I am a Civil War

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> And those in the right fire on the others in the right.[1]

Unbeknown to me, my body had launched an insidious campaign to meticulously destroy itself. The initial invasion crept in silently and undetected. Nausea and crushing fatigue were shortly followed by bilateral shoulder and upper chest pain of a severity that could not be ignored. My descent from robust health to chronic illness had been rapid and relentless.

The pain worsened so quickly that I couldn't wait the required two weeks to see my regular doctor. The following day, the general practice registrar brushed away my concerns about the bizarre nature of my pain and assured me that I most likely had the flu. I retorted that whatever this was, it was certainly not the flu.

My hopes of an instant diagnosis of polymyalgia rheumatica were dashed when my blood tests showed significantly raised liver function results and a nearly normal C-reactive protein level and erythrocyte sedimentation rate. Off I went to the emergency department where I have worked for thirty years. I was seen immediately by a long-time colleague who listened carefully while I told him my story.

The first realisation that this was not going to be simple and straightforward was when my creatine kinase level came back at over 24 000 U/L. I was going to be spending the Easter long weekend in hospital and I would not be flying to Melbourne the following week to celebrate my husband's birthday. But thankfully, I was not in renal failure.

Ten days later, I was sitting in front of the rheumatologist as he explained that my bizarre illness was probably a myosotis. He outlined the process to get a diagnosis, and then went through the range of probable treatments. Until he examined me, I had thought my lack of movement was due to pain. I was shocked by how weak I was.

It was slowly getting through to my befuddled brain that this was much worse than I had thought and that this was not just some weird reaction to a virus from which I would soon recover. My rheumatologist looked at me and asked me how I was, but the fatigue and nausea were overwhelming every effort my brain was making to process what was happening to me. It felt like nothing was real and that at any minute I would wake up from a nightmare.

By the time my muscle biopsy result came through, I was unable to raise my elbows from my sides and could no longer extricate myself out of bed, but amazingly I could still walk! I was diagnosed with seronegative immune-mediated necrotising myositis … a diagnosis that meant nothing to me at that time.

Not that my literature search was very satisfying. It was more like doom-scrolling war news — bad news followed by no news. Most academic papers were case studies of only a few patients. There were no case–control trials delineating the latest evidence for the myriad of different treatment options.

At least now I was on prednisone! My rheumatologist warned me that the high dose would make me feel very unwell, but I facetiously replied that surely it wouldn't be as bad as I was already feeling. I was expecting mania and insomnia to replace fatigue and nausea. That sounded like a reasonable exchange.

My body's immune system was supposed to be correct, but that patently was no longer the case. My own body thought that my muscles were now the enemy — to be sought out and destroyed. But it wasn't just my body that was being destroyed. It was also my mind.

This would be the beginning of a second civil war, the one that would play out in my brain rather than my body … the war between hope and fear. So far, I knew little about what there was to be afraid of, but it wouldn't take long to discover that this was not just a disease involving the muscles of my hips and shoulders. This was a disease of my entire body.

I had three lovely days of no nausea and pleasant prednisone-induced mania, before I experienced right-sided pleuritic chest pain. I naively put this down to ambitiously spending half an hour doing a jigsaw puzzle that afternoon and straining my recently underutilised chest muscles.

After a sleepless night and no improvement from paracetamol, I reluctantly returned to the emergency department, my fear of ignoring sepsis due to my immunosuppressants outweighing my fear of overreacting to muscular pain. Nobody was more shocked than me when my computed tomography pulmonary angiogram showed bilateral pulmonary emboli! I now had a respiratory physician as well as a rheumatologist.

I also had more fear. My blood tests post-discharge showed a white cell count of 21×10^9/L, which is something an emergency doctor cannot possibly ignore. I left a message with my respiratory physician's receptionist to ask if he was concerned. Did I also have pneumonia? He replied that it was all probably due to my prednisone and not to stress.

Stressing is unfortunately what doctors do best when they are patients. They not only stress about sensible things such as the best management of their disease. They also stress about what they should stress about. Most of all they stress if they should bother their specialists with questions that no regular patient would even think about or if they should just be patient. And then they feel guilty about unduly annoying their specialists, which also stresses them.

My rheumatologist never told me not to stress. He knew only too well that stress was a very natural response to what was happening to me. He could see in front of him a previously well and healthy doctor having to come face-to-face with the possibility that she may never be well again and may never work again.

With only slight improvement during my first two months of treatment, the application for intravenous immunoglobulins was approved quickly. Again, my rheumatologist made it clear that this was not necessarily going to work. Reading my anxiety about the future, he leaned back in his chair and, looking at me seriously, said, “This is a nasty disease — really nasty — it’s going to take a long, long time.”

This seemingly simple statement validated my frustration with feeling so unwell for so long without making me feel like I was weak or depressed or anxious … even though I was probably all of those things, but that they are all valid responses because it is all just really hard and it is the disease that is nasty and it’s not me not coping, which ironically made me feel better.

But I still had to deal with the battle between hope and fear in my mind and not let fear get the upper hand. Ironically, the week after getting approval for immunoglobulins, I hit the lowest point of my illness. With a ten-day wait for the haematologist to return from leave, I panicked. Without stopping to think, I texted my rheumatologist to see if there was a way to get the immunoglobulin infusion organised quicker.

It was too late. I realised that texting the rheumatologist was what I would typically do as a doctor if I wanted to query something about a patient. I forgot that I was now the patient and not the doctor. I was so stressed and sleep deprived that I forgot that it probably wasn’t an appropriate patient thing to do.

A couple of weeks later, my rheumatologist would text me to see how I was while in hospital, and my anxiety about how I was supposed to behave as a patient lessened, and I learned to accept that even though I am a patient, I am also a doctor. I may not be a perfect patient, but I am doing my best.

As an emergency doctor, I have minimal opportunity for continuity of care of my patients, apart from ringing them with test results and to organise appropriate follow up as needed. Without fail, they all appreciate my call. I am now much more aware of the reassurance this can bring.

My experience has taught me how hard it is to be a patient. I struggled to tell my history in a coherent manner, especially when unwell. I also learned of the importance of listening in patient care. It is easy to be more focused on explaining the illness and its probable management to the patient, rather than listening to their stories about the impact their illness had on their life. I discovered that listening can be more important than having answers.

Listening to my patient’s stories is what I enjoy most about being a doctor. Now I cope with the vagaries of my illness by writing my own story. Writing helps me process what is happening to me. I write down my fears so that they are no longer nameless and nebulous. I write down my hopes so that I remember that they exist. Stories help us to connect with each other. When we tell our stories, we feel heard and understood. The civil war in both my body and my brain is vanquished by writing and sharing my story.

> And then it’s quiet.
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> A calm composed of fatigue and darkness and empty shells.[1]

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[1] Gouri H. I’m a Civil War. Translated by SF Chyet in: Words in my lovesick blood: poems by Haim Gouri. Detroit: Wayne State University, 1996. ■