

# *Twenty-One Percent*

Inspiration of  
Xi Wangmu

Twenty-one percent is the memoir of young man and his family's struggle with Leukaemia, family deceit, life threatening complications and ongoing uncertainty.

A man's life, and that of his family, is transformed upon diagnosis of a rare and aggressive Leukaemia. Less than two months from his Ph.D. submission and amidst the quest for a second child, a young couple struggle to raise a 2-year-old throughout an aggressive treatment protocol.

The search for a bone marrow donor forces a family revelation. Peter, whose life was taken at 33 and who stimulates few memories in the man, is not the man's biological father. The father is alive. The man questions the meaning of fatherhood as he attempts to remember Peter; explores his relationship with his step-father; searches for and begins a relationship with his new-found father; and tries to survive long enough for his daughter to remember him.

A bone marrow donor cannot be found, neither from within his family nor the 19 million registered donors. The setback brings with it a new prognosis – a twenty-one percent chance of surviving two years.

The man completes six months of chemotherapy. He submits his Ph.D. and returns to the Federal Government where he leads the earthquake risk program. The couple resume IVF and fall pregnant. They lose the baby – they continue trying. Meanwhile, looming over them is an ever-present likelihood of relapse and probable death.

Relapse occurs after 1.5 years. Seven days chemotherapy unleashes a life-threatening septicemia; pneumonia; chronic diarrhoea; and a fungal infection requiring partial removal of both lungs. The man breaks – he wants no more treatment – his wife refuses, convincing him to fight on. He is discharged after six months hospitalisation. Likelihood of further relapse remains high.

Medical advances present new hope, the potential for long-term survival via transplant from a half matched sibling, a procedure impossible one year earlier. The couple moves to Sydney, interrupting their daughter's first year at school. The man receives a transplant. He experiences a month of raging fevers and partial paralysis – he is unable to walk or swallow. A feeding tube is inserted and the bed-ridden man transferred to a high dependency ward. Can the family endure more hardship? Will the man regain enough strength to be a good father?

Twenty-one percent is the story of an every day family in suburban Canberra whose hopes and dreams fall apart due to cancer, family deceit, life threatening complications and ongoing uncertainty. Will this family ever be the same again?

## **Outline and Progress Report**

### **FOREWORD**

To be written by Dr Michael Pidcock  
Verbal agreement with Dr Pidcock

### **CHAPTER 1**

Draft completed – ready for external review  
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### **CHAPTER 2**

Draft completed – undergoing author review  
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### **CHAPTER 3**

Draft 70% complete  
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### **CHAPTER 4**

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### **CHAPTERS 5 to 9**

To be drafted  
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### **AFTERWORD I**

Leukaemia Foundation and the work they do  
Leukaemia Foundation to be invited to write

### **AFTERWORD II**

Red Cross – on blood donation  
Red Cross to be invited

*Chapters 1 and 2 form the basis of this submission*

## Chapter 1

Saturday 18 October 2009—Friday 5 December 2008

I

The air had a harsh chill the day Xi Wangmu presented herself to me. She squinted her eyes under the rising sun, hospitably raised her hands and composed a warm welcoming smile – a smile broken only by voids left behind by once upright teeth, now lost through years of malnutrition. I knew that I needed to meet her the moment I gazed upon her old frail body. Her faded navy tunic, mended multiple times with pale blue patches, was well worn and torn around the hip. The light cotton trousers extending from the bottom of her outerwear were three inches short, exposing a pair of thick grey woollen socks. On her feet she wore mud-stained slippers, scarcely capable of providing comfort from the brutality of a cold autumn morning.

The skin of Wangmu's face, neck and hands was covered in deep wrinkles, which narrated the story of a difficult life. One consisting of hard manual labor, with days worked in the terraced fields bordering Yingxiu Township and nights spent raising a family of four children. Her weariness was also evident in the fine strands of white-grey hair that fought their way loose from the black scarf wrapped tightly around her head.

Next to Wangmu stood her residence, a refugee shelter built from scavenged logs, tarpaulin and a variety of colorful canvases. The fast-flowing waters of the Yuzixi River rushed behind her and were all that separated the shanty house from the steep, landslide-scarred slopes of the Siguniang Mountains. The bubbling sounds of a boiling pot of water came; from inside her house, and the sweet aroma of Chinese green tea filled the air.

I called for my guide, who was inspecting the ruin behind me. Xun Guo trod carefully through the rubble between us and joined me on the river's edge. I

explained that I wanted to talk to Xi Wangmu, and he began speaking to her in Sichuanese Mandarin, a language spoken by roughly 120 million residents of Wenchuan County, China. Wangmu spoke of the horror that had befallen her town four months earlier. She explained how the ground trembled, the mountains roared and the buildings fell. I glanced behind me where less than one in five multistorey buildings remained standing. A bulldozer-cleared road barely wide enough for two vehicles was the only route to where we now stood.

Wangmu explained how the ground adjacent the river turned to liquid under heavy shaking; how the sheer slopes on all sides of the valley failed to contain landmass; and how boulders as large as buses rolled down the steep slopes, annihilating everything in their path. She spoke of the horror immediately following the earthquake and how survivors, desperately searching for loved ones, became acutely aware of their isolation upon realisation that ubiquitous landslides had enclosed the valley within which she lived. The residents of Yingxiu were left to fend for themselves in their greatest time of need.

Downstream, the path of the Yuzixi River had been dammed by one of thousands of massive landslides. The steep walls of the valley offered no place for the river to meander and the water began to rise. Within hours, the rapidly flowing waters engulfed the low-lying ruins of Yingxiu Township, forcing survivors to flee to higher ground. Those who could, fought bravely against the odds treating the injured with whatever they could find until, some 24+ hours later, the army arrived in droves with supplies and much needed medical capabilities.

After describing the horrors of that day, I noticed Wangmu's expression turn to grief. She reported the ill fate of her own family of four children, their spouses and three grandchildren, all counted among the ninety thousand lost during the earthquake and ensuing flood.

It was unfathomable to me that after what she had been through, Wangmu could compose a smile. That she could greet me, a foreigner unable to provide

any hope of comfort or support, with such warmth and happiness. I knew immediately that there was something special about Xi Wangmu, that her resilience and desire to survive was incredible and that her ability to remain positive was a special trait. A personal quality, previously buried beneath a hardened exterior, now brought to the surface through severe trauma. Several months would pass however, before the importance of this meeting would truly dawn upon me.

## II

In the beginning of that year's Northern Hemisphere summer, the residents of Yingxiu found themselves deep-seated within the kill zone of the Great Sichuan Earthquake, the 12 May 2008 magnitude 7.9 catastrophic disaster. In its aftermath, more than 69,000 people were confirmed dead, 370,000 injured, 18,392 missing and more than five million homeless. Over 21 million buildings were damaged leading to an estimated direct financial loss of \$86 billion US dollars.

Everywhere I looked I saw the telltale signs of a massive earthquake. The extensive building damage, the landslide scared slopes and the 2m vertical offset, or fault scarp, in the road to the left of where we stood. Scientists who visited the area earlier reported finding vertical offsets exceeding 6m in some areas, a phenomenon only created by the world's largest quakes. Piles of rubble, taller than I, extended in all directions.

I had travelled to the region with an international consortium of seismologists, engineers and architects; joining a local government organised field trip of earthquake-affected areas. The purpose of the exercise, to demonstrate progress of cleanup efforts and educate those of us not directly impinged, about the magnitude of devastation and ruin. After years spent modelling the impact of potential earthquakes on communities around the world, this field trip offered my first opportunity to observe the devastation first hand. I knew that it would be difficult, but nothing could have prepared me for

the scale of destruction and despair that I observed. On the one hand, the scientist in me wanted to learn from the physical signs of the earthquake and the failure of the built environment to survive its violent shaking. My humanity however, made it difficult to shift my thoughts from those killed and the 18,000 still missing, presumably buried under my feet as I navigated piles of debris. A compelling sense of melancholy overcame me and I found it necessary to stop regularly to reflect on what had befallen these people and how heroic they were.

### III

Two days before leaving for China I called my doctor's surgery. A poor traveller at the best of times, I knew that I needed to restock my supply of sleeping tablets before boarding the plane. 'Doctor Morvai is not available tomorrow,' informed the receptionist, 'you can see Doctor Wong if you like.' 'She'll do,' I replied.

The following day I entered the room where Doctor Wong practiced, meeting her for the first time. Her petite fit figure and glowing fresh skin, evidence of her own good health. In complete contrast to my initial observation, she took one look at me, squeezed out a fleeting 'hello' and insisted that I jump on the scales. She promptly recorded my height and sat down at her computer. '92 kg, 171cm ... I am sorry to say this but you are technically obese,' she said with a bluntness that was no doubt unintended. 'When was your last general medical examination,' continued Wong whilst scanning my medical records to answer the question herself. 'I can't see one here. We better do something about that I think.' She scribbled onto a pathology request and began speaking again as she passed it to me. 'The nature of your physique makes you susceptible to cholesterol, diabetes and a range of other medical issues. Please see to these tests as soon as possible. Now what else can I do for you?'

'I'm travelling for work tomorrow and need some sleeping tablets to ensure I get some rest on the plane,' I replied. 'You should see from my medical records that Dr Morvai has prescribed them before,' and I pointed to her computer

where my medical history remained open. 'Yes I can see them,' she said while extracting her booklet of empty scripts from the top shelf. She began madly writing once again and flicked me the script. 'Good luck with your trip ... don't forget those tests,' she commanded and I was quickly on my way.

I entered my car and adjusted the rear-view mirror so I could see my face. 'As if doctor,' I said quietly to myself with all the nonchalance of a 30 year old male certain of his own immortality. I recognised that I was well rounded, due largely to a reduction in physical activity over the last few years. My belly was more pronounced. But obese, I thought, nah! I folded the pathology form and upon filing it in the glove-box, began driving to the pharmacist for my sleeping pills.

#### IV

I returned from China in late October, landing in Canberra, Australia's largest inland-, entirely planned-city and the seat of its Federal Government. By this stage I had been working in the public service for more than seven years. Employed by Geoscience Australia, the national agency for all things Earth Science, since 2001, I had already grown to love Canberra and greatly enjoyed working as a practicing seismologist to serve and advise a range of national and international stakeholders. I didn't return to my Geoscience Australia office however. A couple of years earlier I had been posted to the Australian National University where I was undertaking a research project, of interest to both agency and university alike. I returned therefore, to the university where my project was conducted under the umbrella of a Ph.D. and was now well developed. My research on earthquake location in poor recording situations had largely been completed, my thoughts and conclusion materialised and more than half my dissertation written. I was expecting to submit my thesis within three months and was looking forward to returning to Geoscience Australia where my immediate future lay. My health had a different plan for me however.



A month or so passed. It was Friday afternoon (21 November 2012) and I was madly working on the final chapters of my thesis. My mobile rang. 'Hello,' I greeted. 'Hi David, it's Arul here, how are you?' replied my brother inlaw from Singapore. How pleasant, a chance to chat with Arul my initial reaction. Then, acknowledging the unprecedented nature of a workday call from Singapore 'is everything alright?' I asked. 'I've been trying to get ahold of Kavitha,' my lovely and strong natured wife, 'do you know where she is?' he inquired. 'She's probably in a meeting Arul, is there anything I can help you with?' 'Something's happened,' he said. 'Dad's had a heart attack! We're at the hospital now and he's about to go into surgery. They are going to put in some stents to open the blocked arteries.' We continued the discussion for a short while, the conversation concluding when I was satisfied that I understood all-important details. I began to track down Kavitha.

That night we booked tickets for Kavitha and Rathiga Tiah, our two-year-old active and gregarious daughter. We decided that I would stay in Canberra to tend to our circus of domesticated animals, two cats and two dogs, and keep the momentum in my thesis writing. We planned a Saturday morning departure and two-week visit for the girls. Meanwhile, my father inlaw's operation finished and he was moved to the intensive care unit to begin his recovery. My own throat was beginning to tingle and I was falling ill.

My beautiful girls left for Singapore on Saturday morning and I hit the sack. Recuperating in bed for the better part of a week, it was clear that I had a nasty virus. Both my father inlaw and I, albeit from a far less serious illness, recovered quickly. He returned to his home and I began to feel human once again. As my mind cleared of congestion I recognised the impossibility of this situation. How is it that Raju (my father-inlaw), a regular exerciser and healthy man in his early sixties, is having blockages in his arteries, I thought to myself. Then it dawned on me. We are not immortal are we! I must do something about those tests.

The following day I was at the pathology outlet as they opened their doors for Saturday morning trading. A quick prick later, the blood collected and I was

sitting at the local cafe. Why didn't I just do that straight away? I began reflecting. Never mind, it is done now. I settled into a serve of eggs benedict and my usual morning startup, a double-strength espresso and thought about my thesis. Where was I before I fell ill... that's right... if I start there I will be back on track in no time. I soaked up the last dribble of runny yoke and headed into the university to resume my scientific writing, finishing late that evening and returning early on Sunday for another long day.

## V

It was 8:55am Monday 1 December and I had already been at university for two hours when my mobile rang again. 'Hi David, it is Doctor Wong here. Your test results have arrived and I need to see you immediately! Can you get here as soon as possible?' 'Sure! I'm on my way now,' I replied, walking past the printer to grab a draft of Chapter 5 on my way to the car.

My mind was racing at a million miles an hour. Geez, it must be important. Immediately! She did say immediately didn't she? What could it be? Glandular Fever? I thought of my recent bout of virus and congested bed time. No, you don't say immediately for Glandular Fever. Diabetes ... Oh Shit ... I have type 2 diabetes. Yeah you would say immediately for that wouldn't you... Damn! I am going to have to change my diet... But ... I like my diet... And insulin, I'll need that too! Before I knew it I was parking my car, with no recollection of having driven the 10-minute journey to the GP's practice.

I didn't have to wait for the doctor. I was ushered to Doctor Wong's room as soon as I announced my presence. 'So what is it?' I barked as the door swung open. 'Please sit down David,' replied Doctor Wong. 'I am sorry to tell you this but the tests indicate that you have Leukemia.' I glanced at the print hanging behind her, unable to look directly into her eyes. I recognised the painting but couldn't recall the artist. Phew, I thought to myself, that means I don't have Diabetes; and in a complete state of abnegation I turned to Wong. 'Okay! But how is my cholesterol level. Will I need to change my diet?' I asked. 'You don't need to

worry about you cholesterol now. This is extremely serious David! I have contacted Canberra Hospital and they are expecting you. You need to report to the Emergency Room within the next couple of hours.' 'But I feel fine. Are you sure?' I asked. 'They will repeat the tests when you get there. I suggest you pack a small bag. You may need to stay overnight,' she replied and I got up to leave. 'There's no need to pay for this one David, just get to the hospital as soon as you can,' her final words as I left the office.

I was at home and on the phone to Singapore by 10am. With daylight savings the time difference is three hours so the time in Singapore, 7am. Saroja, my mother inlaw answered the phone. We exchanged pleasantries, I sought information on Raju's recovery and she asked how I was going. 'Can I speak to Kavitha please?' I requested. 'She is sleeping,' the reply. 'Can you please wake her? I need to speak with her now.' A few moments later and a faint greeting echoed down the line. 'Hi babe, it's me,' I replied. 'David, how are you?' she asked more clearly now as she began to wake. 'Is everything okay?' she continued. 'No, I have just seen the doctor.' 'What, what is it!' she interrupted with a great sense of urgency. 'They think I have Leukemia. I have been asked to report to the hospital as soon as possible.'

I passed the little information that I had to Kavitha and we agreed to wait until I had seen the specialists before arranging her return. At least, I thought we had agreed to wait. Kavitha, who is not known for taking advice from her less-informed husband, was far too anxious to wait. She began packing and made arrangements to return to Canberra that evening.

I made two more phone calls. One to my parents in Adelaide and a second to my sister Amanda, who lives three suburbs to the east of me in west Belconnen. Amanda agreed to join me. I called for a cab; collected Amanda on the way and one ridiculously enormous fare later, arrived at the Emergency Room of Canberra's largest hospital.

After a small wait I was seen by the triage nurse and shown to a bed in the treatment area. Two doctors arrived, Emma a Hematology Registrar who did most of the talking and an accompanying intern on short-term rotation. Emma took a detailed medical history, gave a brief introduction to Leukemia and extracted a blood sample for repeat analysis. She explained that the new tests would determine the nature of my Leukemia, detailed knowledge of which would influence the treatment plan and determine the potential of its success.

I was admitted to the cancer ward with minimal fuss. Amanda left for home and I called Kavitha for the second time that day. I then settled into the first of many featureless hospital meals and switched on the television, freely available only in the cancer ward.

## VI

I slept restlessly and woke early Tuesday morning. It didn't take long to discover that a prerequisite for all hospital patients is patience. I waited ... waited ... and waited some more. Eventually, I was reunited with Kavitha and Rathiga who had taken the overnight flight. It was a relief to have my girls with me once again. I filled Kavitha in on the latest details while Rathiga coloured quietly in the corner.

Later that morning I met Deidre, the cancer care coordinator, a nurse who would be integrated within my medical team and with whom I would develop one of many new friendships. Deidre's first responsibility when a patient arrives is education.

In India, a guru or 'darkness eliminator', is recognised as someone who eliminates the darkness of ignorance by passing knowledge (light) and educating the pupil. Deidre was to become my guru and there was a black-hole of darkness to eliminate. I couldn't help but recall how I'd inappropriately asked Wong about cholesterol, having just learnt of my Leukaemia diagnosis. Having had little personal experience with Leukaemia, I knew only that it was a cancer of the

blood, that it was more common in children and typically lead to hair loss somewhere along the trajectory of treatment. I had little idea where it came from, how it was treated or what to expect. Fortunately, Deidre started at the very beginning.

Bone marrow is the soft, spongy tissue found inside the majority of bones. In the kitchen it is the ingredient responsible for flavoring the highest quality meaty soups and can be a delicacy in its own right. In the body however, its role is somewhat more fundamental to our survival. It is responsible for producing the blood cells which, when suspended in liquid known as plasma, circulate throughout our bodies.

Blood cells can be categorised into three groups: red blood cells, white blood cells and platelets. Red blood cells collect oxygen from our lungs and transport it, via arteries, to body tissue. White blood cells, a fundamental component of the body's immune system, defend the body against infectious disease and foreign material. Platelets are responsible for clotting and hence necessary to stop bleeding. They also deliver proteins and hormones that stimulate cell division and, along with white and red blood cells, assist wound healing.

Leukaemia is a cancer of the blood or bone marrow. It leads to the rapid generation of immature white blood cells that are unable to function properly. In developed cases these malignant cells, also known as blasts, swamp the blood reducing the number of healthy functioning cells. As a result the carrier becomes susceptible to infection, excessive bleeding and lack of energy due to poor oxygen transport. Intense bone pain may also be experienced as the bone marrow becomes overcrowded with immature cells.

There are four primary forms of Leukemia, broadly classified by the type of white cells involved and how quickly the disease develops. Acute leukaemias develop quickly and can make the sufferer ill within weeks. In contrast, chronic leukaemias get worse more slowly and may not require treatment for years. Myeloid leukaemias impact white blood cells known as myelocytes, whereas

lymphoblastic leukaemias affect lymphocytes, another form of white blood cell. The four main categories therefore become; acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML), chronic lymphoblastic leukaemia (CLL) and chronic myeloid leukaemia (CML).

‘We won’t know exactly how to treat your Leukaemia until the type is confirmed,’ stated Deidre. ‘However, we are pretty certain that it is acute and that it will involve chemotherapy,’ she continued. ‘Let’s talk about chemo now.’

Chemotherapy involves administering combinations of cytotoxic drugs that attack and kill rapidly dividing cells such as the malignant blasts in my body. Unfortunately however, there are no chemotherapy regimes that target only ominous cells. That is, chemo assassinates both healthy and unhealthy cells alike and consequently leads to a raft of side effects, some of which can be lethal in their own right. Common side effects include ulceration of the digestive tract, hair loss and reduced blood counts. All three of the primary blood types are affected leading to poor oxygen delivery and exhaustion (red blood cells), immunosuppression and increased risk of fatal infection (white blood cells), excessive bleeding/bruising (platelets) and poor wound recovery (all).

‘Your blood counts will drop after your chemo!’ Deidre continued. ‘It is important that you understand that you are susceptible to all sorts of infection when this happens. This state is known as neutropenia, and your body will not have an operating immune system so you must be extremely careful. You will need to wash your hands continuously and avoid public places, even common areas of the hospital. You will also have to be careful with what you eat. You can’t have anything raw unless you peel it and you should only drink bottled water. Just imagine that you are travelling in a developing country,’ and I thought how much more wonderful that would be. Deidre wrapped up her lesson and I was left alone to reflect upon what lay ahead.

## VII

‘The blood test has confirmed your Leukaemia David,’ said Emma, who returned to see me again on Tuesday afternoon. ‘It looks like you have AML. We would like to take a biopsy of your bone marrow though. This will be more accurate than the blood analysis and will help us confirm how developed your disease is.’ ‘Emma... are you sure?’ I replied. ‘I don’t feel sick at all,’ I continued. ‘We’ve caught it early, David. Acute diseases like this propagate very quickly. Left untreated... You would be very sick and possibly die within weeks.’ ‘What if I had done the tests in October when I first saw the doctor?’ I asked. ‘It is possible that we would not have seen the disease at all a few months ago. I would say that you are very lucky. Lucky that you undertook the test when you did! The disease has developed enough to be detected but not so much that you are symptomatic. Now, let’s get on with this biopsy shall we?’ suggested Emma.

This would be the first of more than a dozen bone marrow biopsies. The procedure involves extracting a sample of bone marrow from the hipbone. Following Emma’s directions, I lay on my side and crunched my legs in a foetal position. She selected and marked the entry site. There was a sharp prick as the needle punctured my skin. She injected local anesthetic to numb the area. Then, a spirited PAIN as Emma twisted her hand, the needle piercing the hard outer-casing of bone and entering the bone cavity. She attached a syringe and sucked out the aspirate or liquid marrow. Then she swapped to a trephine needle, a larger instrument with a cylindrical blade, and felt further pain as she rotated it to extract a sample of solid marrow.

The biopsy was conducted in my room and general anesthetic is not used. Sedation is provided and on a good day the patient will remain responsive during the procedure but will not remember it afterwards. This day, in early December was not a good day. I clearly recall the pain as the needle entered and twisted within the bone. The torment occurs because local anesthetic is unable to penetrate the bone, and is hence useless during the bone-piercing stages of the procedure. The bone aches for a few days after each biopsy.

## VIII

Emma returned on Wednesday morning. This time Doctor Michael Pidcock, the lead consultant on my case and head of the Haematology Department, joined her. 'The bone marrow aspirate suggests that you have ALL and not AML,' he said. 'The difference is probably not significant for you; it just changes the chemo protocol that we use. We need to wait another day or so however, to get the results from the solid marrow sample,' continued Pidcock.

'We have booked the theatre for tomorrow to insert a Hickman Line,' Emma pitched in. 'A Hickman line?' I asked. 'It's a special type of intravenous catheter that is inserted in your chest above the nipple. It will allow us to take regular blood tests without poking you and will be the means by which we administer your chemo. Unlike a cannula in the wrist which must be changed every 48 hours or so, the Hickman line can remain in place for extended periods. If it doesn't get infected we will continue to use it for the duration of your treatment.'

Kavitha and I interrogated the doctors on a range of topics. They responded courteously to each question and waited patiently for further digging. 'What are my chances?', the latest gradation in our long inquisition. 'The road will be difficult but your chances are reasonably good! We are aiming for a long disease-free life here,' replied Emma. 'We hope to start the chemo on Friday. Try not to worry, we think you'll do ok,' they concluded before leaving my room.

## IX

I was allowed to leave the hospital with Kavitha briefly on Wednesday afternoon. The purpose of our expedition was a visit to the local IVF clinic. Deidre had explained that there was a high chance that I would become infertile after receiving HyperCVAD. We knew that we wanted more children so we decided to freeze some sperm. It helped me to think of Han Solo's cryogenic freezing in the Empire Strikes Back. Somehow, this made the whole process seem manlier.



That night, I was back at the hospital and I thought of Xi Wangmu. I recalled the warmth of her grin and positive outlook. 'If she can cope with her torment, then I can deal with this,' I said quietly to myself. My thoughts drifted however, to the man I knew as my biological father. Falling to a long illness when I was only four, I knew that Peter's last days were a struggle. Dying at the meagre age of 33, only 2 years older than the 30-year-old frame lying in my bed, I held very few memories of him. Contemplating his premature death abducted my concentration to the fragility of life and my own mortality. 'Will my daughter remember me?' My brain was once again racing at a million miles an hour. 'The inspiration of Wangmu... the slow painful passing of Peter ... what would become of me?' Wangmu won this one, the first of countless battles over my psyche. 'It will ... WILL be okay!' I convinced myself as I tried to settle for another sleepless night.

### X

The night nurse woke me as she prepared to take another set of observations. I was glad to be awake now for I had been dreaming. Subconsciously, I'd been processing the few memories that I had of Peter. The clearest of these, a pantomime, taking place in the kitchen of our old house in Christie Downs, an outer suburb on the southern fringe of Adelaide. Peter was leaning over the bench, blood as red as vine-ripened tomatoes streaming endlessly from his mouth at an alarming rate. The memory was so vivid that I could feel the ossicles in my ears vibrate to the sound of blood crashing into the sink. I searched my soul but couldn't find a more buoyant memory. I couldn't remember him chasing me; I couldn't recall him throwing a ball; I couldn't educe a single moment where the two of us were playing. Then, all of a sudden, a great sense of guilt swept over me. Four years and this was the best I could muster. Blood ... blood ... blood everywhere!

Sweat was pouring from my forehead and I was uncomfortable with my dark thoughts, when, all of a sudden, it struck me! I had found my second source of inspiration. I was determined that I would not fall to the same fate as Peter. I

could not and would not do that to my gorgeous Rathiga. There would be ballet concerts; math exams to prepare for; bust-ups with inappropriately selected boyfriends; and teenage dramas. She was going to need her father. Nothing was going to stop me from being there for her.

## XI

Thursday dawned and I began fasting for the Hickman insertion, not scheduled until the afternoon. Before the Hickman procedure I was taken to nuclear medicine for a gated heart pull scan to confirm whether my heart had the pumping capability to adequately distribute chemo throughout my arteries. The test involved the extraction of a small sample of blood, which was mixed with radioactive material and reinjected into my arm. After a short wait, I was attached to an electrocardiograph (ECG) and positioned under the gamma camera; a purpose built imager to track gamma rays emitted during the decay of my blood bound radioactive nuclei. 45 minutes later the ECG leads were removed and my heart was deemed ready.

I was escorted back to my room and Deidre dropped in for the next verse of my education. 'Now we know your type of Leukaemia we can start planning the chemotherapy,' she said. 'You will be treated by a protocol known as HyperCVAD. Reserved for the most aggressive forms of Leukaemia and traditionally administered to young fit patients, HyperCVAD is separated into two arms. During arm A we deliver the following drugs: Cyclophosphamide, Vincristine, Doxorubicin (also known as Adriamycin) and Dexamethasone – hence the acronym CVAD. Arm A also includes doses of Cytarabine, Mesna and Methotrexate.' My brain rattled with all these foreign terms and Deidre continued, 'in course B you will receive Methotrexate, Leucovorin, Sodium Bicarbonate and Cytarabine.'

'Because these drugs are so aggressive we have to deliver them in a hyperfractionated fashion. This means that each of arms A and B will be repeated multiple times with drug doses at tolerable levels. We will most likely give you

three rounds of each so you will have six courses of chemo in total. We will start with course A tomorrow. It will take four days to deliver the chemo,' continued Deidre.

'You can expect your blood levels to drop shortly afterwards and you will become neutropenic. Remember our discussion the other day? You are at serious risk of infection when you are neutropenic so you must follow the precautions carefully. Eventually, your blood levels will bounce back and once the doctors are satisfied with your health we will start arm B. For all intents and purposes, arm B is the same as A only the drugs differ. Again, you will receive the chemo over a four-day period, become neutropenic and then recover. Each cycle should take about three weeks, depending on your recovery. We will try to get you out of hospital between the courses of chemo if we can. It all depends on your health.'

Deidre continued 'Most of the drugs will be delivered via your Hickman line. There is a chance with your Leukaemia however, that it might cross into the brain or spinal cord. At least one of the drugs, the Methotrexate, will therefore be delivered by a lumbar puncture or spinal-tap,' and upon hearing the term spinal-tap my thoughts drifted to the 1984 cult mockumentary "This is Spinal Tap" a humorous satire following the wild life of a fictitious heavy metal band. Deidre continued, unbeknown to how my mind has so easily drifted 'a sample of the cerebrospinal fluid will be collected at the same time. The sample will be analysed to determine whether your Leukaemia has indeed crossed into the spinal cord.'

## XII

The Hickman insertion was my first experience with theatre since my knee reconstruction; necessary to repair a torn anterior cruciate ligament sustained playing football three years earlier. Unlike the knee reconstruction however, I would not receive the benefit of general anaesthetic for this one.

I lay on my back on the operating table. Theatre nurses draped my chest with sterile sheets and washed the open areas with antiseptic. There were several pricks as the surgeon injected local anaesthetic on the right side of my chest. He paused to allow the local to take affect and then made two incisions. The first of these, known as the entrance site, was located at the jugular vein near my collarbone. The second, the exit site, was roughly 12 cm lower on the chest wall. He created a tunnel under the skin, joining the exit and entrance sites. The singular tube of the Hickman line was then pushed into the exit site and through the tunnel until it emerged at the entrance site.

The surgeon bent the tube, changing its direction and routing it towards an opening in the jugular vein that he had made earlier. The idea is to insert the tube into the vein and advance it through the superior vena cava; a thick vein transporting deoxygenated blood from upper body to heart, until it reaches the heart's right atrium. This was proving problematic however. I could feel the surgeon pushing at the line as he attempted to position it. He was zoning in on the desired location when, all of a sudden, the pressure became overwhelming and the line popped out again. He repeated the process over and over again. Each attempt ended with the line blasting out in vigour. He began cursing, seemingly oblivious to my consciousness.

As if I wasn't nervous enough to begin with, now the doctor was ranting somewhat aimlessly at an obstinate piece of silicon. I was becoming more agitated with each passing attempt. The theatre nurse squealed as I squeezed her hand with force and the surgeon asked someone call his supervisor. A second nurse moved towards the phone, the nurse under my grip detained and unable to move. The surgeon was explaining that he needed assistance when, miraculously the line reported into place and he cancelled his request.

An X-ray was taken to confirm that the line was in the correct position, the surgeon placed a stitch at the entrance site to hold it in place and a nurse began cleaning the blood which had spilled all over my chest. A clear waterproof

dressing was placed over the exit site. In the end, only the tubing below the exit site was visible. A vertically aligned rise in the skin joining the two incision sites, the sole evidence of the catheter above the exit point. Below the dressing, the Hickman line separated into two tubes and dangled freely. Each tube had its own clamp and bung, and was designed to accept a syringe. As well as sampling blood and delivering chemo, the Hickman line would be used to administer other drugs such as antibiotics, saline fluids and blood transfusions.

Kavitha was standing outside the theatre. Later she recounted her growing concern as she waited 1.5 hours for the '40-minute' procedure to finish. We really were juveniles at this stage. There were far more tormenting waits to come.

### XIII

That night I turned to sleeping tablets, my old friend, to ensure that I was well rested for the initiation of treatment. My mother arrived on Friday morning and Emma visited me on her daily rounds. 'I am sorry David, but I have some more bad news for you. We have completed the bone marrow analysis and you are Philadelphia positive. This means that your Leukaemia cells have an abnormality in which parts of chromosomes 9 and 22 swap places. Sadly, it impacts your prognosis. Philadelphia positive ALL is excessively aggressive and patients are more likely to relapse after treatment. It is likely that chemotherapy alone will not be enough to hold your Leukaemia at bay. You will need a bone marrow transplant after the chemo is finished. This could add up to another year to your treatment.' I looked at her in horror. I knew that I now faced more than a year and half of hell.

'We will talk more about the details of a transplant once we find you a donor,' continued Emma. 'In the meantime, I need to ask you about your family. We will start with the family; this is the most likely place to find a donor. Failing that, there is an international register of donors. We can usually find a suitable match from the global database if there is no one in your family.' I filled Emma in

on my family members. She decided to begin with type matching my mother and sister.

‘There is one thing I was wondering Emma,’ I said. ‘Of course David, go ahead.’ ‘The chemo is starting today. Will I be able to keep drinking coffee? Coffee is really important to me.’ ‘Of course David! You can drink as much coffee as you like,’ and Emma left me alone to reflect on the latest disagreeable news.

It was then, that I realised I had not asked the old Chinese earthquake-refugee her name. If she was going to be a source of inspiration then she needed a name. By this stage I accepted that I was entering the fight of my life. So, after some deliberation, I settled on Xi Wangmu, the ancient Chinese goddess of immortality and dispenser of longevity, prosperity and eternal bliss. She is the cultivator of the peach of immortality, a fruit whose juicy flesh imparts a new lease of perpetuity to the immortals every six thousand years. As I settled on her name, I imagined my self eating her potent peach and breezing through treatment.

Not only did I feel it appropriate, perhaps even necessary, to enlist the support of a goddess of immortality; I realised that this choice suited my other galvaniser. Almost three years ago, and after much debate, my wife and I named our daughter after two deities; Rathiga a goddess and beloved of Lord Krishna in the great Sanskrit epics that form the philosophical foundation of Hinduism; and Tiah, a recognised derivative of Theia, the mythological Greek goddess of light and mother of the sun, moon and dawn.

As my chemo drew closer I thought of Xi Wangmu and I thought of Rathiga Tiah. I had no idea what I was in for but somehow I knew that, with three deities behind me, it would be okay.

## 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 scarring. 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 entralls 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 (paracetamol 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 than 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 uncharted 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 Lorraine'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 Lorraine 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 afflicted 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 pulsed 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 ...  $P(A \cap B) = P(B|A) \times P(A)$  ... 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 antibiotics 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 to 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.

