# 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 creaking and groaning until the stand reached its resting place on the left side of where I lay. Alison then walked to the door where she had left her chemo trolley and moved it to the bottom of my bed. She dressed into a poly-coated protective gown, safety glasses and dark purple gloves, all the necessary precautions for handling chemotherapy, and then 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 blue Alaris 7231 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’s line, placing them neatly on my side where they were easily accessible. She grabbed one of the lines; rotating it so that it stood upright and started wiping the bung with a chlorhexidine alcohol swab. ‘It is really important that everyone who handles your Hickman’s 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’s line dumps drugs directly into your heart. Failure to clean it properly can lead to infectious bacteria entering your blood stream, something you particularly want to avoid as you enter a period of neutropenia. It can make you very sick. It is 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 that she had 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 Alaris, two mechanical arms massaged 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 only noticeable sign an increased sensitivity to smell, particularly towards food and an unusual taste in my mouth. In fact 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 resumed 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 continued to heave 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 stomach muscle contractions as it desperately 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 began to lean heavily on Kavitha that night, a trait that would become more and more common of the ensuing months. We went through many sick bags that evening, the onslaught waning only once my antiemetics were modified and my body became more tolerant to the cytotoxic drugs. Eventually, I managed to fall asleep and rest.

## III

The likelihood of 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 small. 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 continued, explaining 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 a ‘charismatic Italian gentleman’ with whom she had a fleeting relationship before meeting Peter.

This was a complete shock to me. I had absolutely no idea. A large portion of my life, previously shrouded in lies, now revealed in unvarnished truth, the ‘great conspiracy’ unveiled. Flabbergasted by this revelation, I couldn’t help but feel that the world as I knew it was collapsing around me. I reflected upon the week that lay behind me. First, I discovered that I have a rare and difficult to treat form of Leukaemia, now I learn 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 as a good man and none of this had changed. I just couldn’t help but feel cheated, masqueraded by my own family who had kept this secret from me, camouflaging the veracity of my lineage.

Despite the discovery that Peter was not my 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. Now, I discovered that he was infertile, a reality that now faced me due to the highly toxic nature of my 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 thirty-one years earlier, and with whom I had not had the fortune of knowing at all. Then there was Sam, my stepfather of twenty-four 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 he who I felt the most love.

## IV

Another day dawned and the latest revelation about my pedigree remained fresh in my mind. Most of all it made me more determined to be a good father to the angelic Rathiga. Not because any of my fathers had been bad, but simply because that was an opportunity that I myself yearned for. 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 anyone else on his side would agree to testing. 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 solution and then another of those sharp stings as she injected local into my lower back and along the intended path to my subarachnoid space. 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 cleaned up their paraphernalia and I started tracing my history to identify potential causes of this, the latest difficulty.

The most likely candidates leading to scarring in my spinal area, 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 one and a half 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 quietly to myself, knowing that I couldn’t face the other two potential candidates with the same guilt free consciousness as the Nowra fall because both were clearly products of my own erroneous judgment. The first of these, a nasty 8m 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 travelling well until my concentration slipped and I fell into a classic traversing mistake. The natural inkling when climbing is upwards and not sideways. The trick is to know when to exit the horizontal section and start climbing towards the sky. 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 was becoming more and more apparent that I was off route. The climbing was tremendously 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 slotted into the destinationless finger crack and 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 hundred plus 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, arrogantly slapping in a piece of protection without much attention and reaching the roofs lip and climb’s crux. I started rounding the lip moving my hands onto the headwall and attempting to pull myself out of the roof and into a more natural upright position. It was clear however that I was too far to the right, the good hand holds out of reach. My arms, starved of oxygen, started convulsing violently. I was able to hold on just long enough to acknowledge that I was coming off. The inevitable becoming reality, as 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 my blue-back bruised back.

I will never know if these climbing accidents lead to the spinal scarring that now made my treatment more difficult. Regardless of this unknown, I took comfort in knowing that I had at least had fun along the way and I knew that the skills I had acquired during those climbing days would now be useful in overcoming the mental battle of cancer. Most of all I acknowledged that I could pull myself together, that I could attain control of my mind when things appear impossible and everything hurts. I was comforted in the knowledge that I could make sound judgments when exposed at great height, at times when failure to do so could be fateful. This I felt would help me now. 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 and 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. Every morning one of the nurses would extract samples of blood from my Hickman’s line and return again when the pathology reports were ready. Red and white blood cell and platelet counts were transcribed to a record sheet on my pin board. We became accustomed to interpreting these numbers, recognising that the levels would determine how I would feel that day, what I could eat and drink and whether or not I would need any transfusions.

After a few days 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 that 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 had finished I would have been through this process over seventy times for red blood cells and another thirty-to-forty platelets. Having depended on some hundred or so donations I developed a new appreciation for the blood donors who voluntarily receive needles and give up their time for the wellbeing of others. As well as the transfusions, which were only used to boost my red blood cell and platelet counts, I took daily injections of steroids to stimulate my bone marrow to begin generating more white blood cells, transfusion of which are not typically used due to problems associated with

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 and 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 of 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 of time. As I began to cope better with the treatment I was able to focus for greater periods and could tackle 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 as I mustered the strength to briefly tackle the sustenance of normality. Our discussions would remind me that there was more to life than hospitals, blood tests and poorly appointed food.

## VI

Eventually 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 to the area more difficult. My back was again cleansed with antiseptic solution. The radiologist took a number of X-rays and invested some time studying and marking his access route. Then, I felt the sharp sting of local followed by a pushing sensation as he tried to route the spinal needle into position. Even with the aid of imaging the radiologist found it difficult to get through my vertebrae and into the subarachnoid space. The doctor took several attempts, each time taking more X-rays and giving more stinging local to ensure that I was relieved of the more painful needle insertion. I recall getting pins and needles in my legs as I tried to lie still for extended periods. The usual time for this procedure is about twenty minutes. After about an hour of constant poking the radiologist had some joy and the needle was in place. 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

Eating difficulties – weight up and down. Anal repair

Bone Marrow typing – genetic match – Mother and sister both half matches

Making Friends – first didn’t want it – then Peter and Mark…

Migraines – morphine – unexpected stay in hospital

Tracking down my father – Yvonne – bakery

No match in international database – same day Mark hears of delay in transplant

Plans for extended chemotherapy and stem cell transplant

Visit to transplant physician Westmead – Ian Kerridge – 21%

Father doesn’t match –I have a brother (also doesn’t match) – get Dr address

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

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

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

My treatment rounds continue - Days into weeks into months

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

Peter goes to transplant

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

Tired – slowly regain strength – return to work.