# 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. The four plastic castors creaked and groaned until the stand reached its resting place on the left side of where I lay. With the stand in place, Alison walked to the door where she had left her chemo trolley and moved it to the bottom of my bed. She 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 at the top of the drip stand’s stainless steel pole. 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.

Alison asked me to raise my shirt and extracted the two tubes at the bottom of my Hickman line, placing them neatly on my side where they were easily accessible. She grabbed one of the lines; rotated it so that it stood upright and started wiping 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 to thirty, offering 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. It can make you very sick so it’s really important that you watch everyone who accesses your line. You need to make sure that they clean it twice. Also, they should use a red chlorhexidine swab and not one of these blue alcohol only swabs,’ and she held up the packaged swab that shouldn’t be used.

Alison connected the IV tubing to the bung she had just cleaned and then repeated the entire process, this time connecting my remaining bung to the second IV bag. She pressed a few buttons on the pump, two mechanical arms began massaging the IV tubes, a light pumping noise echoed in the room and we were off and running.

## II

My first day of chemo was an anticlimax. Chemo was ingested continuously by my blood system for more than 24 hours with few side effects. The most noticeable signs: an increased sensitivity to smell, particularly towards food; and an unusual taste in my mouth. It was Saturday morning when this became noticeable for the first time. Kavitha brought me my habitual morning espresso, only for us to discover that I could tolerate neither the smell nor the taste. It was apparent that my fears about being allowed to take coffee were ill founded for I had experienced my last sip of palate–cleansing acidic full-bodied brew. I would not touch another coffee for over seven months and would only be able to resume my morning ritual when my HyperCVAD was well and truly completed and my taste buds had regained their rightful place on the surface of my tongue.

Late on Saturday evening the chemo kicked in, I became nauseous and began vomiting for the first time. I heaved the contents of my stomach; over and over again; until there was nothing left inside and I started dry reaching, my body contorting to painful muscle contractions as my stomach searched for more fluid to expel. My only comfort, the cool feeling of a wet towel regularly wiped over my face by Kavitha, who had chosen to stay with me in the hospital. I leaned heavily on Kavitha that night, a reality that would become more and more common in the ensuing months. We went through many sick bags, the onslaught waning only once my antiemetics were modified and my body became tolerant to the cytotoxic drugs. Eventually, I fell asleep and garnered some much needed rest.

## III

My mother’s suitability for bone marrow donation was unlikely because she was only responsible for half my genetic makeup, the remainder of course coming from my father. Typically, the best chance of finding a family donor comes from full siblings that share both parents. Since my sister and I were birth products of different fathers the chances of her suitability were also slim. Nevertheless, both had given blood samples and we were anxiously awaiting news of the tissue typing. We were however, well grounded by Deidre, who had explained that we needed to be realistic. Consequently we had begun discussing an extended family search, cousin’s, auntie’s etcetera, in the hope that someone else might be miraculously found suitable.

The chemotherapy continued into Sunday. My mother and wife exchanged shifts, Kavitha going home to spend time with Rathiga and rest, and Mum sitting by my side in hospital. I drifted in and out of sleep as the pharmaceuticals negatively impacted my energy. Mum waited for a lucid moment of consciousness and mentioned that she had something important to tell me. She explained that Peter, the man I knew as my father and whose life had been dramatically cut-short, was in fact not my biological father at all. My true father was instead, a ‘charismatic Italian’ with whom she’d had a fleeting relationship before meeting Peter.

This was a complete shock to me. I had no idea. A large portion of my life, previously shrouded in lies, was now revealed in unvarnished truth. Who else knew this secret? Who else participated in this conspiracy? Why didn’t I know my background? I couldn’t help but feel that the world as I knew it was collapsing.

I reflected upon the week that lay behind me. First, I had discovered that I have a rare and difficult to treat Leukaemia, then I discover that my father is out there somewhere, probably alive. 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 this news from me. That he, a man rendered infertile by his own medical treatment, desperately desired a child. That 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 a bit 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. Here I was, hospitalised and receiving treatment for a life-threatening illness in my early thirties. Peter, of course succumbing to his medical issues at a similar age. Then I discover that he was infertile, a reality that I would also have to face.

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 latest revelation about my pedigree remained fresh. Most of all it made me more determined to be a good father to my angelic Rathiga. Not because any of my fathers had been bad, but simply because that was an opportunity that I myself 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.

The doctors began the week with Monday morning rounds. Emma explained that my IV chemotherapy would finish later that evening and that she would like to do my first lumbar puncture in the afternoon. We discussed my new discovery and acknowledged that it no longer made any sense to undertake typing with my cousins on Peter’s side. Instead, we agreed it more logical to track down my biological father to see if he, or any of his relatives would agree to being tested. Upon reaching a conclusion, Emma left my room to resume her rounds, returning several hours later for my spinal‑tap.

Once again I found myself lying side-on in a foetal position. Emma prepared my back with antiseptic and I received another sharp sting as she injected local into my lower back. She inserted the spinal needle and attempted to guide it towards the fluid filled cavity surrounding my spinal chord. After several attempts, and much discomfort for the patient, I heard Emma speak, ‘this is proving difficult David. It looks like there may be some scar tissue that is preventing me from getting the needle into the right area. It is rare, but this happens with some patients. Perhaps a previous back injury has lead to the development of some scaring. I am going to book you into radiology. They will give it a shot under the guidance of imaging. Hopefully, they can do it without too many problems.’ Emma and the assisting nurse gathered their paraphernalia and I started tracing my history to identify potential causes of this, my latest difficulty.

The surmised that the most likely candidates for scarring in my spinal area was one of a number of falls, sustained as a rock-climbing junkie in my undergraduate years. I recollected those enjoyable years, paying particular attention to three falls, any one of which could have lead to internal 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 after fumbling with his Petzyl Grigi, failed to arrest my weight as I leant back into the rope after topping out on a short but powerful route in Nowra, a favoured sport climbing region 1.5 hours south of Sydney. I free-fell 9m as I plunged away from the overhanging wall, dropping to the ground and hitting the earth ass first in a dramatic thud that attracted great enthralls of laughter from other crag dwellers. The affair left me somewhat bruised and battered but generally grateful that my injuries had not been worse.

I then smiled, knowing that I couldn’t face the other two candidates with the same guilt free consciousness as the Nowra fall because both were products of my own erroneous judgment. The first of these, a nasty fall on the flat-faced golden Pagoda Wall of Moonarie, or ‘Moon’ as locals affectionately know it, a remote traditional sandstone climbing 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 fell into a classic traversing mistake. The natural inkling when climbing is upwards and not sideways. The trick when traversing is to know when to exit the horizontal section and start climbing upwards again. On this day I retired my traverse far too early, entering an inviting upward tending finger crack. As I climbed further along the sweet crack it became apparent that I was off-route. The climbing was difficult, the crack thinning, protection poor and I was tiring. I peeled off in a classic display of awkwardness, popping the protective nut that had been poorly placed and I fell a good 8m before crashing into the wall. The hit sent a shock wave through my entire body, jolting everything that had any give. The brunt of my injuries was sustained in my left ankle, which swelled instantaneously, converting the one-hour descent to the vehicles 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. This classic 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 then 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 and the good handholds were out of reach. My arms, starved of oxygen, convulsed violently. I held on just long enough to acknowledge that I was coming off. The inevitable became reality and I fell from the lip; popping the poorly placed gear in the roof; pivoting on the remaining protection; and smashing back first into the footwall. I mustered enough strength to repeat the climb, this time completing it successfully and then proceeded to camp where a friend passed me a pack of frozen peas to ease the pain of a bruised back.

I will never know if any of these incidents lead to the spinal scarring that made my lumbar punctures difficult. Regardless of this, I took comfort in knowing that I had at least had fun along the way. Most of all 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, 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

I received my last dose of chemotherapy 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 recall feeling dirty as I watched someone else’s blood enter my body. I knew that this was nonsense but I couldn’t help but focus on the fact that this blood did not belong inside me. I appreciated that it was necessary but I simply didn’t like the sensation it gave me. I would sit and stare at the clock as it ticked through the three to four hours necessary to infuse one donation of blood, often only to watch the nurse hang a second bag of packed cells 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. Having depended on some 100 or so donations I developed a new 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 injections of steroids to stimulate the generation of more white blood cells, transfusion 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 a unique ability to distract my thoughts from being sick. He would simply encourage me to focus on ‘normal’ things. A typical visit from Alexey would begin with an update on my health but quickly move to other topics of interest. We would discuss geophysics; political affairs; and Russian literature, a keen interest for Alexey, who had migrated from Russia almost two decades earlier. Alexey introduced me to the great works of Anton Chekhov, Mikhail Bulgakov and Leo Tolstoy. At first it was the short stories of 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 Bulgakov and ultimately, although only after many months, Tolstoy.

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

## VI

I was taken to radiology for an image-guided lumbar puncture. This time I was asked to lie flat on my stomach, a position that aids the 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 study and mark his access route. I felt the sharp sting of local followed by a pushing sensation as he tried to place the 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 time for this procedure is about twenty minutes although it was taking considerably longer this time around. Why must all my procedures be complicated, I thought to myself. I received pins and needles in my legs as I remained still for the hour or so of poking and prodding before the radiologist managed to position the needle. He took a sample of the fluid surrounding my spinal chord and then injected the required chemotherapy.

After days of waiting my blood counts picked up again. I was discharged from hospital and admitted into the Oncology Outreach Service (OOS) a travelling service, which tends to patients at their residence. I returned home for the first time since my diagnosis and was visited every morning by the OOS nurse who would take a blood sample, check my vitals (temperature, blood pressure and oxygen levels) and discuss my general health and wellbeing. In the afternoon she would report on my test results and advise if I needed to visit the hospital for more transfusions. This process continued for a week or so and I was able to enjoy Christmas at home with the family before being readmitted into hospital for my second round of chemo, and first exposure to the arm 2 drugs, on Boxing Day.

With my antiemetics (anti-nausea medication) now sorted, I suffered only light nausea and seldom vomited. Food remained a challenge however. My taste buds were compromised by the chemo and the blandness of the hospital prepared food was hardly apetising. Despite the challenge, I managed to force myself to keep eating throughout my second stay in hospital. I knew that this was the only way that I could keep my strength up, a necessity if I was to remain strong. Also, some foods, particularly salty crisps, seemed to temporary allay the light nausea that I was suffering.

The drugs that I received in arm B are known to be more aggressive on the kidneys so there was a greater emphasis on fluids in this round of treatment. In particular, sodium bicarbonate was given before, during and after the methotrexate. As well as detailed analysis of my daily blood samples, I was required to monitor fluid volume, keeping detailed records of ingoing and outgoing liquid and I was required to undertake pH testing on all urine to ensure that acidosis did not occur. This was more of nuisance than anything. With already low energy a task as simple as toileting became more difficult as I was required to use purple protective gloves, to ensure that my toxic urine did not get onto my skin as I attempted to pee in a bottle and subsequently pour it onto pH indicator strips. Nevertheless, this round of chemo was administered without any major complications and the four days of infusion finished without major fuss.

I was again discharged from hospital, this time before my blood levels dropped and prior to the onset of neutropenic. My doctors felt that it was 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 get me away from the other bugs or infections that typically follow sick patients into a hospital. As in cycle 1, the OOS nurse visited me daily and called me into the clinic whenever I needed a transfusion. At home I was required to take my temperature every two-to-three hours to catch any oncoming fevers as soon as possible. A fever would lead to instant re-admission to hospital and IV antibiotics so mandatory temperature measurements was something I reluctantly undertook with considerable trepidation. Being at home also meant that I had to become comfortable with injecting myself with steroids every daily, a task that I adapted to without much fuss. On the occasions that I was called back into hospital, either for a transfusion or consultation, I was required to wear a facemask to reduce the chances of inhaling unwanted infectious pathogens.

## VII

The days passed and my blood levels again began to fall. We recognised that a bone marrow transplant in Sydney would result in many months away from our home in Canberra. Therefore, it was necessary for Kavitha to return to work to save and continue accumulating the precious leave entitlements that would see us through an extended period outside of Canberra. She approached this requirement graciously, undertaking the difficult task of balancing a full-time and demanding career with the care of a sick husband and two year old daughter. When I look back on this period I remain astonished by Kavitha’s breathtaking and heart-stirring ability to juggle countless demands on her time, despite the uncertainty that faced my own health and our future life. She kept things going under extremely difficult circumstances and with little noticeable fuss or difficulty. At work, she remained professional as always, opting to maintain her workplace as a sanctuary, refusing to accept any form of pity or reduced workload. In fact, many of Kavitha’s colleagues remained unaware of the double-life that Kavitha was indeed forced to live. My ability to help around the house was also severely compromised, forcing Kavitha to take more and more responsibility for daily household chores.

A typical day for me involved getting up in the morning to see Kavitha and Rathiga off to work and childcare, respectively. I would then return to bed to get more sleep before the OOS nurse would arrive, late morning to undertake a round of tests. When she left, I would return to bed again, often sleeping well into the early afternoon, when I would rise for a small snack for lunch. This was typically followed by a little bit of television and, whenever I felt capable, a trip to the kitchen where I would prepare something for dinner, a rare source of enjoyment for me during long periods where I found it difficult to concentrate on reading or any other form of interesting or challenging use of my brain. This process was broken only on the days where I was required in the hospital, either for a blood transfusion or a doctor’s consultation.

Chemotherapy is known to affect bowel motions so common side effects include both diarrhoea and constipation. During my second period of neutropenia I experienced a bout of constipation that proved both painful and degrading. It was some eight years earlier that I had first been introduced to constipation so I already knew that if a choice was presented one should always choose diarrhoea over constipation. Sadly, I was not gifted the choice so it was constipation that I had to endure. My original introduction to constipation came during a six-week period of high altitude trekking in the Sagarmatha, or Everest, region of the Nepalese Himalaya. I was there to climb a number of over 5000m peaks offering varying views of the top of the world. These included Gokyo Ri (5357m), Kala Pathar (5644m) and Chukung Ri (5546m). While the views are great at this altitude the availability of fresh vegetables is not. Consequently, I found myself consuming a low fibre diet for many weeks, a ….. that lead ultimately to a severe case of constipation. The constipation was indeed so bad that I developed an anal fissure (or tear) and external hemorrhoid. Ultimately, I had to evacuate the mountainous region, flying from Lukla, commonly recognised as the world’s most dangerous and freaky airport, to Nepal’s capitol, Kathmandu where I could obtain a steady supply of glycerol suppositories and consume a much-needed fibrous diet.

At the lower altitude of Kathmandu I was able to regain control of this situation and things improved gradually over a week or so. Sadly however, this early experience with constipation left me with two ailments, the anal fissure and hemorrhoid, neither of which completely healed. Under normal chemo-free circumstances these problems would flare from time-to-time but could typically be quickly addressed with a change of diet and a couple of uncomfortable days. Under the blood level reduced effect of chemotherapy, the problems became unbearable. I was not allowed to use suppositories due to an enhanced risk of contaminating an infection during insertion. Therefore, the constipation management involved the use of a combination of laxatives, fluid and cooked high-fibre foods, to soften my motions and analgesics, which offered limited pain relief but presented the unwanted side-effect of hardening my stool.

At times the pain became so unbearable that I could do little but lie in bed for days waiting for my blood counts to increase enough that my body could repair the damage around my anus. In fact the experience was so unpleasant that I would opt to eat as little as possible so as to reduce the number of times I had to toilet. Unfortunately the constipation itself meant that even when I did manage to pass stool, the process was ineffective meaning that I had to go through the excruciating process multiple times per day, even with a lite diet. Each time, I went my fissure would re-tear, often filling the toilet bowl with squirts of red blood. I used a variety of creams but they offered limited relief. I bathed in a sitz bath of hot water and table salt five to six times a day to reduce the chance of the fissure becoming infected, a worry that so easily could become fatal in my neutropenic state.

## VIII

The results of type matching for my mother and sister came in, and as anticipated, both were only half matches. This meant, that with current technology, neither were a suitable donor for my transplant. We needed to expand the search further. The first and obvious place to search, the international bone marrow donor’s database or Bone Marrow Donors Worldwide (BMDW). Founded in the Netherlands in 1988, the BMDW is an international consortium of participating donor registries from 110 donor banks in 48 countries. Collectively, the BMDW has amassed nearly nineteen million potential stem cell donors and half a million-blood cord units from around the globe.

Add details about process for BM matching etcetera

I felt confident that a donor would be found somewhere among the nineteen million volunteers. However, my doctors were reluctant to commit with the same level of confidence, explaining that sometimes an unrelated donor cannot be found. They encouraged me to pursue the possibility of tracking down my biological father. I had been considering this since gaining the new insight into my heritage but I had been dragging my feet. I was procrastinating. It was clear that now was the time, except for the first time in my life, I found myself lacking the courage to do what needed to be done. I am not sure if it was the uncertainty regarding his potential response or whether it was my recently acquired fractured sense of mortality. Either way, I wanted it done but I lacked the backbone, the fortitude to do it. I enlisted the support of Yvonne, the cancer ward social worker, who felicitously accepted my proposition.

All I had managed to learn from my mother was my father’s surname and the fact that his parents used to own an Adelaide bakery in the family name. With little to work on, Yvonne expediently took the task of tracking down my father. She returned within two days with the news that she had been successful in her exploit. With as little as four telephone calls she had found the man. The bakery, no longer run by my Grandparents who were now long gone, had been taken over by a distant relative who didn’t know how to contact Joe directly but knew someone who might have the details. A couple of phone calls later and Yvonne was speaking with him. As one might expect, Joe was somewhat baffled by the revelation that he had a son that he knew nothing about. One can only imagine what must have been going through the man’s head at the time. Nonetheless, he willingly and immediately agreed to do anything that was needed. Armed with the contact details for Joe’s GP, Yvonne returned to let me know that he agreed to testing. A few days later Joe had been tested and the samples sent to the Red Cross for type matching. The search for a bone marrow donor was moving forward by two independent paths.

Later we learnt that since the search for Joe had been conducted under the premise of Canberra Hospital, we were not able to access his contact details. They were protected under donor privacy laws. We had successfully managed to arrange Joe’s testing but still, I had no way of contacting him if I wanted a relationship. After extensive discussions the hospital agreed to release, not Joe’s contact information, but the details of his GP in Adelaide. We were to write to the GP, who would in-turn forward the letter to Joe who maintained discretion of returning contact. We now had a route that I had every intention of now following. However, with my treatment schedule ongoing it was far too easy to fall back into a state of procrastination so, I did nothing.

## IX

The severity of my treatment, typically lead to isolation in private rooms on the ward or in the high dependency area. This meant that few opportunities presented themselves to meet other cancer patients. Furthermore, I was reluctant at first to make new friends with other ‘sick people’. I foolishly felt that this was my journey and that there was nothing to be gained by sharing it with others. This line of thinking was in complete contrast to my selection of Xi Wangmu as a source of inspiration. Her selection had been a deliberate effort to importantly remind me that this was just a hiccup, that no matter what I was going through, there were other people surviving and rising above far worse circumstances. As I became more comfortable in my diagnosis and my immediate fate of hospital arranged lifestyle I began to see the importance of meeting new people who were suffering similar ailments. This was helped by the fact that I was released from hospital between chemo cycles and that during those periods I had to frequent the OOS day treatment area. It was here that I met Mark, a personable gentleman in his early fifties.

Mark was an AML patient so his Leukaemia differed to mine. His battle with leukaemia was already extended much longer than mine. He had once been diagnosed, obtained remission and then relapsed again after only months out of the hospital regime. He had already received his second set of chemo cycles when I met him and was now receiving a raft of treatments for the side effects while he patiently waited for transfer to Sydney for bone marrow transplant. Among the side effects, Mark had contracted a fungal infection while neutropenic that now required daily administration of IV infused anti-fungals. This meant that he was at the hospital every day and was hence there whenever I needed a transfusion. Mark also had the same doctor as me so we would often meet on clinic days.

I bonded with Mark immediately. He was jovial all the time and seemed to approach his treatment with acceptance and ease. The more I talked to him the more I appreciated his graciousness. Things had been pretty 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. The two of us would chat for hours, passing the otherwise mundane experience of transfusions and IV drug infusions. We met Mark’s wife Vicki and their gorgeous daughter, Rani, who like Rathiga had been gifted an ancient name of Sanskrit origin. Mark and I agreed that when the two of us felt up to it that we would get the families together for dinner.

Not long after meeting Mark, Deidre introduced me to Peter, an avid skier and professional instructor roughly two years younger than I. Like me he had been diagnosed with Philadelphia positive ALL and was undergoing Hyper CVAD. His diagnosis preceded mine by two months so he was further along his treatment rounds than I. I didn’t see Peter as often as Mark because our cycles were slightly out of sink but as much as possible the two of us would catch up, visiting the other whenever he was admitted. I knew of Peter’s exploits well before actually meeting him. Partly because he also had the same rarely observed form of Leukaemia (there has only been two other cases in Canberra since our diagnoses in 2008) and partly due to his lengthy, thick and widely appreciated dreadlocks, now long gone thanks to the unfortunate hair destroying nature of chemotherapy.

Peter was fortunate in that his sister was immediately identified as a suitable bone marrow match so plans were already underway for his transplant. The locale of my donor still unknown, the potential for my transplant remained uncertain.

## X

My treatment rounds continued in a cyclical fashion. My days turned into weeks, the weeks into months. Each cycle of chemotherapy was followed by periods of neutropenia and constipation induced issues with my anal fissure and hemorrhoid. I would spend days lying in bed consumed by pain and eating as little as little as possible to reduce the number of number twos. Each time I came out of neutropenia the doctors would madly start scheduling me for the next cycle and I would resist as long as possible to try and give sufficient time for my anus to repair itself before the next round of vicious chemotherapy. My waistline ebbed and flowed during each phase of my schedule. Each time I dropped my diet I would lose three or four kilos only to regain it again in great attempts to recapture my appetite. I was like a camel, storing fatty tissue during good stints only to loose it again in leaner times. I thought of Xi Wangmu often during this period. Focusing on the warm welcoming smile and positive demeanor with which she greeted me, I would relentlessly search my inner-self for the strength of character that miraculously gave her the conviction to carry on. There was a doctrine in her precept that I felt must be learnt, which must be replicated if I was to survive this hellhole.

During one of my cycles I developed a headache so severe that I could hardly stand. I took paracetemol and endone but nothing seemed to ease the searing pain that was taking over every aspect of my guise and carriage. It was clear that I needed to make the thirty-minute journey south to the hospital. I rang the hospital to advise that I was coming and waited for Kavitha to return from work so that she could drive me. By the time I reached the hospital the pain had failed to subside at all. I was swiftly admitted to the ward where nurses began injecting me with morphine until the pain began to ease. Kavitha stayed with me all afternoon as I slept off both the morphine and the pain. I remained in hospital for a few days to ensure nothing sinister was happening and that the headaches had passed. I returned home, the unwanted and unexpected admission behind me.

My hospital stays were short but the close confines of four walls were sending me insane during every hospital visit. I am not sure what it is but I found myself constant anxious as I waited for something to happen. I would try to meditate, listen to music or watch television nothing seemed to work. Reading also escaped me, I simply wasn’t able to concentrate enough to absorb the written words. I’d lie in bed for a few minutes before jumping out in fits of anguish to drag around my drip stand. Then after, regaining some semblance of normality, I’d return to the bed where my anxiety would again grow until I found myself pacing the small room’s floor once again. The only relief from this vicious cycle coming when receiving visitors such as Kavitha or Alexey, who could extract my thoughts from dark places and assist in passing the boredom of repeated hospital visits.

Meanwhile my friendships with Mark and Peter continued to blossom. We would share ‘war stories’ and exchange anecdotes of how we were passing the time and maintaining sanity throughout the uncertainty and turmoil of treatment. Mark and I continued to plan our dinner date, a target that constantly required shifting due to one or the other of us falling neutropenic or experiencing the latest medical setback.

## XI

It was clinic day and several of us had been called into the hospital to receive updates from the consulting physicians. Mark and Vicki were both there, as were a number of other patients facing a variety of malignant blood disorders. Mark was before me in the queue. I patiently waited to hear the latest development regarding his progress.

Mark returned with Vicki, who with tears of anguish rolling down her cheeks began cursing the system. Mark’s bone marrow donor, an unrelated volunteer from Europe, had decided that the proposed transplant date, which had previously been agreed and was now less than three weeks away, was no longer possible because he wished instead to take a holiday on the Mediterranean. “Bloody sun-bathing hippie” she said, focusing no longer on the sacrifice that he was willing to make but the casualness with which he was now treating Mark’s life, which to be frank was simply on the balance. Their disappointment was understandable. This was the latest setback in a long and complicated passage of treatment for Mark. Having waited so long to get to this point, he now needed to wait two more months for the donor to return from holiday and to regain a place in the busy transplant schedule at Sydney’s Westmead Hospital. I felt sympathy for them both. I was trying vainly to offer some condolence when my name was called. I left the waiting area and proceeded to the private room for my consultation.

‘The type matching for your father has come in,’ said Pidcock. ‘Unfortunately, like your mother, he is only a half match,’ he continued. ‘Okay! Does the test confirm that he is my biological father?’ I asked. ‘It is highly likely. The fact that he is a half match is suggestive that he is closely related and probably responsible for half your genetic makeup. We have some other test results here from your brother who is also only a half match.’ ‘I have a brother,’ I said, 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! Adrian!’ he replied as he fumbled through the report on his lap.

Pidcock continued ‘I am sorry to tell you this but I have some other bad news for you as well. We have been unable to find you a match from the international donors registry.’ ‘You mean no match amongst all nineteen million of them?’ I interrupted. ‘There are no matching adult donors David! We did find a couple of matching umbilical cords, donated after the delivery of babies, but there are more risks with transplants from blood cords. Because the quantity of blood is small we would need to use two cords with different genetic makeups. This can cause extra complications during transplant. The other big problem is engraftment. With less cells it can take a lot longer for the donor marrow to start generating your own new cells. This means that you could be neutropenic for an extended period.’ ‘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 quite high during such a long period of neutropenia,’ he replied.

‘I have spoken to Associate Professor Ian Kerridge at Westmead. He is going to see you next week to discuss your options. He is a transplant physician and is hence far better placed to plan the path forward. In the meantime, I recommend that we increase your number of HyperCVAD cycles and consider preparing you for a stem cell transplant using your own stem cells. You should be aware that we are in unchartered territory here. No one really knows the best way forward. Philadelphia positive Leukaemia is very aggressive and almost always comes back without a transplant. We debated your case for a long time in the weekly haematology meeting and the truth is that not all of the specialists agree whether or not the stem cell transplant is worth pursuing. What is clear is that you need to keep taking Glivec.’

Glivec is an oral enzyme inhibitor that I had been taking since my Philadelphia positive diagnosis. It is useful in treating Philadelphia positive ALL because it interrupts the processes that lead to the generation of malignant cells. ALL is caused by abnormal chromosomes, which produce an enzyme, known as tyrosine kinases, that in turn leads to the uncontrollable growth of immature lymphocytes, the category of white blood cells relevant to 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 rapid spread of immature cells. Unlike chemotherapy, which kills all rapidly dividing cells, Glivec is a highly targeted drug impeding the generation of ALL.

‘Let’s see what Ian says when you see him next week. In the meantime we will begin making plans for extended HyperCVAD cycles and a stem cell collection. I will talk to you again after you see Ian,’ concluded Pidcock. ‘We’ve arranged transportation with the Leukaemia Foundation for you and Kavitha for your trip to Sydney next week. 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 with whom I had been spending much time, attempted to console me while tending to my Hickman’s dressing. 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.

## XII

The Leukaemia Foundation was founded in Brisbane in 1975 to assist patients and their families cope with the trauma of leukaemia and other related blood disorders. A coalition of staff and volunteers 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 free accommodation to families forced to relocate to major centers for treatment; and organised volunteer drivers who collectively accumulated some 8,000km of travel in 29 Holden and Bridgestone vehicles to deliver patients to critical medical appointments. The foundation also invested 3.8 million dollars into vital research to improve treatment and find cures, growing its total investment in research to over 20 million dollars.

Bruce, one of several thousand Leukaemia Foundation volunteers, arrived at our house at about 6:30am in the morning to collect Kavitha and I for the three and half 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 well below the maximum legal speed limit of 110km/hr. We were a little over half way along the Hume Highway when the rain became so heavy that we simply had to pull over.

I was watching the clock tick over and was growing ever conscious that we were in danger of missing our appointment. Bruce, picked up the phone and called the Westmead Hospital to advise that we could 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’m afraid that if you are late I am going to have to re-schedule his appointment… I suggest that you continue your trip and I will see what I can do.” My stomach dropped. I already felt too ill to be travelling and I couldn’t bare the possibility that we were going to drive all the way to Sydney, only to turn around none the wiser about where my treatment was taking me. The uncertainty was killing me and I was becoming noticeably agitated, when, without warning the weather cleared, the sun’s rays pierced the clouds and we were able to resume the drive.

We arrived in Westmead’s Cancer Care Centre about thirty minutes late, only to discover that Ian was running even later after getting caught amongst the 28% of Sydney residents that cram the highways for the daily commute to work. Ian arrived, our crisis had been dodged and Kavitha and I were taken into his room where we exchanged pleasantries and began discussing my future.

HyperCVAD – no trips to ICU – whatever you are doing to stay healthy – keep doing it.

‘Philadelphia positive ALL is a very aggressive form of cancer,’ he said. ‘Preferably we would like to take you to transplant now! While you are in remission! As you know however, we have not been able to find you a donor. Our only option is a transplant from blood cords. We have found several of these that we could use. The problem is that this is a very risk procedure. The potential for complication is high and the success rate small’. ‘How small? How many have you done and how many of the patients made it?’ I asked. ‘These are all good questions,’ he replied. ‘It is early days so we don’t have a large sample. Our unit has undertaken eight transplants for patients with a variety of different Leukaemias.’ ‘And how many survived’ I interrupted. ‘Sadly, only one of the cord transplant patients is still alive today’ he stated with the kind of remorse that could only be experienced by a doctor, who despite all efforts had failed to save the patients he so desired to help.

‘I have discussed your case with all my colleagues in the transplant unit and the consensus is that we do not try the transplant now. 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 molecular testing will provide an early indication if your Leukaemia is mutating to a Glivec resistant strain. Hopefully we will catch the mutation early, before the disease becomes overwhelming,’ continued Ian. ‘And if it does mutate? What then?’ I asked again. ‘If we catch it early 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 you just put me on that now?’ the latest in my barrage of question. ‘The rules about using Dasatinib are very strict. We can only administer it when Glivec fails, otherwise the PBS won’t cover it.’

‘If you do start to relapse … then we will be forced to conclude that your ALL has declared itself! The combination of chemotherapy and enzyme inhibitors will have failed and you will have to undergo a transplant,’ Ian continued with a reality that was difficult to swallow. ‘So what are the chances that the Glivec can hold my remission?’ I asked desperately. ‘It is difficult to say. Glivec is still relatively new so we have no long-term statistics to go by. I would guess that it is 90% likely that you are going to relapse. Maybe 70% at a pinch.’

Ian continued talking. This I knew because his lips were still moving. I had no idea what he was talking about though. My inner geek was coming to the forefront. ‘If I let A be the event of relapse then the probability of relapse (written P(A)) is 9/10. Now, let B be the event of surviving a cord transplant. Then 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)) then the probability of me dying in transplant is 9/10 times 7/8, which is 63/80 or 79%. This means that the chance of me surviving Leukaemia is 21%. Damn!’ I was shell-shocked at this number, which seemed desperately low. I was after all only thirty-one. I have a three-year old daughter for Christ’s sake. Somehow I mustered the courage to rejoin the conversation.

‘I am a transplant physician so I would be happy to take you to transplant. But I simply don’t think it is worth the risk at this stage. So, if you are happy, this is my proposal. You remain on Glivec and undergo detailed blood tests regularly. Canberra can collect some of your own stem cells, while you are in remission, in case we need to do an Autologous (I am my own donor) transplant. However, I suggest that we don’t do either transplant now. There is not much evidence to suggest that an autologous transplant will help you now and, well the cord transplant is simply too risky. We will store your stem cells just in case we need to rescue you at some later stage and we will continue scanning the bone marrow registry to see if a better option presents itself. I do agree with Pidcock that we should extend your hypoCVAD treatment and eight cycles should be appropriate. I am really sorry that you find yourself in this predicament David. Try to stay strong

## XIII

Typical check-in dilemma (day treat. room) – chemo dropped – misses Rathiga

Stem cell collection – fails – in-between chemo rounds.

## XIV

Mark gets infection – very sick – close call but improves – then sudden death

Psychological effects of Mark’s death – treatment a relief - can’t get to his funeral

## XV

Cycles continue

Peter get’s infection in his last round of treatment – recovers

Peter goes to transplant

## XVI

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

Tired – slowly regain strength – return to work.