



COVID-19: endocrine patients' perspectives

Nine endocrine patients share with us their experience of access to medical services during the COVID-19 pandemic. How do phone appointments compare with seeing an endocrinologist? Have they been able to access the services they need? And how have they coped mentally as well as physically? You can find this article in an abbreviated form in *ESE News* issue 43: www.es-e-hormones.org/publications/newsletters/2020.



Tina Schrøder Kallestrup

Tina lives in Denmark. She has Addison's disease and vitiligo.

For about the last 4 years, I have gone for a medical appointment once a year. It's 7 years since I last was hospitalised with a crisis. I have handled the other episodes by myself.

This year, I self-isolated from 11 March to 27 May, with no physical contact and keeping

2-3 metres distant. My parents took care of all my shopping. No-one came inside my apartment. I still don't do handshaking or hugging, except for my son (since May). Between March and May I did not touch anyone.

I had an appointment on 23 April. They mailed me and said we could do it over the phone, and that the blood test should not be done, because of COVID-19. That was also my own thinking. This did not affect my medical care. Since I have been taking Plenadren I am much more stable: Plenadren has been life-changing.

Although I agreed not to go for my appointment, I would like to have it later, to have my blood test and blood pressure taken as usual. Besides that, I also value knowing my endocrinologist as well as he knows me.

It has been confusing to hear different attitudes from different endocrinologists in Denmark, England, Norway and especially their health authorities. I have read that, in Norway and England, patients with Addison's were put in groups with others with chronic critical diseases that should isolate during COVID-19. So what is the right thing to do?

I feel lucky that my workplace has accepted my isolation without questioning my decision.

'It has been confusing to hear different attitudes from different endocrinologists in Denmark, England, Norway ... So what is the right thing to do?'



Gillie O'Flaherty

Gillie has multiple endocrine neoplasia type 2B (MEN2B) and lives in Scotland.

Just before lockdown I transferred from the paediatric endocrine clinic (for ages 3-18) to the adult clinic. I attended the paediatric one every 4 months, while the adult one is every 6 months. At each clinic, I have tests for calcitonin, free thyroxine, thyrotrophin and plasma

metanephrines, plus a 24-hour urine test every 6 months, ultrasound scan of my neck and adrenals and an MRI scan every year on request. I take levothyroxine.

'Because I transferred from child to adult services just before lockdown, this complicated things even further'

I came back to my family home from college during lockdown, and my care is still under the hospital local to my family home. I had no clinic or meetings with the consultant. My regular clinic in May was cancelled. My parents and I talked to and emailed my endocrinologist and his secretary, as I was having possible pheochromocytoma symptoms and we needed to repeat tests because the samples taken just before lockdown were not handled correctly and were therefore wasted. Due to pressure from my parents, the doctor allowed bloods, an ultrasound of abdominals and MRI.

Because I transferred from child to adult services just before lockdown, this complicated things even further. The personal relationship that had developed over many years with my paediatric consultant would have eased any recent issues I had during lockdown. Lockdown made it harder to contact my adult endocrinologist.

Regular appointments were cancelled, hospitals were busy with COVID-19 and emergencies. This had a psychological effect on prioritising my own needs. Communication was harder as doctors were harder to reach.

I haven't seen my endocrinologist since December 2019 and I don't know when I will see him next, so I have not received the care that I would normally have received. My tests have happened because my parents pushed for them to happen. The tests are done by nurses and radiologists.

While the threat of COVID-19 is present, I don't see much change in the future. This makes me feel anxious. Everything that has happened for my regular care and monitoring has only happened when my parents initiated contact with the medical professionals and they had to push quite hard. Once contact was made with my consultant, he responded promptly and positively.



Robert Tyler

Robert, from England, is a patient with advanced adrenocortical cancer.

At present I see a healthcare professional weekly because I'm receiving chemotherapy. I started a course of chemotherapy in December 2019. I was feeling very poorly after four cycles of EDP (etoposide-doxorubicin-cisplatin), so it was decided on 25 February that I should stop the treatment.

The coronavirus was being talked about then, so I avoided going out. I received a text from the UK Government on 23 March to say that I was classed as extremely vulnerable. I live with my wife who shielded with me.

I continued to attend the hospital for scans and had phone appointments with oncology consultants. I started a different course of chemotherapy in June 2020. I have had a combination of phone calls and appointments where I've worn PPE and socially distanced. The care has basically been the same, but I find face-to-face better than a phone consultation.

One problem I've encountered is that I have a hearing impairment and, with everyone sounding muffled with masks on, I sometimes struggle to hear what people are saying. We have now been given permission for my wife to accompany me. I also get mouth ulcers and gum infection (managed with salt water and Difflam mouthwashes). I don't know what I'd do if I needed a dentist.

My care could be affected if London was closed down, as I live 70 miles (110km) away and presume I wouldn't be allowed to attend the hospital for my chemotherapy and 3-monthly scans.

'I have a hearing impairment and, with everyone sounding muffled with masks on, I sometimes struggle to hear what people are saying'



Louis Hughes

Louis is 16 years old and has Prader-Willi syndrome. He lives in Ireland with his parents and sister.

Pre-COVID-19, I attended a Prader-Willi syndrome-specific multidisciplinary endocrine clinic once every 6 months,

where I typically saw an endocrinologist, dietician, physiotherapist and psychologist. I also attended an orthopaedic clinic every 8 months for the treatment of scoliosis and an annual orthotics clinic where I was fitted for a new back brace. As well as an annual otolaryngology clinic, I had psychiatry appointments about every 2 months, and regular physiotherapy and occupational therapy sessions. I visited my family doctor monthly. In 2019, I attended over 50 medical and health-related appointments.

Restrictions were first announced in Ireland on 12 March, with the closure of schools. By 27 March, all non-essential businesses had been closed and non-essential travel was prohibited. Restrictions began to be eased on 18 May, as part of a five-stage plan. From 12 March to 8 May, I did not attend any health-related appointments. Since 9 May, I have attended only six essential appointments. Most other appointments that I was due to attend were postponed. During the six appointments that I attended, all staff wore protective equipment and I wore a mask and was not in contact with any other patients.

Overall, I found the lockdown difficult mainly because I couldn't go anywhere. I have autism and greatly missed the routine I had been used to, in particular socialising with my friends in school.

'The complexity of Louis' care needs makes him vulnerable, as there are no family members or social care providers who could provide care if his parents became unwell'

Marguerite Hughes

(Louis' mother and main carer)

I feel that Louis was fortunate that lockdown occurred at a time when he was not awaiting any surgical procedure. His medical treatments were able to continue largely unchanged, with the support of medical professionals who were available to advise by phone. Had this occurred during other periods of Louis' life it would have been more difficult. I am grateful too that our family has managed to avoid the virus.

Although I believe that Louis has managed well, if the disruption to services were to continue indefinitely it would become a problem, as telephone and online appointments cannot adequately replace the types of face-to-face consultations that Louis had been receiving prior to COVID.

The greatest level of disruption to Louis' life was caused by the withdrawal of educational and social care services. Prior to COVID-19, Louis received 7 hours of personal assistance per week, as well as over 30 hours of education. Louis has been unable to access either since 12 March, and has been entirely dependent on his parents. The complexity of Louis' care needs, in particular relating to behaviour, mental health and hyperphagia, makes him vulnerable, as there are no family members or social care providers who could provide care if his parents became unwell. The need to provide full-time care with no respite or end in sight has proved very challenging for our family.

My greatest fear is that an economic recession caused by COVID will lead to reductions in support for people with disabilities, particularly in relation to social care services, which are so important for people with Prader-Willi syndrome. I expect there will also be long waiting lists to access some medical services, due to the many postponements that have taken place since March.



Liz Henderson

Liz lives in England. She has multiple endocrine neoplasia type IIA (MEN2A).

My MEN2A was diagnosed in September 2019. My endocrinology appointments are usually 6-monthly, but I am still under the head and neck surgeon, so I have had follow-up appointments with them. I had a parathyroidectomy in May 2019 following diagnosis

of hyperparathyroidism, and a total thyroidectomy was performed in February 2020.

During the initial COVID-19 outbreak, I continued to go out when necessary within the Government guidelines at the time. I was advised 6 weeks into the pandemic that I should have been shielding, by means of a phone call from my local council. However, I spoke to my GP and endocrinology consultant, who advised I didn't need to be shielding, as I was post-surgery and not receiving active cancer treatment. I was



working from home but still doing some work outside my home in social care. I live with my husband and one of my sons. My son underwent similar treatment for the same condition during lockdown.

I had consultations booked at Guy's Hospital, but I did not attend hospital. Two appointments became telephone consultations, and blood tests were organised locally via my GP. These results have been shared with my medical team. Some changes to my appointments with one of the team had to be made, due to pressure on the clinic. Travel and organisation of time off work etc., were easier during lockdown. I think I received the same care that I would normally have received for what I need at this stage. Both consultants took time, checked on how I was coping with the pandemic, and I didn't feel rushed.

In future, I would be happy to have a mixture of face-to-face and phone appointments, which can be useful for reviews. The better use of local services to support specialist care may require extra resources. Our local hospital had queues of 1–2 hours for blood tests some days, and not all tests are available at local hospitals.

Under the extreme circumstances experienced under COVID-19, I have received good care.

'Our local hospital had queues of 1–2 hours for blood tests some days, and not all tests are available at local hospitals'



Christiene Groeneveld

Christiene lives in The Netherlands and has Sheehan syndrome.

I suffer from Sheehan syndrome: a lack of growth hormone and adrenal insufficiency. As the thyroid tends to fail in time, my thyroid function is checked every 3 months. Twice a year, I have an appointment in the hospital.

During the pandemic, I spent a couple of months only going to

work and the supermarket. Fortunately I was not alone, as I live with my husband and four kids. Later, I started to see friends and could go to the gym, keeping a 1.5m distance.

My medical care was not affected. I take human growth hormone every day and, in case of illness, I need cortisone. All my appointments were changed to follow-ups by phone. Prior to the appointments I sent some information to my doctor as preparation. The doctor was well prepared and had already discussed my questions with her colleagues. The only thing which was more difficult was the approximate time of the call. One test which needed to be performed under day care in hospital was postponed and should be done soon, but that wasn't a high priority. I think in my case I received the same care as I would normally have done.

Maybe more appointments will be changed to telephone follow-ups in future, but as I have had good experience with the latest ones, I have faith in those. I hope one day the time to diagnose a patient suffering from a pituitary illness will be decreased enormously. I think personal stories during studies or congresses might help.

'My appointments were changed to follow-ups by phone. The doctor was well prepared and had discussed my questions with her colleagues'



Kevin Hill

Kevin has multiple endocrine neoplasia type 1 (MEN1) and lives in the UK.

My condition is mostly managed by medical means. I did have all four parathyroids removed and a bit placed into my left arm in January 2020. The doctors adjusted my medicines by giving me calcium supplements.

I was advised to stay indoors due to the pandemic, as I was

on the vulnerable list, but it was not enforced. So I was able to follow the Government guidelines and go out for essential shopping. Later, restrictions were relaxed and more freedom to meet friends was allowed.

All my appointments were conducted via phone and not in person. This changed when I was admitted into hospital twice. The first time my calcium levels were sky high. Then they crashed and I was readmitted. When I was in hospital, most of the time I was looked after by nurses and non-endocrine doctors, who did not have a clue about my condition. What they said and did often went against what the endocrine team suggested when I did get to see them.

I was able to be with my family except the month (in total) I spent in hospital. When I was in hospital it was surreal, as I only saw the doctors and nurses. No one was allowed to visit me, and that included my wife and family. My rare condition of MEN1 became a super-rare condition as my calcium levels are still going high and then dropping to crash levels. The doctors know what is happening but do not know why.

I still have to have regular blood tests to check on my calcium levels. The blood department is run by booking appointments and it is extremely difficult for me to just walk in. Booking blood tests online is near impossible, unless you can wait a month or more. I need to have mine done weekly or sometimes twice a week. So, getting an appointment is very difficult and the staff are not very understanding about my condition. I explain it to them and tell them I have been sent by my consultant but that does nothing. It can be frustrating for the endocrine team as well.

I think it will get more difficult to get my blood taken. I am aware of the symptoms of both the sky high calcium and the crash, so I can talk to the endocrine team. However, my levels are still up and down and have not stabilised.

'When I was in hospital, I was looked after by nurses and non-endocrine doctors, who did not have a clue about my condition'

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Sue Kozij

Sue lives in Australia. She has type 2 diabetes mellitus with diabetic gastroparesis, treated Cushing's disease, heart disease and sleep apnoea.

Normally I have an endocrine appointment every 3 months for diabetes, when my HbA1C is measured. My Cushing's disease is monitored by means of a general overview and bloods once a year.

I have medications for my diabetes

and heart disease, and an oral appliance and sleep tests for apnoea.

I live with my husband. We had a strict lockdown from 29 March to 1 May (34 days). Fortunately, no appointment dates occurred during this time and my medical care was not affected. In early to mid-March, I was due to attend both a sleep study appointment and a gastric emptying study. I declined at first, not wanting to go to a hospital environment, but I was encouraged to attend as another opportunity would not arise for a very long time. At that point, only social distancing and hand sanitiser were required. The results were phoned through months later.

I underwent my endocrine blood tests, and was offered a special endocrine appointment after the results came in around mid-March, but I declined because of the COVID scare and entering a major hospital. Instead I said I would see my local GP for management. I could not get another endocrine appointment till the end of June.

I believe the quality of my care was the same as normal – they are very dedicated. However, speaking face-to-face gives you an opportunity to explore issues with your health professional. Talking over the phone negates this and is very impersonal.

I had a heart attack at the end of June and was in hospital for 6 days. We were out of severe lockdown by then, but COVID regulations were in place. There were restrictions on visitors, and my husband visited twice only (once on admission). I told my family to stay away. On my arrival home, my daughter and grandchildren were there to greet me. Instead of being embraced in her arms, I told her to back off until I had a shower first, in case of COVID. So sad, for her and for me. We both sobbed.

Having a routine blood test (locally near home) for follow-up was daunting, as the pathology clinic had hundreds of potential COVID patients lined up for screening. I decided to go elsewhere for the blood test. Cardiac rehabilitation has been irregular due to the prevalence of COVID in the area.

As long as the virus stays under control in Australia, I believe my face-to-face appointments will resume and I have a face-to-face endocrine appointment booked. I have already attended a heart failure clinic, using a mask and sanitiser. My husband was able to attend with me.

'Speaking face-to-face gives you an opportunity to explore issues with your health professional. Talking over the phone negates this and is very impersonal'

ESE thanks all the patients and the following patient advocacy groups for their help in compiling this article:

Addison Association in Denmark www.addison.dk

AMEND (including ACC Support UK and

Phaeo Para Support UK) www.amend.org.uk

Dutch Pituitary Foundation www.hypofyse.nl

International Prader-Willi Syndrome Organisation www.ipwso.org

World Alliance of Pituitary Organizations www.wapo.org



Karen Williams

Karen has a genetic pheochromocytoma and paraganglioma syndrome. She lives in the UK.

In 2017, I was diagnosed with a carotid body tumour, or paraganglioma. It is hereditary, caused by a mutation in the *SDHC* gene. I had an operation to remove the tumour in April 2019. I also have a diagnosis of glaucoma.

I live with my husband and

children, and have not been subject to any restrictions outside those placed on the general population. However, I have had my follow-up appointment in the paraganglioma clinic changed three times now due to COVID-19, so have not yet actually been seen in the outpatient clinic since I had surgery. Normally I would expect to have been seen at least once. I feel this is important, as I have not had the opportunity to discuss issues that may or may not be relevant to my ongoing care. I have not had other tests that I would normally have on a yearly basis either, and this has contributed to feelings of anxiety.

I have attended an appointment for an MRI scan, where social distancing and protective measures were in place. I am due a telephone consultation with one of my consultants soon, but this is not for the main condition itself.

'Clinicians are urging the public to access care as normal when they are concerned. However, accessing care – especially secondary care – is not easy'

Though I fully understand that COVID has significantly impacted patient care across all areas, it has been hard having my appointments rearranged so much, as I have been unable to seek reassurance and ask questions about post-operative symptoms, general symptoms that could be related to the condition, scan results and when other tests important to my ongoing care are going to take place. I feel I haven't had the same care as I would normally have received.

I have no objection to telephone consultations where appropriate. My concern is that regular testing and examinations should take place and, certainly at the moment, these are not happening. This is a disease that can be very unpredictable and the recommended protocol includes regular testing. Also, I feel that clinicians get a better understanding of a patient when talking with them face-to-face – you can read a lot from a person's facial expressions. Telephone consultations may be more 'hurried': it's much easier to end a conversation via a telephone.

It has been publicised that clinicians are urging the public to access their care as normal when they are concerned during COVID. However, accessing care – especially secondary care – is not easy. The ability to see the team that is caring for you and have your regular testing goes a long way to reassure you that, should you develop further issues, they will be picked up and treated in a timely, effective manner. As this disease is so rare, there are very few experienced secondary care settings: I have to travel quite a distance to see the team that cares for me. Telephone consultations would reduce the need to make a lengthy journey, but my ongoing care cannot always be conducted over the telephone, and I am concerned that testing will continue to be delayed or overlooked in the future.