# Chapter 3

## Wednesday 20 May 2009—Tuesday 18 January 2011

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It is not that difficult to live on borrowed time. Like a credit card – you borrow a little each day and you move on. Somewhere, someone is keeping the books though and its not the growing debt that gets you – it’s the compounding interest. Insurance is your only combatant. My insurance was Glivec, the drug designed to slow – stop? – the relapse, and the molecular testing that would identify the drug resistant mutation of my Leukaemia. Insurance was all that I had. The rest … you learn to forget about the rest and you let the debt and interest accumulate.

I had climbed Mount Chemotherapy and I was free. I was in remission, but I was weak. I had to rebuild my strength. I walked and walked … and then I walked some more. At first I would stay close to home. I’d ramble up and down the street. Then, I tackled the block, sauntering past my neighbours’ on daily jaunts until I gained sufficient strength to stride into adjacent blocks and eventually, neighbouring suburbs. My brain also needed a workout. I hadn’t concentrated on anything for months. I started to read, it was time to start perusing some of Alexey’s Russian favourites, and I used the computer to reconnect with friends and colleagues.

For 6 months I had received daily medical attention: blood tests, pressure readings, temperature measurements and oxygen saturation. Each day a medical professional would provide a summary of my health. Now, I was lucky if my bloods were taken once a week. In between I had only my faith … faith that nothing obscure was happening to my blood counts. I had begun adjusting to this newfound freedom when I was called back to the hospital. It was time for a second attempt at harvesting my stem cell.

The stem cell collection was kick-started with chemotherapy. It was nothing like the four-day epics of HyperCVAD – it was a day job. I went to the clinic in the morning and I was home for dinner. My blood counts dropped over the following days and I injected myself with hormones twice a day to boost the stem cell growth. I returned to daily blood testing and when my counts were sufficient we would repeat the stem cell harvest, but the counts never got there. I didn’t manage to produce enough stem cells – a second stem cell collection had failed. Later, my medical team discovered evidence in the literature that suggested that Glivec, which is known to suppress blood cell generation, was the culprit. No one was game to take me off Glivec, my remission was in balance and Glivec was instrumental in keeping me there. We made no more attempts at the stem cell collection, any future treatment would have to make do without it. In the back of my mind I knew that if I made it to two years then I would have to stop taking Glivec – it was best not to think about it.

A decision was made, soon after the failed stem cell harvest, to remove my Hickman line. This signaled the end of all treatment. I recalled how the surgeon had cursed the line when he has putting it in – was it too much to ask that it come out with ease? Apparently it was! The Hickman line had been a fixture for eight months – my skin had engrafted. Skin was detached, layer-by-layer, painful scalpel-stroke by scalpel-stroke. It took 80 minutes. My only relief, jabs off local anaesthetic administered whenever I informed the doctor that the cutting was too painful.

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My strength continued to improve but it was time to take my recovery to the next level. It was important to push myself. Kavitha and I planned a road trip to the Sunshine Coast, Queensland. We visited my Great Aunt and Uncle in Newcastle; stopped at Byron Bay to visit mainland Australia’s easternmost point; and ….. km later, arrived at our destination on the Sunshine Coast, Peregian Beach. We explored the local beaches, national parks, towns and cafes; watched movies; and enjoyed some time together.

In Brisbane we saw Peter, who had completed his transplant, opting to do it in Queensland rather Sydney so that he would be close to family. He was clearly weak, and he had suffered from graft‑versus‑host‑disease (GVHD) but he was alive and wandering the slow path of recovery.

A bone marrow transplant is a nasty undertaking – I once heard a surgeon call transplant patients the heroes of the hospital. There is a reason for this. First they go through heavy chemotherapy and full body radiation, either of which can lead to any number of insufferable conditions. Then their blood levels drop. Most suffer violent temperature variations – uncontrollable fevers that transport the patient from the frozen ice fields of Greenland to the sweat drenched dunes of the Sahara. So much fluid is used to stabilise them that their own body becomes unbearable – feet swell – ankles and knees disappear. Then comes the GVHD, white blood cells from the donor attack host cells, damaging any combination of the: skin, liver, mucosa and gastrointestinal tract. Common symptoms include pain, diarrhoea, vomiting and rash. Mild cases indicate that the donor cells are actively fighting the disease (graft-versus-leukaemia), which is good, but severe cases of GVHD can be fatal. Then, once the patient is through all of this, they are left extremely weak – some take months just to walk around the block and even when they are through that hurdle they have to deal with a compromised immune system, the transplant resets everything so that the patient has no acquired immunity against any diseases. Transplant survivors must repeat childhood immunisations and suffer from every little pathogen from which they previously held immunity. Long‑term complications are ubiquitous and include: cataracts, osteoporosis, renal dysfunction.

The good news was that Peter was through the worst of it. We didn’t know what the future held for either of us but both of us were relatively well. It would take Peter longer to return to his pre-caner life but he was well on the way. We said our farewells to Peter and his mother: Kavitha, Rathiga and I continued our holiday.

Throughout my illness Rathiga had not gone anywhere near a swimming pool. She had gone from a child who was comfortable in the pool to one who was terrified of water. We went to Streets Beach on the southern bank of Brisbane River. It was Rathiga’s first experience with water since I had fallen ill. We dangled our feet in the water and watched the other children play. Rathiga was interested but she was glued to the sand. Kavitha and I tried to coax her into the water but she wanted nothing to do with it. After several hours of failed attempts, Kavitha sprung into action. ‘I’ve had enough of this,’ Kavitha said as she grabbed Rathiga underneath her shoulders and carried her into the water. The whaling child ruined the peace of some 100-beach-goers. Rathiga carried on as if she had been thrown into a pool of molten lava. I sought refuge behind the nearest tree and pretended that I knew neither the earsplitting child nor its cruel mother. My efforts were in vein, however, ‘your daughter doesn’t think much of the water, hey,’ ockered a passer-by.

A few days earlier we had been building a sand castle at Perigian Beach, on Queensland’s Sunshine Coast, when a shock wave took us by surprise. Kavitha and I were gathering our things, which had been strewn all over the sand, when we realised that Rathiga was completely missing. I recalled being struck by a sudden and uncompromising fear. ‘There she is,’ Kavitha said and I turned to find that she had dumped her parents and climbed half way up the sand dunes. It was clear that it was time to teach Rathiga how to swim. We vowed to enroll Rathiga in swimming lessons as soon as we returned to Canberra.

Walking was a big part of the remainder of our holiday. We did day walks in Bunya Mountains and Lamington National Parks and to my surprise I coped reasonable well. It was Rathiga, who seemed to have the most trouble, but with the regular enticement of marshmallows we managed to keep her going.

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* Tired – slowly regain strength – return to work (start 1 Sept 2009 at 3 days per wk – 4hrs/day. Gradual increase until full-time return 19 Oct 2009.
* I had been so close to completing my Ph.D. when I fell ill—it was time to finish it. I returned to work at the ANU. I had a thesis to complete.
* A typical graduate student, myself included, will start their Ph.D. with enthusiasm and energy. They will attack their research with drive but they will make many mistakes. They are green! With time they will gain essential experience and fine tune their skills. This is great, but their enthusiasm falls. They are tired by the time they are writing their thesis—they are over their topic and they just want to go home. I felt like a new student starting their project for the first time, but I wasn’t a new student. I had the benefit of three years detailed study of my topic. I was already the expert and I was fresh! The combination of knowledge and enthusiasm was lethal. Finishing my thesis was not work
* Make trip to Melbourne – Dali exhibition (9 Sept 09 – 14 September) –National Gallery of Victoria

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With an estimated world population of less than 1600 the Giant Panda, or bamboo bear, is among the world’s most endangered species. Its plight was formerly recognised in 1961 by the World Wildlife Fund (WWF) who chose the iconic creature as the centerpiece for its logo. Recognised alongside the Chinese Dragon as a national emblem of the People’s Republic of China, the Giant Panda holds a special place in the hearts of people around the world; and like Xi Wangmu, the species is important in ancient Chinese culture. The bamboo bear was kept by emperors, throughout the Hahn Dynasty (206 BCE—220 CE), who believed it to be: a noble animal, a symbol of goodwill and a magical creature capable of warding away natural disasters and evil spirits. Sadly, the Giant panda’s presence in Wenchuan County, where greater than 30% of its population resides, could not prevent the great Sichuan Earthquake of 12 May 2008.

In the 1970s the Chinese Government loaned pandas to zoos in North America and Japan. At the time, the loans represented the most significant cultural exchanges between China and the West, an achievement now sanctified by the term “Panda Diplomacy”. The practice of loaning pandas continues today and in November 2009 two Giant Pandas, Funi (Lucky Girl) and Wang Wang (Net Net), were loaned to the Adelaide Zoo. They are the only Giant pandas in the Southern Hemisphere.

In December, Kavitha and I took Rathiga to Adelaide to celebrate Christmas with some of my family. We visited Wang Wang and Funi during the first week of public viewing and I was introduced, for the second time, to two survivors of the Great Sichuan Earthquake. Both pandas were in the Wolong Giant Panda Reserve when it was devastated by the magnitude 7.9 event. Both were sent to the Baixiongpin Yaan Research Centre to receive intensive care. Both recovered, but Wang Wang’s mother (Mao Mao) was not so lucky. She was crushed when her enclosure collapsed.

Visitors to Wang Wang and Funi’s enclosure are presented a taste of southwestern China. They are transported to an exotic mid-altitude paradise of dense bamboo and tall trees, of steep slopes and misty mountain breezes. The experience was different for me, however. Watching Wang Wang and Funi took me elsewhere. I was hauled back to the ruin of Yingxiu village. I thought of the 87,000 killed and missing—I thought of Xi Wangmu, and the journey we had followed since our encounter 14 months earlier. It was a time of reflection. I had observed the devastation and ruin of one of the world’s greatest catastrophes and I had lived through my own trauma. It was time to be thankful—thankful for all that we had.

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By mid February I had a complete draft of my thesis. I gave it to Malcolm, my supervisor, and Kavitha, Rathiga and I flew to Fiji for a holiday. We booked a week at the Radison, Denarau Island and stayed in style.

I can still remember how we had struggled to convince Rathiga to enter the water in Brisbane. Her expression of horror remains so vivid that the event could be unfolding in front of me right now. It was different by the time we reached Fiji. A few swimming lessons at King’s, Macgregor and she was ready to tackle the water. In Fiji, she swam every day and sometimes at night. She no longer required enticement to enter the water – the problem was convincing her to leave.

In June of 1999 I arrived in Nkhata Bay on the western shore of Lake Malawi, the southernmost of Africa’s Great Lakes, a body of fresh water lying in the East Africa Rift. I was 3 weeks into a 10-week overland journey between Nairobi, Kenya and Cape Town, South Africa. I spent five days in Nkhata Bay, studying the theory and practice of scuba diving, a sport whose sense of weightlessness remains alluring. For ten years I promised myself that I would do it again but I had never seemed to find the time. My post cancer world was different, however; Fiji presented the perfect opportunity to return to scuba.

Four dives later (two from South Sea Island and two from Tavarua), I had seen a coral reef for the first time, swum with blacktip sharks, stroked the belly of an Orangefin Anemonefish (or clownfish) and been attacked by a nesting titan triggerfish. I had assumed the guide was joking when he had warned me about the triggerfish.

My most memorable dive was a fly through in the strong currents; a stone throw from Fiji’s famous Cloudbreak, home to the fourth fixture on the ASP World Tour. The judges’ stand towered above the water and was clearly visible from our boat as it rolled and pitched in the light swell.

My dive-buddy, Donna, was a forty-something ex-pat Australian divorcee who had recently created a new life for herself in Fiji. Our guide was Junior. Clearly his nickname had followed him from childhood. There was no longer anything junior about the near seven-foot giant. We were the experienced group. I am still unsure how I had graduated to the experienced group. It was only my eighth dive – the first 6 were completed more than ten years earlier. The other group contained a second guide and a honeymooning couple undertaking a diving course. The recent bride was nursing bloody wounds from the earlier triggerfish assault. We dropped the newly weds into the water along with two snorkelers and proceeded towards the judges tour for a couple of minutes. It was our turn to enter the water.

‘The current is going to be very strong where we are going,’ said Junior. ‘Don’t fight it, let it carry you … AND … make sure you stay with me,’ and on that note he raised his hand, began deflating his BCD (buoyancy control device) and signaled the beginning of our decent. We reached a depth of 9 metres. The current pulled me lightly towards my left as I followed Junior but there was nothing strong about it. The diving was effortless; I was absorbed in my thoughts. It was puzzling me how Junior, a hulk of a man, could be so soft. The current is stronger in my driveway when it rains. A few moments later the drop-off appeared. Junior signaled that we were going over.

We swam over the edge of the under water cliff and released some more air from our BCDs. I descended a further five metres. The water collected me … there was no resisting it. I drifted along the reef … my heart raced … it was exhilarating. The currents possessed the strength of a surface wave, it was as if I was surfing but the water column extended 14 m above me. Fish navigated the current with ease, swimming in and out of nooks in the reef as we flew past. I had neither the ability nor the inkling to navigate the current. I was a passenger. We had thrown ourselves to the mercy of the current and were going wherever it cared to take us.

Time seemed to hang which was convenient because I didn’t want the dive to end. I was reveling in the power of Mother Nature when Junior disappeared behind me. I turned against the moving water to see that Junior’s spool line was caught on an outcrop. I tried to swim towards him but it was helpless. The current was too strong. I was nothing against it. I grabbed a protruding piece of the reef. It took all my strength to hold on. I turned into the direction of the current, a faint silhouette of Donna was all I could see … she had continued drifting. In the other direction there was Junior, bouncing against the reef as he attempted to disentangle the spool line. Should I leave Junior, or should I leave Donna?

The experience should have been confounding … the choice confusing … but it was neither. A sense of clarity swept over me. It was Donna that I should follow. Donna was my dive-buddy. We were the least experienced. Junior was a qualified guide. He had no doubt survived similar situations. By the time I reached Donna she had turned and was trying to fight against the current. This created enough delay for me to catch her.

She shrugged her shoulders. I pointed back towards Junior, who was now out of sight, and shrugged my shoulders back at her. She pointed towards the surface and I did the same. We took care to rise slower than our air bubbles and reached the surface a few minutes later. I explained what I had seen to Donna. ‘Coming up was the right thing to do,’ she said.

We were bobbing up and down in the swell. I looked around. Occasionally I would catch a glimpse of the judges’ tower but that is all I could see. There was no sign of the surface marker buoy and no sign of our boat. I listened for the boat but the ocean was noisy … I could hear nothing over the choppy waves. Was Junior okay? Had he managed to release himself?

In 1998 a Great Barrier Reef dive operator left behind a married couple, Thomas and Eileen Lonergan. Their story was all over the news. It inspired the 2003 horror film Open Water. Time seemed to hang again but this time it was not a blessing. Would we be left adrift?

The boat was almost on top of us when it appeared above the swell. Junior had a grin that befitted his physical stature. ‘You did the right thing,’ he said as he pulled Donna into the boat. ‘We have to go back and collect buoy,’ he continued as he helped me in. My last dive was over. It had been exhilarating and scary. I was eager to get back into the water.

Fiji had been our best family holiday. Life was good—we hoped that it would stay that way.

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It took me two weeks to address Malcolm’s comments. I submitted my thesis on Friday 12 March. It was a comfortable time frame; I spent the final day reclining on my office sofa, listening to Mile Davis. Davis once said, “My future starts when I wake up in the morning … Every day I find something creative to do with my life.” It might be surprising that a seismologist would think of his Ph.D. as creative but that is exactly how I viewed it.

The role of a scientific graduate student is to take a piece of the world and attack it from a new viewpoint. This is particularly true in the field of mathematical modelling. Located at the crossroads of science and mathematics, mathematical modelling involves the description of nature into bight size segments of tractable equations, which, with their Greek letters and rules of grammar, translate the natural world into a computational domain. Whether the computations are undertaken on a single PC or on a cluster of 100s of computers, the results lead to new insights.

Mathematical modelling is governed by rules; but without creativity the field lacks the depth required to progress scientific evolution. Under the supervision of two accomplished scientists, Malcolm from the Australian National University and Roel from the Colorado School of Mines, I had created an original and exciting technique for locating earthquakes, which significantly reduced location uncertainty for poorly recorded earthquakes. My thesis was a collection of creative insights, harmonised and explored within the boundaries of a modeller’s rulebook.

Reclining in my sofa that Friday, I appreciated for the first time the full meaning of what Miles Davis was saying. He was not talking upon creativity without rules because music that fails to respect the boundaries of rhythmic structure will be unpalatable; it would be no more appealing than a toddler beating the keys of an un-tuned piano. Some artists will push the boundaries from time-to-time; they may even manipulate them, but any attempt to leap outside them will leave listeners behind, a result that no musician desires.

Mile’s had a special way of expressing himself. It was fitting to spend my final student moments with him – I was submitting my expression of three and a half years research, my opus of over seven years of university study. If cancer had taught me anything … it was that my “future starts when I wake up in the morning”. I was ready to enter the next phase of my life. I submitted not only my thesis but also my fears of cancer. 21% no longer meant anything to me. I would not share the number with anyone – not a sole.

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It was not so easy for Kavitha. She had been strong throughout my illness but now, with me in good health, she feared my relapse. The more active I became the more she was consumed by a fear. I pushed hard, every day needed to count

Friday night was

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Kavitha and I have experienced our share of bad luck in the health department. …. years before my leukaemia diagnosis Kavitha’s stomach began to grow at an alarming rate. At first we put it down to weight gain. Kavitha dieted and exercised but her stomach kept growing. She experienced continuous stomach cramps, which were heightened during her menstrual cycle. On the ……. we visited Doctor Morvai who examined Kavitha’s stomach. ‘Ooh! Um! I don’t like the feel of this,’ she said. ‘Have you felt your stomach lately?’ she asked Kavitha, but before Kavitha was able to respond Morvai continued: ‘Put your hand here,’ and she placed Kavitha’s hand on her lower abdomen.

After Kavitha had felt her abdomen, Morvai invited me to touch it. Kavitha’s stomach felt like a rock but it was no six-pack. It was round and protruded, and as if she was six months pregnant except we knew she was not.

‘You need to get an ultrasound as quickly as possible,’ Morvai said. She handed us the referral

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January is a quite time in Canberra. A lot of people travel to visit family or to enjoy the coast. I prefer to stay and work. January is the best time to dust off your research and get your teeth into the interesting things that are buried at the bottom of the pile during busier periods. There was nothing unusual about Tuesday the 17th January, the sun was shinning, the office was clear and I had spent a solid 7 hours working on an article for the Journal of Geophysical Research. I knocked off on time that day, 7 hours of writing is enough for me, and collected Rathiga from childcare (she was due to start school in less than a month).

I noticed my mobile on the bench as I entered the house. It had never occurred to me that I didn’t have it all day. All the better, I thought to myself, less disruptions to my writing. I picked it up and saw that there were 6 missed calls, one from an unknown number, one from Kavitha and four from a 6244 number. I stared at the number for a while and then it came to me. It was the hospital. I saw that there was a text message so I looked at that:

Hi David, Emma here. I need to talk to you ASAP. Please call me as soon as you get this message. Dont worry if its late. Just call me.

I knew then and there that it was bad. I’d had my bi-monthly bone marrow biopsy the day before. Just how bad, I didn’t know.

I went to Rathiga and I held her. Then I sat her in front of the modern babysitter and picked up the phone, pacing the dining room as I dialed Emma.

‘Hello Emma, it’s David,’ I said.

‘Hi David,’ she replied.

‘It’s not good is it?’ I interrupted.

‘It’s not good David. I’m sorry … your Leukaemia is back. We have seen it on both the biopsy and the blood test.’

‘It’s too late for the second generation inhibitor isn’t it?’ (I was of course referring to Desatanib, the drug they had tried to get me on 6 months earlier).

‘We are going to put you on Desatanib David. But you are going to need more chemo David. The Leukaemia has progressed to far for the Desatanib to correct it by itself.’

‘And a transplant?’ I asked.

‘That’s up to the team in Sydney but I suspect you will need a transplant this time.’

‘So tell me about the chemo Emma,’ I asked.

‘This time we are going to use a protocol called HAM,’ replied Emma. She explained that HAM involved the use of 2 cytotoxic chemicals, Cytarabine and Mitoxantrone, which would be delivered over 3 hour infusions morning and night every second day for seven days.

I recall how easy I thought this sounded. I’d had chemo before – last time it lasted six months and the infusions ran continuously for 4 days. HAM had rest days – how hard could it be.

‘So how long will I be in hospital?’ I asked.

‘It will take us seven days to deliver the chemo – then we would like you to stay in hospital until your blood counts rise.’

‘But! I’ve managed neutropenia at home before. Can’t I come home after the chemo?

‘You need to understand something about HAM David. It is not like HyperCVAD. The drugs are more concentrated. This is about as toxic as it gets. Most people who have HAM get at least one infection. You need to prepare for the fact that you will be sicker this time.’

‘Okay, when do you want me to come in?’ I asked.

‘We would like you to come in tomorrow morning,’ replied Emma.

‘Will you be working on my case Emma?’

‘I’ll get you settled when you arrive but I’m still in the lab,’ (Haematology registrars must complete 2 years of training in the lab, 1 year overseeing patient care at their host hospital and second year at another hospital. Emma had done her 1-year with patients in Canberra and was now in her second year in the lab) ‘there is a new registrar, Amy, who is working with Doctor Pidcock. She will be the one overseeing your treatment. Also, Dr Pidcock is away at the moment. We will admit you under another of our consultants, Dr Anna ……, and move you back to Pidcock when he returns.’

‘Emma,’ I interrupted.

‘Please, go on David’

‘Can I come in Thursday? That will give me a day to sort things out.’

‘One more day should be okay. Do what you need to do and come in Thursday morning. Is 8:30 okay?’

‘Yeah, that should be fine.’

‘I’ll schedule a Hickmans insertion and heart pull scan for Thursday and we will start your chemo on Friday. Make sure you fast from midnight.’

There was a silence. Emma continued, realising that I had no intention of asking any more questions: ‘I’m really sorry David. Just stay strong – it will be okay.’

I sat down in the grandfather chair. The first thing that came to my mind was the discussion with Dr Ian Kerridge, my Sydney transplant physician, in which I had learned that they his team had managed to save one of eight adult blood chord transplant patients.

One phone call and the likelihood of me reaching 35 had dropped from 21% (based on two events occurring: relapse and transplant) to 12% or 1/8 (based on the transplant only). Even that number didn’t take account of the fact that HAM itself had the potential of killing, a possibility that did not occur to me at that time, but one that I would come to realise.

‘So what I am going to do now,’ I said to myself. ‘It’s 6:25. Kavitha is working back late so I need to … Uhm … cook dinner. Yeah we need to eat.’

I have no recollection of cooking. I know that I did cook and that we did eat but I have no idea what it was. I was preoccupied with working out how I was going to break the news to Kavitha.

After dinner I asked Kavitha to join me for a walk. We had made a habit of walking around the neighborhood after dinner. I had some vague notion that I could get my weight into the 70’s, knowing full well that if I did need a transplant the blood chord had a better chance of succeeding if I was lighter.

‘Shall we bring the dogs with us?’ asked Kavitha

‘No. Just us tonight I think.’

My feet had barely left our driveway when I told her: ‘The Leukaemia is back.’

She stopped dead in her tracks: ‘Oh fuck no!’ It is a rare event to hear my wife swear.

‘Why didn’t you just tell me?’ she continued. ‘I’ve been home for over an hour.’

‘I know. Come on let’s keep walking,’ I said.

‘I don’t want to walk! What are we going to do?’

‘Come on. Let’s walk and talk.’

I assured her that this was a minor setback, that I could undergo chemo – I’d done it once before, and I considered myself strong enough to fight off most problems. I told her that if one person could get through a blood cord transplant then I could also do it.

‘I’m strong,’ I repeated many times.

I said all this because she needed to hear it. She needed more than anything to believe that I would keep fighting. The truth is, I needed to hear myself say it because inside … I was wrenching. The odds were against me seeing the years end. It bothered me that I would leave my daughter and wife behind but I wasn’t scared of dying. I was, however; petrified of the path that would take me there. I knew that it would get ugly before it ended.

We walked and talked for hours, returning to the house only when we had reconciled our fears sufficiently that we thought it possible to sleep. My heart was heavy that evening though and sleep proved illusive. The insurance policy had failed. I had 18 months debt to repay but what of the interest?