# Chapter 2

## Friday 5 December 2008—Tuesday 19 May 2009

## I

It was Friday evening when Alison, the chemo nurse, arrived to begin my first arm of treatment. She gathered the drip stand from the corner and rolled it across the room; collected the aluminium trolley from the doorway and moved it to the bottom of my bed; dressed into a protective gown, safety glasses and thick purple gloves, the necessary precautions for handling chemotherapy; hung two intravenous (IV) bags on the fastening arms of the drip stand; extended the stand until the bags dangled above her head; and ran the plastic IV tubing through either side of the double IV pump.

‘Can you please lift your top David,’ asked Alison and she extracted the two Hickman tubes from under my shirt. Grabbing one of the tubes, she wiped its bung with a sterilised swab.

‘It’s important that everyone who handles your Hickman line follows this process,’ she said and began counting aloud. ‘I counted to thirty to allow enough time for the alcohol to dry.’

‘We clean the bungs with two swabs,’ she continued as she wiped the bung a second time: ‘your Hickman 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. YOU need to watch everyone who accesses your line and YOU need to make sure they clean it twice. Also … make sure that they use a red chlorhexidine swab and not one of these blue alcohol ones.’ She held up the packaged swab that shouldn’t be used.

Alison connected the IV tubing to the clean bung and repeated the process, cleaning and connecting my remaining bung to the second IV bag. She pressed a few buttons on the pump; a light pumping noise echoed in the room as two mechanical arms massaged the IV tubes. The chemo had begun.

## II

First came an increased sensitivity to smell, particularly towards food, and an unusual taste in my mouth. Kavitha, my wife, brought my morning coffee but I could tolerate neither its smell nor taste. I could not recall the last day that I had not had coffee. It would be seven months before I again longed for a sip of full‑bodied brew.

At 24 hours: I was nauseous and vomiting. I puked repeatedly; until there was nothing left inside and I dry reached. My body contorted to painful muscle contractions – my stomach searched for more fluid to expel.

Kavitha wiped my face with a wet towel. It was my only comfort. The ward nurse adjusted my antiemetics (anti-sickness medication) and the onslaught waned.

Chemotherapy continued into Sunday. Kavitha, who had been sleeping on a foldout, went home for a few hours to spend time with Rathiga, my daughter, and my Mother joined my side. The likelihood of a parent becoming a bone marrow donor is small. This is because they are responsible for only half of a child’s genetic makeup. The best candidate is a sibling that shares both parents. Since my sister and I are of different fathers the probability that she would match was also slim. Nevertheless, there was some hope. Both had given blood samples for testing and we awaited news of the tissue typing. The doctors wanted to pursue an extended family search (cousin’s, auntie’s etc.); however, recognising the slim chance of mother or sister matching and in the hope that by some miracle, a more distant relative would match.

My mum is a single child so there was nowhere to search on her side. I informed my mother that we should contact the cousins on my Father’s side to arrange typing. I encouraged her to discuss Peter’s death with my medical team. Was there a relation between his passing and my health – could it be important for my daughter? Mum mentioned that she had something important to tell me. It was clear that she was uncomfortable … but how important could it be. I’ve just been diagnosed with Leukaemia. Surely, everything else pales in comparison. How naive I was.

The pause was vexatious … and then she hit me with it: Peter, the doting father, whose life had been dramatically cut-short, was infertile and could not have kids. He was not my biological father. Mum was already pregnant when she met him. My true father was an Italian immigrant with whom she’d had a fleeting relationship before meeting Peter.

The world I knew was changing – my life struck by its own earthquake. I reflected upon the week behind me. First, I had discovered that I have a rare and difficult to treat Leukaemia, then I learnt that my father was not my father. My father was supposed to be dead – now he is alive.

A 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 …

It was explained 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 also an opportunity for fatherhood. I didn’t remember him well but I knew Peter as a good man and none of this had changed. It seemed plausible, but it didn’t ease the burden. I felt cheated, masqueraded by a family who camouflaged my lineage and concealed a truth that would have remained buried had I not fallen ill.

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, a 33 year-old Peter had succumbed to his own medical issues and, as if that wasn’t enough already, I discover that he was infertile, a reality that I would face after chemotherapy.

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 whom I have 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.

Kavitha returned in the evening to spend the night at the hospital. We discussed my recent discovery. She did not seem shocked – at least she didn’t show it.

## III

Another day dawned and the revelation about my pedigree was raw. It motivated me to become a better father for 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 re-find my health and remain actively involved in Rathiga’s upbringing.

I had to fight for Rathiga – her visits, her unconditional love, her smiles and her playfulness. Her ignorance was bliss – it filled me with courage. I wondered if she was the only person in the world who enjoyed being in hospital. She played on the foldout bed and had many sleepovers. Again, it was through Kavitha’s magic that this situation was crafted. At first I resisted Rathiga’s overnight stays. I felt that they would be bad for her – I was wrong. They were good for both of us. They allowed us to keep growing together. Rathiga was the focus of my thoughts when my medical team entered the room.

Doctors rarely travel in ones. The consultant has a registrar, the registrar a resident, and the resident an intern. They may also be joined by any combination of: 1 or 2 students, a couple of nurses, a dietician, a social worker or a dentist. Such an entourage could be intimidating but they didn’t intimidate me. I enjoyed the attention; it helped break the monotony of hospital. Besides, I was comfortable in the presence of great minds and my entourage composed some of the best.

‘Your chemotherapy will finish this evening David. I think we should try your lumbar puncture today,’ said Doctor Emma Terwiel.

‘I have some news about my family,’ I replied, ignoring her suggestion and explaining my complex background.

‘We know,’ replied Deidre and Emma simultaneously. My mother had already discussed the situation with Deidre.

We discussed my new discovery and acknowledged that it no longer made sense to seek a donor on Peter’s side of the family. Instead, we agreed it was more logical to track down my biological father. We should find him, and ask if he, or any of his relatives would agree to donor type matching.

Emma returned to the topic of my lumbar puncture, ‘are you happy for me to do your lumbar puncture today?’

‘About as happy as I could be,’ I replied.

Emma left my room to resume her rounds, returning with a nurse several hours later for my spinal‑tap.

The nurse positioned me on my side in a foetal position. Emma doused my back with antiseptic and I felt a sharp sting as she injected local into my lower back. She inserted a 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. It is rare, but this happens with some patients. Maybe a previous back injury caused 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 left the room. I traced my history to identify potential causes of this, my latest medical difficulty.

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

First, I recalled a mistake by my belayer, who failed to arrest my weight as I leant 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 7 metres, hitting the earth ass-first in a dramatic thud that attracted enthralls of laughter from other crag dwellers. Luckily, I walked away but I was somewhat bruised and battered.

I smiled … I knew that I couldn’t face the remaining candidates with the same guilt free conscious. Both were products of my own poor judgment. I recalled a nasty fall on the flat-faced Pagoda Wall of Moonarie, or ‘Moon’ as regulars know it, a remote sandstone mecca on the southeastern wall of Wilpena Pound in South Australia’s gorgeous Flinders Ranges. I recalled entering 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. I followed 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, forcing me onto tiny ripples on the steep face. The protection was poor and I was tiring. I peeled away in a classic display of awkwardness, popping a protective nut, and falling 8 metres. The shock wave jolted my entire body as I hit 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 painful four-hour trudge.

The final fall that I remembered was on “Kachoong”, arguably Australia’s most 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. Access to “Kachoong” is from the top of the monolith so the climb towers some 100+ meters above the plains. The climb consists of 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 and monkeyed my way along the roof, slapping in protection with minimal attention and reaching the roofs lip and climb’s crux. Moving my hands onto the headwall, I 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 holds were out of reach. My arms, starved of oxygen, began convulsing. I held on long enough to acknowledge that I was coming off. Butterflies filled my stomach and I fell; pivoting on my gear; and smashing back first into the footwall. I mustered the strength to repeat the climb, this time completing it successfully. Back at camp, I was given a pack of frozen peas. The peas eased my back but it was my ego that was most bruised.

It is unclear if these falls are responsible for my spinal scarring but it was comforting to remember good times. I needed something to distract me from the saga unfolding around me. Besides, I knew that through climbing I had developed a skill that would be useful now. I had learnt to control my mind when things appeared impossible and everything was hurting. With the exception of the aforementioned examples at least, I could make sound judgments when it mattered most – when failure to do so would be fatal. This I knew would help me – help me to overcome the mental battlefield of cancer. No matter what, I could … would hold myself together, remain positive and look forward to the future.

## IV

My first round of chemotherapy ceased on Monday night. I remained in hospital and after a few days my energy levels plummeted. 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, after which I would return to bed.

Each morning a nurse would extract samples of blood from my Hickman line and send them to pathology. The nurse would return when the pathology reports were ready and transcribe my blood counts onto a sheet on the room’s pin board.

The blood counts of interest were: hemoglobin, neutrophils and platelets. Haemoglobin is the predominant protein in red blood cells. It delivers oxygen from the lungs to the body tissue and it returns the waste product, carbon dioxide, to the lungs from where it is exhaled. Measured in units of grams per unit litre of blood, a typical Haemoglobin count ranges between 135 and 180. When your count falls below 90 you feel tired and weak. When it falls below 80 you need a red blood cell transfusion. I would have many transfusions – more than 70 before my treatment was over. Each red blood cell transfusion involved the infusion of up to 500 milliliters of packed cells from a single donor.

Platelets stop bleeding by forming blood clots. They are measured in billions per litre. The expected range is 150 to 400. Counts below 50 are associated with abnormal surgical bleeding. Values below 10 place the patient at risk of uncontrollable bleeding and will usually be addressed with a platelet transfusion. I would receive 30 to 40 platelet transfusions over the coming years. It takes 3 to 5 donors to create a single 100 milliliter bag of platelets.

The absolute neutrophil count is the number of infection-fighting white blood cells. It has the same units as platelets: billions per litre. The normal range is 2.5 to 6. Counts below 1 are associated with neutropenia and increased risk of infection. Below 0.5, the patient is at serious risk of contracting a life threatening infection. White blood cell transfusions are rarely used due to problems associated with transfer of infectious diseases such as the commonly found cytomegalovirus (CMV) and due to the relatively short life span of activated neutrophils. Instead of a transfusion, whenever my neutrophil count fell below 1 I would administer daily hormone injections until my bone marrow generated sufficient white blood cells to keep the neutrophil count above 1 on two successive tests.

We became accustomed to interpreting my blood counts. The numbers indicated how I would feel that day, what I could eat and whether or not I would need blood.

On day 9 (measured from the first day of chemotherapy) my neutrophil count fell below 1 and on day 11 it hit 0, which means that the pathologists was unable to detect any neutrophils in my blood. That is, I had no ability to fight infection. It remained below 1 until day 13. I stopped my hormone injections on day 14.

My Haemoglobin fell below 80 on day 13. The nurse entered my room carrying an IV bag.

‘This is you first transfusion right?’ she asked.

I nodded in reply, preoccupied by the starkness of the red liquid that filled the bag. She carried on:

‘Okay. I need to get someone to check this with me. We don’t want to give you the wrong blood do we? That would be bad!’ and she gave me a cheeky grin – an expression that demonstrated her comfort in what was about to happen.

She walked to the door and signaled to someone in the corridor:

‘Can I have a check please?’ she asked. A second nurse entered the room and the two nurses poured over the details on the bag, cross-checking them against my medical file.

‘Can you tell us your full name please?’ asked the second nurse. ‘And your birth date?’ she continued. ‘Now, do you know your blood group?’

‘I have no idea,’ I responded.

‘It looks like you are A‑minus,’ and she left the room

The original nurse hung the bag on my drip stand, cleaned one of my bungs and attached it to the IV tubing. She took my vital signs (temperature, blood pressure, heart rate and oxygen saturation).

‘It is possible that you could react to the blood. You need to press the call button if you feel: nauseous; chest pain; fever, chills or clammy skin; or if you have trouble breathing. If you are going to have a reaction it is more likely at the beginning, so, I will be back in ten minutes to check your vitals.’

‘How long is it going to take,’ I asked.

‘I have programmed the transfusion for four hours. It is best to go slow. This reduces the chance of an allergic reaction. Call me if you experience any problems.’ She started the pump and left me alone with the blood.

Time seemed to hang as I watched the blood drip through the tubing. I looked at the clock, gazing not at the hour or the minute markers, but the hand that counts seconds. My body shuddered with each tic and I was overwhelmed with a sense of dirtiness. I needed it but I didn’t like it … this blood belonged to someone else.

Working hard to distract myself, I thought of Xi Wangmu, the refugee who had suffered terrible loss, and I wondered what she was doing. It had been seven months since the devastating earthquake. Had she moved out of her makeshift shelter? It would be winter in China. The surrounding mountains would be covered in snow, perhaps even the valley floor. Was she warm? Did she have food? Was she really as optimistic as she led me to believe? Could someone really be that strong?

The IV pump beeped and I had survived my first transfusion. The nurse responded to the call button. ‘I was expecting that to finish,’ she said as she entered my room.

‘Is that for me?’ I asked, upon seeing what she carried.

‘Yep! Two bags today David.’

I slumped back into the bed as she repeated the process from earlier, calling in a second nurse and starting my second transfusion. I turned to the clock … the second hand was as sluggish as earlier.

## V

Things that once mattered to me no longer mattered at all. My career for instance, it had been a great driving force in my life … but now, I couldn’t seem to give a damn whether or not I would ever work again. It surprised me how easily I dropped everything to start treatment. I had imagined myself more important than I really was and now I worried not only about my health but also what it would be like when came out the other end. Could I rediscover my identity and if so, what would I stand for? Would I ever approach life with the same gusto as before?

I questioned whether it was okay to focus on your health at the expense of everything else. Was it self-obsessive? Should I be planning for the future? Whenever I considered the future my thoughts turned to the contents of my will.

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. We would discuss topics such as: geophysics; political affairs; and Russian literature, a keen interest of Alexey’s (Alexey migrated from Russia almost two decades earlier). At first it was the short stories of Anton Chekhov that appealed to me most. These were accessible – the chemo made it difficult to concentrate for extended periods. As I began to cope better; however, I tackled the longer works of Bulgakov and ultimately, although only after many months, 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. His presence reminded me that there was more to life than: hospitals, blood tests and poorly appointed food; but only for a short time. As soon as he left I found myself questioning everything that had, in the past, been so critical to me.

## VI

There was a knock on the door, the nurse was talking as she entered: ‘the wardsman is here to take you to radiology David. Are you ready for your lumbar puncture?’

‘Do I have a choice?’ I replied.

‘No!’ she shook her head and directed the wardsman into my room.

The radiologists asked me 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 and the radiologist took a number of X-rays, which he used to study and mark his access. There was a sharp sting associated with the local; followed by a pushing sensation as the radiologist inserted the spinal needle. Even with the aid of imaging, he found it difficult to direct the needle into my subarachnoid space. He made several attempts, each time taking more X-rays and injecting more stinging local. The usual length of this procedure is 20 minutes … he was still positioning the needle after 1 hour. Pins and needles consumed my legs and I was wondering why everything was so complicated, when, 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 – the cytotoxic chemicals that would flood my spinal cavity and circulate throughout my brain.

I was discharged from hospital after two-weeks and 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 two visited my home each morning to take a blood sample, check my vitals (temperature, blood pressure, 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 transfusions; and, if I did – I would go to hospital. This process continued until I was readmitted into hospital on Boxing Day for my second round of chemo, and first exposure to HyperCVAD arm B.

With my antiemetics (anti-nausea medication) sorted, the nausea and vomiting were manageable during my second cycle and indeed during all following cycles. Compromised taste buds; however, and the blandness of hospital fodder meant that food remained a challenge, especially when I was admitted. Recognising the importance of food, I would force myself to eat – it was essential for maintaining my strength. Some items, particularly salty crisps, allayed the nausea – they became part of my daily routine.

The drugs of arm B are more aggressive on the kidneys so there is a greater emphasis on fluids in arm B. Sodium bicarbonate was given before, during and after the methotrexate and I was required to monitor my fluids, keeping detailed records of ingoing and outgoing liquid and undertaking pH testing on all urine. Bathroom visits were frequent due to the heavy intake of fluid and with low energy, a task as simple as toileting became 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 urine-diluted drugs from within should spill onto my skin.

My 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 spent 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 isolate me from the bugs that circulate 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 approaching the thermometer with trepidation; any sign of fever and I’d be re-admitted and on IV antibiotics. I even had a high clinical priority pass, otherwise known as a get into jail free card; a special coupon allowing uninhibited travel through emergency and back into the realms of hospital. I continued with the daily hormone injections and whenever I went to hospital, either for a transfusion or consultation, I wore a facemask to reduce the chance of inhaling unwanted pathogens. I seldom went anywhere else.

## 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. Her ability to juggle conflicting demands, and to do so without complaint was incredible, 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 remained 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. As soon as they left I would stagger back to bed for more sleep, resting until the OOS nurse arrived late morning to do her thing. Afterwards, 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 during long periods where everything else felt too difficult. It also meant that I had control over my diet, an important factor in keeping me eating. My daily routine was broken only when I was called into hospital for a blood transfusion or consultation.

Kavitha’s younger sister Astha, who was between college and university, had planned a 2-month trip to Australia. Arrangements were in place months before I fell ill. She didn’t cancel her trip, but rather arrived to a house in turmoil, experiencing a holiday that differed greatly from what had originally been imagined. Despite her youth (she was 19), she proved invaluable, helping around the house and keeping an eye on me while Kavitha was at work. She extended her stay to 5-months.

## VIII

Chemotherapy can alter bowel function, leading to either diarrhoea or constipation, or even both – one after the other. I suffered constipation in a big way! It was not my first experience with constipation … I already knew how painful it was.

In 1999 I spent six-weeks trekking in the Sagarmatha, or Everest, region of the Nepalese Himalaya. Summiting three peaks: Gokyo Ri (5357m), Kala Pathar (5644m) and Chukung Ri (5546m) I absorbed the top of the world from three vantage points. It was neither the climbing nor the low oxygen that caused me problems, however. It was the change in diet. 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 and suffered accordingly. A severe case of constipation forced me to evacuate the mountains after weeks of failed attempts to evacuate my bowel. Flying from Lukla, rated among the world’s most dangerous airports, I landed in the capitol of Nepal.

Back in the lower reaches of Kathmandu, a steady supply of glycerol suppositories and a much-needed fibrous diet and my situation improved … but the real damage had already been done. I was left with two ailments, permanent markers of my time in the mountains: 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 and when they did 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 would come, the fissure would tear and my hemorrhoid would pop out. Low blood counts rendered the natural repair system useless and the pain grew to levels I had never experienced.

Neutropenia meant that I could eat few fresh vegetables so attaining fibre proved difficult. Management involved a concoction of laxatives, fluid and cooked vegetables 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 specialty.

Consumed with pain, I would lie in bed for days, waiting for my blood counts to rise sufficiently to repair the damage. Meanwhile, I ate as little as possible in the hope that it would lead to less twos. Constipation; however, made toileting inefficient, so, when I did go it was ineffective and I’d repeat the excruciating process 3—4 times per day, even with a lite diet. The 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 wound, a worry that could turn fatal in my neutropenic state. The doctors increased two new prophylactic antibiotics, ciprofloxacin and metronidazole, for fear of an infection taking hold.

## IX

The first round of donor 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.

Founded in the Netherlands in 1988, the international bone marrow donors database or BMDW (Bone Marrow Donors Worldwide) is an international consortium of registries from 110 donor banks in 48 countries. It has amassed 19 million stem cell donors. I needed only one match and the donor would become the source of my life saving transplant. Sounds easy, at least it did to me.

I was hopeful of finding a BMDW donor but my medical team was 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 informed them that this would be impossible. All I knew was his name – he could be anywhere.

‘We know more than that,’ said Deidre. ‘Your mother said that there was a family bakery.’

Deidre knew more than me.

Weeks passed – I considered the search for my father but I dragged my feet. I lacked 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. Kavitha and I discussed the subject at length but it was not easy to take the necessary steps. My mother backed away – she wanted nothing to do with my father. I considered backing away myself – I had no business disrupting another family – but Kavitha refused to accept any attempt at delaying contact. She begged me to do something for Rathiga’s sake. Finding my father could be the key to giving Rathiga the opportunity of knowing her own father. I enlisted the support of Yvonne, the cancer ward social worker, who felicitously accepted the task of finding him.

I had no idea if our limited knowledge was sufficient but I passed the information to Yvonne. I didn’t expect to hear anything for weeks 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 Giuseppe (Joe) must have been thinking. Nonetheless, he agreed to type matching. He provided his GP details to Yvonne … my medical team would arrange the testing. I had instigated the search … I had provided the search parameters … but I did not receive his contact details. The search was conducted by the hospital; his details were protected under donor privacy laws. Eventually, but only after considerable dialogue, the hospital agreed to release the GP’s contact information. To make contact with Joe, we would need 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. I wanted to know my father but my hesitation remained. I was undergoing cancer treatment. That’s enough for one to deal with. I didn’t need more uncertainty. It was easy to procrastinate … I would write later.

## X

My friendship with Mark grew from a sequence of fleeting meetings rather than a single memorable introduction. We would acknowledge one another as we crossed paths in the corridors of ward 14A but we shared few, if any, words during my first or second admissions. It was the manner in which Mark greeted me that is most memorable. Like Xi Wangmu, Mark had a welcoming persona that, with each passing smile seemed to tell me that I should not worry and that all would be okay.

At some point, the passing smiles became conversations and the two of us bonded. I learned that he had AML; that his battle with leukaemia had begun some two years earlier; and that he had once been diagnosed; obtained remission; and then relapsed again.

The longevity of his fight could have been worrying but it was not. It was quite the opposite. Mark was living proof that you could fight leukaemia – his attitude was inspiring. It was a comfort to find him in the clinic whenever I needed treatment and it seemed, at least to me, as though he was always there.

An unrelated donor (from the BMDW) had been identified for Mark. He was awaiting transplant but there were two complications: 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. His consistent presence in the clinic was driven by daily IV anti-fungals and regular (every 2—3 days) platelet transfusions.

Mark was jovial and approached his treatment with acceptance and ease. The more I talked to him the more I appreciated his graciousness. Mark had experienced all the side effects of chemo 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 time as we received 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.

Peter was the second Leukaemia patient that I met. 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 (Canberra seems to average less than one per year); and he was terribly ill when diagnosed. But these were not the reasons that I had heard of Peter. When he arrived at hospital, Peter had an impressive collection of dreadlocks, now long gone thanks to the chemo. I knew about Peter because I’d overheard the nurses talking about the tragedy of the lost dreadlocks.

Peter’s diagnosis preceded mine by two months. We were on the same protocol (HyperCVAD) so he was further along his treatment than I. The two of us would share stories of our pre-cancer lives and provide each other tips on remaining sane. His sister was a suitable match so plans were underway for his transplant.

The locale of my donor remained 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. As soon as there was any sign of improvement I was scheduled in for another round of chemotherapy.

My waistline varied during each cycle. 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 hospital admissions were short: 3—4 days. Nevertheless, the close confine of four walls was oppressive. I struggled to relax and was constantly waiting for something to happen. I tried meditation, listening to music and watching television. Nothing seemed to work.

I was consumed by anxiety whenever I sat still. I’d jump from my bed to drag the drip stand around the room. After a few minutes of pacing, I’d return to bed where the process would begin again. This ritual, repeated hundreds of times each day, offered little solace. 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. I’d focus on her welcoming smile and 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.

Occasionally my cycles were interrupted by unexpected hospital admissions. During one period of neutropenia, when I was staying at home, I developed a migraine. It was severe … 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 didn’t want too … I had no choice … I went to hospital.

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 was over.

## XII

‘Have a look this,’ said Mark, who sat beside me in the clinic. He pulled an A4 envelope from his bag, extracted a pile of documents from the envelope and shuffled through them until he found the glossy flier. ‘This … this is what I want you to see.’

I took the flier from Mark who continued talking: ‘I’ve decided to change careers. I’m going to do this correspondence course and become a counsellor. I want to help people deal with cancer.’

‘Wow!’ I replied. ‘Are you up to that – I mean, do you think that you can study now, while you are still receiving treatment?’

‘I can’t do nothing anymore,’ he replied. ‘I’m sick of doing nothing. Besides I think that I have something to offer to people. I really feel that I could make a difference to people’s lives.’

‘I am sure that you will be a great counsellor Mark,’ I said, as I continued processing our conversation. I had dispensed with my career so easily and could now think of nothing except getting healthy again. Mark was actually thinking about the future. He was sicker than I and yet he was planning his future. He believed that he was going to survive.

‘So you’re in for some more chemo?’ Mark asked, changing the subject.

‘Yeah – round 3A. I am just waiting in the clinic until they find me a room.’

‘Okay, well I’m done for the day. If I feel up to it I’ll drop in tomorrow to say hi. Good luck,’ Mark concluded as he left the clinic.

There was a problem with my room allocation. It was 7pm and I was still waiting. The chemo nurse decided not to wait any longer and opted to start my chemotherapy in the clinic. Agitated by the delay, she was fumbling at the IV bags when one slipped from her grasp. It crashed onto the floor, spraying toxic chemicals in all directions. My heart dropped … the girls had joined me by this stage. I turned to Kavitha and Rathiga; the chemo had missed them by inches.

We looked at the floor. Liquid gathered into puddles. Thousands of dollars of pharmaceuticals were gone, wasted in an unfortunate accident. I slouched into my chair. I was simply relieved that the stuff had not fallen on either of my girls, nor the nurse

‘This has never happened to me before,’ said the nurse, and she took a moment. ‘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 and the nurse’s training kicked in. She collected a chemo spill kit from the wall. 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 laughed. We knew that I was stuck in hospital for days.

The following day, I received news of Peter’s unexpected hospital admission. He had contracted an infection during his final HyperCVAD cycle and presented with a temperature and rigors (uncontrollable fever related shaking). Peter was neutropenic, his infection bad – its source unknown. His Hickman line, a potential source of infection, was removed; he was taken to ICU; and was given broad-spectrum IV antibiotics. We awaited news of his progress.

Peter’s infection abated after a few days and he was brought back to the ward, where, to everyone’s surprise, he could no longer see. A low platelet count had lead to bleeding in his retina (a haemorrhage) that impaired his vision. The ophthalmologist assessed his eyes and came to the view that his eyes should repair themselves but he would have to wait several months to retain full vision.

Eventually, he was discharged. He had made it through 6 cycles of HyperCVAD. His eyes improved over the following months but they were not his primary concern. Peter needed to prepare for his bone marrow transplant.

## XIII

Another round of chemotherapy passed and I was back in the clinic. It was consultation day. Mark and Vicki were called in first.

Vicki was crying when they returned. Mark’s 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 making but the casualness with which he treated Mark’s life – a life that lay 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 from holiday 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 … Doctor Pidcock and his entourage were waiting for me.

‘The type matching for your father has come in,’ said Doctor Pidcock. ‘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.

‘More than likely … almost certain.’

‘We have some other test results here for your brother … he is also a half match.’

‘I have a brother … a brother?’ I asked, no longer thinking about their inability to donate bone marrow but trying to comprehend 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 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.’

‘Blood cords?’ I asked.

‘Umbilical cords saved after child birth,’ replied Pidcock. ‘There are only half a million of them in the database but they are simpler to cross-match because they require less tissue matching. We’ve found 3 that are suitable.’

‘There is a problem with cord transplants though,’ Pidcock continued. ‘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 means a long time before the donor marrow starts generating new 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 neutrophils, is high during such a long period,’ he replied.

‘I have discussed your case with the transplant centre at Westmead and we are not sure about the Cord transplant. Another option is 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. It is not clear whether an autologous transplant will help. There is simply no evidence in the literature. Your case has created significant debate amongst the haematologists. We failed to reach a consensus on the merits of an autologous transplant but we do agree that you need to keep taking Glivec.’

Glivec is an oral enzyme inhibitor that I began taking after my diagnosis was confirmed. It is useful in treating Philadelphia positive ALL because it interrupts the processes that generate malignant cells. Philadelphia positive ALL is caused by abnormal chromosomes (in my case: cytogenic abnormalities 9:22 and -7), 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, decreasing their activity and slowing (or sometimes stopping) the spread of immature cells. Unlike chemotherapy, which kills all rapidly dividing cells, Glivec is a targeted drug and hence has fewer side effects.

The full cost for a 30-day supply of Glivec (1 box of 30 400mg tablets and a box of 60 100mg tablets) was around $6000 per month. Fortunately, Glivec is a PBS (pharmaceutical benefit scheme) drug in Australia. Which brought the cost down to $32.70 per box. The catch; however, is that the PBS only approves Glivec’s use for two years. I knew that after two years, the annual cost of $72,000 would be unattainable and that 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, the Haematology Care Coordinator, who had been quietly listening to my conversation with Pidcock.

I needed to get my Hickman dressing changed so I returned to the clinic. Looking around as I entered, I could not see anyone that I knew. I was walking towards the waiting area when I felt someone grab my hand. It was Lorraine, the OOS nurse who had been caring for me in the outpatient clinic, she had been in the room when Pidcock had given his news.

‘Come, I’ll change your dressing,’ she said, leading me towards one of the beds. It was Loraine’s last day at work, she was retiring – changing my dressing was among the last of her tasks. Steeling glances as she removed the dressing, she looked upon me in a way that no one has before. She pitied me, this I understood from her silence and the dullness of her wide eyes. It was as if, through some magic ball, she had seen the future and she knew that failure to find a donor was the beginning of my demise. She looked at me as if, despite all their efforts, I was going to die. Holding back her tears, she finished the dressing change and as soon as I got out of the bed, she wrapped her arms around me:

‘don’t you stop fighting,’ she said, as tears came to both our eyes. She gave me a piece of paper that she had prepared earlier. ‘It’s my contact details,’ she said. ‘Call me if you need anything.’

Later I learnt that Loraine spent the rest of that afternoon crying.

## XIV

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 accumulated over 8,000km 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 forcing Bruce to drive below the speed limit of 110km/hr. We were half way along the Hume Highway when the rain became so heavy that Bruce had to pull over.

From the back seat, I watched the clock … we were in danger of missing our appointment. Bruce 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.’

I wanted to get out of the car and yell at the weather. Nothing seemed to be going in our favor. The Hickman procedure – the lumbar puncture – the failure to find a donor – we couldn’t even drive to Sydney without drama.

I felt too ill to be travelling. I couldn’t face driving all the way to Sydney; with the potential of turning around, none the wiser about where my treatment was going. The uncertainty was burning and my agitation growing, when, without warning 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 stuck among the 28% of Sydney residents that cram the highways on their way to work. We had to wait longer … longer 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 6 cycles of HyperCVAD, 3 each of A and B. 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 continued, shaking his head. ‘It’s very aggressive! Our preference would be an immediate transplant … while you are in remission. As you know; however, we have not found a donor. Your only transplant option is a blood cord transplant. There are a few cords available. The problem is the risk. It’s very high,’ and he shook his head again.

‘There’s a high chance of complication … 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 … we have not done many yet. Our unit … eight cord transplants.’

‘And how many survived?’ I interrupted again.

‘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. 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 any mutations 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.’

‘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 your Leukaemia does mutate … 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!’

Ian put his hand on my knee, ‘are you okay?’ he asked.

It was my turn for a deep breath: ‘so … what are the chances that Glivec will hold my remission?’ I asked.

‘It is difficult to say. Glivec is still relatively new …’

Everything is new, I thought

‘… we have no long-term statistics to go by,’ continued Ian. ‘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. 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 not surviving a cord transplant … the probability of B given A … written P(B|A) … is 7/8. Probabilities’ multiplication axiom … P(A∩B)=P(B|A) × P(A) … tells me that the probability of dying is … 9/10 times 7/8 … that’s 63/80 or 79%.

That gives the chance of survival of … 100 minus 79 … 21%.

I shuffled on my chair and placed my hands under my bottom. It was the only way to stop the shaking.

I rejoined the conversation. Ian was still talking: ‘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. There is no evidence to suggest that an autologous transplant will help you now. So; let’s store the stem cells in case we need to rescue you at some point down the track. In the meantime, we will continue scanning the bone marrow registry to see if any new donors match. I support the plan to extend your HyperCVAD. More 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. I hope that it doesn’t happen but you need to prepare yourself for the possibility. While you are in hospital 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 around 5—6 months. 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 Kavitha and I farewell. Bruce collected us and we began the journey back to Canberra.

I was 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 clasped her hand but I didn’t look at her. I imagined myself standing outside Thai Westmead saying goodbye to Rathiga and turning my back on her as I walked towards the hospital with all likelihood that I would never see again.

Xi Wangmu could not save me now. I was mourning.

## XV

There was no time to lament the news that Kerridge had given me. I had to get on with things so that is what we did. The doctors doubled my hormone dose (to two injections per day) to stimulate the generation of extra stem cells and they counted the stem cells in my blood every day until, a week or so after that ominous meeting at Westmead, I was back in hospital for my stem cell collection.

Doctor Terwiel inserted a femoral line (an arterial catheter) into my femoral artery. Blood was extracted from the femoral line and passed into a cell separator; which selectively separated the stem cells; and re-infused the remaining blood via my Hickman line. Blood was extracted and recycled in this fashion for five hours, the stem cells accumulating in an IV bag. At the end of the collection the bag was sent to pathology for counting. The count would determine whether the stem cell harvest was successful.

The femoral line remained in place, in case we needed to collect more stem cells the following day. Keeping the femoral line meant that I had to spend the night in hospital, but, with no rooms on the oncology ward, I faced a transfer to an unknown ward. I twisted a few arms and arranged to stay in the clinic, adjacent the ward where the oncology nurses cared for me with their usual vigour.

I woke early that morning to the sounds of a clinic in preparation for a busy day. Not long afterwards, Vicki brought Mark into the clinic: he was leaning on her and clearly too weak to support his own weight.

Jenny, the OOS nurse, helped Vicki to get Mark into one of the beds.

‘He has a temperature,’ Jenny said as she removed the thermometer from his ear.

Mark was gasping for air and coughing violently. Blood was spraying in all directions. Vicki tried to catch the blood in a bag but Mark could not keep still as he coughed.

‘Don’t worry about it,’ Jenny said as she inserted a nasal cannula in Mark’s nostrils.

‘I gonna call for help,’ she said as she hit the nurse assist button and signaled the code blue.

I recalled having seen Mark the day before – he had been jovial and happy as always. It was unimaginable that this was the same man.

Multiple nurses rushed in. A hematologist followed. The hematologist 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.’ A red-haired nurse left the clinic to organise Mark’s room. 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 meropenem,’ added the ICU doctor. One nurse hung the bag of IV antibiotics. Jenny took the blood cultures.

A technician arrived with a mobile X-ray. Jenny raised Mark’s backrest, and the nurse who’d hung his IV antiobiotics sat him up for the scan. ‘Clear,’ said the technician and everyone moved away. The technician took a few X-rays and the nurses rushed back to support Mark before he tumbled from the bed. The red-haired nurse returned, ‘room 107 is ready,’ she said. Mark was wheeled off to his private room, an entourage of doctors and nurses trailing behind.

I placed my hand on my chest where it was consumed by the throbbing of an unrecognisable beat.

## XVI

The clinic returned to normal as fast as it had turned chaotic. Doctor Pidcock visited me. ‘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 had received little news of Mark’s condition and was desperate to know how he was going. Kavitha went to check on him.

Mark was sleeping when Kavitha found him. She spoke to one of the nurses 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 will be okay,’ 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!’

There was a silence; it was hard not be shaken by how fast things had turned for Mark.

‘I am going to sit with him for a while,’ Kavitha said, breaking the silence and leaving the room.

Kavitha returned an hour later. ‘He 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 … confident that he is through the worst patch.’

Kavitha went home for the evening. I slept and the second day of my cycle began. Needing to get out of my room, I fabricated some chemotherapy questions and went to visit the chemo nurse. Nola was sitting at her desk when I found her. She knew I was seeking to pass the time but she entertained my questions nonetheless.

‘I’m happy that Mark has recovered,’ I said and 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 to my room but there I was … I could no longer hold back my tears – I was weeping. I cried like I never have before.

His wife and 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?

It seemed hopeless. If Mark couldn’t make it then what hope did I have? Philadelphia positive ALL is among the most aggressive leukaemias. I’m screwed! There is no hope.

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 visited 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.

Eventually, Doctor Pidcock visited me. He emphasised the uniqueness of each patient and, presenting a suite of logical arguments tried to convince me that there was no reason to assume that I would succumb to the same fate.

‘Mark’s bone marrow never recovered properly from his chemo David. That is why he had too few platelets. Your bone marrow is recovering well each cycle,’ he said.

But logic, usually the cornerstone of my thinking, was lost on me. He may as well have thrown a bucket of water over my head. It was just as likely to pull me out of despair.

It was clear to Pidcock, that in that room and with his entire entourage present, that progress was improbable. He arranged for me to see a psychiatrist and ensured that I did so that very day.

A few sessions later, I had found my way again. Wangmu found her way back into my psyche and I was able to reflect on the brief time that Mark and I had together. He was a giant in my mind; his strength and courage 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 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. His passing reminded me of my own mortality. I wasn’t strong enough. I regret my cowardice now. I should have arranged a leave pass to attend his funeral. After all, it was Mark’s family who felt his loss most and they mustered the strength to attend.

We never managed our dinner but I am glad that I met him.

## XVII

I completed cycle 7 (4A) and entered my final cycle (4B). 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 for the last time, hugged me, kissed me and wished me well. We both knew that I would be back but we didn’t discuss it … we didn’t need to. It was time to celebrate.