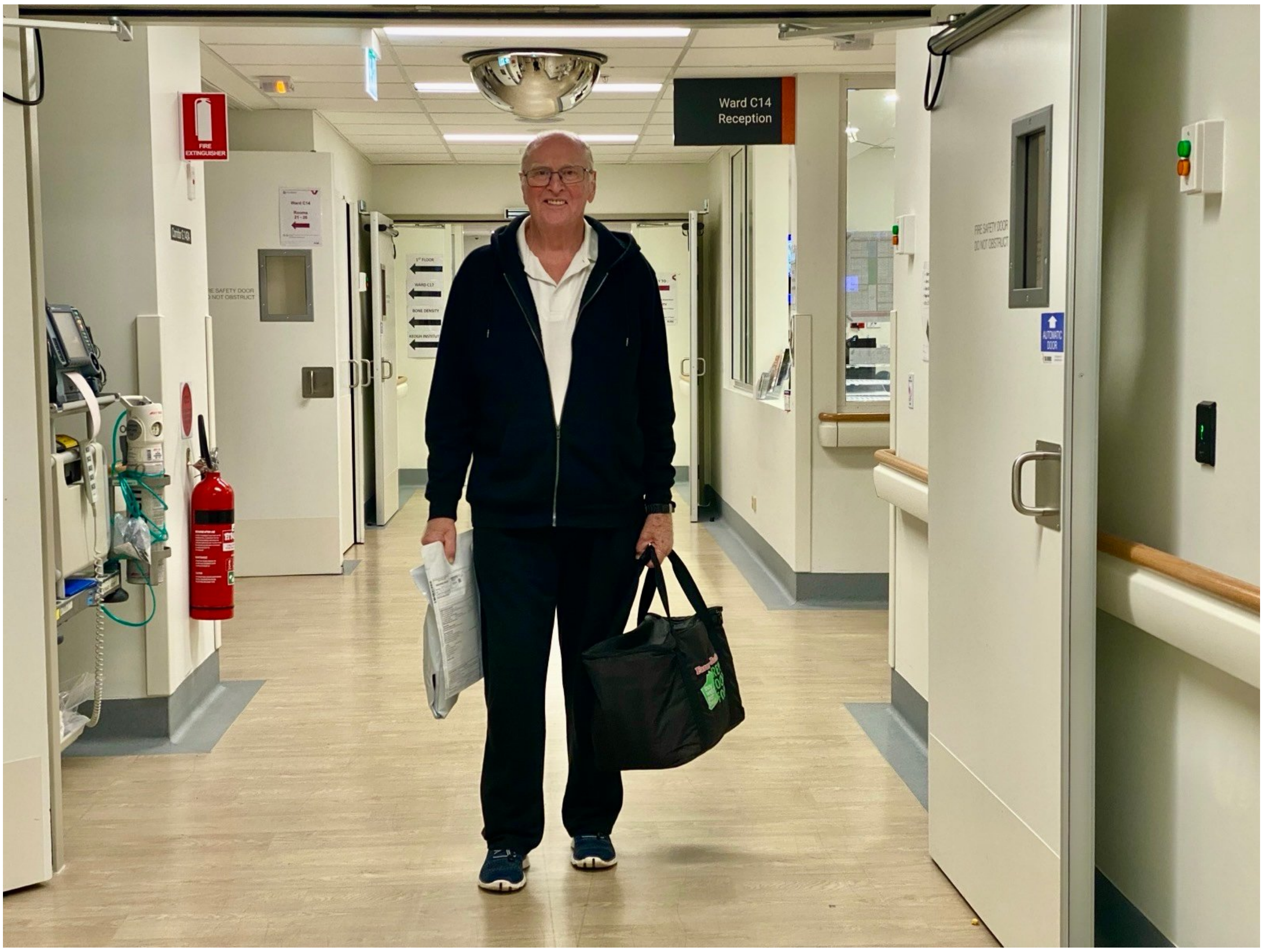
# Where Have We Been?

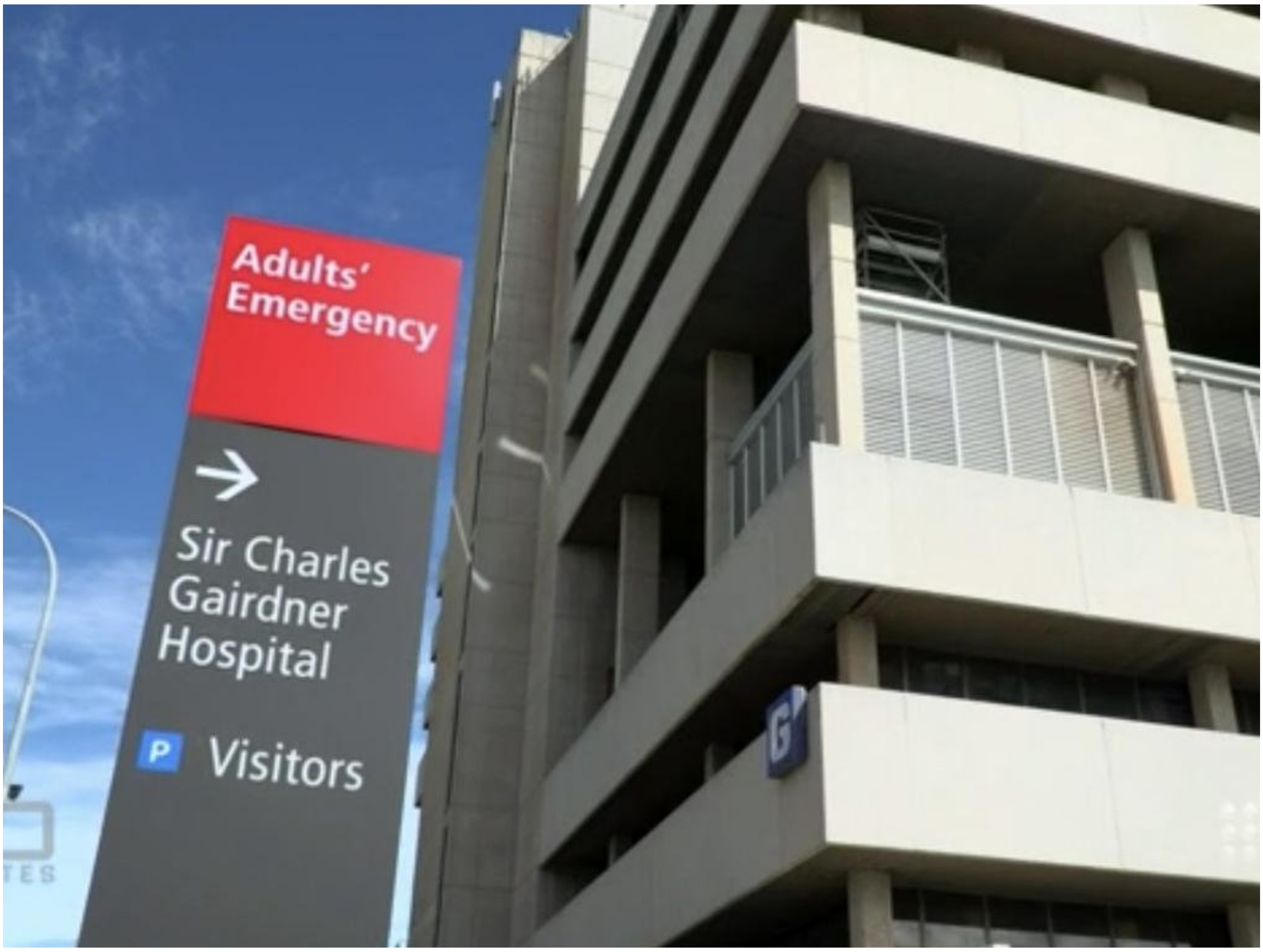


Indisposed actually. Let's bring you up to date, and ask Michael to tell the story as he remembers it.

I'd written this just after I was given the warning order that discharge from Sir Charles Gairdner Hospital was imminent; this is much abridged – however the detail in here may help you or someone you know, identify symptoms down the track.

I only get a few clear, lucid hours each day at the moment, and I'm slowly trying to claw my life back.
Almost three weeks in ICU on some crazy treatments and more weeks in the neurology and rehab wards after that.

## So why am I here?



I've been diagnosed with Myasthenia Gravis.

In simple terms, it's an autoimmune condition where my immune system messes with the signals between my nerves and muscles.

The result is muscle weakness that comes and goes — the more I use muscles, the more they fade out. Rest helps initially, but it's a constant balancing act.

It can a?ect things most of us don’t think about — breathing, swallowing, talking, eye movement — so it needs ongoing management.

The kicker is this. From October through to February, as the condition worsened, not one GP visit (and there was a lot), nor two hospital EDs diagnosed the issue.

I had a cataract operation in mid-February and as a result of the review a week later, finally the cataract surgeon connected the dots – he nailed it within minutes.

What’s actually happening in my case is the signals from my nerves aren’t getting through properly to my muscles. So they don’t contract like they should.

That’s why things like droopy eyelids, double vision, slurred speech, can’t chew or swallow, and general weakness show up — and why they improve a little with rest.I’d start talking quite relaxed and then within a minute or so I was speaking like a drunken sailor.

Similarly with food, I’d start a meal and after a few chews and a hard time swallowing, I had to give up. Breathing became an issue and the only slight relief was Ventolin (psychosomatic?).

The big problem was getting diagnosed wasn’t straightforward.

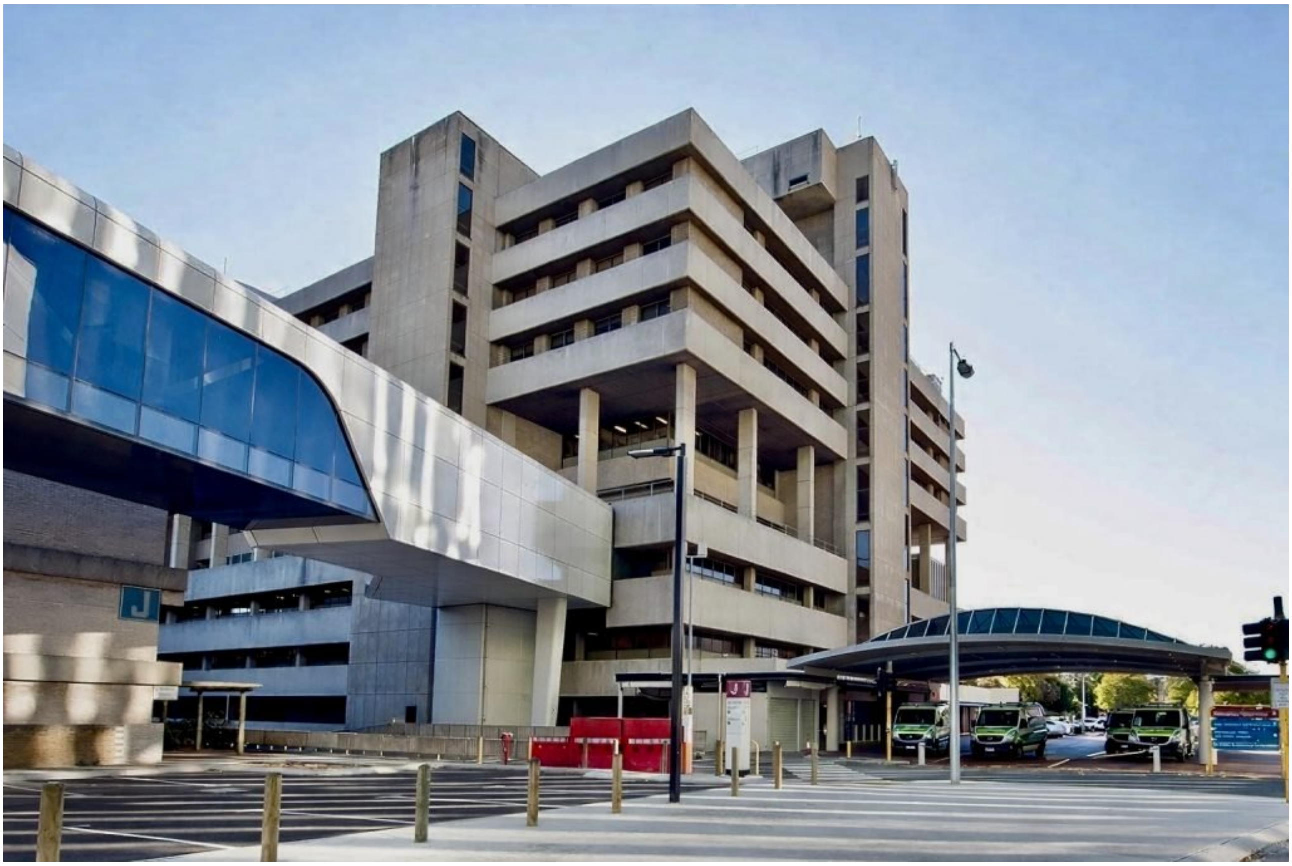
That diagnosis gave me just enough time for Kay to get me to the ED at SCGH and have that diagnosis largely confirmed.

I have no recollection of the first week or so (of nineteen days) in ICU.

Specialists (in the wrong discipline, ENT) recommended by my GP were quoting appointment times of 4 months away – frankly, I wouldn’t have been here then.

My last proper meal before Sunday last was 7 January. Between then and being admitted, I was surviving on 300–600 ml of iced co?ee a day and trying to swallow medication.

Since admission it’s been tube city. Never without an NGT and a liquid diet of Fresubin (energy-based meal replacement – eight a day!). Until just over a week ago when I started on pureed foods as well.



**Back to the history**

The swallowing function — like speech — and getting enough breath gradually just starting gradually grinding to a halt.

### The short version

- It’s autoimmune — my body is basically getting in its own way

- Weakness gets worse with activity

- It can hit at any age

- There are treatments, and it’s manageable but no cure

- Life expectancy is generally normal — just a rougher, tougher road getting there

### Common Symptoms

- Drooping Eyelids (Ptosis): One or both eyelids may droop.

- Double Vision (Diplopia): Blurred or double vision can occur due to weakened eye muscles.

- Difficulty making facial expressions, such as smiling or raising eyebrows.

- Difficulty swallowing can lead to choking, food being ingested into the lungs, or food coming out of the nose.

- Slurred speech may sound soft or nasal due to weakened throat muscles.

- Di?culty lifting objects, climbing stairs, or getting up from a chair.

- Trouble holding up your head.

- Shortness of breath can occur, especially when lying down or after exertion. Severe cases may lead to a myasthenic crisis, requiring emergency treatment.

Symptoms often start with the eye muscles and may spread to other muscle groups over time.

The severity of weakness can vary, and you may experience significant fatigue after physical activity.

Recognising these symptoms early is crucial for diagnosis and management.

It looks like so few doctors, hospital or GPs get exposed to this insidious bloody disease it’s outside their frame of reference. They don’t think about it while they’re looking.

Do yourself a favour please. At least be aware of the symptom profile. Stick it on the fridge door, it seems to be a growing thing.

**The weekend update**

On Friday I finally got to see the neuro team leader who reckons it's a remarkable turnaround so we're being discharged (with a ream of paperwork to adjust meds, future tests and inoculations and guidelines. On the same evening with none of the much-mooted long-term toxic infusions, starting with extra pills and crossing fingers and toes it all works long term.

Lost a shipload of weight and in need a new wardrobe that fits.

It's good to taste freedom for the first time in nearly 7 weeks.

**The hospital**

How was the treatment at Sir Charles Gairdner Hospital? In a word, outstanding.

From the first shu?ing steps into the emergency department, to shu?ing out the doors some 7 weeks later (after an amazing set of teams from ICU, to a neurological ward, then on to the rehabilitation ward), the recovery so far has been a credit to the doctors, nurses and support sta?.

ICU in particular were just amazing considering the behaviour I exhibited whilst on some of the drugs in there. After a few days out I started to recall some of the episodes and I was pretty embarrassed as I vividly remembered a few of them.

In retrospect now, a few more days on those memories are starting to fade – I should have dictated a book as the images (videos really) were so vivid for awhile.

The surprising thing is that it was like being in a movie. In it, not watching it happen. From the first bout of hallucinations through to the night when one of nurses called the crash cart, they’d have each made episodes in an excellent mini-series!

The SCGH neurological team, physiotherapy, speech pathologists, occupational therapists and dietitians, I can’t fault any of them. The care and commitment has been way beyond anything I would have anticipated in a teaching hospital.

So, I have a long way to go yet but planning to get as close to normal (whatever that is) asap. We plan to be back on the road soon!