

BECOMING NORMAL

By Cathy Koning

One of my mother's favourite sayings whenever my brother Peter and I were mucking around was 'act normally'. I never asked her what being normal meant, or why it was better than wrestling Peter to the ground and sitting on him for a while. Since I embarked on my journey with Acute Myeloid Leukaemia all I have desired is to live a normal life, but that state became elusive. Cancer is not business as usual. Abnormal white cells, abnormal life.

The confirmation of cancer by the Registrar at the emergency department came as a big shock. And yet, given the previous months of sluggish health and the GP's urgent phone call after the blood test, it did not come as a complete surprise.

My admission, and the treatment regime that followed, was all about set procedures and systems. It all happened terribly fast. An identification band was created for my wrist. Every time I had a procedure or was given medication or blood products my details were checked, or even double checked by a second nurse, especially when chemotherapy was involved.

I became preoccupied with my perceived inability to cope with all the procedures due to extreme needle phobia. I decided it was best to look at each one as an obstacle to be faced and then endured.

My first day in the ward commenced with a blood test. I approached the experience with extreme trepidation; stiffening and praying for it to be over. I became my own coach. 'Come on, you can get through this. Just hold your breath. It is scary but you will feel great afterwards.' Phew, that's done. Next up was a bone marrow biopsy, the first of five over the coming months. A local anaesthetic and a sedative were administered, then a bone marrow sample withdrawn via a hollow needle inserted into the back of the right hip. The cells were then examined at the laboratory. In theory this reads like an awful body invasion. In practice it was quite tolerable thanks to the sedation.

Next up, a visit to the radiology department. Patients in beds were quietly lined up like cars in a carpark ready for their procedures or tests. Under sterile conditions I lay on my back and my radiologist covered me in cloths. He injected local anaesthetic into the skin in the upper chest then inserted a Hickman catheter into one of the large veins deep inside my chest close to my heart. I started to weep and wail a little bit as he began the procedure. The actual procedure was bearable although I kept my eyes tightly closed the entire time. The

Hickman facilitates the taking of blood and the delivery of drugs and fluids. Not being jabbed with needles was a privilege. Still, it was strange to see tubes coming right out of my chest, anchored by a dressing of transparent adhesive plastic, and I always felt anxious when the nurse came along to change the dressing.

Finally, a test of heart function, which also involved needles. Between each procedure I lay there stiffly on my hospital trolley, mostly in numb terror. My mind raced and my heart was going a hundred miles an hour. I feared being jabbed, cut and prodded. I called on my meagre reserves of courage. I felt tremendous relief as each procedure was completed and counted the hours until the whole thing was over for the day. At times my natural inclination for curiosity kicked in and I could amuse myself by observing exactly how the hospital functioned.

After two rounds of chemotherapy accompanied by nausea, hair loss, weight loss and a general feeling of malaise, I was in remission. Although I still had low levels of immunity after the second chemo, I was going home. But not so fast! My temperature had been 38 degrees the previous night. The next morning I could hardly be bothered getting dressed. The nurse took my temperature again. It registered 39. A very bad number.

I had contracted a life-threatening blood infection. My body was fighting itself rather than the invaders. The nurse triggered the emergency code blue. Soon doctors and nurses were leaning over me and removing the Hickman. The last thing I remembered was asking the nurse to please, please make me unconscious. I've had enough. I'm so frightened. I can't stand it anymore. My wish was finally granted.

I was incredibly fortunate that I was in the ward when the sepsis hit. I was put in an induced coma in the intensive care unit and did not recall anything that happened during the next harrowing week. My husband Fred was taken into a small room adjacent to the ICU ward. The doctors were gentle and calming. They had done this before. He was told he needed to prepare for the possibility that I may not survive the night.

All my bodily functions were beginning to fail. Only a bank of hi-tech machinery, drugs and the skill of the doctors and nurses kept me alive. The ventilator took over my breathing. I was infused with massive doses of antibiotics. A dialysis machine took over my kidney function and a massive amount of noradrenaline was administered to treat a huge drop in blood pressure.

However, slowly but surely my vital signs improved. After five days the doctors decided to reduce the sedation. It was a fine dance of drugs, support and interventions.

As I started to become conscious I became more aware of my surroundings. I had the weirdest hallucinations. At first I was inside a beautiful, surreal, huge art work. Incredible Salvador Daliesque patterns and swirls in orange and bright blue are inside my brain. Nothing made any sense. Nothing came together. Where am I? I heard somebody shouting at me. 'Wake up! Wake up!' Maybe I will, maybe I won't. I was too out of it to respond and didn't care anyway. Time to go back inside my artwork.

The ICU became incorporated into my fantasy world. Everything had a common theme – struggling to overcome an impenetrable obstacle to reach a place of normality. At the time comedian Dawn French was featuring in supermarket ads on TV. She became my nurse, my best mate, my smiling protector, deftly administering finger prick blood tests which I happily succumbed to.

I lay in my hospital bed right next to beef cattle on the open deck of a freighter which was going nowhere in a murky world of half-darkness. Then I was inside a post-World War Two hospital train carriage. Hospital beds with high sides were lined up in rows. My bed had the words 'Alfred Hospital' in gorgeous, ornate Art Nouveau plastic lettering hanging off the railing. I heard people discussing the Second World War and how to deal with me. I did not fit into their plans.

Then I found myself trapped by a drug affected art dealer in a huge room with walls thirty feet high. All the walls were covered in magnificent artworks. The dealer floated through the air and offered to sell me this art. I told him they were far too big for me to take home. He then tried to kill me. I managed to get away though the powers of my mind. I then found myself on another train where a fake theatre show was being performed to keep me captive once more. The tricksters/actors chattered excitedly backstage as everything, including the set, fell apart out front, exposing their ruse. Some of the 'dreams' mirrored the hospital situation. I had to save my family from being attached to a beeping medical contraption resembling a dialysis machine which would hurt, if not kill, those who got near it. It was as big as a refrigerator but I tried to move it anyway.

In the ICU there was a clever, and very expensive, high tech system by which a glass wall to the next room became opaque at the touch of a button. It evolved in my mind into a screen slamming shut, preventing me from getting near the elixir which would make me normal again.

The ICU room became a weird, long, dreamlike set of railway carriages. In one carriage an African nurse in colourful traditional clothing was grinding corn in a pestle and mortar. She would not share any with me. In reality the nurse was compounding my

medicines and putting them down my feeding tube. I felt the potion running down my nose and throat. In another delusion a patient was bouncing a ball over and over again outside the train carriage. The rhythmic sound of the dialysis machine pumping away had penetrated into my brain.

High up above earth, once more I was on a big ship; this time an ocean liner with passengers. I was being read to. So soothing. Fred was actually reading a magazine article to me.

Eventually I opened my eyes and responded to questions from doctors and Fred. I could whisper slowly with effort. Walking was out of the question. I was very fragile and weak. The dialysis machine was turned off and my kidneys kicked in. I still had a feeding tube inserted into my stomach via my nose. It looks like a small rhinoceros horn.

Fred asked me how long I thought I'd been asleep. I had no idea but thought I had better give him an answer so guessed seven hours. I saw him go quiet. The next day he told me it was seven days. At least I got the seven correct.

I was desperately thirsty but Fred told me I could only have liquids via large cotton swabs to ensure I did not aspirate the liquids. He was being silly. I was fine and not going to choke. He gave me giant earbud dipped in water to suck on. I could hardly lift my head. More please. I sucked a bit more. I made a plan to steal and guzzle an entire glass of water behind Fred's back.

Intensive care was an especially strange place to spend over three weeks. Yet there was enjoyment in the details of the space-age design; checking the many uneaten food containers which were lining up on the Corian benchtop and the classy way the blue 'privacy' curtains had been designed with a swirly pattern. Looking up at the huge light well as the night closed in above me. At night the atmosphere was especially surreal. The nurses walked around like somnambulists. They must have been hypnotised. One night I told the nurse that I was really, really afraid. He chatted with me which helped a little. When I couldn't sleep the nurse gave me a sleeping tablet which only worked for four hours. Sometimes the tablets did not work at all. I had to ask for another, which could only be obtained with special permission from the doctor.

My brain was still scrambled like Scrabble letters in a velvet bag. Toxins had built up due to all the drugs and lack of proper kidney function. I could not read the time on the wall clock. Half the hands were gone or appeared to be back to front. Time took on a new meaning. I did not know what time it was. A mental miscarriage. I asked Fred the date, assuming sometime around my birthday, 27 June but it was actually 2 June. For a second I

pondered how I could have got so far ahead of myself date wise. I did not spend too much time worrying about it though. My memory was fuzzy and everything he said was only urgent at that moment.

My poor brain was not working properly. I'm ashamed to say I abused a nurse, a lovely nurse from South Africa. 'You are crazy to be doing this sort of work,' I said. 'All you do is torture people. Why don't you just quit, get a better job and let me get out of here. Just leave me alone or else help me to leave. Please, I really need to get out. Help me escape.' OK, my request was ludicrous. I did not even know where my clothes were. The drugs were doing the talking and thank goodness she knew this. She had heard it all before.

Cannulas were inserted here, there and everywhere, including in my groin. I was an overmedicated pin cushion. This precluded the usual tossing and turning that happens during a normal night's sleep. It focussed the mind, and provided the opportunity for more fantasising. The cure was killing me. I could not take much more of this. I had reached the end of my rope.

I pictured how to do it. Option one: somehow stockpile a selection of the myriad of drugs being pumped into me. That won't work, even though I was often asked if I felt any pain and could store a Panadol or two under my pillow. The nurses generally compounded the drugs. It was impossible to secretly get hold of a large enough supply of tablets. Option two: will myself to expire using my superior mental powers. Option three: Stop breathing. No go. The nurse would revive me and I could only hold my breath for a short time anyway. It looked like I would have to keep on living. ICU was the last place I could bump myself off, seeing the whole aim of the place was designed to keep me alive. Next fantasy ...

In my addled imagination the muscle-bound man in the room next to me was a central European criminal hiding out from his enemies. I was surprised no-one else saw that he was in ICU under false pretences. Look everyone, I saw him walking around. What I didn't see was him projectile vomiting all over the place. Fred later described it in some detail to me.

So, hanging out in ICU is not an average day at the office and neither is being kept alive artificially with high-tech machinery and bucket loads of drugs. It was heaven when all the apparatus, all the lines and all the tubing was removed from my body in the following two weeks. A little bit of normality.

But what is my concept of normal? Physically, normal is waking up and feeling reasonably energetic. Normal is being ready to face the day. Normal is not feeling tired, like a fog or mist is hanging over my brain. Normal is living life without facing big psychic shocks.

Normal is the luxury of taking my good health for granted, and expecting it will continue. Normal is ordinary, and maybe a little boring. Normal is being like other people.

Being in hospital is not normal. Coughing up blood that looks like coffee grounds is not normal. I can't make any argument for chemo either. Or developing diabetes as the side effect of a drug I had to take. Having all my blood levels (and immunity) wiped out and then waiting while they built up again, having my hair fall out, dealing with vomiting and total lack of appetite is not the usual experience. For me, being unable to walk six steps to the door of my room was not normal. Neither was being jealous of everyone who could walk about the place without giving it a second thought.

It was not my fate to die in a coma with a multitude of tubes and lines protruding from my body like a high-tech octopus. After I recovered from the sepsis I received the life-saving gift of a donor stem cell transplant. It was not normal to have another person's DNA inside me but over time that has become very much accepted. I now take it for granted.

So, how to deal with the new world of abnormal? There are no easy answers. I do believe abnormal can become normalised for a short time while ill; a place of equilibrium can be found quite quickly within all the drama.

Acceptance and patience are key. These concepts can't just be conjured up. Some serious mind-work is required. I had regular private conversations with myself; some strong words were thrown around. I mixed it up with a bit of coaching and plenty of encouragement.

'Stop it! There is no point in wanting to escape from hospital. You know you are in here for weeks. You just have to wait for the bloods to build up to normal levels. Each day you can see improvement and everyone cheers for you, so think about that. Be open to change.

'You just don't know if you will die or if the transplant will work. It is going to take a great deal of time. Try to get through the day. Check out what the interns are wearing. Look forward to having a shower.

'Just accept that this could go either way. Resistance is futile. You could be well and truly stuffed. But then again a cure might be coming your way ... Fred will be here soon. Amuse yourself in the meantime.'

I never denied the reality of my situation, which turned out to be a positive. And this might sound crazy, but, despite being terribly ill, I did not see myself as intrinsically unhealthy. I was just dealing with some powerful, abnormal rogue cells.

Nowadays a normal life means feeling well, having mental equilibrium, having the correct blood readings and not worrying too much about the leukaemia coming back. But I'm

seriously questioning the concept of normal. Nothing is the way it 'ought to be' and I'm happy with that. There is too much change going on in my life to think otherwise.

Becoming Normal, a short story based on my cancer experience, received a High Commendation in the **Grace Marion Wilson Emerging Writers Competition 2020**. Judge's comments: The three highly commended works ... clearly demonstrate the personality of the writers, and are strongly written, generous, and highly original.

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