

## **All-Party Group on Coronavirus - Oral Evidence Session 13**

Transcript by Communique Communications Ltd.

12 January 2021

### **Layla Moran MP**

Well welcome everybody to our session of the All-Party Group on Coronavirus on Long Covid. So, this is an important week for the All-Party Group, we're hosting a debate, a background business debate on the floor of the House on Thursday and the purpose of this session today is to brief our fellow Parliamentarians on Long Covid, a disease that has been growing in understanding. We had our very first session on this actually back in August when it was very little understood and we have had a lot of change and movement since then and as an All-Party Group we feel it's really important to be able to hear first-hand experiences of those who are living with the condition and that's what we'll be focusing on in the first 45 minutes, at which point I will pass over to Caroline Lucas MP who will chair the second half which is with Professors who will be able to talk more about the medical profession's response to Long Covid.

So, I'll start by introducing our first panel, and it's a real delight, thank you all for coming and speaking to us today. All three of our panellists are living with Long Covid and I know that one of the symptoms of that is very often tiredness and so I thank you in particular for taking the time to be with us today. We have Dr Nathalie MacDermott who is a clinical doctor sub-specialising in paediatric infectious diseases in the NHS and has also had significant experience in medical response to disaster and epidemic situations in Africa and Asia, so welcome Nathalie it's wonderful to have you with us. We also have Geraint Jones who's an advanced pharmacist specialising in HIV and home care at Cwm Taf Morgannwg University Health Board in Wales. Geraint is also living with Long Covid, welcome Geraint. And we also have Linn Järte who is an anaesthetist who previously worked in an ICU in Wales and Linn also lives with Long Covid, so welcome to you all. And what I thought I'd start by asking is in turn if you might just explain your story, how did it start and where are you now and how is it going, so perhaps Nathalie if we can start with you.

### **Dr Nathalie MacDermott**

Thank you for this opportunity to speak with you. So, I was working at Great Ormond Street in March when I was exposed to a colleague who had Covid in an office that we were sharing and I became unwell a few days later. I actually fully recovered from that episode and went back to work after ten days and then was working on the Covid ward at Great Ormond Street in May and at the end of May I became infected again, although having said that I've never tested positive for the virus but I had all of the symptoms and I had all of the symptoms all over again and at the end of that time I developed neuropathic pain, so nerve pain in my feet and slight weakness in my legs. It wasn't really clear what was going on at the time but I couldn't walk very well, so I had an MRI scan which didn't really show very much but over the summer and particularly then in September I had a significant deterioration and the neurologists believe that Covid has somehow damaged my spinal cord but it's unclear exactly how and now I can only walk about 200 metres without some form of assistance. I can walk a bit further with crutches but the damage has affected my bladder and bowel as well so I get recurrent urinary tract infections and I also get a lot of pain in my arms and I'm getting weakness in my grip now as well. So, that's my story at the moment.

**Layla Moran MP**

Thank you very much and thank you for sharing that, it sounds very trying. Geraint how about you, tell us your story if you're able.

**Geraint Jones**

So, again thank you for inviting me to be a part of this today. So, I'm Geraint like you said, 30 years of age. I initially became unwell over Easter weekend having worked on the Covid positive ward and just a general feeling of dehydration, lethargicness, tiredness, pins and needles on the upper half of my body. After ten days I began to feel better and returned to work after my isolation period. I felt OK, my chest was still quite tight and laboured breathing but nothing that wouldn't stop me from helping out. And then in July I had intense stomach pain whilst in work with my GP referring me to A&E with suspected appendicitis. The bloods and x-rays coming back inconclusive and then exactly a week later I had chronic diarrhoea and abdominal pain which would last seven, eight hours a day at one point and this lasted for 14-15 weeks, still to the point now where I experience four to five loose motions a day. The pain is still there as a background pain. It does get more trying on times than others but I've also been left with like the brain fog that people explain where I can't seem to recall the most basic of words or phrases or I put mugs in the fridge when I go to make a cup of tea. I've got tinnitus in my one ear which is quite distracting when trying to communicate with others. Palpitations at rest which is quite painful to the point of not knowing whether to go to A&E with a quite sharp stabbing chest pain. And yeah, to be honest that's my story really so I'm still on-going and awaiting further tests to kind of understand my on-going symptoms.

**Layla Moran MP**

Thank you very much for that, and Linn how about you, how are you and what's your story?

**Dr Linn Järte**

Thank you too for inviting me today, it's a real honour to be here. So yes, I'm a junior anaesthetist in South Wales and I initially developed Covid in mid-March after a stint of on calls and I got shortness of breath and a dry cough and a flu-like illness that put me to bed and then a week into that illness I also developed sinusitis, but I managed at home and after about two weeks I thought I had recovered so I was back to work and I was pretty much well all throughout April and then at the start of May I crashed deep into severe Long Covid. So, at the start of my Long Covid even just taking a couple of steps would make me feel absolutely horrendous, it felt as if my whole body was just filled with lead but at the same time I had this sort of painful burning sensation and it also made my heart rate shoot through the roof and I had painful pins and needles throughout my arms and legs and I got recurrent sinusitis. And the more I tried to do anything the worse all of these symptoms got, so it would lead to what we call setbacks. So after having done anything at all, anything as basic as having a shower or cooking food for myself I would become even worse. So, this left me bed-bound then for many months. And then I also had similar to what Geraint was explaining, the brain fog. It sort of feels like a thick cloud that just fills the brain and I just stopped being able to think, and then I also had short-term memory issues and word finding difficulties and I couldn't tolerate stimulations, even listening to some soft music was just too much, so I spent a lot of time during those first few months when I was the sickness just sort of staring into thin air. And then after about three months into the Long Covid, sort of towards the end of July, I started developing symptoms of pericarditis, so inflammation of the lining around my heart and now today I still struggle a lot with chest pains and pins and needles

and excessively fast heart rates and muscle aches and brain fog, but thankfully I'm a lot improved compared to at the start of everything. Prior to this I was very fit and active, so outside of work I'm a coastal skipper and I'm very outdoorsy, so hiked all around the world and I would do martial arts several times a week and go to the gym if I didn't make that and cycling along the South Wales coast and now, I'm only able to walk maybe a few hundred metres. Yeah.

**Layla Moran MP**

Oh, thank you for sharing that and sadly a very common story that we've been hearing at the All-Party Group, but not one I think the public has totally taken on board as a possible consequence of what's happening right now. If I could quickly just follow up to ask, and Linn you've described how your symptoms are getting, have changed over time and some are getting slightly better but you're still left with quite difficult ones, could I just ask Nathalie and Geraint, your symptoms have they also been morphing and are they generally better now than before or have they sort of stabilised? Just to give us a sense of the trajectory of how this has affected you.

**Dr Nathalie MacDermott**

Mine at the moment are continuing to get worse, so my neurological function is getting worse and I've got quite a lot of spasticity in my legs now.

**Layla Moran MP**

Thank you.

**Geraint Jones**

Any myself, like I said my chronic diarrhoea has kind of subsided at the moment but just as you find you're getting over something there's something else. Like for the past three or four weeks I've had really painful palpitations, the brain fog again has eased slightly but just as you think you're getting better there's just something else really and it's just hard to know when you are better or when you're recovering or when you can expect the next turn really.

**Layla Moran MP**

Thanks very much. Caroline Lucas.

**Caroline Lucas MP**

Thank you Layla, and thank you to everyone for sharing those stories, they're so shocking just to hear the severity of what you're living with, so thank you for sharing that. I wanted to ask you how it impacts in terms of your work life, I mean I don't know if any of you are still able to work, whether or not your illness goes into remission for a while which means you can maybe work for a while and then maybe you can't and obviously you all work in healthcare, or you have done and maybe that means employers are more sympathetic to the situation than perhaps in other areas, by Nathalie's face maybe that's not the case, but maybe I could start with you Nathalie, just if you could say a little bit about how this has impacted on work.

**Dr Nathalie MacDermott**

Yes, so I was off clinical work for three months in the summer after my episode being infected in May and then from September I have been back in my academic role, so in my academic role I can work from home and so I do a reduced number of hours but I do several hours a day academically. I don't know how I'll go back to clinical work at the moment, I have one year and three months left of training to do to become a consultant and they are currently trying to work out how to do that, they want me to do virtual clinics from March, so we'll see how that goes but yeah, there will need to be quite significant modifications in place for me to be able to be on the wards. And yeah, I don't know what that looks like at the moment.

**Caroline Lucas MP**

Thank you, Dr Järte.

**Dr Linn Järte**

So as a junior anaesthetist all my work is clinical so I haven't been able to work at all since I became sick. I'm just physically not able to and also the brain fog just wouldn't have made it safe even if I would have been able to.

**Caroline Lucas MP**

And have you been able to get the support that you need, you know in terms of sickness benefits and everything, has that part of it worked as well as it could do?

**Dr Linn Järte**

Yeah so I'm very fortunate to have very supportive seniors and thankfully then under NHS employer guidance for Covid sick leave I'm still retaining my salary so I haven't had any financial worries as of yet.

**Caroline Lucas MP**

Good, and Geraint Jones.

**Geraint Jones**

So, from July to September I was able to work from home even with the abdominal pain and diarrhoea just out of stubbornness to be honest and just a desire to kind of want to keep on going really. But to be honest I woke up one morning in September and I just thought how long can I live like this, how long can I sustain this for and I've been off work since really undergoing quite a number of different investigations and in a few different clinical trials. We can't seem to determine the cause for all my multiple and on-going symptoms really. I'm awaiting urgent referrals to ENT and neurology, cardiology but again there's obviously such a backlog that it's quite difficult to understand who is clinically urgent at the moment and to be honest I don't know how I've even got the physical or mental

capacity to be even safe to practice as a pharmacist at the moment which is unfortunate because I love my job and I want to get back to helping my colleagues during these difficult times really, but I just physically can't do it at the moment which I'm just yeah ... it's just so hard.

**Caroline Lucas MP**

And within that have you been able to get the support that you need in terms of just getting by for the moment?

**Geraint Jones**

So, initially it was difficult obviously because of everything just being quite new and quite novel with the illness, it's very difficult to say what is Covid, what is not and I found it really difficult to find support really from clinicians and other sufferers really because there wasn't at the time, July there wasn't much information out there regarding Long Covid and post-Covid illness and Long Covid, so it was kind of a bit of an unknown grey area to be honest. Fortunately, I think the evidence and the guidance has seen that these symptoms are due to Covid and yeah thankfully my employer has said that, yeah I can maintain my financial sort of package at the moment, but again for how long that's sustainable I don't know how long I'm going to be unwell for. I'd like to think I could go back to work tomorrow but it's just kind of a long drawn out illness it seems like.

**Caroline Lucas MP**

Thank you very, very much.

**Layla Moran MP**

Yeah, thank you. I have a quick question for you all and I don't know if it's easier if just one answers or if your experiences are all different, but we're becoming increasingly aware of other people who have this and I think there's one Facebook group that has 30,000 people in it. When did you first become aware that it wasn't just you and that there were other people who were also suffering from what is now being described as Long Covid, what's your experience of that. Linn when did you first find other people?

**Dr Linn Järte**

So, I was really fortunate in that I came across one of Professor Paul Garner's blogs in the BMJ at a really early stage in my illness and reading that was an absolute light-bulb moment, you know just realising that he was describing pretty much what I was going through too. So then straight after that I posted on Facebook and then was contacted by some old acquaintances who also had Long Covid and then it kind of snowballed from there and I found several different Facebook groups and various support which was absolutely amazing, a bit of a life-saver because it can be such an incredibly lonely illness when you don't have the support, especially if people around you don't know about it or there's a lot of misunderstanding around the illness.

**Layla Moran MP**

Thank you, and Geraint and Nathalie, is that a similar experience for you?

**Geraint Jones**

For me yeah it was, I'd been to A&E in September with on-going abdominal pain, again just doubled over in pain, awake all through the night so I thought I'm going to have to attend the hospital to try and determine the cause for the pain really. And I was there for a couple of hours and they couldn't determine the cause of the pain or determine any diagnosis really so I returned home quite upset, quite lost, quite anxious, quite distressed that I didn't really know what was happening, they couldn't essentially find anything wrong with me at that time. So yeah I was literally sat in the living room crying on the floor, searching Twitter, Facebook trying to find just typing in key words such as Covid, abdominal pain and that's when I stumbled across a couple of the support groups and again like Linn said they've been an absolute life-saver. It's quite worrying to see how many other people are out there with very similar or also very different symptoms and it's quite reassuring that people are going through the same but it's such a sad, sad situation as well when yeah, there's just nothing that people can seem to find wrong with you really or even just get back to your pre-Covid way of life and you just sympathise with all these new people posting within the past couple of weeks saying this is my symptoms because they mirrored mine in July and I'm here now in January, OK yeah slightly better but again six months down the line and we know the journey they've got ahead of them which is quite scary.

**Layla Moran MP**

Thank you. Nathalie.

**Dr Nathalie MacDermott**

Yeah, I think I became aware of the Doctors Long Covid group on Facebook in about August time, a colleague mentioned it to me and I can echo what Geraint and Linn said that it was an absolute life-saver at the time because I think at the time I was struggling with sort of employment issues, not so much I was still being paid but just getting any kind of support clinically from my employer was not really happening and I think coming across it I found other struggling with the same issue and I think maybe something I'll just raise because I feel like the three of us have been relatively fortunate in terms of our employment status, but there's now over 900 doctors on our Doctors Support Group for Long Covid, we've had 100 members join in the last weekend, so I think we're starting to see the second wave of people affected by Long Covid now coming in. 900 doctors is an awful lot, not all of them have Long Covid, some are just interested, but the majority do and many of our GP colleagues have actually really struggled with employment issues so GP partners don't have the same protection that we have, we were granted protection of sort of Covid sick leave that doesn't fit within our standard sick leave policies and I think maybe lasts for a year or something, so that's really good. But GPs don't necessarily have that and several of our friends have been made unemployed and removed from their partnerships after six months because that's the partnership agreement. So not only are they struggling with a lot of symptoms, they're also now unemployed and have no idea what their source of income will be.

**Layla Moran MP**

Thank you, that's very troubling to hear. Tracy Brabin.

**Tracy Brabin MP**

Yeah, we have covered a fair bit of it, but the question is about the support that you're getting and certainly you're going to be very supportive of others like you say on your journey and thank you so much for your honest submissions, it is really ... I mean it's just blown my mind the complexity of the symptoms, it isn't just exhaustion and fog there's so many other things attached to it. One question to deposit is I wonder if it's the viral ... who is doing the work on viral overload, particularly because you're obviously in the health service you are hyper-exposed to the virus, whether that has any impact. But my question is your associations, your Unions, your trade bodies, are you getting support from them and where is the support coming from for you? We have sort of covered it in some degree but I wonder Linn would you care to kick us off, do you know of associations or Trade Unions or others in hospitals or NHS that are actually supporting people at the front line like yourselves?

**Dr Linn Järte**

So my Union, so the British Medical Association, they've been helpful when I've contacted them for some minor sort of salary questions and issues, but that's the only involvement that I've had with them, so I don't think I can comment beyond that.

**Tracy Brabin MP**

Are they understanding about Long Covid, do they understand your circumstances?

**Dr Linn Järte**

They weren't initially, initially I was given the wrong advice actually so I wasn't under the Covid sick leave, having communicated from my department correctly but not been registered correctly with HR I think I wasn't really sure about the details, so my pay was then affected very, very early on and speaking to the BMA they gave me advice without them mentioning that I should be under Covid sick leave, so it wasn't until I wrote a second more generalised letter to them as a Union that they got back to me and sort of questioned why my salary was affected in the way it was, so it sort of went sort of the long-winded back road for me to get that sorted. But that was back in June so ever since communicating with them now they've been quite good.

**Tracy Brabin MP**

It does seem that the Unions also need to catch up with you about actually the scale of the problem potentially. Nathalie.

**Dr Nathalie MacDermott**

Yeah, I think I had some contact with the BMA, certainly from an employment advice perspective they've been helpful. I think they're just about catching on in terms of Long Covid and the impact that

that's going to have on the medical workforce, so I think they're starting to make inroads into that. I would say the Royal Colleges have been very variable, the Royal College of Paediatrics and Child Health has basically emailed me to say oh, well this doesn't affect children so it's not really a problem and I've kind of said well actually it does affect quite a lot of teenagers. They haven't really been interested in terms of the members' perspective, they've been interested in how it will affect our paediatric population which obviously is important as well, but yeah there's no real support there in terms of as a member.

**Tracy Brabin MP**

And certainly, picking up about children is something that people really don't understand, so that was really great to raise that. Geraint?

**Geraint Jones**

Yeah, so with, this is a professional support body The Royal Pharmaceutical Society and speaking to colleagues from there and the MD [inaudible 0:29:00.5] insurance provider I had obviously concerns that my pay could potentially be stopped due to sickness or health or what would really happen to be honest with a sickness that doesn't really have any explained causes. So, they were really great with me to be honest, they gave me a lot of good advice and I also submitted a professional blog entry just to inform other professionals really about the risks of Long Covid and how patients might present with Long Covid because working on the wards they potentially could come in and I could be seeing a mirror image of me if I went back to work in the next couple of months which again is just trying to get the message out there really. But in terms of support it's been quite difficult to get any really because of it being such a novel and unknown illness. I've been fortunate to have CBT sessions for Health Professionals Wales just because I find it so difficult to find that I'm even now so unwell and they're essentially giving me sessions to cope with living with a chronic illness really. And again, as a 30 year old who used to play football, go to the gym a couple of times a week, now get out of breath even walking up one flight of stairs at home, it's just really, really difficult. But I think you've got to try and find the support which is quite difficult when you've got a lot of confusion, a lot of symptoms, a lot of lack of understanding of it, it's just a minefield to be honest.

**Tracy Brabin MP**

I think certainly we are going to face a mental health crisis aren't we in the coming months, so many people isolated and affected and confused with what's happening to them, thank you Layla, thank you for those submissions.

**Layla Moran MP**

Thank you Tracy. A quick follow up, are any of you involved in or going to Long Covid clinics that have been set up in different parts of the country? If it's a ubiquitous no then I'll pass onto the next question, that looks like a no, so we'll come back to that.

**Dr Nathalie MacDermott**

I have been, I've been seen at the UCLH Long Covid clinic but through my neurologist, so I'm based at Queen's Square seeing the neurologist there and they have now set up a Covid neurology clinic, so I'm under their Covid neurology clinic. They've been excellent.

**Layla Moran MP**

OK, thank you.

**Dr Linn Järte**

I just wanted to comment, as far as I'm aware Wales is yet to introduce something similar to the clinics that are being set up across England.

**Layla Moran MP**

OK so it's a bit patchy. Baroness Masham. I'm afraid you're on mute. Baroness Masham. It's the phrase of 2020. You're unmuted, go ahead.

**Baroness Masham**

I'm unmuted now. My quick question to the three is were they tested positive, because there's an awful lot of people who seem to get Long Covid and they've never had a test. What have they had? Are the three speakers there?

**Dr Nathalie MacDermott**

Yes, so this is Nathalie, so I was tested in March and there was a problem with the sample, so it turned out to be negative but I think there was an issue. It was repeat tested at ten days, it was negative. I never had any antibodies to it and then I tested negative again in May, so it's very confusing but I had every single symptom to meet the case definition plus a positive history of exposure.

**Baroness Masham**

That's exactly what I've found with several people.

**Layla Moran MP**

Geraint and Lynn?

**Dr Linn Järte**

Yeah, similar to Nathalie, I was tested in March and also tested negative but I completely fit the criteria for a clinical diagnosis. I then had an antibody test but it was at the end of September so that was negative which isn't very surprising.

**Layla Moran MP**

And Geraint.

**Geraint Jones**

And I tested positive over Easter weekend in April and then I had subsequent exposure on my return to work in July which the test returned negative then but I had antibodies a week prior and I'm also in a clinical trial which is monitoring my antibody levels and I've still got antibodies at the moment. So, I had a positive swab then a negative swab, although we probably think it was too early due to the time of exposure and the swab and also on-going increasing levels of antibodies as well.

**Layla Moran MP**

Thank you, that's very helpful because one of our concerns is that there is under-reporting of Long Covid because it needs to be linked directly to a positive test, so your stories are very interesting in that regard. And just to follow up, we are obviously trying to raise awareness of Long Covid but we have a particular interest and so we know it's here, what's your sense of public awareness of Long Covid and what more do we need to communicate to the public about it and perhaps I'll start this time with Geraint and then go to Nathalie and then to Linn.

**Geraint Jones**

To be honest there's very little awareness of Long Covid in the communities, the media, the public and this was kind of my motivation really to share my story with public, professional, media. Like I said I'm a 30-year old man, I was literally crying on the floor because I didn't know what to do, who to turn to with no support, so for me it's just I'd hate to imagine there's other people out there who are going or will go through something very similar to myself. It's just such a complex illness how it fluctuates, it changes with no real underlying pathology and you obviously experience setbacks which again make the symptoms very difficult to diagnose. Like we touched on before, as adults we can communicate this as well but children again not so able to do so. And yeah, it's just again trying to raise awareness of all the on-going symptoms, like my symptoms are very different to Linn's symptoms, they're very different to someone else's but we all fit this kind of Long Covid bubble and nobody knows what to do with us really so I think the more we raise awareness and the more we all share and help educate others really going forward, especially as we move through the pandemic.

**Dr Nathalie MacDermott**

Sorry, was it me next, I wasn't sure. So, I think awareness I think has improved over the last few months. I think it's still not great, certainly among the general public as Geraint was saying but I think even amongst the medical profession it's certainly much better than it was, but I think we really need to have much more awareness in primary care for people to be recognised when they first present to their GPs. There's a lot of, I think, misunderstanding to some degree how this may have been presented at the very beginning that this is a post-viral fatigue or chronic fatigue picture and I think we need to be clear that this is actually a very different illness. There may be a subset who fit into a post-viral fatigue category but the vast majority of people have very clear organ pathology which means it doesn't fit within a chronic fatigue syndrome diagnosis. And I think that's what we need to

get out there and it's one of the reasons I think maybe the BMA was a little bit slow to catch on at first because a lot of people were just sort of putting it down to a post-viral fatigue category. I think that realisation is changing but certainly I think we need better recognition by employers because I think that there are a lot of people who have struggled with employment issues and support from their employers recognising that this is a genuine condition and that they might be off work for a significant period of time. And I think we need better recognition in the public particularly the younger public who think that they're invincible and you know I'm 38 and I wonder if I'll ever be able to walk properly without crutches again, will this continue to get worse, will I end up in a wheelchair and I think if people thought of Covid of not just a mild illness, they thought of it as ... you know people think mild or severe and if you're old you're gonna get severe and end up in hospital and if you're young you'll have a bit of symptoms, get over it and it'll be fine. I think they need to realise there's an in between there where yes you may not die but you may have long-term problems following it.

**Layla Moran MP**

And Linn.

**Dr Linn Järte**

I can only echo everything that Natalie is saying, absolutely. I think the average adult who's not at high risk of getting severe Covid just don't consider Long Covid to be a risk that applies to them somehow. Awareness definitely has increased but we still have a long way to go and I think a lot of employers also think that people can be put back into work before being completely well without realising how Long Covid has such a relapsing and remitting pattern, so yeah.

**Layla Moran MP**

Thanks very much, Paul Strasburger.

**Lord Strasburger**

Hi there, welcome to all three of you. Thank you for sharing your story. I didn't hear anything said about any treatment that you might be getting. Are you receiving any treatment that is relieving symptoms or taking you to a better place and if so is it working? Would you like to go first Geraint?

**Geraint Jones**

Yes, so I've had prescription medication, prescription pain relief, didn't change my symptoms at all to be honest. Sometimes as soon as I was taking the medication I was just passing them completely through me to be honest, it was like as if my body just didn't want anything inside it. I've had colonoscopies, I've had biopsies taken and nothing seems to be showing at the moment so I'm still a bit ... it's reassuring that there's nothing concerning of underlying pathology but again there is still my on-going symptoms and the fluctuating and the changing symptoms as well. Fortunately, I've just out of interested I've tried to get well myself, I've pushed myself to be in a couple of different trials and I think a lot of my diagnosis has come from trials instead of primary and secondary care clinicians, so yeah to be honest no, nothing has helped really.

**Lord Strasburger**

Thank you, and Linn?

**Dr Linn Järte**

I'm only on a tablet to treat my pericarditis and then medication to lower my very high heart rate, that's it.

**Lord Strasburger**

So, it's all about treating symptoms rather than curing. And Nathalie.

**Dr Nathalie MacDermott**

So, I have had a lot of investigations and I think everything is a little bit inconclusive in terms of exactly what's going on, so I think the neurologists have been a little bit loathed to try and treat me with anything that would suppress my immune systems but at the same time because things are getting worse, I think there's lots of conversations about what should happen, but obviously it's slightly unknown territory. I'm on some quite strong medication to relieve neurological pain, I get a lot of pain in my back and in my spine and down my arms to I'm on some pain relief for that, but that's it really.

**Lord Strasburger**

So, it's all about suppressing symptoms but medical science hasn't really come to your rescue as yet. Thank you.

**Layla Moran MP**

Thank you, Baroness Brinton.

**Baroness Brinton**

Yes, thank you very much. It's interesting to hear about all the different symptoms and different medical disciplines, can I ask if there's any coordination between those disciplines and whether having one lead discipline who actually took responsibility for the whole patient would help. As with gerontology I have auto-immune disease, so as with auto-immune disease.

**Layla Moran MP**

So, Nathalie do you want to go first and then Linn and then Geraint this time?

**Dr Nathalie MacDermott**

Yes, I think it's really important that there is sort of one named individual that's going to coordinate particularly because in my case I largely have neurological problems but a lot of people have multi-system problems and there needs to be communication between different specialists and I think that's best served by having one nominated healthcare professional who takes the lead and then helps with the coordination. I think I'm quite fortunate with the neurology team, they since the beginning of the pandemic have had neurology MDTs to support people who were in-patients with Covid and had neurological problems and so that's kind of been expanded now to dealing with people who have on-going problems even if they weren't hospitalised.

**Dr Linn Järte**

So where I am here in Wales since we don't have any clinics at all I completely agree with Nathalie that it should be one lead that then links in with everything else because symptoms are so overlapping and it can be multi-system or it can be a symptom that seems to be from one system but it's actually caused by another system, but at the moment in Wales it's nothing, so there's no coordination at all so people are basically waiting for many months for appointments to several different specialties which makes care extremely disjointed and inefficient.

**Layla Moran MP**

And Geraint, anything to add?

**Geraint Jones**

Yeah, just again to echo Linn really, there's nothing in Wales for us at the moment and I'm under gastroenterology, ENT, neurology and cardiology and again like Linn, it's just so disjointed and there's nothing here for patients in Wales really. I do think we do need multi-disciplinary teamwork, we need to kind of help the patient really and I know in England a lot of the support is more rehab support rather than again diagnostics, but I don't think we're quite there to be able to be rehabilitated, some of us at the moment we need to recover first and then we can perhaps look at the rehabilitation side of the illness. But without kind of support or early guidance into helping patients we could be looking at something which is on-going for quite some time, with one in ten patients having symptoms for over 12 weeks, yeah we could be looking at numbers, if it's say 10% of the amount of people who have Covid at the moment there could be a significant amount of people affected long-term.

**Layla Moran MP**

Thank you Geraint and that's something we're going to be very much keeping an eye on and pressing on. Barbara Keeley.

**Barbara Keeley MP**

Thank you Chair and thank you for the evidence you've given us today in helping us to understand the real impact of Long Covid on your lives. Just a question for each of you, what more must be done urgently to support those living with Long Covid and perhaps we touched on medical support but

things like financial aid, you know changes at work, re-skilling, whatever you think you might need and others with Long Covid might need. So, we'll start with Nathalie.

**Dr Nathalie MacDermott**

Yeah thank you, I think particularly from a healthcare worker perspective I'd say one of the things we need to do is try and prevent it, I know that sounds impossible but actually for healthcare workers we really do need better personal protective equipment and I say that because the ... as somebody with experience of PPE and training people in PPE our guidance in the UK is the lowest level of guidance of anywhere in the world, it was lower than the WHO guidance, maybe only slightly but was lower and that needs to change, especially with this new variant, it is highly transmissible and we need, I would advocate for FFP3 or FFP2 at least masks for anyone working with known Covid patients and even possibly outside of that, we need to try and prevent people being infected and we can do that as well by vaccination. And I know that the Government has now brought forward vaccination for healthcare workers but I think we could argue that if that had been done in December and they had been prioritised in December we may not quite have the problems in the NHS that we have now because we wouldn't have so many people off sick or isolating. So, that's one part. I think we need to advocate for the Health and Safety Executive RIDDOR reporting so that employers should be RIDDOR reporting anyone who's been infected in the employment setting but many employers are somewhat loathed to do that because it does result in a significant investigation sometimes, and also the HSE said that if people were given adequate PPE and by that they just mean a surgical face mask, then it couldn't possibly have been transmitted in a healthcare setting, well we know that PPE is not 100%, even if you have really good PPE so I think we need to have that changed. And you know I've been trying to get Great Ormond Street to report this for four months on my behalf and I'm still waiting. And they're going through a process to try and get Occupational Health to confirm that it was an occupationally acquired illness and so on, so that's one area.

I think to help with that it needs to become recognised as an occupational disease, not just for healthcare workers, I mean it's affected bus drivers, it's affected you know people in many different sectors, but it needs to be considered an occupational disease particularly in a healthcare setting and that will help with the RIDDOR reporting and then that will help with counting it, so I think we need the Government to count it in a sense of when we're reporting our statistics we don't just report survived versus died, or percentage died, we need to also be reporting percentage impacted with a long-term condition and we need definitions therefore of the condition to do that which we now have a little bit through the NICE guidance, we have coding that can now be used, but it does need to be reported because this is going to be a significant impact of this pandemic in the long term, even once the surge is over, even once the vaccine has helped to allow us to lead slightly more normal lives, it's going to be a problem. And then also identifying it appropriately in primary care as I mentioned before and I agree, I think there needs to be some form of hardship fund for people who've lost their jobs and can't you know very suddenly and need to access some kind of fund fairly urgently. And then also for people who need access to specialist equipment, I can't drive at the moment legally, I don't know if I'll ever be able to legally drive again in a normal vehicle but I have no idea even how to get to work at the moment because I can't walk far enough to get to a train, I can't afford to take a minicab every day, so it's just lots of different things like that where I think actually I just need a modified vehicle and then I can get around, can get to work, can do my job. But it's just things like that that I don't even know how to access myself and I'm a healthcare professional.

**Barbara Keeley MP**

Thank you.

**Tracy Brabin MP**

If I could just jump in there, sorry Barbara but just to say ...

**Layla Moran MP**

We're running out of time, so we really need to ...

**Tracy Brabin MP**

Whoever is your MP Nathalie please contact them because they will be able to try and support you.

**Layla Moran MP**

Completely agree, yeah. If we can go to Linn and Geraint.

**Dr Linn Järte**

I think I'll just echo everything that Nathalie has said, she covered it very well.

**Barbara Keeley MP**

Thank you, and Geraint?

**Geraint Jones**

Yeah, like we said in Wales there's no clinics at the moment so the sooner we can get support for the patients in Wales really the better. Again, I think unless you have Long Covid you don't really understand Long Covid and the only support I found was from speaking to other patients living with Long Covid to be honest. So, we are quite an untapped resource in terms of understanding the illness, being participants in research, like I said the amount of understanding I know of my illness has come from trials and sort of self-interest and being involved in research to be honest, but that could be just part of my background, if you've got someone who's not able to kind of engage in that type of care then I really think it's going to be difficult to be part of some kind of trial, which again if we leave patients at home they could have undiagnosed organ failure or undiagnosed organ damage which again has a further burden long-term on the NHS, long after the pandemic has finished.

**Barbara Keeley MP**

Yeah, thank you. Thank you all of you.

**Layla Moran MP**

Yes, well thank you all so much and that brings us to the end of this portion of the evidence session but this panel, I'm sure I speak for everyone who's been watching and everyone who's been questioning, your contributions have been invaluable very much echoing the over 1,000 other contributions we've had, but I think hearing it from those who are in the middle of this has really again brought it to light for us and we will be raising the issues that you have raised both in Parliament on Wednesday itself, sorry Thursday itself for the debate but also on-going and we will be writing to ministers and the Government again basing our recommendations on this evidence, so a big heartfelt thank you from everyone on this panel for sharing so openly and honestly your stories and so Natalie, Geraint and Linn thank you so much from all of us. You are very welcome to stay for the next panel which I think will also be a very fascinating panel so don't feel you have to rush off if you don't want to, but equally you are busy people with other things to do as well, so if you do have to go we shan't be offended please just go ahead and do that.

And for the second part of the session I'm now going to pass to Caroline Lucas to chair, thank you everybody.

**Caroline Lucas MP**

Thank you so much Layla and thank you again from me for everyone who took part in that first session, it was incredibly powerful. Really happy to be able to introduce two expert witnesses for our evidence session now, Dr Nisreen Alwan and Professor Danny Altmann, thank you both so much for being here. Dr Nisreen Alwan is Associate Professor in Public Health at the University of Southampton and Honorary Consultant in Public Health at the University Hospital Southampton NHS Trust and she is living with Long Covid. And Professor Danny Altmann is Professor of Immunology at Imperial College London and during the pandemic he's acted in several advisory roles including the House of Commons and House of Lords Science Committees and the Immunology Task Force to SAGE, so thank you for your time and welcome to our session.

I wanted to just start off by asking you both really are we once again seeing, or as we are once again seeing a huge rise in cases of Covid across the UK, what does that mean for Long Covid, will we imagine that the Long Covid cases will go up in proportion to the overall cases of Covid and in particular what impact does viral load have on your likelihood of contracting Long Covid and the seriousness with which it might hit you if you do. Maybe I could come to Dr Alwan first on that one please.

**Dr Nisreen Alwan**

Thank you so much for inviting me to give ... to talk here. So, it's really very concerning, in the last seven days, just in the last seven days there were over 400,000 confirmed Covid cases, so if we take the most conservative, a conservative estimate really of 10% this is the Office of National Statistics estimates, so 10% of people you know not recovering, still having symptoms after 12 weeks, that's 40,000. But actually, if we do take the kind of the estimates from the ONS about how common the infection is, because a lot of people are not testing and not accessing testing, that's over one million, you know and that's the estimate from the end of December, early January. So that basically means over 100,000 Long Covid, I mean the numbers are staggering and that means more illness, more disability and you know affecting work, affecting caring responsibility for people who are largely previously healthy people, in a younger age probably.

The main issue is which I've been kind of talking about for months now is that we do not have a system to record this, we do not have a system to measure this huge morbidity burden of Covid, like we now see statistics every day on the number of positive cases and the number of deaths and the number of

hospital admissions and people going into ICU, nobody is measuring that and that is really key to do anything. If we don't quantify the problem how can we do anything about it? And I think to quantify it it's difficult, it's difficult but actually it's doable because you can quantify it in two main ways, one is you measure who recovers, you try and quantify who recovers so if we are testing people and there's a test and trace and we know who's got it, you know some simple follow up, even a text message to ask people after a while have they recovered or not. And then the other way is having some patient registers of Long Covid now that GPs are diagnosing Long Covid and we need to get better at this because we need some universal case definitions because there is still a huge variation clinically in giving that diagnosis. But once we have them we need some patient registers and we can quantify it.

**Caroline Lucas MP**

Thank you, and Professor Altmann.

**Professor Danny Altmann**

Yeah let me kind of hone in on some of those points and reinforce some of them. So, you know I agree with obviously all that was just said, you know by my calculations even if we take the conservative lower limit for prevalence of Long Covid, this country at the moment probably has more than 300,000 cases and you know the world probably more than seven million cases. So you know when we heard Chris Whitty earlier in the week talking about a kind of existential crisis in the NHS because of the current acute cases, how much more so if you don't think of them as acute cases but you think we've added a disease burden as large as all the arthritis patients in Britain, again from this one disease, and we have no plan, no NHS provision, we don't know whether this is for three months or six months or six years or forever, but you can't just say we need some Long Covid clinics to deal with this extra threat because who's in the clinics, where are they, who are the doctors, where are the extra doctors, where are the extra nurses? You know many pertinent points that were raised in the first session. Unless we've got a lot of research to work out what this is and understand the mechanism how do we know what are the care pathways, which doctors need to be linked up in that clinic, what therapeutics they're going to be given to make this better, unless we can address any of these things you know we can't ever improve it.

And the only other point I'd add as a sort of opener is again reinforcing some of the points we heard earlier, every time I go on TV or radio I'm faced with that kind of devil's advocate response of well I'm not an old person, not in a care home, do I need to care about this, do I need a vaccine, do I need to socially distance, it doesn't really concern me and I think the kind of evidence we have on show here and me talking about 300,000 plus people presently in Britain means it's a real game of Russian Roulette because you don't know whether you're going to be one of the people who's better in two weeks or one of the people who is going to be on crutches or in a wheelchair for months or years or forever and how many of us want to take that risk?

**Caroline Lucas MP**

That's incredibly powerfully put, thank you. Could I just press you on that point about viral load, is there any correlation that we know of in terms of your propensity to get Long Covid and the amount of viral load you might have received?

**Professor Danny Altmann**

Yeah, I heard your point before, so anybody who loves the details of this there's a paper that I'm waving around that you can't read but it was in The Lancet last week and it's the biggest study that's yet been published out of Wuhan on 1700 people and it's a minutia of their disease and the correlates. And what it says to me is that there are some manifestations like long-term lung changes and CT changes where the risk goes up with the viral load and severity of the disease and lots of other stuff where it doesn't and it doesn't matter. So, you could be somebody who barely knew you had Covid and never had a Covid positive test and could still be dogged for months or years with Long Covid. So, a complex answer to your question, the answer is yes and no, something's go up with viral load, other things not.

**Caroline Lucas MP**

OK thank you, Baroness Brinton.

**Baroness Brinton**

Yes, thank you very much. We heard from the witnesses in the first session about the inconsistent support for Long Covid patients is probably the most diplomatic way of putting it and I just wondered what is needed most urgently now to support and treat those with Long Covid. Is clear guidance yet available for all primary and secondary care environments on treating Long Covid, I mean I know we're all learning a lot. And can I repeat the question I asked them about should there be one lead to cover all the multi-disciplinary areas that are covered by Long Covid, as with auto-immune disease and gerontology, to ensure that there is coordination not just for the benefit of the patient but also for the benefit of the research that Dr Alwan was talking about that we need so urgently.

**Dr Nisreen Alwan**

Shall I go? So, thank you very much for this question. I think first of all people living with Long Covid need recognition and although that is getting slowly better and we've heard in the first session how at the start maybe that was a very big problem, you know dismissive behaviour, really not knowing, disbelief about you know this can't be linked or this is not Covid. I think it's still a problem and so I think recognition of the people having Long Covid and recognition that we don't know, you know of our really vast ignorance on this area, we've heard different symptoms. There are patterns emerging in these symptoms in terms of some people have different things later on and more at the beginning but really it's a very, very unknown area so acknowledging we are not knowing and honouring patient stories really and there are patterns, so I think we can come up with some sort of universal and inclusive case definitions for the clinicians to recognise.

I think the other thing is to actually once you have a suspected Long Covid people need thorough physical examination, thorough investigations, medical investigations because a key thing to do, and this was definitely a concern for me, is that you don't want to miss something that could be treated, you know like a blood clot for example or a block in your heart vessels and these are things that we can find with a proper investigation, so this needs to be done and there shouldn't be a quick premature jumping into let's go and treat this with psychological interventions or things like that, which obviously are an important component but I think it's really important to have these investigations and they need ... you know obviously people need to rest and we've heard again it's an illness that's fluctuating, it comes and goes and people tend to go back to work and then not being able to work and there needs to be a recognition, an adequate sick pay and ability to take time off.

And just to answer your questions about what one kind of ... somebody responsible. I think that is a really great model to have, somebody I would maybe call it more coordinating because again what we know so far is most patients have multi-system involvement, so it's not just one system involvement. They might need more care for certain systems than others but I think having a coordinating point would be very helpful.

**Baroness Brinton**

Professor Altmann.

**Professor Danny Altmann**

Yeah, so I think between them Baroness Brinton and Lord Strasburger have brought up the key points to highlight and these are the points I would urge you to bring up to all your influential friends and spread the word because it is the heart of the matter that until we understand what it is, who has it and what the mechanism is we don't know how to treat it, we don't know who has to treat it and what therapeutics you can give people to make them better so that they can resume their lives, but there's no point ... and it's a great start to have a Long Covid clinic and you know put the sign over the door, but who is going to sit in that clinic and how are we going to join up that care? So, the analogy I'd make is you know everybody's come across people who have lupus, so lupus you know an immunological disease, it's caused by auto-immune antibodies against DNA binding proteins which sounds very simple and yet the disease is very complex and multi-system and sometimes you might want to see a rheumatologist and sometimes you might want to see a neurologist and sometimes you might want to see a renal doctor depending on the symptoms you have and where and how it's affecting you. But unless you've got a joined up model for why all those things are happening, how on earth are you going to help that person?

The other sort of example I'd give you is that one of the ways that I got into this is that as an immunologist I'm very interested in another viral infection in Brazil, it's a mosquito borne disease called chikungunya and in Brazil they're very used to mosquito borne diseases, they've got dengue and they've got Zika but what they weren't ready for was a variant on that kind of viral infection chikungunya where sure it infects you and you get the fever and you get the malaise and you feel ill for a little while, but 30 or 40% of those people go down with a long-term chronic arthritis afterwards that wrecks their lives, it puts them out of work, it makes them feel suicidal, it excludes them from society and their healthcare system is just packed out with these long-term cases that they weren't ready for, hadn't budgeted for, didn't have the clinics for and didn't have the doctors for, so you can hear from my voice I'm kind of saying let that be a warning to us and let's plan ahead.

**Caroline Lucas MP**

Is that OK Baroness Brinton, shall I move onto Debbie Abrahams?

**Debbie Abrahams MP**

Thanks very much Caroline and good morning everyone. I was very interested when I was reading the NICE guidelines around Covid and particularly around Long Covid, and I wondered in terms of your perspective around whether you feel that the 12 weeks cohort of patients who are still experiencing symptoms after, whether there is anything akin to post-viral syndrome and what we can learn from how that has been managed and what we need to be looking out for.

**Dr Nisreen Alwan**

OK thanks, so I think obviously we've had recently just before Christmas we've had the NICE sign and RCGP guidelines and that's been great to actually have these guidelines. I think one very positive thing that the guidelines brought was that they really stress it's very important not to discriminate based on whether you've had a positive test or not in diagnosis and management of Long Covid. That's a very, very important point for people with Long Covid because that's been an on-going problem. I think as I said we really still don't know, Long Covid is being used comfortably by many people, mainly people living with Long Covid, as an umbrella term and I think there's a wide recognition that it could be that there are multiple conditions within that umbrella term that it's still difficult to distinguish. I think putting everything ... so the new term that's used in the clinical guidelines is post-Covid syndrome and I think that kind of implies that we might know the mechanisms underlying what's going on, which really we don't, it could be this is classical post-viral syndrome for some, it could be this is very similar to ME, chronic fatigue syndrome for some, it could be there are other things, you know multiple system, so there may be other things and particular syndromes that might emerge later once we understand more about the mechanisms and how the symptoms cluster and the organ damage associated with it.

So, I think we need to recognise that this is unknown and continue to [inaudible 1:07:16.2]. The cut off itself, the 12 weeks I do think you know I mean the most anxious period for me really, and although that was kind of early on was that period between maybe four weeks and 12 weeks, because you know I think people need support during that period. So, I think if we say, well nothing can be done until you get to 12 weeks, you know that's not right. But also, the guidelines don't say that because they have the categories of on-going symptoms from four to 12 weeks and then 12 weeks after. I think the time cut off can be ... is a bit arbitrary. You need a time cut off for definitions as long as you acknowledge that it varies. I do think anything beyond four weeks needs attention, but also you've heard very, very startling from the first session that this very striking kind of fluctuation and the coming and going of the illness which has been, you know it's very distressing and I've experienced every time you think you're almost there and you're recovering and then it comes back and I think in between people can function much better than when you have the relapse of symptoms. So clinical guidelines need to acknowledge that very well because it seems to be a very prominent feature of the illness.

**Debbie Abrahams MP**

Thank you, and Professor Altmann.

**Professor Danny Altmann**

All I'd add to that, I think I wrote somewhere that just stating the obvious really that this is a chapter of the medical textbooks that hasn't yet been written, but God it urgently needs to be written because when we first started talking about this, I had clinical colleagues saying to me, well you know you're bound to feel a bit rough and depressed when you've been in hospital, what do they expect? You know that's all it is. And you know it so isn't just that, you know as you've heard in the evidence this morning that you know my job as someone who's spent my whole life in medical research is to observe the pathology and try and understand the pathophysiology and try and attach a gene or a transcript or a molecule or a cell to the mechanism and work out what's gone wrong and what you would need to do to make it better. So, when I try and gather together all of the evidence in this field I see an awful lot of people on planet Earth who didn't have these symptoms before and now have wheeze and chest pain and cardiovascular problems and joint problems and brain fog and movement

disabilities and all the things that healthy young people didn't have before. And I think we have a real obligation to do the medical research and fund the medical research to work out what on earth is going on and do something about it. So, you know we mustn't get lost in some sort of diffuse, oh you know they feel a bit rough, you know poor dears, you know we've got to characterise it and sort it out.

**Debbie Abrahams MP**

Absolutely, and I think people who've had both post-viral syndrome or ME or chronic fatigue syndrome would say that it hasn't automatically been taken seriously by many in the medical profession, so again I just want to make sure that we are looking to see what we might learn from those areas where there may be some overlap, thank you so much.

**Dr Nisreen Alwan**

May I just add very quickly because I think that's very important, I think if we want to be positive and look at a silver lining here, these conditions have been largely neglected.

**Debbie Abrahams MP**

Yes, they have.

**Dr Nisreen Alwan**

In medicine, in all sorts of aspects, so if we want to maybe use this pandemic and this huge weight of Long Covid as a way to actually give more attention and support and recognition and care for this group of conditions that would be great.

**Debbie Abrahams MP**

Thank you, thank you very much both of you.

**Caroline Lucas MP**

Thanks Debbie, coming to Tracy Brabin.

**Tracy Brabin MP**

Yes, thank you. Well the current vaccination policy in the UK rolls the vaccine out to the most vulnerable, given we don't know yet the impact of the vaccination reducing transmission what do you think the impact can be on Long Covid? Professor Altmann.

**Professor Danny Altmann**

Can I go first?

**Tracy Brabin MP**

Yes, please.

**Professor Danny Altmann**

So you know it's something I get asked about a lot, my sort of high level answer has become a simple answer that you know we've had a ghastly year and a debacle of a pandemic and the only trick we have up our sleeve is to reduce the pandemic and block transmission and apart from social distancing, by far the biggest weapon in our armoury are these amazing effective vaccines that we have, you know two on board at the moment and about to be three. And if currently we're generating 50,000 cases of Covid a day and 5-10,000 cases of Long Covid for our medium to long-term future the best way to stop that happening is to get the vaccine to as many people as possible as fast as possible. And that's absolutely by a million miles the best thing we can do because if you have any of these vaccines you'll have a pretty good level of neutralising antibodies and if you have those the virus can't get into your cells. So, that's step one. And you know step two is what do we think about vaccine for the people who've already had the virus or even people who have had the virus and had Long Covid and I know that people have been very perplexed about that and you know the jury is out because all of these things are being learnt in real time and we've never been there before and I know that some people in the Long Covid community say well I feel very vulnerable, I should be on the list to be vaccinated soon because I feel terrified of reinfection, and some people feel quite the opposite, they feel well maybe I've over-reacted to the virus in the past in some way, it's been deleterious so perhaps I'd rather wait with my vaccine because I'm worried it might do me some harm. I'm sympathetic to both those views and the data aren't there yet to know which group are more correct and people are very diverse and there may be different answers for different people, but my simple answer is that this is a horrible virus and people who have the vaccine will be better off than people who don't.

**Tracy Brabin MP**

But the question still remains doesn't it that those who are suffering with Long Covid, do we know yet what their response would be to the vaccine?

**Professor Danny Altmann**

I'll let [inaudible 1:13:38.2] come in a minute, I just want to say one more sentence that on the whole the general advice is people who feel or who know they've been infected before should nevertheless come forward for the vaccine because we fear reinfection and you know from my immunological concept I have at the moment got no particular reason to think that making an enhanced immune response to the spike antigen would exacerbate or increase your risk of Long Covid, but you know no data yet.

**Tracy Brabin MP**

Dr Alwan.

**Dr Nisreen Alwan**

Thank you so much for this question. This is really key now because I do get concerned about hearing the approach of we will vaccinate the vulnerable and then we'll open up and then you know there's no reason that we think the virus could stop then and get scared and go away. The virus will continue to spread, really concerned that it might spread uncontrollably among people who are not vaccinated. We don't know who's vulnerable in terms of morbidity, in terms of developing Long Covid and organ damage. So, the danger it poses is that you would then get more morbidity, but also by the vaccinating just the priority group and then letting the virus spread that means more chance of the virus getting more mutations and the mutations could then become vaccine resistant, you know leading the virus to becoming vaccine resistant and then everybody you know will be liable for infection again. So, I think it's really important that we have a clear strategy, absolutely right to vaccinate the priority groups who are at more risk of death but we have to have a clear strategy that we still need to control the infection until most of the population is vaccinated really because of those risks. And particularly I think for people, and in terms of that control you know it's mainly about systematic structural changes not entirely focusing on individual behaviour instructions, I think we need those and we need to see those while we're in this terrible lockdown. And particularly for the disadvantaged because the vicious cycle here, we've heard a lot about the inequalities in Covid mortality but the inequalities in morbidity will probably turn out to be higher because people are more likely, more disadvantaged people are more likely to be exposed, get Covid, and then get Long Covid, more likely not to rest, not to have sick pay, not to have even adequate recognition by the health and care sector because we haven't understood and we haven't got very specific case definition yet. And then the vicious cycle continues, so we really need to have that in mind and we need to manage expectations for everybody, that this needs to continue. That doesn't mean remaining in lockdown forever, that means that we need to prepare how to keep the infections low when we come out of lockdown, we really need to have a tight strategy for that.

**Tracy Brabin MP**

Yes, hear, hear to that, Caroline, thank you.

**Caroline Lucas MP**

Thanks Tracy, Lord Strasburger could we come to you next please because Catherine's not here.

**Lord Strasburger**

Good afternoon. We've heard mention of the guidelines on Long Covid already, there's been some criticisms of them and I'm just wondering how you feel they reflect the reality of Long Covid. Would you like to go first Professor Altmann?

**Professor Danny Altmann**

I think I'm going to let Dr Alwan go first because she's been at the heart of this.

**Lord Strasburger**

I'll take your advice. Dr Alwan.

**Dr Nisreen Alwan**

Yeah, thank you so much for this question. I think I touched on the guidelines a bit and I did, they are I think they're commendable because they came in very quickly and we're ahead of most other countries if not the first in this regard, so this is great. They are living guidelines so that means they need updating all the time. And also, I commended the bit about the recognition of people who haven't got that positive test, you know in terms of accessing care, but I think we need more details in the guidelines. I think particularly from the point I've been working on and advocating a lot on, in terms of what are these criteria for referral of people to all these services, what are the exact investigations, do we have different case definitions indicating different kind of pathways and all of that. So, there are kind of layered details that I'm hoping will come, you know, as these guidelines are updated. But also I think I also touched on what we're calling it and I think it is wiser to stick to that broad term of Long Covid because basically all that term is saying is saying this is a condition and it's long and it's not going away, while actually having labels including things like the actual label of post-Covid syndrome means it is implying that we know the mechanism that something has gone and there is a post stage and I think we're still not there yet. And the guidelines do refer to the condition as it's also known as Long Covid, but I think it's really, really important because the patients are the experts here, they are the absolute experts, you know people ... even for us, I have kind of a double hat of the public health and the patient, but actually it's talking to patients because they understand the condition and they also, because they have been such a cohesive network of support a lot of the patients understand what other people living with Long Covid are living with and I think their input is really important in developing everything around Long Covid.

**Lord Strasburger**

Thank you for that. We've heard today and in August from six victims of Long Covid and maybe by chance they've all been working in the medical profession, is there any evidence that there's a preponderance of people working in the medical profession who are suffering from Long Covid?

**Professor Danny Altmann**

No, I don't think so at all, I think that's ascertainment by us if I may because as you'd imagine people who come out of medicine are vocal and informed and well-connected to comment on it, but I promise you amongst those, the people I've flagged up, the >300,000 people who I suspect probably have it in the UK there are supermarket workers and bus drivers and all the people representing those who've been exposed to SARS-CoV-2 in the last year. But you know when you talk about how it's all going to work and come together in the NICE guidelines, I feel like it's a work in progress and the NICE guidelines were actually a rather good document, but it is very much in progress, so I don't know at the moment for any of those people how good their chances are if they feel really rough with their difficulties in movement or breathing or brain fog or concentration or whatever it is and they turn up at their GP, will they get into an appropriate care pathway, will they be referred to an appropriate team and will there be some sort of management that might help them. That's a tall order at the moment and we need to really, really work on that.

**Lord Strasburger**

OK, thank you very much.

**Caroline Lucas MP**

Thanks, I'm going to go back to Tracy Brabin now for a further question.

**Tracy Brabin MP**

Yes, thank you, this is just so interesting and thank you so much for your brilliance and the work that you've done so far. My question is what's the impact on Long Covid from a public health messaging point of view because obviously it's protect the NHS, protect the vulnerable, the concern is that maybe when numbers of admissions go down or mortality numbers go down that we will change our public health messaging and whether the public need to be aware that Long Covid is also still out there and could potentially impact on their lives. So, basically is the impact of Long Covid understood at public health level and what the impact that can have on the messaging, Dr Alwan.

**Dr Nisreen Alwan**

Thank you so much for this question. I think despite the fact that we've come a long way in Long Covid, that people are recognising it, there's much more cover of it, I think that we still unfortunately have this black and white picture in public messages. You know our leaders when they come and talk about the restrictions that we need to have, the vaccine, all the topics that everybody wants to know about they seem to be talking about deaths as the only bad outcome from Covid-19 which we know isn't, because of this huge problem for morbidity burden. And I think this partly could be tackled as I mentioned by measuring it, because if we have the stats, we've heard the stories, there's so many stories, you've got the stories, hundreds of stories and evidence but that needs to be, there's another layer, we need the stats to quantify the problem to everybody, to the policy makers, to the scientists, to the doctors, to the public so that they understand. And I think the messaging as well about you know protecting the NHS, obviously but the NHS is not an it, it's them, you know they are people, so obviously you are protecting these people but also I think the message needs to be protect yourself, protect your family because you don't know, you know if you get this virus whether ... if you're younger, if you're completely healthy, it's unlikely that you'll get admitted to hospital or to critical care or die, which is fortunate, but actually there is a ... it's common, Long Covid is common, there's a chance as I said at least one in ten and actually one in five for symptoms lasting more than five weeks, that you won't be able to go back to your normal daily activity and you will be having these strange symptoms that people are not being able to largely explain at the moment. You won't be ... if you have caring responsibilities it's really painful, I mean I have three children and I managed to care for them but obviously not in the way that I would before I had the infection and I think if you have, depending what work you have, you know it's a disability and I think this message is not coming through yet and it needs to, definitely. Definitely, at this stage.

**Tracy Brabin MP**

Professor Altmann.

**Professor Danny Altmann**

Yeah, I'd endorse that, I think it's such a really key point where we so need to reach out to people like yourselves to get the right message out because you know at the moment we're talking about the

NHS at breaking point and the assault on the NHS with a sense that if only we can get through these dark days of January and February everything will be OK. Everything really won't be OK because you know if we're talking about, I gave the analogy of the situation in Brazil where the healthcare service has been almost broken by chronic disease following viral infection, you know I'm normally quite an optimistic person but I feel very bleak about this, that if we've got hundreds of thousands of extra patients in clinics in the NHS for the next one or two or five or ten years, that has implications for you lot for policy, for healthcare provision, for taxation, for employment law, you know that's really the ball in your court on a grand scale with really serious issues, so let's get the message out that we can't take this lightly and it doesn't matter whether you think you're low risk and might not die from this infection, there's other risks out there as well.

**Tracy Brabin MP**

And certainly, the public health message has been save your granny and we do know that children are now potentially sufferers of Long Covid, so there is maybe scope to discuss how we widen that public health message to potentially also protect the future of your children. Dr Alwan.

**Dr Nisreen Alwan**

OK, yes absolutely agree, actually we say Long Covid has been neglected, we don't know much about it, we don't know almost anything really about Long Covid in children and any potential long-term effects and I think we need to be cautious about this rather than say you know that's fine, they can get it and nothing happens to them, the approach really needs to be precautionary. But definitely in terms of also surveillance and measuring and research we need to quantify this problem in children.

**Tracy Brabin MP**

Professor Altmann.

**Professor Danny Altmann**

Yes, so one detail to add to that, I think sure we've known all the way through that it can affect people at all ages and the Long Covid groups contain children and teenagers, but my sense and there's not much data on this yet but my sense is that with the new mutation being around particularly in the UK the B.1.1.7 mutation colleagues are talking about hospitalising whole families, you know grandparents, parents and children and it being much more across the age spectrum and much less a disease of old people. So, however much that message was crucial before it's ten times more so now because it really has somehow seems to be morphing into a disease of all age groups.

**Tracy Brabin MP**

Well, that's a very grim note to end on, Caroline.

**Caroline Lucas MP**

Thanks Tracy, yes thank you. I'm going to come to Barbara Keeley now.

**Barbara Keeley MP**

Thank you and thank you for all your evidence today it's been very worthwhile. Final question really, just a wrap up question but perhaps most important in terms of what we might take forward in our reports and recommendations, what do you feel is urgently needed now to support and treat those with Long Covid, what are the most urgent things that need to be done? Dr Alwan if we start with you.

**Dr Nisreen Alwan**

So, the urgent things I think in terms of the population number one is we need to have our surveillance system and I'm not just talking about research I'm talking about normal surveillance system that is reporting to us, that's basically reporting the numbers of the infection and the deaths and that is determining policy basically, but nothing around morbidity is determining policy at the moment because we don't have that sort of surveillance and the numbers so that needs to happen on a population level. Also, on a population level we need to get the public health messaging right, it's not about scaring people it's about telling them this is happening and then telling them these are the measures that could prevent this happening, so these two things.

On a patient level I think the stage is really as I said, it's recognition and giving the patient the diagnosis, listening to them, listening to their stories, having good evolving case definitions which take into account people who haven't got that lab evidence whether it's a PCR test or an infection or an antibody test because we now know very much the limitations around all of these lab tests and the problems accessing them, you know and the incentives around access. So, I think regardless we need those case definitions. And then once you have the case definition listening to the issues, doing a proper clinical assessment and then having the proper investigations that are needed. Particularly in the first instance to rule out anything that we know how to treat because Covid is predisposing people to lots of things and I just want to throw in a statistic because I don't think it was mentioned widely before, another ONS statistic where they compared people who have been discharged from the hospital with Covid and some of them not in critical care, so not went into ICU, just went into hospital and then some controls and they found that actually the incidences of things like diabetes and cardiovascular disease and chronic kidney disease and chronic liver disease is so much higher, you know so for example diabetes, they found 131 in 1,000 patients have that in the discharged Covid patient as opposed to 15 per 1,000 patients in the control group and similar with cardiovascular disease. So, these are underlying problems developing potentially because of the infection and they need to be picked up, so that's the investigation and then treating these conditions promptly because we know how to treat them.

And then what we don't know how to treat, we need to basically ... you know we have the Long Covid clinics, we have to learn how to do it, there are rehabilitation approaches, if they are appropriate and if these are conditions that, serious conditions can be excluded we could try and I think the research will tell us more about that, but basically these are the stages.

**Barbara Keeley MP**

Thank you, and Professor Altmann.

**Professor Danny Altmann**

Yeah well you know as a medical researcher I'm sort of contractually bound to add to those points that we have to understand the pathophysiology, what's going wrong, what are the mechanisms so that instead of offering people platitudes or symptomatic treatment we can work out what to properly do for them so that they can have their old lives back and I think that's doable and we have the will to do it and just take this one really seriously so that we know, you know it's great to have Long Covid clinics but we need to know what to do for people once they're in them.

**Barbara Keeley MP**

OK, thank you. Thanks both. Thank you Chair.

**Caroline Lucas MP**

Thank you, so we are almost out of time and I just wanted to put one last question which is potentially quite a big question but it just came out of what you just said actually Professor Altmann, really about people who have been living previously very healthy lives and suddenly their lives changing actually very, very quickly and also at a time when there's so much isolation and I just wondered if you could just finish by saying a few words maybe about what you're aware of in terms of the mental health impact of how this is striking people because it must be just so difficult right now. Maybe Professor Altmann first.

**Professor Danny Altmann**

Well, let's go to Dr Alwan first because again she's been living and breathing this for a year now.

**Dr Nisreen Alwan**

Thank you, thanks Danny. So, I think huge, the mental health problem is huge. There is the mental health burden of having a condition, being very anxious about having it and not knowing where you will end up, whether you will get better. Not getting the recognition so therefore you know that creates a lot of anxiety but also we're seeing now the pattern is there are people with symptoms developing, so there are cognitive symptoms developing, you know there are neuropsychiatry symptoms developing, you know a wide range so something triggered by the illness itself. So, I think the burden, the mental health burden is huge really and we need to kind of ... we need at least to relieve the mental health caused by not getting adequate recognition, not being able to take time off work and be off sick and try and recover properly, having adequate care and we need to properly look at the mechanisms and potential treatment for the issues caused by the infection.

**Caroline Lucas MP**

Did you want to add anything Professor Altmann?

**Professor Danny Altmann**

Nothing I could possibly add to that, it's big and it needs attention.

**Caroline Lucas MP**

Thank you so much and in particular Dr Alwan we wish you very, very well in the future and hope for a speedy recovery, I mean the evidence that you've both given us has been so powerful and just looking at the chat I know that many of our colleagues have found it incredibly powerful and very, very helpful as well. So, we'll do our very best to reflect the considerations that you've put before us with other colleagues and with Ministers and Government, so thank you again so much and thank you to all of my fellow panellists for this session and now I will bring it to a close, so thank you again.

**Dr Nisreen Alwan**

Thank you so much, thank you.

**Professor Danny Altmann**

Thank you.