

Transcript of interview with Participant A

[Note: This evidence has been redacted by the Committee. Text in square brackets has been inserted where text has been redacted.]

Transcript of interview conducted by the Select Committee Engagement Team and Participant A on Thursday 14th October 2021. Interview conducted as part of the House of Commons Health and Social Care Committee inquiry 'clearing the backlog caused by the pandemic.'

Thank you for joining us this morning and for taking the time to speak to us today. The Health and Social Care Committee are holding an inquiry into tackling the backlog in the NHS and treating patients with long-COVID is part of that, so your comments today will help feed into this inquiry. I have around six questions to ask about your experience with long COVID and then at the end there will be a space for you to add anything that the questions haven't covered, or that you think has been missed. I'm sorry to hear that you are struggling with long COVID, and for context, can you tell us a bit about when this began.

So, I'm probably fairly typical in that my husband and I got COVID in March 2020, along with the other half of London that got it then. And of course there was no testing. In fact, I remember on the day when I was saying to my husband that we really need to get a test, that was when the Government announced that they were abandoning all testing, and we can all go home and die basically. And I thought, oh great. So that was that, and we never got tested. We weren't very ill, we weren't in hospital, we just thought that this is the strangest cold or flu. We also didn't have the fever or the cough, but we had everything else (extreme tiredness, sore throat, headache, short of breath, tight chest) and now that the knowledge has increased, we know that that is quite a normal state of events with COVID. We were both pretty much flat on our back for 10 days and then we got better.

But then we started getting these relapses, which is almost like a mini rerun of what we had had initially. It could be extreme fatigue or a headache; I had a tight chest, and I couldn't really breathe. And because nobody was talking about long COVID at that time, we thought that these relapses it were proof that we didn't have COVID. And so, every two to three weeks we would get like two to four days flat on our backs, and then we would feel normal again. And we were almost making a laugh out of it, we said 'oh, that's kind of funny.' And then in the two to three weeks that we were feeling good, we were trying to make up for lost time and working extra hard and that, of course, is precisely what we shouldn't have done. But I'm not blaming anybody, because nobody knew at that time. And so over the year 2020, I know that for myself definitely and I think for my husband as well, our good periods were getting less good. It was still the same rhythm, but the good periods were not so good anymore. By Christmas we were feeling pretty weak all of the time, but there were still good days. And then we started to take this seriously, and we read up on chronic fatigue and things like that and we radically changed our approach to things. We said that we have to pace ourselves, we have to take lots of supplements and we have to basically recognise that we are seriously ill.

I should also mention that I did have some extra bits thrown in. From the end of May until mid-July I had the weirdest nerve pain, which was incredibly scary. It was like little electric shocks all over my body, and it was getting worse and worse, and my GP referred me to neurology. The date that I got for this appointment was September, but at the beginning of July I was so scared that I saw a neurologist privately, and he did a brain scan and some other scans, and he said that I don't have MS or a brain tumour, so we paused there. And that eventually got better. I also had a bunch of

excitements with my heart, like an irregular heartbeat, palpitations and sometimes funny heartaches, and a few times- because I've never had a problem with my heart before- it felt so bad that I ended up in A&E. The second time that happened the doctor on duty said that this is getting ridiculous, we need to refer you to cardiology. They saw me at a London hospital in March this year, and because it was an urgent referral, they did an MRI and an ultrasound, and they said 'yes, we can see inflammation, suggesting that you did have some damage of your heart but it's not major and it should heal itself over time.' And I think that's the only thing that got better, I don't have problems with my heart anymore. But I'm still stuck, I'm just in the middle of another crash which means I barely have enough energy to get breakfast and make this call. After this, I am going need to lie down again for a couple of hours. So it's not great.

I'm really sorry to hear that you've been so unwell and that it's still continuing, and I'm very thankful to you for taking the time to speak to us today, particularly if you are unwell and in a down part.

No, I really wanted to talk to you, because I think awareness needs to be raised about this. I watched the ZOE webinar on long COVID the other day, and they say, 'don't worry, you will get better' and the thing is, I haven't really gotten better. And of course it causes a lot of anxiety, and that's quite a hard thing to manage. I think my husband is getting better, he's better at managing anxiety not doing too much, but I'm not.

It must be really, really difficult. You've spoken about part of this, but the next question is asking what it has been like living with long COVID.

Speaking of anxiety, I spent most of 2020 in an acute state of alert and anxiety. I think that probably a lot of people did that, but I had this extra problem of not just worrying about the pandemic but worrying about having this thing and that nobody knew what it was. It made me incredibly anxious. And that of course is not good for recovery. The other thing that made me anxious right from the word go, is the Government mismanagement of the whole thing. I was just flabbergasted at how at every juncture they took the wrong turn, and they just made the same mistakes again and again and again. I just felt powerless, and I think that really hasn't helped.

This year I would say that my ability to work is 5-10%, which is not great when you're self-employed. I'm really lucky that I own my house with no mortgage, and my husband has a pension and some income coming in so we can manage, but if I had children or if I was in a job that didn't give me sick leave then it that would be a catastrophe. To put it in perspective, I'm an artist and normally I produce about one artwork a month, but I also apply for projects and do all the stuff that you have to do as a solo entrepreneur; get gigs, take part in exhibitions and network. But networking is completely out because social interaction, particularly in the evening, kills me. I had a solo show abroad lined up for this year and luckily, I was able to make all the work last year, when I was still able to work, which was until around November. Of course, I shouldn't have done that, but I did. I also had a show in Europe that I managed to pull off in November last year, and this year I made two new paintings that went into a group show in London and that was it. I've got nothing lined up for the future. I don't have the energy to put proposals in or talk to people. So, the individual economic impact is a disaster.

Life wise, I just have to really pace myself. So my crash is probably going to continue for another few days, so I pretty much can't do anything. And then very, very slowly it gets better, but you have to do one thing a day. If you go to the shops, then you can't talk to your friend on the phone. It's really hard. Luckily, I'm not bedbound, my husband I have never been bedbound, and I know that there

are people that have been, but it's still incredibly hard. We used to be so active, both of us. I am 57, but I think I often passed as 10 years younger because I was just doing so much and being very physically active, walking everywhere, cycling everywhere, doing sports, not even thinking about what I was doing because I seemingly had boundless energy. And now, it's like you have to budget every activity and think how much energy this is going to cost me. I'm supposed to go to abroad for work next week, for the whole year they have waited for me to come, and in August I was able to visit my family and it went ok so I arranged this trip, and of course since then I've had two crashes. It is obviously not ok, so I'm still not sure of I'm going. Does that sort of illustrate that it's all a bit of a struggle?

I think it really does, and I think you've shown how it impacts the different parts of your life. You've spoken about your work and how it's impacted your ability to create your work, but also...

And the social thing, I've just felt so lonely and isolated. I have some good friends, and they came around over the summer when I said I can't come to the café right now, can you come to the garden. And so we did sit in the garden and it was really lovely, but that is getting more difficult with the winter coming. People have been really lovely, but you know people have their own lives. So the social aspect it really not very nice.

And thank you for sharing that, because I think it's really useful for the Committee to hear. Obviously, they hear about accessing treatment, but there's also all the other parts of long COVID, and the impact that it has, and the idea of being on your own and isolated is really important to hear so thank you for sharing that.

There was one more thing that both my husband and I experience when he used to get the crashes and I get them now, it just likes somebody flips the switch and you get really, really depressed. It's like the world turns black, and it's really horrible. When you get out of it, it's almost like the switch flips back again and you wonder 'what was all that about?' But I've never been so depressed in my life and that is really scary. I'm hopefully getting some talking therapy through my local authority pretty soon. The other thing is, in terms of limited ability to do stuff, in the ZOE COVID seminar they were saying that people with long COVID should get themselves into long COVID clinics, and on those trials for medication, but half the time you don't have the energy for that. I actually cut down on my doctors' appointments because I would rather have a coffee with a friend, because it takes so much energy to chase medical.

That's understandable and, as you said, if you're budgeting your time you still want to have that social time, so trying to pick between the two much be really difficult to do. You spoke in your answer to the first question, about how you were having weird nerve pain- which must have been really scary- and the heart palpitations and that you went to hospital and sought treatment for those, and I'm just wondering if you've sought treatment for other aspects of long COVID? When did you first seek treatment when you started to feel unwell last year?

I think I first sought treatment in May last year. It was quite interesting, because up until the winter last year it was actually possible to get something done in the NHS, but now it's pretty much ground to a halt. I mean, the reason I ended up in A&E the first time with my heart in June last year was because the GP said you better go to A&E. I just wanted a GP to reassure me, and he wasn't reassuring, he said you better to go to A&E and check yourself out. They weren't seeing anyone in person, and my GP still isn't. The second time I went to hospital was in December, I think. There were more people in A&E then, but I still got done in an afternoon. And the third time, I was lucky and unlucky. I felt like I was going to pass out- and if you've never had a heart problem and then you

suddenly have something with your heart it scares you- I was so scared and my husband looked at me and said I was really white, so we called an ambulance, and they came really quickly. That was in February and it was definitely trolley beds in corridors, but we did get seen eventually and at that point I'd already been referred to cardiology. And, like I said, they did the heart scan and MRI in March and the ultrasound a couple of months later. In the summer they also put me on an exercise bike to see what my heart would do with cardio. I haven't heard back from them. That was a big step to get that diagnosis, that there was something wrong with your heart, but luckily it didn't look like it was major, and it was not a case of putting me on steroids. So I did have that conversation with cardiologist, and it was incredibly helpful. I'm doubting if this would happen now because everything seems to be overworked. When I eventually got to see a neurologist from the NHS, not see but talk to on the phone, they got all my data from the private doctor. They finally called me for an MRI of my legs in May this year, and I haven't heard anything back. The fact that I'm not hearing anything back shows me that these services are really overloaded at this point.

I think from autumn last year, when the news about the long COVID clinic came out, I got onto our GP about it and at first they didn't really know anything about it. About two months went by, and I then I got referred to my local authority service, which at this point wasn't a long COVID clinic- it was just an occupational therapist and a respiratory physio trying to assess people, which they did over the phone not in-person. That was I think, sorry I didn't keep a record or that, but it was definitely in the winter, it might have been in February. It was a very nice man who interviewed me, and I asked if he was in anyway connected to these long COVID clinics proper, and he said that they weren't. And I wanted to be referred to a proper long COVID clinic, so the GP got back on it and eventually in May I got to see someone in a hospital, she again was a physio. She was quite good, and she did a test to establish that I didn't have PoTS, which is a thing that could cause dizziness, because since March I've been really struggling with an incredible debilitating dizziness and headaches. So that was kind of helpful. She was looking at me and saying that 'this is crazy; I'm seeing you here, you have your GP, you've got an ongoing file in neurology and cardiology, this really should be joined up.' And I said no it isn't and nobody is taking a holistic view. And she said that we can do something about it, but I think you should be under your local authority because they have now declared themselves a long COVID clinic. It's the same two therapists, but they are now a long COVID clinic. Eventually the local authority people got back to me and told me that they now had an app that patients can use to track their symptoms, and have a fatigue diary, and it has some helpful information to help recovery. So I did that and for a while they monitored my symptoms, and they asked me if I can keep a fatigue diary, because I am probably not pacing myself. So we had a conversation about that, and I think I managed better. Then suddenly in July, I got a call and they said that they are discharging me because they can only do assessments and they can't really look after people because they haven't got the staff. They said that that the guy who had initially interviewed me had left, and they haven't been able to fill his post. I've had further conversations with this woman (who herself has now left as well) and she said that they are having this monstrous staff recruitment crisis. They can't get people, and I think that's probably not just the long COVID clinics. It just shows that people are trying, but they are desperately understaffed and under resourced, and it's a bit of a postcode lottery. I think the hospital are still running their long COVID clinic in the hospital, but they've probably got patients coming out of their ears, and I don't know how they're doing so I'm not exactly trying to get back into there.

I've now decided that I'm just going to have to manage this myself. You can't get in to see GPs, you can't make an appointment, you have to fill out a form that takes 45 minutes to fill out in order to get seen and half the time I just can't be bothered. So then you have to make an emergency call at 8:00 in the morning, and be on hold for 15 minutes, and then you may get a call the next day, but

I'm kind of thinking what is the point? The lady at the long COVID clinic that I was speaking to when she was still there, I told her that I think that my dizziness is a vestibular problem, and to establish whether that's true I should see a vestibular physiotherapist- I know that because I had another viral infection six years ago that destroyed my balance, so I kind of know what that feels like. And she said OK, you should, but I can't refer you, I have to ask the GP to refer you to ENT and they will then refer you to the physiotherapist. And I said 'good luck with that.' And sure enough I never heard a thing. So come August, I got an earache as well, and I thought this is just getting out of hand so I went to see an ENT consultant privately who specialises in vestibular issues, and he diagnosed me right away. He said I had a vestibular migraine, and that it's quite common in people like you who've had previous trauma, and then having further trauma with COVID and the stress of that. He has referred me to a vestibular physio who I'm paying for privately. Thank God that from a previous job, I have insurance that pays a part of that otherwise it wouldn't be happening. She is now giving me exercises to do. This is what should have happened months and months ago, but the lady at the long COVID clinic couldn't even tell me about a locally based vestibular therapy because she didn't know any, so we probably wouldn't have gotten very far with that. So that's the sad story.

It sounds like you've been pushed around from department to department and seeing lots of different people, and that it's been a real struggle to access the treatment that you need, and you've mentioned that you've had to go private to cover that.

Yeah, it's a real problem which is that there is not enough staff. Of course, at first it was not knowing what to actually do. A lot of the long COVID clinics are set up to deal with lungs, but in fact it seems that for a lot of people the lungs aren't the problem, my lungs are fine. It's a multi-disciplinary thing and that's very hard to set up. It seems that the well-meaning people in the local authority long COVID clinic had only limited authority to refer me to, or liaise with, specialist services and that's a catastrophe. It shouldn't be like that. They should be the hub, instead the hub in my case seemed to be the GP and they're already completely overloaded, so that doesn't work.

So my next question, is something that you've covered quite well already, but you may have more to add and it's how supportive did you feel the NHS was in helping you to access care?

Well I've described the system, but I should say that when I actually got to see people most of them were really good. Starting with the paramedics who picked me up in January, they were two of the loveliest people in the world. The doctor in A&E who referred me to cardiology was amazing. It was 8 at night, and he said that this is getting silly, and you need to be seen by someone. These are all people who are trying to make the best out of a very impossible situation for the NHS. The cardiologist that I've spoken to over the phone has been very good, but he has to split himself into a million parts so he can't speak to me very often. I know why, but it is difficult. With neurology, I don't know what is going on, but they are obviously very under-resourced as well because if the GP can't even get a result of a test that you had four months ago that's not very good. When the second clinician left the long COVID clinic, she told me that she has to delete me from the app because it needs a clinician to be associated with it, and I told her that this is just madness isn't it. It's just me doing it, so why do you have to kick me off? She agreed, and they had a meeting and they found that there was a way to technically keep the app on my phone and keep me doing it for my own good self. One thing that she could do directly was refer me to talking therapy, and there was another hiccup with a letter that I didn't get so the whole thing was delayed by four months, but I'm finally starting to get it.

I think that that is something that the Committee have heard in this inquiry, that the people are supportive, but that the system may be making that difficult so thank you for sharing that. My next questions is, what do you think that the system, so the NHS, could do to better support you?

I think there needs to be a whole lot more resource and money put into long COVID clinics, and they need to be the hub with the authority to refer people to specialist treatment that may be required. In the hospital, they at least had a protocol whereby before referring, GPs needed to carry out a number of very simple in person tests, such as blood pressure, sitting, standing and running and they wanted an x-ray of the heart and the lungs, and you had to get that through the GP. You cannot do all this over the phone. The tests that the lady did about PoTS, you had to be there. So it has to be better resourced. And the long covid clinics have to be a hub, because you can't put in every long COVID clinic a cardiologist, a neurologist, and a bunch of different therapists. That would be my number one recommendation. My guess is that 90% of the long COVID clinics are under-resourced, because if it's the case that they can just assess you, but can't do anything with you, then why bother?

I also wonder about the data gathering, whether there is actually a record being kept centrally about what's going on and how many people like me are still sick after 18 months of having this. How joined up is this? It should be. For example, in terms of data gathering, my husband got assessed, because I told him that we want to ensure that he counts as a number. But he decided that he was much better off just managing this by himself, he didn't want to put his energy into doctors, so he's just fallen off the radar and people don't know that there is a formerly very fit man with 18 months of long COVID, just sitting around somewhere. So that needs to be a whole lot better.

Thank you. So just to feedback, some of the things you've talked about include seeing GPs in person, particularly to do the tests, because you're going to hospitals and in theory, they could do some of these tests at the GP. So more GP appointments in person. We've got better resourcing for COVID clinics, and with that allowing them to do more than just assessing. At the moment they're very much focused on assessing patients, but there isn't much they can do on treatment, and that needs to change. And then there is data gathering, so how much is being shared. I know you spoke earlier about how it took a long time for people to realise that long COVID is, and how it's impacting people, and I guess that could go back to data gathering and how that could have helped.

I think there is a huge difference in long COVID clinics. The service in my local authority is very, very tiny and they're probably better in the hospital. It seems to have proper recovery programmes. It's probably unfair to generalise based on one experience. If they had a protocol for every GP, where if a person looks like they have long COVID they do those tests right away, the preliminary tests, then refer to a long covid clinic for assessment, and the assessment needs to be in person as well, and then ideally the people can then be channelled into the kind of support that they need, which can be anything from talking therapy to respiratory physio or occupational therapy. They may need to see a specialist consultant. Don't forget that there is this huge variety of long COVID, and I can give you just a few examples [...]—My husband gets incredible joint pain and muscle cramps, particularly at night-time, but I don't get that. I'm dizzy, which seems to be a vestibular issue, and I get headaches and I'm seriously exhausted which seems to be due to what is called mitochondrial dysfunction. I think everybody is extremely exhausted, that is the common thing. And that is part of the problem, how do we manage it when it's so varied. In the long COVID clinic they need to establish what type of long-COVID we are looking at, and then channel it appropriately.

I think that's a really interesting point around recognising what support people need, and what their symptoms are. My final question is linked to the last one. As you've seen the Committee makes recommendations to the Government based on it's inquiry, so if you could make a recommendation on how to support people, like yourself and your husband, who have long COVID what would it be? It's quite a big question, it's also quite linked to the last one so if you'd like to leave it that's fine as well.

I have a huge issue with the lack of public awareness and lack of public education about long COVID, and the severe economic impacts that it has on individuals and for the macro-level economy.

SHORT BREAK IN CALL FOR TECHNICAL PROBLEMS

Awareness around long COVID also needs to include an understanding that it is not continuous, that it comes in waves and that there may be times when the patient feels fine. Patients who start to develop long COVID need to be told to rest and pace themselves and not to ignore or push through weakness, so that they do not become chronically ill like I have become. I strongly believe that if I hadn't pushed myself so hard in between long COVID episodes I would be ok now, or at least much better. Instead I am worse. This is also a key lesson from decades of ME, post viral fatigue or chronic fatigue sufferers. It is absolutely vital for every GP, every employer, every work colleague, and everyone who has COVID to understand this. This applies particularly to people who like me who were previously fit and active and only had COVID mildly as they are most likely to brush aside any signs of ongoing bouts of fatigue. I think people who were very severely ill understand intuitively that gradual recovery takes time, and they won't ignore the signs from their bodies telling them to take it easy.

The fact that people do not bounce back from COVID needs to be recognised, by granting statutory or employers sick pay to those recovering from COVID. Also, every effort needs to be made to be flexible and accommodate long covid sufferers who are only able to work part-time. The economic and financial benefits of cutting people some slack earlier in order to avoid them being out of the workforce long term are obviously hugely significant. If people are still suffering from long covid after 6 months this must be recognised as a disability, so that they are eligible for financial support.

The other issue is the resourcing of the long COVID clinics, that is going to cost some serious money and of course money is the thing that is lacking in the NHS. GPs and Long covid clinics need to be much more aware of supplements that have worked for chronic fatigue sufferers and are helping people with long COVID. Supplements are not a cure, and are not one size fits all, but they can help people have a better life. Some supplements for example, COQ10 and NADH, are very expensive so it would be a great help to have them on prescription

And if I have a personal one, that is that there is a huge question about the menopause and long COVID, whether the menopause can make it worse. It doesn't apply to everyone, but a lot of middle-aged women are struggling with long-covid. But seeing as how menopause is under researched and long-COVID is still under researched we're probably not going to be very lucky there. There's also this odd matter about the connection between long COVID and ME and chronic fatigue syndrome (ME/CFS) and how the lessons learned from managing ME/CFS can be applied to certain types of long covid (like mine). Nobody wants to mention it because ME/CFS has this bad reputation and nobody wants to work on this topic, and it's been underfunded for years, but people with ME/CFS are now hoping that as long-COVID is essentially chronic fatigue they're hoping that there might be more research put into it.