The End Times

November 17, 2018 By Grace Campbell

Who gave cirrhosis such a catchy generic title? End stage liver disease. There's a name sure to invoke confidence.

Living with a chronic disease can be challenging. Living with a couple of them (there's another word I hate: comorbidity) can be a right royal pain. Ask me one day about how I confused the term morbidity with mortality. It's a lot funnier in hindsight.

Now I no longer have HCV, my health has largely stabilised. But as you get older, often things start to wear out, break down or not function they way they should. This includes me. I am on medication for a couple of things: hypertension and portal hypertension are the two main offenders.

Now it seems I can add type 2 diabetes to the list. For some reason, this diagnosis hit me hard. I think diabetes, like hepatitis c, is a stigmatised disease. One immediately thinks of obesity, a sedentary lifestyle and a sub-optimal diet. In fact when my GP was talking to me about it, I railed against the unfairness of it all ("BUT I'M SLIM! I EXERCISE EVERY DAY! I EAT PRETTY WELL!"). I had internalised the stigma myself and was quite judge-y.

Usually you'd have a crack at a few lifestyle changes before starting medication, but I was already doing everything expected to control it. I'm not overweight. I have a pretty healthy BMI of 23. I swim close to a kilometre every day. My diet is reasonable, although I do like my carbs. With all this in mind, my GP put me straight on to medication. I was Not. Happy.

As well as being Not Happy, I started to become Very Worried. Was this it? Had the "end" part of end stage liver disease finally caught up with me? Was I circling the drain? Was I looking at only a few years left?

It's safe to say I'm not getting any younger, and as I continue to age retirement looms larger in my peripheral vision. Being closer to the end of my working life than the beginning, I started to think: if I only had a limited time left, did I want to spend it at work? Was I going to be one of those people who work till their 60s, then retire and die? Is that how I would see out my "end"?

If I didn't have a long time left, I didn't want to spend it in my office.

But how do you find out how long you have? There are so many intangibles. And there are just so many ways to die. I could get cancer. I could die in an accident. I could have a heart attack. I could

be eaten by a shark. Or I could get sicker and sicker from everything I already had.

Not being an expert in health or mortality statistics, I decided to ask two people I thought would know more than me: my GP and my specialist.

First I spoke to my GP. It was gratifying that she didn't laugh out loud at me.

Yes, she said, you do have a number of conditions that complicate your care (and while we're at it, let's add another specialist to the mix, would you like to go see this endocrinologist?). But you are doing a pretty reasonable job of looking after yourself and you are actually fairly healthy.

Based on that, I felt comfortable enough to renew my yearly newspaper subscription.

Next I saw my specialist. Last week marked the time for my 6 monthly check up: an ultrasound and blood tests, plus an appointment to touch base. I don't know what sort of training doctors have to deal with questions like "how long do I have left", but I imagine there are times when that conversation must be a very difficult one. We had already had a moment last year when my ultrasound showed a suspicious lesion and he had been able to deliver the good news that it was not cancer.

So I asked: putting aside random acts of god and things like cancer or heart attacks, did I have a few years left? I explained I was concerned about the diabetes diagnosis and felt it was adding to an already significant disease burden. I said I just wanted to know if I should bring my retirement forward, or if I could conceivably keep working until I'd planned to retire - another few years.

As expected, the answer was nuanced and had a smattering of statistics that even I could understand. He told me the mortality rate for cirrhosis, but also told me I was pretty stable, all things considered. Of course some things can never be factored in to those sorts of questions. In many ways they are unanswerable. But the response was positive enough to allow me to push the worry away and focus on the positives. It seems I'll live long enough to experience another restructure of my workplace, if not two (insert eye roll here).

I think maybe it's time to shift my thinking on a few things. I've viewed a lot of what's happened over the past years as failures. Failure to stay healthy. Failure to arrest changes. Failure because I've had to add another tablet to the mix. Failure because I have to have another test. Failure because I have to see yet another specialist.

Perhaps instead I should see them as opportunities. Maybe I should look at the appointments with my doctors and other health professionals as opportunities to engage with people who are doing their best to keep me alive. Perhaps I should view the latest tablet as a gift to my health because without it, I would not be as well as I am. Maybe I should think about how lucky I am to have such a range of experienced and caring health professionals who have chosen to work with me.

Perhaps I should look at health care as this incredible network of researchers, clinicians, academics, nurses, administrative staff and other professionals who are working together to make

us as healthy as possible. And just maybe I should be grateful that I am in a position to access it. Because I know that access to health care is often a privilege, when it should be a right.

And there are positives. I feel better now than five years ago. I'm fitter. More active. Although I might not use the word "healthy" to describe myself, I am more proactive about my health and manage it better.

Maybe I should do more than pay lip service to feeling lucky I have more years left. Maybe I should realise you make your own luck, and I need to get out there and do just that.

Because if I wasn't around, who would my children have to poke fun at?

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