hep

Eternal vigilance - redux

December 9, 2017 By Grace Campbell

There have been countless movies and books devoted to it: that moment where your life is changed in a millisecond. Where the ground under you shifts and lurches. Where all of a sudden you are heading down a path you never saw coming.

Two weeks ago I headed down to St Vincents Hospital for my usual 6 monthly scans, blood tests and appointment with my specialist. I’m a cirrhotic survivor of hepatitis C. My liver is battered and scarred but somehow it keeps ticking along. My liver function tests are consistently normal, apart from my pathetic platelet count, a result of portal hypertension and spleen keen to keep those platelets to itself. I’m in no fear of liver failure, but my liver has not improved after treatment. So we keep a close eye on things. Every 6 months, like clockwork.

Tick tock.

Normally my ultrasound takes a while. They are careful, precise. They only see me every 6 months so it’s important they get the best possible pictures. This time it took even longer. And this time there were other people coming in and looking over the technician’s shoulder. Bits of paper with measurements on them held up to be read. Comparisons.

And finally, the technician told me to tell my doctor they’d seen something they were unsure about and for him to look at the pictures.

“When are you seeing him?”

“In an hour”

“Get him to call Dr Name-I-Honestly-Can’t-Remember if he needs clarification”

And there it was. The first faint shift of the ground under my feet.

My specialist is one of the coolest guys ever (for a doctor who specialises in hepatitis research and treatment). He calmly told me this kind of thing can happen a fair bit. Artefacts on the scan, could be any number of things. He referred me for an MRI to get the best possible information and told me to stay calm. In addition, he sent me for my 6 monthly blood tests and told me to make an appointment to see him the day after the MRI. And not to panic.

My blood test results came back that weekend and my very thoughtful specialist emailed them through early on a Sunday morning. My eyes shot straight to the AFP result. Alpha-fetoprotein is a tumour marker for certain types of cancer, in particular hepatocellular carcinoma, the type I am at risk of. The normal range is 0-7. When I started treatment 3 years ago it was 60+. When I concluded treatment it was 8. This time it was 4.3. No guarantee of Not Cancer, but a slight tick in the right direction.

I felt the ground stabilise a little.

The next two weeks flew by in a blur. It’s the end of the school year here in Australia: I had reports to read, end of year school activities to arrange, budgets to plan and staffing to organise. I didn’t have time to panic.

I flew to Sydney on Thursday morning and headed to St Vincents for the MRI. The bustle of the imaging department didn’t leave me any time to dwell on anxiety, but the 40 minutes in the MRI machine certainly did.

Lying in that claustrophobic, bright, loud cylinder, I was surrounded by noise and instructions and sensations. The necessity to stay still collided against my involuntary movements as the machine clunked and groaned and roared around me.

So I consciously disassociated. I took myself off on my morning walk with my dog. I left that tunnel and headed into the sunshine of a warm early summer morning with my dog at my side. I could hear the birds calling as I walked up the dirt road that took me to the top of the hill behind my farm. I saw the sunlight illuminate the wild oats that grow along the road, shining through their seed heads, casting a golden light across the verge. I noted the fat glossy cattle on the hillside, their heads turning to watch me as the dog and I strode past. I watched my dog run past me, scenting something in the grass, then turn to come back as the scent faded. As I walked past the final paddock they finished - and I came back.

My appointment to see my specialist was the next morning. My daughter had travelled down to come to the hospital with me for it. I knew if the news was bad I would need someone there to remember what I was told, so she was there as my memory.

She suggested breakfast in the morning, but I couldn’t eat. She suggested coffee, but I couldn’t do that either. So we sat in the waiting room. I told her I would come to get her if the news was bad.

I have often wondered how doctors are trained to deliver news like this. Is there a protocol they must follow? Do they ensure the person is sitting down? Is there a script? And when someone is about to give you news that could change your life, what do you do? Where is your script? How do you respond? How do you make sense of the words that come at you?

I was lucky. As soon as I sat down, Greg told me the news was good. That the MRI showed a benign cyst. He also said that the original ultrasounds looked pretty bad. And even though I knew the news was good, I felt that sickening ground-tilt.

It made me realise how complacent we can become. We assume because we are cured, that it’s over. For people like me, it’s never over. For people with compromised livers it is never over. We must remain eternally vigilant. We need to keep our follow up appointments, turn up for our scans, do our blood tests. We cannot afford to throw away our cure by being half hearted about our health following treatment.

I walked out into the sunlight of Darlinghurst (after making my 6 monthly appointment for 2018). St Vincents looked beautiful. Darlinghurst looked beautiful.

I’ve made another 6 months.