# Chapter 4

## Wednesday 19 January 2011—Someday March 2011

I got up early, as usual, Wednesday morning. I dressed as I normally do, poured my cereal for breakfast, helped Rathiga prepare for the day and I dropped her off at child‑care. Kavitha went to work; she needed to arrange a few things so she could take a couple of days off work once I was admitted.

I returned home and tidied up. I’d never spent a month in hospital before but I knew enough to know that it would turn our life upside down. Tidying the house was the least I could do for Kavitha who would soon find herself juggling all the daily tasks – the chores that feel onerous enough when there are two to share the load.

I called my manager at work.

‘Hi Jane, it’s David,’ I said.

‘Monday’s biopsy didn’t go so well. It looks like the Leukaemia is back. I’m starting chemo tomorrow,’ I continued.

‘Damn! I’m sorry to hear that David, Is there anything I can do to help,’ she replied.

‘It’s okay. It sucks, but we’ve done it before, I’m sure we can do it again.’

I continued: ‘I’m going to be in hospital for a month or so, which will be followed by a good three months recovery. It’s possible that I might need more treatment after that.’

We discussed the important deliverables that I was working, what should go to whom and what could wait until I returned.

‘You should prepare for me being away for at least four months … potentially more,’ I continued.

It was easier not to mention the transplant. Even though I knew it was certainty, I figured it was best not to discuss it until I was through the first phase.

Afterwards, I met Kavitha for lunch. I ordered octopus salad. Most seafood, and certainly salad, would be out of the question after a few days, when my blood levels fell. I don’t recall what Kavitha ate.

Kavitha returned to work and I went shopping for supplies. First, I bought myself a mobile broadband plan, my Ph.D. supervisor had supplied one the first time I was ill – it had proved useful in the hospital. Then I bought some toiletries: toilet paper (the softest that could be found), moisturiser and lip balm; followed by snacks, anything that I thought might be helpful in keeping me eating.

This time, I was prepared for hospital. The chemo was going to be a breeze; it was the transplant that I had to worry about but I didn’t have to worry yet … that would come later.

I returned home, packed my bags and waited for the girls to return. We went out for dinner. Where we went and what I ate: completely blank.

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Thursday morning came around. We dropped Rathiga at child-care and Kavitha and I went to hospital. We found a home in the waiting room and we waited for the Emma. Sue, the ………., came to see us.

‘It’s going to take a while to get you a room … but we will get you one,’ she said.

Emma arrived with Dr Amy Holmes, the new registrar and an intern. They outlined the plan for the day, a heart pull scan at 1000 and the Hickman’s insertion at 1230.

‘Can I go home after the Hickman’s and come back tomorrow?’ I asked.

‘I can’t see why not. So long as the sedation has worn off; and you don’t drive. Why not go home for the night,’ replied Emma.

The heart pull scan was undertaken without incident. My heart was strong and would once again prove a successfully distributor of the toxins. Next, I was ushered off to radiology for the Hickman’s procedure.

There were three nurses present when the wardsman wheeled my bed into the theatre. We exchanged pleasantries but I was eager to explain my concerns about this procedure … concerns of course which were based entirely on my earlier experience of an uncooperative piece of silicon and a cursing surgeon.

‘Last time I had one of these inserted it didn’t go very well,’ I said.

‘I don’t respond very well to sedation. Is it possible to get more than the usual dose of Midaz?’ (Midazolam, or Midaz, is a sedative used during procedures where it may be required to rouse the patient. A good dose and you forget the procedure all together – a useful trait if you have to come back again. I remembered my previous Hickman’s insertion too easily and was keen not to have another memory to add.).

‘When I have a bone marrow biopsy they have been known to use 8-10g of Midaz to knock me out,’ I continued.

‘Oh we can’t give that much said one of the nurses. In a bone marrow biopsy you are on your side that makes it easier to keep your airways open. You need to be on your back for this procedure. We can’t give large doses of sedation on your back because your airway could become blocked by your tongue,’ said one of the theatre nurses. The nurse was probably in her late forties; a pretty face, a little tired perhaps, but she would have not doubt attracted significant attention during her youth. She looked and spoke with experience. It could have sworn that she was my only friend.

‘Are you sure you can’t bend the rules for me?’ I asked.

She was shaking her head when another of the theatre nurses pitched in: ‘Don’t worry about it. This procedure is really simple. I would much rather a Hickman’s insertion than a bone marrow biopsy.’ Presumably, she was referring to the pain as the treffarine needle enters the bone.

I snapped my head around to see the intruder.

‘Have you ever had one of these?’ I asked.

Her body language told me that she hadn’t.

‘Well I have … and it was fucking horrible so don’t stand there telling me that it is easy because it is not.’

I am not sure who was more surprised, the unsuspecting theatre nurse or the screaming patient. I had never sworn at a nurse before. I hadn’t even raised my voice at one. In fact, I hadn’t raised my voice or shed a single tear since learning of my relapse. Suddenly it felt the theatre walls contracting towards me.

‘You can hold my hand during the procedure,’ interjected my friend, before I could say anything else that I might later regret. ‘Dr Walton will be putting your Hickman’s line in and he has done loads of them. I have assisted him many times and he is one of the best.’

She kept her word and held my hand throughout the procedure. The remainder of the team completed their business, one team member down. The Hickman’s line was inserted and I was in and out of theatre within an hour.

Kavitha was waiting, where we had parted, at the entrance to radiology. We left the hospital and went to pick Rathiga up from child‑care. This would be the last time I would see her at child‑care. She would be at school before I was discharged.

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The HAM started on Friday evening and progressed throughout the week. My blood counts plummeted and I became neutropenic within four days of the chemo’s onset. With three days chemotherapy to go, it was clear that my bloods were going to fall lower than ever.

I took sitz baths (hot salty water) 3—4 times a day to keep my anus clean and reduce the chance of an infection entering via my fissure. The medical team did a fabulous job of managing my antiemetics.

It was Tuesday night when Marg, a straight talking no nonsense chemo nurse, came to prepare my latest dose of chemotherapy.

‘I feel really good,’ I told her. ‘They said I would be sick this time round but it feels easy. I’m working on the computer every day. I haven’t vomited once – in fact, I hardly feel nauseous.’

‘You know David. HAM is brutal. We don’t give it often but every time we do the recipient get’s sick. You mat nt feel it yet but it will come. Make sure you’re ready when it does,’ replied Marg.

This conversation became a running joke over the following two nights. Marg would come into hang my chemo and I would tell her how great I was feeling and how I wasn’t going to get sick. Truthfully, I was starting to feel a bit tired but I was going to tell her that. Marg would simply shake her head and remind me of the facts: ‘everyone get’s sick with HAM.’

Friday morning, a week had passed and I received my final dose of chemotherapy. My neutrophil count was 0 (meaning that I had zero ability to fight infection) but I felt pretty good. I had some breakfast, a sitz bath and I pulled out the computer to e-mail collaborators (predominantly those from outside my own agency) to advise that I would not be working for the foreseeable future.

Friday afternoon and I ventured to the shower. I felt a sudden urge to toilet in the middle of my shower and, sure enough it was the onset of diarrhoea. I visited the toilet twice more that afternoon but it was nothing unusual – diarrhoea is a common side effect of chemotherapy. The nurses insisted that I have a sitz bath after every motion so the diarrhoea was a nuisance but I continued to feel good. If this was as bad as it was going to get then I would be fine.

Friday evening and I was still eating. I had not been to the toilet for a few hours, which was a relief – I was sick of the sitz baths. Kavitha and I were chatting away when I felt that rumble in my stomach, it was the kind of warning you get 5 seconds before disaster. I am quite sure that I would not have made it had I been attached to the drip stand – fortunately I had not been receiving an infusion and the crisis seemed to be averted.

‘Kavitha,’ I called form the toilet seat. ‘I need a sick-bag.’ I was not prepared to get up because I didn’t feel that my business was quite finished. She held the bag – I vomited and pushed (to borrow Steven King’s …..) simultaneously for a few minutes.

Once the onslaught had subsided I spoke:

‘I don’t … I don’t … I don’t feel so …’

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‘David! David! Can you hear me David,’ I woke to the reverberations as the young doctor shook my right shoulder. I was in the bed.

‘It’s … It’s … It’s so cold!’ I replied as I became aware that my entire body was rigoring (shaking uncontrollably).

‘My name is Neal, I’m the JMO this evening. You passed out,’ continued the doctor.

I recognised 2 or 3 nurses but largely the faces were unknown to me. There were so many people – they were spilling out the door.

‘Here, you need to be oxygen,’ said Neal as he inserted a nasal cannula.

‘I can’t get a blood a pressure – there’s nothing there,’ said one of the nurses. Another tried but it was the same: ‘He’s hypotensive,’ she said.

‘We need to get some fluids up. I need some IV paracetamol and let’s start some antibiotics – I want him on Timentin, Gentamicin and Metronidazole,’ said a second doctor. ‘David, I need to get some blood,’ he continued as he pricked my left arm for the ABG (arterial blood gas).

‘I was … on …on … on the toilet,’ I said. ‘I don’t think … I didn’t wipe … wipe my bum.’

‘It’s okay David,’ replied Neal.

‘No … I need … need help to … to wipe my bum.’

‘I’ll help you David but we have to stabilise you first,’ said Neal.

On my right, Neal made way for the incoming nurse: ‘I need to take some blood cultures, David,’ said the nurse. There was another prick. She took the blood from my vein. ‘I can’t get to his Hickman line,’ she said to Neal. One of my Hickman tubes was receiving saline, the second was receiving the IV panadol.

“It’s okay. That will do,’ replied Neal.

‘My bum. Can … can you … you … wipe it?’

John, a nurse who I knew well entered the room. He had been standing in the doorway and was now holding an IV bag.

‘The antibiotics,’ he said to Neal.

‘His Hickman’s is full,’ said someone.

‘David, I need to start your antibiotics. Your Hickman’s is already being used so I need to cannulate you,’ Neal said.

There was another prick as he inserted the cannula into my right forearm. John connected the antibiotics to the new cannula. There were three infusions running.

‘I feel so … so … so dirty. … Please … help … help me clean it.’

‘X-ray,’ was the call from outside the door.

‘Give us a minute David. We need to get a chest X-ray,’ said Neil. ‘We have to sit you up for this David.’

The technician wheeled the machine into my room. John used the bed controller to raise my backrest.

‘Aaah. It hurts … It hurts!’

‘Where does it hurt?’ asked the doctor who had not said anything for a while.

‘Stomach … Back … Everything,’ it was getting harder and harder to breathe.

‘We need this X-ray. It won’t take long David. We put you back down as soon as it finishes.

John and Neal pulled me away from the backrest and the technician slid the hard board behind me (inside the board was the film).

‘It’s so hard,’ I said, referring both to the difficulty in breathing and the presence of the board, which felt like an elephant on my back. Everyone cleared the room. The technician took the X-ray. Everyone rushed back in.

The box was removed form behind my back and the bed was lowered.

‘Is that better?’ Neil asked.

I nodded, saving my breath for a more important question: ‘My … my bum?’

‘We’ll get there,’ replied Neil, ‘we’re worried about keeping you alive right now. We will get to your bum when we can.’

The IV panadol finished and something else was hung in its place. Kavitha snuck in and grabbed my hand.

‘It’s going to be alright,’ she said. ‘Don’t stop fighting.’

We had discussed this possibility many times. She was reminding me of my promise to fight all the way to the end. It dawned on me that had she not been with me, had she not raised the alarm, I would have died on the toilet – hardly an ending that anyone would find acceptable.

I was shaking anymore. The room remained full but the pace was less frantic. Most were watching me.

The dizziness began to ease.

‘I’ve got a blood pressure,’ said the nurse who could not find a pulse earlier.

My breathing improved. Expressions of relief rolled onto the faces. Kavitha kissed me on the forehead.

‘Okay, let’s clean this bottom now, David,’ said Neil. They rolled me on the side to clean me. Neil inspected my fissure to look for any obvious signs of infection.

Neil joined the other doctor and a nurse at the doorway and returned after a brief conversation.

‘We think that you have an infection,’ Neil said.

He explained that septic shock represented a