# Chapter 2: Round One

## I

It was Friday evening when Alison, the on-duty chemo nurse, arrived to begin my first arm of treatment. She went to the far corner, collected the drip stand and rolled it across the room. Four plastic castors creaked and groaned until the stand reached its resting place on the left side of where I lay. She collected her trolley from the doorway and moved it to the bottom of my bed; dressed into a protective gown, safety glasses and dark purple gloves, the necessary precautions for handling chemotherapy; and hung two IV bags on the fastening arms of the drip stand. She extended the height of the adjustable pole until the bags dangled above her head and ran the plastic tubing; attached to the bottom of both IV bags, through either side of the double IV pump which had been left, attached to the stand.

‘Can you lift your shirt please David’ asked Alison. I obliged and she extracted the two Hickman line tubes from under my shirt. She grabbed one of the tubes and wiped the bung with a chlorhexidine alcohol swab. ‘It’s important that everyone who handles your Hickman line follows this process,’ she said and began counting allowed. ‘I’m counting to thirty to allow enough time for the alcohol to dry.’ She cleaned the bung a second time with a new swab. ‘We clean the bungs thoroughly with two swabs,’ she continued. ‘The Hickman line dumps drugs directly into your heart. Failure to clean it properly can lead to infectious bacteria entering your blood stream, something you want to avoid as you enter a period of neutropenia. A simple infection will make you very sick. So … it’s important that you watch everyone who accesses your line. You NEED to make sure that everyone cleans it twice. Also … ensure that they use a red chlorhexidine swab and not one of these blue alcohol ones,’ and she held up the packaged swab that shouldn’t be used.

Alison connected the IV tubing to the clean bung and repeated the process, connecting my remaining bung to the second IV bag. She pressed a few buttons on the pump; two mechanical arms massaged the IV tubes; a light pumping noise echoed in the room and we were off and running.

## II

After 12 hours my only side effects were: an increased sensitivity to smell, particularly towards food and an unusual taste in my mouth. Kavitha brought me a coffee on Saturday morning but I could tolerate neither the smell nor taste. My fears about being allowed to take coffee were ill founded. I no longer wanted it. I had experienced my last sip of full-bodied brew and would not touch another coffee for seven months.

The effects of chemotherapy materialised after 24 hours. I became nauseous and began vomiting; over and over again; until there was nothing left inside and I started dry reaching. My body contorted to painful muscle contractions as my stomach searched for more fluid to expel. Kavitha wiped my face with a wet towel. It was my only comfort.

The onslaught waned only once my antiemetics (anti-sickness medication) were modified. I leaned heavily on Kavitha that night, a reality that would become more and more common in the ensuing months.

## III

The likelihood of a parent being a suitable bone marrow donor is small. This is because they are responsible for only half a child’s genetic makeup. The best candidate is a sibling that shares both parents. My sister and I are birth products of different fathers’ so, like my mother, the probability that she would match was small. Nevertheless, both gave blood samples for testing and we awaited news of the tissue typing. We began preparations for an extended family search, cousin’s, auntie’s etcetera, in the hope that by some miracle, one of my relatives would match.

My chemotherapy continued into Sunday. Kavitha, who had slept in my room on a foldout bed, went home to spend time with Rathiga and Mum sat by my side in hospital. I drifted in and out of sleep. Mum waited for a lucid moment and mentioned that she had something important to tell me. She seemed nervous … but how important could it be. I’ve just been diagnosed with Leukaemia. Surely everything else pales in comparison.

She took a deep breath and explained that Peter, the man I knew as my father and whose life had been dramatically cut-short, was not my biological father. My true father was instead, a ‘charismatic Italian’ with whom she’d had a fleeting relationship before meeting Peter.

I had no idea. No idea that my father was out there. I thought he was dead. I reflected upon recent events. The world I knew was crumbling around me. First, I had discovered that I have a rare and difficult to treat Leukaemia, then I learn that my father is out there somewhere, probably alive. All this I learnt in one week.

A large portion of my life, previously shrouded in lies, was revealed in unvarnished truth. Who else knew this secret? Who else participated in this conspiracy? Why didn’t I know my background?

Perhaps I have other siblings. Perhaps Rathiga has cousins. Perhaps I should be able to speak Italian. Perhaps … perhaps … perhaps! All those years lost!

It was explained that Peter had begged my mother to withhold the truth. That Peter, a man rendered infertile by his own treatment, desperately desired a child and upon meeting my mother, he found not only love but an opportunity for fatherhood. I didn’t remember him well but I knew Peter was a good man and none of this had changed. It seemed plausible, but it didn’t ease the burden. I couldn’t help but feel cheated, masqueraded by my own family who had kept the truth from me by camouflaging the veracity of my lineage.

Despite Peter not being my biological father, the parallels between our lives’ were uncanny. There I was, in my early thirties, hospitalised and receiving treatment for a life-threatening illness. Years earlier Peter had succumbed to his medical issues at a similar age. Then I discover that he was infertile, a reality that I faced.

I spent the afternoon thinking about my fathers. Peter, the ill-fated sick man that I could hardly remember, who desperately wanted a child but was not graced with the good fortune of raising one. Giuseppe (Joe) the charismatically charmed Italian, who procreated some 30 years earlier, and with whom I had not had the fortune of knowing at all. Then there was Sam, my stepfather of 24 years whom I recognised most of all as my Dad. It was Sam who fed me, not only bread, but the nourishment of a value system which now ascends all that I am. It was he who had sacrificed years of his life towards my betterment and wellbeing and it was towards him that I felt the most love.

## IV

Another day dawned and the revelation about my pedigree remained fresh. It motivated me to become a better father to my angelic Rathiga. Not because any of my fathers had been bad, but simply because that was an opportunity that I yearned. I knew and accepted that this desire would only be fulfilled if I could cling to good health and remain actively involved in Rathiga’s upbringing.

Rathiga was the focus of my thoughts when my medical entourage entered the room. ‘Your chemotherapy will finish this evening David. I think we should try your lumbar puncture today,’ Emma said. We discussed my new discovery and acknowledged that it no longer made any sense to seek a donor on Peter’s side of the family. Instead, we agreed it more logical to track down my biological father. We would find him, and ask if he, or any of his relatives would agree to type matching. Upon reaching a conclusion, Emma left my room to resume her rounds, returning several hours later for my spinal‑tap.

Emma positioned me on my side in a foetal position and doused my back with antiseptic. I felt a sharp sting as she injected local into my lower back. She inserted the spinal needle and guided it towards the fluid filled cavity surrounding my spinal chord. After several attempts on her behalf, and much discomfort for me: Emma spoke, ‘this is proving difficult David. It looks like there may be some scar tissue that is preventing access to the subarachnoid space. It is rare, but this happens with some patients. Maybe a previous back injury has lead to the development of some scaring. I am going to book you into radiology. They will try again under imaging. Hopefully, they can do it without too many problems.’ Emma and the assisting nurse gathered their paraphernalia and I traced my history to identify potential causes of this, my latest difficulty.

The most likely candidates for scarring in my spinal area were one of a number of falls sustained as an avid rock-climbing during my undergraduate years’. I recalled those years, paying particular attention to three falls, any one of which could have lead to spinal damage. My primary purpose of this line of thought was one of remembering happier times, rather than one offering any hope of easing the lumbar puncture process.

First, I recalled the mistake by my belayer, who failed to arrest my weight as I leant back into the rope after a short but powerful route in Nowra, a favoured sport‑climbing region south of Sydney. Plunging away from the overhanging wall, I fell 9 metres, hitting the earth ass first in a dramatic thud that attracted great enthralls of laughter from other crag dwellers. The affair left me bruised and battered but grateful that it had not been worse.

I smiled … I knew that I couldn’t face the remaining candidates with the same guilt free consciousness. Both were products of my own erroneous judgment. The first of these, a nasty fall on the flat-faced Pagoda Wall of Moonarie, or ‘Moon’ as locals affectionately know it, a remote sandstone mecca on the southeastern wall of Wilpena Pound in South Australia’s gorgeous Flinders Ranges. I entered the exposed horizontal traverse on the second pitch of “Hanging Fred Bonet” and was climbing well until my concentration lapsed and I entered a classic traversing mistake. The trick when traversing is to know when to exit the horizontal section and start climbing upwards again. This time I exited too early, climbing into an upward tending finger crack. At first the crack accepted my fingertips and I was able to scale the cliff with ease. After a few meters; however, the crack thinned and disappeared, forcing me onto the tiny ledges of the steep face. The protection was poor and I was tiring. I peeled away in a classic display of awkwardness, popping the protective nut that I had placed earlier, and fell 8 metres. A shock wave jolted my entire body as I swung into the wall. The brunt of my injuries was sustained in my left ankle, which swelled instantaneously, converting the one-hour descent to camp into a slow and unforgettably painful four-hour trudge.

The final fall that I recalled was on “Kachoong”, arguably Australia’s most internationally acclaimed route. “Kachoong” is located in the Northern Group of Mount Arapiles, an island of solid quartzite rising above the flat wheat fields of the Wimmera Plains in Victoria, roughly half way between Adelaide and Melbourne. Access to “Kachoong” is from the top of the monolith so the entire climb towers some 100+ meters above the deck. The climb can be divided into three sections; a 10m footwall of glorious face climbing; a 3m horizontal roof meeting the foot and head walls at right angles; and the headwall, an easy and forgiving finish to the arm pumping mid-section. I climbed the footwall easily, took a brief rest at the beginning of the roof and monkeyed my way along the juggy flakes, slapping in a piece of protection with minimal attention and reaching the roofs lip and climb’s crux. I moved my hands onto the headwall and attempted to pull myself out of the roof and into an upright position. It was clear; however, that I was too far to the right … the good handholds were out of reach. My arms, starved of oxygen, convulsed violently. I held on long enough to acknowledge that I was coming off. The inevitable became reality and I fell from the lip; popping my poorly placed protection; pivoting on the remaining gear; and smashing back first into the footwall. I mustered enough strength to repeat the climb, this time completing it successfully. Back at camp, I was given a pack of frozen peas. The peas helped to ease my back but it was my ego that was most bruised.

I will never know if these incidents lead to the spinal scarring that made the lumbar puncture difficult. Nevertheless, I took comfort in knowing that I’d had fun along the way and I acknowledged that climbing taught me to control my mind when things appeared impossible and everything hurt. I was comforted in the knowledge that I could, with the exception of the aforementioned examples at least, make sound judgments when exposed at great height and at times when failure to do so could be fateful. This I felt would help me – help me to overcome the mental battlefield of cancer treatment. No matter what, I could hold myself together, remain positive and look forward to the future.

## V

My last dose of chemotherapy was administered on Monday night. After a few days I found myself lacking energy and having to fight to get out of bed each day. Despite my unwillingness, Kavitha would encourage me to follow a daily routine that required basic activity. I would get up, shower, brush my teeth and take a short walk. Each morning a nurse would extract samples of blood from my Hickman line and return again when the pathology reports were ready. Red blood cell, white blood cell and platelet counts were transcribed to a sheet on my pin board. We became accustomed to interpreting these numbers, recognising that the levels determined how I would feel that day, what I could eat and whether or not I would need any transfusions.

I was given my first red blood cell and platelet transfusions. I felt dirty as I watched the blood enter my body. I knew that this was nonsense but I couldn’t help it … this blood belonged to someone else. I appreciated that it was necessary but I didn’t like the sensation it gave me. I would stare at the clock as it ticked through the 3—4 hours necessary to infuse one donation of blood, often only to watch the nurse hang a second bag and start the timer once again. By the time my treatment finished I had gone through this process over 70 times for red blood cells and another 30—40 for platelets. I benefited from over 100 blood donations and now have an enhanced appreciation for the donors who voluntarily receive needles and give up their time (and blood) for the wellbeing of others. As well as the transfusions, which were used to boost my red blood cell and platelet counts, I took daily steroid injections to stimulate the generation of white blood cells, transfusions of which are not typically used due to ………….

During my second week of hospitalisation I received the first of many visits from my good friend and colleague Alexey who, more than anyone else, had the ability to distract my thoughts from illness. He would encourage me to focus on ‘normal’ things. A typical visit from Alexey would begin with a brief update on my health and then move to other topics such as: geophysics; political affairs; and Russian literature, a keen interest of Alexey’s, who had migrated from Russia almost two decades earlier. At first it was the short stories of Anton Chekov that appealed most of all, particularly because the chemo made it difficult to concentrate for long periods. As I began to cope better however, I began tackling the longer works of Mikhail Bulgakov and ultimately, although only after many months, Leo Tolstoy.

Alexey’s visits became an essential component of my mental game. For a time during each visit I would forget that I was ill and I would tackle normality. Our discussions reminded me that there was more to life than hospitals, blood tests and poorly appointed food.

## VI

It was time for my image-guided lumbar puncture. I was taken to radiology and asked to lie on my stomach, a position that aids imaging but makes access through the lumbar vertebrae more difficult. My back was cleansed with antiseptic solution and the radiologist took a number of X-rays, which he used to study and mark his access route. I felt the sharp sting of local; followed by a pushing sensation as the radiologist inserted a spinal needle. Even with the aid of imaging, the radiologist found it difficult to direct the needle into my subarachnoid space. He took several attempts, each time taking more X-rays and injecting more stinging local. The usual length of this procedure is 20 minutes but the radiologist was still trying to position the needle after 1 hour. In fact, I was forced to lie still for so long that I developed pins and needles in my legs. Why must all my procedures be complicated, I thought to myself. Finally, after much poking and prodding, the needle found its home. The radiologist took a sample of fluid from around my spinal chord and injected the chemotherapy.

I left the hospital after two-weeks and was admitted into the Oncology Outreach Service (OOS), a travelling service operated by two nurses, Lorraine and Jenny who tend to patients at their residence. One of the nurses would visit me each morning. She would take a blood sample, check my vitals (temperature, blood pressure and oxygen saturation), and discuss my general health and wellbeing. In the afternoon she would call to provide my blood levels and advise if I needed to visit the hospital for more transfusions. This process continued until I was readmitted into hospital on Boxing Day for my second round of chemo, and first exposure to the arm 2 drugs.

With my antiemetics (anti-nausea medication) sorted, I suffered only light nausea and seldom vomited … but food remained a challenge. My taste buds were compromised and the blandness of hospital food was far from appetising. Despite the challenge, I forced myself to keep eating throughout my second stay in hospital. Food was necessary to keep my strength up and remain strong. Some items, particularly salty crisps, would allay the nausea—they became part of my daily routine.

The drugs of arm B are more aggressive on the kidneys so there was greater emphasis on fluids in this round of treatment. In particular, sodium bicarbonate was given before, during and after the methotrexate. As well as daily blood analysis, I was required to monitor my fluids, keeping detailed records of ingoing and outgoing liquid and undertaking pH testing on all urine. This was more of a nuisance than anything. Bathroom visits were frequent due to the heavy intake of fluid and with low energy levels, a task as simple as toileting was tiring. I had to pee in a bottle, measure its volume and pour it onto pH indicator strips, accurately recording each measurement. It was also necessary to wear purple protective gloves … heaven forbid the drugs pumping inside me should spill onto my skin.

Mt chemotherapy finished after four days and I was discharged from hospital, this time before my blood levels dropped. The doctors felt it best that I spend as little time as possible in hospital. Their rational, in part recognising the psychological benefits of being at home and in part an attempt to remove me from the bugs that circulate in all medical facilities. As in cycle 1, the OOS nurse visited my home daily and called me into the clinic whenever I needed a transfusion. I took my temperature every 2—3 hours to catch oncoming fevers. A fever required instant re-admission and IV antibiotics. Consequently, the thermometer was an instrument I approached with trepidation, always fearful of a high reading. I injected myself with steroids each morning and whenever I went to hospital, either for a transfusion or consultation, I wore a facemask to reduce the chances of inhaling unwanted pathogens.

## VII

We knew that a transplant would require relocation to Sydney for 3—6 months, so, Kavitha returned to work to save her leave entitlements. She approached this graciously, balancing a full-time and demanding career with the care of a sick husband and a two‑year old daughter. When I reflect on this period I remain astonished by Kavitha’s ability to juggle countless demands on her time, despite the shadow of uncertainty that clouded our future. At work, she remained professional, rejecting pity and refusing to negotiate a reduced workload. In fact, many of her colleagues were unaware of the double-life she was living.

A typical day for me, involved waking in the morning to see Kavitha and Rathiga off to work and childcare, respectively. I would then stagger back to bed for more sleep, resting until the OOS nurse arrived late morning to do her thing. When she left, I would return to bed again, often sleeping until the afternoon when I would rise for a late lunch. This was followed by television and, whenever I felt capable, an expedition to the kitchen to prepare something for dinner. Cooking was a rare source of enjoyment for me during long periods where everything else felt too difficult. My daily routine was broken only when I was called into hospital for a blood transfusion or consultation.

Kavitha’s younger sister Astha, who completed college at the end of 2008, had planned to spend a couple of months with us in Australia before starting university. Arrangements for her visit were in place months before I fell ill … but things had changed. She arrived to a house in turmoil and experienced a holiday that differed greatly from what she had imagined. Nevertheless, she proved invaluable and despite her youth (she was 19), became a useful pillar of support. She helped around the house and kept an eye on me while Kavitha was at work.

## VIII

Chemotherapy can affect the bowel and lead to either diarrhoea or constipation. I suffered constipation in a big way! It was not my first experience with constipation … I already knew how painful and degrading it could be.

In 1999 I spent six-weeks trekking in the high‑altitude Sagarmatha, or Everest, region of the Nepalese Himalaya. I climbed three peaks: Gokyo Ri (5357m), Kala Pathar (5644m) and Chukung Ri (5546m); each offering magnificent views of the top of the world. Fresh vegetables are hard to find at high-altitude, so, in hindsight, it might have been wise to carry fibre supplements. But alas, I lacked the foresight when packing my rucksack and consequently suffered a severe case of constipation. I evacuated the mountains, flying from Lukla, arguably the world’s most dangerous and freaky airport, to Nepal’s capital … but the damage had already been done.

Back in the lower reaches of Kathmandu, I obtained a steady supply of glycerol suppositories and consumed a much-needed fibrous diet. My situation improved but I was left with two ailments, permanent markers of my time in the mountains. I had developed an anal fissure (or tear) and an external hemorrhoid, neither of which completely healed. Ever since then, these problems would flare from time-to-time … I would change my diet and after a couple of uncomfortable days things would return too normal. Under the influence of blood-sucking chemotherapy; however, the problems became unbearable. Constipation management involved a concoction of laxatives, fluid and cooked high-fibre food to soften the motions. No matter how bad it was I could not turn to suppositories due to an enhanced risk of contamination during insertion. I used analgesics to reduce the pain but these had to be managed carefully due to their unwanted stool hardening infernality.

The pain was so unbearable that I would lie in bed for days, waiting for my blood counts to rise sufficiently to repair my damaged anus. I would eat as little as possible in the hope that it would lead to less twos. The constipation made toileting inefficient … when I did go it was ineffective and I’d have to repeat the excruciating process 3—4 times per day, even with a lite diet. My fissure would tear and the toilet would fill with blood. I bathed in sitz baths (hot water and salt) 5—6 times a day to reduce the chance of infection in my open fissure, a worry that could have turned fatal in my neutropenic state.

## IX

The first round of type matching was completed. My mother and sister were unsuitable donors … they were both half matches. Without a donor my chance of long-term remission was slim. We needed to expand the search.

The obvious place to look … the international bone marrow donors database or BMDW (Bone Marrow Donors Worldwide). Founded in the Netherlands in 1988, the BMDW is an international consortium of registries from 110 donor banks in 48 countries. It has amassed 19 million stem cell donors of which any one could be a potential match and provide the source of my life saving transplant.

I was hopeful of finding a BMDW donor but my doctors were reluctant to commit with the same enthusiasm. ‘Unrelated donors are common but not guaranteed,’ they said, as they encouraged me to seek my biological father. I’d been considering this for weeks but I was dragging my feet. I found myself lacking courage. Perhaps it was the uncertainty regarding my father’s potential response. Maybe it was my newly acquired fractured sense of mortality. Either way, I wanted to contact him but I lacked the fortitude to do it. I enlisted the support of Yvonne, the cancer ward social worker, who felicitously accepted the task of finding my father.

I knew only two things about my father: his name (including his surname) and the fact that his parents had operated an Adelaide bakery in the family name. Would this be enough? I had no idea. I didn’t expect to hear from Yvonne for at least a week but she returned, with news of success, after only two days. The bakery had been taken over by a distant relative who didn’t know how to contact Joe but knew someone who might. A few phone calls later and Yvonne found my father.

One can only imagine what Joe must have been thinking. The revelation of an unknown child … no doubt enough to shake the most steady of spirits. Nonetheless, he willingly and immediately agreed to type matching.

We were not given Joe’s contact details. The search was conducted by Canberra Hospital so his details were protected under donor privacy laws. The hospital agreed, after extensive discussion, to provide the address of Joe’s GP. We were to write to the GP—who would in-turn forward our letter to Joe—who maintained discretion of returning contact.

I had every intention of writing to Joe’s GP. I wanted a relationship with Joe but my hesitation remained. I was undergoing cancer treatment. That’s enough for one to deal with. I didn’t need any more turmoil. It was easy to procrastinate … I did nothing.

## X

Initially, I was reluctant to make friends with other ‘sick people’. Leukaemia was my journey and there was nothing to be gained by sharing it with others. This was rubbish … it conflicted with my idealisation of Wangmu. She was supposed to remind me that cancer was a hiccup … that no matter what I was going through, there were others surviving and rising above worse. I recognised a need to overcome this nonsense and with time, I became more comfortable in my diagnosis and I saw benefit in meeting others with similar ailments.

Mark was the first Leukaemia patient that I met. A personable gentleman in his early fifties, Mark had AML. His battle with leukaemia began earlier than mine. He had once been diagnosed; obtained remission; and then relapsed again, after 6 months. By the time I met him he had already undergone his second round of chemo. An unrelated donor from the BMDW had been identified for Mark. He was waiting for transplant but he had two problems: a fungal infection, contracted while he was neutropenic; and a low platelet count, resulting from a failure of his bone marrow to produce sufficient platelets. He required daily IV anti-fungals and regular (every 2—3 days) platelet transfusions. This meant that he was in the clinic whenever I was at hospital.

I bonded with Mark immediately. He was jovial and approached his treatment with acceptance and ease. The more I talked to him the more I appreciated his graciousness. Things had been rough for Mark—he’d experienced all the side effects that chemo could dish out and yet he was still standing … ready … and waiting … for the next round … the transplant that would save him. We would chat for hours, passing the otherwise mundane time while receiving IV drugs and blood transfusions. I met Mark’s wife Vicki and their gorgeous daughter, Rani, who like Rathiga was gifted an ancient name of Sanskrit origin. Mark and I agreed that when the two of us were up to it, we would get our families together for dinner.

I knew of Peter’s exploits well before meeting him. There were several plausible reasons for this: we were a similar age; we both had the rarely diagnosed Philadelphia positive ALL (there were only two other cases in Canberra during 2009—11); he was terribly ill when diagnosed. But these were not the reasons that I had heard about Peter. When he arrived at hospital, Peter had an impressive collection of long dreadlocks, which were now long gone thanks to the chemo. I knew about Peter because I’d heard the nurses talking about the tragedy of the lost dreadlocks.

Peter was an avid ski instructor two years younger than I. His diagnosis preceded mine by two months so he was further along his treatment than I. The two of us would catch up as often as possible, visiting the other whenever he was admitted. He was fortunate. His sister was a suitable match so plans were already underway for his transplant. The locale of my donor was unknown, my transplant remained uncertain.

## XI

My treatment continued in a cyclical fashion. Days turned into weeks … weeks into months. Each cycle of chemotherapy was followed by neutropenia, constipation and inflammation of my fissure and hemorrhoid. I would lie in bed for days, consumed by pain and eating little to reduce the number of number twos. Each time I came out of neutropenia the doctors would schedule the next cycle but I would resist this as long as possible, my objective, to allow sufficient time for my anus to repair.

My waistline ebbed and flowed during the cycles. I would lose 4—5 kilos each period of constipation, only to regain them again as I recaptured an appetite. I was like a camel … storing fatty tissue during good stints and loosing it in leaner times.

Most of my hospital admissions were short: 3—4 days. Nevertheless, the close confines of four walls sent me insane during every visit. I couldn’t relax. I was constantly waiting for something to happen. I tried meditation, listening to music and watching television. Nothing seemed to work.

My anxiety would grow until I’d jump form the bed to drag my drip stand around the room. After a few minutes of pacing, my anxiety would calm and I could return to the bed where the process would begin again. Temporary relief came when receiving visitors, such as Kavitha or Alexey who would extract me from the self-pitied boredom, but I would fall back into the same routine as soon as they left. Ultimately, I found myself turning to Wangmu. Focusing on her warm welcoming smile, I’d search my inner-self for the strength of character that gave her the conviction to carry on. There was an ideology in her outlook that must be learnt … a doctrine that must be replicated … if I was to survive this battle.

## XII

During one period of neutropenia, when I was staying at home, I developed a migraine. It was so severe that I struggled to stand. I tried managing it with analgesics (paracetemol and endone) but nothing eased the pain. It consumed every aspect of my guise and carriage. I needed to go back to hospital. I didn’t want too, but I had no choice, I couldn’t manage the pain.

I was admitted to the ward. Nurses administered morphine to combat the pain and I slept the headache away. The cause of my migraine eluded the doctors. They kept me in hospital for a few days to ensure nothing sinister was happening and then released me, the unwanted and unexpected admission over with.

## XIII

My friendships with Mark and Peter blossomed. We would share ‘war stories’ and exchange anecdotes of how we were passing the time and maintaining our sanity. Mark and I continued to plan our dinner date, a target that kept moving due to the onset of neutropenia or latest medical setback.

I went back to hospital for my next cycle but there was a problem with my room allocation. I waited in the clinic for another patient to be discharged. It was 7pm when the chemo nurse decided not to wait any longer, opting to start my chemotherapy in the clinic. She was agitated by the delay and was fumbling at the chemo bags … one slipped from her grasp. It crashed onto the floor, spraying toxic chemicals in all directions. My heart dropped … the girls were with me. I turned to Kavitha and Rathiga; the chemo missed them by inches.

We looked at the mess on the floor. Yellow liquid gathered into puddles. Thousands of dollars of pharmaceuticals were gone, wasted in an unfortunate accident. I slouched into my chair. I was relieved that chemo had not fallen on my girls.

The nurse pulled herself together with a deep breath. ‘This has never happened to me before,’ she said, ‘I am terribly sorry.’ She knew that she had been rushing—she slowed everything down. ‘I … I need you to take your daughter out of here,’ She said to Kavitha. ‘We don’t want to get any of this stuff on her.’ Kavitha and Rathiga left the room.

There is a special protocol for chemo spills. The nurse’s training kicked in. It took her 30 minutes to return the area to safety. ‘The pharmacy is closed for the day,’ she said, ‘I am going to call the pharmacist. He will have to come back to the hospital to make a new bag of chemo. I am sorry, but this means it might be late before we get started.’ ‘Never mind,’ I replied, ‘I have no plans this evening.’ We both giggled. We knew that I was stuck in hospital for four days.

## XIV

Another round of chemotherapy passed and a week later I found myself in the clinic. There were several of us in the waiting room. Mark and Vicki were called in first. I waited to hear the latest development regarding Mark’s progress.

Vicki was crying when they returned. Mark’s bone marrow donor, an unrelated volunteer from Europe, had decided that the proposed transplant date, which had previously been agreed and was only three weeks away, was no longer agreeable. The donor had instead decided to holiday on the Mediterranean. ‘Bloody sun-bathing hippie,’ she said, focusing no longer on the sacrifice the donor was willing to make but the casualness with which he was treating Mark’s life—a life that was in balance.

Mark and Vicki’s disappointment was understandable. This was the latest setback in a long and complicated path. Having waited so long to get to this point, Mark now faced two more months of waiting, the time required for the donor to return and for him to regain his place in the busy transplant schedule at Sydney’s Westmead Hospital. I felt sympathy for them both and was vainly offering my condolence when my name was called. I entered the private consulting room … all of Pidcock’s entourage was there.

‘The type matching for your father has come in,’ said Doctor Pidcock. ‘I am sorry … he is only a half match … he is not a suitable donor.’ ‘Okay! But does the test confirm that he is my father?’ I asked. ‘It is highly likely … almost certain.’

‘We have some other test results here for your brother … his also a half match.’ ‘I have a brother?’ I asked, no longer thinking about the negative results but the fact that I have a brother whom I’ve never met. ‘What’s his name?’ I continued. ‘Looks like it’s … ah! Here it is. Adrian!’ he replied as he fumbled through the report.

I had little time to think about my brother. Pidcock continued ‘I am sorry to tell you this but I have some more bad news. We have been unable to find you a match from the international database.’ ‘You mean … no match amongst all nineteen million?’ I interrupted. ‘There are no matching adults David!’

‘We’ve managed to find some matching blood cords that were donated after new births,’ Pidcock continued. ‘There are only half a million of them in the database but they are simpler to cross-match. We’ve found 3 that are suitable. There is a problem with cord transplants though. The risks are higher because the quantity of stem cells in each cord is small. This means that we need to use two cords with different genetic makeups. Combining them can cause extra complications during transplant.’

Pidcock went on, ‘the other problem is engraftment. A small number of donor cells leads to a long time before the donor marrow starts generating your own blood cells. This means an extended period of neutropenia.’ ‘Extended period?’ I asked. ‘It could be more that sixty days. The chances of you contracting a fatal infection, one that you can’t fight with no white cells, is high during such a long period,’ he replied.

‘I recommend that we increase your number of HyperCVAD cycles and attempt a transplant with your own stem cells ... an autologous transplant. We are in unchartered territory here though. No one knows the best way forward. Philadelphia positive ALL is very aggressive and almost always comes back without a transplant. What is not clear is whether an autologous transplant will help. There is no evidence in the literature. In fact, we debated your case for a long time during our weekly meeting and the truth is that not all the specialists agree whether or not we should do the autologous transplant. What is clear is that you need to keep taking Glivec.’

Glivec is an oral enzyme inhibitor that I was prescribed after my Philadelphia positive diagnosis. It is useful in treating Philadelphia positive ALL because it interrupts the processes that generate malignant cells. ALL is caused by abnormal chromosomes, which produce an enzyme, known as tyrosine kinases, that leads to the uncontrollable growth of immature lymphocytes, the category of white blood cells malignant in ALL. Imatinib, the active ingredient of Glivec is a molecule that attaches itself to the enzymes, decreases their activity and slows (or sometimes stops) the spread of immature cells. Unlike chemotherapy, which kills all rapidly dividing cells, Glivec is a targeted drug and hence has fewer side effects.

Glivec is a PBS (pharmaceutical benefit scheme) drug in Australia. This means that the full cost (about $7,000 per month) is subsidised to $64 a month. Without the PBS, Glivec’s annual cost of $72,000 would be outside the reach of most Australian’s, myself included. The catch: the PBS only approves Glivec’s use for two years. I knew that after two years I would be on my own … no Glivec and no idea what would happen.

‘I have spoken to Associate Professor Ian Kerridge at Westmead. He is going to see you next week to discuss your options further. Ian is a transplant physician and is better placed to plan your ongoing treatment. I will send him our recommendation and we will see what he thinks,’ Pidcock said.

‘We’ve arranged transportation to Sydney with the Leukaemia Foundation for you and Kavitha. They will pick you up in the morning, drive you to Westmead and return you home in the evening,’ chimed in Deidre, who had been quietly listening to my conversation with Pidcock.

I returned to the waiting area where Loraine, the OOS nurse, attempted to console me. This was the latest misfortune in a growing list of setbacks. Where is this going? What will become of me? Is it going to work? My mind wandered as Loraine’s voice faded into the abyss of consciousness.

## XV

The Leukaemia Foundation was founded in 1975 to assist patients and their families cope with leukaemia and other related blood disorders. The foundation constitutes a coalition of staff and volunteers who work tirelessly to ease the burden on inflicted families. In 2011, the foundation: facilitated face-to-face education programs for over 6,500 people; provided 13,864 nights of free accommodation to families forced to relocate to major centers for treatment; and organised volunteer drivers who collectively accumulated over 8,000km of travel in 29 Holden and Bridgestone sponsored vehicles. The foundation also distributed 3.8 million dollars to vital research, growing its total research investment to over 20 million dollars.

Bruce, one of Canberra’s Leukaemia Foundation volunteers, arrived at our house at 6:00am to collect Kavitha and I for the 3.5 hour drive to Sydney. The temperature was unseasonably low (for early autumn) and the weather inclement. Visibility was poor and Bruce was forced to drive below the speed limit of 110km/hr. We were half way along the Hume Highway when the rain poured … Bruce was forced to pull over.

I was watching the clock … we were in danger of missing our appointment. Bruce reached for the phone and called Westmead to advise that we would be late. The receptionist’s response pulsated over the car’s speakers, ‘Associate Professor Kerridge is coming in from the university especially for this appointment. He is very busy today and only has an hour at the hospital to see David. I may have to reschedule your appointment if you are late’. There was a long pause before she continued, ‘look … keep driving and I will see what I can do.’

Why must everything be so complicated? The Hickman procedure—the lumbar puncture—we can’t even drive to Sydney without drama. I felt too ill to be travelling. I couldn’t believe that we were going to drive all the way to Sydney; to turn around, none the wiser about where my treatment was taking me. The uncertainty was killing me. My agitation growing, when, without warning the weather cleared, the sun’s rays pierced the clouds and Bruce resumed our drive.

We were 30 minutes late when we arrived at Westmead’s Cancer Care Centre, only to discover that Ian was even later. He was somewhere among the 28% of Sydney residents that cram the highways on their way to work. We had to wait to learn my fate.

‘Sorry I’m late,’ Ian said as he took my hand and shook it. ‘And you must be Kavitha! Come with me,’ he continued, guiding both of us to his consulting room. He shuffled his notes, ‘let’s see, you’ve been through …….. cycles of HyperCVAD. No infections! No trips to ICU!’ ‘No,’ I replied, ‘nothing like that.’ ‘Whatever you’re doing … keep doing it. HyperCVAD is brutal. If you can get through it without infection you are doing well.’

‘Philadelphia positive ALL …’ he said, shaking is head. ‘It’s very aggressive! Our preference would normally be an immediate transplant … while you are in remission. As you know; however, we have not been able to find a donor. Your only transplant option is a blood cord transplant. We have found several cords that we could use. The problem is the risk. It’s very high,’ and he shook his head again.

‘There’s a high chance of complication and the success rate is small,’ he continued. ‘How small? How many have you done and how many patients made it?’ I asked. ‘These are good questions,’ he replied. ‘It is early days so we have not done many yet. Our unit … eight cord transplants.’ ‘And how many survived?’ I interrupted. ‘One!’ he responded, conveying the remorse of a doctor who despite all efforts and the best of intentions, had failed to save his patients.

‘I’ve discussed your situation with my colleagues and the consensus is that we do not try the cord transplant. Instead, we would like to keep you on Glivec. We will monitor your blood regularly and send the samples to Adelaide where they will undergo molecular testing. The high resolution testing will indicate if your Leukaemia is mutating to a Glivec resistant strain. We will catch the mutation early, before the disease becomes overwhelming,’ continued Ian.

‘And … if it does mutate? What then?’ I asked. ‘We will swap you to Dasatinib, the next generation of tyrosine kinase inhibitor. Dasatinib appears to offer greater resistance to mutation.’ ‘Okay, so why don’t I take it now?’ the latest in my barrage of question. ‘The rules for using Dasatinib are very strict. We can only administer it when Glivec fails, otherwise the PBS won’t cover it.’

‘Now …’ and Ian took a deep breath. ‘If you do relapse … your Leukaemia will have declared itself! The combination of chemotherapy and enzyme inhibitors will have failed. You will need a cord transplant!’ There was a pause in the conversation. Ian put his hand on my knee, ‘are you okay?’ he asked. It was my turn for a deep breath … this reality was difficult to swallow. ‘So … what are the chances that Glivec will hold my remission?’ I asked. ‘It is difficult to say. Glivec is still relatively new … we have no long-term statistics to go by. I would guess that it is 90% likely that you will relapse within 2 years. Maybe 70% …’

Ian continued talking. This I knew because his lips were moving. I had no idea what he was talking about though. My thoughts were elsewhere—if I let A be the event of relapse then the probability of relapse … written P(A) … is 9/10. Now, if I let B be the event of surviving a cord transplant … the probability of B given A … written P(B|A) … is 7/8. If I use probabilities’ multiplication axiom … P(A∩B)=P(B|A)P(A) … the probability that I am going to die … it’s … 9/10 times 7/8 … that’s 63/80 … 79%. Hmm!

The chance of me surviving … let’s cast it that way; maybe it will look better … 100 minus 79 … 21%. Only 21%! Death is a real possibility … this is bad … I’m only 31 … I have a three-year old. For Christ’s sake!

I was shell-shocked. The likelihood of survival seemed desperately low. I took another breath; and, somehow mustered the courage to rejoin the conversation. Ian was still taking, ‘I am a transplant physician. My instinct tells me to take you to transplant. But it’s not worth the risk … this is my proposal: you remain on Glivec and undergo regular blood tests. Canberra will collect your stem cells, now, while you are in remission. We will freeze these incase you need an emergency autologous transplant at a later stage. There is no evidence to suggest that an autologous transplant will help you now. Let’s store the stem cells in case we need to rescue you at some point. We will continue scanning the bone marrow registry to see if any new donors match. I do agree with Doctor Pidcock that extending your hyperCVAD cycles might help you stay in remission. Eight cycles should be appropriate.’

‘You should also know, that if you have the cord transplant you will be in hospital for at least 60 days. During that time you will not be able to see your daughter. The transplant ward has a childfree policy,’ Ian continued, ‘It’s awful, I know, but it’s in the best interest of all our patients. You will be in Sydney for a few months after the transplant as well. All up, you might be away from home for 5 months or so. It won’t be easy, but the Leukaemia foundation has apartments nearby and they have an excellent support network.’

‘I’m really sorry that you find yourself in this predicament David. Try to stay strong and remain positive,’ Ian said and he bid us farewell. Bruce collected Kavitha and I from the clinic and we began the journey back to Canberra.

I was sitting in the back seat with Kavitha. The car was not moving. We had stopped at the traffic lights adjacent Westmead’s shopping precinct. I was looking at the restaurants. ‘Are you alright?’ asked Kavitha. I put my hand on her knee and continued staring through the window … I couldn’t look at her … I couldn’t speak … I was choking back tears. I imagined myself standing outside the Thai restaurant saying goodbye to Rathiga—saying goodbye with a 7 on 8 possibility of not seeing her again.

I didn’t think of Xi Wangmu. I didn’t think about the promise I’d made to stay strong for Rathiga’s sake. I was mourning—lamenting my predicament and wallowing in self-pity. I was worried that I wasn’t going to make it.

## XVI

A week later my medical team attempted the stem cell harvest. The process started with another round of chemotherapy. The doctors watched my blood levels drop and doubled my steroid dose to two injections per day. The steroids were necessary to stimulate bone marrow to generate extra stem cells, which would spill into my blood stream. Blood tests were taken daily for …….. days to monitor the number of stem cells and I was readmitted when the count reached the required level.

Doctor Terwiel inserted a femoral line, an arterial catheter, into my groin (femoral artery). Blood was extracted via my femoral line and passed into a cell separator machine, which selectively separated the stem cells and placed them in in an IV bag. The remaining blood was re-infused into my body via my Hickman line. My blood was extracted and recycled in this fashion for five hours. At the end of the collection the bag of stem cells was sent to pathology for counting.

The femoral line was left in place incase. The pathology count would determine whether we needed to continue the stem cell harvest the following day. I spent the night in hospital. There were no rooms available on the ward so I slept in the OOS clinic. The ward nurses cared for me in the standard manner, waking me every few hours for observations. I hate that part of admission. Each time you fall asleep someone wakes you with a thermometer to shove in your ear.

The following morning Vicki brought Mark into the clinic. I’d seen him the day before and he was fine then. We had been joking and carrying on but he did not look good now. He was leaning on Vickii as they entered the room. He was too weak to support his own weight.

Loraine, the OOS nurse, helped Vicki to put Mark into one of the beds. ‘He has a temperature,’ Loraine said as she removed the thermometer from his ears. Mark was struggling to breathe. He was gasping for air and coughing uncontrollably. Blood was spraying from his mouth. This can’t be good I thought. Loraine inserted a nasal cannula and connected Mark to the oxygen supply. ‘I am going to call for help,’ said Loraine as she hit the nurse assist button, signaling a code blue.

Multiple nurses rushed in. A hematologist arrived … she took her stethoscope and listened to Mark’s chest. ‘I need a chest X-ray now,’ she said, ‘and let’s get a room organised for him as soon as possible.’ Two more doctors arrived, one from infectious diseases and one from ICU. ‘Let’s get some cultures,’ said the infectious diseases specialist. ‘And hang some antibiotics check type??,’ added the ICU doctor. One nurse hung the bag of IV antibiotics. Another took the blood cultures. Everything was happening so fast.

A technician arrived with a mobile X-ray machine. One nurse raised Mark’s backrest, a second nurse sat him up for the X-ray. ‘Clear,’ said the technician and everyone moved away. The technician took a few shots and the nurses rushed back in to support Mark before he tumbled from the bed. Another nurse came in, ‘room 107 is ready,’ she said. Mark was wheeled off to his private room, an entourage of doctors and nurses trailing behind.

My heart was racing. That was horrible I thought. I hope he is going to be okay.

## XVII

Doctor Pidcock visited. ‘We’ve counted the stem cells David and we didn’t manage to harvest enough yesterday,’ he said. ‘So, we are going to continue the collection today,’ I asked. ‘No … this morning’s blood test shows that your stem cell count has dropped. There are too few stem cells in your blood to warrant further collection. Unfortunately, this collection has failed. It is rare that this happens. Maybe it’s because we are collecting during your HyperCVAD. I can’t be sure. We will try again, a month or so after you complete your HyperCVAD.’

My femoral line was removed and I was discharged. I rested at home for a couple of days before returning to hospital for my next round of chemotherapy. I was desperate to know how Mark was going. Kavitha went to check on him.

Kavitha spoke to one of the nurses. Mark was sleeping. Kavitha took note of the nurse’s summation and returned to fill me in. ‘It was touch and go for a while but he is stable now,’ said Kavitha. ‘It looks like he has dodged the bullet,’ she continued. ‘Apparently he refused to go to ICU. He said that the ICU nurse was rude and that he wanted to stay on the ward … he wanted to remain with the nurses that he knew.’ Kavitha turned and stared into my eyes, ‘don’t you dare do that! If they want you in ICU—you’re going!’ We paused for a while. It was scary; things had turned so quickly for Mark. We were relieved that he was doing better. ‘I am going to sit with him for a while,’ Kavitha said, breaking the silence and leaving the room.

Kavitha returned after an hour or so. ‘Mark is drifting in and out of sleep,’ she said. ‘I’m not sure if he even knew I was there. The nurses seem confident though, that he is through the worst patch.’

It was day 2 of my cycle. I needed to get out of my room so I fabricated a couple of chemotherapy questions and went to visit the chemo nurse. Nola was sitting at her desk when I found her. I am sure she knew that I was looking to pass the time but she entertained my questions nonetheless.

‘I am so glad that Mark has recovered,’ I said. Nola’s jaw dropped, her mouth hung open for a few moments before she responded, ‘you haven’t heard?’ ‘Heard what?’ I asked. ‘Mark died last night.’ ‘What!’ I barked. ‘There was a bleed in his brain. He didn’t have enough platelets to stop the bleeding. I’m terribly sorry … I thought you would have heard by now.’ ‘But the infection,’ I stammered ‘I thought he was fighting it’. ‘He was,’ she said. ‘It was the bleed that was fatal, not the infection. I’m really sorry. We all loved Mark.’

I don’t recall the walk back to my room but there I was … weeping. I would miss Mark. His wife and his two children—what would become of them? What does this mean for the rest of us? I thought about Mark—he had been fighting leukaemia for two years. It had been horrible but he kept fighting. What for? It got him in the end anyway. Why fight? What’s the point?

I sank to a new low. It seemed hopeless. If Mark couldn’t make it then what hope did I have? My Leukaemia is known to be more aggressive. I’m screwed! I’m not going to make it am I?

News of my demise travelled throughout the ward. Everyone was mourning Mark’s passing but it was obvious that I wasn’t coping. Nurses and Doctors came to visit me. Each of them tried to get me to re-focus. They wanted me to regain a positive outlook but I couldn’t do it. I was lost. I couldn’t see the point.

Eventually, Doctor Pidcock came to see me. He explained that each patient was unique and that there was no logical reason to assume that I would succumb to the same fate. Of course there wasn’t—but I couldn’t see that. Pidcock pointed out that Mark’s bone marrow never recovered from chemotherapy and was hence ineffective at producing platelets. He reminded me that my platelet count would recover after each cycle. All this made sense but I remained despondent.

Discussing my feelings has never been my strongest quality. So, in the presence of Pidcock’s entourage, it seemed natural to freeze up. Sensing that this was the case, Pidcock encouraged me to see the psychiatrist. I accepted his proposition and sought the assistance of the cancer unit’s mind-doctor. It took me a couple of sessions but I found my way again.

Kavitha was desperate to attend Mark’s funeral but it was held out of town (Mark came from Cooma, an hour’s drive away) on the last day of my treatment. I was stuck in hospital. It was the perfect excuse … the truth … I wasn’t ready. Mark’s death was too raw and it was too close to home. I wasn’t strong enough. I regret it now … I regret not asking for a leave pass. My medical team would have granted one and I could have attended to say goodbye. After all, it was Mark’s family who felt his loss most and they mustered the strength to attend.

Wangmu found her way back into my consciousness and I was able to reflect on the short time that Mark and I had together. We didn’t know one another well but Mark’s impact on my life was profound. It was sad that we never managed our dinner but I am glad that I met him. His strength trumped mine and to this day it is difficult to accept that I was gifted life and he was not. I don’t feel any more deserving.

Kavitha and I still talk to Vicki from time to time. It took a long time but she has found peace with Mark’s passing and is now doing well.

## XVIII

I was receiving another round of chemotherapy when Peter was unexpectedly admitted to hospital. He had contracted an infection during his final HyperCVAD cycle and presented with a temperature and rigels (vigorous shaking). His infection was bad but its source could not be found. His Hickman line, a potential source of infection, was removed; he was taken to ICU; and he was given broad-spectrum IV antibiotics. We all waited for news of his progress.

Peter’s infection abated after a few days and he was brought back to the ward. His condition improved further and he was discharged. He had made it through 6 cycles of HyperCVAD and was now on his way to transplant. I was happy for Peter but I wished I were finishing. I needed 8 HyperCVAD cycles and still had 4 to go. A donor also remained elusive and the small chance of survival was a constant weight, a burden that was difficult to shake.

My cycles continued. The anal fissure and hemorrhoid remained a constant problem. They flared up each time I was neutropenic. It didn’t get easier but I got better at dealing with the pain.

It was fitting that Alison was on duty the day my HyperCVAD finished. It was she who began the process 6 months earlier and now she was there for the finale. She detached me from the IV pump, hugged me, kissed me and wished me luck. We both knew that I would be back but we didn’t discuss it … we didn’t need to. It was time to celebrate.

Move to next chapter

## XVIII

I get one-month rest – more chemo + stem cell collection – also fails.

Later – doctors return – Glivec reason for failed stem cell collections…

Tired – slowly regain strength – return to work.