

## Hypopituitarism and COVID-19; personal reflections

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5<sup>th</sup> April 2020

At the end of May 2019 I was admitted to hospital in Edinburgh with a terrible headache, an aversion to light and severe vomiting. A brain scan revealed a bleed into my pituitary gland (a *pituitary apoplexy*), and a sodium level so low (so called *hyponatraemia*) that the doctors found it hard to believe that I wasn't fitting. Two weeks later, and following excellent medical care from the neurosurgical team and endocrine doctors I emerged from hospital into a world so utterly transformed that life has not been the same since, nor will it be again.

The pituitary produces a range of hormones that in turn moderate other hormonal systems in the body. It mediates between the brain and the body. It is responsible for overseeing the body's homeostatic regulations and responses to stress, internal and external. Over the following months - and some of the most unpleasant medical tests I have ever had to experience - it became clear that I would face some major issues. Firstly, and with this I can count myself lucky, repeated brain scans revealed that if it was a tumour that caused the bleed (which is probably the commonest cause), it has not returned - although, as to why I had the apoplexy in the first case, this has not been ascertained, or at least there has been no associated underlying pathological cause that the doctors can find. But, secondly, I have residual so called *hypopituitarism*. For me, this means two potentially major life threatening issues: not producing cortisol (the so-called stress hormone, vitally produced when the body is under stress) - adrenal insufficiency - and the need for hydrocortisone replacement, and all that this entails; and secondly, a diagnosis of *diabetes insipidus*, with the need for the drug desmopressin to replace the hormone vasopressin, which moderates urine output and the levels of sodium in the blood. (Some of the hormones produced and released by the pituitary, that may or may not be affected, but are not measured in the NHS, like oxytocin, have little been studied in men, and aside from vague references to probably affecting mood, the implications are unknown). This all meant, in short, learning to live in a body with a heightened consciousness of previously unnoticed and taken for granted functions that now don't work properly.

So much for the medical diagnoses, which say little of the personal and emotional impact on myself and my family: the nearly constant exhaustion, fluctuating day on day, and my shifting cognitive levels (it feels like a fog can descend upon me for hours at a time); the memory loss; the fluctuating moods, particularly crying, which seems to come upon me suddenly and without warning at the slightest provocation; the need to now be constantly near a toilet, or a space where I can discretely urinate; the constant thirst; and last, but not least, the impact on partner, family and friends who have been so supportive, and without whose support I would not have got through this. And then there is the fear, too, of the future, and of whether I will be able to get back to work again, and if so, in what capacity? The future seemed for a number of months stolen away. The world

contracted down to our small flat, the hospital outpatients, and limited areas in the local vicinity (Parks, the local riverside etc).

Aside from my family, and friends, there have been several areas of professional support during this period. Firstly, the endocrine team at the Western General Hospital in Edinburgh – consultants, junior doctors, and nursing and support staff at the unit - have been wonderful. This has been assisted no end by my being allowed to call the on-call team when I need advice (their suggestion, as this was better than contacting the GP they said, as they would have little experience of the condition). I have learned more about hypopituitarism and its complexities, how to live with these, and have a GP who listens and is supportive, but who had never seen a case such as mine, encouraging me to become the expert in my own condition. The pharmacists have been excellent too, helping me to understand the medications my life now depends upon and fielding my questions.

Finally, there has been the Pituitary Foundation. I immediately joined and availed myself to all the advice I could on the website, in the advice booklets, and have particularly benefitted from the magazine: for me, one of the main mechanisms of support was the moving stories and testimonies from those suffering from this and the many other endocrine conditions. How they have coped with the experiences has been inspirational (although less helpful, I confess, are some of the extraordinary stories of almost superhuman feats of physical and personal endurance; it is the ordinary stories that, for me, are most helpful). Unfortunately, there is no local support group in Edinburgh, and I don't (yet) feel strong enough to assist in setting one up; perhaps one day.

Thus with time, love and support I have been able to get up and about, and have improved month on month. I have grown to understand how to manage the cortisol replacement with hydrocortisone doses (including the so-called “sick day rules” – when, and by how much, to put up the dose when faced with infections, trauma, and emotional distress, to mirror the usual homeostatic responses in such situations); and the vagaries of my urine output and desmopressin doses. I am registered on a Lothian wide red alert list in the health system; I wear my steroid and desmopressin dependency necklace; have entered my medical and emergency details into my phone; carry my hydrocortisone injection and steroids in a special purse (I have not yet had to administer an injection, but have on several occasions put the hydrocortisone up orally for periods of time). And I am now on a so-called “phased return to work”, with good support from colleagues and at work; my driving licence has been returned to me (I had to surrender it until it was clear that I did not have a residual tumour). I managed three weeks ago, with a friend, to drive into the Scottish hills and take a short walk. Spring was around the corner, and I felt optimistic as the longest winter I have ever endured under almost constant lockdown around the flat where I live seemed to be opening out into the wider world again. The future had reappeared...

And then COVID-19 struck, both as a pandemic and personally. Let me state from the start that despite my worries and anxieties, I, and my family, have emerged from this and are now relatively well. I share this experience in the hope it may help others who are, as we were, very frightened as to what this might mean for those of us suffering from hypopituitarism.

Firstly, as news emerged of this new infective agent sweeping the globe, I had been wondering how to react personally. Am I more vulnerable or not? As someone who had received both the flu and pneumonia jab, it seemed that I fitted into one of the government “at risk” categories. I could not find out how at risk I might be, as there is little evidence for coronavirus or other infections and their impact on hypo-pituitary patients (the existing evidence that I could find points to the highest association between increased mortality and hypopituitarism is with acute gastroenteritis infections). I am still unsure what risk category I am in, although it is probably advisable to be self isolated for the three month period that the old and vulnerable are now recommended to partake of. I received a call from my line manager at work, who aware of my condition, suggested that I should probably not come into work, but stay at home, and work from home. I was so grateful for this active and helpful instruction from a proactive and compassionate boss, and that the decision had been made for me.

I have a diary entry from 17th May: “As recommendations as to what to do shift, from self-isolation to social distancing - terms that will long define this period I am sure - it seems that those in the categories of the elderly and vulnerable are going to be most affected. Three months self-isolation... I have been so looking forward to the spring and summer after last year was snatched away from that fateful day of 29<sup>th</sup> May, and the winter has dragged on, made bearable, in part, by the thought of spring both close to home, and more distant mountainous longings. That this has been taken away seems particularly cruel and hormonally mediated (or non-mediated?) tears well up with the self-pity... I am exhausted, just trying to get through each day an effort of will and I am not sure that I can stand another unfortified winter this far north. I am not sure I have the resilience as the seasonal melancholia will inevitably start to bite. I guess that I am now seeing what so many chronically ill and elderly experience as part of their lives everyday. At least having been so ill and consequently isolated over the last 10 months is some form of preparation for what is to come”.

It started innocuously enough on March 13th, just a tickly cough. My partner and toddler had one already, one of those ones from the nursery we had convinced ourselves. By the weekend, we were self-isolated as per instructions from the Chief Medical Officer and NHS advice: this was, then, only for the infected person, and for seven days, and other household members could carry about their business. By March 16<sup>th</sup> instructions had changed: now it was for 14 days, for the entire household. In the outside world, beyond the confines of our walls, the pandemic was progressing at a truly alarming rate globally and in the UK. Everyday life, as we know now, was grinding to a halt as lockdown approached. And the cough persisted, remained dry, and I started to feel a little fluey, although with no fever. It started to wake me in the night, and the coughing

would not go away, hacking away, unproductive of any sputum, leaving me exhausted. I worried about steroid levels, doubling the dose, after talking to the on-call endocrine doctor at the endocrine unit in the hospital. Urine output remained OK, but it seemed to be darker for longer during the day (I probably need to explain how obsessively we *diabetes insipidus* sufferers observe our urine outputs, monitor our thirst and fluid intake, and ponder what our serum sodium levels are up to). My partner's asthma got worse with her cough. Our daughter coughed her way through the night. A colleague tried to persuade me to stop work and sign off sick. Yet, even as the university shut down, I felt I couldn't further let my students down and was determined to work. My brother became worried, and his partner's sister, a GP, was suggesting that I get myself off to hospital. By the weekend I was persuaded to call 111, and I still cannot really understand why I did not do so earlier, except that I expected that they were already busy enough.

The wait to get through was nearly two hours. I went through my symptoms. Once I had described my pre-existing problems, I was referred to a nurse practitioner who heard me out and said that an on call GP would call me back. Within the hour this happened, and much to my delight it was the same on call GP I had seen when I pitched up in the hospital with a rotavirus infection not two months previously. Do you remember me, she asked? There is an advantage to having a condition that is unlikely to have been encountered before, you become an "interesting case" and not easily forgotten it seems. At least I didn't have to spend half an hour explaining everything, again. Her advice: keep the steroids up, and if I peak a fever or if my cough becomes productive get back in touch. That night the fever struck, at 38.8C and by morning I was really quite ill, with the cough now productive of green-brown sputum: 111 again, this time just half an hour wait, and the GP on call called me back. He had all my notes, and seemed particularly concerned with how I managed fluid balance, saying that it sounded particularly difficult. He puts me on antibiotics, for a secondary chest infection, and he faxes the prescription through to the nearest open pharmacy. This was picked up for me by my eldest daughter and left outside the flat. In the mean time, the on-call GP had advised to get back in touch with the endocrine specialists on Monday, and get my blood tested to check the sodium levels with my regular GP. He toyed with the idea of sending me to hospital, but felt that this should be avoided if at all possible. It seems that the advice is to refer to hospital only if oxygen is required, and I was not vomiting so able to drink fluids. While shorter of breath than usual, I did not have the tell tale blue nail beds, or lips, of a severe lack of oxygen in the body.

From the Monday morning the support system really kicks in, and I realise how lucky we are to have the NHS. While I cannot get through to the endocrine unit at the hospital (switchboard is not picking up), I leave a message for my GP via the new online app AskMyGP. She responds within hours, and will contact the on-call endocrine registrar for me, and can I come in for a blood test first thing the following morning? Still feverish all day, the fever seems to break in the night day two of the antibiotics, leaving me sweating and concerned for fluid balance. Am I replacing enough fluids? Last year I had over compensated during a nasty

bout of diarrhoea and had managed to drop my sodium levels, then over compensate for that and dry myself out too much. It is a constant balancing act.

I drove up to the GP surgery through eerily empty streets. Ringing the bell, I am instructed to wash my hands and put on a mask, and am alone in the waiting room, now decked out with only three chairs. The nurse who takes my blood is clearly nervous, and I am ushered out quickly. Later, I receive an unsolicited call from the on-call endocrine consultant at the hospital, and she takes the time to talk through my fears and concerns. Don't worry about taking the higher doses of steroids, and do so for at least as long as you are on antibiotics, and longer if necessary. She, as have all the doctors, ask if I am OK to administer an injection of hydrocortisone if necessary? We talk through fluid balance, and my concerns. She is patient, and attentive. She says she will call with the results of the blood test, and she does so the following morning leaving a message on my answer phone, that the numbers are fine, and then phones later to talk again. We are so relieved to have had this reassuring advice, and now all we can do is wait and see what happens.

The news, by now, is totally dominated by COVID-19, and the media fuels fears and anxieties. My partner does not want to hear any more, but I am fascinated despite it fuelling my anxieties. The run on toilet paper seems utterly bizarre, but the stories of being unable to get food because of stockpiling is a concern. However, here we have been so lucky: Some friends drop milk and fresh supplies off for us during the weeks we are self isolated; the Costcutters on the high street drops some supplies off when we phone an order in (we leave the money in an envelope), and we are contacted by Sainsbury's out of the blue saying that we have been identified as vulnerable and can order online (the ethics of such surveillance needs questioning – but at a later date - and we have no idea how they came about this information). Friends and family text, phone and talk: we are physically alone, but supported. Our anxieties dissipate a little as by the weekend it seems that the symptoms are beginning to abate. I am left with no sense of smell, but the cough today as I write has all but disappeared. My partner's asthma has stabilised. Our daughter's cough has now almost disappeared.

Outside, in the local park, on a walk for some exercise yesterday, spring has emerged. As ever, after a prolonged period of time indoors, the world appears particularly vibrant, even if people are eyeing each other somewhat suspiciously and avoiding each other - as indeed they should. We have come through this, and contracting (what the doctors say must be) the virus has not been the death wish that I had thought it might be. I am so thankful for all the help we have received over this period from the NHS, concerned friends and family. Thank you everyone, and please, my advice to those suffering from rare hormonal deficiencies and conditions is reach out and ask if you need help and feel vulnerable. In so many ways, I am fortunate, of course, in these times of extreme vulnerability, and am acutely aware of being fortunate; there are so many who are less so. Yet, society is not dead, far from it. The constant gestures of kindness and help we have experienced, and that we hear of in the media everyday are testament to this.