

An update from day 68 in hospital...

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Image: Heart rhythm monitor with ECG line illustration (Image free for use under the Pixabay Content License (<https://pixabay.com/service/license-summary/>). No attribution credit line found at source.)

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Here's an update on my health, at Day 68 in hospital.

There are lots of people I have wanted to update personally, but it's incredibly difficult to find time, for the reasons listed below. Once I have done my work at Knowledge Commons, there is hardly any time left in a day. So the below is somewhat generic.

Isolation Station

One of the main concerns that people have had for me is that I am in an isolation room at the hospital and have been for months on end... and the challenges this might pose for my mental health or wellbeing. The sense of desolate quiet pervades such thinking.

This is not how things go at all. From 6 till 12 there is a non-stop barrage of medical interventions (obviously, this is why I am in hospital). It starts with observations at 6 followed by blood sugar levels shortly thereafter at 6.35 or so. Then they must take my weight, apparently by 7am. The drug round follows shortly to make sure I have taken (all) my (many, many) pills correctly. Then the IV feeding stops and the nutritional trainer comes round to train me to disconnect myself and then returns later to do the connection training. I have now, I think, mastered this process! After that come the doctors themselves, perhaps the most important part of the morning's onslaught.

Then at 12, lunch comes (an hour without any other intervention as eating is valued on this ward! So I scoff it down and get some stuff done) and from 1pm to 1.30pm the porter will arrive, five days a week, to take me to the dialysis unit two floors up in the main hospital which is attached to this one. I usually have four hours of dialysis but there's usually half an hour faffing (by which I mean: connecting me up or disconnecting me), then there's waiting for porters. I also have to wait for a nurse to come from the ward to accompany me back down. So I usually get back to the ward

between 7 and 8.30 depending on how things are going. I do get a good solid chunk of work done during the dialysis period (noise-cancelling headphones are a must) but then I work in the evenings (as I am not going anywhere).

As a result of dialysis five days a week in the afternoons, I am only able to have visitors two days per week. But if I do not have visitors, this is also a lovely quiet period where I can get some things done and caught up on things for myself. Like writing this update.

So overall, although I am isolated in solitude, 1. I like isolation and solitude! and 2. if only I could get them.

Health

So what's actually going on medically? The Intestinal Rehabilitation Unit team have been carefully calibrating an intravenous feed for me that balances lipids and vitamins and everything I need in my current state of acute malnutrition. It's all very complicated because if you have too many lipids you wreck your liver... especially in the longer term. At the same time, if I have too many fluids, it becomes problematic from a kidney perspective, because all of that fluid has to come out via dialysis. So, to give more calories you need more fluids, giving more fluids needs more dialysis, and it's all very difficult. Another example of this difficulty, I have now been placed on a 500ml fluid restriction per day, because I am getting extra fluid from the feed. That's **one cup of tea and one glass of water**, by the way, per day.

I still eat by mouth as much as I can, but norovirus symptoms are ongoing. Well, they kind of have been...

Norovirus *Content warning: discusses bowels*

Last week I had a full-on cessation of norovirus symptoms. In fact, I was constipated and had to take drugs to counter this! This lasted for seven days and I had three straight days of no bowel movement at all.

I genuinely thought that the norovirus had gone. I have had constipation and bowel dysmotility for years and this felt like I had gone back to that! Yes, that really isn't ideal, either. It causes pseudo-obstructions and hospitalisations. But, oh my word, I thought I had escaped norovirus. If the norovirus went away, I would also be able to put on weight again and the IV feeding, with all its dangers and challenges, would not be necessary.

But then, last night, well, it all came back, with a vengeance. Diarrhea was intense and blocked all of my sleep. It was bad. So I don't know what this acute oscillation means. But I'm moving between diarrhea and constipation. I also don't know what this means for their attempt to balance my vitamin and electrolyte levels. It will surely alter the electrolyte balances and they may find that what they have set up is now problematic or incorrect. Hopefully, I will see the doctors today and tomorrow to discuss this (Wednesday was their MDT day).

So: Am I Getting Better?

When they scanned me body weight wise to work out my body mass composition versus my fluid levels in my body, 57.6kg and 57.8kg were the two readings that came out. Not good.

However, at dialysis my weight has shown itself to be about 61.5kg. I can tell this because, when we approach that weight at dialysis, without fluid and without little food content, I start to get cramps, headaches, and my blood pressure drops. So I have put on some weight. Not much, but some.

The primary goal of this lengthy admission is a long-term preventative outcome that stops me from dying from malnutrition, which was the prevailing risk given the direction of my situation. It will take many months before, hopefully, improvement is seen. What we really want is for me to be out

of hospital, out of the range of infection risk, and administering the feed at home so that, over time, I can gain weight, have a better functioning immune system as a result (even though it will always be impaired), and for me to have some freedom from hospital again.

Getting Out

To get out of hospital I have to be stable for two weeks on the IV feed prescription. It then takes two to three weeks for the home care company to set that up, get all the provisions in place and be ready to support me at home, should I need it. I was told by someone that three weeks is much more likely.

In the meantime, I must be trained to set up the line, disconnect myself from the line, work through all the hygiene procedures (which are many and extensive), and ensure that I can perform all the procedures safely. Because the line that goes into my heart area is implanted in my arm, my wife, Helen, has also kindly volunteered to be trained so that she can change the dressing and apply the extension that allows me to do the rest of the work myself. I cannot get two hands, you see, to the point near the elbow (where the line goes in), to work with the line.

So I think we're looking at mid-to-late November, perhaps, for discharge. But anything can happen. Then I would be on the IV feed at least for the medium-term future while I try to put some weight back on and reach a healthy level. Christmas at home will be starting very early this year for us (I have decided). The imagined, nostalgic, homeliness of that Christmas discharge is my focal point for how things will improve. I do have to remember, though, that I am so weak now that I will also have to learn things like "how safely to climb the stairs", again. But I'm imagining instead that perfect end of the year when I am back home. It will be Christmas time and all will be well.