie could process what she heard and respond appropriately. No need for that. Viv handled the whole conversation and all Julie had to do was laugh, smile and agree.

Viv was just one of many friends who were concerned about Julie. Julie was an easy person to love. All her friends were balanced between hope and fear and I knew Viv believed I had overstated the seriousness of Julie's condition. To all appearances, Julie looked fine. Except for the problems with speech *aphasia*, she appeared absolutely normal and fine.

Julie's best friend, though, was Vicki. I was benignly jealous of the friendship that bonded Julie and Vicki simply because I had never had a friend for that long to whom I was that close. Julie and Vicki had been best friends since they were eight years old, for 35 years. Even though Vicki had left school at the end of Year 10 and completed a secretarial course and Julie had completed her Higher School Certificate and become a teacher; their friendship never waned. They would meet for secret women's business. They had an intimacy with one another that was really never tested by distance.

Vicki and Julie were two small town girls who stayed in the small town. Their dreams were modest: Julie to ride, Vicki to raise her children. Within these boundaries of love and trust there was a complete understanding, a sharing of goals and purposes. I don't think that there was ever a cross word between them. They loved one another with the selflessness born from complete familiarity and complete acceptance.

Naturally their friendship started with horses. They grew up riding together; belting around paddocks, both on board Vicki's ageless pony, Banjo. Vicki was a good rider who looked beautiful and elegant on a horse. Julie was a functional rider who extracted the last measure of performance from her mounts without really caring how she looked. Vicki was tall, slender and beautiful and looked the gifted equestrienne, a picture of blonde stylishness on a horse. Julie was shorter, dumpier, but was the more knowledgeable rider. Julie's ambitions for her riding were limitless. Vicki was content to potter around the country shows in Lady Rider classes.

I was never able to penetrate what bonded them. I don't think they knew themselves. They had never desired anything from the affiliation except the pleasure of one another's company. I imagine the instantaneous, complete and innocent acceptance that eight-year olds have of one another had drawn them together and, perhaps, like strawberries and cream, gin and tonic or Abbott and Costello, a perfect partnership was born. No wonder I was jealous.

Just like the television spruiker, there's more. Sandra was equally close to Julie. Sandra's association was almost of the same duration as Vicki's. Julie had taken Sandra under her wing in Year 7 in high school. Shy and self-deprecating almost to a fault, Sandra's friendship was as deep and as strong as Vicki's. Sandra also completed the Higher School Certificate with Julie and trained as a primary school teacher at the Goulburn College of Advanced Education.

Sandra and Julie had a lot in common. They felt uncomfortable in large groups of people, were charitable about the faults of others and incapable of duplicity. Whereas Vicki was more tightly controlled with her emotions, Sandra was more easily affected by slights and unkind words. She was more introspective than Vicki, and Julie and she would talk for hours about that which troubled them: fears, insecurities, doubts about themselves. I had no doubt their likeness to one another kept their friendship strong. They could share truths about themselves they probably thought they could share with no one else including, in Julie's case, me.

The news of Julie's illness and the serious nature of her affliction devastated these people. Vicki wept openly and unashamedly. Sandra, when I saw her, was red eyed and tremulous. Julie received hundreds of cards from students, friends and colleagues. They were gradually taking up an entire wall at home. Each time I put out a different edition of "Julie's Journey" replies flooded my e-mail inbox from all over the world. People forwarded it to people that had never met Julie simply because they found her courage and equanimity inspiring.

Sandra's younger sister, Kerry, lived in a cottage in the rural community of Exeter about an hour from Goulburn. On March 19 Sandra and Vicki were going down to Exeter with Julie for a girls' day out. Secret women's business would be transacted and the bonds of friendship would have another strand woven into the cable.

Sandra took pictures on the day; nothing artistic or spectacular, just the easy intimacy of friends who were comfortable with one another. She produced a five-page booklet showing the group of friends sitting placidly in Kerry's verdant garden.

I have looked at that little booklet a hundred times and tried to divine the secret of the photos –what it was that made Julie so special to so many people. The significance of the occasion, which meant a great deal to Julie, is not duplicated in the images but rather woven into their lives. The photos were just a reminder but one which was as significant to Julie and her two dear friends as any wedding or christening photos. Julie was thrilled when Sandra gave her the booklet. Sandra, kind soul that she is, gave copies to Julie's mother and father and, of course, made a copy for Vicki.

Julie came home tired that night, but content with the day. She would occasionally pick up the booklet, which she proudly displayed on the shelves with all the horse trophies and look at the pictures with a little smile, turning over the mystique of their friendship like some treasured family heirloom, which could not be damaged with use but flourished with it.

We continued to run the horse stud the way we normally would. The horses we were breeding now were the nicest horses we'd ever produced. Julie was very enthusiastic about them, although she still wanted to keep almost everything we bred.

Refusing to isolate ourselves, we advertised horses as normal, entertained visitors, some of whom wasted our time just 'kicking the tyres' of the horses instead of cars in the car yard, and occasionally we sold one.

Alan called about a filly and ended up buying a gelding that was more to his needs. He came right on time, worked with Seismic, the gelding, and really liked him. He promptly rang back the next day and made a deal with one condition. Could we move the horse to Sydney? I agreed, with Julie nodding enthusiastically in the background.

We had to teach Seismic to float. He went well. He was a clever little boy. He walked on and off the float with a minimum of effort and, on 31 March we took him for a little float ride down the road 15km or so to give him the hang of travelling. He went like a dream.

I'm not really sure what happened when we arrived back home. I had to get something out of the house, I can't remember what. I could see Seismic loose and Julie on the ground. I caught Seismic and took him back to his paddock. Julie had been kicked, badly.

Apparently Seismic had stepped over the lead while Julie was holding him and letting him graze on the front lawn. The lead had tightened up under his gut, panicking him, and he took off. He kicked at the lead and nailed Julie. I found her on the ground moaning that it wasn't Seismic's fault.

I helped Julie to the house. She had been kicked in the meaty part of her right thigh. Julie, within minutes, had a massive bruise and a wound in the middle of it that looked disturbingly like a bullet hole. She could walk so, of course, she refused to go to the doctor. I treated and bandaged her leg as well as I could and she went to bed. I served her dinner in bed and she finally relented and took some analgesics for the pain so she could sleep.

She insisted on coming to Sydney with me the next day in the F-100 despite the pain from the leg, which must have hurt like hell. Every jolt and every corrugation in the dirt road must have been so painful. She could not stretch out the leg to rest it. Julie would not hear of me travelling alone with the horse in case something happened, and when we arrived in Sydney and Alan saw her limping, she dismissed it as trivial. By the time we arrived home the blood had seeped through the bandage and through her track pants.

Because of the *dexamethasone*, this wound lingered, refused to heal and tormented her by repeatedly becoming infected.

A girth, a roller and a bit were the next step for Biscuit. Horses don't buck at the rider. If they buck, it's at the constriction of the girth, the band under their gut to keep a saddle in place. At least that's what we thought. Like everything Julie did, it was a gradual process.

"Hold him, I won't tie him for this." Julie, as usual, was being redundant. I knew the drill and I knew she wouldn't want Biscuit tied for this. We were in the relative cool shade of the wash bay. Biscuit was used to being tied up here while he was handled and groomed.

The constant refrain of "Good boy" punctuated this. Julie draped the roller over his back, keeping the girth on the near side. She moved around to the off side while I held the girth in place on Biscuit's back. Julie then eased the girth down so that it was hanging with me keeping it from sliding. She didn't want the girth to flop or slap him the first few times he wore the roller. Julie reached under Biscuit's belly and did up the girth loosely. She wiggled it about so he would get used to the movement of gear on his back. I stroked his neck and reassured him.

Julie did up the girth, the belly strap, on the roller that would simulate a saddle, but just the first two holes. It was touching him, but was no tighter than the average wristwatch. And we waited. Biscuit waited. He wondered, I suppose, what we were doing.

Julie took up the girth another two holes but it was not tighter than the average wristband on a tennis player. We waited another couple of minutes for Biscuit to accommodate to the girth.

"Take him for a walk, please."

Biscuit didn't put a foot wrong.

"He's fine with it, Julie. He's good."

Julie looked at the girth and tested the tension on the girth straps speculatively.

"One more hole, for today," she decided.

Julie took up the hole and Biscuit did what horses always did: took a deep breath and puffed his gut out against the girth.

I took him for another walk.

"It's still four holes away from saddle tight," Julie observed. "But it will do for today."

I went with her because Biscuit had learned a new trick. The riding arena was big and he learned to take off down the long side to try and evade Julie. I stood in the middle with a lunge whip and headed him off. It took two weeks before he gave that away.

Julie worked him for 15 minutes in the new gear at the walk and the trot with me acting as the whip-wielding sentinel in the middle. By the time she came back in the girth was loose but it had stayed in place.

Biscuit was just beginning to break a sweat when she brought him back into

the wash bay. Julie had hung up a plastic work bridle over one of the taps. Roller off, brush over the sweat marks.

“Do you want to leave the head stall on?” I asked.

“No, he’ll be fine.” She wasn’t often wrong.

I looped a lead around his neck to hold him at his shoulder while Julie took the work bridle and stood on his near side in front of me. Resting the bit in her left hand, she held the poll strap in her right and jiggled the corners of Biscuit’s mouth with her thumb and middle finger. Biscuit started to play with his jaw in response to the minor irritation.

The bit was in his mouth and the bridle on before he knew it. Julie was that deft and quick. Now my job was to stand and hold him for 10 minutes while he became used to the bit.

Julie was right. Biscuit was a good boy and a smart boy.

Because Biscuit was going so well, Julie didn’t think about the tumour. She had faith in herself and her doctors. She hoped that Dan’s regime and her own determination to try so hard was making a difference. But we still had to liaise with the doctors.

On March 29 we had our second follow-up consultation with Professor Dan. The traffic was horrible, and I narrowly avoided being the fourth car in a three-car pile-up near Campbelltown on Sydney’s south-western outskirts. We made it in time for Julie’s MRI, and then we went to Ecclesbourne and Julie dozed on the lounge while I read the Herald. Despite her weariness I could not persuade her to stretch out on the lounge. She refused to put her feet on the lounge. The staff at Ecclesbourne made it a point to come to see her and to chat briefly, while still allowing her to rest.

We had made arrangements to meet Virginia for lunch in Double Bay and while we were walking the three blocks from Ecclesbourne to the Sheaf Hotel, Julie almost broke down emotionally. Julie told me that she needed to rest and we both sat on a low wall in front of some nondescript apartment building. She was a wreck. She began to quietly weep and I put my arm around her and tried to console her.

“I don’t want to die. I have so much. You’re so good to me.” She whispered and sobbed. “I’m so lucky.” This phrase had crept into her vocabulary. Along with her standard response of “Lovely! Amazing! Fabulous!” she had begun to say this all the time.

She was lucky to have friends like Vicki, Sandra, Viv and Virginia.

She was lucky to have her parents.

She was lucky to have doctors like Professor Dan, Dr Christina, Dr Rust and Dr Renton.

She was lucky to have colleagues like Joe and all the rest of the staff.

She was lucky that her kids at school loved her so much.

She was lucky to have the horses.

She was lucky to have me.

I held her and tried to reassure her. We needed to wait for the results of the MRI. She was just nervous about that. We would know in a few hours. She was feeling better. Maybe the radiation (which we had been told would continue to work for up to six weeks after her therapy finished) had shrunk the tumour dramatically. She was definitely better than when she'd finished the therapy.

Julie finished crying, nodded her head in agreement, and chided herself for being weak. I blamed the drugs, said the *dexamethasone* was making her emotional again. This gave her the reinforcement she needed. She cleaned herself up, said how ashamed she was and we went to lunch.

The consultation with Professor Dan did not go well. The tumour had only reduced in size by about 10%. He told us that it was the best possible result that we could hope for. Julie greeted this news with frantic tears of delight. She hugged and kissed the stately figure of Noel Dan.

I was devastated and quaking inside, Julie was beside herself with relief. Julie was close to hysterics with elation and I had trouble restraining her. Professor Dan had told us that he was going on a trip to China and Julie wanted to buy him a gift for the trip. We went upstairs to the little shopping centre and found something. Julie percolated with good cheer and enthusiasm. She insisted that I call her parents on the mobile and I gave them a detailed account of what Professor Dan had told us. I didn't mention my disappointment but repeated his analysis of it being the "best possible result we could hope for". It was the first remotely positive news we had received from any doctor since Julie was initially diagnosed.

We had an oncology appointment at RPA the same day and were interviewed by a smug and haughty Pom named Symcox, who vaguely reminded me of an arrogant cricket commentator. He talked about Julie rather than to Julie. He discussed her condition like he would a batsman with a problem playing leg spin. He was all knowledge with no compassion; all answers without empathy.

Symcox's recommendation was that we immediately commence a dramatic and radical course of chemotherapy. We had discussed the possibility of chemo with Professor Dan that day and he had advised against it. I knew Dr Renton would as well. I nodded in agreement, allowed him to make an appointment knowing I would cancel it, and we drove back to Goulburn.

We didn't arrive home till 9.45pm. It had been a long day, with what I thought

were inconclusive outcomes and findings. I wanted to talk with Professor Dan candidly, without Julie being there, to give me a more definite prognosis. I had that conversation a week later on Tuesday, 6 April. Six months was his best guess, and I had been right about my own disappointment. Although Professor Dan had spoken about “the best possible result we could hope for”, his eyes in the consultation had told me a different story. He confirmed to me that he had been dissatisfied and frustrated with virtually every aspect of Julie’s surgery and progress.

Professor Dan asked me how she was doing. I told him that it varied but the periods of emotional instability were becoming more frequent, she seemed to be a bit weaker lately and her cognition skills were slipping further.

“Three months.”

He followed that with the usual caveats about the unpredictability of the syndrome, the variable rates of growth and the areas of the brain, which could be affected, by the oedema and the tumour. The bottom line was that she had a very large, unstable mass, and what would happen next was largely a matter of the way in which the tumour would arbitrarily develop. He apologised to me and gave me his sympathy.

I steeled myself and rang Mother and Father. Father took the call and thanked me. Julie was outside working Biscuit and she had three months. I didn’t know what to do next, so I went and fed the horses.

Julie felt as confident as she would ever feel when dealing with horses, brain tumour or no brain tumour. I wanted to be able to comment and discuss Biscuit’s progress. I tried to anticipate Julie’s needs. She could not be allowed to fail because her perception of failure would cut to the core of her being and she would interpret problems with Biscuit as an indication that the ravages of the tumour were more severe than she anticipated.

Julie brought him along through the established steps and increments, anticipating both his resistance and compliance. Julie had done this so many times it had become part of her reflex responses. It was a strange process: automatic yet considered, reflexive yet measured, instinctive yet designed. Julie had spent thousands of hours with scores of horses watching and anticipating; training them with diligence and affection. Biscuit wasn’t her finest hour; he was her bravest.

The work with Biscuit rolled along. Slowly. And I watched Julie degenerate. Quickly.

Julie only rode Biscuit once. It wasn’t until 10 May. Julie’s condition had

worsened to the point that she was pathetically weak. She could not get on him. The tumour and the drugs had debilitated her to the point of being an invalid.

I made her get on.

I didn't say anything as she worked Biscuit in the arena on the lunge. I just thought it was now or never. It was past the point of danger. By early May, I knew Julie was dying. Her physical deterioration and her worsening psychological health were frightening. I went into the shed and found her riding helmet and the reins for the bridle. I went over to the house and found stirrups and stirrup leathers, which had been stripped off the saddle. Biscuit was now working in a saddle. He had become reliable enough that Julie's valuable saddles were used rather than the roller.

I threw a lead, the reins, stirrups and leathers over my shoulder and carrying the helmet under my arm I went into the arena and asked her if she wanted to get on. Julie looked at me with uncomprehending uncertainty.

"Just take him for a pony ride," I urged. "I'll lead him."

There would be no more *piaffe*, *passage*, *renvers*, canter half pass or multiple flying changes. Julie would never ride those again and I knew it.

We put the leathers and stirrups on and roughly adjusted them for her. Julie's usual precision in fiddling with the length of her leathers by small increments would not be needed. I adjusted them "short" so her boots would be firmly in the stirrups, giving her reassuring support. She already had her gloves on, but her usual meticulous attention to detail with her gear drove her to fine-tune and change the gear till it was to her satisfaction. Biscuit stood patiently through this, which took five minutes or so. He wasn't working, standing here was an easy gig.

Julie could not get on. When we finished with helmets and saddlery, Julie held Biscuit while I went for a bucket so she could mount. She was so weak she could not lift herself on to the bucket. Julie was just about in tears with frustration. She had gone from being hesitant about riding Biscuit to being fervid with anticipation, even if it was only for a pony ride around the arena. I went over to the machinery shed without really knowing what I was looking for. I was desperately trying to think what we could use for Julie to get on. A ladder would do it, but there was no way Biscuit would stand there while a stepladder was set up next to him.

A garbage bin. I turned the plastic garbage bin upside down and hopped up on it. I bounced up and down and it buckled a little, not much, and I was much heavier than Julie.

I grabbed the bin and jogged out to the arena, trying not to move too fast. I didn't want to startle Biscuit, but I needed to hurry. Julie's endurance, patience and strength were fading. She was becoming discouraged and emotional. I needed to rush in slow motion.

I set up the bucket with the garbage bin next to it. I held on to Biscuit and Julie put her left foot on the bucket. Her right leg was useless because of the kick from Seismic and I lifted her up on to the bucket by sticking my right arm under her crotch and lifting her up while she put her left hand on my shoulder to steady herself and pushed up as well. With much grunting and straining on both our parts, she made it. She then kept a hand on my shoulder and made the step up to the upturned garbage bin, which was level with the stirrups. Biscuit was only little. It was high enough. She would get on.

Julie stepped into the left stirrup and I half threw and pushed her arse across the saddle. She was on. Biscuit had stood there through this whole ordeal. Julie wanted me to move the bucket and the bin. I couldn't. Even though he was quiet, this was Biscuit's first ride. If he got a fright or just decided to ping off, Julie would not have the strength to control him. I just pushed him away from the bin and the bucket and walked away. It was a big arena. I could avoid them.

All the nervousness was gone from Julie. Her intuition allied itself with the rhythm of Biscuit's walk. The cadence of his walk became the tempo of her being for the next 15 minutes. She put her seat on Biscuit and began with the subtle shifts in weight and the light touch of her leg to attempt to communicate with him. Julie's concentration was fiercely intense. A small half smile tempered by her intense focus spread across her face. No *Grand Prix* dressage horse was ever ridden with such devoted focus for that quarter of an hour. Julie had begun to feel that she would never get on a horse again. I had made her. Maybe it was foolish, I didn't care. She needed to feel the movement of a horse beneath her; she needed to feel alive again. For this time she was. She murmured directions to me. "Right." "Straight." "Another circle." "Change rein."

Julie was in heaven. She was riding. Circling to the right was hell for me because Biscuit was on the inside circuit to me and I had to power walk to keep up with the desired pace. Julie kept track of the bin and bucket, not wanting to disturb Biscuit's fragile attention. They were a unit. He felt her. She subtly adjusted her weight and put her seat bones on to his back. He responded and the half smile became a grin. She crooned, "Good boy!" repeatedly to him and slid a hand up his neck to pet him. The haunting uncertainty of her health faded with the reality of this little horse under her. All the hours that Julie had spent in the arena were worth it. She had broken this horse in and he was good.

After 15 minutes I suggested to Julie that it was enough. My legs and back ached with controlled tension. I was deathly afraid that Biscuit would shy, that Julie would become unbalanced and chaos would follow. She nodded in silent agreement and she slid off. She made a fuss of Biscuit and took him from me while I had to go into the fridge in the shed and get a double handful of carrots. Her eyes were shining.

We unsaddled Biscuit in the wash bay and Julie gushed about how well he had gone. I put him back into his paddock with his rugs on. It had been the perfect day to ride him. No wind. Clear sky. Perfect conditions. Julie was too tired to walk him back to his paddock. I met her at the house and she looked at me with those piercing blue eyes and hugged me and thanked me with such sincere gratitude I was moved to tears.

Julie never rode Biscuit again. She would only live for another 12 days.

That day remains one of my most treasured memories. We were never closer.

CHAPTER EIGHT: DECLINE

By the first of May, I knew Julie was dying and that it would be sooner rather than later. The inevitable consequences of mitosis, the cruel calculus of exponential cellular division coupled with the destruction of neurons and nerve tissue had transformed from slow erosion to a collapse. Our avalanche had begun. The process had been so gradual it was like a truck driver losing control of his rig when a gentle hill becomes a steep mountain by such slow degrees that he is lulled by the ease of the transition and loses focus. His momentum out-paces his control and he must ride the juggernaut praying that the incline will end.

I knew that our descent would only worsen but I felt out of control. The changes that had taken place in Julie's personality were subtle and profound. The *dysphasia* had metamorphosed into *dementia*. Her problems with cognition had become hallucinatory apprehension. Her emotional distress had become psychosis. The basic elements of her character were still there: she was as sweet, as kind, as loving and as charitable as ever. Those essential elements were now filtered by the chaos in her mind caused by the tumour and the long-term steroid usage. We were exquisitely poised on the horns of the classic dilemma regarding the use of the *dexamethasone*. If we stopped using the *dexamethasone* the swelling and the oedema would run rampant. Julie would become increasingly dysphasic, nauseous, and would probably eventually lapse into a coma. The continued use of the steroid would keep her alive, but in this largely altered state. We were no longer living day to day; it was now minute to minute.

Julie continued to do the things she wanted to do with the same rigid and dogged determination. She worked Biscuit; she drove the ride on-mower; she cleaned stables; she worked with the young fillies we were teaching how to lead. I watched her drag herself to these tasks, sometimes looking haggard and drawn, despite the puffiness and the 'moon face' symptomatic of prolonged cortisone use. Julie had gained 10kg since she was diagnosed. When we had married she was a waif, weighing only 49kg. Through her 20s, 30s and 40s this had levelled off at about 53kg, still very slim and trim. The *dexamethasone* stimulated appetite and caused stomach upset. The kind of gnawing, craving and insatiable "I had 12 beers last night, and these two quarter pounders, large fries and shake will settle my burning ravenous gut" hunger. She couldn't control it.

Her uncle came with a gorgeous Poppy Seed Cake from an elegant patisserie. After he left she ate four pieces, smearing the orange icing all over her face and letting it mix with the tears of anger and frustration. The rest of the cake sat in the cupboard till it went mouldy and was then thrown out.

Julie became obsessed with order. She progressively worked her way around every closet in the house going through its contents and choosing what to keep and what to consign to the rubbish bin. I sometimes helped her, but most of the time let her do what she would. On 11 May she started on the linen closet while I did some paperwork. Vicki wanted to take Julie on a trip down the coast to visit Mother and Father for a few days. Sandra would also go. Vicki thought it would be beneficial for Julie to spend some time with Mother and Father and that it would also give me a break. Since she had been diagnosed, except for a couple of afternoons when she'd gone to the movies or spent some time with Steve and his kids, I had been with Julie 24/7. I spent the morning exchanging e-mails with Vicki telling her Julie's medication regime and also how she would have to deal with her.

I was waiting for Vicki to reply to an e-mail and went downstairs to see if Julie needed a hand. She was sitting on the floor of the hallway amidst the contents of the linen closet. All the towels, face cloths, sheets and pillowcases were stacked in an orderly manner around her. She was looking bemusedly at the empty closet. I asked her if she needed a hand and she cheerfully replied, "No, I'm just deciding how to arrange things."

Julie had all of the linen arranged according to size. All the beach towels, bath towels, hand towels, face cloths, sheets and pillowcases precisely arranged by type. I commented that was a job well done but she was looking at her work with puzzled dissatisfaction. "I'm not happy with that." She began to systematically remove the contents again, stack them in her orderly piles again and reassess how she wanted the closet to look. I went back upstairs to the computer.

I came down again in about 15 minutes and Julie had restored the contents of the closet but this time everything was arranged by colour. The rich blues and bright pinks along with the sterile whites and restrained browns were on different shelves regardless of type. Pillowcases were with beach towels. Bath towels of the same set stacked neatly with the face cloths. I again commented that everything looked orderly and tidy. She again shook her head slowly with silent discontent and began to remove the linen for a third attempt. I went back to the computer.

I returned in another 10 to 15 minutes and Julie was back in her original position: sitting cross legged on the floor surrounded by a rich rainbow of linen trying to find symmetry and order in its arrangement. I asked her how she wanted to put everything back and she shook her head this time in slow bafflement. Discontent and the desire for order had been replaced by confusion and

bewilderment. Julie wasn't angry. She was mystified.

"I was trying to do something...I had an idea..."

Her words trailed off in silent perplexity.

"Do you want me to give you a hand?" I asked.

She smiled brightly. "That would be so good," she replied cheerily.

I started to stack things back in the closet by type. She watched me for a moment then apologised for feeling tired and said that she wanted to have a little nap. I just nodded and she went off to bed. I finished and went in to check on her and slid into bed next to her and when her eyes opened, I told her I'd finished.

She immediately bounded out of bed and went to look.

Face wreathed in smiles, she pronounced my work, "Lovely, amazing, fabulous!"

Her notation in the diary was, "Linen closet a disaster!"

This was the runaway truck I had to ride with Julie. She poured milk into the fruit bowl rather than the cereal bowl. She would ring people, forget that she had, and immediately call them back. She would ask me things not just once or twice but up to a half a dozen times with the insistence of a kid asking about Santa on Christmas Eve. But she was still amazingly sharp. She would remember things I would forget. She would tick off a list of necessities for our frequent trips to Sydney with the precision of a quartermaster: mobile phone, answering machine on, computer off, cold drinks, money, referrals, you name it. I couldn't name it, I would forget. Then before we would go she would be in an agony of indecision about which hat to wear.

When Viv came to visit in late April, she was appalled by Julie's condition. I suppose the difference was so dramatic. I had told Viv back in February that Julie was probably dying, but she read my e-mail bulletins and clung to the same hope we all did: that somehow Julie's strength, Dan's regime and providence would intervene. By late April it was obvious to Viv that my former warning was accurate. Julie was tired, still chirpy as hell, but the previous few days had been hectic.

When Viv arrived Julie was worn out by activity, exhausted by shopping and visits from the family: dysphasic and haggard. The physical contrast from before was marked, profound and shocking. She asked how Julie was and I levelled with her.

"She's dying." I said flatly.

Viv's eyes filled with helpless tears.

"None of that please, Viv." I implored. "We need to stay positive ..." I let the

phrase tail off.

Viv and I talked about what was going to happen and I told her that from here on in things would not be so cheery. Julie was becoming physically debilitated, mentally impaired and it would become worse. Viv asked me how I was coping. I shrugged my shoulders. I was coping. I tried to explain to her that Julie was amazing with the working of horses, housework and property maintenance.

“What’s going to happen?” Viv was beside herself with worry and fear.

“Ugly things, very ugly things.”

Julie had insisted I show Viv Psychic because she was so proud of him. I had ulterior motives. I wanted Viv to have Psychic. I’d already thought about placing the horses and, because Psychic was unique, I thought it the perfect home.

“Viv,” I pleaded with her, “He’s special.” I tried to explain the inexplicable. Somehow, Julie and I both knew that this horse was different. Julie adored him. I knew I could demand substantial money for him. I didn’t care about \$4000 or \$5000, I wanted him to go some place where he would be valued and appreciated. I knew Viv needed another horse. I thought that Psychic would fill the bill and he would go someplace where Julie was loved.

Viv agreed to take him without really knowing why.

A year later she would refer to Psychic as “the wonder horse”. Everything we thought about him proved to be true. Viv would later maintain it was Julie guiding the horse. I have no reason to disagree. She also said that every time she looked at Psychic she thought of Julie.

On Friday, 14 May, Vicki and Sandra wanted to have a day in Canberra with her, another girls’ day out. In their infinite charity they wanted to participate in Julie’s care, and part of that care was to give me some respite.

The plan was to have lunch and then go to a movie followed by a leisurely drive home. They went to see *The Girl With a Pearl Earring*. Vicki thought that Julie didn’t understand much of the plot, but she knew it was a love story with very refined camera work and beautiful music. Lunch in the leafy Canberra suburb of Manuka was amiable and pleasant and Virginia, who was in Canberra for business and to see her daughters, joined them. Julie arrived home wreathed in smiles with Sandra and Vicki. She gave her standard pronouncement that the day was “lovely, amazing, fabulous”. It was probably her last really good day.

We attempted to pack for her trip to Mother and Father but Julie had trouble deciding what she needed to take. What type of clothes along with simple matters like how many sets of underwear to include left her in an agony of indecision.

Familiarity doesn’t only breed contempt; it breeds a type of impassivity. I was

so close to Julie and the transition from existing in the short term to living in the moment was so gradual I was not aware of it. It is only with the perspective of time that I can identify when the situation changed from living with Julie to managing her; when the paradigm shifted from dealing with the illness to the illness dominating the situation. I had given up the outer walls of the castle and I had retreated to the castle keep for the end of the siege.

Monday 17 May was a lovely day, but the weather forecast was that a change was coming through, possibly bringing rain, but definitely lots of wind. Julie was worried that I would have too much to do while she was visiting and I had to persuade her gently that I'd be fine. In the middle of packing she was struck by a bout of weeping. I kept asking why she was crying, but she would not tell me. She sobbed quietly and I tried to discuss what I was packing for her trying to ignore the crying and being terribly cheerful about what a great time she would have with Mother, Father, Vicki and Sandra. She would only nod mutely or shake her head at what I packed for her.

The muted crying persisted on the trip into town to meet at Sandra's. About five minutes from Sandra's she burst out that Vicki and Sandra were angry with her because she had not paid for her lunch on the previous Friday in Canberra. Her three best friends had split the tab to shout her lunch and she perceived they were offended by her negligence to pay. The quiet weeping became a sustained outburst of crying and I pulled the car over to try to console her. I only managed to quiet, not quell, the crying.

When we arrived at Sandra's, Vicki was already there, transferring her gear to the back of Sandra's Forester. Vicki was immediately worried about Julie's upset. I told her as briefly as I could what the cause was and advised her to ignore it. Vicki wanted to talk it out with Julie and settle the matter but, thankfully, followed my advice. Julie would not deal with the issue logically and any mention of it would only cause more problems. Ignore it, talk with her cheerfully and, hopefully, it would pass.

So the three friends set off. I hoped the trip would go well and I promised Vicki I would call her in a couple of hours to see how it was progressing.

The trip did not go well. Vicki attributed Julie's continuing distress to being away from the familiar environment of the farm and me. I talked with Mother and Father and told them I was contacting Dr Ruth about Julie's anxiety and dementia and they concurred with me that some type of medication might help her. I called Ruth, who promised to investigate some alternatives without delay. She called back in the late afternoon and told me that after discussions with both a gerontologist (an expert with dementia) and a psychiatrist (an expert with panic and anxiety attacks) the advice was that Julie start on a medication called *Zyprexa*®. It was used for psychiatric patients with schizophrenia and bipolar

disorder. That gave me pause, but what I had seen over the last couple of days did as well.

I made an appointment for Thursday. Ruth's surgery was closed on Wednesdays. Vicki rang me and told me they'd be returning on Tuesday. Julie had experienced a very bad night, and I assumed at the time Vicki put her foot down with Mother and Father who would've wanted Julie to stay. I was wrong. It was a communal decision.

I met them outside the grounds of Trinity in the late afternoon. Vicki looked haggard and distraught. Julie looked fine and chatted gaily with Sandra while the two of them fussed over transferring Julie's luggage from one Subaru to another. Vicki looked at me with worried compassion and said, "I don't know how you're coping."

I just laughed and shrugged my shoulders. I tried to allay any idea that Vicki might have that somehow they'd mismanaged the trip. I just said, "You're probably right. She just feels more comfortable at home."

I rang Mother and Father to let them know Julie had arrived home safely and was comfortable. I didn't tell Julie, but I put the maximum dose of the sedative Dr Renton had prescribed in her evening herbs from Henry and put her to bed early. We sat up in bed while she began to doze off and I promised her that we would paint the verandah tomorrow. She asked in detail about the horses and I promised her that all had been well. She thanked me drowsily for dinner and repeated her two mantras: how lucky she was and how she had "lovely, amazing, fabulous" friends, family and a farm.

I let her drift off to sleep then rang Vicki and assured her that Julie was home and resting. Vicki's distress was as palpable as Julie's attacks. Her best friend was so ill and there was nothing any of us could do. I tried to reassure Vicki about the new medication and how that would at least ameliorate the hallucinations. I was saying it more in hope than in expectation. The level of torment was about to ramp up exponentially.

I was up early the next morning, Wednesday, 19 May. The next few days were flawless Indian summer days: crisp clear nights which were chill without being cold, followed by warm sunny almost windless days with a few high, fluffy, cumulus clouds to give the sky depth and perspective. I slipped out of bed on a perfect Wednesday morning and worked my way round the horses, feeding, allowing Julie to sleep in and rest. Today would be a far better day. The weather was perfect for painting the deck. We would get that done.

Just as I was finishing, I saw Julie was on the verandah putting on her boots.

I waited down by the gate to the paddock by the stables. As she approached, my own sense of ease vanished. Julie was wide-eyed with panic and teetering on the edge of hysteria.

She took my arm and said to me, "I'm evil."

I just stared incredulously. I had not expected this. "Don't be ridiculous!"

Julie wagged her head from side to side in sad denial. "No, I am."

This was our absurd conversation for the next few minutes: I trying vainly to reassure her of her innate goodness and worth, her insisting that she was transcendently "evil" and had been inflicting great hurt on everyone who made the mistake of loving her.

I tried a different tack. "How do you know you're evil?" I countered.

Julie looked at me with her incandescent blue eyes reflecting naked sincerity. She grabbed my forearm for emphasis, and with her voice quavering with guilt and sorrow, told me, "The voices tell me. They know everything about me."

I don't remember what I said; I was quailing with fear and desolation. I wasn't afraid of her, I was afraid for her. I had no strategies for this: psychotic whisperings that Julie was hearing were providing a subversive and seditious counterpoint to the soundtrack of the present. I was left wondering how long this had been happening and the pathetic voice of my inner self just kept repeating, "What the fuck am I going to do? What the fuck am I going to do?" while I gently led her back to the house to make breakfast, all the time mouthing mindless comforting platitudes while she told me of her illusory wrongdoing.

I sat down with Julie after breakfast and we talked about the voices. She knew they weren't real, but their persistent presence in her interior self gave them a veracity, which she couldn't deny. They knew everything about her, while I could only try to overcome the tortured logic of hallucination with sweet reason.

The key incident down the coast was "a man" had come into her room and told her that she was responsible for the death of Sandra's father, Cliff, 10 years ago. Cliff was a gregarious battler who had died of leukaemia after a long illness. I tried to refresh Julie's memory. Didn't matter. If he had died of leukaemia, that was only a symptom, an element. The real cause was Julie. The man had told her.

I knew "the man" was just her father checking on Julie. I didn't even bother to bring it up. She would have worked herself up about her father somehow becoming tainted and added another care to her burden.

After breakfast, we made a list of principles she agreed to follow. It seemed to reassure her.

- *Ignore voices in head*
- *I'm a good person*
- *I love my husband*

- *I love my family*
- *I love my friends*
- *I try hard to be and do good*
- *I will make mistakes but I will make it right*
- *I forgive people and they will forgive me and I will forgive myself*

This last point troubled her. The insidious whispering siren's voice insisted her sins were so vile a just God would find them too hideous. After an hour, she seemed happier. I don't know if I convinced her or if the voices were just taking a coffee break. It was more disturbing than anything that happened that terrible weekend at the hospital.

We spent the rest of the day painting the verandah and that went splendidly. We worked in perfect conditions exchanging little pleasantries. Julie sought the validation she always needed when doing unfamiliar things. By early evening we had finished and I cleaned the brushes, applicators and trays and put them in the truck. The job looked so good we thought we might give it another coat in the next few days. I told her it would be best to leave it for 48 hours to let it dry thoroughly. After we showered and still smelling of oil, we stood at the front of the house and admired our handiwork in the gently dimming sun. Julie was buoyed by the effort.

That night was hell. We had been watching forgettable TV, when Julie began to weep. She sadly told me about the evil again. It was permeating her being. She was now capable of transmitting iniquity just by sight and refused to look at me. She touched me and gasped with horror and said she could feel surging wickedness infecting me. I tried to divert her by telling her Dr Ruth would help us and told her about the plan for the following day. We would get up, do our Chi Gung, have breakfast, feed the horses... I wasn't able to go any further, she shrieked with horror.

Julie was afraid she would harm the horses through their feeds. She began to wail with despair and hyperventilate. I managed to settle her, and the thought went out of her mind for a moment and then returned with redoubled intensity. I didn't know if her distress would precipitate a seizure. We had been spared seizures, fits or convulsions up to this time. It was one of the small blessings. Dan Reich had been beset by scores of seizures. Even with the *Epilim*® acting as a prophylactic, I was deathly afraid that Julie's distress would trigger a bout of convulsions. I found a paper bag in the wardrobe in the next room, dumped the contents on the floor and told her to breath in and out of it. I had seen people on TV shows give patients a paper bag. I had no idea what else to do. I found out afterwards that it was a myth and improper treatment but, thankfully, Julie focused on that while I rang Palliative Care. They had told me to call them if

there was trouble; I thought this fitted the definition.

They had nothing to give to Julie. They contacted Dr Renton, and within minutes, had arranged a prescription for *Xanax*® which would counter her anxiety attacks. Julie calmed herself when I told her that Palliative Care was coming to help. Julie wanted help. We somehow endured the time waiting for Pal Care to arrive. I was very careful not to touch Julie. She was deathly afraid that she would harm me. Rosie from Pal Care arrived with the script of *Xanax*®. She administered an injection, to which Julie compliantly agreed. Rosie implanted a butterfly cannula on Julie's collarbone and left me with five syringes of medication in case she had another outburst in the next few days. After an hour, Julie had relaxed. She was chatting cheerfully with Rosie and gave her a hug as she left.

I called Mother and Father and told them what had happened. I could not speak candidly in front of Julie. She had wanted me to call Mother and Father to reassure them that she was now better. She had some presumption that Mother and Father would know she was distressed and I needed to call them. She spoke to them briefly and told them she had been "upset" but now everything was fine. Pal Care had come and they were, as usual, "Lovely! Amazing! Fabulous!"

I spoke with Father, who asked me what was going on. I told him that what was going on was to be expected, but it didn't make it any better when it happened. Julie was fine now, and when we had her new medication sorted out she would be "better". Julie smiled happily and nodded her approval. What followed was both frustrating and upsetting. Father told me, point-blank, that the following Wednesday, when her next visit with Professor Dan was scheduled, that she must have an MRI. I just told him that I thought it was a lousy idea. He sounded tired, anguished, drunk with the shared agony of a father. I had experienced this conversation previously. I couldn't believe it. Did they need to see the spreading mass on the Rorschach test of the MRI to know what was happening? I had previously explained to Father that if Professor Dan gave Julie an MRI he was legally bound to discuss the results with her – dementia or no dementia. If we were trying to maintain our strategy of withholding from Julie the rapidly advancing terminal nature of her illness, than there could be no MRI. We knew how the game was going. Did they really need to know the exact score?

Mother and Father seemed to have no idea of the legalities of modern medicine. They seemed phaselocked in a gentler and less litigious time. She was a middle-aged woman who would be told the truth by Professor Dan. I had discussed this with Professor Dan who told me if he thought she was slipping badly, he would send us home with benign advice to maintain the sliding status quo. It was an ugly, contentious conversation, made more difficult by Julie, now tranquilised, gently smiling in the background, unaware of the content. Loaded on *Xanax*®.

Back in February, Mother and Father had contacted Professor Dan's rooms

after our first initial discouraging postoperative consultation demanding from the receptionist that they be given access to Professor Dan and that he give them the analysis he had given me. I only found this out in March when Peta, the receptionist, had complained quite crossly about how abusive Mother had been but the argument about maternity had not cut any ice with Peta. I had apologised profoundly to Peta, sent a letter giving Mother and Father access and clearance to discuss Julie's case with Professor Dan and then called them and told them I had done so.

I could not dissuade them from insisting on the MRI. Father's contemptuous assertion was that if Professor Dan "was any kind of a doctor" he "could get round" having to discuss medical results with a patient.

I terminated the conversation and talked with Julie for a while. She was feeling drowsy. I lifted Rose the whippet, onto the bed, who promptly settled down against Julie's hip, and she began to drift off to sleep while absently petting Rose.

I felt like Popeye who, when subjected to one too many indignities would growl, "I can stand so much and I can't stand no more." And then reach for his can of spinach. I needed to set the record straight with Mother and Father. There had been too much meddling, too much suspicion, too much distrust. On 11 April, Julie had hit the wall taking to her bed and refusing to get up. I asked them to come up and they did and I could remember hugging Mother with gratitude and thanking her as deeply and sincerely as I could. I had thought that perhaps a breakthrough had been made that day; that we were working together. I realised later that my calling them on that day only demonstrated to them how unsuited to the task I was. I imagine they rationalised away Julie's problems two days previous. With time, they would have made her happy and well, believing I never could.

I went upstairs and wrote a long letter. I tried to level with them that for the short term we must work together but that I did resent their obvious mistrust and suspicion. The bottom line on the neurosurgeon's consultation scheduled for the following Wednesday was that if Professor Dan recommended an MRI, she would have one; if he didn't, we wouldn't. I didn't think they could disagree with that strategy.

We saw Ruth the next day with Julie quaking with the anxiety of the visit. Ruth talked with her and Julie's responses teetered on the brink of hysterics. She screamed at Ruth in warning at one point that something evil was running across the floor of the office. I had cautioned Ruth about Julie's reluctance to touch anyone and Ruth refrained from her customary hugs. Ruth wrote the

script for *Zyprexa*® but wanted some precautionary blood tests to test whether an infection from Julie's leg could be causing the delirium.

I asked Julie if I could give blood while we were in pathology and she snapped into focus for a moment and declared that a good idea. I thought if she recoiled at having a needle inserted, seeing me doing the same would possibly allay her fears.

I had my brief private interview about whether or not I had tattoos, had been to Rwanda or had AIDS, when a horrible wailing came out of the waiting room. A nurse, the very same nurse who had tended to Julie all those years before when Apparition had kicked her so savagely and who now was a parent whose children were at Trinity, had stopped to talk with Julie. She screamed, "I don't want to hurt this woman!" repeatedly, trembling with fear, recoiling with dread and refusing to look at someone who she knew well.

I calmed Julie and told Jane, the nurse, that she was worried and upset. She recognised Jane and turned to me and said quietly, "Don't let me hurt her!" I told her that Jane was safe because she was a nurse. This seemed to placate Julie and she allowed the blood to be drawn without demur, but avoided eye contact with anyone.

I had a problem. I needed to fill the script for the *Zyprexa*® and I could not imagine leaving Julie in the car while I did it. I would need to take her with me. Julie was afraid of walking through the main thoroughfare of the mall. She told me to hold on to her and said she would look down and not talk to anyone. I had never before felt so alone and so desperate in a building full of people. At the entrance to the mall one of Julie's colleagues saw her and started to make a beeline for us. I shook my head violently and they slowly halted as we shuffled past. Halfway up the mall one of Julie's favourite students stopped in our path. Julie refused to look up. I tried to say as kindly as possible that Julie was most unwell and couldn't stop, even for a moment, to talk. The girl was devastated by what she could see and the perception of rejection.

I guided Julie to the traditional chairs for waiting in the chemist and grabbed one of the shop assistants. I told her to inform the pharmacist what was being prescribed and to fast track the script. The assistant knew what *Zyprexa*® was and it was filled in what seemed like seconds.

I took Julie home and in the fading light, she wanted to go for a walk. I insisted on going with her. I had no idea what she would apprehend in the eerie half-light of dusk. We went for a brief stroll, but she was so tired that a hundred metres after we began, we finished.

I cooked eggs for dinner. It was the only thing in the fridge. There had been no thought of shopping.

On Friday we had an appointment to see Dr Renton. This was another source of conflict with Mother and Father. They insisted that Julie must see Dr Renton, but they could not really give me a reason for their insistence. The only reason Father could give me was that “she needed to have a little talk” with the doctor fortnightly. This was exactly what would happen each visit. Dr Renton would ask Julie how she was feeling and, by and large, Julie would rely on me to answer for her and Dr Renton would examine her in a perfunctory manner. He would listen to her heart and chest and take her blood pressure. I would enquire about her medication and the respective dosages and that would be that. Dr Renton had extensive commitments at the hospital and he would invariably run late, sometimes for as long as two hours. Dr Renton told me that he really did not need to see Julie. We knew what the problem and likely outcome were to be. Why should Julie spend all her time seeing doctors?

Mother and Father would not be deterred.

Our appointment was scheduled for 1.30pm and Dr Renton’s receptionist, Colleen, told me to ring to see how far he was running behind before we made the half-hour drive into town. Julie seemed relatively rested this morning and we fed the horses, did a few chores and showered before heading into town. Before I could ring Dr Renton’s rooms, Mother rang. She asked if she could accompany us into the appointment. I joked that she would have to hurry to get there, as the appointment was only an hour or so from now. Mother informed me that they were already in town. They hadn’t told me they were coming. I had no choice but to agree to her request.

I told Julie that Mother and Father were meeting us in town and we would have lunch at a café across the street from Dr Renton’s rooms. With that I called his rooms and was told he had been held up at the hospital and would be at least an hour late, probably later. Julie appeared to be slightly agitated by the news that Mother and Father were going to be there. She always felt under pressure to please them, but she was calmer than she had been the day before.

My hopes proved to be premature. On the drive into town, Julie worked herself into a frenzy about the cannula, saying that it had to come out, as it would allow the omnipresent evil to find a way into her body. I grabbed her hand as she was reaching under her blouse to tear it out and only stopped her when I convinced her that Dr Renton would have a look at it.

We met Mother and Father at the café. Julie was feeling more relaxed, but obviously hallucinated about something as she shrieked at one point and Mother began to fuss. Mother’s theory was that if you distracted Julie she would not be able to focus on what was troubling her. I usually tried to talk her through it. I left Julie with Mother and Father and checked with Colleen. It would be at least 3pm for a 1.30pm appointment. I could not complain. Dr Renton had spent a

great deal of time with us at the hospital.

Lunch was a forced affair. Julie was right on the edge. Her face was flushed and Mother could not restrain herself. Julie could not follow her prattle. It washed over her, but I remember looking over at her with her eyes staring wildly, her face flushed and puffy with angst and her voice shrill, anxiety charging her every word.

We decided to go for a walk in the park and I walked with Father. I told him that I had not changed my mind about the MRI. He refused to discuss it. Their plan was apparently to follow whatever advice Dr Renton gave. It was a beautiful day again. The deciduous trees in Belmore Park were shedding their leaves and the warmth of the sun contrasted with the gentle chill of a benign autumn afternoon. I remember looking at Julie's back and wondering what she was thinking, how she was feeling, whether or not she would cope. Unfortunately, like many of the psychotropic drugs, dosages of *Zyprexa*® had to be increased progressively till a therapeutic level was reached and this would take 10-14 days.

We sat in Dr Renton's waiting room from about 3pm till sometime after 4pm. The only positive was that Julie was not exhausted. She sat quietly and I think Mother finally realised that allowing Julie to rest quietly was probably the best alternative. Father excused himself and went to the hospital to give blood. Father had been a regular and prolific blood donor for over 30 years.

When we finally saw Dr Renton it did not take Julie long to rev up again. I gave Dr Renton the rundown on her progress since the last appointment. I told him about the visit with Ruth the day before and queried him about the efficacy of the *Xanax*® which he had prescribed as opposed to the *Zyprexa*® prescribed by Ruth. He conceded that the *Xanax*®, would quell the anxiety and relax Julie, but would do nothing to ameliorate the psychosis and the hallucinations. I told him that Julie was quite concerned about the cannula and would he please have a look.

Julie began to hallucinate. I'm not quite sure what she said, but it involved something which she perceived in the room. With that and the obsession with the cannula she screamed that she could take it out there and then and started to reach under her blouse to wrench it out. Dr Renton and I calmed her and he said if it was upsetting her he would take it out. He removed it behind the screen in the office and did his usual ritual of heart, chest and blood pressure. I told Dr Renton that she had an appointment with Professor Dan the following week and the intention was to have him examine her and he would decide about the aptness of an MRI. He nodded in concurrence and I thought we could swiftly withdraw.

Mother could not leave it at that. She spoke not of Julie's needs but of their need to "know" what was occurring. Julie began to shriek again at something Mother said to her, and I seized Julie's hand and tried to talk to her. Mother tried

to explain her technique and said something about how “like with little ones” if you “distracted” her, the hallucination seemed to pass. I hated both treating Julie as a child and talking about her in her presence. Mother began to question Dr Renton about Julie’s prognosis and the MRI and she could not stop herself. She took over the consultation in much the same way as she did down at Concord.

She eventually pressed Dr Renton to say that we knew, what the “inevitability” of her condition was. I couldn’t believe it. I had been desperately trying to withhold that fact from Julie and Mother was sitting there smiling now content that the doctor that they trusted had told them in front of Julie what I had told them repeatedly.

I don’t know how much Julie picked up on this conversation. I don’t know just what she comprehended. Julie was psychotic; she would hallucinate constantly; she was teetering on the edge of hysteria. Julie was neither obtuse nor stupid nor dense. I was cringing about what she would have gleaned from the dialogue. I was also furious and just about grinding my teeth with rage. I had guarded her serenity and peace like a Rottweiler and now her own mother had compromised the integrity of my pitiful secret.

We made our goodbyes and I took Julie to the car. She was spent. The claustrophobic, cluttered nature of Dr Renton’s office frightened her, and by the time we left, she was right on the brink of frenzy again. The shopping would again have to wait.

I drove straight back to Bannister and Julie took to her bed. The days were getting short. I fed the horses at dusk and sat up next to Julie while we talked. We had visitors coming on the weekend and Julie was worried about facing them. Virginia was coming through on the way to Canberra to see her daughters, and Dr Ruth was coming for lunch the next day bringing a quiche and a salad. We discussed what we would do, and I hit upon just listening to music with Ruth. Julie seized on that. Would she be able to do the same with Virginia? I assured her that Virginia just wanted to sit with her to demonstrate her love and friendship. The music would be fine. This calmed her and she rested while I made a tuna casserole. I had always been the cook in the house. Our family joke was that as a cook, Julie was a great rider.

Julie had a request that night. She needed “space” she said.

“Everyone’s at me! You’re at me, Mum’s at me, doctors are at me.”

I asked her what she wanted. Time, on her own. One of her habits was to occasionally go for a solitary drive and walk. Julie knew she could not drive and asked if she could have some time on her own. We looked at the calendar and I needed to get some bits and pieces for the property for some minor repair jobs. I would go to Canberra the following Monday and she would have the place to herself to go for a walk around the horses, out the back of the property and down

to the big dam. It was such a modest request I could hardly disagree.

She downed “Henry” which I had spiked with her sedative, the maximum dose. It had been a taxing day. They all seemed to be lately. The prospect of time on her own cheered her; she seemed in much better spirits. We sat up for a while till she felt sleepy and I kissed her goodnight. I slipped upstairs and indulged in one of my rituals: watch the first half of the Friday Night Football and fall asleep for the second half. I went to bed late and reached over and squeezed Julie’s hand. She did not respond. She was sleeping very, very soundly.

CHAPTER NINE: JOURNEY'S END

*It's so easy to slip
It's so easy to fall
And let your memory drift
And do nothin' at all*

I've always found great solace in literature and music. I became an English teacher because my love of literature precluded any other career path. Literature and music provided a lens through which the vagaries of life could be explained, evaluated or, in some cases, remain ambiguous. Only my very best students ever really understood what I meant when I told them: "The ambiguity in the work is its greatest strength."

Easy to Slip from Little Feat's seminal "Sailin' Shoes" album has always been one of my favourite songs. The lyrics are simplicity itself, but Hemingway would have loved it. There is an ambiguity in its unadorned lyrics, which, despite the infectious upbeat tune complete with a great guitar hook, contain complex ideas about love, life and memory. For some reason, despite the almost melancholy lyrics, it had always been a song I played in the morning to energise myself.

Saturday, 22 May 2004 was a beautiful day. I crept out of bed early to feed the horses while Julie slept. I had for years sometimes rose early to feed while Julie slept in. What had changed was that there was no interrogation over breakfast about whether or not I had fed the right horses the right amount. Julie always overfed the horses. It was one of those debates that endure without resolution through the course of a marriage. I would tease Julie that she only ever saw the horses in two modes: starving and in dire need of feeding or obese and to be immediately locked up and given nothing lest they founder. I had amiably accepted the fact that Julie overfed them, and she had, with equal amity, accepted my opinion that some could do with less and occasionally with nothing at all.

Mother and Father rang while I was brewing Henry. They were heading back down the coast and wanted to say goodbye. I remember looking in the bedroom and noticing that Julie was awake and sitting up with the same startled anxious expression that now had become normal. I said something like I would check whether or not she was awake loudly enough for Julie to know that the phone

was for her. I cannot honestly remember whether or not she spoke with Mother and Father or whether or not I passed on her good wishes. Certain aspects of this day I would remember in minute detail while others remain indistinct, obscured by a fog of confusion and bewilderment.

We had breakfast and did our Chi Gung. I remarked that I would need to go into town for a quick trip. We were just about out of chaff – both lucerne and wheaten and – as the produce store closed at 1pm on a Saturday, I would need to make a quick run in.

Julie was not looking forward to the visitors, and I reminded her about our strategy of listening to music. We chatted about what I could play for Ruth at lunchtime. Sarah McLachlan, The Cowboy Junkies, Kate Rusby... I assured her I would find things she would like and I would carry the conversation. She seemed calmer.

I didn't want to take her into town. I thought it would be too traumatic. In a week or so, when the *Zyprexa*® kicked in and alleviated some of the psychotic symptoms, we could think about shopping together again. She agreed with me about not going into town and I asked her if there was anything else that she wanted. She shook her head and asked what she could do while I was in town. I thought for a minute and asked if she felt up to vacuuming the house. Again she nodded with enthusiasm.

Julie almost pleaded with me about the time I would be back. She seemed frightened and worried that I wouldn't be back before Ruth arrived and I assured her that I would be quick. I kissed Julie goodbye and she admonished me not to drive too fast.

I told her that if I were quick enough we would probably have time to put another coat of oil on the verandah. She nodded, smiled and told me, "That will be great!" as I gave her a quick kiss goodbye.

At the front gate, I noticed the time was 10.13am, according to the clock in the Subaru. I thought I would only be 30 minutes driving into town, 30 minutes driving back, 10 minutes at the supermarket and five minutes at the produce store – back by 11.45am or so. This is basically the way it worked out. I paid cash for the two bags of rolled oats and the two flagons of Pepsi Max at Woolies and waited on myself at Fife's, the produce shop. Fife's was a drive through arrangement, and there was a line of utes and four-wheel drives from the horsy and farming communities; it was Saturday morning and they were busy. So I pulled into the parking area beside the side door, didn't get in the queue, served myself and let the guys know what I had loaded: two bags of lucerne chaff and two bags of wheaten chaff.

I drove home and noted that it was only 11.35am. Quick time. Rose saw me through the door and she was wagging her tail feverishly. Through the window

I could see the vacuum cleaner where I had left it at the front of the house and thought absently that Julie must have forgotten to vacuum. On the way in, I might have bent down to pat Rose or let her out. I couldn't hear the stereo, so I thought I'd walk in and see Julie on the lounge chatting on the phone to Vicki, Sandra or her mother, or bustling about the house or focusing on some other task; so it was a moment before I was able to process the tableau in front of me. I was not ready for what I saw. I would never be ready.

There was a moment, like every cliché ever written, that seemed like hours. I knew I had walked in the front door of the house and been looking around the room for Julie. I know I didn't call out to her, but it took me a moment to see that Julie was almost miraculously dangling inert in midair. It was profoundly strange and deeply shocking, so much so that it didn't register with me for a long moment.

I saw her but could not understand.

Julie had hung herself from the roof beams or, more correctly, the collar ties that reinforced the roof beams in the house. She'd used the extension cord left on the front seat of the truck parked outside the house with the power washer. I thought I might need it again to clean the verandah.

Then I started to scream. I don't know what I said, but I know I was screaming and yelling. I think I yelled, "My poor fucking baby, my poor baby..."

Julie had taken one of the old dining chairs from the table we kept in the corner when we had more than six people and stood on it while she haphazardly knotted the extension cord about her neck and then stepped off the kitchen chair and out of the chaos her life had become.

A week later I realised what a struggle it must have been and how gritty she must have been; 12 days before she hadn't been able to stand on a bucket to climb on to Biscuit, and the chair was about the same height. She had left her glasses neatly folded on the island bench, which she had used to assist her tortured climb onto the chair. The glasses were tear-stained.

Absurdly, I ran to her and tried to lift her back on to the chair and to untie her makeshift noose. Her body was too heavy and flaccid for me to steady. I used all my strength and lifted her up to take the tension off the noose while I tried desperately to think what to do. My screaming and rambling were non-stop. I eased her down again and ran for the knife block. I slashed through the double thickness of cord while holding her about the waist and lowered her as gently as I could to the floor. I was wailing with fear and anguish and trying to console her.

I didn't know whether to ring 000 or to try to resuscitate Julie. I looked at her face for the first time as I ripped the cord from around her neck. Her face was swollen, yet her features looked pinched and cramped. Her mouth was a faint purplish colour, her lips were flecked with a wash of white foamy mucous.

There were deep purple ligatures around her neck. I cleared her airway, tilted her head back and checked for a pulse. None. Gave her five quick breaths, 10 quick chest compressions and grabbed the phone and dialled 000.

I started to bellow down the phone line when the operator answered my panic-stricken plea. The operator had a polite urgency about her manner. I told her my wife had hung herself and that we lived at 177 Prices Lane in Bannister. I needed an ambulance and paramedics. She coolly asked me how my wife was. I remember howling that I thought she was dead.

I began to try and retrieve her in earnest.

Two breaths, 15 compressions.

I settled into a routine and tried to ignore the absurd spluttering sounds as the air evacuated from Julie's lungs like faulty and wheezy bellows.

I kept this up for 10 minutes and took a pulse. There was none.

Two breaths, 15 compressions.

Two breaths, 15 compressions.

I didn't look at her face. I didn't listen to the cacophony in my head. I just locked myself into that rhythm and united my being into the rocking tempo of my compressions and my surrogate breaths.

After another 10 minutes, I took another pulse and opened one of Julie's eyes to see if there was a dilation response. There was none and when I let the eyelid go, it fluttered halfway down and stayed there. This frightened me more than seeing her initially.

The phone rang. The ambulance couldn't find the property. The operators asked me for directions with the same mannered imperative restraint while I gave strangled out of breath, but apparently correct directions, to Bannister Springs then I returned to my ritual while a cold sense of futility began to dawn. The scrupulous operator had again asked me how my wife was. I told her she was dead.

Everyone would blame me. I had left her on her own to go shopping. I had dropped the ball.

Mother and Father would look at me with calculated dismissive abhorrence knowing that I had fucked up my mission.

Steve and Jason would be cold and silent. I had let their sister die.

All Julie's friends, but especially Vicki and Sandra, would despise me for my negligence.

The perceived scorn of those to whom I felt I had made an implicit yet unsaid promise, along with my long devotion to Julie, kept me breathing, bending and pushing.

Thirty minutes after I had begun to attempt retrieval, I stopped. I was almost exhausted. I was out of adrenalin.

A more essential notion had occurred to me, “Why am I doing this?”

Through the chaotic soundtrack in my head this thought kept coming back to me.

Why was I trying to restore her ruined consciousness only to die even more horribly than this terrible death in a few weeks or even a few days?

I knew what the short term would bring. I knew the awful truth behind bland terms like “morbidity”, “vegetative”, “incontinence” and “non-responsive.”

So I stopped.

I looked at her blank, pinched and swollen face and said, “I’m letting you go, baby.”

I sat down, leaned against the island bench, took her hand and I cried. Great wracking heaving sobs while I cried for her suffering, her despair, our truncated dreams and myself. Most of all, I cried for a smiling blonde girl on a horse who tried to actualise her dreams through love, will, laughter, grace and charm.

I cried because the fragile crystal of our trajectory of hope had crashed and shattered against the pitiless implacability of cellular division.

And when I had finished crying I just sat there numb, dumb and waiting.

*All the love that you missed
All the people that you can't recall
Do they really exist at all?*

*The whole world seems so cold today
All the magic's gone away
And our time together melts away
Like the sad melody I play*

The ambulance came tentatively down the driveway. They could have been Jehovah’s Witnesses with their copies of *Watchtower* about to make a leisurely conversion. No gravel flew. No lights flashed. No sirens blared. I gently let Julie’s hand go and dutifully went to the front door.

Like that night at Concord with Mr McNally, there was no haste about the paramedics. They parked the ambulance, went to the rear of the van and began to assemble what they thought they’d need. I looked at the clock, it was 12.25pm. One of them peered at me from around the back of the van, waved at me and yelled jocularly, “We’ll be with you in a minute, mate.” I held the door open for them and waited.

The two paramedics were named Chris and Lloyd. I held the door open while they carried armloads of medical equipment into the house.

With practised care they unpacked the gear they needed and placed two sensors on Julie's chest after loosening her top. I didn't need them to tell me she was dead; their looks to one another said it all.

Lloyd looked at me and with infinite compassion said, "Mate, there's nothing we can do for your wife. What can we do to help you?"

I shrugged my shoulders.

They steered me outside on to the verandah with almost imperceptible manipulative gestures and signals. I sagged down on the top step and sat there. I would spend most of the rest of the day sitting on the top step. Lloyd sat with me while Chris went to ring the police. Pal Care had told me that if I called an ambulance when Julie died, they were bound by law to call the police.

Lloyd asked, "Is there a support person I can call? Julie's family?"

The one thing I didn't want was any family there.

He enquired again and I asked him to ring Vicki.

Lloyd's mobile reception was poor. I told him the cordless phone was on the counter and he went back inside to get it. It wasn't on the counter. It was on the floor next to Julie where I had dropped it. He rang Vicki and very formally told her that Mrs Barber had "passed away" and Mr Barber was requesting her as a support person. Could she come? Lloyd told me they were on their way immediately.

"Ring her brother, please," I asked Lloyd. I gave him Steve's number for him to repeat the same bland message. Steve wasn't there and he rang me back in two minutes. By this time, I felt composed enough to speak with him. Worry surged down the line. There was no longer any need to worry.

"Julie's dead." I told him in a flat dead voice. I pleaded with him, "Call your parents, I can't deal with them."

"How did she die?" he tentatively asked me.

"She hung herself. She killed herself." I said in the same monotone.

"Oh Jesus..." There was a strangled moaning grunt on the end of the line and the phone went dead.

He rang back minutes later and I told him not to come out. He thought that he should be here. No one was allowed anywhere near Julie; the police were on their way and the house was a crime scene. I told him to use his judgement about what to tell his parents, but to tell them not to come here. They would be driving and I didn't want them to have an accident.

I rang Virginia since she was coming later that afternoon. I caught her while buying flowers in Goulburn. I told her that there was "a problem", not to come, to go straight home and call me back. I didn't think it fair to tell her what had

happened on her mobile in the middle of a shopping centre. When she rang I told her and she broke down. I called Joe Steyns. He would have to manage his school on Monday and would need time to plan how to deal with children who would be falling about with real, imagined or collective grief.

Vicki and her husband Peter arrived. I told her how Julie died and the tears coursed down her cheeks. Vicki would cry a lot in the next few months. I learned a lot about tears in the next few months, and I learned even more about people. I would only cry one more time. I was driving up to Cowra in June to get out of the house and to visit Viv and Chris on Julie's birthday. I didn't want to be alone in the house for that first significant anniversary, and in the open country between Boorowa and Cowra where radio reception fades I would play a CD. When the old Phil Spector song, *I wish I never saw the sunshine* from Beth Orton's "Trailer Park" came on, I had to pull over. I didn't stop the song. I didn't know if it was wise to let this wash over me. It had only been three weeks since her funeral.

*Baby do you know what you did today,
Baby do you know what you took away,
You took the blue out of the sky,
My whole life changed when you said goodbye,
An' I keep crying, crying.*

*Ooooh baby,
Ooooh baby,
I wish I never saw the sunshine,
I wish I never saw the sunshine,
An' if I never saw the sunshine baby,
Then maybe I wouldn't mind the rain.*

*Every day is just like the day before,
All alone a million miles from shore,
All of my dreams I dreamed with you,
Now they will die and never come true,
An' I keep crying, crying.*

Ellie Greenwich; Jeff Barry; Phil Spector, *I wish I never saw the sunshine*

Vicki and I felt the same way. Her crying was an expression of loss and love, of grief and of her unique relationship with Julie. They were a sign of her strength of character.

And I cried for one other reason. I had broken a promise to myself. Julie had died alone. And I will never be able to rationalise myself out of that one or console myself that there was nothing I could do.

Constable Dean Murray was the one-man band from the Tuena Police Station. It was about 50 km North of Crookwell on the way to Bathurst via the back roads. Goulburn and Crookwell were closer than Tuena, I can only imagine that he was in the area and was diverted to the property. He came down the drive in his four-wheel drive with the police logo and the red and blue lights on top. I imagined the phones in the neighbourhood were beginning to run hot. The progress of the ambulance and the police car would have been monitored by a network much more pervasive than the one Winston Smith faced.

Constable Murray was tall and burly with sandy short hair and a shy, polite almost diffident manner. He acted like a deferential Rugby League forward. All the officials I dealt with that afternoon treated me with blokey awkward courtesy. There was a sincere compassion in their manner and their fumbling contained a basic honesty that oily smoothness would have lacked.

I gave Constable Murray the chronology of the morning, along with the background of Julie's illness and treatment. He was somewhat sceptical that I could be so precise about time – 10.13am and so on. I didn't realise it at the time, but I was being investigated for complicity or aiding Julie with her death. The fact that I had stopped in at Fife's would prove to be important, although the detective who later attended would pretty much eliminate me as a suspect. Julie had quite noticeable bruising on her abdomen where she had strained and reached leaning over the balcony to drape the extension cord over the collar tie.

Constable Murray politely asked if I could show him what I had done when I arrived home. I re-enacted my stepping on to the verandah, pointed to the vacuum and indicated how I had looked for Julie around the room. I could not explain why I had not seen her through the glass of the door.

I walked with him to Julie's body, which the paramedics had covered with a white sheet. They would leave the sheet behind and I kept it for a while. I don't know why. The paramedics asked if I was up to identifying Julie.

So they actually did this. One part of the TV shows was right. They told me that Ruth (who had arrived for our planned lunch together) could do this; I didn't need to put myself through it. I thought it was important that someone

who loved Julie performed this duty. I needed structured bureaucracy to confirm the outcome of the image I had seen coming through the door. For months afterward, I would hear a sound and expect Julie to walk into the room and ask me if I had given enough feed to the horses. Several times I would take two cups out of the cupboard to make two cups of tea. They pulled back the sheet and asked me, quite formally, if this was Mrs Julie Barber. I looked at her bloated, swollen and blotchy face, tinged with purple and pallor. The mental image I always had of Julie did not look like the person on the floor. I nodded and said, "Yes, it's my wife." The sheet was gently replaced and Constable Murray and I finished our tour.

Julie had wanted to die. She had opened every cupboard in the house looking for some means of killing herself and, in her haste, had not closed them. Bottles of metho and turps along with cans of Drano were on the counters. I wondered why she had not used them and then realised that she would not have been able to open the childproof caps.

The wood fire door was open. In it was a card she had started to write to Mother and Father. She had not gotten beyond an opening before the confusion in her mind had overtaken her. On the dining room table she loved so much was a note. It was only two lines:

*I love you all I have hurt you & I don't know
why these works Please forgive you*

I looked at this note a thousand times once the police returned it. Mother and Father wanted a copy, and I dutifully provided one. They didn't understand initially why the police confiscated it; I believe they thought I was withholding something and keeping it for myself. The ambiguity in the note accentuates the ambiguity of Julie's act. I will never know why she chose to step off that chair and out of this world.

To this day people try to ascribe motive to the act. I don't. A welter of impenetrable and unanswerable questions surrounds this day. I don't try to answer them. The competing priorities of Julie's personality vied with the demons of psychosis and the strength of her will. Assuring me that she would rather die than lose her mind is one answer. Anyone who saw the constant torment of her last few weeks in a nether world of obscure voices and illusory images would know that these drove Julie as well. And she was tired, exhausted by drugs, cancer and pain, and she knew more was to come. It chilled me when I recalled the conversation from the night before she died when she so earnestly wanted "some time to herself".

I don't know.

It really doesn't matter. It bothered me for a long time, gnawing away at my conscience, giving rise to my own sense of misgiving and uncertainty. But the motive for her death was inconsequential. What was important was the design of Julie's virtually blameless and inspiring life.

A forensics officer from the police arrived and later a detective who gave me a perfunctory sentence of condolence. My initial impression of him was that he was oily and glib. Months later he would formally interview me about Julie's death for the coroner. He was a good man, as kind and as charitable as the other officers had been, and later, he spent a lot of time with me.

They removed Julie's rings with difficulty. She had an old worn gold ring with the emblem of a horseshoe on it that she had worn since she was about 12. I mistakenly thought that Vicki had given it to her. It had actually been her mother and father. I kept the wedding ring and gave the other to Vicki, who accepted it with tears and gratitude. I think Mother and Father were offended, but I didn't know or had forgotten they'd given it to her.

I rang Bede and briefly told him what had happened. He listened and asked what I needed. To stay with him for a while. I didn't know if I would be able to sleep in my own house. I was afraid that there were demons there. They would be demons of my own construction and imagining, but demons none the less. I told him I didn't know how long I would be staying there and apologised for the inconvenience. Bede dismissed my apologies. My voice just trailed off in a mixture of confusion and grief. He asked if I wanted him to come out to pick me up. I assured him that I would be able to make it to his place, but I didn't know when.

Constable Murray found me and asked if I wanted some time to say goodbye to my wife. I didn't know what to say. I had never thought about the end of our marriage. I had made the conscious decision to cease resuscitation and the guilt I felt over that act was uppermost in my mind. I felt unworthy to say "goodbye" to Julie because I was feeling that I had neglected her. At the same time, I knew our life together was going away. Her spirit and being were now separated. What was expected of me? I was dreadfully worried about others' expectations. I perceived my every action, gesture and word were being analysed as for sincerity. I wanted to behave well, yet I wanted to grieve. I didn't know how to do either.

I was trying to play a role for which I had neither a set of stage direction nor dialogue. No one ever taught you at school how to love. No one ever taught you what to say to someone who was dying or to a friend who had experienced loss. You bumbled through both. I told Constable Murray that I thought I would like

to do that, if that was OK. He nodded and told me that they were still “working” and would let me know when they had finished and I could try to work my way through what I thought I needed to do.

In the meantime, could I give them Julie’s medication? They needed her scripts and her drugs to run against the toxicology reports from the autopsy. I looked at him and, when he saw my confusion, he informed me that there would have to be a post mortem examination. I nodded again and followed him into the house.

I went through the unspoken rules of behaviour that had been established. I could only come into the house at their request. I could only open a cupboard or fill a water glass if they gave me their permission. For the afternoon, it was their house.

Her drugs are kept in that cupboard, I pointed to the kitchen cupboard above the stove and to the right, next to the pantry. They nodded. Her medication for the week is kept in that cupboard. I pointed to the kitchen cupboard underneath the microwave oven sitting on the counter.

The written regime of medication was clipped neatly to a green enviro bag. I took out the bag and placed it on the island bench along with the pill organiser. I asked permission to go to the cupboard and silent nods gave authorisation. I pulled what had been prescribed out of the cupboard.

I told them there were bandages, Elastoplast, gauze and binding for her injured leg in there as well. They demurred. They didn’t need them. I told them that was everything...except for the drugs Pal Care had left me for the hated cannula. Constable Murray knew about the visit from Pal Care. I had included it in my narrative of the day’s and week’s events. I told them the drugs were in the fridge with the vet gear for the horses. The two police officers were standing nonchalantly leaning against the kitchen counters while I rummaged about for the bits and pieces they needed. I stuck my head into the fridge, picked up the five syringes and turned around with them in my hand and pandemonium erupted.

Both the sergeant and Dean Murray bellowed one word, “Sharps!”

I stood there dumbly and they were galvanised into action. I couldn’t be sure but I thought that the sergeant’s hand dropped down next to his weapon. I went to hand them to the sergeant, who seemed to be in charge, and he went rigid with formal authority and stepped back. They were casually indifferent no longer.

“Mr Barber, I would like you to put those syringes in your right hand down on the bench next to you and then step back.” The sergeant did not bark this at me, but spoke with precise and ceremonial authority as if the conversation were being recorded. And then the penny dropped. Drugs, AIDS, needle sticks, demented junkies waving blunt needles in filthy syringes at convenience store owners.

I wasn’t reacting quickly enough. I was looking at the sergeant with blank, thick-witted confusion and he repeated with exaggerated slowness and emphasis

his previous order. "Mr Barber, I would like you to put those syringes in your right hand down on the bench next to you and then step back." I did so.

Nothing was said. He reached into his tool kit and pulled out a pair of enormous rubber gloves that looked as if they would shield him from a plutonium scare let alone five syringes (without needles) capped off and full of a sedative. Protocols, training, routine. He gathered them up and placed them in a yellow biohazard container that he carefully placed in the evidence bag and returned the gloves to his toolbox. Only then did they relax. I was shaken by the incident and simultaneously felt foolish and scared.

It was late afternoon. Low cloud had moved in and there was a chill in the air. I was feeling cold. I had not eaten lunch. I could not conceive of eating with Julie lying on the floor. I think I was beginning to feel cold and sick with shock. I asked if I could get a jumper or a jacket. Constable Murray followed me into the bedroom. While we were in there he told me that "the contractors" were coming. For the first time, he didn't look at me. While telling me this, he found something supremely interesting in the dim half-light outside the bedroom window. I just stood there, uncomprehending and stupid. They are coming for your wife, he gently reminded me.

He informed me at least three times that "We're almost ready for you. Only a couple of minutes now." Constable Murray came out and solemnly informed me that I could say goodbye to my wife but that I needed to understand that the sergeant could not leave me alone with her. I nodded and walked into the house. I had shown them where the lights were, and in the dim restrained lighting of the restored fixtures we had bought, cleaned, sanded and repainted, I went to Julie.

I knelt down next to Julie with no idea of what I was doing there. I now felt the situation to be contrived and artificial. An anonymous functionary would be standing there bureaucratically doing his duty for a remote government authority, with no interest in my intimate affairs. I took Julie's hand, half because I wanted to and half because I thought it was expected of me, and looked at her. I was as barren emotionally as the tumour that had destroyed our life together. I could not summon either the sensation or the sense of occasion to do other than whisper, "I'm sorry, Baby. I'm so sorry." I looked at her for a moment, but as when I identified her, the body in front of me did not correspond with the persona in my mind's eye. I let go of her hand and touched her cheek, half whispered and half thought, "Goodbye, Baby."

It dawned on me at the same time that she had started to go away from me the previous spring when the cruel process had begun and, by increments, she had been deprived of fragments of her character, intelligence and personality. And then I realised that it and her struggle had not taken her identity and essence. Julie had remained uniquely herself, undeniably strong, individually inimitable

and exceptional to the end. I didn't cry, I didn't care whether it was expected of me and whether they would think me a callous bastard for not doing so. I stood up, nodded at the sergeant, turned around and walked out. I didn't look back. I wanted to hold that fundamental nature of Julie within me; some meaningless and empty ritual would do nothing to alter that reality.

The contractors were feeling their way down the driveway with their lights on in their plain label white van. I told the constable that I would need to pack a bag and asked did he need to go with me. He shook his head and then followed me into the bedroom. He told me that he wanted me to stay in the bedroom while the contractors removed Julie. He emphasised that there had been some disturbing reactions if family members were present while they tended to "the deceased".

I packed my bag, putting in what I thought I would need for a day or so at Bede's, and then sat on the bed dumbly while I could hear the zips being pulled on the body bag, the sergeant could then cease his vigil as the contractors were duly authorised officers of the court.

I asked permission to come out and they called that I could. Two of my ex-students were there as part of the removal team. I went outside and had a minor argument with Peter who did not want to let me drive. Sandra was going to take Rose. I assured them that I needed to drive, that I would need my car at Bede's. They finally agreed. I promised to drive slowly into town and Peter and Vicki would follow me in convoy.

I drove sedately into town because of both the kangaroos and my promise to Peter.

I went in through Bede's back gate and he, along with his wife Bronwyn, was waiting for me. Bede and Bronwyn fed me. I told them I didn't want anything to drink. I think they both would have been more comfortable if I had drunk myself into oblivion. The slightly out of focus image of normalcy I was presenting was far more disturbing to them than raging insane fury or hysterical wailing grief.

I went to bed, the day playing out in my head like a demented video loop. Julie was dead. I kept having to say it to myself. It didn't make sense. At the same time yesterday she had been alive and, as the clock ticked away the night, I could not sleep. I slipped up at 2am, and grabbing my journal, I sat at their tiny kitchen table. I wrote in my journal till I noticed it was light, meticulously trying to recall the details of the day through the chaos in my head. It was no longer a diagnostic tool for Julie. It was a therapeutic instrument for me. I vaguely remembered a quote from Hemingway, who was always a favourite of mine: "The world breaks everyone and afterward many are stronger at the broken places." I hoped that would be Julie's last gift to me: that I would be a better person and stronger as a result of our life together. I had always thought that my life with her had made me a better man. Now I had to prove it without her.

*Well I don't want to drift forever
In the shadow of your leaving me
So I'll light another cigarette
And try to remember to forget*

*It's so easy to slip
It's so easy to fall
And let your memory drift
And do nothin' at all*

Lowell George, *Easy to Slip*

CHAPTER TEN: AFTER

*Now the blueprint for sorrow is just to put off the hurt
'til the price of tomorrow becomes more than love's worth.
'Til what's begged and what's stole is just the hollow remains
of some beautiful failure that we cling to in vain.*

*For those who plant nothing but the seeds of the falling
there is a phone booth in heaven that no one is calling.
The truest word heard there is the word that's unspoken
'cause you can't mend what the Good Lord designed to be broken.*
– Jim White, Phone Booth in Heaven

I didn't sleep at all that Saturday night. I went to bed exhausted but adrenalised. The video was still playing in my head, but there was no coherence to it. If anything, it had become more disjointed, more bewildering. The image I had of Julie suspended in midair when I walked into the house dominated. The image was so strange and shocking that I tried to apprehend what had happened, to give it depth and meaning. I could not. It was horrifying and grotesque, and I kept replaying that hour in my mind. I would do so for months to come. I could barely grasp the reality let alone the resonance.

After writing in my journal till first light, I went back to bed and lay there. I stayed in bed till 7am not wanting to disturb Bede or Bronwyn, and when I got up Bede was up. He made me a cup of tea and the phone rang. It was Steve.

"What about the funeral?"

"A funeral?" I repeated stupidly.

The notion that I would need to deal with a funeral hadn't penetrated or occurred to me yet.

"Mum and Dad want to know what's going to happen with the funeral?"

This would become our mode of communication. Mother and Father only spoke with me directly less than a dozen times thereafter. Most of their requests, demands and communication came via Jason and Steve. Shuttle diplomacy.

There seemed to be unseemly haste about this.

"Steve, I don't give a shit about the funeral. They can do whatever they want."

Steve seemed taken aback. I hoped I hadn't offended him.

I didn't give a shit about the funeral. Julie was dead. I had heard the zips on the body bag. What happened next was irrelevant.

I tried again. "Look, don't be offended. I really don't care what happens."

"OK."

I went on. "There needs to be some sort of ceremony or ritual. I accept that. The form it takes means nothing to me. Julie's gone... That's all that I care about. I don't want to get into any argument about the funeral arrangements. The funeral means nothing to me, but I know those sorts of things mean a great deal to your parents."

He seemed to accept that. But he persisted, "Is there anything you want to happen at the funeral?"

"I've got a couple of things. Nothing much. There's some music that I want played. I'll write the eulogy. That's it. We can work all this out. The only thing I'm not negotiable on is the eulogy. I write that. OK?"

He told me, "Yeah, that should be OK. We'll need to catch up today."

"I need to go out to the farm today to check the horses. Bede will come with me. That's all that I need to do. After that...?" I was just going to try and get through the day. Everything had changed again.

There had been a change in the weather. The Sunday was overcast, blustery, damp and raw. There was a chill in the air, the precursor to winter. There would be no more balmy or kind weather until spring.

Bede and I returned to the now icy cold house at Bannister. Nothing was on the floor; everything except the sheet, which covered her, had been confiscated as evidence.

I carefully folded it up and put it in the cupboard under the stairs. I don't know why.

I met Steve and Jason up the driveway and they walked around with Bede and me while I finished checking horses. When we went back down to the house, Steve would not come inside, so we sat on the verandah and discussed the funeral.

The reality was I had thought about the funeral while Julie was alive. I could hardly avoid thinking about it. I wanted it to be a positive occasion: a celebration of her life rather than a mourning of her death, which has become a cliché in our society. Nobody has funerals any more; we all celebrate the person's life. Unless, of course, the son of a bitch who died was universally despised by all.

I said I didn't care and, at the time, I thought that I didn't. My indifference wasn't feigned. I realised later I would grow to care deeply about the funeral. As the week progressed, my involvement deepened. My own sense of what I wanted to occur became more prominent and more important to me. I unconsciously put in place what I wanted. I took over more and more. I ended up getting what

I wanted, I usually did. At the time, I kept saying that I didn't care. I was lying, but I suppose I was lying mainly to myself. Perhaps it was the shock. Perhaps it was just me being an asshole. What I didn't want was something tacky, saccharine and dripping with industrial grade maudlin ick.

I knew all along I wanted to write the eulogy. Julie essentially existed in three worlds: family, school, horses. I was the only one who had intimate knowledge of all three. The eulogy would be brief and beautiful. I would try to encapsulate all the laughter, good cheer and happiness that Julie had radiated. I also wanted one of her colleagues to speak. It would require the in-depth knowledge of a close associate to put perspective on her 22 years as a teacher. Mark Leseberg adored Julie, and the ironic part was they were complete opposites. Mark was a rigid disciplinarian who exacted top class performances from the kids through dint of an authoritarian, almost tyrannical, approach. I used to joke that the Gestapo lost a good man when Mark became a teacher. There were kids who were terrified of him. He seemed to dote on Julie and called her "Sparky". While she had been ill he wrote her three quite touching letters full of friendly stories about the school and his family suffused with affection and warmth. Julie treasured them.

The other reason I wanted Mark to speak was that he was a leukaemia survivor. A few years previous he had been diagnosed with leukaemia and had only survived due to a bone marrow transplant. I thought that he, more than anyone, would know what demons Julie had faced: what her fears, uncertainties and sorrows had been during her illness.

I would ask Joe to chair the proceedings and I would ask him for one student to say a few brief words.

I hoped I would be able to deliver the eulogy. If I didn't think I was up to the job, Joe would present it on my behalf.

I sat with Bede on the steps by the carport while Steve and Jason went over a few details.

There would be a meeting with the funeral director on Monday.

"What about the body being released?"

Apparently they were way ahead of me. That would happen quicker than the police had predicted. I began to detect the vibe that Mother and Father were driving this: they thought by hastening the funeral they would give themselves that elusive concept, closure. I kept seeing that image of Julie defying gravity and knew closure was hard to come by.

Jason cleared his throat. He was having trouble phrasing exactly what he wanted to say. "If you were planning on the funeral on your own; what would you want?"

"What would I want?"

He nodded, and Steve and he exchanged glances.

“I’d want a private funeral with only immediate family and a few very close friends, followed by a memorial service a few weeks later in whatever building, The Great Hall at Trinity, the Cathedral, whatever was big enough to hold all the people.”

Jason looked down and shook his head. “Father is adamant that it must be a church ceremony.”

I looked down as well and I hoped that they didn’t see me smile bleakly. They still didn’t get it. They still didn’t see my role in Julie’s life. They still saw their perceptions as paramount, their sensibilities as the most important and their sense of occasion as being non-negotiable. I didn’t care – church, auditorium, tavern – it was all the same. Julie was dead.

I looked up and smiled, “Then why ask?”

“They just wanted to know..”

They would get what they wanted and so would I.

I just shook my head. Mother and Father wanted what I wanted as long as I agreed to what they wanted. It crossed my mind to let the inner prick prevail and insist on the private funeral, just to be contrary, but that would accomplish nothing other than to prove an infantile point. Or to be even more contrary and insist that the funeral be conducted in the Catholic cathedral. Father hated Catholics on general principle simply because his father was from Northern Ireland.

I was both a lapsed Catholic and a lapsed atheist. I knew where that put me.

The conversation petered out. They would call me when they knew more details.

In the conversation Sunday morning Steve had told me that “the family” (which meant Father) wanted to keep Julie’s suicide secret.

I told Steve, “Too late. There were two of my ex-students on the crew that collected her and I imagine it’s all over Bannister that the police, the forensics wagon and the contractors from the morgue were all over my place. Besides, Vicki, Peter, Sandra, Ruth, Bede, Bronwyn, they all know. You can’t keep a lid on this Steve, this is a small town.”

I would find out many months later Father had made one of his pronouncements: “This will never leave this room and will never be spoken about in this family again.”

Steve pleaded with me. “What will we tell the kids?”

“The truth. Do you want me to tell them?”

Steve, gentle soul that he was, was in an agony of indecision. I realise now he would have been dealing with a cyclone of conflicting emotions, family dynamics

and philosophical perspectives.

“Steve,” and I tried to be gentle, “Julie and I never had children, but I’ve been in the kid business all my life. It’s always been my experience that good kids, and you have really great kids, will try to be as mature as you treat them. Tell them, they’ll surprise you. They’ll cry. There would be something wrong with them if they didn’t.”

He was listening, I kept going. “Also, this is a small town. If you don’t tell them, they’ll find out somehow. And do you want to control how you tell them or have some 16-year-old bully shirtfronting Brad on the playground or down the street and saying ‘Yer aunt necked herself didin’ she?’ and watch Brad crumble.”

“I don’t know, I don’t know...”

“Look, if they find out later, they won’t fucking trust you again, mate. They’ll really hold it against you. This is the most important thing that’s happened to them, so far.”

Steve ended up telling them. They handled it better than he thought they would.

I stopped in at Steve’s on the way back to Bede’s. I had wanted to make myself go back into the house and begin to call the people I felt needed to be notified. I also had some strange notion of cleaning the house after what had happened on Saturday. I had not done much cleaning. Bede had cleaned upstairs and I had gone through the motions of doing something. I didn’t feel as uncomfortable in the house as I thought I would. I knew I was going to have to live there. I knew I would have to walk past where Julie had stepped off that chair every day I was here. I put the chair back in the corner where it belonged.

I didn’t retell the story at Steve’s. He had asked me earlier why I had called the police, why it could not have been kept quieter. To a certain extent, I couldn’t believe their naiveté. Someone had died violently and the authorities must involve themselves; that was the law. I just said that even if Julie had died of natural causes and I had called an ambulance to help, the ambulance would have contacted the police. They accepted that. I told them I had made a conscious decision to stop resuscitating Julie. I don’t know how they took it. Mother and Father looked like skulls with eyes sitting at Steve’s table. Mother tried to look magnanimous and said, “We don’t blame you, Charley.”

We would meet at 7pm at Steve’s to go meet the funeral director and begin to arrange the funeral.

No one in the family asked me how I was coping until Jason did in the car on the way down.

That meeting went as I expected. I had to sign a lot of forms. Mother and Father wanted Julie's maiden name to appear in parentheses after Barber in the death notice because there "might be people who didn't know what her married name was". I wasn't surprised, even though I thought it inappropriate; Julie and I had been married for over 24 years. I let it go.

We had discussed earlier how Julie should be dressed. Vicki had suggested her riding clothes. I didn't like that. I thought it tacky. Mother suggested some of her good clothes. I pointed out that due to the bloating and the weight gain, nothing would fit. Any clothes would have to be slit up the back to fit Julie. The question had not been resolved when the funeral director suggested a shroud. That would be fine. It was simple and unpretentious.

We had to pick out a casket. I was going to let Mother and Father do it. They wanted my input. We looked and I just pointed. It would do. Julie and I had put it in our wills that we would be cremated when we died. Apparently Mother and Father did not like this, but said nothing.

The funeral director gave us the chronology regarding Julie's body being released to them. Did anyone want to view the body? Mother and Father did. I didn't. I had said goodbye earlier at my contrived farewell.

Father cleared his throat and asked the funeral director for a quote on the cost of the funeral. I couldn't believe it. Father said, "So Charley would know what he was up for." I said it didn't matter but the funeral director was already magically producing a calculator and pushing buttons. I murmured again my demur but by this time the ball was rolling. The quote was pushed down the table to me. I didn't know how I was going to pay for it.

I drove Jason home and he went ballistic in the car. He could not comprehend the behaviour of his father. Why did he have to ask for a quote? I had seldom heard Jason swear, and he really let rip. I tried to appease him by saying that I was neither surprised nor offended. I simply told him his father could not help being who he was.

The next day we had a meeting with Dean Thompson, the minister in charge of St Saviour's Cathedral in Goulburn, where Julie's funeral was to be held. That night I could not sleep and tossed and turned. At 1am, I crept quietly out of bed and went into the kitchen with my journal and a notepad.

I wrote Julie's eulogy. I had tried twice before on early Sunday morning and Monday evening to write it, but had given up. I wrote till 4.30am and what flowed out of my pen pleased me. It was relatively brief, about five pages. I read it twice more before I packed up my gear and went back to bed. I think I dozed

but, after that night, I would have little trouble sleeping. I suppose, like anyone, I would have the odd sleepless night but not the restless anguish that I experienced on that Saturday and Monday night.

The meeting with Dean Thompson did not go well. Steve and Lisa, Jason and Jane and Mother and Father attended. Dean Thompson outlined how the service would be conducted. I told him the songs I wished played.

Mother and Father wanted a country and western song called "Daddy's Girl" played. I didn't like it. It had everything that I despised about bad country music. They had given Julie a burned CD with the song on it, which she dutifully listened to once and never played again. They later told Dean Thompson it was, "Julie's favourite song". I knew it not to be so, but why argue? I had played all three songs for the family and told them if they found any too wrenching or too trivial, that I would delete them and find alternatives. I told them one was pretty much non-negotiable. I thought for a fleeting second to disallow "Daddy's Girl". It was hokey, corny and saccharine with a sexist refrain that Julie should have been a boy because Daddy "loves me like I was his son". They saw no anomaly in the fact that I was technically in charge of the funeral because I was paying for it, but felt no need to ever talk about their wishes directly with me. I said nothing and let it pass. Their desires were communicated to Dean Thompson. I just wanted to get through this.

I also wanted the lovely e e cummings poem "somewhere i have never travelled" read at the end of the eulogy.

We seemed to be winding up. Dean Thompson appeared to be working up to something. He told us that we had given him some facts about Julie's life but when he was conducting a funeral he needed to get a "sense" of the person's life, a feel for their personality. He looked at us arrayed around the circular table expectantly. Mother, that week, had kept repeating like a mantra that, "They broke the mould with Julie" on a number of occasions. She repeated it now. Father said, "She was the best daughter a man could have."

I had thought about what I had just written in the eulogy as carefully as anything I had ever written before in my life. I began to speak about the great passions of Julie's life, about the enthusiasm and intensity she brought to almost every task, and her almost pathological determination to be positive and friendly no matter what the circumstances: her "relentless good cheer" as I had long characterised it. I spoke for several minutes with committed conviction.

Dean Thompson took it all in. I felt a palpable wave of resentment begin to creep across the table from Mother and Father. I think they believed because I was able to speak that way about Julie in detail about my great love for her, her enthusiasm and zest for life, that their love was diminished or threatened. All I could think of was the Native American superstition that if their photograph was

taken, so were their souls. By being able to speak so eloquently about Julie, I was damaging their role as parents. I thought it sad.

There were details: a program, decorations for the church and photos.

There were meetings. Joe, the principal of Trinity and the counselling process began with me. I would have a lot of it over the next year. There were others who were grieving. I talked with them in the common pool of sorrow filled by Julie's death.

Bede and I stayed at the farm on Wednesday night. We had a couple of glasses of wine. It was pleasant, just two old friends watching State of Origin football. The house had no fears for me. There were no demons. Julie and I had invested a great deal of love and commitment in the house. She had died in the house she loved; looking at the land she loved and, most important of all, at the horses she loved. It was going to be OK, lonely but OK. It would be terribly hard, but I would manage. Everything would be different, but I would recover. I'd have to.

I ran through our personal phone book and rang everyone in it. I used the free Telstra hour on the mobile plan and told people the time, date and location of the funeral but, sorry, I couldn't talk. I needed to call people. I left my mobile number with some of them. Call me later if they wanted to chat.

I slept well enough that night. I decided to have no expectations about myself the next day. I wrote in my journal: "Whatever happens, happens."

The day of the funeral was clear and cold with a sharp blustery wind. I put together my clothes with great care. I packed a bag for staying overnight at Bede's who insisted that I stay there that night. I wasn't going to argue. I actually packed long underwear for the ceremony. The cathedral would be very cold and I knew I'd feel shaky at some point.

I was at Bede's for lunch but we just sat there watching the clock. By 1pm I just had to move so I dressed and went to the funeral home. I parked the Subaru, waited, chatting idly with the receptionist. I was still hoping I could read the e e cummings poem and I made sure I had a copy in my jacket. I read it over several times and I had told Joe to check with me as to whether or not I could read the poem. By this time, I was pretty sure that I had the poem memorised but I still wanted a copy in front of me.

The family met me at the front of the funeral home. Mother and Father

greeted me impersonally then ignored me. Father discussed real estate with one of the funeral attendants. The hearse pulled up with the mourning car. No arrangements had been made with me as to who was riding where. The door for the mourning car was opened for me and it was then I realised that I would be alone in the car. No one from Julie's family was going to ride with me. I was deeply shaken. Jason touched my arm and asked if he and Jane could join me. I just nodded in thanks.

Then the penny dropped. Mother and Father had behaved all week as if I essentially had no role in Julie's life.

I was later deeply offended and then angered. I felt a sense of betrayal. I had known they were against my marriage to Julie but had thought somehow, over a long period of time, perhaps they had seen the qualities in me that brought Julie and me together and kept us together. I had thought of them for a long time with affection and respect. I hoped the incident at the hospital back in February was one of those irrational responses stimulated by stress and ignited by fear. Not so. It was a basic belief.

They believed that I really had nothing to do with Julie's life and any semblance of respect and esteem directed my way by them had all the sincerity of a McDonald's waitress saying, "Have a nice day!" It troubled me then but later, I would accept that. They weren't about to change.

With Jason and Jane sitting with me, we began our slow circuitous drive to the cathedral. The plan was that the funeral cortege would drive through the junior campus of Trinity College via the main drive and out the back exit and then onto the cathedral. The junior students were lined up on each side of the drive. Some of the girls were weeping openly. No child spoke, fidgeted or even twitched. Many of the boys seemed to be standing at rigid attention with their thumbs aligned with their trouser seams and, despite their brave faces, some were trembling on the edge of weeping. As the car climbed the inclined drive slowly, I thought about how many mornings I had dropped Julie off or had picked her up while these same faces, or thousands just like them, had swirled about us with cheery gossip or were beset with the unique angst of teenagers. Today, they were united in their solemn grief and silent esteem.

We pulled out the back exit and made our sombre way through the back streets of Goulburn to Bourke Street. I thought that was the extent of the guard of honour but I was wrong. The senior students of Trinity Catholic College silently lined Bourke Street for two blocks, ending in a gently curving sweep into the entrance to the cathedral. I was stunned. Their soundless love and respect echoes with me still.

I went into the church, which was already beginning to fill, and I was directed to the front right pew. I sat with Vicki, Virginia and Sandra. Bede and Bronwyn

joined us, along with Peter and Vicki's children.

The ceremony went well. Dean Thompson played his part. The haunting sounds of Sarah McLachlan's "Angel" resonated gently round the vaults of the cathedral. There were very few there that would have realised my dual intention in playing the song. Most only sought to hear that I thought Julie an angel; that was fine. The undertone of seeking validation and understanding in the face of self-doubt was there. I made the message available for all. If they chose to hear it and bothered to think about it; that was fine, too.

*Spend all your time waiting
for that second chance
for a break that would make it okay
there's always some reason
to feel not good enough
and it's hard at the end of the day
I need some distraction
oh beautiful release
memories seep from my veins
let me be empty
oh and weightless then maybe
I'll find some peace tonight*

*In the arms of the angel
fly away from here
from this dark cold hotel room
and the endlessness that you feel
you are pulled from the wreckage
of your silent reverie
you're in the arms of the angel
may you find some comfort here
– Angel, Sarah McLachlan*

The usual prayers proceeded and Joe took centre stage and introduced Elise Thistleton, a Year 11 student, who gave a brief and dignified tribute to Julie. Mark Leseberg then attempted to sum up Julie's career at St Patrick's and Trinity. As I predicted, he spoke sensitively about Julie's enormous vitality and affection for "the boys", especially. But what he most admired was her iron will and her commitment to excellence. It was a great speech.

Joe conducted the proceedings with classy grace, blending the solemn and the sombre nature of the occasion with the charm and good cheer of Julie's life, reading my eulogy verbatim with wit and sincerity.

“The capacity to love was what made Julie special to me. She loved so many things with an innocent enthusiasm which didn’t cheapen the emotion, but rather demonstrated the largeness of her heart and spirit. She loved her family, her friends, children, horses and me. Her capacity for inclusion was awe inspiring. Julie would fix you with her luminous eyes, smile that radiant, ebullient smile, and that pealing, resonant laugh would speak to your heart. Julie seemed to have the capacity to see into your character, and to see you exactly as you would like to see yourself. This talent is a rarity.

We live in a cynical world where shop assistants are trained to enquire about your emotional well being. Julie’s open heart was spontaneous and authentic. The pretence of good cheer, friendship, even affection, is common. To genuinely feel those qualities and be able to communicate and transmit these feelings is a unique gift. This quality of love and reassurance is probably what endeared her so much to her students. She came home from school one day, both indignant and upset. A casual teacher, who had encountered the whirlwind of Julie’s enthusiasm and affection, had remarked to her: “Are you for real?” Julie was quite irate. I thought the incident funny – she was as real as you get: honest, loving, passionate, determined and brave.

It was her love of horses which will always be the dominant memory I have of Julie. I always joked that she became interested long enough in men to marry me, and then went back to horses. On one occasion we bought an expensive filly and, after prolonged negotiations with the owner, Sylvia Archer (who I think was assessing our worthiness and competence), agreed to the sale. Julie reacted typically. She burst into tears of joy, hugged Sylvia and hugged the rather bemused filly. Not me mind you. I turned to Sylvia and said, ‘Now I come fifth.’

She trained horses with the same sensitivity, passion and determination she brought to her teaching. She was absolutely determined. When Julie was riding or working with a young horse, time stood still. She would work herself to exhaustion and beyond. Nothing was too hard, nothing was impossible. Anything was achievable. This determination and steely resolve pervaded everything she did. This in the gentlest person I ever met.

This reflected the complexity of her character that was redolent with these sorts of contradictions. Julie craved approval, yet was embarrassed by praise.

She lavished compliments on the smallest achievement, yet she dismissed her own as trivial. She gave her love and affection with the simple naiveté of a child, yet was frequently uncomfortable with the emotion of others. She was charitable to a fault about the shortcomings of others, yet constantly doubted her own worth. This duality, this doubt, drove her constantly, and her relentless, cheerful and chirpy exterior enclosed a heart and soul which would be wracked by concerns, which of course she concealed.

These contradictions and her rigid sense of duty did nothing to inhibit the open nature of her character and heart. Her greatest sense of duty and her greatest love, she extended to her family. She idolised her father and adored her mother, and talked to them virtually every night through her illness. Her news was always positive, her outlook always bright. She sought to reassure them and inspire them. Such was the depth of her love for them. She doted on her brother Steve, despite his recurrent ambition to throw her in dams, tumour or no tumour, and she was more worried about the effect her illness was having on him than on herself. It was a never ending source of pride to her that she was able to guide and advise her youngest brother, Jason, through his time at St. Pat's while she was teaching there. Julie was eagerly anticipating performing the same role with her nephew Bradley, and her niece Laura, at Trinity. The moral and ethical centre of her world began with her family.

I did not wish to touch upon the nature of her illness. I wanted this speech to be about how she lived, rather than how she died. It is, however, impossible to separate how she lived from the terrible ailment which caused her death. Her greatest worry was the effect her illness was having on others. Julie was told the day she was diagnosed that she was terminally ill – that her type of tumour had no survivors. She was undaunted. Being a compulsive organiser, she immediately started a folder called "Getting Better". Twelve hours after surgery she tried to get up and help the nurse make the bed. One particular severe and sober Swedish doctor at Concord questioned me closely as to why Julie, who had an incurable brain tumour, was always so happy. She walked around the waiting room of RPA, where patients were usually grim and morose, and chatted, joked, laughed and inspired. She hugged Gavin who supervised her treatment every day, and virtually leaped on to the treatment table despite the fact that the radiation was making her violently nauseous. Julie told everyone – doctors, nurses, fellow patients, family, friends, me – one recurrent phrase: "I'm so lucky".

We must walk out of here today without heavy hearts. Tragedy is about human weakness, folly and vice. Pride, greed, ambition, jealousy and lust pervade the great tragedies of Shakespeare. These weaknesses remind us of our own vulnerability.

This is not Julie's story.

At Concord, in the hours and days after her diagnosis and surgery, I was overcome with despair and fear. I wanted to walk into the chapel and pray to God for a miracle. I didn't do that. I had an insight which has sustained me ever since, and will continue to do so. I was wrong to ask for a miracle. The miracle was Julie. What I needed to do was to go into the chapel and thank God for my 24 years with her.

Julie would hate all this fuss being made over her. I can only humbly ask that you walk out of here with a sense of affirmation, that the gift of her life will have some meaning in the context of our own.

Julie was right. She was lucky, and so are we."

Joe kept things moving, mentioned Julie's mother and father, made a great deal of Julie's involvement with Riding for the Disabled that had presented him with a rose bush, a Julia rose, to be planted in Julie's honour at Trinity and paid homage to all the qualities of Julie's character which had brought the hundreds of mourners to the cathedral.

Joe glanced at me and I shook my head. I just wasn't up to reading the poem and I felt slightly ashamed that in the midst of all this dignity, I wasn't sure I could maintain mine.

somewhere i have never travelled

*somewhere i have never travelled, gladly beyond
any experience, your eyes have their silence:
in your most frail gesture are things which enclose me,
or which i cannot touch because they are too near*

*your slightest look easily will unclothe me
though i have closed myself as fingers,
you open always petal by petal myself as Spring opens
(touching skillfully, mysteriously) her first rose*

*or if your wish be to close me, i and
my life will shut very beautifully, suddenly,
as when the heart of this flower imagines
the snow carefully everywhere descending;*

*nothing which we are to perceive in this world equals
the power of your intense fragility: whose texture
compels me with the color of its countries,
rendering death and forever with each breathing*

*(i do not know what it is about you that closes
and opens; only something in me understands
the voice of your eyes is deeper than all roses)
nobody, not even the rain, has such small hands
– e. e. cummings*

Joe returned to his seat after stopping to shake hands with me. I thought the Robert Earl Keen song perfect. I still think so.

*I climbed the mountains and I swept the plains
I crossed the border and I broke my chains
I walked the back roads 'til my shoes wore through
I'm still without you without you*

*I lie awake at night and say your name
I paint your picture in a starlit frame
I try imagining a rendezvous
I'm still without you.... without you*

*I thought I'd find
You would leave my mind
But my dreams they just don't know
They can't seem to let you go
I'm so sad I don't know what to do
Without you*

*I often wonder how it came to this
If I could travel back to our last kiss
If I had a different point of view*

*I'm still without you.... without you
 The moon is sitting just beyond the hill
 The wind is resting but my heart won't still
 It happens every night right on cue
 I'm still without you.... without you*

*I thought I'd find
 You would leave my mind
 But my dreams they just don't know
 They can't seem to let you go
 I'm so sad I don't know what to do
 Without you*

– *Still Without You/Conclusion: Road to No Return*, **Robert Earl Keen**

Dean Thompson then gave an address and, unbeknownst to me, would read a statement from Mother and Father. The funeral director was very annoyed. It wasn't in the script, but I was hardly surprised. I would not have objected to its inclusion, but as usual, they didn't trust me. "Daddy's Girl" had been played earlier but that had not been enough.

Final prayers and the commitment were intoned and as Dean Thompson introduced the John Prine song as a song of affirmation and reconciliation, we prepared to leave the cathedral.

Vicki had been weeping quietly throughout the ceremony while holding my hand. Her grip became deathly when the congregation was directed to stand. Dean Thompson preceded Julie's casket, and Father and Mother attempted to follow directly behind. The funeral director anticipated this and stepped in front of them and gestured to me to follow the casket.

When I turned around I was overwhelmed. The cathedral was packed. I don't think there were any spare seats and the crowd overflowed outside where there were about 100 people who had silently and reverently listened. I was stunned.

*Everything is cool
 Everything's okay
 Why just before last Christmas
 My baby went away
 Across the sea to an island
 While the bridges brightly burn
 So far away from my land
 The valley of the unconcerned
 I was walking down the road, man*

*Just looking at my shoes
 When God sent me an angel
 Just to chase away my blues
 I saw a hundred thousand blackbirds
 Just flying thru the sky
 And they seemed to form a teardrop
 From a black haired angel's eye
 That tear fell all around me
 And it washed my sins away
 Now everything is cool
 Everything's okay
 Everything is cool
 Everything's okay
 Why just before last Christmas
 My baby went away
 And I find it real surprising
 For myself to hear me say
 That everything is cool
 Everything's okay
 Everything is cool
 Everything's okay
 Why just before last Christmas
 My baby went away.
 – *Everything Is Cool*, John Prine*

I nodded at many people in silent acknowledgement but one face stood out in the crowd and I don't know why. One of my former colleagues, Bob Hagan, who had retired 10 years previously, was standing in the vestry. He had been the head teacher of Mathematics at Mulwaree and was an interesting and talented man with a delightfully wicked sense of humour who didn't suffer fools gladly. He seemed to delight in provoking principals and although nearly insufferable in meetings, he could be incredibly charitable in working with children. He was known to give reading lessons to students who he thought needed it, despite his field being Mathematics.

He was once probably a powerfully built man but gravity and age had given him a quite substantial paunch. Bob had a round face, creased with wrinkles, frown and laugh lines and darting eyes. I nodded in his direction, acknowledging his presence, and was touched by his look of profound hurt. I seemed to see all the grief and sorrow of all the people there condensed in his lined and expressive face and rheumy eyes. I passed by him and waited outside for the obsequies.

He didn't stop to give his condolences. He didn't need to.

Many people I had not seen in years had bothered to come. Some people I recognised and knew I should remember their names and knew later I would but, at the time, they eluded me. I shook hands, gave fake kisses and hugged people. When that stopped I stood on my own, truly alone for a moment, and decided that was enough. Feeling cold and drained, I went and sat in the mourning car on my own, hiding behind my sunglasses, protected by my invisible barrier of grief.

We pulled out of the cathedral, the funeral director striding purposefully ahead of the hearse. We pulled out on to Bourke Street and I was surprised as the hearse turned left and we turned right. I realised that we were heading in different directions and Julie was being taken to the crematorium in Canberra. I craned my neck to watch the hearse pull silently away as we made another turn.

The wake was an artificial affair. Everyone wanted to buy me a drink and it was the last thing I wanted. I had a couple of Diet Cokes, exchanged pleasantries and tried to chat with as many people as possible. The finger food was suitably odious and greasy cuisine: enough to feel like your money's worth but really unpalatable. I ate nothing.

After a couple of hours, the crowd began to thin and I excused myself and went back to Bede's. I was exhausted. I insisted I pay for dinner and we sent out for some Thai, opened a bottle of wine and I had a couple of glasses. I think I frightened Bede and Bronwyn because I was beginning to free associate.

I spoke about the horrible montage back at Bannister Springs and the pastiche of random emotions it elicited from me. It had only happened six days previously and I could not make any sense out of either what happened or my response to it. They were horrified. Bede had heard it before and it frightened him then. It frightens me still, and I realised later I would possibly never make any sense of it. As only tangentially connected stream of consciousness thoughts bubbled to the surface I talked of Julie, her struggle, the arbitrary and casual disposition of fate but, most of all, I spoke about how brave she was.

I will never know what prompted her final act. I like to think it was our situation, that we had faced her illness together, but the reality was that it was her situation. I tried to be there but she was really alone in her cocoon of uncertainty, apprehension and faith. The whole story is one of both hope and bravery along with fate and the cruel providence of an indifferent universe. I'd like to think that as she stepped off that chair it was an act of defiance and an attempt to preserve her identity before that would finally be taken away from her. I would

like to think she metaphorically raised her middle finger to an indifferent cosmos and kept that last vestige of the sense of herself.

We ate, we drank and, most important of all, we laughed. There had been too little laughter for a long time. A great many people commented about the story of the crass casual teacher from my eulogy and thought that it was a great anecdote about Julie; that it encapsulated her character. Most people thought the ceremony beautiful. That made me happy and I was proud of her. I think we opened a second bottle of wine. We told a lot of “Julie stories”.

The three of us all laughed when Bede observed, “I only know one thing and that’s Julie would have hated every minute of it today”. I think I had a Scotch with Bede. Grateful for their friendship and support, I lurched off to bed, more drained than drunk, and slept dreamlessly.

EPILOGUE

It was a long winter. But it passed. There were some very bad days and not many good ones. I found out that grieving is a Do-It-Yourself job and I tried to take a leaf from Julie's "Getting Better" folder.

I dealt with the sympathy cards, gave the \$900 raised at Julie's funeral to Riding for the Disabled. I had asked for donations to RDA in lieu of flowers and learned how to live alone. I had object lessons in the fine shades of meaning between solitude and loneliness and living and existing.

One of the very bad days came early. I picked up Julie's ashes on 28 June 2004. I had completed a lot of the details of Julie's affairs and estate and I did not anticipate that this would be any more difficult than giving copies of her death certificate to her employer, the solicitor, cancelling her driver's licence and straightening out the ownership details of the horses. Those things weren't easy, but this was different.

I chatted with the funeral director who had been sympathetic and decent and wrote a cheque for the account for the funeral. He came in with a paper shopping bag with Julie's ashes packed in two Styrofoam containers with a quite formal "Certificate of Cremation" attached to the top. I was rocked to the core of my being.

The envelope nestling in the top of the upmarket bag was pretty fancy. The flowing font's elaborate script should have said "Wedding Invitation" rather than "Certificate of Cremation". While the funeral director left on silent footsteps on the muffling carpet of the funeral home office to write a receipt, I sat in thrall at those three words. I would never open that envelope.

I drove slowly to the park in the centre of Goulburn only two blocks away and parked the Subaru. I had put the ashes in back of the passenger seat on the floor. I didn't want to look at them. I went to one of the cafés and bought a large black coffee and sat in the park. I found this more difficult than the funeral; perhaps because I was alone; perhaps because it synthesised all the elements of Julie's death and gave it crushing definition. I sat in the park for an hour, sipping my coffee and regaining a semblance of control.

I left the ashes in the back of the Subaru for three days until I could decide where in the house I could put them so that I would not see them. I put them in the back of Julie's wardrobe on the floor in a back corner. There would be nothing in there that I would ever need.

There was further conflict with Mother and Father over Julie's ashes. Unbeknownst to me they had gone to the funeral home and asked for Julie's ashes; a request that the funeral director refused. I had thought about the ashes,

almost as an abstract exercise, until I picked them up. It was a reality that I didn't really fully grasp. Two little Styrofoam bricks just could not hold Julie's essence. Jason called me. Mother and Father wanted half of Julie's ashes to scatter on their grave plots so, as Jason phrased it, "they could go and visit her." I knew where Julie would want her ashes scattered: on Clive's grave over at Tanglewood. I could not ask the new owners. I knew they would think it spooky and strange. I had thought later I would scatter them at Bannister Springs at the back of the property, up on top of the hill which had sweeping views not only of the property but off to the Southeast for almost 100km. It was beautiful and isolated; commanding and alternately wild with windy blustery weather and then serene, peaceful and tranquil.

The only thing that bothered me about scattering Julie's ashes at Bannister Springs was I would sell the property in the next year or so. I knew it was too much for me to maintain and, sadly, I would have to disperse the horses. Both aspects of our dream would be no more. It was inevitable. It was too hard and too dangerous for me to maintain the stud on my own and I could not sustain the property on one income.

I thought long and hard about Mother and Father's request. I thought it bizarre and macabre. Julie was so energetic, so ebullient that I thought a cemetery a grim and sombre setting for someone so lively. The resonant poetry of Ecclesiastes kept running through my head like a faint and elusive memory. The resounding phrase "the earth abideth forever" was foremost in my mind. I read this passage a score of times and sent a long e-mail to Jason. I would sell Bannister Springs but the earth would abide forever. New owners would come and go; but the land was forever. Australia was an ancient continent. Our generation would just be a blink. I would scatter Julie's ashes on the hill at the back of the property at a time of my own choosing.

Mother rang me and made the request to me directly. I told them that this is what I had decided and I thought dividing the ashes was "a sundering of her spirit". Mother told me she agreed with me. We ended the conversation amiably.

I would only speak to them one more time.

That spring, I retired from my job at Mulwaree.

In early October a memorial was dedicated to Julie at Trinity in a prominent location with her recurrent phrase of "I'm so lucky" as an enigmatic inscription. I didn't expect succeeding generations of students to really understand why this epitaph was chosen. Those that bothered to find out who Julie Barber was would understand. That's all that I expected. And people that knew her would always understand. That was one of the good days. The rose from Riding for the Disabled was planted. The photographs show people smiling and, except for Vicki, there were no tears.

After careful consideration, I decided her memorial was the proper setting for her ashes. If there is any of the spirit inherent in the substance, she would be in a place that she loved, in which her contribution was valued and remembered. I didn't find it inappropriate that the perpetual swirling bustle and chatter of children within inches of her memorial would be a constant. I thought it fitting. Joe obtained permission from the Christian Brothers for her ashes to be scattered on the campus.

Several of her friends, Vicki and Sandra, as well as some of her family asked if they could be there. I made the decision to scatter Julie's ashes on my own. I did not want another public or private ceremony. I essentially felt that I had not been permitted any private or intimate moment to reflect on our lives and our marriage. Everyone accepted that and understood. I intended to tell no one which day I would do it. And I never have. That one's mine.

In mid-December, after Trinity had finished for the year, in the time before Christmas, I went to Trinity early one morning, 5.30am with flowers (purple, of course) I had bought the evening before. I tended to Julie's garden with the sun coming up, a little early morning mist hung over Goulburn and the Trinity campus. It was going to be a hot day, however, the morning felt cool, clean and new. I scattered her ashes, rearranged the garden and sat by it for a few minutes. I didn't cry. I felt pretty good about it. Or as good as I could feel, under the circumstances. I said goodbye and went into town for coffee.

“One of the most chilling experiences a person and their family can have is to be told, You have a brain tumour.”

– Professor Noel G Dan, from the foreword of *Please Forgive You*

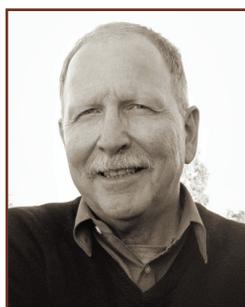
Julie Barber is a dedicated rider, an inspiring teacher and a wife when she is confronted with that diagnosis. Her story is about grace, courage and the humanity to deal with a condition as uncompromising as her own will. Having spent her life inspiring a generation of students in her teaching with her cheerful and vibrant personality, she brought the same attitude to her struggle with a brain tumour. But underneath the bubbly exterior, there was a steely will that was as uncompromising as her illness.

“To read Charley Barber’s account is to be humbled by the grace and dignity displayed by Julie. It is also a telling insight into the difficulties that such a horrible tumour creates within the family and the stresses that are brought to bear on loved ones.”

– Professor Noel G Dan, from the foreword of *Please Forgive You*

Her struggle lasted 167 days and in that time she never complained. Not once.

The outcome was as inevitable as gravity, but her journey touched all of those around her.



Charley Barber was born and raised in Rhode Island in the United States. Educated at the University of Notre Dame (where he wishes he had paid more attention) and graduating in 1971 he began teaching in Southampton, New York before migrating to Australia in 1975. A career teacher with the NSW Department of Education and Training, he spent his career as a teacher and head teacher of English at Mulwree High School in Goulburn, retiring in January 2005 after the death of his wife, Julie.

Please forgive you was written in response to the requests of friends that Julie’s life be commemorated, celebrated and remembered. A lifelong lover of writing, literature and music, Charley began the book with some trepidation in 2004. Supported and encouraged by his friends, editors and agent, the manuscript in final form was completed in 2010. Charley now lives with his partner, Rosemary Howe (Rose), at Bannister. He has completed a second book, a young adult’s novel about a slightly disagreeable girl riding a horse she feels is beneath her talents, and is currently working on his third, a comic novel.



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