Sarah’s Journey

by her mother
who walked it with her.

Prologue – October 2014

I was hosing the footpath with ‘Feed and Weed’ this morning in my lycra when the young mother who lives next door backed out of the garage in her BMW. She stared at me and looked … perplexed.

I am fifty; and to be blunt, no-one looks good in lycra (least of all middle aged women). I had forgotten I was still wearing it. I’d been meaning to do something about the weeds for weeks.

I realized that I had become ‘that Odd cat lady’.

I don’t think she knows I own a bike. It dawned on me, that I didn’t actually care what she thought. I smiled to myself, and happily finished the lawn. Being fifty is brilliant!

I was not always so self-contained.

A happy, relaxed and abundant life would have been nice. But life does not always work that way.

I firmly believe that it’s how we ‘pick ourselves up’ that makes us who we are. Like a phoenix out of ashes, it’s the hard times that define us. Not that I didn’t wish for an easier path.

* * *

I am cycling 1000 km in the month of October to raise money for childhood cancer research and support. I hope to do so every year until I am one hundred.

This book explains why I am doing this. (*And yes, I have three cats*).

For our Sarah.

She would love Ride4Sarah.

To my mother Carmel Sarah's Grandmother and my sister Mary-Clare for their endless faith, love and support.

For seriously ill children and those who love them.

For the nurses, doctors, allied health and other staff who do all they can.

“Whatever may happen to you -
was prepared for you from all eternity
and the implication of causes
was from eternity spinning
the thread of your being,
and of that which is incident to it.”

Marcus Aurelius

-1-

Life and Happiness.

"We are not to lead a life that is not tested."
Epictetus

I woke early and stared at the clean white ceiling. Asleep in the bed next to me was a stranger; and I let the tears slip quietly down my face.

I had created for myself a prison.

In the living room I cleaned up the debris left by his friends as they dressed for the wedding, and made coffee for my new husband and myself.

I imagined that people thought I was successful. I had worked very hard at becoming so. I was a corporate lawyer. I liked the river view from my office and the fact my secretary asked me if I wanted a cup of coffee each morning. My clothes were gorgeous. I was slim and I supposed, quite attractive. I thought people must think I'd "made it", that I was a "winner". I very much needed them to think this…because I was deeply, desperately unhappy.

I was searching for something that seemed always out of reach. I busied myself everyday in doing what I thought I ought to do and in being what I thought I ought to be. But for me there seemed end in sight, no hope, no light. I believed I had all the ingredients for happiness but could not figure out why it eluded me. I was a white mouse running madly around inside a little wheel.

Perhaps I if I worked harder; made some more money; perhaps if we had a nicer house I would be content. My husband wanted "the perfect wife", so I tried to be this too. The problem was that what he wanted of me kept changing, like a game where the rules are a secret.

I could not escape. I was caught my own need to be a success, to live the dream. I did not want the marriage to fail because this would expose the fact that I was a fraud. I wanted so very much for it to be the relationship that it appeared to be from the outside. But he remained closed to me and it always felt like pretend.

* * *

My wise mother accused me of being in denial about my pregnancy. She was probably right. In a lift at work a man asked, "When is the big day?" I stared at him blankly wondering how on earth he could possibly know about an impending trial date.

As fate would have it, the trial date and the birth date were the same. I had to do the final brief to the barrister over the phone during early contractions. I remember thinking that God had a sense of humor. Clearly she / he was trying to tell me something.

Labor was traumatic.

From the first gentle contraction until the birth was a grueling 36 hours. My Sarah arrived on the planet on Anzac Day, 25 April 1998. Life for me was never to be the same. I was completely, utterly, uncontrollably, madly, deeply in love with my beautiful baby girl. Love of a depth and power I didn't know existed. She had translucent skin, full red lips, auburn curls and huge hazel eyes. I had a strange sense about Sarah from the very beginning. I felt I recognized her. She seemed to me to be an old soul. She was demanding and loving and so very full of life. I loved her with every essence of me. I did not know where she ended and I began.

Giving birth had shaken my reality. It had reconnected me for a moment to an energy I could not then define. I did know however, that Sarah's birth had lit within me a quiet gentle instinct, a timeless powerful maternal love. I was only vaguely conscious that I had begun to change.

When the senior partner from the firm called the next day to announce we'd won the case, my reaction was something along the lines of "….Oh…. That's nice". His news was like a message from another life … a message meant for somebody else.

Always though, there was this subtle fear. Every night I would stand and watch my little girl as she slept. I knew on some deep level that I would not be able to protect her. My soul knew what was to come.

I kept working, part time now. My heart was with my baby, but my head still demanded, “Try to be a success,” and my husband wanted the money to keep coming in.
My son Tom was born just over two years later on 8 August 2000. He had blond curly hair and the blue eyes of an angel. You just wanted to check his shoulder blades for budding wings. He was placid and slept a great deal, unlike his sister who had been alert and a poor sleeper. He had big hands and big feet and was a joy from the moment he arrived.

Two children had been my plan. But I was taken with the certain knowledge that there was another soul I needed to bring into the world. Not given to 'flights of fancy' this was unusual for me. I lived in my head, not my heart. This feeling was undeniable, even for me.

My Kate was born sixteen months after her brother, on 20 December 2001. I bought her home from hospital on Christmas Eve. She was gorgeous, her hair dark and her eyes deep brown, almost black. She had a lovely little face with a dimple on her cheek and was very petite… just so beautiful. A gift.

My three wonderful curly haired darlings, my hobbits I called them ... I loved them so much.

* * *

I loaded the kids into the car one Saturday after a swimming lesson. Kate was one, Tom just over two and Sarah, four. The day was swelteringly hot. I sat in the front seat of the car and leaned around behind my seat to lovingly squeeze Sarah's foot. She was stone cold. An icy fist gripped at my heart, time paused between heartbeats and an unnamed fear settled in my chest.

Sarah was a pretty child. She'd become more beautiful and stronger willed with each passing year. She did not seem sick. Little things were not adding up though, something was not right. She was starting to need sleeps during the day like when she was a toddler. She'd have the odd mild temperature and she'd complain that her right leg hurt sometimes. She was crying more but I'd put this down to getting used to having a nanny. I was just back at work again after my third maternity leave in four years.

I thought I'd probably be labeled a neurotic mother, but at the doctor that Monday morning I asked for a blood test. The doctor ordered the test without comment. Sarah was frightened but crawled up onto the bench and put out her arm for the nurse to take the blood. I was struck by how skinny her arm looked and how pale and bruised her legs had become. When had this happened?

I buried the fear.

At 10 am the next morning the phone rang on my desk at work. I was vaguely surprised when I recognized the doctor's voice and slowly got to my feet.

Her tone held a warning … I braced myself …"Sarah has Leukaemia".

As I struggled to breath, the world changed. Everything went sharply into focus. Reality pushed sideways and I was no longer on the same earth as everyone else. Nothing that mattered with the previous breath - mattered Now. I was intensely aware of the edges of my body. I felt completely alone, disconnected, isolated. Normal life was over. Everything up until now had been in preparation for … This.

I learnt in that hideous instant that control over our lives is illusion. In a moment everything and anything that we consider safe and solid can dissolve in the ether.

As I asked, "Could there be some mistake?" it dawned on me that there was no mistake, and that I had known this was coming. I had known it as she suckled at my breast. I had known it as I had watched my little girl asleep in her cot. I asked about a second opinion and, in my cloud of shock and fear demanded to see "the best specialist in Queensland".

I sat and tried to figure out what to do next. I just settled on doing something … anything. I put in a call to my husband's office and told the secretary to get him to call me, to pull him out of any meeting, no matter whom he was with.

I collected the files I'd been working on and dumped them on a chair in another lawyer's office. He was on a call but could see the desperation in my face. I mumbled, "I can't believe this is happening". I reached out and touched his hand, it felt cold, but the ice was inside me.

My husband worked a few city blocks away so we shared a cab home. Shaking and in shock, I eventually managed to get the specialist on the mobile.
He spoke calmly. It was just a 'day at the office' to him. I needed to explain… this was not just another patient … this was my little girl. I said, "Sarah is my heart." It almost seemed as though he thought I was overreacting. This was a twilight zone.

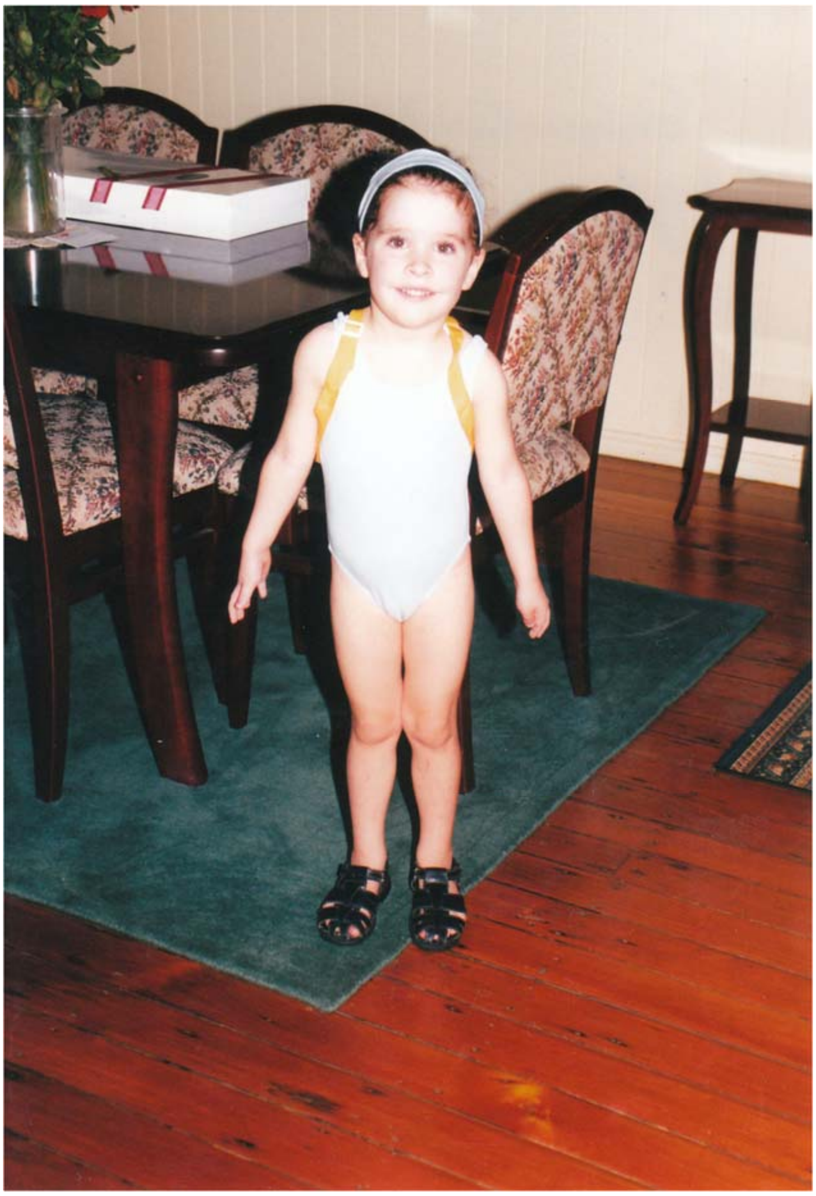
We picked up Sarah from preschool. I exchanged polite non-committal pleasantries with her teacher. It is a wonder that I appeared in any way normal. Couldn't she tell? I was walking through thick air. Each step, each breath needed conscious effort. At the same time I was not even in my body – Shock.

Sarah had fast food for lunch. I watched her eat, unable to swallow a morsel myself. I struggled to hold the tears inside knowing that when the crying started, it would not stop. I needed to choose my time. She chatted away to us, so happy to have her mum and dad all to herself. She thought she was having a special day, a treat. She was delighted when we bought her the most beautiful pair of pink pajamas we could find and some new slippers.

I called my parent's number from a pay phone in the shopping centre. How was I going to tell them? I couldn't get through at first and in anger, frustration and pain, punched the phone with my fist. Dad finally answered. I settled on the same words our doctor had used "Sarah has Leukaemia". I quietly listened as his world fell apart too.

I would forever measure life in two parts: before that awful day, and after. We arrived at the Royal Children's Hospital. I asked directions to the children's oncology outpatients department. I heard myself asking this as if from a long way away. The look in the eyes of the volunteer behind the desk was one of pure love, my face told our story. When we walked into outpatients I struggled to choke out Sarah's name and the name of her doctor to the receptionist.

Just three months earlier, at her kindergarten break-up, she had danced in front of the class, beautiful, happy and full of the joy of life, confident, oblivious to the adoring crowd of parents and grandparents. I had never been so proud and never seen her look so beautiful. How could we be here?



There were mothers, fathers and beautiful bald children on drips everywhere. I could not grasp that my healthy, active, confident, gorgeous, curly haired, Sarah was to be one of them.

-2-

The View from Hell

"We are disturbed not by things,
But by the view we take of them."

Epictetus

At first Sarah enjoyed her new celebrity status. Being the center of attention was definitely 'up her alley'. She sat in the middle of the big hospital bed smiling. It was all so novel.

The first blood tests and the drip made it real. A new intensity and fear crept into her eyes. She was wary and suspicious. Within an hour or so of arriving at the ward she seemed different, her face had become 'thin' somehow, her eyes too large. Her left hand now had a drip in it and was bandaged up with a board to keep it straight. She was tied to a pole with a bag of intravenous fluid hanging above. She hated the arm board and the metal pole.

Someone had tried to make the hospital room look friendly, there were pictures on the walls, but these were tired, standard issue. A hospital bed, grey tin bedside table, oxygen and power outlets behind the bed, a drip stand, emergency button on the wall and strangers coming in to poke and prod her all the time. The Grey walls were supposed to be cream; the doors were moss green. This was no child's bedroom.

I stayed in hospital with Sarah that night, the first of countless nights. I sat watching my little girl whilst she slept, impossibly beautiful and vulnerable, her first blood transfusion dripping into her pale little arm. I could not accept this reality.

I tried to understand why God was letting this happen. I tried to bargain with the distant paternal figure I imagined him to be. "*Whatever you want of me I will do. PLEASE make her well. PLEASE make her well. Please God. PLEASE make her well.*" I resolved never again to complain about stupid little things. Compared to this, <u>all</u> the everyday problems I could think of were stupid little things.

The next morning I woke thinking it must have been a dream. The realization we were still at the hospital, that this was the way things were now, descended on me slowly like a cold, thick, inky black fog. It sank into my bones, drained the life from my body and froze my soul.

Sarah had her first bone marrow biopsy under a general anesthetic that day. I gowned up in the standard green cotton shift and went into the operating theatre with her.

I had trained as a nurse when I left high school and had practiced as one for over twelve years before and during my legal studies. I had been inside operating theatres countless times. But then I had been playing another part. There was nothing in this scene to which I could relate. The room was full of people, all dressed in green or white theatre garb. They all wore caps over their hair and masks on their faces. I could recognise no one. There was the operating table, big lights hanging from the ceiling and the anesthetic machine at the end of the operating table. Trolleys, all covered in green sterile cloth were ready.

I held her in my arms until the anesthetist put her to sleep. I then laid her limp little body on the operating table. I looked around at all the pairs of eyes above the masks and said "*Look after my baby*", then walked out, straight back, blank face, leaving her in that sterile foreign place with nameless strangers.

I wandered out of the theatre and down to the cafeteria. I ordered something that tasted like cardboard. It was the usual hospital café, staffed by nervous harassed volunteers, serving fatty food, milkshakes, soft drinks and ordinary coffee.

I sat letting the tears flow as quietly as I could until the waitress bought over my meal. The pain was building and I felt my control slipping. I was in the middle of a whirlwind. There was nothing ordinary, nothing rational or understandable about my level of despair and fear.

The learned restraint and dignity I constantly and carefully held about myself, my persona and my mask - were not enough to anchor me to the earth.

I'd forgotten to get cutlery so went back inside. On the way back to my chair I lost control. I repeatedly thumped the table smashing the plastic knife and fork. I kicked my chair over and jumped up and down, I cried hysterically and over and over again mumbled to myself, "*It should have been me, not her, not her, not her. Dear God, not her.*"

I left the café, plate in hand, not a shred of dignity in place. I ate my cardboard meal head down staring at it and at nothing, far away from the café where no one could see me. No one offered to help. No one could have done.

I got through that first week one day at a time and gained a few insights along the way. Among them the realization that nothing in life is certain. That anything can change and end. Nothing and no one is to be taken for granted. I learned how important it is to look at and really see the people I love - to treasure every moment with them - to treasure "this moment". I resolved to never ever again allow myself to be consumed by worry about small everyday things.

Much to my surprise I discovered that hope is always there, no matter how bad things get… it might take a few days to surface, and sometimes I'd have to search for it… but it would be there. Two days after diagnosis I wrote in my journal, "Yesterday I thought life had given me more than I could bear. But today I think maybe I will manage it eventually. I will get her through this".

I prayed for help. My God and I took a step towards each other.

The view from Sarah's hospital room was good. I could see the city and my office building. That reality and that me, the insecure driven me that needed to appear a success, was a stone's throw from where I stood and an irrelevant memory from another life. The fact that I'd been able to see my office building from the Maternity Hospital when Sarah was born seemed to resonate with me; seemed somehow significant.

Leukaemia is an evil disease. Blood is mostly plasma. Floating in the plasma are red blood cells: that carry oxygen around the body; white blood cells: that fight disease and infection; and platelets: that help to stop bleeding when it starts. These blood cells are made in the bone marrow. In children with Leukaemia, the bone marrow produces large numbers of abnormal white blood cells. These crowd the bone marrow so it cannot make enough normal red blood cells, white blood cells or platelets.

The symptoms include weakness and tiredness, regular infections and high temperatures, bleeding that takes a long time to stop and pain in the bones and joints.[1] Treatment involves chemotherapy, Lots of it. This is a Brutal medicine that kills the abnormal blood cells. Problem is it also kills the good ones and the side effects are hideous.
We need to find a better cure, because this treatment is more violent than the disease.

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[1] www.betterhealth.vic.gov.au

Before giving Sarah her chemotherapy the nurses would don purple surgical gowns, purple gloves and eye-glasses to protect them from exposure to each cytotoxic drug.[2] The treatment room on the ward was a windowless cell, with feeble cartoon pictures on the wall and ceiling, as if these could soften the fact that this was a place of fear, of evil medicine, needles, tears and pain.

I'd watch as the purple nurses injected this toxic substance into my little girl's veins. Usually I'd have to hold her still, hold her down whilst it was done. It might have hurt less if it was just me being injected. I'd have volunteered to have every needle, every drop of that poison, if I could have spared her. I cried bitterly and quietly every single time, for months.

Try as I might I could not bring myself to tell Sarah she would lose her trademark gorgeous curly auburn hair. In the end my husband told her. I think he said too much because then she refused to take the medicine.

Sarah's dad relieved me at the hospital at some point during that first awful week. I could feel the sympathy and understanding in the eyes of the other mothers as I wheeled the double pram holding Tom and Kate out through the ward. I kept my head down; I'd not the strength to meet anyone's gaze.

It was all lost on baby Kate but two year old Tom watched everything, listening quietly as his mummy cried and repeatedly mumbled one prayer all the long walk to the car … "Please let us get her into remission before her 5th birthday."

* * *

We took Sarah home six days after diagnosis. I was filled with fear. The twisted parallels to bringing her home from the Maternity Hospital as a new baby were there in my head, mocking me. I wondered how I would cope.

The first night I got up to her three times; and up to Kate as well because she was teething. The normal demands of motherhood did not stop for Leukemia. The next day our dog knocked Sarah over and she hurt her thigh. She then could not walk so we had to carry her everywhere. The vomiting and diarrhea were constant.

In the space of a couple of weeks my gorgeous confident little girl had become emotional, prone to tears, traumatized and physically weak, frail beyond belief.

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[2] "Cyto- toxic" meaning - toxic to the cells.

Even when the kids slept through which was rare, I would lay awake. My husband watched television late into the night. His approach to adversity was to retreat into the 'strong man persona'. It was a role he played convincingly. It was a way of coping; it kept him safe. Let no one see you cry. Admit to no emotion. Find relief in the distraction of television, lots of alcohol, and inane conversation about football.

It might have helped if we could have talked about it. He just seemed to pretend it was not happening. I needed much more than that from my partner in life. I was never to get it and eventually I stopped reaching out to him.

Men and women deal with grief and crisis in different ways. But he and I had struggled to find common ground even when things were 'going well'. He had hidden behind his mask even before Sarah was sick, just as I hid behind mine.

I'd known from the beginning that the emotional distance between us was some sort of awful compromise. If I'd had more courage, or been more in touch with myself, or been less determined to live the stereotype, or perhaps been less catholic, I might have fled the relationship years before. To my eyes, this was my reality and that was that. I could not step outside of it and look at my situation with any objectivity.

Not that I was any expert at intimacy. But I knew the 'happy marriage' was a façade, a cardboard cut out of what I had wanted. That was why I tried so hard. I wanted to believe it was actually as we presented it to the world. It was not. It was however, enough for him. When I became a mother, the children were my love, my solace and my reason for being.

In the backyard late one night I lay on the kid's slippery slide and stared up at the stars. It felt like I was the only person on earth. Not that I wanted company. I drank two cans of rum and ginger beer and let the tears flow.

Over and over I prayed aloud, "*Do not shorten her life. Please let her grow up. Please let her have children. Take me instead. Shorten my life. Take me*." My fears overtook me. From where I was I could see only the darkness.

* * *

The battle to get Sarah to eat and to take medicine, and to keep her from vomiting it all up again continued every day. At 11am two days after discharge Sarah and I were back for our first chemotherapy outpatient's appointment. We waited 1¼ hour before the nurses even had time to do the preliminaries, measure her height and weight.

When Sarah realised she was to get a needle she cried hysterically, which started a nose bleed. This suggested that her platelets[3] were low. Thus she needed a drip, blood tests and a platelet transfusion. No platelets were available in the hospital and the next Red Cross delivery was not until 4pm, so we waited.

Waiting we learned was an unavoidable part of the nightmare. Eventually we got used to the waiting. We dropped our expectations; there was nothing for it. Hospital visits were an all day affair. Not uncommonly such visits resulted in unscheduled admissions and we'd be in hospital for days. The private room we'd had that first week was a treat reserved for the newly diagnosed, the seriously sick and the dying. It was simply luck to get it in other circumstances.

That day Sarah was upset getting the drip put in, but very brave about the nosebleed. I began to respect her courage. Children are amazing. She looked so beautiful lying there asleep, getting her blood transfusion. I watched her yet again with awe, fear and limitless love.

She was a stunning little girl and was very proud of her auburn curls. Everyone who saw her remarked on her hair. I worried constantly about how she would feel when it began to fall out.

The next day we were told that one of the children Sarah played with the first day in outpatients had chicken pox, which because of Sarah's compromised immunity, could be fatal. This meant two big intramuscular needles, not to mention another chemotherapy shot and a blood test. We had to wait for the test result. The red blood cells were low this time so, another transfusion was needed. Thirteen days after diagnosis she had had countless needles, tests and blood transfusions. She walked with a limp; she was pale, sick and completely washed out - utterly miserable and wretched.

* * *

We were caught in public hospital hell. I refused to leave the outpatient's department one day until someone looked at her. Her abdomen was painful and swollen. Something else was going on … surely this was not right? As her pain got worse, I my control slipped again. We had waited for hours. I walked up to the desk thumped it with my fist and yelled, "I want my daughter seen and I want her seen now". I then walked around behind the desk and again yelled "Now!"

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[3] Platelets are blood cells which enable the blood to clot and thus prevent bleeding. When these are too low nosebleeds are common.

Wires were crossed; there are so many children there, all so desperately ill. If you are not vocal, if you are not a good advocate, if you do not wish to make waves, or if you are just not feeling strong, you get lost in the system. Another lesson.

It worked.

We were ushered into a doctor's office and I rocked her on my lap as they gave her an injection of morphine to settle the awful pain. Within 10 minutes we were in X-ray having an abdominal X-ray. On the X-ray slip the doctor had written a provisional diagnosis of "Constipation or … a Ruptured Bowel". For God's sake didn't they think I could read? The later, would have killed her by weeks end. There were days I wished I had no clinical knowledge.

It turned out to be the former. That night I got drunk.

The next day the first clump of her beautiful curly hair fell out.

* * *

I wish I could say that this was just a bad fortnight. Things did eventually ease up a bit, but these first few days were not unusual, they merely set the tone. The trauma seemed to go on and on. There was not time to process one onslaught before the next thing happened.

The backlog of unresolved and unprocessed trauma built up and up. I am sure it was much worse for Sarah. I thought that my own personal struggle, the pain and despair would consume me and that in the end there would be no Me. Life held no joy any more, only fear and sorrow. Two weeks earlier, life had been 'normal'.

At day 14 the bone marrow biopsy showed no Leukaemia cells and my hopes went way up. But the seesaw of emotions was to hurt so very much… over and over. The next day I descended again to the depths of despair. I did not know why. Perhaps it was just that the weight seemed to lift a little and then I woke to see it was still there.

I had so much yet to learn. At that stage I thought it would be easier to be dead than to live through the pain and fear. I wrote in my journal "*This has destroyed me. Something inside is broken and I don't think it can be fixed. I don't want to live anymore. There is nothing to live for! I can't do this*."

Words of wisdom can come from anywhere. It is important to listen! Bill our turbaned Indian Seike shopkeeper at the local corner store said “There is no use sitting on your own crying – put your trust in God”. He was right. This was too much to carry. I had to put it in God’s hands.

I began to experience the power of faith in times of despair. Its true value only became apparent when there was nothing else left to sustain me. It was a painfully fine thread but it was all I had to hold on to and thus tested it was to become stronger.

Wonderful reading

Redfield, James	The Celestine Prophecy, An Adventure Bantam Books, Sydney 1995

-3-

The Nature of Love

"Love is patient, love is kind…
It is not rude, it is not self-seeking, it is not easily angered,
it keeps no record of wrongs.
Love does not delight in evil but rejoices with the truth.
It always protects, always trusts, always perseveres."

1 Corinthians

I realized that if all I could do was to put one foot in front of the other, this was sufficient.

No matter how tired, depressed or distressed I was, there was always enough strength the next morning to get through the day, always… although, often not an ounce more. One only ever has to survive today. Trust in this: unconditional love enables enormous incalculable fortitude and perseverance.

I remember exactly two months post diagnosis; Sarah, Tom and Kate were playing, running through the house and laughing just as they had always done. It had been so long since I'd seen this. I paused and watched with joy.

Sarah gradually got used to the life. I remember she walked into the operating theatre one day and did not even need me to hold her hand. We were living in a reality where going to theatre for surgical procedures became routine. I lifted her onto the table and she chatted happily. She had a couple of seconds of upset when the IV went in and then was asleep.

What a child.

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Less than a week later Sarah was again in hospital, another unscheduled admission… this time with a high fever. Instead of the brief outpatient's appointment I had expected, we were admitted to the ward and stayed for days.

We were sharing a room with other children. Parents 'slept' in fold out stretchers which we would set up by the hospital beds. Drip machines beeped all night; nurses went from bed to bed with torches, taking observations, giving medications and doing what nurses do. Children cried and so did the parents. There was little sleep to be had. I would sit in my own pain and absorb the pain around me. I did not know how to protect myself from it. As usual, after two or three nights I was exhausted and functioning on autopilot.

In the ward corridor I held the phone and listened numbly as my husband vented his anger. I had parked my car (the one with the child seats) outside the hospital. This caused him inconvenience. I was being selfish again, he said, always thinking of myself. I did not think I could feel any more. His words seemed to bounce off me. But at the same time I knew each utterance was like a little arrow piercing my heart. I vaguely wished I knew how to defend myself against them, to pull them out, or to heal afterwards.

It would be years before I grasped that his frequent anger was a projection of his own pain and self-perception. What he said he hated about me and criticized in me was usually his own projected self-loathing. He could not grasp (and I think never will) that it was aspects of himself that he hated. It was easier to hate me.

Lots of people do this. Until we become self aware, until we wake up. All I knew at that stage was that his angry words hurt, always, every time and very much. The ward walls were pale green but I always remember them as grey.

I told myself that I could cope with the distance between us, with the lack of emotional support. I thought I could cope with what I saw as his inability to communicate or to connect emotionally or spiritually. Could he have been a ‘mirror’ for me too? Was my view of him a projection of my own fear of intimacy? In any event, I convinced myself I could interpret his feelings, even if he would not share them. I was a strong, successful resilient woman wasn’t I?

But as the crisis continued, his anger became more frequent. I felt it was destroying me… like an attack from behind my defenses. I never saw it coming and could not understand why he verbally and emotionally abused the woman he was meant to love, a mother going through unutterable despair.

That night he stayed at the hospital with Sarah. When I bought the other children in the next day for a visit he told me I was a dreadful mother, a failure. He knew what to say to cause the most damage. He said, “What kind of mother would forget to bring in Easter eggs and carrots?” God I thought, “Was it Easter?” With the wisdom of hindsight, I can see that he was projecting his own self-hatred. It was easier to believe it was me who was at fault. He had no personal insight.

I didn’t defend myself, get angry or shout back or ask why he had not organized Easter. I did not reject his criticism at all. I looked for compassion from him and was always surprised by its absence. I had become a victim. The verbal abuse always happened in private. In public we held ourselves up as the perfect partnership. He treated me with kindness and respect when others were around. I didn’t want anyone to know what it was really like either. I wanted others to believe us. I wanted to, needed to try to believe in the facade.

I took the little ones to the supermarket and bought the blasted eggs and carrots. Whilst there, I ran into a mother from Sarah’s preschool, a woman I barely knew… and cried in her arms.

I delivered the goods back to the hospital and went home. When I called the hospital later that night my husband did not acknowledge that anything destructive had happened between us. Whether he realized it or not, it made him feel strong to make me weak, he was taping into my energy and taking it for himself. This sustained him. He did not know how to source and replace his own energy.[4] He was in effect an emotional vampire.

This was not Love. This was a stranger in Love's clothing. This was a parody of Love. Watch for such people. Defend yourself against them. They can be cured but not by others, they must start their own cure from within their own selves.

Looking back I can see a pattern in the marriage; a pattern that others in my family could see at the time, but that I could not. Every few weeks he would reduce me to tears. He would abuse me, yell at me, and berate me until I cried, sometimes curled in fetal position on the floor. It would always take me days to regain my emotional and spiritual strength. Yet he would immediately forget each incident, as if these attacks had never happened.

Much later, I realized that if I did not escape the marriage, I would pay with my sanity. Some people find their energy within and some take it from others. The dynamic worked for him. But it was for me unsustainable. I was struggling and felt as though I would disappear. I went through a large pile of tissues and a bottle of very good red that evening. I was beginning to drink more than was wise.

I have since learnt to feel when someone is taking my energy and to put a stop to it as necessary. I have learned to nurture and guard my life force. I wish I had known this then. We all have the ability to monitor personal energy levels. Each of us can refill, nurture our souls whenever the need arises. Once learnt, we naturally have more energy to give to others and are more willing to give it.

* * *

Tom and Kate were quiet witnesses. Like all children, they absorbed what was going on around them like little sponges. We would try to shield them from the fear and pain. But children, even very young children are not deceived. With a moment's twist of fate, they had lost the attention of their parents. They were pushed to the side. For a seemingly endless time these two poor little souls received at best peripheral attention. And we, their parents were deprived of the joy of those toddler years.

I tried to make life as normal as possible. Easter morning and the traditional family egg hunt was a source of delight for Tom and Kate. They were still in their winter pajamas. They looked gorgeous in flannelette just begging to be cuddled. Kate wore a hand-me-

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[4] Evans, Patricia, The Verbally Abusive Relationship, page 106

down. It was dark blue with the feet sewn in to the pants, undeniably cute but not nearly feminine enough for such a pretty little girl.

Tom struggled around the house dragging my old wicker picnic basket, way too big for him but the eggs had to be put somewhere. Baby Kate waddled around after him in wrapped attention. She had no idea what it was all about but she knew it was good. Each hidden egg was greeted with whoops from Tom. Kate's mystified but delighted face was a joy to behold. Soon she was whooping too, on cue. Easter bunny had eaten most of the carrot. Tom was impressed.

Watching the egg hunt was a chance for me to share vicariously in their delight. I marveled at their innate ability to enjoy "*this* moment", to forget everything else and surrender themselves entirely to the sheer joy of now. Children have an inherent ability to do this. Thus they find happiness where adults cannot. As we grow up (to quote Eckhart Tolle) we forget how to "stay in the Now". I think this can be relearned, or remembered. It has of late become an aim in my life to nurture this inner child, or perhaps to reanimate her, mine had died. I needed her.

My husband bought Sarah home from hospital for a few hours that morning. He did not participate in our celebrations. Instead he shut himself in the master bedroom and slept. I did not expect any more of him than that. Still I was happy. I had all three of my babies together for a while that Easter.

Sarah was discharged the next day but developed another very high fever in the middle of the night. Panicked and stressed, I rushed her back to hospital. In the emergency department I sat next to her on a cheap plastic chair until almost morning. In deference to her vulnerability, we were given the use of a little clinic room out the back. Thus Sarah had a stretcher and went to sleep.

This was one of many such nights. My little girl more or less took it in her stride. She would go quiet sometimes though. I worried for her, and not just for her physical wellbeing.

The day before her 5th birthday we got the news for which we had been waiting six long weeks. Sarah had the Standard Risk Leukaemia as opposed to the High Risk variety. I cried tears of relief and of joy. This meant her treatment would be 'simpler' and her prognosis better.

My husband spent eight hundred dollars on a gold bracelet for her birthday. She preferred the Playstation and 'Spyro' game. This game involved the adventures of a little purple dragon that wandered from place to place defeating bad guys and collecting diamonds.

We had bacon and eggs for breakfast and a birthday lunch with just us, no family party this year. She was too vulnerable to infection to mix with anyone. We bought her a huge, magic, absolutely gorgeous Cinderella birthday cake. It was pink (of course) and pale green. On top were figurines of Cinderella, her prince and the horse drawn carriage that took her to the ball. It was the stuff of little girl dreams. I could not get her to eat any.

Wonderful Reading:

Grad, Marcia	The Princess Who Believed in Fairy Tales, A Story for Modern Times Melvin Powers, Wilshire Book Company, Chatsworth, California, 1995
Fisher, Robert	The Knight in Rusty Armor Melvin Powers Wilshire Book Company, Chatsworth, California, 1990
Evans, Patricia	The Verbally Abusive Relationship, How to Recognize it and Respond. Adams Media Corporation, Avon, Massachusetts, 1996
Tolle, Eckhart	The Power of Now, A Guide to Spiritual Enlightenment Hachette Australia, Sydney 2007

-4-

Children, Honesty and Trust

"Your children are not your children, they are the sons and daughters of life's longing for itself."

Kahlil Gibran

Sarah had a fascination, a deep love for babies. She was entranced by them; and they her. I took the kids to see a friend and her newborn daughter. Sarah couldn't take her eyes off the little one and wanted to hold her the whole time.

On the drive home Sarah was sitting in the back seat chatting away about the baby girl. She then said, "When I grow up I'm going to have lots of babies". She caught me off guard with this comment.

I remember every second of the next few minutes. I had to tell her the truth. I could not lie to her. I had been honest with her all the way through her treatment, about everything – if I had not, she would not have been able to trust me. I wish that just this once I had let it go or put off what had to be said.

How do you tell a five-year-old girl that her treatment would probably render her sterile? I said as gently as I could, “Because you have been sick, you might not be able to have your own babies”. I had to tell her.

She became hysterical, screaming and crying over the loss of her future children, the death of her dreams.

I was driving down a main road close to home. Caught in the center lane of traffic, I could not immediately pull over. I turned into the first side street I could, dived out of the front seat and dragged open the back door.

I held her in my arms and we cried together. I held her as she threw up on the road beside the car. We cried for her and her babies. I cried for me too, for my lost grandchildren. Our hearts broke together. Our pain and sorrow overwhelmed us, leaving both mother and child shivering helpless in its wake.

Tom and Kate just watched in reverent silence. They could see our tears but could not grasp the enormity of our loss.

I promised I would do everything in my power to help her have children. I would do anything, pay for anything. Even help her to adopt little babies from overseas if she wanted.

After a while she became very quiet in my arms and seemed to take my words on board.
From then on instead of talking about having her own babies, she would talk about the little ones she would adopt from overseas.
Where did she find such faith and strength?

* * *

Sarah like all children deserved and needed honesty, as gently presented as possible and given in terms that she could understand. Children always and especially when going through something so difficult need unshakable trust in their parents. Trust in love and honour the faith and wisdom of children. There is so much we can learn from them.

Wonderful Reading:

Thompson, C; Lissiat, A	The Short and Incredibly Happy Life of Riley Lothian Books, Sydney, 2006
Gibran, Kahlil	The Prophet, William Heinemann Ltd, London, 1980

-5-

Hope and Peace in the Eye of the Storm

"It is hope which makes the shipwrecked sailor
strike out with his arms in the midst of the sea,
though no land is in sight."

Ovid

Nothing was smooth sailing. I was diligent about Sarah's care, a little paranoid even. I'd been a nurse so I knew what to do. Still things happened which were beyond my control.

Over the first few months Sarah was exposed to chicken pox three times; developed infections of the port-a-cath[5] and bone marrow biopsy site, she suffered fevers, flu, abdominal pain, vomiting, mouth ulcers, and anaemia.

Parents of children with cancer are all swimming against the tide. I battled continual guilt, debilitating worry, fear and depression. At times I could see nothing to look forward to… no joy. I had no goal other than getting Sarah better and that involved watching her endure the disease and the treatment. There was no way out but through it.

Each step of the way we'd conspire with the hospital staff to administer treatment… to help put in drips, give needles, tablets, take tests, do anesthetics… over and over again. It felt like legalized child abuse. But there was no choice. This was part of the pain. Control of our child's care, of our lives was taken from us. Of necessity of course, but that knowledge did not make it easier. All we could do was go with it.

Because of the risk of infection we would visit no one, go nowhere, do nothing. The social isolation took its toll. I had little support and felt sad all the time.

Being a good parent was hard under those circumstances and at times I believed I failed miserably. One night after I'd fought with Sarah to have a bath and take her medicine she was so upset she vomited. I said, "I wish I was dead" and said so in front of her.

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[5] Sarah had a port-a-cath inserted in her chest. This is a permanent site for the administration of intravenous medication.

This was so far from the image in my mind of the mother I wanted to be. After the kids were in bed I went out and bought some tins of rum and ginger beer and sat in the car in the garage for an hour and cried. I was drinking alone more often.

The next morning Sarah had to fast from 5am for another anesthetic. I got up at 4.20am and made ravioli, her favorite food. We had a fight again because she refused to eat and she then spilt chocolate milk all over the bed. I told her I hated her and I told myself I was an awful, horrible, useless mother.

As usual, we were at the hospital all day, this time for a lumbar puncture, spinal chemotherapy and a blood transfusion. We did not get home until 7pm. I had a sore throat, and realized I'd been unwell at that point for about three weeks. Pain and despair had become a way of life.

I might just skip over things a bit now. This is how it was. It was like drowning. Still, life took on a certain pattern, even seemed routine. There was a degree of solace in this. I would not have believed it if you'd told me in the beginning, but we became used to the existence. It felt almost normal. One can adapt to almost anything. Even in times of great distress, life can take on a comforting normality. I was surprised by this innate human ability to adjust. Routine, even a bad routine, can be a source of comfort. I was later to discover the vital importance of changing the negative routine, when the need for it had passed.

On 10 May 2003 Sarah had another temperature so she and I spent all day at the hospital. When we got home my husband turned on me yet again blaming my working as a lawyer for Sarah's illness. He then threatened to leave me and take my children. He was irrational at times like this.

Verbal abuse is very common. There are no bruises, but it is deeply wounding to the spirit. Almost without exception it occurs behind closed doors.[6] I could not at that time understand the attacks and thought perhaps I had done something to deserve them. Negative words hurt as much as punches. Especially so if the words come from someone you love. As usual the next day he acted as though nothing had happened. This invalidated my pain. I almost thought I had imagined it. The experts call this crazy making.[7] As always it took me days to recover.

I would try to work out what I had done to provoke him. But it was not me. Whether he consciously understood it or not, the attack itself was the motivation. By doing this he

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[6] . Evans, Patricia, The Verbally Abusive Relationship, op cit.

[7] ibid

took my energy. It was a way of 'filling up' at my expense. It would make him feel strong. At the time I did not know the mechanics of verbal abuse and could not defend myself against it. I did not have to suffer the theft of my energy. But first I needed to realize it was happening. At that time in my life, I did not have this insight.

* * *

Sarah eventually got to the stage where she could go to preschool occasionally. I will never forget the first time. We went in for the class photo. Her face was a little puffed up from the steroids. Her hair was thinner than it should have been, but under a hat you barely noticed that. It was good to see her in a pretty dress rather than pajamas. She played with her friends just like always. She was chirpy and loved the attention. It bought tears to my eyes. I hid them as best I could. When we got home she slept all afternoon.

* * *

She and I would have a 'ladies lunch' at the local Italian restaurant to celebrate the end of each cycle of chemotherapy. Each stage of treatment behind us was a milestone, a battle won. This became our tradition. She would always want ravioli, a soft drink and some ice-cream. We'd sit and chat, or just quietly enjoy being together.

We managed to go to a couple of her friends' birthday parties. I remember the first one. I was emotionally exhausted because I had to recount events to several different mothers. It was really too much for both of us but worth it to see her get to be a normal kid for a little while.

My poor Tom and Kate continued to take second place. One evening little Kate fell over downstairs and hit her face on the tiles. I picked her up to cuddle her but Sarah started to vomit at the same time so I handed Kate to her dad and went to her big sister. Only after I had settled Sarah did I see the bleeding from Kate's mouth. I gave her some infant paracetamol and warm milk and put her to bed. The next day I realized my poor little baby had chipped both front teeth. It must have hurt. I felt awful; felt that I had failed her.

If one child is ill, the whole family suffers. I used to feel it would take every day of the rest of my life to try and catch up on the maternal love and attention denied Tom and Kate. When at the hospital with Sarah I would think about Tom's goodnight hugs, the way he'd put his arms around my neck and say 'I love you Mumma'. I'd imagine giving Kate her bottle; see her intense beautiful dark brown eyes staring into mine.

The love of my children kept me from going under. I stayed afloat for them alone.

* * *

My husband's verbal attacks hurt. But our own negative self-talk is just as or even more damaging than the unkind words of others. It is self-abuse.

Also, thoughts are creative. We manifest the life we expect. In time I began to learn to monitor my thoughts. I found that where my thoughts were positive, so too were my emotions and my actions. This gains momentum and becomes self-perpetuating. Negative thoughts produce negative outcomes. This is such an important idea to grasp.

The place to find peace and tranquility is within one's self. Then you never have to be at the mercy of chaos. I wish I'd have known this then. I was eventually to realize that blaming myself; and feeling guilty about circumstances beyond my control - was to be actively resisted. It was of course, easier to understand this cognitively than to internalize and accept the truth of it.

I had to learn to be gentle with me. It helped to realize that inside of me resided an inner child, the little girl that was. And she too deserved to be nurtured, and to be loved.

Wonderful Reading:

Covey, Stephen R	The Seven Habits of Highly Effective People, Powerful Lessons in Personal Change. Simon & Schuster, Sydney. 1989
Byrne, Rhonda	The Secret. Beyond Words Publishing, Atria Books, New York 2006

-6-

Reactive Depression

"My grace is sufficient for thee; for my strength is made perfect in weakness."

2 Corinthians 12:9

I kept seeing a scene in my head. I was sitting in the front pew of our local church, left hand side, closest to the aisle. The sun was streaming in bathing the altar and me in morning sunshine. There were people all around in other pews but I was alone in the light. An arm's length away was a little white coffin.

I felt empty, a shell. I wore a mask of composure but there was nothing behind it. My reserves of strength were gone.

The next cycle of chemotherapy was delayed three times. Sarah's blood count was not high enough to cope with a new cytotoxic onslaught. Each time I braced myself and built myself up only to be disappointed because Sarah was not well enough to proceed. Each delay seemed to put the end of treatment further out of reach.

The nurses were mostly wonderful. It takes someone special to work every day in children's oncology. The woman on duty that particular day however, should not have been caring for children. She was efficient but cold. I quietly asked if she had considered working in theatre – where the patients are unconscious.

The oncology ward was full. So we were admitted to another ward. Crowded into a six bed room were four cancer children and their parents and two other children in for 'behavioral reactions to food intolerances'. The mother of these later two kept using her mobile phone.

Back then, mobiles could not be used in hospital wards because they interfered with the equipment (such as intravenous infusion machines). All four cancer children were on high does of chemotherapy via these machines. I was close to walking across the ward and wring the stupid bitch's neck.

As usual it hurt being away from Tom and Kate. Tom had been waking up at night missing his mum; and Kate would cry when she had to leave the hospital after visits. I kept torturing myself with the thought that such little children should not be away from their mother.

I stayed in hospital with Sarah for about a week with each dose of chemotherapy in that cycle. The lack of sleep was driving me crazy. I had developed a dread of the hospital. I would feel sick and anxious for a couple of days before each visit. Considering the number of times we were required to be there, this was a problem. My husband started to do more of the hospital stints.

One day Geoff Huegill (a famous Australian Olympic swimmer) was shaving his head in the ward as publicity to raise awareness for cancer research. Sarah fascinated by the goings on, wanted to be a part of it. I went with her pushing the drip stand. My husband was angry. He accused me of wanting to be on TV, of ignoring Tom and Kate and not letting them have time with their sister. This did not stop him leaving early and taking the kids with him. It turned out he wanted to go to the gym. In my journal that day I described him in somewhat unflattering terms which I'd be embarrassed to recount here.

My journal entries were actually getting a bit 'out there' by this stage. The one dated 2 July 2003, for example, speaks for itself:

> "I can't handle the emotional abuse any more. He is not happy unless I am unhappy. It is pathological. I have to suffer for him to be content.
>
> He makes me wish I were dead. I often think of dying – an overdose of his sleeping tablets; a piece of hose in the exhaust pipe into the back window of the car. I have a piece cut already. I did this one day when I was very upset. Today I have been thinking about jumping from the hospital roof, though not really seriously. It would be better to just die of a cerebral hemorrhage in my sleep.
>
> I hate life – it hurts too much now. When the kids grow up, if I am still on this earth, I will leave him. I don't know if I can keep going, I don't think I want to, why bother? What is there to live for? I hate him. I hate God. I hate my life."

I had not managed to get on top of how I was feeling despite exercise, prayer, and talking with family and friends. Comfort eating and the occasional reliance on alcohol were not helping.

One of Sarah's specialists had a quiet word to me one day (and just in time). She had seen countless mothers nurse their children through cancer. She suggested I see my own doctor to talk about how I was feeling. This I did.

No matter how strong and capable you think you are, any one of us can be given too much to deal with on our own. It is not just ‘Ok’ to ask for help at this stage, it is absolutely essential.

I was prescribed an anti-depressant. This took about six weeks to kick in. But once it started to work, it was like being lifted out of a fog and being able to see the horizon. In that fog, I could see nothing but the darkness. The medication did not stop me feeling. Everything hurt just as much. But I was able to function again.

Depression is a chemical imbalance in the brain. If not recognized and treated it can become permanent. The problem is that the person going through it may not recognize that there is a problem. Certainly I didn’t. What is worse, often the sufferer tries to hide it. I did.

If you think someone you love is suffering from depression, don’t be afraid to say something or to offer a hand. You may just be saving their life. Feeling down for a few days in a row is normal, protracted depressed feelings are not. It is strength, not weakness to admit a need for and then to accept help. Sometimes people try to be strong for too long. It takes humility to face it.

Not being particularly humble, I tried to present to the world a strong calm capable face. I still tended to refuse most help offered. But I was learning. I was recognizing that it was beginning to take more and more of my reserves to pretend to be strong.

One’s reserves of emotional and spiritual energy (essentially the same thing) are like a bucket of strength, a bucket of ‘self’ which has to be replenished. I was eventually to learn that it was vital to keep an eye on my own energy levels, never to wait for the bucket to be empty to ‘fill up again’. It is important to notice when the level drops and then to fill it straight away. This is reasonably easy to do, but like all of us, I had to learn how.

My husband was diagnosed with depression also - surprise, surprise. Unfortunately he denied his diagnosis and decided to ‘tough it out’. He stopped taking his medication after a few days. It would have been easier on us all if he had been willing to listen to advice. He then decided because I was depressed, (and he wasn’t) that I was weak, a failure. He was projecting again of course, but there was nothing I could do to change this.

Wonderful Reading:

Ford, Debbie	The Dark Side of the Light Chasers Hodder & Stoughton, London 2001

-7-

Learning to Cope,
Looking for Happiness.

"Start by doing what's necessary, then what's possible,
and suddenly you are doing the impossible."

Francis Of Assisi

Good things happened.

To get away for a couple of days we visited Tom and Pam Leahy who lived outside Dalby. The family was very famous for their role in 'colonial' New Guinea. 'Uncle' Tom was my husband's second cousin (or something like that). We were welcomed as family at their farm 'Cowora Two'.

It was a wonderful magical happy place. Uncle Tom had spent most of his life in New Guinea. There were native spears and masks hanging on the walls. Two huge crocodile skins took pride of place on the living room floor. Tom had killed them himself, or so he said. Pam's soft floral lounge suite made the place feel homey. To say the décor was eclectic would be an understatement.

Pam saved orphan joeys. She'd raise them until they were old enough and strong enough to cope on their own in the bush. Kangaroos from her current group hopped into the kitchen morning and night to be fed. The smallest ones slept in hessian bags inside, close to the fire for warmth. My children were beside themselves with amazement and delight. Sarah just could not believe it.

There were also chickens, a couple of dogs, cows and a parrot. Peacocks wandered around the yard near the house.

Tom chased the chickens all around the paddock the first night…. No eggs that day. I'll always remember Kate half running, half waddling across the yard at dusk yelling "Roo!" at the top of her voice and scaring the kangaroos half to death.

We'd have a scotch and dry at sun down. Pam cooked a feast each evening, enjoyed with good red and good conversation. After dinner each night we gathered in the living room around the fire. Uncle Tom sat with Sarah curled up in his lap. She sucked her thumb and he rubbed her feet.

* * *

Pam died about a month ago, as I write, of lung cancer. I will always remember her as a beautiful lady who created magic around her.

* * *

We were back in hospital the following week for the next dose of chemotherapy. I remarked in my journal about how much easier things were than at the beginning of Sarah's treatment. This life, horrible as it was, had become almost routine.

When Sarah woke the next morning at 6am she said the bed was wet. The drip tubing was disconnected and the cytotoxic high dose chemotherapy was running into the sheets. Worse, her needle was blocked and after several attempts to unblock it the nurses had to remove the needle and re-inject her port-a-cath without anesthetic cream. I held her as it was done. I held her down as she screamed in pain and fear.

Sarah was hysterical going into theatre that morning for her lumbar puncture. She was shrieking, thrashing and punching me as I carried her in. I helped them hold her still so they could put the mask over her face. I continued to hold her until she was asleep.

Unable to stop my tears I went into the pan room to hide. There was nowhere else to go. One of the volunteers followed me in and gave me a hug - though what I really needed was to be alone.

She told me she'd lost her own daughter in an asthma attack. Her daughter, a physiotherapist, had worked here at the hospital with the cancer kids. Here this brave lady was following her heart, doing all she could for other parents in pain. She was continuing her daughter's work. I did not know her well but remember her with love.

After theatre Sarah vomited three times. Then she decided she wanted to see the 'Clown Doctors'. These clowns wander through the Royal Children's' Hospital dressed as doctors … big floppy shoes, funny hair, false noses, stethoscopes and medical coats. They cheer up sick children and parents alike. Very occasionally they miss the mark, you either love them or hate them, but for the most part they are worth their weight in gold. I'd be willing to bet there are days they go home from work and bawl themselves to sleep.

My back hurt terribly the next morning. Carrying the struggling Sarah into theatre had done some lasting damage.

That afternoon our little family was asked to feature in the Royal Children's Hospital Foundation Christmas advertisement that was to be filmed the next day. The Foundation raises money for clinical research and to make the lives of sick children and parents a little easier. They sponsor the Clown Doctors.

This was all very well, a great cause and a good idea in principle. The kids were keen. But I of course, looked and felt like hell. On spec I called into our local hair salon. I told the ladies my dilemma and they agreed to help. They were staying back to do their own hair they said, so they agreed to do mine too. Tom and Kate were positively angelic whilst mummy was being pampered. Mind you the packet of chocolate biscuits worked a treat.

The next day, Kate, Tom and I arrived at the hospital looking gorgeous and with clean, ironed clothes for Sarah and her dad. The filming was fun. Sarah had a speaking part. She was great, simply ate up the attention, I was so very proud of her. Tom and Kate were quite comfortable; they did not seem to notice the lights, camera and film crew. My little stars.

* * *

As times were hard and the future held fear, I slowly learned to live for the day. I realised that sometimes it was wise to consciously avoid looking too far ahead. This became a necessary survival strategy. I learned to only gaze as far as I could manage.

"Look for joy", I told myself, "Assume it is coming". When it presents itself, grab it, shake it, run with it and delight in every second. Stay in the moment. Try to choose happiness - as children do.

Just after the film crew arrived, Jill, the bone marrow transplant coordinator exchanged a joke with me; and with the next breath told me we did not have a bone marrow match in the family. I struggled to digest that information. It was not expected that Sarah would need a bone marrow transplant, so the information was of interest only. Still, the knowledge stirred an unsettling premonition, a fear somewhere in the pit of my stomach.

* * *

Sarah's beautiful hair proved remarkably resilient, but by late July, 4 ½ months after her treatment began, her gorgeous auburn curls were a thin covering of scattered hairs through which I could see her head.

I borrowed my husband's shearers, sat her down on a chair under the back deck and shaved it off. It was a moment in time that will stay with me, ordinary but not ordinary. Sarah was actually happy with her new look. So I smiled and saved my tears for later.

Bald kids looked normal to us now.

The next stage of chemotherapy went by without incident. This time when I carried her into theatre I told her to put her head on my shoulder and pretend she was already asleep. That lumbar puncture showed no leukemia cells. The specialist said he did not expect it to return. Strange… I had forgotten that it might.

On the way home from that hospital stay Sarah and I stopped at our Italian restaurant to celebrate.

* * *

My gorgeous Tom turned three on 8 August 2003. My sister, her children and my parents came over for a morning tea party. I made the best chocolate cake I have ever made. The kids ate rubbish, wore party hats and played with streamers and whistles.

The following day Sarah danced around the lounge room. She wore the same blue leotard she had worn at her first ballet concert when she was three. She had on little pink socks and ballet shoes. The sun was streaming into the room, the moment felt magical. She was bald and thin but just so beautiful. My eyes filled with tears of sorrow, admiration, pride and joy. "Miracles happen" I thought.

◆

When the next chemotherapy cycle began on 11 August 2003, we were told to expect it to be ‘hard going’. Her vomiting began half an hour after the first intravenous dose and continued for months. She had tolerated the previous cycle of treatment so well. I was unprepared for how violently ill she was now. As usual, I’d sit by her bed and watch her sleep. Even with no hair and so thin, her beauty was otherworldly. She looked to me like an earthbound angel.

My journal entry on 16 August 2003 read:

> “Why did it have to be my child?
>
> I took Sarah to her dancing lesson. She did not want to go and I did not want to take her but my husband bullied me into it. She wouldn’t get into her ballet clothes so we were running late. When we got there she refused to get out of the car. I carried her in, threw my keys and the $6 on the table and walked her into the studio. She refused to participate and disrupted the class. We had to leave.
>
> All the little girls looked pristine and perfect, it broke my heart. I was so proud of her the last time we went, the Saturday before her diagnosis. I began to cry as I picked her up to carry her back to the car and bawled hysterically all the way home.”

I took a sleeping pill that night and felt better and stronger the next day. I knew I was again nearing saturation point with the pain, sadness and the fear. I was a bit worried about myself. I could not remember anything. I’d forget even simple, basic and routine things. I’d cook for the kids but could not be bothered eating myself. I could not imagine the future, let alone look forward to anything. My only interest, my obsession, was Sarah’s next treatment. I was tired all the time but when I crawled in to bed I did not sleep. I no longer cared about me.

The bank was starting to get on our backs too. That month we could not pay the interest on the mortgage.

◆

On 20 August 2003 at the invitation of Starlight Children’s Foundation, the kids, their dad and I had a day at Dreamworld on the Gold Coast. Tom and Sarah even got to be in a video for a children’s musical group, ‘High 5’. Sarah looked forward to it for days and spent the day bouncing around in delight. She was happy and seemingly full of energy all day. How did she manage that?

That night I watched home videos taken before during and immediately after diagnosis. I could not have said at the time why I deliberately put myself through the pain. I think it was because of a conversation I'd had that day with the mother of another little girl with Leukaemia. I was very envious because her little girl was almost through the 2 years of treatment.

We had talked about how we both constantly analyzed our mothering to see if we had done something wrong. I wondered for example, if I could have discovered the illness earlier if I had not been working. I wondered if I was somehow to blame.

Up until about a month before diagnosis she had looked well. She then started to become a little thin and then pale. The changes were gradual; I could not have caught it sooner or much sooner. It was dreadful to see how healthy and beautiful she'd been just a few short weeks prior to diagnosis. I had taken what I now considered "that joyous life" for granted.

Never again would I complain about the 'little' things.

Her eyes had changed now. No longer where they the eyes of a five year old. There was fear and sorrow in them now, a haunted look. The photos and videos of ‘before’ made me sad. The joy and innocence had gone, I thought, never to return.

The other mother was saying her daughter was not and would never be the girl she was before. She was not as bright nor as physically strong or coordinated. I had not thought of that. Until then I had been thinking Sarah would eventually get back to normal. This news was heart wrenching. It was yet another emotional ‘punch in the guts’. I should have been getting used to them.

* * *

Tom was behaving badly. He was angry. We realized it was because everything was about Sarah. She slept in our room. Swimming, dancing, even Dreamworld were about her. He didn’t feel important. We decided to try and do things just for him so he would know what he meant to us and how very much he was loved. The only reason Kate was not reacting in the same way was because she was just too young to notice. She was lucky.

A rough few days with Tom and Kate followed. They had high fevers, vomiting and diarrhea. Sure enough, Sarah caught it too. The difference was that a temperature for her meant another middle of the night rush to hospital. No special treatment in the public health system. I sat up in a plastic chair in casualty until 3.30am, though at least Sarah got to sleep in a bed. At the ward it took until 4.30am to put a needle in her port and start antibiotics. I then managed a couple of hours sleep in a stretcher by her bed.

That evening her dad took over at the hospital and I went home to Tom and Kate. I watched them play on the swings in the backyard for ages that evening, just enjoying being with them, loving them. They had a bath later than usual. Kate, God bless her, then decided to tip her dinner over her newly washed hair.

Sarah got worse over the next week. She had a bad cough, diarrhea, vomiting, was pale and would not eat. I wrote in the journal “*I have never seen her look so bad. I am frightened she might die. I am afraid all the time, but especially now.*”

Despite all this, that day Sarah and the kids posed for some Royal Children’s Hospital Foundation photos with Geoff Heugel, the famous Australian Olympic swimmer who had shaved his head in the ward a few weeks before. We had agreed to this request because we thought it would make her happy but had grave misgivings given her frailty. Before the Foundation people arrived at outpatients, she vomited on her clothes, so I had to go home for clean ones.

Once the photographer started taking photos, our own bright happy Sarah emerged for just a little while. At one stage she refused to sit on Geoff's lap. It was on the tip of my tongue to volunteer to stand in for her… Those gorgeous photos later formed the basis of the next Royal Children's Hospital Foundation Christmas Appeal.

Her weight loss was such that a nasogastric tube was 'suggested'. We thought she would hate this so tried to avoid it. The next day I made her ravioli for breakfast, and then fairy bread and a Sustagen egg flip. For lunch, pancakes and more egg flip. For dinner I made quiche and then mince. I went out and bought yogurt, icecream, cream, chocolate spread, tortellini and carbonara sauce…

It was all to no avail. The tube was put down her nose the next afternoon. An awful ordeal, she screamed terribly. "Dear God" I wrote in my journal that afternoon, "How much more of this must she bear?" Immediately after that I wrote, or rather the pen seemed to move in my hand of its own accord: "It will be OK. We will get used to the nasogastric tube and she will put on weight." I cannot tell you where this positive thought came from. I was certain that it did not come from me.

We did get used to the tube and she did put on weight. We still had disasters - like the awful morning the pump fell off the bedside table and hit her on the head. I blamed myself as usual and was a teary mess all day. At lunchtime I went to get a haircut and cried there too.

Sarah would regularly vomit up the tube. This meant another trip to hospital to reinsert it. At that stage I could not bear to replace it myself.

Despite all this, I was beginning to feel positive about the future. My husband was not optimistic; he would often say to me, "Relapse will happen".

In September we got the awful news that Dom, the son of friends we had met in hospital had died of his cancer. My husband went to the funeral but I could not.

On 20 September 2003 we celebrated my father's 70th birthday in my parent's back yard with our very large extended family. They all expressed their support and sympathy, assured me we were in their prayers. This was warming and a bit humbling. Dad gave the customary speech. He cried when he spoke of Sarah. He said he admired me because I wasn't letting this get on top of me. He didn't seem to know how close I'd come to drowning.

* * *

On 2 October 2003 I gave the last chemotherapy needle of the last intensive phase of treatment.

Afterwards I got down on my knees in the kitchen and said my own quiet heartfelt prayer of thanks.

I was beginning to suspect that great pain could be a catalyst for life changing personal growth. I think that this is what pain is supposed to do. I think we are meant to learn from it. I have this suspicion that if you don't get it the first time the lesson will be repeated in another form.

Just a thought: along the way look for hope, joy and beauty … it will be there … somewhere.

“Your pain is the breaking of the shell that encloses your understanding."
Kahlil Gibran

Wonderful Reading:

Gibran, Kahlil	The Prophet, William Heinemann Ltd, London, 1980
Tolle, Eckhart	The Power of Now, A Guide to Spiritual Enlightenment Hachette Australia, Sydney 2007
Richardson, Cheryl	The Unmistakable Touch of Grace. Bantam Press, London, 2005

-8-

Life in the Twilight Zone

"Begin at once to live,
and count each day as a separate life."

Seneca

We took the kids on holiday to Bribie Island for three weeks. It was close enough to the hospital for appointments or to get back in a hurry if necessary. It was our first holiday since I was pregnant with Tom 3 ½ years previously and as such provided some much needed perspective. I even began to feel periods of happiness.

Sarah's nasogastric feeding pump would alarm and wake me repeatedly at night. I still had three kids under five and a half. One night between the three kids I was woken up ten times. I was so tired. Kate figured out how to get out of the port-a-cot and decided that 3.30am was a good time to start the day!

* * *

Things were looking up. In late October, Sarah went back to pre-school again for the first time in months. She loved it – stayed all day and seemed almost like her old confident happy social self.

30 October 2003 was the first day of the more 'low key' treatment, that is, the 'Continuation Cycle'.

For the next 18 months this meant:

- 6MP (oral chemotherapy) nightly,
- MTX (more oral chemotherapy) on Fridays;
- Dexamethazone (steroids) three times a day for 5 days each month;
- VCR (intravenous chemotherapy) each month;
- a lumbar puncture and spinal MTX under a general anesthetic every second month; and
- a blood test once a fortnight.

Much better! By comparison - a 'walk in the park'.

On 1 November 2003 Sarah and I went to a 5 Star resort called Couran Cove on Stradbroke Island for a Mother/Daughter weekend organized by Camp Quality. I rode a pushbike, lounged by the pool with a daiquiri and had a massage. I felt good for the first time in ages.

On 7 November 2003 my husband spoke at a thank you breakfast for corporate sponsors of the Royal Children's Hospital Foundation. Sarah wore a pink sequined dress with a feather bower collar, fluffy pink shoes and wore over her bald head, what had become her signature, purple felt hat. She danced around the stage reveling in all the attention whilst her dad spoke. The ballroom was full and there was barely a dry eye in the place.

* * *

On 9 November I turned 40. At the last minute I decided to have a bit of a party. Good friends and family dropped everything to be there. It was special. I wrote in the journal, "I have a lot of personal healing to do. It might take me the rest of my life to achieve it." But I felt peaceful, even happy that day.

Life became more normal.

Well, normal…ish. Sarah was exposed to chickenpox on her grade one, school orientation day. We did not find out in time for the immunoglobulin needles, so had to wait weeks to see if she would get sick. This illness could of course be fatal for her. After all we had been through, this dumped me right back in the middle of my fear. I was unprepared for this and felt deeply depressed.

Just for good measure Sarah's cough of four days became moist and at 2am the next morning she spiked a temperature of 38.6. I called the hospital to talk it through. The nurse suggested bringing her in… but it was pouring rain outside, the other babies were asleep… For the first time, I decided to leave this until morning.

My husband was only just back at work. I took Tom to childcare, he was hysterical at being left but I had no choice and I fought not to cry too.

At the hospital Sarah's neutrophils (white blood cells) were ok so we did not have to be admitted for IV antibiotics. The doctor was concerned about the chickenpox exposure though and said that her contracting it was almost a certainty. I was so scared. I wrote in my journal "Dear God… Over to you." I immediately felt a weight lift - he took it from me. I was able to put it to the back of my mind and not think of it…much.

Sarah's last day at preschool was on 10 December 2003. I bought presents for her teachers (pretty pots with flower seeds and potting mix). She also had Christmas cards for her friends. She wore her best dress. I picked her up at 1pm. We then made a chocolate mud cake together to take back to preschool that evening for the breakup party and concert.

We loved the concert. Hard to believe it had only been a year between the kindergarten concert and this one. Sarah was singing, clapping, doing the actions and dancing with the best of them. She didn't really know the songs, but improvised beautifully, and no one cared. It was joyous. Tom sat with us but Kate, a chip off the old block, sat in a spare seat next to Sarah on 'stage' and joined in the singing and clapping. She then did an impromptu dance for the audience. Priceless! It was a lovely special night.

Sarah did not get chickenpox. Thank-you God!

That night I went out to dinner with the preschool mums. The ladies dropped me home afterwards. I was locked out, not for the first time. We had a high picket fence and if you threw the bolt on the gate from the inside it was impossible to get in. I waved my elegant companions good-bye and waited till they drove away. There I was late at night, dressed to the nines, drunk as a newt, scaling the 6 foot fence. Yep - glamorous indeed.

* * *

Christmas was a special event that year. All the family came to our place. Cocktails on arrival, and it just got better from there. The best moment was watching the kids open the presents. Sarah's face was radiant. Tom and Kate were utterly gob smacked.

Despite our differences my husband and I were a team in 2003. It was never an easy alliance for me but we did work together and in my way I loved him. I like to believe he loved me too. 2003 ended at last, and on a happy note.

* * *

To write the chapters of this book, I have relied heavily on my journal as well as on memory. Through all those months I had no time to process one event, to mourn a loss or deal with a trauma, before another had begun.

I have learned that one cannot bury feelings. Feelings are energy that if ignored or suppressed accumulate in the soul, the psyche, in the very cells of the body. Sooner or later denied or buried feelings have to be dealt with. If not, they eat away at you causing depression and eventually physical illness. The negativity feeds on itself.

I believe that if I do not try to work through my pain, I will become 'stuck' or bogged in dead energy. I will live my life from a place of pain and miss out on today and tomorrow.

If I do this, Sarah's illness will have less meaning. I will have missed great and important lessons and this book would not be written. As I have typed these chapters I have cried so many tears; tears that I did not have time to shed along the way.

I feel I can close that journal at last and put it away in a box at the back of my cupboard. It is there now gathering dust. I see you in my minds eye, reading my book – and I thank you and send you my blessing.
P.S. Go on holiday more often.

Wonderful Reading:

Cameron, Julia	The Artist's Way Pan Books, London 1995
Oriah	The Dance, Moving to the Deep Rhythms of Your Life. Harper San Francisco, Harper Collins Publishers, New Yourk, 2001

PART 2

-9-

A New Year, a New Beginning

"Change
Is never a loss -
It is change only."

Vernon Howard

In the school shop I helped Sarah try on her new uniform - blue checked dress, white socks with shiny new black shoes. I told her she was the luckiest girl in the world. I was oblivious to her still bald head because her eyes shone with joy and promise for a bright and happy future. School - a new adventure. We went the whole hog and bought the school logo togs, school bag, everything. We even bought a blue checked 'scrunchy' for "later".

Sarah started grade 1 at St Anthony's School at Kedron, Brisbane in January 2004.

On her first day, her hair was so short one of her classmates mistook her for a boy, which made her cross. Frankly I was just relieved she was not starting school bald with a tube in her nose.

We still had to go to the hospital frequently and she was on copious medications. But she was our Sarah back, almost as before. She was just one of the kids.

The fear was there, every morning when I woke up. Chickenpox and other childhood diseases were a constant threat. I wrote a letter to be sent out to all the school families and helped the staff prepare a plan for her care at school. I made sure I was contactable at all times. I would have coped better if I knew then what I know now. But… life pans out as it must.

Just as always Sarah made friends easily and always assumed she would be the center of attention. She loved going to school. It was not always easy. She had become used to being a VIP. She sometimes struggled with no longer being ‘famous’. She assumed she would be first in line, would win all the class raffles and competitions and so forth… and often did, come to think of it.

For her 6th birthday on Anzac Day 25 April 2004, Starlight Children’s Foundation granted her a wish (her own laptop) and helped us throw a fabulous party for the entire class and most of her old preschool friends. It was huge. The theme was Fairies & Pirates.

Tom was a pirate of course. A fairy shop gave the girls gorgeous fairy dresses, Sarah’s bright pink and Kate’s pale blue. There was a party coordinator, face painters dressed as fairies and even a professional photographer. The family was all there… it was an exhausting but wonderful day.

We felt at last we’d won the war against Leukaemia. Life was starting again; it was like beginning to fly.

Icing on the cake, I was offered a prestigious scholarship to do my Master of Laws by Research. I was honoured. I had my misgivings, but it might be a way to start my career again, to do something for me. My husband encouraged me to accept because we needed the money.

* * *

Life changes. Change is inevitable.

In June 2004 Nonno, my husband’s father (who by then had moved into our granny flat) had a stroke at home. He was OK when I left with the little ones to pick up Sarah from school. When the kids and I got back we found him collapsed on the ground near the front door of the granny flat.

I knew it was bad. I told him I would look after him; that he was family, that we loved him. I put a pillow under his head and called the ambulance.

The three kids saw all this; there was nothing for it. They were with me. I called my husband at work and he got there as the ambulance left. As they were wheeling the trolly away Nonno was telling me not to forget about the pasta sauce he had made for Sarah’s dinner. He loved my children and had a special bond with Sarah. He was always cooking for her, usually pasta or risotto.

Nonno did not ever fully regain consciousness. He mumbled constantly about the kids and Wally our dog. He was playing with them in his dreams. He passed away quietly a few days later.

* * *

By October we had begun to relax at last. I was still exhausted. I did not know how much more stress I could bear. My fear was eating away at my sanity. I had been strong for as long as I could; and longed to just collapse in a heap.

I had been up at the hospital with Sarah a few times one week. I can’t remember why, but I was not happy. I was feeling agitated. Something was not quite right. Intuition again... or maybe I was just being paranoid?

On 7 October 2004 my husband took Sarah for the hospital visit. When I learned they would keep her in overnight, I was more relieved than anything. They would sort out whatever was going on. I was tired and her staying in meant a quite and hopefully undisturbed nights sleep with just the little ones.

The babies were in bed, and I was downstairs on my own when my husband called.

As usual I asked him to read the latest blood test results out to me. I don’t think he fully realized the significance of the numbers. To my ears the results spelled despair. The air thickened in my lungs. Gravity doubled and blackness crept through my soul. I think I shrieked and cried out loud. I sunk to the floor and curled up in the fetal position.

The Leukaemia was back.

-10-

Horror… Again.

"Doubt is a pain
too lonely to know
that faith
is his twin brother."

Kahlil Gibran

I gathered up Tom and Kate and drove to the hospital. I was devastated, destroyed. How could I have stayed away? Sarah needed me and I needed to be with her.

That night stays fresh in my memory. The oncology ward was full so we were admitted to another ward with staff that knew nothing of us or our journey. They were efficient enough but professional and impersonal.

It was another ugly green room, my little girl in pretty pink satin pajamas in an adult sized bed, oxygen outlet, power points and equipment behind her head. It was a two bed room; fortunately the other bed was vacant. The nurse caring for us did not understand our nightmare or the implications of the news we were struggling to digest.

Sarah looked so well. She looked normal. I couldn't be true. Clearly there was some mistake.

When we were alone I sat with her on the side of the bed and took both her hands in mine. I starred into her eyes and told her that she was sick again; that the Leukaemia had come back. I sensed that she had gathered this already. Smart kid.

I said she would have to have all the medicines again, drips and trips to theatre. She bravely accepted this. I could see her thoughts on her face, she had done all this once, and she knew she could do it again. I told her she would lose her beautiful hair again. This was ok too; she had been bald before.

I then said that she and I might be separated.

I said that she might have to go to heaven before me. At this she cried. She did not want to be separated from Mummy. We held each other, as if the holding would keep us together, as if by staying close we could keep safe. I wanted to give her my strength, my health, to share with her my life force. I sat on her bed and cradled her in my arms, as I'd done when she was a baby. Her tears finally slowed and I buried mine inside for a while.

As the hours crept by and she slept I watched over her and prayed. I said the rosary on my knees on cold hard tiles three times around her bed. I could use no other prayer. I had no words of my own. I was angry and in intense agony. How could God allow this? I thought then that only a mother could understand my pain, he just had not idea. I did not sleep. I watched through that lonely night alone, and I cried till dawn.

I would willingly have died to save Sarah this; I wanted to die. I would have gone through it all for her… every needle, every dose of chemotherapy, the side effects, all the pain, all of it.

What possible reason could God have for letting this happen to my little girl? This was evil, cruel and pointless.

* * *

The next day the strangers took her to theatre for a bone marrow biopsy. As always I stayed with her until she was asleep. My darling sister Mary-clare sat with me that morning. As we waited for the result, we prayed that there had been a mistake. We prayed for a miracle, asked God directly and over and over for a miracle.

Late that day my husband and I sat in the room next door to Sarah's as the specialist and registrar told us that the biopsy "confirmed what we knew already". I listened with increasing numbness as their words destroyed our hope.

The treatment from here was long, intensive and risky. They would try to get her back into remission, but this might not be possible, they would attempt a bone marrow transplant, if they could find a donor. None of the family was a match.

There was perhaps a 15 % chance she would live.

They then said, "If you want you can choose not to treat her". I took a couple of moments to digest what they were saying, "She would die in a few weeks".

She looked like always, but she was a few weeks from death? We thought about this for perhaps a split second before agreeing to the treatment. If she had a chance at life we had to give it to her.

I had my beautiful healthy happy curly haired little Sarah back, only to have her snatched away again. This was pain worse than dying and in the ensuing months it almost did mean my death. It all started again. The terrible intensive treatment, the chemotherapy, the needles, the tests, only this time it was incomparably worse.

* * *

Within days we moved out of our nice home.

It was more of an evacuation; we did it in one weekend. Diagonally across the back fence hidden behind some lovely trees was an electricity substation. This had always made me feel uncomfortable and over the years even before Sarah's illness, I'd begged my husband repeatedly to move. I rarely let the kids play in the back yard because of it. He had always dismissed my concern, implying I was neurotic. He'd often called me a snob. He accused me of just wanting a better house. No real trust, no real communication or understanding had existed between us even then. Finally, now he listened. If there was a snowball's chance in hell that Sarah would be healthier away from it, it was worth doing.

We moved to a rental property we owned a few suburbs away. I discovered that on the inside it was in a horrible state of neglect, only just livable. The house and the fence were in dire need of a coat of paint. Some of the fence palings and battens were falling off. The boards on the front balcony and some railings on the stairs looked rotten. Inside was horrible old carpet and walls in need of more paint. The old wallpaper in the bedrooms had probably never been pretty and was by this stage sad and peeling off. The toilet and bathroom were functional if in desperate need of a refit. The windows were dirty but at least they opened and closed. There were no security or fly screens on the windows. Given the dubious area and our hot climate, this was a problem. The kitchen was simply a disaster. Not only was it in a nasty state of disrepair, wood had been used as a bench-top and was rotting. You could practically see the fungus and bacteria. But the move felt right and if this was the only alternative then so be it. I would make it work. I believed that there was no other choice.

We might have moved sooner after the initial diagnosis if Nonno had not been with us. It is harder to find somewhere with a granny flat. In retrospect we should have moved anyway. Just found something somehow. Hindsight is a useless notion. When I told the specialist what we had done he said, "I would have done the same thing". I was angry at this comment. I had asked the doctors, this one included, at the time of the original diagnosis if the substation could have been a factor and had been told "no".

* * *

My husband was back working and demanded I also work as well as keep up the research scholarship. This only paid a modest stipend, but he insisted we needed the money.

Working long hours in a law firm was of course not an option. I hadn't worked as a nurse for nine years but managed to reregister and get a part time job in the cardiac ward at St Andrews, a private Hospital, just minutes from the Royal Children's Hospital.

I now clearly see that to try to do this with Sarah so seriously ill and Tom and Kate so young was insane. I should have stood up for myself, and for my children. But by then I just did what my husband told me to do. I have a gentle yet strong nature, but I was too worn down, merely reacting, no longer taking any lead, exhausted, depressed, a puppet on a string.

I endeavored to continue with the scholarship for several weeks. In the end after discussing it with a social worker at the hospital, I put my studies on hold. I did not ask my husband's opinion or permission because I knew he would not agree. I knew this because I had tried to explain to him several times that I was not coping but he would not listen.

I was too frightened to tell him. It took me a couple more weeks to get up the courage to confess that I would no longer be getting the extra $300 or so a fortnight. The verbal tirade hit. He yelled and called me a financial parasite amongst other things. Then he did not speak to me or relate to me in any way for four days. I was not in any state to effectively defend myself against this. It hurt. It was very destructive.

* * *

It finally began to dawn on me how much more he cared for money than for his wife. Money was his love and I was a means to an end and as far as he was concerned, a poor bargain.

* * *

The local radio station B105 does a walk-a-thon each year to raise money for the kids at the hospital. This year they visited St Anthony's school. I lost the argument about which one of us would attend. I felt we needed to thank the school, the children and the families for their support. It was hard to speak of something so personal on air. Sometimes you just wonder where the strength comes from.

* * *

Within a month Sarah was hospitalized with a life threatening fungal infection of her liver and spleen. But it took weeks to make this diagnosis. The doctors did not know what was wrong. She was treated with antibiotics, drugs to increase her cell production, albumin and blood products. She had endless tests. The vomiting and diarrhea were so severe that she could not even tolerate nasogastric feeds. She was fed intravenously using total parenteral nutrition. She was incontinent. Her high fevers kept coming back.

On the days she looked brighter, I would feel brighter. It was strange to realize that my strength or most of it came from her. I would pray the rosary every day. It was still the only prayer I could manage

The days in hospital turned into weeks and then to months. My husband insisted on working full time. They offered him a chance at promotion. He had more money and a government car for his own use. Perhaps if he'd known the impact it would have on the already failing marriage and especially on the other children, he would have approached things differently. Or perhaps not.

To me it was madness; the results would be catastrophic. But he could not be persuaded to take more leave. This was despite having 18 months paid compassionate leave and six months long service leave in reserve. He slept at the hospital most nights.

Tom and Kate went to stay with my parents; it was supposed to be just for a short while ... but it was an eternity for such little children who needed their Mum and Dad. My parents were getting old and unknown to us all my Dad's health was also failing. He was in no state to care for young children.

I spent from 7am to 7 or 8pm at the hospital daily and then went to my parent's place each evening to be with Tom and Kate. On Sundays my mother would care for Sarah, I would work a shift as a nurse and my husband would spend the day with the little ones.

It was particularly hard on Tom. When I left Tom and Kate in the mornings he'd cry inconsolable tears. One day he fought to come with me and tried to climb the gate to chase the car down the road. I pulled up around the corner and cried. I couldn't see to drive. My poor little boy, I wanted to take his pain too.

I wrote in my journal:

> "Life doesn't seem worth living at the moment. It is a hell on earth that we can't escape. The only way out of this is through it – but I don't know if I can bear to live it. I am so desperately unhappy. This is despair."

* * *

A traumatic event can cement us in a moment in time. It is then as though we continue for the rest of our lives to see everything and everyone from the perspective of that moment. Like most of us, I have many such moments.

On 30 November 2004 Sarah went pale and motley, her temperature suddenly shot up and her blood pressure dropped dramatically. The junior doctor standing by her bed did not grasp how serious her condition had suddenly become. The nurse and I knew. Our eyes met across the room and I ran for help.

As luck (or divine intervention) would have it, two registrars were talking at the nurses' station. I demanded they follow me. If necessary I would have picked up each woman, tossed her over my shoulder and carried her kicking and screaming into Sarah's room. I swear in that moment I had the strength to do it.

I realize as I write that I cannot remember what happened next and that I have blacked it out. I know intuitively that if I do not pull this memory into the light of day it will sit in my subconscious and make me sick. So I sit quietly, close my eyes, breath, and go back there. It is as though sets of solid doors block my way.

I rush back to the room, the doctors behind me. But I stop half way between the door and the bed; the doctors pass me and get to work. They ask questions of the nurse and of the junior doctor. They check her pulse, put the foot of the bed up, increased the oxygen, speed up the drip, and give her some intraveous medicine… but all I see is Sarah. Her eyes are closed, she is not conscious, her skin, mottled and pale. It is happening before me but I am absent, removed from the reality, in shock. I take a step back and the kind nurse beckons me to come closer. A good nurse, she watches the mother as well as the child...

At last the tears come.

Later the doctors said it was either anaphylactic shock (an allergic reaction to a new infusion they were giving her) or perhaps septic shock.

* * *

On 14 December 2004 Sarah had a nosebleed in the bath. I know how to treat a nosebleed, so at first I was not worried. I held her nose and with gentle reassuring words calmed her down. But this was different. I could not stop it and it began to dawn on me that her blood could not clot. The blood was all over her face, down her chest, her shoulders and her arms. It was spreading through the bath water. The white bath looked like a murder scene.

I hit the bell but the agency nurse who answered it thought I was overreacting. I could see it in her face. It was a nosebleed for God's sake. I asked her what nurses were on duty and demanded the presence of the best in the list, Cathy the charge nurse. Cathy of course could not stop it either. Within moments we had the specialist, a registrar, three nurses, two orderlies, a nurse running to blood bank for platelets and another running to pharmacy to get a drug to help clotting.

Sarah began to get pale, motley and sleepy. I did all I could to keep her awake and calm. I knew I *had* to keep her awake. Between my years of nursing and my mother's instinct I knew exactly the stakes. She was treated in the bath until she could be gently lifted into the bed, which was delivered by the orderlies into the bathroom. Treatment continued until she was stable and the bleeding had stopped.

Cathy can be best described as formal, efficient and a little cold, but I will remember her with love for the rest of my days. She was on the ball when she needed to be and even had the sensitivity to get me a juice and a couple of biscuits afterwards. Mind you, half a bottle of Scotch might have been better.

Sarah was composed through it all. What an amazing child. Stop and marvel at the trust our children have in us. She was not worried because she believed I was not worried. Thank God she did not see my fear.

Control over life is an illusion we invent to deal with our fear. The only constant is the soul.
Breath…..

Wonderful Reading:

Michie, David	Buddhism for Busy People, Finding Happiness in an Uncertain World. Allen & Unwin, Crows Nest 2004

Chapter 11

People

The only normal people
Are the ones you
Don't know very well!

Joe Ancis

I think that at times like these, it is sometimes easier for strangers to help than friends or family. It takes a great deal of courage to open ones self up to another's pain. Most people are too afraid to do this.

A mother of two of Sarah's classmates popped in to see me at the hospital at odd times. I hardly knew her. But she was there for me in a way that friends I'd known for years were not. She would always bring with her a smile, a quiet word and a few things she thought I might need like a couple of pairs of new knickers or some soap. She did not just make stiff conversation; she sat with me in the moment. I will always love her for her humanity and innate wisdom.

I believe it is best not presume to know the answers when someone is in pain. Sometimes it is better to just listen. Leave it to intuition. The words will come and if not, generally the silence will do, listening is better than blundering in.

It has been my experience that human 'angels' can be relied upon to arrive just when we need them. Expect them and if the opportunity arises and feels right, be one.

* * *

I have three brothers. The youngest lives in Tasmania. He had young children and a sick wife at the time. He would call often - it was all he could do. The two elder brothers lived locally, were unmarried, were healthy and did not have young children. Despite this rightly or wrongly, to me they seemed like strangers during those months and years. I had not realized until I began to write that I'd been angry at them for not being there; for assuming I was strong enough to deal with hell; to leave me without support and at the mercy of my controlling and emotionally abusive husband. They knew what he was like but never stood up to him. How I thought, could they know so little about me? I cried as I dealt with this. I have since realised that my memory is a record of my perception of the events and thus incomplete. I now understand that much more went on ‘behind the scenes’ than I knew.

My parents, particularly Mum and my sister Mary-clare were with me every step of the way. Their support was without reservation, their love limitless. My mother and my sister are Earth Angels.

* * *

People are so very different. Sarah had a best friend in grade 1 named Angela. She was a nice little girl and Sarah adored her and missed her. I explained the situation to her mother and asked for this little girl to be allowed to visit Sarah in the hospital. Angela’s mother coldly refused to bring her daughter up to visit.

Sarah would cry because she could not see this little girl. I think it was just too confronting for this woman, or perhaps it was just too much trouble.

Some people are weak and selfish. I gently explained to Sarah that her friend could not be blamed for the pathos of her mother. I could not get over the contrast between my daughter’s strength and what I perceived to be this woman’s lack of any fortitude or generosity of spirit.

There is and will always be greater and lesser souls in this world. It takes determination not to judge those of the later category. Compassion may lie in the knowledge that they are perhaps just earlier on in their journey.

-12-

Christmas 2004

"Ho Ho Ho"

Sarah slowly improved. Her strength and determination to live, the dedicated care of the nurses and doctors and our limitless love got her there. Her fungal infection eventually responded to the treatment. The intensive chemotherapy restarted. She was again in remission.

We wandered out through the ward one day in December to see Santa, Sarah, me, and the ever-present drip stand. She unashamedly pushed through to the front of the small crowd to claim a gift from Santa's sack. She was not terribly impressed with the little stuffed elephant her efforts produced. You've got to love that girl. Her thoughts were always written all over her face… I had to stop her taking it back to exchange it for something better.

Christmas carolers accompanied Santa. We listened. But the joyful singing was so much at odds with our reality. To me it sounded forced, paper thin, commercial. A false cheer so in contrast to the ice I carried within. I let Sarah enjoy the moment but as soon as I could I got away from the festivities.

* * *

For years after I felt sick when I heard Christmas carols. I hated Christmas. Tinsel, decorated trees, Santa and particularly the carols took me back to the oncology ward. I try each year to replace those memories with new ones. This is a work in progress.

The Firemen turned up at the hospital on Christmas morning. They have this 'tray' on a truck that lifts up several stories to aid in fire rescue. A fiery dressed as Santa was in the tray waiving through the ward windows at all the kids. God bless their little cotton socks. Love those guys!

We'd suffered a chicken pox exposure from a visitor ten days earlier. This necessitated a move to the isolation ward on 25 December 2004, (the end of the incubation period) away from the staff we knew and the extra support and love they shared. Ho, Ho, Ho…

I went to my dear little sister's place after the move for a much needed break and Christmas lunch. The immediate family was getting together to 'celebrate' Christmas. I expected some relief; I needed a few hours of nurturing more than I needed oxygen.

My eldest brother James took me to task for relying so much on my parents to care for Tom and Kate. He accused me of being cheap and saying I should be able to pay a nanny. He actually seemed to be under the impression that I was in control of my destiny, of my life and of our finances! Dear God!

I was barely coping and not prepared. I expected love and nurturing that day. I am always so very slow to anger, but at this - I was livid! He told me my anger was misplaced and then tried to make me angrier, I think he thought that I should express it, 'let it out'.

He'd done some sort of counseling course. His mistake was to underestimate to a horrible degree, the pain I was fighting to contain. He did not realize that my 'more or less' composed exterior was a cracked thin shell, and was all I had keeping me together.

Sometimes all that is keeping our guts in are the masks we wear. For some of us it gets to the point where holding the mask in place takes all our energy. Behind my mask was chaos and despair. I screamed, "Someone get this fucking cornflake packet psychologist away from me". Please understand that my family and I are quietly spoken and we don't swear. I had never before in my adult life raised my voice at a member of my family.

I stormed away from him and went back to the hospital without eating lunch. I took baby Kate with me but left Tom there to have Christmas with his cousins. I hope he forgives me for leaving him that day. I honestly thought he would be happier. Who the hell would want to be at the hospital on Christmas Day?

Mary-clare rushed inside and packed Christmas lunch to take back to the hospital with me. I have it on good authority that after I left she abused the crap out of my brother.

That afternoon at the children's hospital I went for a walk by myself. Christmas Day, so no one else was in the stairwell.

One by one I took the stairs toward the roof. It was a cement fire escape, cement steps, lots of them, it was a long way up and I climbed slowly and deliberately. As I climbed I tossed around in my head the chances of dying. Quadriplegia would not do. I wanted the pain to stop. I needed to die.

I stopped a few paces from the door at the top. I am not sure what stopped me. It was as though the air in front of me was too thick to get through. I also remember being worried that an alarm would go off if I opened the door. For some reason at that moment this seemed important. I was struck by the certain knowledge that it was not yet my time. My children needed me still. And there was still work for me to do in the world.

I came to realize that if I did not take those final few steps at that moment I was never going to do so. I walked back down those stairs very slowly, one by one, each step making me stronger, taking me that bit further away from a point of no return. I had made a decision. I came back down a different woman, humble; more vulnerable, but stronger; stronger than I had ever been before. Vulnerability and strength go together. It is an outdated stereotype and emotional immaturity that considers the two mutually exclusive.

Honest vulnerability and equanimity, rather than wasting energy on false masks means there is more strength and energy for living and healing.

Live an authentic life. Be who you are in all your glorious vulnerability. Use your energy to Be, not to pretend to be. No more masks for me.

I had looked directly into the darkness, and turned away. I will live out this life. Not just mark time till death … live, Be, and do what must be done.

Wonderful Reading

Millman, Dan	Way of the Peaceful Warrior. New World Library, Novato, California, 2000

-13-

Transplant

One may not
reach the dawn
save by
the path
of the night.

Kahlil Gibran

In January 2005, we had a brief period at home, thirty-one days to be precise. There were frequent visits to hospital, endless checkups, tests and preparations for Bone Marrow Transplant ("BMT"). Sarah put up with it all. She was a patient cooperative cheerful little angel. There was no choice at any point. There was nowhere to go but forward. With all our might we lived and breathed as though each day were just another day.

Sarah, used to having 100% attention from her Mum or dad at the hospital, found adjusting to 'normal' home life difficult at times. She was very demanding and easily upset. Still, she looked better than she'd looked since relapse, wonderful really. I treasured each moment.

One night when everyone else was in bed, I prostrated myself on the floor, face down; arms and legs outstretched, humbled myself before God and begged for my daughter's life.

I always slept in the room with her. I'd wake up in the middle of the night and early mornings to look into her beautiful pale face. I always checked if she was breathing. I could not help myself. There'd be moments of terror until I was sure she was still with me. As much as I prayed she would live, if she were destined to die, I felt it better that it happen now, before the suffering that was to come.

I fought desperately for Hope. I kept praying for it, looking within. I talked with a counselor when I could and with family and friends. I read self help books. I tried to grasp it, to find it, hold it, lean against it; pull it into myself. I could not face this fight without it. I could not get up in the morning, care for my children, clean the house; walk the length of the hospital corridor, breath, without it. For me putting one foot in front of the other was impossible without Hope.

* * *

I needed money for groceries, to pay the household bills, but my husband was in control of the finances and kept tight reigns on the cash. During yet another fight one evening he told me he was ‘putting money aside for the funeral’. He actually said this, taunted me with it; and then watched my face for my reaction. I thought at the time, was he deliberately trying to hurt me or was he completely and utterly devoid of compassion or emotional intelligence? I just didn’t know. Either alternative was incomprehensible.

I told him he had better pray that Sarah lived. My meaning was that if she died, the marriage was over. But I finally realised as that night wore on that regardless of what happened, the marriage was already over.

That night I gave up trying to understand him. I had tried for years to know him. I realised I no longer cared. That night our marriage ended. I knew that a man married to me for so long with absolutely no knowledge of who I was and who did not care about my feelings, was a man I did not wish to know, let alone spend my life with. Love needs a pilot flame if it is ever to rekindle. That night our pilot light died.

Later I sat alone in the dark on cold concrete under the house. I cried bitter angry tears; tears for my child, tears for my marriage, tears of utter despair. The next morning he acted as if nothing had happened. Could he really have been oblivious? What was really going on?

* * *

A few days later, Jill, the Bone Marrow Transplant (“BMT”) co-ordinator stopped Sarah and I in the corridor outside outpatients. A bone marrow donor had been found. It was a Melbourne man in his early forties. He was a “10/10 match” she said, “a mismatch really, but the best Sarah could hope for without a sibling donor”. This was good news. Whilst Jill was talking, a family stopped to chat with her. Their girl had a transplant five years ago that very day. This seemed like a gift, the Hope I needed.

* * *

Despite everything, it was a joy to be at home with my three babies, to just be together. Sarah’s illness had been hard on Tom and Kate and I prayed every night that our pain would not damage them.

I remember giving Sarah some nasogastric medication whilst she slept and being struck yet again by the beauty of her sleeping face. I fought constantly to ‘stay in the moment’. I tried not to look too far ahead, to focus on today, only on today. The future was too much to bear.

I wrote in my journal:

> “I am dreading this treatment but the doctors tell us without it she will die. This at least gives her a chance. Dear God please don’t let me lose her.”

* * *

We were admitted into hospital on 9 February 2005 for BMT work-up including anti-rejection drugs, severe high dose chemotherapy and Total Body Irradiation (“TBI”); all designed to destroy Sarah’s bone marrow.

TBI involved her lying on a table by herself in a lead lined room. The table would be raised high off the floor and everyone would evacuate. They would not let me stay with her. Then whilst she was alone quietly watching a cartoon, they circled a huge particle accelerator machine around the table, bombarding her little body with high doses of radiation.

She had several of these treatments. She always lay there quietly. I watched on a closed circuit television, utterly in awe of her. I cried bitterly every time, shook with the sobbing. And I prayed, rosary after rosary through every treatment. I wiped my tears and smiled when I went back in to help reposition her or to take her back to the ward.

I wished it were me.

I knew that this treatment was destroying her ovaries and causing untold damage to the other cells in her body. It ended even the remote chance she had had of bearing children. If she lived she would need hormone replacement therapy even to enter puberty, even to start to grow into an adult. I could only hope that the Leukemia cells were being destroyed too.

There was no choice in anything. My precious little girl was at the mercy of cold cruel science and an evil disease. Everything was beyond my control. There was not a bloody thing I could do. As a nurse I probably knew too much. Ignorance might have been an advantage.

TBI destroyed her immunity as well as her bone marrow. She was therefore placed in isolation to protect her from normal bacteria and viruses that the rest of us fight with ease. To go to her bedside I had to enter through three doors, gown up, don a mask, change my shoes and scrub my hands twice. This went on for weeks.

Transplant went ahead late in the evening of 16 February 2005. I stayed until 10.40pm watching as the cells were given through her drip. I sat on the edge of my seat by her bed and prayed the rosary. My ex-husband (as I now thought of him) slept in the corner. All the schoolchildren, our families and friends were praying for us. I felt their prayers; the energy was palpable.

Sarah vomited much of the night and all morning. The nurses and doctors were supportive and kind. The long wait began to see if the donor marrow would take. Her own bone marrow was gone. There was no going back. If the marrow did not take, it was over.

The small room became more or less our universe for weeks. I know every inch of that room. We existed inside it. But for some reason I can't remember the colour of the walls. I think it was a sort of hospital colour, not green, not grey. Those lifeless paintings designed to make it homely never work. The window looked out on a sad little garden squeezed between the transplant unit and a corridor. Hospital bed, oxygen and power points, lots of infusion pumps, all connected to my baby, the metal bedside table, television on the ceiling, a sterile en suite; a cupboard full of medical supplies, couch in the corner for the parents, sealed in - a clinical fishbowl.

The weeks were a blur. I remember very little. I know I went to Paris almost every night in my dreams. I put myself to sleep by going to Paris in my head. Why Paris I don't know. Perhaps because it was a long way away; or perhaps because when I was there I was young, carefree, confident and happy. I would walk down Champs Elysees and stop for a coffee in a café in sight of the Arc de Triomphe. In my dream Paris, the streets were never busy and there wasn't any traffic noise or fumes. I'd decide half way through what I would be wearing and it would inevitably be something comfortable but rather smashing. Then for good measure I would generally be a bit younger, a bit taller, incredibly fit and toned and a martial arts expert…. Sometimes I'd rescue an old lady's cat from a tree. Occasionally I'd shop for clothes. It's a bit tame… but it was my fantasy… worked for me.

I did not write much in my journal. Every day I gave Sarah all the love and support I could muster. I took care of her, fed her when possible, bathed her, gave her medication, played with her, painted with her, held her when she was sick, we watched endless cartoons. I prayed.

Her cardiac function went off at one stage and we ended up in intensive care. This was a new terror. I knew what every beat of her heart on the monitor meant. We needed to be there for the expert monitoring, but Sarah could not be properly isolated. The nurse caring for her one night did not seem to grasp the enormity of the infection risk. She was not an oncology nurse. She prepared for a dressing with as little care as a ball boy might use to put a band-aide on a muddy footy player mid field. I quietly picked up her dressing pack, binned it and requested that she start again. I had come too far to lose her now.

Some nights I stayed with her but mostly Sarah's dad did the night shift. Nights cannot have been easy. But the days were filled with painful tests, medicines and endless treatments. Mum was looking after Tom and Kate at our house this time. Bless her. Often I'd cry the whole drive home. Some nights if things seemed to be going well, I felt elated.

One day we saw the first sign the new bone marrow was going to take. It had actually begun to function as normal bone marrow should. It was producing white blood cells! I waited anxiously for every blood test result as each day these precious cells grew more and more. They were written up on a white board in our room so we could see her progress.

* * *

On 7 March 2005 they opened the doors to Sarah's isolation room. She had actually now enough of her own new white blood cells to fight off minor infections. This awoke in me a surge of joy and hope so small and precious that I dared not rejoice. I held it close to my heart like a precious candle flame shielded against the wind.

Her care was intense at this stage but it was not the life and death struggle with unforeseen infections and complications that she had experienced in the months leading up to transplant.

Six weeks later we were home, all of us.

* * *

I am staggered that the journey through transplant took up only one chapter of this book. Writing about it has left me shattered. I know that to write thus is healthy. I need to cry the tears and revisit the emotions I could not process at the time. I believe that this journey of words means I will not spend the rest of my life an emotional cripple. But my God it hurts.

I remember so little of transplant. Perhaps it might have been better, healthier to write more in my journal, but I did not have the heart for it. I know that memories and old issues may continue to surface at odd times. These will control me if I do not recognize them for what they are. I am determined to choose the thoughts that shape me. Not let my thoughts, emotions and therefore my behavior be a product of buried pain and other 'programming'.

One step at a time, anything can be accomplished. I have learned that I need to grasp what I can handle, if that is just today, just this step, this breath _ *fine*.

Wonderful Reading:

Jevne, R.F & Miller J.E.	Finding Hope; Ways to See Life in a Brighter Light Willowgreen Publishing, Fort Wayne, Indiana, 1999

-14-

Learning to Live Again

"Live by faith until you have faith."

Josh Billings

My ex-husband coped with the months in hospital by burying himself in his work, by putting his head down and driving his way through it like a steam train pushing through dirty snow. He found solace in the sympathy and support of his colleagues. His workmates and the outside world were not aware of the private cost. He would push us just as hard, me in particular. His harassing me to work and to study at a time of so much stress; his insistence that I was a lazy, financial parasite, a failure; the control tactics and emotional bullying, his constant judgments made something inside me die. I shut down more and more.

The pushing was all so unnecessary. He could have taken so much well paid leave. But perhaps he needed the distraction of work to survive. Or perhaps he regarded the leave as assets that he did not want to spend. In any event, he seemed to give little thought as to how the rest of us would cope.

I wanted us to be a family. I wanted to love him and wished I could. But I no longer trusted him on any level. Love was not possible. No amount of counseling was ever to change this. There was no way back. I agonized over what to do.

I worked part-time as a nurse through transplant but stopped when Sarah got home afterwards. Her care was just too exacting, too important in those early days. The finances were hopeless. My ex-husband said he had decided to sell the family home and put the money into his investments. I wrote him this letter:

> "You said the other night that you loved me… more than the children. You said you respected me because now I had been through hard times. I don't love you more than our children. I love them more than I love everyone in the world put together, you included.
>
> They must come first. I do not believe you are thinking clearly at the moment. You cannot sell our home and put the money into your investments. The money must go into another home for us. The money is not a windfall or a lottery win. It is not yours

> to spend how you wish. Your children and I must have a home. We have a right to a home.
>
> You cannot force me to work now, just after our six year old daughter with Leukemia has been through a bone marrow transplant. She has a 50% chance now of dying from infection. She needs me to be focused on keeping her safe. It is that simple.
>
> I will work at the hospital on Sundays when I feel it is safe to do so. I will return to study part time when Sarah is well enough to return to school.
>
> If I have to leave you to keep my daughter safe I will do so."

I don't think I ever gave him the note. All he cared about was that I would earn some money to supplement his income… He was on around $120,000 per year plus rent from four residential investment properties. Money had always been important to him. But it seemed to have become an unnatural crutch. It had become his security, his strength, his God. I found I was not sufficiently in the light to counter the degree to which he was in the dark.

* * *

Months of clinical isolation at home followed. I had to keep the house spotless because of the risk of infection. I'd wash the bath before Sarah got in. She needed clean sheets every day. All her water had to be boiled. She was on a very restrictive low pathogen diet. I kept her food in a separate small fridge. I fed her via nasogastric tube. She was on copious medications.

We were not allowed visitors at first and when we eventually were allowed to let family visit, they had to be healthy, wash their hands and leave footwear at the door. The hospital visits continued.

I wrote in my journal in May 2005:

> "I am so frightened. I'm so messed up. I love my children more than life itself. I am obsessed with Sarah's care. But I see nothing more in life for me. I feel my dreams and hopes and wants are over, have come to naught. I do not know what if anything I feel for my husband. I need a home."

We were still living in the horrid house. I did what I could to make it livable. I painted the front veranda and the fence. I pulled up the ugly old carpet in the lounge and chiseled up two layers of tiles laid in the fifties with tar. I arranged to replace the kitchen. My brother's former employer did this at cost and my parents loaned me the money. I organized fly screen/security grills for the windows. Still the place was ugly and depressing. It did not feel like a home to me. My ex-husband said to me, “I like seeing you in this house. It brings you down to size”.

I wrote in my journal on Mothers Day:

> “I have to work on Mothers Day – as a nurse. He has not even bought me a gift. Not enough money he says. Why have I tried so hard, worked so hard, studied so hard? This is crap. We are living in a hovel. I have no real job, no career, no social life, no life, no fitness, no pampering, nothing for me, no rest and no marital love.
>
> I do have great maternal love and joy – this keeps me alive.”

Despite my precautions, Sarah contracted septicemia twice, a life threatening infection of the blood, which required hospitalization and intravenous antibiotics.

I bought her back to hospital at 2am on 17 May 2005 with a high temperature and abdominal pain. It took a few days to confirm septicemia, ‘staphylococci in the blood’. They did a CT scan to check if the fungal infection of her liver and spleen had returned. It had not, thank God, but she had developed pulmonary oedema and a bilateral pleural effusion secondary to a low albumin level. Her lungs were seriously compromised. God help us.

She had an albumin infusion that night and diuretics to get rid of the extra fluid in her body. She also had a blood transfusion for her low hemoglobin. She was bleeding from somewhere, probably the gut. They said it could be stress related to the infection but was probably Graft Verses Host Disease (“GVHD”). Her new marrow was ‘rejecting her’. So she had an endoscopy to check this theory, as well as a bone marrow aspirate, lumber puncture, T-cell eye test and engraftment studies blood tests.

The nausea, vomiting and diarrhea continued. She vomited up the nasogastric tube repeatedly. The ordeal was so endless and relentless. I prayed for peace.

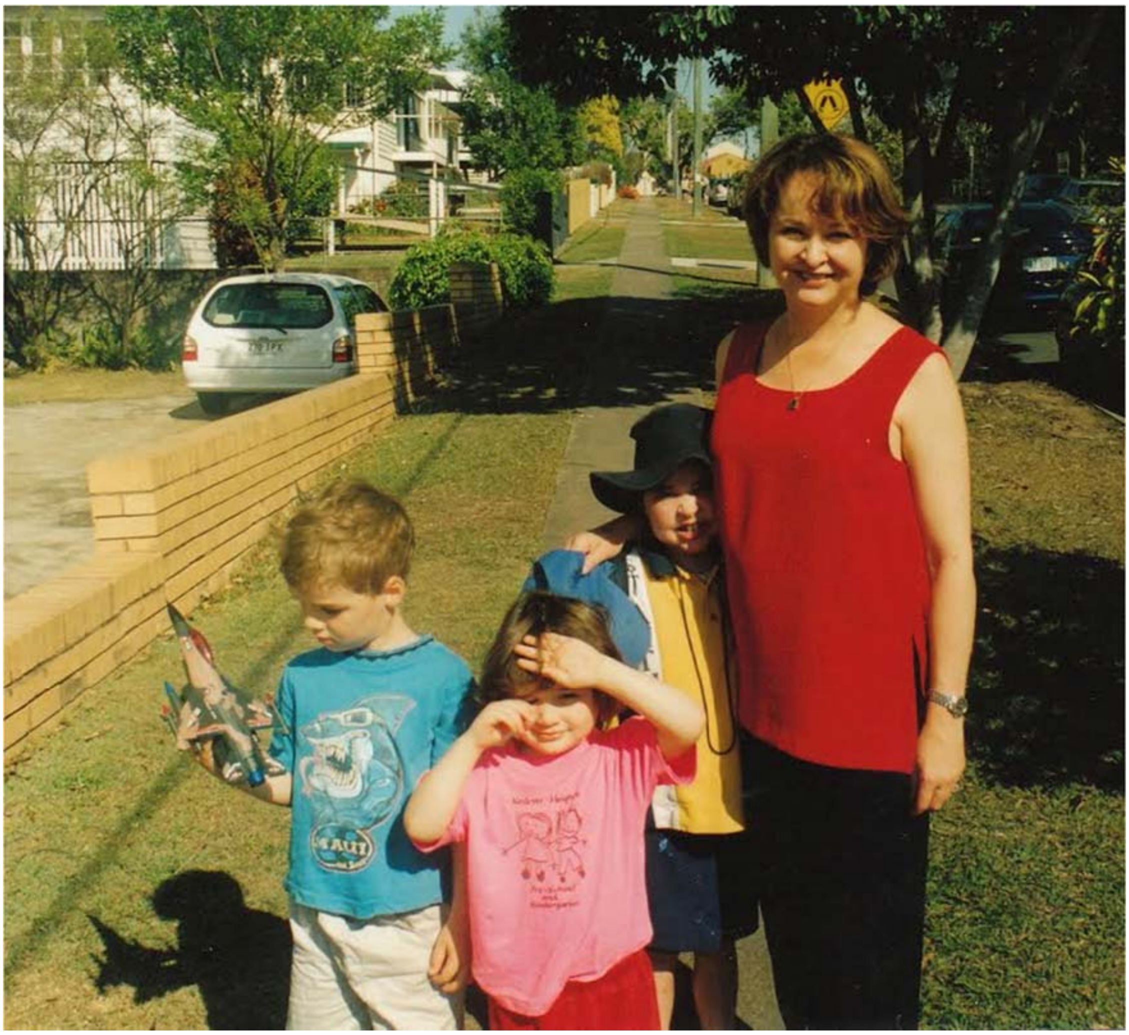
Things started to settle down in mid June 2005. No dramatic improvement, life just gradually and almost without my noticing it took on a more even keel.

I had grown used to my beautiful little girl being bald. She would grow her gorgeous hair back only to lose it again over and over. But the anti rejection drug, now made her hirsute. Like all of the other transplant kids, she grew excess hair all over her body, back, and her pretty face. I wished every day that I could somehow spare her something of the struggle. It was so unfair. Fortunately we were for the most part in home isolation during this time.

There was worse to come. The only way to control the GVHD was with a steroid called prednisone. This caused bloating of Sarah's whole body including her beautiful little face. She was dismayed by what she called her 'puffy cheeks'. People would stare at her when we were out because of the way she looked. For a child that had always been admired for her beauty, this was simply cruel.

* * *

On Monday, 3 October 2005 Sarah had her first day back at school since relapse on 7 October 2004. This had been an entire year of intensive treatment, of pain, fear and struggle. It was so strange and glorious to be at school. Something everyone else took for granted! I felt joy, cautious joy, tinged with fear. Fear that it could all happen again. I was frightened to move on even though I wanted to. I struggled to believe we were there.



But that day it was enough that Sarah was at school. I had not really been able to believe that it would happen. I did not even dare to hope for so much or to even look forward to it. It was as though I could no longer trust good things to be real, like they would crumble to dust if touched. I sat in that day and felt it - tried to hold on to the moment.

I went into the local Church in the afternoon and with tears streaming down my face thanked God that I still had my little girl and that she was actually at St Anthony's with her friends.

That same day, despite all the delays, the Detailed Research Outline for my Master of Laws (Research) thesis first submitted the week Sarah relapsed, was finally accepted by the Law Faculty Research Committee.

Icing on the cake, that day we signed a contract to purchase a house near school. I'd found it the week before. I was not exactly looking for a house. I just happened to drive past when the agent was showing someone else through. When I walked in, I knew I was home. It needed a lot of work, but the rooms were large with big windows, the ceilings high, the yard huge and the outlook good. All the original cornices and features were intact and it even had original wooden doorknobs.

I read a story when I was a child about a lady who lived on her own in 'Rose Cottage'. The thought popped into my head, "This is my Rose Cottage". I knew instinctively and immediately that if and when necessary I would be able to live in this house by myself. I felt a welcoming, nurturing feeling there, a feminine, maternal energy. It was only much later that I discovered the lady who had owned it had lost her daughter to cancer and had raised her grandson there. It was as if something in the house recognized me, knew I needed love. Her rose bushes were still in the garden. I love roses.

There is no such thing as coincidence. I have learnt to be open to intuitions and to watch for these so-called 'coincidences'. I believe that help and guidance are ours, that we should expect these and - be alert.

Of course, my ex-husband insisted we rent it out and not move in straight away. He had his own spiritual blockages and lots of them. He would not let good into his life, and by extension, into my life. Still it was a start.

Wonderful Reading:

Vaughan, F & Walsh, R	Gifts from a Course in Miracles Jeremy P. Tarcher/Putnam: New York; 1995

-15-

The Beginning of a Humbling Yet Healing Journey

"I am what I am today because of the choices I made yesterday."

Stephen R Covey

I wrote in my journal in August 2005:

> "She had a night sweat the other night and all my fears came back. For a while I was sure I was going to lose her and that recent improvements meant naught. I prayed, said the whole rosary this time and went to sleep clutching the rosary beads.
>
> I don't know that this fear will ever leave me; that I will ever be able to move on with life. I keep being drawn back into my own personal hell, drowning in the fear that my precious girl will be taken from me. I cannot fight it again – I do not have the strength any more.
>
> I'm fragile now. I wonder if I'll ever feel strong or in control again."

My ex-husband was earning good money. He was acting second in charge of a government body charged with the care of children. He was getting rent from investment properties. The interest on the loans was exorbitant but he claimed he could not sell one.

I realized with horror that I hated him. I was constantly judged and found lacking. Whatever his expectations were I could not meet them. If I came close, the bar would be raised. The battle could not be won. Thus I drew even further away both physically and emotionally. We could no longer communicate on any level. I could put no trust in him. It was over, no going back.

I knew that I needed to work through my pain or it would consume me. I felt expendable. I felt I was treated without regard, without consideration. No courtesy was extended, no manners used. My thoughts were not asked for, my opinion considered worthless, my feelings disregarded. He would mock me and then laugh as though it was just a joke. I was undermined, maligned in my own home. I was shown no affection, nil.

I was empty, lost. I did not exist. I was a dusty old crone, a shriveled dry corpse. I felt unloved and unlovable. I was a victim. I had been abused verbally and emotionally for years. Quietly, secretly, behind closed doors. I doubted anyone would believe me. No one else saw it. I even had the habit of hiding the reality from my own conscious mind. In public I pretended we were the couple we were supposed to be.

A penny drops as I write. Realizing I was a victim is repugnant to me. But the truth is the first step to healing. I wanted to be strong, powerful; I wanted to be whole. I hate that I did not defend myself. In truth I lost the ability to do so. I lost my resolve, my strength, and my stubbornness over the years. With time I became undermined, my roots, my foundations lost their footing in the earth.[8]

* * *

At last, by late 2005, Sarah was stable. The doctors were now optimistic. The fight seemed won. Though I could barely grasp it, life was moving forward. With the crisis over I needed to do something, to heal or die. But I did not know where to begin. I had no starting point. The only choice was a break, some sort of reprieve - or I would not have the strength to face the future. But I thought “Where to from here?”

Having resumed my Masters studies, I was having a meeting over lunch with Barbara my supervising professor and representatives from my law firm and Queensland Medical Laboratory. This was an amazing treat, it was a lovely restaurant and I was dressed up for once. I was enjoying the food but struggling to bring the conversation around to my thesis when Barbara casually asked if I would consider going to Paris to meet with some European academics. I had to stop myself gagging on a mouthful of food and spitting it all over the tablecloth. I nearly leapt over the cutlery and plates to give her a hug.

My spiritual friends claim I manifested the Paris trip. They said because I’d been there so many times in my head that I made it happen. Food for thought, I mean… what are the odds?

So what is manifesting? It is a metaphysical theory that thoughts are creative. Where our thoughts go, energy flows. Thoughts affect the way we feel and the emotions affect our actions and the events in our lives. I have come across similar ideas in several books written by theologians, psychiatrists, physicists; people of various religious and non-religious backgrounds. They use different terms but most of the core concepts are essentially the same. There are some fascinating expansive liberating ideas to be explored. Life is an adventure.

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[8] If you are reading this and something resonates, please, please, please read Verbally Abusive Relationships, the details are in my book list.

So I went to Paris… on 9 November 2005, my 42nd birthday. It seemed an escape from pain and despair. It felt like the gift from God that it was. What's more, a Qantas executive I cared for in intensive care a few days before I left surprised me with an upgrade to business class on the first leg of the trip.

On the plane I wrote in my journal:

> "I feel a little bit free, a little bit alive. I fear to drop my control though. There is too much pain buried beneath the surface, acid to seep through the cracks and burn or destroy me, make me weak … or to heal me???
>
> I want to be whole again, want to be alive, to feel like I used to feel. This marriage has been very damaging, has come close to destroying me, dissolving me. Where am I? Who am I? Do I still exist? Can I find myself again? Can I even survive in my husband's company? I want to live, to love… and to physically love.
>
> I want to be with someone who won't suck my life force. Am I being unjust? Is it my fault I feel this way? Is it me letting him do this to me? I feel alive for the first time in years since I began pulling away from him."

On my first day in Paris, jet lagged though I was, I walked down the Champs Elysees and stopped for a coffee (and lunch) in that restaurant - which was exactly where I imagined it to be. I ordered coffee, a glass of wine and some salmon. The waiter and owner was Italian, so in the course of ordering my meal and the pleasant brief conversation after, I switched from my few words of faltering French to my faltering Italian and then to English.

Sitting there alone waiting for my meal I pulled out my journal:

> "Am I really here, or am I just imagining it again?
>
> Perhaps this is a dream and I am really at the hospital by Sarah's bedside. The very thought brings tears to my eyes. How is it that I am here? Why am I here? Is God telling me that everything is going to be alright? I think…hope… pray that might be it."

There were two little old ladies at the next table. I know they wondered at the tears of this lonely woman. Somehow I knew then that despite everything, things would be ok.

In Paris I spent a couple of days with an English lawyer named Peter. I'd arranged to catch up whilst I was there. We had been friends in our early twenties, long before I met my ex-husband. I'd sometimes thought of him over the years. I wondered what life would have been like had I married him instead. He had recently lost his wife to a brain tumor. They had loved each other dearly. We had traded emails, sharing our stories and our struggles. We'd become friends again.

He was good company. It was something of a revelation to be treated with kindness. This was in stark contrast to how I had been treated in my own marriage and thus was a painful wake up call. We talked, ate in interesting little French restaurants, drank good red, and wandered around sightseeing and shopping.

I felt myself in love. Though I did not admit it to myself at the time, I believe I knew deep down this would happen. I needed to feel I was still alive, still attractive, still a woman. I felt invisible. I was trying to exist. I could not have imagined this happening with anyone else in the world but Peter at that time. He was the one that got away. A man I had already loved. But he was an illusion; the past is the past.

Of course I was in love with a memory, not a real person. I was in love with being in love. I needed to feel again, breathe. It is a constant frustration that so much is only clear in retrospect. It never ceases to amaze me how we lie to ourselves.

Honesty and healing can be painful. But honesty particularly with the self is necessary for healing. At the risk of stating the bleeding obvious, life is not an easy journey. When I discussed all this with Maureen my counselor, ever the realist and not one to moralize, she said "Good for you!" And now as I reread this passage written months ago, I can understand my counselor's response – "Good for me".

It was impossible for me to deny that my own marriage was over. The obvious pretense of such long duration was now unbearable. I could no longer lie to myself about the excuse for a marriage. I was not who I claimed to be. The marriage was not and would never be as we presented it to the world. It had become a barren hurtful union. I was frightened, shattered, but - the lie had to end.

I missed my children desperately whilst I was away and in the end I came home a couple of days early. I also missed the security of who I wanted to be. A habit, even a bad one, can be comforting. With the facade shattered I lacked a point of reference. I needed to hide behind my mask for a while to gain some balance and gather courage for what must be done.

The Paris trip was a personal shock on many levels. I could not believe how much I had altered. How different I was to how I used to be, how different to the woman I thought I was. I needed to see this. I needed to be thrown out of my comfort zone, so I'd look at myself.

In my early twenties I had backpacked around the world for two years. Some of the time with a very nice Irishman named Tommy (another story); but much of the time I'd been alone. I had been a confident brave capable young woman. I wondered where this 'me' had gone.

The world saw me or so I thought, as a dignified quietly spoken self-controlled lady, a mother, a lawyer, a nurse. But who the hell was I really? If I did not know, only God knew. It was time to be authentic. If I was not my real self, the person I was inside, the person I knew I could be, I was a lie, pointless, directionless, a waste of a life.

The trip was for the most part confronting. I was lonely and lacked confidence - an uncomfortable realization. I had to heal, to claw back my power, to regain my self. I knew I had to stretch, to learn to live again, to rediscover independence - Be.

I had been through too much pain, too much fear. I had been stripped to the core and was trying to come out the other side, hoping and praying this was the other side. I knew I lacked the strength to fight Leukaemia again. I could not bear to contemplate it. I knew I needed to focus on positive thoughts to find peace, and to heal.

It was up to me.

I wrote in the journal:

> "Theresa used to exist, perhaps she still does. You are what you do!"

I had meant to spend some time in the UK but changed my plans and came home via Singapore. This proved difficult because my ex-husband would not let me have a credit card and the bank initially refused my independent application. They agreed eventually after I called and gave the bank manager a blast. I know our credit history since Sarah's illness had been suspect but under the circumstances I was doing bloody well. I was still a qualified lawyer and would practice again. He eventually gave me a Visa with a $1000 limit. The resultant delay though meant I did not have a credit card for the trip. This meant I could not book a hotel or arrange anything ahead of time.

One of my first moves after the divorce was to change banks.

Singapore was unscheduled, but I figured if I was going to be lonely and confused I may as well be warm. I was determined to do something for no other reason other than the fact that I felt like doing it. Now there was a new concept!

I wrote:

> "I miss my babies very, very much. I am lonely, but that is OK. I am growing, or remembering whom I am. It was as if the edges of me had blurred. I felt I'd merged with the background, was disappearing. I almost didn't feel able to be on my own…as if I did not exist alone."

The independence was frightening but healing.

In fear and insecurity, in an effort to crawl back into my comfortable hole, in effect to put on my mask again, I made a list of changes that would be necessary to stay in the marriage. It was not drastic. Move to the new house and make it nice; keep a little of the money I earn to spend; sell a property or two so our debts do not drown us; do what makes us and the kids happy; find couple time once a week; have some fun occasionally.

In the end, though I tried to raise some of the issues with him, I did not show him the list. It was too late. The things in the list were a bandaide, the wound was a malignancy. Love and trust had already died. I could not and would no longer live life pretending to love. The marriage lie was killing me and as much as it hurt and as much as I wished it were otherwise, it needed to finally and formally end. I worried desperately for my children.

No matter how much I tried I could not make my husband grow or heal. If you start with your own self, sometimes others follow your lead and thus start to do their own healing. Sometimes they don't. You are only half of every relationship in your life. Heal your half, heal the self, lead by example, there is no other way. Do what you can within your sphere of influence; try to accept what is outside it.

Truth is the first step. It is hardest to be honest with yourself. Truth is the knife that opens the festering hidden wound. The second step is forgiveness of self and then of others. The next is self love. Once you love yourself you can finally and genuinely love others.[9]

Out beyond the ideas
of right and wrong,
There's a field
I'll meet you there"

Rumi

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[9] Ruiz, Don Miguel, The Mastery of Love. I recommend this wonderful book.

No doubt the universe is unfolding as it should.

Desiderata

Wonderful Reading:

Ruiz, Don Miguel	The Mastery of Love – A Toltec Wisdom Book, A Practical Guide to the Art of Relationship. Amber-Allen Publishing, San Rafael, California 1999
Gilbert, Elizabeth	Eat, Pray, Love - One Woman's Search for Everything Bloomsbury, London, 2006

-16-

A Life Lost

The most difficult thing – but an essential one –
is to love Life,
to love it even while one suffers,
because Life is all.
Life is God, and to love Life means
to love God.

Leo Tolstoy

Shortly after I got home from Paris, on 16 December 2005, our beautiful Kathy, my younger brother Michael's wife died from her mental illness.

Kathy was a delight. I'd never heard from her lips a critical word about anyone. At family parties she was always the first one in the kitchen washing up. She never missed a birthday. The gifts she bought were always obviously from the heart. She was gentle, down to earth, generous and kind. She was the love of Michael's life.

Quietly and with Michael's help, she battled her chronic and severe depressive illness. They even moved to Tasmania so she could be near her family. They stuck it out and did the best they could. She seemed to heal and life seemed to move on for them. For the most part they kept their problems to themselves.

One morning though Kathy organised her home and her children. She cut Michael and her daughter's hair and then went to visit her parents on their farm outside Launceston where she grew up. Her illness took her from them that afternoon.

Her pain was so severe that she died. She left behind a loving husband and two gorgeous healthy girls, one a baby. From the outside she had everything to live for.

Depression is an illness, a chemical imbalance in the brain. It dropped her into a dark cloud that she could not see beyond. She now rests gently in the arms of God.

The image of our darling lovely Kathy in her coffin will stay with me all my days. If you see the symptoms in someone you love or within yourself, please talk to someone, anyone, your doctor… or to a counselor.

In honour of her and in memory of the beautiful soul that she is I want to say this: Remember compassion for those in pain. Just because you cannot see or understand an injury, does not make it any less real for the one lost in the dark.

We deserve to be happy, we are meant to be happy. If you are inexplicably and protractedly sad… something is not right. Remember to care for yourself. You are unique, valuable; worthy of happiness. Tell yourself this every day.

Life is a gift. It is short and precious, it must not be wasted.

One day at the end of each life, our body will lie quietly in death. Try to sit in solitude for a moment or as long as it takes and see this, imagine it, be there, accept this, embrace this inevitable moment. Until then, live.

Live with all your energy and Love with all your heart.

Wonderful Reading:

Malins, Ian	In Your Time of Sorrow, Words of Comfort & Hope Omega Discipleship Ministries, Brisbane, 2006

-17-

Friends, Counselors and Women for Women

"I know of no more encouraging
fact than the unquestionable
ability of man to elevate his life by conscious
endeavor."

Henry David Thoreau

Thank God for my friends, my counselor and Women for Women… for their friendship, love, guidance and support.

One friend for example has four children and works two part-time jobs selling school uniforms and at the local kindergarten. She is a wonderful dedicated mother, one of the wisest women I have ever met and is a talented artist. She is authentic; she loves and does not judge. She is what I'd term an earth angel… but of course might reject the notion were I to suggest it. She lost her own little brother to Leukaemia when a child. She was determined to be there for me despite and in part because of her own sadness.

Rachel gave me the name of my counselor, Maureen[10]. There are counselors and counselors. Just because someone can pass exams does not necessarily mean she or he has the wisdom to help those in crisis steer their way through. "Healer heal thyself" is a motto all counselors, psychologists and psychiatrists should take to heart.

Maureen is a woman on her own healing journey. She is part psychologist, part earth mother. She is good at what she does because she has walked her own path to well-being and is therefore passionate about her work. She believes in healing the women of the world. Her motto, "Heal the mothers - help the children". She is a deeply spiritual woman.

When we first met I sat in her office and cried because all I had left to hold my guts in were the masks I was wearing. The masks of course were: 'happily married', 'good wife', 'good mother with a functioning family', 'successful dignified educated professional woman', 'good catholic', 'good girl'. Much of my meager reserves of

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[10] Check the internet or with your doctor for a counsellor, if in Australia you could also try www.naturaltherapypages.com.au/therapist/2867

energy were going in to maintaining the masks instead of healing the woman behind them. I was floundering.

After a couple of sessions Maureen challenged me to attend the next Women for Women[11] ("W4W") weekend workshop. She said it would fast track my healing, like two years of counseling. I agreed. What was there to lose? Thank God I said "Yes". The workshop though only on twice a year, was scheduled for the following weekend. There are no coincidences.

The weekend was challenging and confronting, but I embraced it. We were cut off from the outside world. It pushed me way beyond my comfort zone. Her methods and those of W4W were somewhat unorthodox I suppose you would say. However, I worked through a large chunk of my personal baggage that weekend. I left there with the tools to continue my healing journey. It was still up to me to do the healing, no-one else could do it for me. This is the crux. Get this. It is up to you to heal. Others can help, give direction, get you started, but it is up to you.

I left with some idea of where to start, which direction to take and an understanding of what was possible. I had an idea of the woman I could be. And as a bonus I discovered a network of women who I knew would be there for me if I needed them. Women need other women, our sisters, our mothers, our friends. The same can be said of men.

Obvious though it may be in retrospect, I discovered something about myself that I did not at that time fully comprehend. I was profoundly, bitterly, blackly, wretchedly angry at God. I carried this energy and grief inside me, in my psyche, in the muscles, the sinews, the very cells of my body. Holding this there and hiding it from myself and from the world took effort, consumed my strength. It would have poisoned any chance of future happiness and peace and would eventually have made me very ill.

It is amazing, astonishing to me that I carried so much inside of me, but did not even know it was there. Each painful event or feeling in our lives leaves something behind. I believe this is why by middle age many of us are completely shut down, are unhappy, and chronically unwell.

There are two types of people on this earth, those who are alive and those who are dead. I have met young people who have been dead for years and old people filled to the brim with life and mischief; with a sparkle in their eyes. Know what I mean? I know which version I want to be.

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[11] www.womenforwomen.net.au

This healing journey is worth the effort. I thank God for the each and every painful step. Driving down from the mountain after the weekend, I found myself quietly singing to myself. I stopped in surprise and laughed out loud. I could not remember when I'd last sung.

I needed help to start healing. It is not a sign of weakness to admit this and to reach out for that help. It is being realistic; it is a sign of strength. It takes courage to confront one's own demons. The important thing is to start, to make the decision to begin. The catch is that each of us must do this for ourselves.

"Whatever you can do, or
dream you can, begin it.
Boldness
has genius
power and
magic in it."

Goethe

I have learned that if an opportunity presents itself to heal, to learn something new or to push outside your comfort zone, it is as easy to say 'yes' as to say 'no'. What is so good about a comfort zone anyway? Stay in it and you'll learn almost nothing, grow or heal not at all.

On the journey foster personal discernment, a healthy 'inner compass' but keep an open mind.

When you ask God for help, he delivers. There is no such thing as coincidence. Watch for synchronicity, there might just be a reason for the things happening around you. We are constantly offered divine help and guidance.

Wonderful Reading:

Sark	Succulent Wild Woman, Dancing with Your Wonder-Full Self Simon Schuster Inc, 1997
Chopra, Deepak	SynchroDestiny: Harnessing the Infinite Power of Coincidence to Create Miracles. Random House Australia (Pty) Ltd, Sydney. 2003

PART 3

-18-

Be

"To live is to suffer.
To survive is to find meaning in the suffering."

Viktor Frankl

I moved to the new house on 10 February 2006. I packed nothing belonging to my husband. I wanted to leave him and anything of his behind. But on moving day, to my dismay he took an unscheduled day off and moved his belongings too. Now you might assume that this incited a screaming match. But I responded with silence. Although I knew what to do I did not know how. I was still so very lost and I was grieving for our Kathy. I was not thinking clearly and could not see a way out. I felt trapped.

On 12 February 2006, two days after the move I finally confronted my ex-husband with the inevitable. I did not plan it that way, I just got to the point I could not hold it in any more. The marriage was over. It was far past the point where something could be done. There was no hope for it. We had not even slept in the same bed for 16 months and there had been little or no physical intimacy for years before that - a symptom of course of something deeper.

I asked him to move out. I did not have the money to go anywhere, no savings in my name, no bond, no income stream. He was used to my backing down, used to my being easy to manipulate. He considered me a coward and seemed to assume he would override my will. Why he wanted to stay in such an awful relationship was at that stage beyond my comprehension.[12] He used delaying tactic after delaying tactic but said he was "making plans". He lived in the main bedroom, the little ones shared and I bunked in with Sarah as usual. It was awful. All the while he presented to the world a mask of familial functionality.

We had Sarah's eighth birthday party in the back yard on 25 April 2006. The theme was fairies. She wore a dreamy pink bridesmaids dress and wings of course. She invited lots of her friends. The children spread joy and happiness like fairy dust over the sadness.

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[12] The Verbally Abusive Relationship, op cit.

* * *

Each weekday morning Sarah strode out in front of Tom, Kate and I on the walk to school. I'd quietly smile at her determination; she'd be cross if the rest of us lagged behind. It would not do to be late.

I noticed one day that she had developed a slight limp. Her right hip had started to hurt. She did not tell me about it until I asked. She didn't like to worry me.

Her specialist recommended a scan of her right hip. During the test I sat next to her as I had done so many times before, wearing a lead gown. The test took longer than it should. They wanted to take some "extra views". I had 'that feeling' and determinedly ignored it.

The technicians called in the radiologist to review the films; I knew something was going on. I followed her into the office and saw the results as she put them on her computer screen. There was a large dark circle at the top of the femur where there'd been only a smudge months ago. The word tumor was mentioned.

I can't remember what I felt. I have buried this memory. Shock again. I demanded to speak with Sarah's oncologist on the phone. He said he would arrange some further tests, but as it was a Friday, these would not be until some time in the next week.

That evening I drove down to the local park and sat in my car. I did not want the kids to see the tears I'd been holding in all afternoon. I called my sister to tell her the news. Poor Mary-clare, I leaned on her so very much. I downed a can of scotch & dry; I cried and cried. Tears full of fear.

The blood tests and bone marrow tests were normal. A full body-scan showed no other abnormal results. My hopes grew.

We were referred to a private orthopedic surgeon. He was reputedly the best there was, a 'charming' man, with the personality of a bulldozer. He said Sarah had either an infection or a relapse of leukemia. Apparently after BMT it could reoccur this way. He did not want to perform a biopsy. It didn't suit his schedule or he couldn't be bothered.

I think I just found another bit of unresolved anger!! If you are smart and thinking of studying medicine but have no people skills … do the world a favour and consider Law.

Just a thought. When you are harbouring anger at someone try this … sit quietly by yourself and take some deep breaths until you are calm and as at peace as you can manage. If you can meditate do so. Now imagine this person sitting in front of you. Say out loud what you want to say. Let it all out, hold nothing back, shed tears, yell, whatever it takes. When you have spent the anger look into his eyes and imagine him as a child. Now listen to what he has to say.

This has nothing to do with that person. This is about you. You should have heard what I just said to the image of that bastard.

Sarah's specialist arranged for this delightful man to do the biopsy at the Wesley Private Hospital the following week. Given our fears you'd think he would have considered doing it a little sooner?

In the interim I decided I needed to be positive. I slowly felt more confident, more at peace. I prayed.

I had a counseling session with Maureen that week. I wanted her kindness, her emotional support. Her first words to me were "In all this do not forget you have two other children". She did a mental or a spiritual process with me whereby I visualised cutting the chord connecting me to Sarah. This 'chord' felt a mile wide and gold coloured, it seemed to connect us torso to torso. But it felt as though I needed this connection more than Sarah did.

Maureen said she had shown a picture of Sarah to a woman called Katinka, a deeply spiritual woman, a healer. She'd taken one look at Sarah's photo and said, "This is an old, old soul and anyone who spends five minutes in her company is blessed."

Maureen warned me that if Sarah was an old soul she would go when she was ready, when she chose. I did not doubt that. I was inclined to begin thinking a little outside the square by this point. I was slowly beginning to accept that there is a lot more to life and spirituality than my mortal mind could grasp.

I went to a W4W meeting that same week. I was challenged to push 5% out of my comfort zone. Later that night Cathy, one of the ladies and a Reiki Master told me about Reiki, a form of 'energy healing'. She said if I wanted and when I was ready I could come to a workshop free of charge.

This concept of healing seemed a bit 'out there' to me and was certainly outside my comfort zone. But there was more than coincidence at work. What I was trying so far was not working, I was emotionally exhausted, and I did not know where to find the energy for each day ahead. I agreed.

Cathy did a minor ‘attunement’ that night. I went home and began sending the kids ‘universal love, universal energy’. I figured it would help even if all I was doing was spending a few minutes giving my full attention ‘one on one’ to each of my children. But I had this feeling that there was much more to it than that. The pain and stress that illness had bought into our home had wounded us. The children and I needed to heal and not just on the physical level. Also I needed to focus on the children because I had not yet grasped in my bones that it was OK to love and nurture myself.

My ex-husband was very resilient at that stage for which I was grateful. He thrived on stress. He seemed almost glad of it – this was how he lived and coped. He believed life was supposed to be hard that it consists of suffering. Thus this was the life he attracted to and created for himself. But I needed to and was determined to move on from a life that tumbled from one crisis to the next.

I saw Maureen again the following week. We talked at length about my fears for Sarah, about organising some counseling for her too and about the urgent need to give Tom and Kate time and attention. She also helped me see the anger I felt towards my ex-husband and helped me let go of some of this. It was a shock to realize how much I still hated him.

* * *

The ‘delightful’ surgeon finally did the bone biopsy on Sarah’s hip on the 25 May 2006, two weeks after the first scan. It took much longer than we were told it would. A cardiac surgeon from St Andrews ICU passed me in the corridor and we nodded a quick hello. He was from my nursing job… another world, a different me. My ex-husband and I paced the waiting room not speaking, making little eye contact. The other parents, waiting for children having tonsils out or tear ducts cleared existed in a separate universe. I held my rosary beads the whole time. I prayed.

We were finally asked into a square white windowless little cell to talk to the surgeon. There were three chairs; a small cheap desk was pushed against one wall. On it was a pad, a pen and an empty coffee cup. The walls were bear, no pictures.

My ex-husband sat in one corner of the room, the surgeon in one corner and me in another. “It took longer than I thought” he said. “I could not find it at first.”

It is Leukaemia.” I threw my rosary beads across the room.

* * *

There was no touching, no consoling each other. We walked up to the ward like the enemies we had become. I sat on the floor of Sarah’s hospital room and sobbed until she woke. The cut on her leg was huge. There was a drain protruding from the wound. With everything else she had to deal with, she now had to recover from unexpectedly invasive surgery. A wheel chair was never far away from then on. It was just a month since we had celebrated her 8th birthday.

* * *

The next day, on 26 May 2006 I wrote:

> “Sarah is dying.
>
> We do not know how long she has, maybe 3 to 6 months at best guess. It is a nightmare.
>
> I have to let her go. I have to accept this and let her go back to God. She is an old soul and she will go when she is ready. I love her so very much.
>
> How do I watch her grow sick and die? How do I learn to accept this? How do I share my mother’s love and help Tom and Kate through this and then through the rest of their childhood?
>
> How do I learn not to fear it so Sarah does not fear it? How do I accept it so she may accept it?
>
> How will I keep living without her? How can I possibly live without her?”

-19-

Breath

“To one who has faith, no explanation is necessary.
To one without faith, no explanation is possible.”

St Tom Aquinas

I completely shut down for two or three weeks. I was tired, I cried all day. I drank too much. I supposed that at some stage I would get over the immediate shock and the need to obliterate the pain.

I was in an almost constant state of panic for days at a time. I remember standing in my kitchen, paralysed by fear, hyperventilating, unable to move. Every now and again I would explode into complete irrationality. I would rant and rave at God. I was not in control of my emotions or myself. I could not talk to anyone, or see anyone. I hid from the world. I cared for the children on autopilot.

One day I went to pick up toys in the girls’ room. The task seemed too hard. Instead I sat on the floor in the middle of the mess and dissolved into tears. That is how I felt, I was dissolving, disappearing, awash in a vast ocean of sorrow; drowning. I sat there helpless; reality a whirlpool around me.

A pastoral care parent from Sarah’s school arrived just then right on queue with flowers and determined maternal intent. She breezed through the house helping me re-establish order. She washed up the morning dishes, and then breezed out again. There are no co-incidences.

The next thing I knew, she and another mother, had the school mums cooking and they began dropping over meals. I could feel God’s hand in the people who were coming into my life. Beautiful people appear when you need them. This is not coincidence, they are meant to be there. Let them in, they have a job to do.

I opened ‘Conversations with God’ by Neale Donald Walsh one of those awful nights at a random page. Why that book I don’t know. I just reached for what called to me. The words leapt out at me, “All relationships are to make you become who you are”. Maybe that was the case with Sarah.

I wrote:

> "I have been transformed by knowing her. What a metamorphosis. She changed me completely. I know I will continue to grow for the rest of my life because of her and the changes she has made in me. Strange how one little girl has had such an impact on her mother… or perhaps not strange at all. Perhaps only natural, as it should be – or more – as it was meant to be. So, so much love in one little person. She floods me with it.
>
> Dear God how do I find the strength to get through the next few months?"

I then wrote these words. They came into my head seemingly of their own accord:

> *"I will help you. I will provide the strength. I am the light and the way – I will show you the way – do not doubt it – do not fear it – I will be there for you and in indeed for Sarah."*

Was I having my own conversation with God I wonder? I think so. I believe so. The words of hope simply did not come from me; and I was not capable of saying them. I felt God's peace, God's love with me. I did not feel alone.

* * *

I slowly began to realize that these next few months were a special time, a blessed time, a gift. They must not be squandered. I must look back and regret nothing. I must not miss an opportunity to make the few days left joyful for Sarah, Tom, Kate and I.

I could hear her downstairs dominating the play as she had always done. The kids would miss her terribly. She would not see another birthday, would probably not see Christmas. She would not be a teenager, kiss a boy, travel the world; she would not go to university, get married or have children. I told myself that these were sorrows I must not dwell on, not yet.

I wrote:

> "I think she has been here before… has done such things before, and this time her life is to be short. She is an old soul. A blessed soul, a special soul, and she will go when she is ready. This I must accept and enjoy her for the precious few more months that I have her in my life.
>
> I must somehow help her accept it is time to go. I must somehow help the other children accept this. The hardest challenge of my life is now ahead."

* * *

They gave her radiotherapy treatment to her hip within that first week to try and retard the spread of the Leukemia. There was a profound risk of a pathological fracture. Again she was left alone in that lead lined room. She calmly lay on the bench while the particle accelerator machine was raised high and circled her, bombarding her little leg with radiation.

We told her she was going to go back to God; that she would leave her body behind because she would not need it. She seemed so brave. We told Tom and Kate too. We were open and honest.

Some days Sarah was upset and said that she “did not want to go”. She would cry and say she did not want to be separated from me. I told her it would seem like no time at all for her until we were together again.

When all that is left is faith, believe… and breath each breath, one at a time.

Wonderful Reading:

Walsch, Neale Donald — Conversations with God, An Uncommon Dialogue
Hodder Australia, Sydney, 2000

-20-

A Necessary Compromise

"Watch with serenity through the winters of your grief."

Kahlil Gibran

My ex-husband insisted he delay moving out until Sarah died. I was sitting on a cement step at the bottom of the back stairs. Were we to wait for her to die before we could get on with our lives? It was an intolerable compromise. Things were impossible between he and I. Being in his presence was debilitating. Amongst other things he said my going to Paris caused the relapse, that it was my fault she was dying. I needed to escape him to heal, to live, to rediscover joy. But the alternative, to share custody of Sarah and the other children during her last days was not an option. I agreed but my words fell from my lips like stones.

As I said them a desperate weight settled in the center of my chest.
He smiled.

* * *

I did not have the energy to do anything. The house was a mess; I was a mess. I felt I was a poor mother. Life seemed cruel, black and sad, cold, hard and unfriendly, loveless, affectionless. I worried about my poor children coping with this nightmare and with their inadequate parents. How would I live without her? How would I cope with the death of one of my darlings?

I put the study and the nursing work on hold of course to be there for Sarah, Tom and Kate. Consequently I had no money. My ex-husband said he was putting all his income into the mortgages. He refused to sell any of the properties. I had no money for even the basics.

Meals arrived in a continuous stream from the school pastoral care team. It was amazing and humbling. My pride just had to hang it. What did pride matter anyway? If it were not for the meals, I could not have fed us. Maureen said I was being served humility in spades. Perhaps I needed a serving of it more than most. I had lived through horrible times in the past but this was the worst. I wanted to scream at God.

I could not wish the time away… that was the irony. I had always wished away the bad times. I'd fanatically mark treatment dates on the calendar. I'd plot the battles in advance, brace myself for them and… wish them away. This time, I had to find it in myself to enjoy the last of Sarah's precious days.

Sarah wrote at the bottom of a page in my journal, "I love you Mum, from Sarah". She wrote in yellow and drew herself as an angel complete with wings and a halo.

I was paralyzed by despair, unable to do anything but wander around the house and deliver basic care to my children, I was no support emotionally to Sarah or anyone else and here she was already imagining herself as an angel in heaven.

* * *

By early June, her leg was worse not better. It was very painful one day because she said her dad wouldn't help her get into his car and she hurt herself. I wished then it were him dying of painful cancer and not my beautiful darling little girl.

Her left shoulder was now sore and I feared the leukemia was already there too. This did not bode well for her time left and her pain levels along the way. I wondered how I would survive sanity intact. There was a dagger in my heart being slowly turned...

I knew her body was failing her… that it could not sustain her for much longer. Slowly I began to see that when the time came it would be a relief for her to escape the constant sickness, the immobility and the pain.

I wrote:

> "I cry every day. I try to both support and gain strength from Tom and Kate and in the knowledge I will still have them.
>
> I am a shadow, an outline only, a ghost with no substance, an automaton. I am dead. I need my ex-husband to go; I cannot cope with his presence *and* with Sarah's dying. Perhaps it would just be easier after all if I died. I hate being here anyway. I would kill myself if I thought my only future was with him. Better death than living hell. …. He thinks control and subjugation are love. He has no understanding of love."

Sometimes it is good to look back at one's life with a little perspective. I was projecting much of my pain and grief onto my ex-husband. He was not completely to blame for my pain. He was as much a victim of circumstance as I was.

He was still an utter bastard … but in retrospect, he is probably not the antichrist. Perhaps I'd better do that meditation technique again … the one about letting out anger and then imagining the protagonist is a child.

Even then I realized I needed some perspective, an outsider's viewpoint. When in the depths of trouble and pain, it is hard to step back. When you cannot be objective, speak to someone who can. Maureen (God bless her black, traitorous, hard, honest, wise heart) said I had to deal with my own issues so I could support my children, all three of them. Her advice? *Stay in the Moment*! Live it. Let Sarah, Tom and Kate be happy. Laugh, smile and have fun - whilst we can.

I wrote:

> "This time together is a blessed beautiful gift. Sarah has been on borrowed time for years. I think she has stayed so long against the odds because I would not let her go. But she is an old soul and she has chosen to leave. She I suspect is much older; more blessed than I.
>
> Going to Heaven will not be such a fearful journey because I know I will meet her there. We are I think soul mates. We will be together eventually again and forever. It is just not yet my time, though I have frequently wished I could go with her.
>
> Since the news, my ex-husband and I still have offered each other no comfort, no touch, only harsh words and criticism, instead of kindness. We have no choice but to live under one roof for now so we can both be here for the children. It is so sad that the parents of such a soul, of three such wonderful children, should loath each other so much.
>
> I will need all the help and support I can gather. It will not come from him."

In my pain I considered my ex-husband to be evil, cruel, a controller, a consumer of my energy. I thought him a destructive emotional force; a blackness. I felt I needed to escape him in order to survive. This was not possible. The children came first, simple as that. I knew staying in the moment was not going to be easy, but if I did not, my pain and sorrow would bury me.

Neale Donald Walsch in 'Conversations with God' and Julia Cameron in 'The Artist's Way' both suggest writing a question on paper and then scribbling the answer that comes into your head without premeditation. The implication being the divine can be that close, that accessible.

On 11 June 2006 I wrote in my journal:

> "How the hell do I live through this?" The answer came… *"You will and you will be happy again. You will even find love."*
>
> *"Theresa, Let go of the fear – trust in God and live in the moment"*.

Sarah said to me "When do the doctors say I am going to heaven?" I said "They don't know darling… why?" She said, "I am excited about it". Thanks God. She did not get that from me.

Let go of fear; Trust in God; Live in the moment. Easy to say, hard to do.

-21-

Light, Love & Lessons

The way of love is not
A subtle argument.
The door there is devastation.
Birds make great sky-circles of their freedom.
How do they learn it?
They fall, and falling,
They're given wings.

Kabir

The Reiki course on 16 July 2006 with Cathy lit another candle in the darkness.[13]

I wrote:

> "This discovery may well be my salvation. It has shown me a source of spiritual and emotional energy, of universal love that I did not know was there. I have been reaching for this for so long not knowing exactly what I was trying to grasp. I almost felt it sometimes whilst saying the Rosary.
>
> I feel like a soul in the desert who finding a pool drinks in grateful mouthfuls of cool blessed water. But more, I can reach for the pool and drink whenever I need and wherever I am. This is the most precious knowledge, a priceless gift from God. I can now tap into universal love."

The children seemed calmer after my Reiki course. They began to cope better because I was coping better. On my ex-husband's birthday the kids wanted balloons and decorations. I helped them make cards and birthday cake for their dad.

Sarah looked well and happy. The prognosis seemed unreal. The new fentanyl patches were controlling her pain without needles. Fentanyl is a powerful narcotic analgesic. A recent innovation meant it could be administered by applying a patch allowing the drug to be absorbed through the skin. She was now walking quite well. Except for the steroidal swelling she could almost be a normal kid. I rarely took her to the hospital now. There was no longer any point.

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[13] See www.thesoulgarden.com.au/

My ex-husband got Tom into football training and playing. His confidence and happiness improved. Tom put his arms around me one night and said "I just love you so much Mum". *Wow.*

Kate, protected from our reality for so long by her youth, was feeling things more deeply now she was getting old enough to understand. I was trying to give her extra attention. She was worried about Sarah dying and was upset at times. What a thing for a 4 year old to have to face!

* * *

That same month, five weeks after getting the news about Sarah, we learned that my father too had cancer. His doctor did not know how much time he had. I wondered how any of us could take any more.

There was a time when such news would have devastated me. I adore my Dad. But I did not have the capacity to feel any more pain. Acting on an instinct I did not understand, with a wisdom I did not question, I put this grief to one side. I would cry about it later.

His body had been badly damaged. His hips had to be pinned or might have broken. Poor Dad, barely sick a day in his life, he now had to face a bilateral total hip replacement, months of chemotherapy and a bone marrow transplant. At first he was upbeat. He had no comprehension of what was in store for him. I knew.

I kept back from Dad's fight. I left this to Mum and my sister to face. I phoned often, I visited him when he was in hospital, but I stayed away emotionally and for the most part physically. I still do and I am beginning to understand why. As I write I am uncovering another one of those little pain and guilt pustules that I hide from myself so well.

I let them down. I have since apologised for being and continuing to be so distant, although they did not expect it. I am trying to remedy this, to break down this barrier. I know Mum and Dad understand and do not judge me. But my heartfelt "Sorry, please forgive me" was mutually healing.

I also had to actively forgive them for no longer being able to be there for me. No, of course I do not judge them for that either. This is about healing of the self and of a rift in a relationship; a rift that until this moment I had not admitted was there. Love of self and of them, now unimpeded will hasten healing on both sides. Truth – forgiveness - love, in that order - works.

* * *

On the evening of 20 July 2006 whilst Dad was in surgery having his hips pinned, my ex-husband launched another verbal and emotional attack. This huge 6 ft 2” man stood over me in the kitchen and yelled directly into my face.

He said I was an academic and financial failure for not working and studying. He called me a failure as a mother and as a wife. He had me on the later but the rest was garbage. I had finally been pushed too far and his timing sucked. I slapped the bastard across the face. If you could call it that, I just caught him with the tips of my two middle fingers. Long overdue, it has to be said but to do such a thing was utterly foreign to my nature.

His reaction was interesting. He acted as though I’d actually hurt him. He grabbed his jaw and then called the police, or pretended to, I am not sure which. No policemen appeared on our doorstep. Might have been interesting to see their reaction if they had. He demanded I help take a photo of his non-existent injuries and wrote out a statement as ‘evidence’ and asked me to co-sign it.

I realized then what a terrible mental and emotional state he was in. I also realized the lies of which he was capable, all the more believable because he believed his own tales. I saw first hand how manipulative and dangerous he could be given his practical knowledge of the law, of policing, and of administrative process. I was quietly grateful that night for my legal training. No, I didn’t sign it; but I did help him take the photo.

As I write, I am trying to look back on this incident with compassion. My ex-husband was as stressed as I. He was I believe, not capable of beginning to heal himself or of dealing with his pain because he would not admit he had a need or a problem. Personal insight is a necessary first step. We all hide our wounds. I believe healing will elude him in this lifetime. His energy was consumed by holding up his masks and by projecting all his faults onto others, me in particular. Blaming me for most things helped him accept himself and let him continue to believe in his own masks.[14] This approach is of course a coping mechanism doomed to failure.

* * *

Maureen arranged a special outing for the children, my ex-husband and I at Australia Zoo. One of the W4W ladies worked there as a zoo-keeper. The staff gave us a guided tour; Sarah was a VIP for the day.

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[14] The Verbally Abusive Relationship, op cit

I hadn't slept for two nights and was an exhausted mess. But we actually hand fed elephants! There were three of them. This moment will stay etched in my memory all my life. Tom stood back with a big grin on his face and said, "I just don't know about this". Kate had no fear; I struggled to keep her out from under their huge feet. Sarah just delighted in it all, as did I.

There were tigers, crocodiles and snakes. The look on the kid's faces when they were handed an enormous snake was priceless. We have photos. Sarah actually tried to look aloof, as though this was no big deal. She cracked of course. God bless the Irwin family and the staff at Australia Zoo. Steve Irwin died shortly afterwards in a dreadful accident. It was as though his soul was too big for his body. I have a feeling he is an old soul too.

Looking back through the photos of that day brings a quiet smile to my face. Sarah had started dressing beyond her years and wearing bright red lipstick. She'd applied it liberally and badly that day at the zoo. I did not restrain this eccentricity. I figured she was trying to fit in some growing up.

* * *

I asked the doctors to try and stop Sarah's steroids. These had been weaned to a low dose but the side effects were awful. Her poor little face and her little body had gradually puffed out to almost twice normal size. Transplant had destroyed her beauty, if only on the outside.

I wanted to see her lovely face again… to see my little girl, as she was. I wanted her to have her pretty face and slim body back. This proved to be a mistake. Sarah had a flare up of her GVHD[15]. Slowly she went off her food, developed nausea and abdominal pains. The steroids were recommenced at a very high level. I thought I was putting her first. But perhaps my own needs clouded my judgment.

I prayed that God would help us (my darlings and my family) to survive the storms that battered our lives. I asked that we grow through the pain. I asked to be shown some reason for all of this. I asked that God protect my Tom and Kate and that he hold my poor Sarah in the palm of his hand and guide her home. I asked for the strength to survive, to be whole, and to go on living.

---

[15] Graft Verses Host Disease ("GVHD"), her new bone marrow was rejecting her again.

On 29 September 2006 I wrote:

> "I just can't bear to lose her. Where do I go with that? I sit here listening to her soft breathing, her little snore, knowing she must die. Where the hell do I go with that? How in God's name can I cope? How do I go on knowing it? How will I ever live without her? Oh God I will miss her so very much. Do all mothers love their babies like this? I'd die to save her – give an arm or a leg.
>
> Why again why? Why the hell why? I love her so much, my angel, my baby, my life, my darling. Thank God I have Tom and Kate. Without them depending on me I would not survive. I will live through this because they need me. I love them with the same passion, the same intensity; with all the life within me; with all my soul.
>
> Dear God I need you."

I found that preparing for the death of my child was a little like preparing for her birth. I found myself frantically busy doing things. I began gardening. I couldn't stop planting, weeding and planning the next garden bed. I rearranged furniture, hung pictures and began renovating.

I was also trying to manifest a future. I was trying not to think.

On 5 October 2006 sitting on my bed in Sarah's room, I wrote:

> "The others are in bed asleep. Sarah and I are watching 'Enterprise.[16]' We often do this. This is a special time, our time. She is drawing pictures… she does this a lot. I think she wants to leave something. She has done several for me and is doing one for each classmate. She is drawing herself and her mummy again. I love her so much. She is a tough little bunny… so strong willed and determined. Quite bossy. She makes me happy at times like this. I will miss her at bed-time for the rest of my days on earth.
>
> Mary-Clare and the kids came over today. Sarah looked after baby Clare the whole time.
>
> M-c said she would not have had Clare if Sarah had not gotten sick. Sarah's illness was what made her want a third child. This was a strange bit of information. Clare was born because of Sarah. She had on a little outfit Sarah used to wear as a baby. It had been a favorite of mine. I cuddled my little niece and tried not to cry."

I have learned that if you are alert and listen, if you are in tune, God helps you prepare for what lies ahead. In that lonely place where all you have is God, the only direction

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[16] Star Trek.

available is forward. Personal and spiritual growth is inevitable. This is what is meant to happen. I tried to be open to this process.

Wonderful Reading:

Stein, Diane	On Grief and Dying The Crossing Press, Freedom, California, 1996
Albom, Mitch	The Five People You Meet in Heaven Time Warner Books, London 2003

-22-

An Oasis in the Heart

"Faith is an oasis in the heart which will never be reached by the caravan of thinking."

Kahlil Gibran

I continued to talk to Maureen on a regular basis. She suggested I try to send 'universal love' to my ex-husband to help heal the energy in the home and to help alleviate a rift developing in the relationship between Sarah and her dad (for her sake).

I wrote:

> "I see the wisdom of this and will try to do so. This is not easy as he too carries anger. He is emotionally violent and frankly scary at times. He does not realize the negative energy he throws around and how we who live near suffer for it.
>
> He used to wound my spirit, control me – he can no longer do this. I will not let him. I grow in my own power… I feel I am "becoming" again, despite or perhaps because of my pain. I believe I will be able to help myself and therefore help my children."

* * *

My anger with my ex-husband was gradually losing its intensity. I'd had years of it bottled up inside. Once I knew it was there it had to come out. This helped. I began to feel lighter. We deny or ignore our own emotional, psychological and spiritual complexity to our peril.

I began to understand something about him. He would choose to feel hurt, whether or not I was in his life. Pain, stress, angst, disaster and trauma were what he had chosen for himself. Such was his path. I had to let him walk it without me. I would no longer follow someone else's path, nor be caught in the fallout. I realized I had it in my power to choose peace, joy and love for myself and for my children.

I continued reading and reaching for knowledge of spirituality. I read what drew me regardless of religious orientation. I was trying to find meaning in all the sadness. Sometimes what I read resonated and seemed more like remembering something than learning it for the first time.

I felt a gradual awakening. Slowly I was beginning to gain a hint of my higher self. I recognized the feeling, knew the energy I sensed. I instinctively trusted it. It felt like love, it felt like God.

I wrote:

> "I have a source of nourishment for my spirit, a lifeline. I need never feel isolated and empty again. Never feel desperately alone, abandoned or afraid.
>
> I have started down this path, I feel drawn to it. I now know age is not decline but growth, which continues to and beyond dying."

This was not something covered by the Reiki course nor by the literature I'd read. It was something I just began to know.

* * *

In the car on the way home from a barbeque with some of my old school friends Sarah remarked calmly, "My soul told me it is almost time to go to heaven". I accepted this. Kate was in the car too and said through tears streaming down her face, "I will miss Sarah when she goes to heaven". Sarah was serene and Kate was heartbroken. I was in the middle of a six-lane freeway; all I could do was love them.

On 18 August 2006 Sarah told me quietly that she wanted to go to heaven. But she said reassuringly and confidently that "Mummy we will always be connected by a tube".

The bruises were back on her legs. She was grumpy and tired more often. I had to double her pain relief. She was not eating as much. She was less active and spent a lot of time doing drawings and writing notes for people. Other than that she was the same old Sarah, considerate daughter, loving, kind, and a dictator to her siblings.

On 19 August 2006 I wrote:

> "Terrible is the knowledge that sooner or later and perhaps sooner I must face losing Sarah and help Tom and Kate face it too. I dread this so much but I am beginning to accept that it must come. I believe I will survive it. But dear God, if only this burden could be removed from us.
>
> Despite all this I am finding some peace inside myself. It is strange that this could happen at my darkest hour. I cannot fathom the human condition, the nature of the soul. This is unexpected. Having experienced some peace, I know I must continue my personal spiritual journey."

I began to notice the light within, my own personal oasis. I believe that there is a part of all of us, an inner wisdom which waits in God's presence. There was no option for me but to reach for this loving energy and in so doing it became a source of peace and personal power.

For God did not give us a spirit of fear,
But of power and of Love and of a sound mind.

2 Timothy 1:7

* * *

Meditation was a natural step. Sarah and I learned to meditate together. My mother gave us some children's meditation disks and one of my beautiful friends gave me some 'adult' meditation CD's.

We began by listening to the children's CDs at bedtime because Sarah was having trouble going to sleep. She would also wake several times each night to go to the toilet; this went on for months. We could not find a physiological reason for it. The doctors did not know all there was to know about radiation and bone marrow transplants. Perhaps this was some new complication; perhaps it was nerves or stress.

We also listened to adult 'chakra clearing' and 'learn to meditate' disks. Sarah said these helped her too. We learned a great deal from these recordings. Meditation became a part of our nightly routine. It remains an integral part of my life, and always will.

"It is not necessary to maintain a conversation when we are in the presence of God. We can come into His presence and rest our weary souls in quiet contemplation of Him."

O. Hallesby

I found that when the mind is quiet, the spirit might be felt. It was a way to sense my own soul, my higher self; the part of me that is always with God. Sarah's understanding was expressed in more childish terms, but she knew this too. No wonder she was not afraid to die.

"The mind controlled by the spirit is Life and Peace."

Romans 8:6

It is funny; I could not even keep a pot plant alive before what I'll call my 'spiritual awakening'. Now my humble garden was thriving. I could feel the energy of the earth and of the plants. I found it nurtured me, gave me strength and peace.

I spent as much time as I could in the garden. As I bought her garden back to life, I felt a connection to Ethyl, the lady who lived in my house for so long who'd lost her own daughter to cancer. In idle moments I wondered if she was encouraging me across time, sending me love.

I wrote:

> "Strange that in the midst of all this pain, fear and sadness, I am finding myself, finding the peace within, feeling a hint of the happiness I am capable of feeling. I feel more connected to God, to the love that is all around me than I have ever felt before. This is an unexpected miracle.
>
> Sarah is drawing a picture on the computer. She has written on it 'I love Mum'. She is a gift from God. She has taught me so very much in her short life. It is staggering the changes she has wrought in me. Where would I be without her having been in my life? Her death has to mean something."

Wonderful Reading:

Nataraja, Kim	Dancing with your Shadow Medio Media, USA, 2006
Rinpoche, Sogyal	The Tibetan Book of Living and Dying Rider Books, Random House, London 2002
Virtue, Doreen PhD	Chakra Clearing, Awakening you Spiritual Power to Know and Heal Hay House, Inc. Sydney, 2006

-23-

The Journey Forward

"Go on girl
You can do it
It's only life
There's nothing to it..."

Celine Dion

In September 2006 I went to see a family lawyer, a woman I'd known from university. My ex-husband was not providing enough money to live on, and had not done so for months. He was allowing $250 to $500 a fortnight in total for all five of us (food, bills, clothing the lot). I had borrowed several hundred from my mother; my ex-husband's sister had given me $200. Girls from the local high school had raised $1000 for Sarah and staff at the local Woolworths had donated $500.

On my lawyer's advice I applied for a sole parent's benefit on the basis of separation under one roof. The alternative was to sue for property settlement or child support, which given the circumstances was not possible. The process was a source of great embarrassment for me. I sat in the social security office and through tears of humiliation explained the intimate details of my life.

Humility in spades, but I could not face more verbal aggression and fighting. I did not want and did not have the strength to confront him any further about money until he had moved out. The pension was granted. This was a profound relief. I did not have to fight that fight until after my girl had gone to God. "One mountain at a time".

* * *

That September I was able to look forward to the school holidays and to spending time with my children.

I wrote:

> "Sarah the darling is writing in her journal as I write in mine. I wonder what she has to say. She rarely shows me what she writes. Every word a treasure I will keep for the rest of my days. Love that kid."

In September a group of teachers from school did a relay walk through the night to raise money for leukaemia research. Sarah's class wrote to local businesses to ask for sponsorship for their teacher. A television current affairs program, Brisbane Extra did a feature story. Tracey, Sarah's teacher as well as Sarah's dad and I were interviewed. Sarah, Tom and Kate were excited about it all. Sarah as usual loved being the centre of attention.

* * *

By mid October 2006 though, Sarah was becoming slowly more ill. I gradually increased her pain medication. I still managed to get her to school most days but only until 10.30am or 11am instead of 1.30pm as in the previous school term. She loved being there, but her staying power was less. She was getting demanding, grumpy and bossy at home. I think she still held it together at school. She was at times tough on Tom and Kate. This worried me deeply. I tried to make life as normal as possible.

I did not want to be reminded of how sick Sarah really was and of what was to come. I'd try to find some peace and happiness each day. "You have to look for it", I wrote, "… grab it when you see it". I sanded the front and back railings, painted them and the back patio. I ripped up ugly old carpet (no offence Ethyl) and striped the wallpaper in the hallway. I even learned to 'no-more-gap' the cracks in the internal walls. I did an abysmal job at this apparently.

* * *

I debated whether or not to write about my past life regression, yep there goes my credibility. It's a bit 'out there' but here goes ...

Reincarnation is contrary to current Christian doctrine. Not that this necessarily bothers me. Have a look and you will see reincarnation mentioned in the New Testament.[17] The Gnostic Texts also reflect the early Christian's belief in reincarnation. It was only several hundred years after Christ's death that the church decided to delete the concept from official doctrine. Eastern religions for the most part 'take it as read'.

I am just going to write this down. I ask you to read it with an open mind….or not. Take from this what you will.

---

[17] Matthew 17:9 – 13. Also see Chopra, D Life After Death at 104.

I went to see a beautiful and deeply spiritual lady named Shanelle[18]. She is a Reiki Master and I went initially for a Reiki treatment. I had taken Sarah to her first. Conventional medicine had failed. If there was a chance I could help Sarah in some other way I was determined to try.

I told Shanelle about the soured relationship between Sarah and her father. I was worried that I had contributed to this. Although Sarah assured me I had not. My ex-husband, despite his attitude towards me, had not really given Sarah sufficient justification for her anger towards him or sufficient reason to distrust him so much. I was trying to understand the dynamics of the relationship between my ex-husband, Sarah and I. I wondered if I held the key to offering Sarah some healing. A dear friend had suggested as much. To that end I would try anything.

The past life regression was a deep, guided meditation. It seemed I was a man of about 39, but I was old. I was a soldier; I could see my hairy legs and ugly toes in sandals. I was wearing an off white tunic like a roman soldier might wear under his armor. It was of a course material and crumpled, perhaps a little dirty. I had big calloused hands.

Sarah, my wife in that life; was attacked by someone I loved and trusted. She was killed and there was rape involved. I knew the culprit was someone I trusted, my brother, or brother in arms, a man very close to me.

The day I buried her I killed myself next to her grave with a tool I knew well, a tool of my trade, a large sharp knife. I plunged it into my torso or my chest.

I had not been there to protect her. I vowed not to let her be hurt again, to love her and protect her no matter what. Towards the end of the meditation I realized that there was some connection to my ex-husband…. I think he was the brother. Shanelle agreed.

I am not saying this is fact. I am not saying anything. I am just relaying what I experienced. I did feel a bit like my psyche had been rewired… in a good way. I could not explain it. It was as though a 2000 year-old wound healed. I felt a spiritual wind swirling around me.

Friends dropped in shortly after I got home, including the one who suggested I held the ‘key’ to some healing for Sarah. As I described my experience she reached across the table and took my hands. She said she’d felt a “great rush of energy from me”.

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[18] www.alternativemedicinebrisbane.com.au

Suspending disbelief for a moment, just for the sake of argument… I thought such a thing might just explain why my ex-husband was so deeply emotionally damaged. It might explain why Sarah was so afraid of him. It might explain the deep bond of love and protection between Sarah and I. It might explain why when she was born I knew I would not be able to protect her.

Without my other children, my anchors to this world, I may have followed her over again. Even then I knew that all this was of course too much to lay at my ex-husband's feet and perhaps a bit much "suspension of disbelief". Food for thought though and I do not altogether dismiss it.

Was there a way forward? What was a way of healing for all three of us whether or not that regression was a figment of my imagination or perhaps cryptically symbolic, in the way of dreams?

Shanelle suggested to me a meditation to bless all three souls. It seemed worth a try.

There is a great deal more to life and death than can be imagined with our mortal minds. None of us, and no religion, doctrine or teacher has all the answers. I decided the best approach was to keep an open mind but practice discernment; to listen to my inner compass as best I could.

Wonderful Reading:

Shroder, Tom	Old Souls: Compelling Evidence From Children Who Remember Past Lives Simon & Schuster Paperbacks, Sydney, 1999
Chopra, Deepak	Life After Death – The Book of Answers Rider Books, Random House Australia (Pty) Ltd, Sydney 2006

-24-

A Change in the Air

"With whatever pattern
you find yourself inwardly blended
(even a moment out of the life of pain),
feel that the whole,
the glorious carpet's intended."

Rainer Maria Rilke[19]

On 30 November 2006 I wrote:

> "I am feeling fragile and vulnerable. I sense a change in the air. This moment is poignant, pregnant with meaning. Something is coming, but I do not know exactly what. I have reached out; called several people this morning… but there is no-one who can give me what I need. I feel Fear…
>
> I sat quietly for a moment and drew in the peace and silence that I knew was there. I imagined love being poured over the top of my head like liquid light. Then I sat in my rocking chair and reikied myself. Next Kate came into the kitchen, crawled into my lap and hugged and kissed me before demanding her breakfast.
>
> I stood up and put one foot in front of the other. 'Mother, Father God', I prayed, fill me with your endless love and strength."

In late November 2006 I had Sarah at casualty twice in one week once with terrible abdominal pain and then with dreadful leg pain. She refused to let the specialist near her. I stood in a curtained alcove in the middle of the emergency department arguing with her, practically shouting over her screams. I told her "There is no bloody way I will let you suffer pain! I - will - not - have - it!" For once I got my way.

The abdominal pain, this time even worse, happened again in the first week of December. I held her while she vomited and screamed.

I got her to the hospital and she was admitted. My ex-husband did the night shift. They kept her in a couple of days for observation. As a result of the emergency admission we both missed Kate's preschool graduation concert. Another mother took her for me so at

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[19] Excerpt from Sonnet 12; The Sonnets to Orpheus.

least she got there. Kate seemed to understand and in the kitchen before bed, sang me the songs I'd missed. Forgive me that one my darling beautiful baby girl. I had a couple of quite scotches and a cry by myself that night.

On 9 December 2006 I took the kids up to the unit on Bribie Island. My ex-husband followed. After a couple of hours, some prawns, cold beer, and a walk along the beach with Tom, the place began to work its magic. I felt a little calmer. Sarah and I even managed to claim the master bedroom for a change.

I wrote:

> "I have been worried as usual about Sarah. She is not eating and is very pale. She gets night sweats sometimes, her legs hurt more and her walking is getting worse. She still has the nausea and abdominal pain. It is hard to watch her slowly sicken and not to be able to do anything.
>
> I hang on to the spiritual perspective; and I try to gaze at this world from that viewpoint, it helps. Nothing else does much.
>
> I continue to play the meditation disks for us both. It is how we go to sleep. I reiki the kids and me every day. This week on Bribie is a godsend. I feel we are being held in the gentle hand of God.
>
> I feel often and very keenly that I am a spirit gazing out through human eyes. It is becoming easier to 'retreat' there, to dwell in the peace that hovers there as I meditate more often. I am becoming acquainted with my true self. I am realizing who I really am.
>
> I stay very much in the present. The future is too painful to contemplate so I stay in the Now. All any of us has is now.
>
> As I continue to fill myself with peace and love, I find I continue to attract kind and loving positive people and energy. What lessons I am learning!
>
> This is a rugged and painful path to joy - but a path to joy none-the-less."

During that time at Bribie, Sarah lost the ability to walk. At the beginning of the week she could and by the end of the week, she was confined to a wheelchair.

I needed to get her upstairs one day. I wanted to carry her but she would not let me. She knew how bad my back was so crawled up the stairs rather than let me carry her. What formidable determination, strength and love in one so young. I would not let her do it again though. From then on I piggy-backed her up and down those stairs. Hang my back.

When we got back to Brisbane the doctors organized some more radiotherapy from the hips down. I argued for this. She needed to move; she needed to be a kid. Over the next several weeks, I helped her learn to walk again. Her determination to do so, her sheer guts was awe-inspiring.

* * *

We celebrated Kate’s birthday on 20 December 2006 with a party in the back yard with all her friends. We had promised all the kids a big birthday party this year because 2006 was supposed to be a year of celebration. Tom and Sarah had had their parties. It was important for Kate to have one too.

On Christmas Day I wrote:

> “Strange, I feel a little island of peace deep inside. I had a moment of joy lying in bed this morning. Sarah was here. Tom and Kate were playing or watching television, the presents were under the tree, all was OK for a while.
>
> Sarah has been getting worse since school stopped. She can’t walk any more. She can’t bear the body weight on her legs and feet. It is heart-breaking stuff. She could not get to mass last night. My husband took Tom and Kate. I got Sarah to bed and had a glass of wine on the front patio – and I cried again.
>
> This is our last Christmas together.
>
> She has had an amazing impact on my life. She taught me love. Pure love. I have adored her all her life. I am forever changed. She has transformed me, formed me. By being born, living and now by … she has made me.
>
> I am sitting on my bed watching her quietly sleeping. What joy she has bought me – and such pain, such terrible pain.
>
> I am not losing her though. She will always be close to me. Never further than a breath, a thought. I will still feel her presence. Love lasts forever. Love and souls are the same, that of which the universe is made. We are all one.”

* * *

On 31 December 2006 I thanked God that the year had finally ended. I wrote:

> “Peace, joy and love will be in my life and in the lives of my children. I do not know what 2007 will hold but I will begin it one step at a time with a heart full of hope and expectation.”

Sarah spent New Years Eve in hospital with abdominal pain.

It seemed to me that the closer she came to her journey forward, the wiser she became. In early January I wrote:

> "Sometimes she forgets and today talked about "When I grow up…".
>
> I used to correct her and talk about heaven. But now I don't. It is her life, her journey and we create our own reality. She then corrected herself and said "But I don't have to worry about that because I'll be in heaven". I just said to her "You won't go to heaven until you are ready" – and she won't. This is her journey, her path, her destiny.
>
> She has changed me completely. How many others has she touched? I'll leave this up to her.
>
> It is mine to journey with her, to love her, to support her. It is my privilege, my honour to live beside her. I was chosen to be her mother. Should I doubt divine purpose? No. Nor should I doubt the purpose of Sarah's soul. I will never on this earth fully understand why this all happened. Why try? I will understand all when I too leave this body behind."

* * *

On 12 January 2007 Sarah's headaches began suddenly. I had spoken to the palliative care nurse, given extra pain relief, was putting cold packs on her head, lavender oil on her temples, relaxing oils in the burner, meditation CD on softly, I kept her sipping fluids… I was worried about this headache. I knew it was not right, not a normal headache. I was worried 'It' was in her poor little head now. "Please please dear God show her mercy".

The next day my ex-husband took Tom and Kate to Deception Bay so Sarah and I were alone. I wrote about the night before:

> "Last night Sarah got a bad headache. All this powerful medication does not fix it. She goes to sleep but when she wakes it is still there. I am afraid she is dying today. I am trying very hard to fight this fear… to only allow love to fill me. But fear raises its head each time I look at her pale sleeping face.
>
> I keep thinking about her birth… the false starts, the long labour. I am trying not to be afraid. I have been at the mercy of my love for this child since she came into my life, into this world. I love her more than life itself. She is my heart and my soul. She is my soul mate. I just adore her. Death will not separate us. We will be together forever more. I will always feel when she is near. She will stay with me and help me. She will continue to love me for this life and after.

> I tried to say the rosary this morning. I did not get to the words. I just held the beads and asked Mother Mary, to be with me. I asked the angels to surround us.
>
> There is no point asking why. I have asked this so often in the past. No answer came. Perhaps I will understand eventually or perhaps not until I have left this life.
>
> I would have given anything to save her. I tried everything that was in my power. I gave it my all but it has not been enough. Why take from me that which I love most? Why take from a mother her first-born child?
>
> Thank you for Tom and Kate. Without them it would be hard to put one foot in front of another. They are my reason for taking breath after she has gone.
>
> I am not ready to see her sicken and die. I am not ready to lose her.
>
> I got her a Burmese kitten…. because she wanted one. Lucky she did not ask for a giraffe. She was so excited about it.
>
> Please Lord let her wake up without pain and be as well as she was yesterday. Please let her see her kitten. Please let her get back to school. Please, please don’t take her yet. I need her. I love her. She is mine. Please leave her with me a bit longer. I will treasure every single moment.”

I lay down next to her and just … held her.

-25-

A Mighty Spirit

"Love is
letting go of fear."

Gerald Jampolsky

Sarah was looking forward to getting back to school. She was counting the days. As far as I was concerned, if she wanted to go to school I would get her there. She was excited too that with Kate starting prep, all three of them would be at St Anthony's. She said she would go and collect Tom and Kate from their classrooms each day after school. She forgot for a moment that she was sick.

I have a photo taken the morning of that first day back at school. The three children are in their school uniforms sitting on Sarah's bed. Shalom the kitten is asleep on her lap. Sarah was looking tired but serene. Kate and Tom look apprehensive, like they were forcing themselves to smile.

She lasted 1 ½ hours that day. She did not go again until the following week and then for less than an hour. She said to me quietly one day. "Mum, how come Tom and Kate are getting used to being at school and I'm not?" I said that it was hard for them too. I could tell she thought this was a 'crock'.

School had been a source of such joy for her. She was now too sick to be there. I watched her darling face as this thought occurred to her. I knew then that a major reason for living was taken away. So cruel was this life. She did not go to St Anthony's again.

My ex-husband had been away in Mt Isa for work most of the week. Sarah seemed to be getting weaker but nothing obvious changed. She had been up and down so often. One day though, she did not have the strength to get from the mattress on the lounge room floor onto the commode.

She had been vomiting on and off. Through the night on Friday though, it began to be blood stained. The nausea was getting harder to relieve. I was worried it might be slipping out of my control.

Lying in bed that night I said out loud, “That’s enough God.” She was in bed too. She did not say anything. I don’t even know for sure if she heard me. But she knew in her own quiet wise way that I was finally ready to let her go. She had suffered too much. In the morning, she got out of bed as usual and made it to the lounge room.

I had one of my feelings that Saturday morning 10 February 2007. I sat my ex-husband down at the kitchen table and quietly told him that I believed Sarah was going back to God in a matter of days, not weeks or months.

He was surprised but seemed to take it in. But he then went out to the shops. Whilst he was away, Sarah’s vomiting seemed worse. She wanted to go to the hospital. I told her that whatever she wanted, I would do.

I called the ward to check if a single room was available. If there was not I was prepared to move heaven and earth to get the medical back up I needed at home. A private room was free. I packed bags for she and I and called one of my beautiful friends Christine to look after Tom and Kate.

When my ex-husband got home, I told him Sarah wanted to go to the hospital. He angrily accused me of putting the idea in her head. I told him to speak to her himself. Instead he went downstairs and mowed the lawn. They say men are from Mars and women from Venus… but he must be from somewhere further away than Mars.

Sarah kept asking to go and I had to explain to her he was mowing. I felt we needed to go immediately. But she was his daughter too. There was no convincing him. I needed to give him time. I had to let him see it was the right thing to do.

The mower then blew up. I think a little divine intervention was involved. I mean… what are the odds? I have this strange image in my head of an angel smiting his mower.

My ex-husband then came upstairs and talked to Sarah. Then she just got up and walked to the front door. He followed. She made it to the front entrance before collapsing backwards into his arms. I demanded he carry her to my car immediately. I said, “I am taking this child to hospital – Now!” At this point Christine arrived.

My ex-husband put Sarah in the back seat of my car. Christine coxed Tom and Kate into her car. It was all happening at once. I had a feeling of urgency. But it felt like I was under water. I knew that I had to keep moving; I must not stop.

I was probably taking her to hospital for the last time, but it did not seem real.

I wanted Tom and Kate to say goodbye to their sister. I did not know for sure that they would not see her alive again. I did not want to believe it. I told them to day good-bye but I did not push them to do so… what would I say? I did not want to upset my children. To them it was just Sarah being rushed off to hospital again. Maybe this was all it was.

When preparing for her birth I did not know if I was really in labour; I did not know for sure if it was 'the time'. It was strangely like this… the same element of disbelief, about the enormity of what was happening. I could not grasp that she might be leaving me.

I drove us to the hospital, Sarah, my ex-husband and I. I was calm, dazed even. I remember only part of the drive.

I parked in the loading bay when we got there. We had not stopped to put her shoes on, so I told her not to step out of the car. It was such a hot day; the tarmac would have been burning hot. She then ordered her father to move the wheelchair closer. Good God that child was born to be in charge.

When you must, you do what you must. When you sense divine intervention, do not dismiss the feeling.

Keep awake then:
For you never know the day or the hour…
Stay in the present moment.

Matt 25:1-13

Wonderful Reading:

Dubois, Allison	We Are their Heaven, Why the Dead Never Leave Us: Simon & Schuster, New York, 2006
Newcomb, Jacky	An Angel Held My Hand; Inspiring True Stories of the Afterlife Harper Collins Publishers Ltd, London 2007
Reilly, Carmel	Walking With Angels Magpie Books, London 2005

-26-

Dreams of Home

"In the depth of your hopes and desires lies your
Silent knowledge of the beyond;
And like seeds dreaming beneath the snow your
Heart dreams of spring.
Trust the dreams, for in them is hidden the gate
To eternity."

Kahlil Gibran

The nurses made up her bed whilst we got settled in. It was the same room she was admitted to that very first day, three years, 11 months before.

I helped her into bed. Just for a moment she looked her normal self. She seemed better and I told her so. I think she was a little disappointed to hear it. We were both relieved to be there; she because she felt safe; me, because I felt more in control. I was worried that the nausea would get away from me. The heat at home had been oppressive. It was good to be in the air conditioning.

I was glad we had come. She was all that mattered. I loved her so much. I would have walked across hot coals to keep her comfortable and happy.

They started a Maxalon and Ondancetron infusion to control the vomiting; starting with a bolus… but it did not work. She kept sitting up and throwing up old blood. It was cruel but she did not complain.

Shortly after that my ex-husband told her we thought she might go to heaven soon. He then turned away. But I saw the excitement in her eyes. She could hide nothing from me; or me from her. I knew exactly what she was thinking and it was written all over her face.

She asked me to lie down next to her for a while, for a snuggle.

The doctor then ordered Lorazepam for the nausea. I gave it to her on a spoon with some vegemite. I knelt on the floor by her bed and reikied her to help her settle and prevent her vomiting back the tablet. I was desperate for it to stop.

At this point an orderly left her a meal on the bench. I could smell the deep fried food so quietly asked my ex-husband to take it out of the room before it made her sick. His response was to yell at me for ordering him around.

She slept then for a few hours. Thank God. When she woke, the vomiting began again. Sarah said "Mummy, I want to go home." At the time I said, "Darling, I will do whatever you want." It was only afterwards that I remembered that 'Home' was her word for heaven.

The specialist ordered another Lorazepam to try to stop the vomiting. I knew the drowsiness this drug caused and in a quiet place in my mind knew that this might hasten her journey home. I gave it to her anyway with some more vegemite on a spoon with all the love a mother could muster.

The three of us dozed on and off through the evening. Even with the second Lorazepam on board, Sarah was still vomiting on and off. So the doctor then ordered something else. The nurses tried to get this medicine from the adult hospital. It came over in a syringe with no label so they refused to give it. I saw the syringe with the unidentifiable substance in it. They were right not to use it.

Sarah sat up to vomit again. She put her legs to the side of the bed as though she wanted to go somewhere. I went out to the nurses' station to give them a serve. "We can do better than this," I told them. They said they were getting the medicine from the 'catheter lab'.

I went back to the room; I would have been away 30 to 60 seconds. My ex-husband said, "I think she is going". My ex-husband stood on her right and I was on her left. We stared into her face. He was right. Her breathing was changing. I said "Fly my darling… go with it… be free". I kept talking. "Who is there to meet you? ... Your angel? Nonno…?"

She died then.

My darling beautiful girl had to leave me. My angel, my heart, my soul-mate, my baby…I held her. I buried my face in her curls and smelled her hair as I had done all her life. I told her I loved her over and over again just like thousands of times before.

I felt a rush of amazement and delight, of joy and peace.

We were always crawling around inside each other's heads. These feelings did not come from me. I was not capable of forming such emotions. I knew I was feeling what Sarah was feeling. She'd given me an insight into what to expect after death. Love survives death.

It was 12.53am 11 February 2007 when she left. Her father and I lovingly washed her little body, dressed her and changed the sheets. I lay next to her and held her, then slept by her bed till morning with my hand resting on her arm.

* * *

Finally there was no choice but to accept Sarah's dying, to embrace it. This truth came to me during that long sad afternoon. There was no fighting it, my only option was to open my arms and let the knife pierce my heart. Yet in so doing, I opened myself to life. I will not fear my own death.

Accept death when it comes, we cannot hold on to life - your own or the lives of those you love. Fear of it shapes your life – and stops you living it. Dying frees the higher self from the shackles of the body for which she has no further use.

"For what is it to die but to stand naked in the
wind and melt into the sun?
And what is it to cease breathing but to free
The breath from its restless tides,
that it may rise
and expand and seek God unencumbered?"

Kahlil Gibran

-27-

Good-bye for now my darling

"Here is the deepest secret
Nobody knows
Here is the bud of the bud,
And the sky of the sky
Of a tree called life;
Which grows higher
Than the soul can hope or
The mind can hide.
And this is the wonder
That's keeping the stars apart.

I carry your heart,
I carry it in my heart."

E. e. Cummings

I was caught in my own shock and grief. But I knew Sarah was at last safe. She was no longer in pain or vomiting. She no longer felt fear. She was happy.

I found that she was not far away. I just could not detect her with the usual five senses. I felt her presence very acutely. It was as if she was in the next room watching TV or playing on her computer as she so often did. On that first day, I walked into the lounge and her bedroom several times to check. I found myself speaking to her as naturally as always.

At the funeral I sat in the front pew on the left side of the church with Tom, Kate and my ex-husband. I was close enough to Sarah's little white coffin to almost touch it. I knew this was where I would sit. I had seen this scene in my head for years. I was alone with the coffin in a patch of sunlight streaming through the windows. I had been prepared for this moment.

It was the right place to sit even though my immediate family was on the other side of the church. In the seats behind me were my earth angels, my steel magnolias, the women who had sent me so much love and support. Even the lady who taught me Reiki, Cathy was there. She was sending Reiki energy to Rachel who was sending to me. I was sending Reiki energy to Tom and Kate.

The ladies from W4W were in the pews to the left. Girls I went to school with; nurses I worked with; nurses from the Royal Children's Hospital; lawyers I had worked with at the firm; cousins, aunts and uncles, kids, parents and teachers from the school; other cancer parents (the most courageous of all) - they were all there. The church was full to the last pew.

None of this really registered as I took my seat. I just knew where I was to sit.

I felt the love and support from every one in the church. I felt the Reiki energy pouring into me and also out of me to my children. I felt Sarah's presence keenly. I could not explain why, but I kept looking towards the top of the coffin and winking.

A few days later my friend Shanelle told me she 'saw' Sarah at the funeral sitting cross-legged on top of the coffin, her head resting in one hand, playing with the flowers. She also said Sarah was dancing across the front of the church near the altar. This deeply resonated with me and I knew I had sensed this also.

The image made me smile. Once again Sarah could dance with joy and abandon just as at the kindergarten breakup nearly four long years before.

"Only when you drink from the river of silence
shall you indeed sing.
And when you have reached the mountain top,
then you shall begin to climb.
And when the earth shall claim your limbs, then
shall you truly dance."

Kahlil Gibran

I knew there were things I wanted to say at the funeral but doubted I'd have the strength or composure. The feeling that I <u>had</u> to speak persisted. I felt I was being told in no uncertain terms that my words were important. I told Father Bernie our priest, that when the time came if I was going to speak I would give him a nod.

After my ex-husband delivered his eulogy I knew I had to get up. I'd not prepared anything formal but there were three clear messages to be shared. These were: my heartfelt thanks to so many; the power of prayer; and most importantly a promise of life beyond death. I said:

> "I'd like to thank God for giving me Sarah; and Sarah for fighting so hard to stay with me;
>
> I'd like to thank this community for drawing my family to its heart and holding us there;
> I'd like to thank St Anthony's School; nothing was too much trouble;
> and Tracy, Sarah's teacher, the woman Sarah loved most on this earth, after me!
>
> I'd like to thank Tom & Kate, my reasons for living, and for putting one foot in front of the other;
> I'd like to thank my husband for his stoicism;
> I'd like to thank my dear family, Mum and Dad especially (Dad can't be here today as he is fighting his own battle with cancer); and Mary-Clare who gives so much of herself.
>
> I'd like to thank the steel magnolias, the earth angels, the women who would breeze through my house and help me clean, who'd turn up with meals, or flowers, or who took my kids to school, or who just seemed to know when I needed a hug.
>
> I'd like to thank every child from school and everyone who prayed, for every single prayer. Some people say all prayers are answered it is just that sometimes the answer is 'no'. I don't accept that. I think a prayer is like a stone thrown in a pond, the stone does not know where the ripples go. When times were really bad we <u>felt</u> the prayers.
>
> Sarah was the strongest person I have ever known. She was in control of dying as she was in control of living. She wanted to go to the hospital. When we got her there in the air conditioning and got her temperature down, she was sitting up in bed. I told her she looked better and I think she looked disappointed.
>
> Later when her dad told her we thought she'd go to heaven soon, I was blessed to see the excitement in her eyes.
>
> Part way through the evening she said "I want to go home". 'Home' was her word for heaven.
>
> When the time came, her dad was on one side of her bed and I was on the other. We talked her through it. I told her "Fly my darling. Go with it. Be free."
>
> After, I felt a sense of amazement and delight, of peace. We were always crawling around each other's heads. We knew exactly what the other was thinking and feeling. I wanted you to know that. That is all I have to say. Thank you."

Everyone in the church clapped… such a strange moment.

Next Tracy, Sarah's teacher spoke beautifully. To honour this very special teacher and mother, I have included her words at the end of this book. Then my friend Christine sang two beautiful songs that she'd written for Sarah. Another dad from school, Darryl was among those who accompanied her. Father Bernie was wonderful. It was the most beautiful funeral I have ever witnessed. It was humbling to see how my darling girl had touched the lives of so many.

I followed Sarah's coffin down the aisle holding Tom and Kate's hands. Kate was crying. Tom became hysterical when he saw the coffin placed in the hearse. I passed Kate into my ex-husband's arms and just held my poor little boy. The kids and teachers from school formed a guard of honour either side of the church driveway and down the street. My ex-husband got in his car and followed the hearse. He did not even offer to drive me to the cemetery.

Kerry, a deputy principal from school bought a CD player to the cemetery. She played "Wind Beneath my Wings" by Bette Midler as they lowered Sarah's coffin into the earth. One of the steel magnolias had told her I liked this song. I would not have thought of music or of this song for that moment.

It was a message of love from Sarah.

"It must have been cold there in my shadow
To never have sunlight on your face
You were content to let me shine, that's your way
You always walked a step behind
So I was the one with all the glory
While you were the one with all the strength
A beautiful face without a name, for so long
A beautiful smile to hide the pain.

It might have appeared to go unnoticed
But I've got it all here in my heart
I want you to know I know the truth, course I know it
I would be nothing without you.

Did you ever know that you're my hero
And everything I wish I could be
I can fly higher than an eagle
For you are the wind beneath my wings…

Fly, fly, fly away… you let me fly so high
Oh you, you are the wind beneath my wings…

Fly, fly, higher than the sky so high I almost touched the sky
Thank you, thank you, thank God for you the wind beneath my wings."

Bette Midler

I have since learned to listen carefully to my feelings and intuitions about Sarah. I often feel her close. I try to be alert and to keep an open mind when I witness 'co-incidences', signs and messages.

Never miss an opportunity to say, "thank you" or "I love you".
Prayer is energy. Send it.
Life is eternal.

Chapter 28

Dreams, Messages, Rainbows and Lessons

“We have not even to risk the adventure alone
For the heroes of all time have gone before us
The labyrinth is thoroughly known
We have only to follow the thread of the hero path
Where we have thought to travel outward
We shall come to the centre of our own existence
Where we had thought to be alone
We shall be with all the world………”

Joseph Campbell
“The Power Of Myth”

On 22 February 2007 I wrote:

> “I went to see Maureen. … I have been unhappy for such a long time in this marriage. There was a time I thought I could fix it. Then I decided I could just put up with it. What did it matter I thought, if I was unhappy as long as every one else was happy?
>
> Through Sarah’s illness I realized that the marriage had gone beyond emotional neglect. I was being subjected to verbal and emotional abuse. This was worse in some ways than physical abuse. The fear and intimidation are the same… but the damage is invisible.”

Sarah had the courage to move on. Somehow this gave me the strength to move on too. Change is only change. I have read that Buddhists believe all pain is caused by trying to hold on to a reality that is by its very nature, transient. I had tried to hang on to my marriage even though it made me very unhappy, mostly because of my children but also because of my own fear. Even a bad habit can be reassuring.

Despite all this, Maureen urged patience. She said for the sake of the children, my ex-husband and I should put off separation for three to six months. I understood her point and would do anything for Tom and Kate, but I didn’t know how I could keep on living on edge and on guard under my own roof. I too needed to heal, but I took her advice seriously. The court date for the divorce turned out to be 24 April 2007, the day before Anzac Day, Sarah’s birthday. The divorce became absolute on 25 May 2007, a year to the day after we discovered Sarah would die. He did not move out until 1 July 2007, over 2 months after the divorce. The property settlement which followed was very difficult as he fought bitterly and blackly to keep the assets of the marriage and repeatedly appealed against paying minimal statutory child support. Still that battle too is over now.

I had a dream. I visited someone else's back yard. There was a dark swampy pool. The shadowy figure that lived there was trying to drain it but the task was going slowly or not working. The yard was a mess. I knew this swampy yard. I'd been there before. But it was no longer mine and not my responsibility, not my problem. We are given messages in our dreams. This one was about my ex-husband.

Maureen suggested I do a Relationships Course that was to start the next day[20]. She told me not to bother about paying for it until I was back on my feet. It was run only 2 or 3 times a year. Synchronicity again. I agreed to go.

Part of the course involved a process to help let go of pent up energy and emotion. The song played for my turn was "Wind Beneath My Wings" by Bette Midler. Maureen did not normally pick and choose songs for specific people. But felt compelled to play this one for me; and hurriedly shuffled CDs when she saw I was next. She was not at the grave and did not know this was the song we played as we buried Sarah.

I certainly released some emotion. I also released Sarah. I found myself saying the same words I said to her as she passed over. "Fly darling. Go with it. Be free." I let her go. I gave her permission to go.

Until that day I had felt my little girl was with me, just somehow in the next room. Her presence was the same as always. Since then she has felt less near. She is still there but somehow at a higher vibration, words fail me but these will do. It was as if she had changed, become more complete, like she had learned more, or graduated. She felt less 'physically' present but stronger, I sensed more wisdom. I also had the strong conviction that she would stay with me now to help, to guide and protect me.

The second song she played was The Greatest Love of All sung by Whitney Houston, also well chosen.

"I believe that children are our future
Teach them well and let them lead the way
Show them all the beauty they possess inside

---

[20] 'Sex & Relationships Course', See www.womenforwomen.net.au

Give them a sense of pride to make it easier
Let the children's laughter remind us how we used to be…."

Michael Masse, Linda Creed

Sarah would often say to me. "Can we be children together in heaven?" I would reply that I hoped so and perhaps we might even come back again and be kids together. I had completely lost sight of the child in me. I could no longer play or be silly. I was weighed down by life, responsibility, pain and fear. I have resolved to rediscover my 'inner child'.

Another thing that happened that weekend was that Kath, a strange little lady I knew only in passing, told me quietly that she was a medium. She said she had seen Sarah and that she was beautiful and surrounded in white light. She also said that Sarah had said "Tell Mummy that she did everything she could, and more". A couple of days earlier I had been pacing the floor at home crying desperate tears saying "Sarah my darling Angel I wish I could have done more, I would have done anything, I am so sorry". At the time I had felt that she heard me. It would seem she did.

Kath also told me I was an Earth Angel (whatever that is). She recommended I read a book called Earth Angels by Doreen Virtue. I eventually did find this book. A bit 'out there' it has to be said… but I felt determined to keep an open mind. What was there to lose? I am still not sure what I think about this one… but I bought an 'Earth Angel' bumper sticker just for fun.

In early April 2007 I stood at Sarah's grave. Crying, I begged for some sign she was still with me. For months before she died Sarah drew rainbows. They featured everywhere in her art. Our friend Darryl wrote a song for her. He said he and his band felt a tingling down their spines as they recorded it. He felt it was a message. The words were…

"I'll send you a rainbow; I'll paint you the sky".

That afternoon the sky was a little cloudy but as usual in the midst of the drought, there was no rain. I was standing in the back yard looking at the sky when a huge beautiful full arched rainbow appeared to the east. I went out to the front yard to find Tom and Kate so I could show it to them. Tom was extremely impressed. Kate seemed to consider it routine. We stood and watched that rainbow until it disappeared. There was this special feeling in the air… a sense of presence, like a pressure change and the light was somehow different. Time seemed to pause. Thanks my darling girl… I'll take that as a 'yes'."

On what would have been Sarah's 9th birthday Tom, Kate and I, Mary-Clare and two of her children went to Sarah's grave. It had just been finished. We'd let Tom and Kate decide how to decorate it. They chose tinker-belle pink and rainbows. Mary-Clare and her kids were crying, it was their first visit and we were trying to be brave to help them. Mary-clare later told me that this song played on her radio as she drove away from the cemetery.

"…..There's some news I need to tell you
Give my mother a kiss tell her I'm OK
I recall the words, if it's too easy it never lasts
I have compromised now I'm finally free of the past.

Now I can dance
Clouds have all disappeared; Freedom, I hold so dear
Nobody knows me here
Though I can only imagine the sadness in your eyes
Please understand; now I can dance.

All alone the other night I came to realize we'll be friends for life
It was always meant to be
For some people the heavens can get it so right
Like an Angel you see
You have graciously offered a hand
You'd be so proud of me, now I'm finally taking a stand…

Now I can dance
Though I can only imagine the sadness in your eyes
Please understand, now I can dance."

Tina Arena

We went to a park with the kids, had a picnic, ate chocolate cake and drank champagne in Sarah's honour. She would approve.

On 22 May 2007 I sat at the grave listening to Sarah's Ipod and writing in my diary:

> "Call me mad. Call me late for dinner for all I care… but for the last 5 minutes, all I could get on Sarah's Ipod's random cycle were two awful instrumental riffs, two songs I don't like any more and a short bit of Sarah's laughter. I turning it off and on several times and pushed the forward button repeatedly. Finally I said "Very funny Sarah" and turned it on again – there was that bit of her laughter again and then the music moved on.
>
> She is with me. She is very happy, very alive and is having fun."

I have no idea how that bit of her laughter was recorded. Perhaps accidentally when taking a picture with the digital camera?? Who knows? I played it for Tom and Kate too who both smiled and said it was Sarah.

On 16 May 2007 I wrote:

> "I was driving home a few days ago I had not intended going to the grave that day but "Wind Beneath my Wings" came on the Ipod as I was passing the cemetery so I stopped and found myself standing at her grave by the end of the song.
>
> I suddenly looked up because I felt or heard something but no-one was there. I felt then that the next song was going to be important. It was "The Greatest Love of All", the second song from my process at Maureen's Relationship course.
>
> Whilst this song was playing Sergio, my ex-husband's cousin walked up. He was there to visit Nonno's grave next to Sarah's. … He and my ex-husband's relatives in Australia and in Italy had not been told Sarah had died. It would seem Sarah or perhaps Nonno wanted them to know."

On 16 July 2007 I found myself at Sarah's grave again. I never sensed that she was there but for some reason I always felt like being there got her attention. I asked Sarah for another sign that she was still with me. I felt weak but needed to know she was there. I love her so much and miss her so much. The next day my friend Louise phoned me. She said she just felt the need to call to see if I was ok. Then, that evening when I got home, there was a phone message from Lana, a mother at school whom I knew less well. She hesitantly said that she had had a dream about Sarah the night before. She said she asked Sarah what she wanted her to do. Sarah said, "Check Mummy is OK". "Thank you my darling girl."

Sarah loved babies. At hospital she'd gravitate to the tiny ones with cancer. The Christmas before relapse she'd insisted on going up to the kids cancer ward to hand out chocolate frogs. She often said she was going to look after all the little babies in heaven. Mum and Mary-Clare came over one morning. As usual my niece Clare came too. Sarah had loved Clare. She would always look after her little cousin whilst she was visiting and would sometimes even cry when Clare left.

This day we adults were sitting at the kitchen table. Clare, normally a high maintenance clingy little girl crawled off down the corridor by herself and sat at the other end of the house playing with pegs and happily chatting away. This was highly unusual for her at the time. All three of us stopped talking at the same moment and stared. We had all felt a presence at the end of the corridor with Clare. It seemed that Sarah was looking after her cousin as usual.

I had struggled for money that horrible year. So much so that Sarah had said she'd send me some money when she went to heaven. My friend Therese and her toddler Imigen came over one day. Imigen was playing happily in Sarah's room. Glad of some peace to have a cup of tea we mothers let her be. Next thing Imigen came out of Sarah's room, came straight up to me and gave me Sarah's purse with Sarah's savings in it. Kate had pretty much pulled Sarah's room apart since she passed. Where this purse came from I'll never know. When Imigen left that day she stopped at the door of Sarah's room, waived and said good-bye to the "empty" room.

I went by myself to Lamb Island for a week a few months ago to write. I stayed in a 'rustic' renovated shed belonging to friends. I found it lonely and frightening. But Glenn had supplied me with good food and nice wine. I began the task of confronting myself, and my grief. I wrote from morning to night and cried every day. At the end of the week I felt physically lighter, as if the pain itself had weight. One particularly tearful evening I went outside and looked up at the night sky. The clouds were a circle around the moon … as if to gain my attention. These same clouds then formed a perfect "S". Our loved ones are so close. They watch over us. Love survives death.

***

I am working again now. I am a commercial lawyer for the Health Department. I am also a director of Karuna Hospice Services, a not for profit organization which offers practical help and guidance for those facing death and for the people who love them. Despite everything, Tom and Kate are well balanced, well-adjusted children. One day Tom came running down to see me after school. He hugged me and excitedly said "God just spoke to me." I said "Really! What did he say?" He said, "Sarah's happy".
I am creating life anew.

Emotional pain is a heavy burden. It takes a conscious effort to let it go. For me this letting go has involved counseling, Reiki, meditation and writing. Unprocessed pain makes you sick. Mine did. Despite my efforts, earlier this month on 7 January 2009 I was hospitalized to remove gallstones. The surgeon also fixed a hernia and in the interests of trying to track down the cause of a pain in my lower right belly, removed a 'suspicious looking' appendix. All this was done via "keyhole" surgery and was supposed to go "without a hitch".

Five days after the surgery I woke in the middle of the night in rigors with excruciating, bent over double, hyperventilating, abdominal pain. The ambulance bless them arrived in around 15 minutes or so and gave me something heady to breath in through a big blue ‘whistle’. I was speedily returned to the hospital and to some morphine. I had several more episodes of the pain over the next 36 hours or accompanied by vomiting, sweating and other associated crappy (pardon the pun) symptoms. Despite a full abdominal Cat Scan, MRI of the liver and an endoscopy (another anaesthetic thrown in just for fun) no one could identify the problem. We did in the process find out what it was not, which was reassuring I suppose, but not an answer or a cure. I was sent home after a few horrible days to ‘rest and get better’.

I found this episode traumatic of course and the first night home remained awake after everyone else was asleep. I was frightened to go to bed just in case the pain returned. I sat on the back deck and cried my eyes out. I needed to express my distress and outrage at the pain, fear, indignity, loss of control and horror of it all. It felt like blackness and turmoil dwelt inside me and I needed to get it out.

I wondered how Sarah had coped with such as this for so long. Then it came to me. She coped because of me. I did that for her. I held nothing back, did all that was in me to do, to help her through. That was me.

What I did for Sarah was wonderful and praiseworthy. I need not feel guilty for not doing more. I need not feel guilty for not saving her, for being alive whilst my little girl is dead. I can move forward with a clear heart and a clear conscience. I can welcome life and need not stay always with pain and death. It is OK to seek the light and dwell there. I had not even realised that I was harboring this survivor guilt. My illness too was a lesson.

We are not to lead a life that is not tested. I believe that we are here to learn. The pain of life is only wasted if we do not accept this and so do not grow. T.S. Eliot said “We must not cease from exploration and the end of all our exploring will be to arrive where we began and to know the place for the first time.”

The moment I was sufficiently recovered to type, I got back to this book and wrote until it was done. All the same, if it is OK with you my God, if at all possible, I would be grateful to have a break from lessons for a bit.

"……we're here and then we're gone
and all that remains
when we're free of our chains
is the love that we've shared……"

Mitten[21]

I love you Sarah.
Thank you for the privilege of being your mother.

---

[21] Mitten, (who sings with Deva Premal) from a song titled 'Soul Of Wonder', from the 'Soul Of Wonder'album.

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My personal theory is to leave thought behind when I walk in the bookstore. I reach for whatever seems to call to me. I've found reassurance and support in writings from Buddhism, Hinduism, Yogic teachings, Judaism, Kabalism, New Age Religion, Pagan or Earth Religions, the Gnostic texts and Christianity. I found there were common threads of truth in them all. One thing that fascinated me was that there was nothing new about the supposed New Age teachings and spiritual practices… these as far as I could tell were just drawing upon concepts and beliefs from older spiritualities. I also discovered my own discerning 'internal compass'. The truth seemed to resonate, to sound and feel true. I'd like to share with you some of the books that have helped me.

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Appendix
-1-

A tribute to the cancer mums and dads:

The Chosen Mothers

Most women become a mother by accident, some by choice
and a few by habit. Did you ever wonder how mother's of
children with life threatening illnesses are chosen?

Somehow, I visualize God hovering over earth
selecting His instruments for propagation with great care and
deliberation. As He observes, He instructs His angels
to make notes in a giant ledger.......

"Armstrong, Beth, son, patron saint Matthew"
Forrest, Marjorie, daughter, patron saint Cecilia"
Rutledge, Carrie, twins, patron saint Gerard."

Finally, He passes a name to an angel and says, "Give
her a child with cancer." The angel is curious. "Why this
one, God? She's so happy."

"Exactly," smiles God, "Could I give a child with cancer
a mother who does not know laughter? That would be cruel."

"But, does she have patience?" asks the angel,

"I don't want her to have too much patience or she will
drown in a sea of self-pity and despair. Once the shock and
resentment wears off, she will handle it."

"I watched her today," said God. "She has that feeling
of self-independence that is so rare and necessary in a mother.
You see, the child I'm going to give her has it's own world.
She has to make it live in her world and that's not going to be easy."

"But Lord, I don't think she believes in you," said the angel.
"No matter, I can fix that. This one is perfect. She has just
enough selfishness."

The angel gasps, "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from the child
occasionally, she'll never survive. Yes, here is the woman I will bless
with a child less than perfect. She doesn't realize it yet,
but she is to be envied. She will never take anything her child does for
granted. She will never consider a single step
ordinary. I will permit her to see clearly the things I see....ignorance,
cruelty, prejudice....and allow her to rise above them."

"And what about her patron saint" asks the angel, his pen poised in mid-air.

God smiles and says..."A mirror will suffice."

Erma Bombeck

Appendix
-2-

Tracey's Speech

She said:

> "When I first met Sarah she was a pale, shy and very bald little girl. But I was soon to discover, although some of the wariness remained, there was absolutely nothing either pale or bald about this very special young lady.
>
> Sarah was very much her own person. She was determined, strong willed and focused (and on bad days she was as cantankerous as a cornered bull). But she was also colourful, joyful, gentle and sensitive and quite likely the most resilient young person I have, or am ever likely to meet.
>
> When I remember Sarah I can't help but smile because she was such a unique young character. Like all 7 and 8 year olds, she liked getting her own way, and certainly knew how to go about getting it. I was a little slow to pick up on her wily ways at first but soon learned that if given an inch Sarah would take a whole roomful and then some!
>
> But I loved this about Sarah – she was a normal kid trying to manipulate areas of her life over which she had some control. There were so many areas of her young life over which she had no control whatsoever: Pain, isolation, sickness, hospitals doctors, tests, medication, tears and loneliness. With so many other things that Sarah could not control, she tried it on in any area that she could. Sometimes she got away with it, sometimes she didn't, but she was always s in there trying. I admired her for that.
>
> Sarah found a way to accept the unacceptable. She could soldier on through the worst of times and still smile and eagerly anticipate so much of what life had to offer.
>
> Sarah was wonderfully creative and artistic (just like her Mum). She loved to draw and colour and glue (and more was definitely better in Sarah's book). Sarah loved to draw when she was feeling low or when she needed her own time and space. She drew pictures to show others how much she cared about them and she received pictures from her friends with gratitude.

Sarah loved to dance and sing. She was energetic and enthusiastic and completely and utterly tone deaf – but who cared?

Sarah loved reading to herself and she loved reading to her friends. I have laughed quietly on many occasions when she'd come across an unfamiliar word and say out loud something like "nah don't know that one" and just continue with the story.

She also loved to play 'teacher' and heaven help the 'student' whose attention wavered while she was reading to them – it was never pleasant to received one of those stares but she certainly got the message across quick smart!

Sarah loved 'Show & Share' and would conveniently forget the '3 questions rule' so that some presentations seemed to go on forever. She also loved story time and would sit glued to the book from cover to cover. I can remember an occasion when Mary (the assistant teacher) offered to read to her (a rather long book as it turned out). Whenever it looked like Mary might be fading a little Sarah would turn and let her know in no uncertain terms that her efforts weren't quite up to scratch.

Sarah did not like missing school. She was surrounded by the love of her dear young friends. It was a beautiful thing to witness. These special young people provided support, comfort, acceptance, protection and most importantly they offered their unconditional friendship. Sarah loved having friends and these she had in abundance.

When I think of Sarah a few very clear images resonate in my mind:
- I see the very pregnant hot pink fairy at last year's Book Week Parade;
- I see Sarah totally ignoring Renae's (another year 2 teacher's) attempts to make pleasantries with her every morning at assembly;
- I see her leaving Bowden Park with a face like thunder because she hadn't been able to run in a race; and on that same day watching her quite literally bound out of her wheelchair and off into the Possum Tent (after Mary had just done the 1000m sprint around the outside of the park to get her there safely);
- I see her dancing with sheer abandon and delight with her friends while Daryl played his guitar on Thursday afternoons and I can still hear her raucous laughter as Craig read to us about 'Gordon and his Snookie' for the first time:
- I see her quiet anticipation when Cec would arrive each week with yet another beautiful gift and choices for the rest of us and then watch her giggle as Cec gave yet another rendition of the ever famous Sniffle Song;

- But one of my all-time favorites has to be the sight of her flying down the big slide at last year's Fun Day with her skirt in the air, caution to the wind and a smile as big as Texas on her face.

I have other memories of course. Grey and sad ones.

But these are not how I will choose to remember Sarah, nor will her young classmates or the St Anthony's school community. We know that Sarah was far more colourful than she ever was dull. She was much stronger than she was weak. And she was far more full of life than she was sick.

In my youngest son's bedroom there hangs a picture of Craig Motram getting up after being tripped in the 1500m Commonwealth Games in Melbourne. Underneath the picture it reads:

"Life is a set of hurdles …And a true champion gets up one more time than they are down."

Sarah was a true champion. We watched her get up time and time again and jump those hurdles. We watched her rise above the pain that robbed her of the freedom to be and feel like a normal 8 year old. We watched her rise above the disappointment and frustration she experienced with the loss of her mobility.

And we watched in complete awe at her ability to embrace the simple joys in life that we all so often take for granted. In every sense of the word, Sarah was a true champion.

For those who knew and loved Sarah, she was a gift, a special, fragile and precious gift. The St Anthony's community will never be the same. I will never be the same. We are all more because we knew and loved Sarah. And we are all less without her. We were blessed to share, for a short time, in the journey of this truly remarkable young lady.

Gran's open letter to Sarah Mary

My precious Granddaughter,

You have occupied a special place in my heart since I first learned of your presence in your mother's womb. I remember this day so well. The family was having a picnic at Mick and Kath's place on the mountain. With your beautiful round face and dark hair, I thought you were the prettiest baby I had ever seen. You were lying in your little cot beside your mother. You both looked exhausted after the long and difficult labour. As your mother nursed you I heard her murmur, "Mummy is here darling". I had such pride in my daughter. I had long thought of her as a brilliant and successful career woman. Now she had instantly become a natural mother.

When your mother returned to part-time work I cared for you at least one day a week. We had such fun. We would visit the neighbours and go for walks down to the park. You were always reluctant to go to sleep. When finally you went to sleep, I was afraid to let a pin drop for fear of waking you.

I remember the night I first realized you were ill. Pa and I were baby sitting while your parents were attending the "Rolling Stones" concert. You jumped up and down with excitement when we arrived, but you wanted to go to bed soon after. This was not like you. Thomas was sharing a room with you and wouldn't let you sleep. I put you in your parent's bed and when you were sleeping I lay down beside you. As I looked at you fear suddenly gripped my heart. I realized you were not well. Little did I know the seriousness of your illness.

A week later, on February 11th 2003, I was minding Mary-Clare's children. Pa rang with the news, "Sarah has Leukaemia". In deep shock I could only respond, "Oh God." You were still only four years of age. That evening when I spoke to your mother on the phone, she instructed me not to cry. Trying to be optimistic, she said, "The doctors said, she has an eighty percent chance." He voice faltered as she added, "This means we have a twenty per cent chance of losing her."

The Chemotherapy treatment quickly took its toll on you and you became a very sick little girl. A memory deeply etched in my heart is seeing you going to lie down on the couch while the other children were playing. You didn't have the energy to go and play.

A feeling of helplessness overtook us. There seemed nothing we could do to help, as your Daddy was able to take time off work. Our hearts ached as we saw your pain, the grief of your parents and the confusion and sadness of Thomas and Kate. They were only two years and one year old. As the months passed, we watched as you became sicker and weaker. You were unable to walk and couldn't eat. Your immunity was so low from the chemotherapy that for a time it was unwise for even us to visit you. After a time a nasogastric tube was inserted in order to feed you. This was a traumatic experience for you and for your parents. There were numerous trips back to the hospital to have it reinserted. Eventually as you body accepted this nutrition you became stronger. You still had to be fed with a nasogastric tube and your beautiful curls had all fallen out, but you became a happy child again. The treatment continued with daily does of chemotherapy and steroids and visits to the hospital three to four times a week. There was frequent admission to hospital for intravenous doses of chemotherapy.

Despite the continuous treatment and hospitalization you were able to commence school at the beginning of 2004 almost a year after your diagnosis. I felt so proud of you when I first saw you in your school uniform. School was hard as you were still having intense treatment and you had missed the pre-school year almost entirely. However you quickly made friends and you enjoyed learning. You were so brave. Sadly your beloved grandfather Nonno passed away during this period. He was much loved by you, Thomas and Kate and is greatly missed.

Despite the sadness of losing your grandfather, life was beginning to settle down to normal for you and your family. You continued to go to school. Your Dad had returned to work and had gained promotion. Your Mum who is a gifted student, a registered nurse and a brilliant lawyer was offered a scholarship in the area of Medical and Legal Ethics. Thomas and Kate were enjoying a more normal life. Your home was full of optimism.

In October 2004 all this changed. We learned the dreaded news that you had relapsed. The Leukaemia cells were once more found in your blood. Pa and I received the news the day we returned from a holiday in West Australia. The whole extended family was in deep shock. We knew the only hope for you was to have more massive doses of chemotherapy, total body irradiation to kill the Leukaemia cells and all you own bone marrow. You would then require a Bone Marrow Transplant. We learned any one of these extreme treatments could be fatal.

You were quickly admitted to hospital for a number of days for the chemotherapy treatment. You went home for just one day when you were readmitted. You were seriously ill with a fungal infection of your liver. For months we watched helplessly as your life hung in the balance. Your Mum remained with you all day. Your Dad stayed all night while he worked all day. Thomas and Kate came to live with Gran and Pa for three and a half months. Your Mum came home to sleep with us at night. This dreadful illness meant your Bone Marrow Transplant had to be delayed for months. You spent Christmas in hospital.

Eventually the infection cleared and you were allowed to come home for one and a half weeks prior to the Bone Marrow Transplant. You were so happy to be home. You quickly resumed your role as the eldest child in your family. Thomas and Kate were so happy to have you home. All too soon it was time for you to return to hospital. You were so brave as you left the house. Our hearts ached for you knowing the trauma that lay ahead. Thomas and Kate quickly demanded all my attention. They were to remain in my care for another six weeks.

While we looked to the Bone Marrow Transplant as a means of saving your life, we were full of fear. The buildup to the Transplant was a very anxious time. Your mother was so traumatized as she watched you receive the Total Body Irradiation. The Bone Marrow Transplant was an even more distressing time for your parents. Again one of them stayed with you day and night for the six weeks of your hospitalization. You were nursed in total isolation for the first five weeks. The only visitors allowed were your Mum, Dad, Gran and Mary-Clare.

As the hours, days and weeks slowly passed, I would wait anxiously for your mother to come home each night with news of you. Often she would be exhausted and full of concern and fear for you. Sometimes she would be light hearted when the news of you was better. Eventually the blood tests indicated you body was accepting the donor’s bone marrow, and very slowly you started to improve. You began to eat. This was the first food you had eaten for over four months. We were so grateful and we humbly thanked God and all those who had prayed so constantly and so earnestly for you. Mary-Clare had a prayer circle going all around the world to her friends via e-mail. She continues to request prayers for you and for your donor. All our extended family and friends were praying. Our parish community continues to pray. My healing touch friends were praying. Some were sending you Blessings and Healings in their own special way. Your name is mentioned twice every Sunday at Mass at Moorooka. Many other parishes also have you on their prayer lists. At the height of our concern the Sisters of Saint Joseph organized a novena through the intercession of Mary Mackillop. A large number of people participated in this novena. We also had other wonderful support from family and friends. I could not have managed to care for Thomas and Kate without Rachael Hoey who took them to Preschool and Kindy. Saint Anthony’s School was wonderfully supportive. Your class and your teacher Tracy prayed and made wonderful gifts for you. These helped to brighten your dreary days in isolation. Pa came to my aid when I needed him. Joanne and Mary-Clare helped me with buying groceries.

At last your room was opened and you were no longer totally isolated. Thomas, Kate, Mary-Clare and Grace were allowed to visit. Finally the day came for your to come home. Works cannot describe our feelings. There was joy. There was enormous relief that you had survived this part of your ordeal. There was also enormous anxiety as you still needed so much care. You were very vulnerable to infection. You still had to be isolated from the rest of the world. You could eat only special food, low in pathogens. Your mother had to exercise such care in the preparation of your food. You were still being fed via a naso-gastric tube. You still had a central intravenous line in a main vein near your heart. You had to return to the hospital every day for blood tests and for doctor's visits. You had over twenty different drugs to be given, some three times a day. Thank God Mum had been a Registered Nurse. After a time she had enough confidence to collect the bloods, and dad took them to the hospital. All this time the two younger children had to be cared for.

As I write this, eighty days post Bone Marrow Transplant much of this is still happening. The drugs are horrible and we look forward to a time when the worst of them will cease. You are still isolated from the rest of the world for fear of infection. Mary-Clare's children are allowed to visit if they are healthy. They are family. Your parents are hopeful you may be able to return to school at the end of the year. Our fervent prayers continue.

As I reflect on the past two years and three months I am so proud of my daughter Theresa, who is you mother, and also of your dad. They were with you day and night during the almost five months of hospitalization. They care for you, Thomas and Kate and bestow abundant love upon all of you. Theresa keeps the house spotlessly clean. Above all she keeps the family cheerful and full of hope.

My darling Sarah I love you. I love all my children and grandchildren equally. Your illness despite its heartbreak, continuous grief, despair and exhaustion has helped us all appreciate the power of love. I feel so privileged to be a mother and a grandmother.

I am your loving grandmother, Carmel.