

A further health update...

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Image: An image of a basic, empty hospital ward (Image from Pixabay)

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As many of you know, I am currently in hospital. This is a factual rundown of how I got here, what's been tried, and what the next steps are in the treatment of my current illness.

Please do feel free to skip the background section and hit [the current info](#) at the bottom if you so wish. But I thought it was worth also setting out exactly what's happened over many years. That might come off as a little self-indulgent. But it helps to have a document with all the info at which to point friends and colleagues.

Background

Mitochondrial disease (MELAS) (1986-)

Since birth (but only identified in 2024/2025) I have had genetically inherited mitochondrial disease, specifically a form called MELAS, which is Mitochondrial Encephalopathy, Lactic Acidosis, and Stroke-like episodes. At core, this is probably the most central cause of my near-lifelong ill health. Here's what my expert consultant in mitochondrial diseases wrote:

I think a lot of his symptoms could be explained by mitochondrial disease. I have explained that although mitochondria are in all tissues of the body, often there are only certain parts of the body which are affected, for example in particular syndromes where it might be 1 or 2 organs or others where it is more diffuse. The commonest adult onset form of the condition which he carries a mutation for is maternally-inherited diabetes and deafness which alongside these two symptoms usually causes myopathy or myalgia and migraine is very common in these patients.

Rheumatoid arthritis (2005-)

At age 19, I developed severe progressive rheumatoid arthritis and rheumatoid vasculitis. This may be related to the mitochondrial disease, but that connection is unproven. The important thing to stress is that rheumatoid arthritis is **not osteoarthritis** (that's a separate, also awful, condition). Rheumatoid arthritis is, instead, an immune system disease in which your own body attacks your joints *and other internal organs*. At this point, I went from being extremely strong and extremely fit to not being able to wash or dress myself within a few weeks. It took many years of experimentation with immunosuppressive drugs (specifically: so-called 'biologics') to find a treatment that worked for me. By heavens, also, some of the drugs that you need to treat this condition – it cannot be cured – are vile. Methotrexate and cyclophosphamide are two of the chemotherapy agents that we tried, albeit in lower doses than for cancer treatment. And they made me feel so, so unwell.

***But:** If my immune system is not adequately suppressed, the rheumatoid arthritis causes me such pain through my spine and neck and into my head that I cannot get up and I vomit.* I cannot stress enough the level of absolute impairment and **unbearable misery** that I experience if this “arthritis” is not controlled. Yet so many people hear the word arthritis and immediately think, “ah, that's what my gran had and it wasn't that bad”. Rheumatoid Arthritis is probably not what your gran had although she might have because it comes in forms of severity too but what I'm saying is this is not just a bit of pain in my hip.

Stroke (2016) and hypogammaglobulinemia (secondary immunodeficiency) (2016-)

In 2016 I developed pneumonia as a result of this immunosuppression to treat the rheumatoid arthritis. This led to severe coughing which led to the dissection of my carotid arteries. As a result, I had a stroke. Yes, from rheumatoid arthritis (via MELAS) to a stroke. The stroke (also via MELAS), has led to a form of deafness centred on speech processing but this was the only side effect, to my fortune. At this point I was also diagnosed with hypogammaglobulinemia, a form of severe damage

to the immune system (here caused by the RA treatment) that means I do not produce enough immunoglobulins and need to inject these for life to retain any kind of immune system function. Over the years, this has led to many hospitalisations from infections.

Severe bowel dysmotility (~2019-) *Content warning: discusses bowels*

Okay, so this one sounds a bit trivial. Trust me, it's not. The arthritis and/or the medication mounted an attack on my ileocecal valve, causing it to function inadequately. In other words, it caused my bowel to shut down. This then caused a pseudo-obstruction on at least four different occasions that required hospitalisation. The pain was immense. This also came with persistent ongoing nausea to this day and a subsequent need to manage my bowel habits artificially.

Total kidney failure due to BK-virus nephropathy in native kidneys (2022-)

This is a bad one. Because of the immunodeficiency, because of the rheumatoid arthritis, my kidneys were destroyed in 2022 by a disease called BK virus. Most people have BK virus lurking in their systems. However, as a result of the JAK inhibitor, baricitinib, that was used to treat my rheumatoid arthritis at the time, my immune system was in a very poor state to treat viruses. The BK virus totally destroyed my kidneys. We pulled me off the rheumatoid arthritis treatment in an attempt to avert this and I was so, so unwell. The attempt failed. I suffered immensely. And the virus destroyed my kidneys anyway. At this point, without ongoing treatment, my condition became terminal.

BK-virus nephropathy in a native kidney is an indescribably rare thing to happen (it *does* happen in kidney *transplant* patients.). I also still have the virus and I cannot get rid of it. The viral persistence means that I cannot have a kidney transplant as the new kidney would also be destroyed. **As a result, I require hemodialysis for the rest of my life, at least three times a week, preferably more.** I have been doing home hemodialysis where I perform dialysis five days a week, eight hours

overnight while I sleep. The average life expectancy is 5 to 10 years on hemodialysis. But that is skewed by an older population, and it is possible to live over 20 years on this treatment. But it is invasive, time-consuming, unpleasant, and generally not what one wishes.

Hip replacement and muscle atrophy (2024)

By 2024, the rheumatoid arthritis had caused severe damage to my right hip, such that I could not walk at all. This was, obviously, extremely debilitating and so, with help from friends and family, I opted to have a hip replacement that year. I made progress on the recovery, but I also began to experience muscle atrophy – MELAS? – and my weight loss began. I should also mention that around this time the haemophilia department discovered that I have a coagulopathy of unidentified origin. That is, it's not clear in the blood test results what's going on, but they observed a problematic bleeding disorder.

The Present

Chronic norovirus (January 2026-) *Content warning: discusses bowels*

In January 2026, my bowel habit, which had been truly severe dysmotility and constipation for years, suddenly reversed and I experienced extreme uncontrolled diarrhoea all night, every night. This sent my electrolyte levels all over the place, which are closely monitored during dialysis. We tested and found that I had norovirus and campylobacter as well as the antibiotic resistant infection CPE. They rechecked a month and a bit later and the norovirus was still there.

In normal patients, norovirus is self-clearing and disappears within a few days. But mine began in January this year and it is now September. By this point I had lost over 20kg of weight and I was never a large person in the first place.

IV feeding (Total Parenteral Nutrition)

In May of this year, I was moved to an intravenous feeding mechanism called IDPN, which stands for Intradialytic Parenteral Nutrition. This basically means giving the patient some intravenous calories when they have dialysis. This meant I could not do dialysis at home anymore though and had to move to going into a centre three times a week. At the same time, I was given an antiviral called ribavirin to try to clear the norovirus. Neither of these approaches succeeded. I continued to lose weight and the norovirus has not yet left me.

On 10 August 2026, I was admitted to the acute renal ward at Kent and Canterbury Hospital for Total Parenteral Nutrition (TPN). This consists of total nutritional replacement using intravenous feeding via a PICC line (a Peripherally Inserted Central Catheter) that goes into your arm, up through your neck, and down into the large vessels in your chest. This has stopped me losing weight, though any gain of weight has been extremely slow and I have now been in hospital for a month.

While I am in hospital I have been working and that has been going well! Except that, for the past week and a half, I have been extremely unwell because I have contracted two infections on top of one another while being in hospital. First, I have a bacterial chest infection, pneumonia. Second, on top of that, I have contracted flu. The coughing from these acquired infections *has caused me to break two ribs* and the consultant has mentioned emphysema. I have felt very unwell with these infections. I also greatly struggle to clear them (and they are serious) because of my immune system problems. I have been on IV antibiotics and tamiflu to try to control these.

This is why hospital is so dangerous for me with immune system damage. I came in for IV feeding and now I face influenza A and a bacterial chest infection/pneumonia, neither of which did I have before.

But now comes the absurdity. It turns out that norovirus can take over three years to clear in patients with immune systems like mine. I cannot stay in hospital for three years. Fortunately, TPN can be done in the community at home! You can be trained up and do it yourself, particularly if you have a partner who can help you. And I am extremely fortunate to have had the support of my wife Helen throughout all of this ill health.

There's a catch though. The East Kent Hospitals Trust, under which I fall, has no community TPN service. If you want to do this at home and need to, you have to be admitted to a hospital called St Mark's in London, who can organise such home provision. St Mark's is the National Bowel Hospital, so it might be a good place for me. However, the admission is extremely lengthy: 6-8 weeks. I believe they use this time to try different feeding strategies to work out what will help the patient most to put on weight and to see what causes an electrolyte balance. But the thought of another two months in hospital is very dispiriting when I have already been in here for a month.

We have also had to arrange hemodialysis at the hospital next door to them. Now this is a real issue because, if all my nutrition is now coming in liquid form, all that fluid has to be taken off during dialysis, because with kidney failure you do not urinate. But you can only take off a certain amount of fluid per dialysis session or you become very unwell. So I need more than the routine treatment schedule that would be offered by such a unit, because St Mark's are going to be piling on two litres of fluid a day, which is more than I'm usually allowed to drink.

So here's the plan. Hopefully I will transfer to St Mark's in the next two weeks and stay for two months. I will receive five dialysis slots per week at the Central Middlesex Hospital adjacent to St Mark's. I will be both trained up and equipped to continue TPN at home, hopefully to regain the weight that I have lost. **Such feeding will continue indefinitely until the norovirus has been cleared.**

I should stress also that TPN runs 24 hours a day, 7 days a week. I will be on a drip into my arm the entire time, waking or sleeping, for an unspecified future duration. There is apparently a portable rucksack system that can be used to go out and about with the TPN feed running. However, I do not doubt that, yet again, this will be a severely life-limiting restriction.

Conclusion

I am attempting to remain calm and to accept what I must face. Once I have cleared the flu and the bacterial chest infection, I will be back to pretty much normal work capacity (it's just that meetings are more challenging from hospital). Knowledge Commons at MSU, run by Kathleen Fitzpatrick, has been extremely kind and accommodating towards me over this all. I am grateful for this example of [leading generously](#).

Selfishly, I feel extremely *upset* that I must spend so much time in hospital, away from my wife and my beloved dogs. Hospitals are not nice places and the sole goal, usually, while you are admitted is to find a way to get out and get home and get better. It turns out in this instance that there is no getting better and the getting home is going to be a very long road. To mix some metaphors, I also cannot help but feel that I have taken another very substantial step down a ladder of health. I think you are in quite a bad state if you require hemodialysis for the rest of your life until you die and concurrently also need full intravenous nutrition so that you do not starve to death.

But this really is self-indulgent. For I am also extremely fortunate in that the National Health Service in our country provides this entirely free at the point of use. I gladly pay my taxes because they support this system. I am a net beneficiary of the NHS because I am so unwell. I genuinely wish it were not so! But I would still gladly support this enterprise so that, were someone else in my shoes, they too would be treated with compassion, respect and humanity. They would be given healthcare.

This turned into a much longer piece than I had intended. However, I think it gives a good background and update on what has been happening to me. If things change, I will post further.

References

This reference list has been generated, in many cases, through an automated process and may therefore contain errors or incomplete metadata. It is provided purely as assistance for finding the items mentioned within this post.

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