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

27 July 2021

### **Philippa Whitford MP**

Thank you, very much and good morning, and welcome to this evidence session of the All-Party Group on Coronavirus. I'm Dr Philippa Whitford, one of the Vice Chairs of the group and I'm chairing this morning. My thanks to our witnesses, we have Ian Archbold who is an Advanced Emergency Medical Technician with North East Ambulance Service. We have Kathryn Harries who was a Hospital Pharmacist in the Royal Gwent Hospital. We have Dr Eleanor Mountstephens who is a GP for over 20 years in her practice and Heather Jones who was a teacher for 30 years. All of our witnesses this morning have suffered from Long Covid and we are going to be exploring their experience and what we can learn from it. And first of all I would like to just give my thanks to all of you, obviously for attending today, but particularly in a way you represent the frontline key workers in many of our public sector, in health, in care, in education but also in local government, police and fire who kept all of us safe, kept us connected and kept our society functioning through what has been a very difficult year and a half, and obviously we are now going to explore the outcome of that for you personally and how you should be supported going forward.

So, if we just crack on, I'm going to ask the first question, Chair's privilege. So if I could start with Eleanor, do you know or can you pinpoint how you got Covid-19 in the first place, you know was it at work, can you identify that, is there anything that could have been done to prevent it and is there a way of you demonstrating that's the time and place that I am certain I got Covid.

### **Dr Eleanor Mountstephens**

Morning, yes I developed my first symptoms actually before the first lockdown and I am as certain as I can be that I caught Covid as a result of the work that I was doing, mainly because the very tight timeframe between exposure and when you get symptoms I actually saw a patient who was very obviously very unwell with Covid and who had managed to get into the surgery building with symptoms without anybody realising that they were there, they weren't actually there to see me but once I realised that they were there and they were unwell I felt absolutely bound to treat them. And this was at the point where we were only supposed to don PPE when we saw somebody who had identified symptoms. So he had been sat right outside my room for about an hour before anybody had realised this, so for about an hour I was in and out, thinking he was seeing somebody else. He was classically unwell with Covid at that point, so because I was being careful in every other aspect of my life I would say that as certain as I can be that is where it came from, but can I prove that? That's an impossible question. I can prove that I got Covid because I was admitted and I was swabbed and I did test positive and I know a lot of my colleagues were never in the situation of being able to be tested, but I know I had it and I can work backwards because where I am we had not very much Covid, we had a cluster, so I could pin it, so as close as I can be, yes.

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**Philippa Whitford MP**

Was that already at a time where the proposal was that people who thought they should have Covid should be following a different pathway rather than going to their practice but just this patient had, or had that not been set up yet at that time?

**Dr Eleanor Mountstephens**

We were still ironing through what should happen, people were supposed to be ringing 111 but 111 were still sort of then saying oh you should ring your GP and I think, and you'll have to bear with me one of the impacts has been a very shaky memory. I think he was expecting, he was on a list to be telephoned to go through the triage process so that if he needed something we could be prepared or we could direct through to the ambulance service, what he actually needed was an ambulance. And somehow he'd ended up in the building. I don't know how that happened, I just know that I picked up the pieces when it came about. So yes, that was at the point where we were trying to put safe pathways in place and there were lots of teething problems.

**Philippa Whitford MP**

OK, thanks very much, Ian, Catherine, and Heather, would any of you like to add about your own identification of when you caught Covid and whether it was unavoidable?

**Ian Archbold**

Yes, I would if that's OK?

**Philippa Whitford MP**

OK, Ian.

**Ian Archbold**

I mean for me there's no sort of doubt in my mind whatsoever that I contracted this at work. Like the doctor says, you can't sort of prove it categorically where you got it, who you got it from, but just given the very nature of my job the fact that I was expected to go into what I would call Covid-rich environments. You know attending to people in their homes who clearly had Covid, the odd one may have tested positive and for some reason obviously they'd become so unwell they needed an ambulance, then sat in the back of an ambulance with them which is quite a small enclosed space, and then also going to Covid wards in the hospital and the Covid side of the A&E Department, we were absolutely exposed to it and yes, we had PPE but in my mind and the vast majority if not all of my colleagues frontline on the road, we believed that the PPE that we had was just wholly inadequate.

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We had basically a flimsy plastic apron that if you're lucky it covered 25% of your body, if you went outdoors or anywhere where there was the slightest breeze the wind would catch it and it would blow it up over your face. And the masks to be fair, the surgical masks like you see most people wearing sort of on the TV and in the supermarkets, they're not really suitable for protecting against virus particles, you need better protection, you need a higher grade of mask. That's all we had. So for me I'm sure I caught it at work, there's no other explanation. My wife was already working at home by then, she's a civil servant, she was working at home from March. I got my first symptoms 9<sup>th</sup> of April.

**Philippa Whitford MP**

During the first wave?

**Ian Archbold**

Yeah, 9<sup>th</sup> of April.

**Philippa Whitford MP**

Were you tested? Did you have a test?

**Ian Archbold**

I was, yeah I went to work 9<sup>th</sup> of April, I had a very slight irritation at the back of my throat as opposed to a cough, it was making me cough slightly, I had to ring Control to let them know and straightaway they said right you're gonna have to come off the road and go and be tested. So I went to get tested, I was sent home that day and waited for the result and the result came back negative on the 10<sup>th</sup> of April. So I was told I had to come back to work on the 11<sup>th</sup>. So I had two more shifts to do. And over that weekend I just got progressively worse and I really started to strongly suspect that I had Covid, the coughing became more pronounced and in effect you know I was at work for two days, for me spreading the virus round, you know going into nursing homes and dealing with vulnerable people and the like. That was for two days, and then a couple of days after that I became so unwell I got another test through my GP and that one came back positive. The result of that was the 17<sup>th</sup> of April, the test was on the 15<sup>th</sup>.

**Philippa Whitford MP**

OK thanks very much, Ian. Heather.

**Heather Jones**

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Yes, I'm very similar to the others. I am, you know pretty sure that work is where I caught Covid. I caught it at the very beginning of the second lockdown in November and I was being so incredibly careful, we weren't, pupils weren't allowed really to wear masks at the time, the Government was telling us it really would interfere with our job, so it was better that nobody wore masks. My school had said that staff could wear masks and I'm even quite sure of the actual incident that infected me because my school had decided to do mock exams for year 11 and I was invigilating in a hall where there was no ventilation with 180 students, and I became ill just days after that. And the evening that I went home and got symptoms was also the day that that entire year group got sent home because of more than one positive case in that year group and it then seemed to just spread throughout the staff. I am pretty sure that I did infect at least one colleague on that Monday that I was in work and didn't realise that I had Covid.

### **Philippa Whitford MP**

And obviously that's one of the key challenges of Covid is that you can be spreading it and you simply don't know. Kathryn, have you anything you want to add before we move on?

### **Kathryn Harries**

Yes, I'm certain I caught Covid in work, so I was a ward-based pharmacist and my ward became a Covid ward before the first lockdown happened and at that point when the first patient was on the ward with Covid, or suspected Covid, we didn't have the PPE because it was so sudden that it was realised that this patient had symptoms and it was only that you wore masks and PPE when you were in contact with patients and there have been studies now that prove that Covid particles would be in the air in the corridors. And my whole team, or the whole team working on that ward fell sick with Covid. A lot of the pharmacists I worked with fell ill with Covid. I didn't get a swab, so I can't prove via a swab that I had Covid but I had all the symptoms and my partner tested positive three days after I did. I just wasn't eligible for a swab because at the time they were only testing 25 healthcare workers a day in my Trust. And I think the biggest kick in the face then was when I returned to work and on my return to work form they put it was a community acquired infection because we couldn't prove it was caught in work.

### **Philippa Whitford MP**

OK thanks very much. We're going to move on now and I'll bring in Ilora, Baroness Finlay.

### **Baroness Finlay**

Thank you very much indeed. I want to ask you all really how you came to think that you had Long Covid, how that realisation happened and I think possibly I might start with Dr Mountstephens again and then go round each of you to add it in.

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**Dr Eleanor Mountstephens**

Sure. I have never got well, so I haven't had an acute illness and then a recovery and then become unwell again, for me it's just gone on and on and I now have recognised end organ problems, so I have myocarditis, pericarditis, neuropathy and all of the cognitive stuff. By June of last year, so about two and a half, three months in, I was flagging up to my GP that I thought there was something wrong with my heart and something wrong with my brain because they weren't working very well and I had all this pain in my hands and my feet. So I just went from not being able to breathe properly and feeling unwell into these things and so there was never a point where I went it's something new.

**Baroness Finlay**

Right. Ian?

**Ian Archbold**

Yes, well as I said before my symptoms started on the 9<sup>th</sup> of April, I've always sort of said that my actual illness with the Covid virus lasted roughly 20 days, so back end of April is when sort of the Covid ended if you like. What leads me to say that is basically my temperature came down finally and I didn't feel quite as unwell, because one of the big things for me with the illness when I had Covid was pain, I had horrendous pain in my back, I had a lot of pain in my chest but that was sort of when I was coughing which was a lot of the time, and I had horrendous pain around my kidneys and the top of my pelvis and stuff. That eventually all sort of petered out, so from sort of back end of April I just sort of, I was left with really, really bad fatigue and for me just sort of taking the dogs out for a little walk was a massive effort. I mean the first time I took the dogs out that was the first time I'd been out of the house for nearly three weeks and I literally got to the end of my street, and you're talking about 30 or 40 yards, and I felt as though I was going to have to sit down, I really had to sort of stop in my tracks because my legs were literally like jelly. I just felt I had no energy at all. And that went on for about two and a half months and that was being investigated by my GP so I mean I had headaches as well, the headaches were continuous, so I started getting blood tests and things and just over a period of a few weeks from when I classed my actual Covid to have ended at the end of April, I think that within three or four weeks myself and my GP started to go down the route of well this is all the after-effects of Covid and by then it was in the media that there was a think that they were looking at called Long Covid and basically I was sort of going down that route and here I am 15 months later, still with a massive list of symptoms that just basically don't seem to be getting any better. The only thing that has improved is the fatigue in terms of I can walk the dogs fine now, I may breathe a little bit harder than what I would expect to normally, but everything else is there and it's just not going away.

**Baroness Finlay**

Thank you. Can I just go to Kathryn and then to Heather, thank you?

**Kathryn Harries**

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Yes, so with my Long Covid I first knew something was wrong just after I recovered when I tried to go for a run, I used to be very fit and active, I'd go to the gym five times a week before I had Covid and I tried to go for a run and I could only run for a minute and I had to call my sister and tell her I was so out of breath, and then it sort of came in waves but by May I was very wheezy and tight-chested so I spoke to my GP and they weren't too bothered but then by the weekend my housemate was very concerned, she's a doctor, and she was worried I had an atypical pneumonia so referred me to GP out of hours who then brought up this idea of at the time it was a post-Covid syndrome. It sort of went from there, so my Long Covid comes in waves, so I have these flares, they get triggered by things like stress, so it's quite difficult with life because you don't know what's going to happen and any little trigger, like I've just bought a house and that was a massive stress and it's caused these flare-ups. So I get tight-chested and for a few weeks I'm out of action, but that's sort of how I realised it was just that gradual pressure of those symptoms and the wheeziness.

### **Baroness Finlay**

So they're really all slightly different presentations from each of you aren't they? And what about Heather?

### **Heather Jones**

I actually started to suspect I'd gone into Long Covid territory probably six to eight weeks after the infection because by then I'd stopped getting the fever and the unbearable night sweats and I went through this phase of feeling like I woke up every day thinking what weird new symptom is gonna surprise me today. And I started to look online for some sort of guidance and support and it really was the social media groups that were the greatest source of information and support for me at the time, and I realised that I had that typical cluster and constellation of symptoms, fatigue, breathlessness, tachycardia, post-exertional malaise, brain fog. The brain fog was so bad that I couldn't really establish between reality and dreams at times. I couldn't remember even my own family members at times, that was pretty terrifying.

### **Baroness Finlay**

Thank you, thank you all for explaining that. We're gonna move on now, thank you. And I think Baroness Masham is asking the next question.

### **Philippa Whitford MP**

Yeah, if we can bring you in Susan, thank you.

### **Baroness Masham**

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Yes, my question is similar but we want to go a bit further. What has been your experience of living with Long Covid, do you find there is stigma and stigma at work, and do you feel you have enough support? It is complicated, I have a member of my family with Long Covid and it is very various, anyway could we hear from perhaps Heather first?

**Heather Jones**

Long Covid has absolutely impacted quite severely on every aspect of my life. I describe it to people as it has taken everything that I have that makes me who I am. You know when your cognitive abilities are impaired it takes you, it takes your personality, my sense of humour, physically it's absolutely devastated me. It's put my job at risk, a job that I love that is part of who I am. It's made friendships a little bit of a strain because I worry that gosh, I'm just not giving anything to friendships, I'm just such a burden, how boring I must be to be with because my life is Long Covid and it seems to be all encompassing quite honestly.

**Baroness Masham**

Thank you so much, and Dr Eleanor.

**Dr Eleanor Mountstephens**

I completely agree with Heather, the things that made me me have gone, I have worked for the NHS since I was 23 years old and I've always worked really hard and being a doctor, being active in that is a massive part of me and that's gone. Instead I am walking a tightrope every day of trying to manage what I do so that I can do the things that I have to do and the things that I have to do involve keeping food in the fridge and on the table and I feel, I agree, I feel like I'm boring, I'm uninteresting, I do nothing. I can't even read. I can't watch a film. I can't do anything that requires concentration. I worry that I am being a barely adequate parent at the moment. I have two teenage daughters and I'm not being what I should be and when I'm not even being what I should be at home, I don't even now have a job to not do that. So, stigma ... yes, I feel uncomfortable telling people that I have Long Covid. Back in the beginning I would say I've had Covid and I'm still recovering but people look at me and they go well you look well, my face is ... yeah there's no marks on my face. But try walking and talking with me and I can't do that. It's too much. And I barely go and see anybody, yeah it's huge and I don't share it. I don't talk about it on social media outside of my groups.

**Baroness Masham**

Do you feel you should have had more help?

**Dr Eleanor Mountstephens**

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I'm not sure what sort of help you mean. I don't know, support ... well my family is not close so there's no family support. This is I think an illness that is unique in that when you get it, you have to isolate and everybody stays away. Now with any other illness, a cancer, a heart attack, people rally round and they bring you cups of tea and in my worst point I was alone at home for the days I had to isolate, I remember crawling across the kitchen floor trying to get myself a cup of tea because there was nobody else and then trying to figure out whether I was going to make it back upstairs to my own bed because there was nobody else. And this has been an incredibly isolating experience and I'm an introvert and I feel isolated. When you're ill reaching out over video and over the phone becomes really difficult, when your head hurts, when you're tired. When you can't string words together, this is taking me an enormous amount of effort. When you can't communicate well, yes you run out of everything and I'm not lucky, I don't have a big support network around me.

### **Baroness Masham**

Thank you so much for sharing that with us. Now we have Kathryn.

### **Kathryn Harries**

Thanks, so for me with the Long Covid I've gone from being a healthy young adult to someone who now has to take inhalers every day, like I was saying earlier my fitness has gone downhill and I'm trying to improve that but it's quite difficult when you have these relapse and remitting waves of symptoms and it's trying to keep positive, it's put a strain on my relationship, my partner really struggled to understand why suddenly his girlfriend just wanted to sit in bed and not do very much. And similarly with my family, my Dad really struggled to understand it, he suggested before that perhaps all I needed was some counselling. It has been very difficult and it's been difficult getting people to understand, so I think that's been the impact really. Like the others say it is quite difficult explaining to others and I don't really say to my friends anymore about my Long Covid, so as far as they know I'm fine because it's just easier that way.

### **Baroness Masham**

Thank you so much, and now we have Ian.

### **Ian Archbold**

Yeah, hiya. Like Dr Eleanor said, to look at me there doesn't look like there's particularly anything wrong, you know I look fine and I do sound fine, but to be fair Covid has absolutely stripped me of my health and fitness. I'm on medication now, I'm on six types of medication that I was never on before. I was, I mean you could say I was exceptionally fit, I ran for England for nine years in the 1990s, so I've got this natural fitness and it's just taken all that away from me. It's left me with a weakened immune system and to be fair that's the main reason I'm not back at work, there's no way I want to go back to doing my job with a weakened immune system with the potential of getting Covid again or picking up any other sort of infectious disease. It's just not something that appeals to me. But the fatigue, the

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tiredness and the breathlessness again would stop me going back to work anyway. I've had all the tests, I've been to my GPs numerous times, I've had loads of blood tests, that's how they found out about the immune system. I've had x-rays, chest x-rays, I've had ECGs, I've had an ultrasound of my heart because I get palpitations and I've even taken part in a clinical study into Long Covid. I went to Oxford, there's a company doing a study called Cover Scan and I had basically an MRI scan on every organ in my body except my brain and there was an issue came up with my pancreas and my liver as well, whether that was there prior to Covid, I don't know. Nobody can say. But they are finding a pattern and they've scanned a lot of people and there's a lot of other people got issues with their pancreas and their liver and then there's all the people with the myocarditis like Dr Eleanor's got and so it starts to create a pattern anyway, you know and all these people surely couldn't have had all those things wrong with them prior to Covid. So there's a whole host of things it's left me with, again I tend not to talk about it much and if anything I would say I'm sort of embarrassed to say that I'm now, I've gone down that route of being somebody who's not disabled or but I'm basically now medicated for a whole host of things and you know I've went from suddenly being a normal, fit person to bang, Covid and then I've got all these issues and there's no sign of them going away. So I think there is quite a bit of stigma with it, I don't advertise it much myself on Facebook, I tend not to go on there much nowadays anyway, but it's not something I sort of parade about and I certainly wouldn't want to wear a badge to say I've got Long Covid. It does affect you mentally, I've had two rounds of counselling myself, I've had counselling through my employer and I've also had counselling through my GP, I mean I would just say really just for me it affects my mood, I can get sort of good days and bad days because the thing is it's there constantly, it doesn't go away and there's a constant reminder that you've got all these symptoms and it just wears you down to be fair. I try and get on and do stuff, as I said earlier I walk my dogs, I can do that. I've even started going in the gym and doing a little bit, but it's a massive effort to what it should be. So, that's where I'm at with it to be fair.

#### **Baroness Masham**

Well thank you very much, we mustn't run out of time but it just shows how complex the whole thing of Long Covid is and how it needs to be understood better. Thank you all very much. Back to Philippa.

#### **Philippa Whitford MP**

Thanks very much Susan. OK, thank you. We come to Barbara Keeley now for the next question.

#### **Barbara Keeley MP**

Thank you and I would like to add my thanks and I believe Debbie has made comments in the chat that you know it's ... we can understand how frustrated the situation is, or we can hope to try to understand what you're saying. Can we move onto the question, how was your experience of Long Covid managed in the workplace? And can I start with you Dr Eleanor?

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**Dr Eleanor Mountstephens**

Yeah, so I worked as a GP, and I was a GP partner, and our partnership agreement says that when you've been unable to work for 26 weeks the other partners can remove you from the partnership and that's what happened to me. The reason they gave was that they didn't really understand what was going on with me and they didn't know what my long-term prospects were and they felt that they were unable to wait to find out.

**Barbara Keeley MP**

I'm really sorry, that's very hard at this point in your career, I understand that.

**Dr Eleanor Mountstephens**

Yeah. I had been there as a partner for 18 years, I was a senior partner and I'd thrown every creative bit of juice I had in me into that, it felt like I had lost, I felt like I'd lost family and a home and my place with 11 days of notice and no options.

**Barbara Keeley MP**

That's truly awful. That's awful. Thank you for sharing that with us. May I ask the other members of the panel. Kathryn?

**Kathryn Harries**

So actually in fairness to my previous employers when I first had my Long Covid symptoms they were very supportive and actually on my return to work form they put it down as a Covid absence so it wouldn't affect my sickness allowance which was great, and then actually I changed roles in August, my job is more sedentary now, I'm not ward-based, I work in GP surgeries so actually I find that helps with my symptoms because when I'm feeling unwell I can still work because I'm sat down, I'm not having to rush about and my colleagues here are really supportive. So I do feel I've been quite fortunate with my work experiences with Long Covid.

**Barbara Keeley MP**

Thank you. Could I come to you next Ian? You said that you haven't been back to your work in the ambulance service.

**Ian Archbold**

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Yeah that's correct. From the outset, sort of February/March last year there was a memorandum came out basically that said if anybody contracted Covid because at that point I think hardly anybody had, if anybody to be fair, it wouldn't be classed as a sickness because obviously like a lot of workplaces now if you're off sick for two or three times in a 12 month period and things like that, you know you can be called in to discuss if there's anything going on and that sort of thing. So they said it wouldn't be classed as a sickness and people would be paid and stuff like that. So, I'm very, very fortunate that I am still getting full pay after 15 months because it is recognised as Covid-related, I don't know how long that's going to continue for but at the minute I am still getting full pay. I'm not at work so they haven't had to sort of accommodate me in you know in any sort of special ways to sort of deal with what I've got going on, I do get a phone call once a week from one of my sort of clinical managers, it's what they call a welfare call just to see if I'm OK, can they offer anything which technically there's not much they can do at all, it's just a courtesy call to say we're here if you need anything. And once a month I get a phone call from my Operations Manager who has been lovely throughout this. You know again she has a bit of a chat with me for 20 minutes or half an hour just to see how I am and it's a case of look Ian, if you need anything we're here and basically that's it, so that's how they've managed me.

#### **Barbara Keeley MP**

Thank you, thanks. And this is really mixed experience isn't it on our panel, can I come to you Heather and how has it been managed in your workplace at school?

#### **Heather Jones**

From my perspective less than ideal. My timeline was as I said I caught Covid mid-November and just couldn't return to work. The first contact I had from HR was in February and that was for a formal attendance meeting at which I received a formal warning and was given a very unrealistic deadline to return of six working weeks. I knew that wasn't possible, I wasn't going to be able to return in six weeks, but I also knew that if I didn't they would then give me a final warning, another deadline and I could within a matter of months been out of a job. So, I mustered every bit of brain power I had remaining and appealed against the caution. I wasn't totally successful, the caution still stood but I was given another six weeks which took me to a deadline to return of Monday the 17<sup>th</sup> of May, which you know I did meet but not necessarily through choice, it was more that I knew that I had to. I then had to negotiate a phased return, the first offer I was given was a two week phased return which just again would not have made it possible for me to carry on working. So with my Union involved and the support of my GP I managed to persuade my employer to give me a seven week phased return. It was still somewhat on their terms because it was doing daily much more than I was comfortable with, by then I'd started to learn my limits and what triggers relapses and about a week before the end of the phased return the inevitable did happen and I did relapse. I ended up having three days off work for that and on my return to work I was called to yet another formal absence meeting. I fully expected another warning. At that point they decided to not give me another warning but they gave me a very strong sort of informal warning that if I continued to have time off work I would be sacked. My school have referred me back to Occupational Health and ... sorry ...

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**Barbara Keeley MP**

Are you OK? Yeah, do you want ...

**Heather Jones**

No, it's OK. I have an occupational health appointment on Friday but my school are, I know that they are very keen to really get rid of me, I know this because when I was issued with the formal warning in February they said that they would be willing to enter into a settlement agreement which for non-teachers would mean that they will pay me to go away and give me an agreed reference, but I would also have to sign away my rights to go to a tribunal. Like you can tell I love my job.

**Barbara Keeley MP**

I'm so sorry. No.

**Heather Jones**

So sorry. I thought I could hold it together better than that, sorry, so yeah that was me.

**Barbara Keeley MP**

Thank you for sharing that Heather, I think we can all understand how awful this is and for Dr Eleanor as well, you know, there's so much for you all to deal with but thank you for sharing that because it's very valuable to know how it's affecting people and how different employers are managing it. Thank you, I'll come back to you Chair.

**Philippa Whitford MP**

Thanks very much Barbara and indeed the different experiences of the four of you, so thank you for sharing that. If we come now to Baroness Brinton for our next question.

**Baroness Brinton**

Yes, thank you very much, I'm aware time is running out so my question is about your financial situation and your future prospects, Eleanor very much for you about your current financial situation and perhaps for others you know obviously we've really picked up your concern but worries about your future prospects as well. Eleanor, over to you first.

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**Dr Eleanor Mountstephens**

OK, so obviously I have no income from employment anymore. I have been in the fortunate position that 20 years ago I took out an insurance policy on my income, so I have, I'm in receipt of insurance payments and I'm lucky that the insurance company are agreeing to pay at the moment and I'm hopeful that they will carry on paying and I'm very grateful for their support, but it feels tenuous because it's out of my control. For the months in between I had savings and I have used my savings, but I bought a house last year, one month before I got sick, based on a GP's income, based on the fact that I was gonna work for another 15 years and so I have a big mortgage at the moment and that has me very worried. So, I'm OK because I have a fall-back situation at the moment but it feels unsafe and it feels like it's not something that I can necessarily influence and in terms of my future prospects, being a GP consulting is a complicated cognitive process and at the moment I know that I cannot safely treat somebody, I cannot be certain that I will not make a mistake and obviously the mistakes that I made can be ... well I could kill somebody accidentally, so I need to know that my brain works and my brain needs to work for ten minutes constantly back to back for hours and hours and hours, I have to be able to make several hundred decisions a day, some of which are easy and some of which are critical and it's a day of unexpected happenings and having to manage lots and lots of things suddenly simultaneously and I am so far away from that that I don't know for certain that I will be able to do that again or when I will be able to do that again. I doubt I will ever be able to work as full-time as I did before because that feels like a mountain to climb. So, I don't know.

**Baroness Brinton**

Can I just pick up on that last point because you've explained to us about the GP practice? In other parts of the NHS staff have been redeployed, is that ever a possibility for you, I mean perhaps not as a GP but would it help if the NHS could help redeploy GPs who can't continue with their present role?

**Dr Eleanor Mountstephens**

So I'm qualified as a GP, I'm not qualified in any other specialty, so I wouldn't be able to just go in and work, but also unless you're a very junior doctor you are an independent practitioner, nobody double-checks our work, we work and we make the decisions for ourselves, so I'm not certain and obviously I have some physical stuff going on as well, so I could probably go and get a job in the local supermarket stacking shelves from a cognitive point of view, but from a physical point of view that also is quite a long way off for me. Yes, could I be redeployed? I'm very limited at the moment, I hope I'm not going to be this limited in a year's time, so maybe, if there was something that would be lovely because I am bored and frustrated and angry and I would love to be doing something.

**Baroness Brinton**

Thank you very much. I don't know if your financial circumstances are affected but particularly want to ask you about future prospects.

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**Ian Archbold**

No, as I said I'm getting full pay so I'm lucky in that respect, I mean I am still financially out of pocket if you want to go down the route of the medication I now have to take regularly, six different types of medication, I've lost out on any potential overtime if I wished to do it, I don't tend to do much of it to be fair, I probably average about four or five shifts a year, very little. But it's still a decent amount of money and that option isn't there for me now anymore. Travelling to various appointments, GPs, hospitals for x-rays and scans and all the other things, again that has a bit of a financial impact. In terms of my job, to be fair I don't think I'm gonna get back, I was 56 in June and I didn't really intend working any longer than age 60 so you're talking less than four years now. There's no sign of my immune system improving and all the other effects that I've got going on so basically for me it's just a matter of time before they call me into the office and give me an ultimatum, you either need to come back or unfortunately we're gonna have to stop paying you, in which case that will be me leaving and taking my pension. So for me that means that I've been forced out the door because of ill health so I won't go down the retirement on ill health grounds which would give me a slightly better pension, but I have done the maths, I've worked it out on paper and I'm still gonna lose out quite significantly compared to if I was to stay at work for the next almost four years and earn my full-time salary. So you know you're talking possibly £45 nearly £50,000 that I'm going to be short over the next nearly four years which is quite a lot of money.

**Baroness Brinton**

Yeah, thank you very much. Heather?

**Heather Jones**

Well, as I mentioned my job is constantly in jeopardy, an accepted part of Long Covid is that it is an unpredictable condition and that you can relapse, so I know that the next relapse means that I will get another formal warning, possibly a final one. I believe that I am able to work, I am eight months, I am doing I think really well considering, you know I've worked hard at getting better, I made it my job, but it just doesn't seem quite enough for my employer at the moment. Returning to work has been quite expensive for me, I had to buy a wheeled walker so that I can get around the school, I bought myself a microphone and a speaker because even projecting my voice across the classroom takes energy. I'm not able to make it to the bus stop to get to work so I'm spending up to £25 a day on taxis. I feel that I'm the equivalent of a faulty kitchen appliance that it's just cheaper to throw me out and replace me with something newer, than you know give me that time to get better.

**Baroness Brinton**

Thank you, and finally Kathryn.

**Kathryn Harries**

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Well, so I've recently bought a house and in the process of doing that I looked into buying income protection and life insurance and I found I'm not eligible because I've got Long Covid and they said until I recover I can't get that insurance, so I'm now in a position where if I get sick I have to rely on sick pay from work and knowing from previous colleagues' experience, depending on how you get sick you're not necessarily entitled to NHS sick pay through work. I'm also in the position that if I'm in a position where I can't work or I die, you know my partner is responsible for the whole mortgage, it's a lot of pressure and that has been very distressing. I was heartbroken when I found out, you know I got sick at work and now I can't protect my family and my partner and my loved ones, so it's very heart-breaking. I mean it's been very difficult.

**Baroness Brinton**

Thank you, thank you very much. Philippa back to you.

**Philippa Whitford**

Thanks very much Sal, and finally to Lord Russell. I'm sorry we're over-running but it's been so important to hear all of your voices in this session, thank you.

**Lord Russell**

Yes, thank you very much indeed it's very moving and very impactful and extremely helpful. Very briefly, given what we've been talking about realistically what can, do you feel, the Government and/or your employer or the NHS do to help you, what do you think is realistic and what are your expectations? Eleanor could I ask you first?

**Dr Eleanor Mountstephens**

Gosh, that is such a difficult question. From the perspective of Long Covid, support those of us that have it as acknowledge the diagnosis, help us to understand what is going on and help us to battle against the you're just anxious, if you go back to work you'll be fine narrative that has dogged I'm sure all of us. I was brought up to be, to expect to be independent and to support myself and to support my family and it is very difficult for me to even recognise that maybe help is necessary but we, I signed up to be a doctor to help people to do my best and we ended up almost being thrown into, it's more like being thrown into a battle than anything else by we were asked to carry on doing what we did and to do our best to protect ourselves but at the point where I got sick we didn't even understand how best to protect ourselves. And when I became ill I thought to myself OK, you're 48, you're white, you're female, you have no long-term health conditions, this should be that mild flu-like illness and you might even enjoy a week and a half's break at home. And then I thought OK so it's either gonna be a mild flu-like illness or I might die. And there was a point where I thought I was possibly going to do dying, but the thought that I was going to end up long-term unwell was never there, it was a very binary thing. So I feel like I have been battle injured and I don't like to say I think there should be compensation because that goes against my grain of you manage yourself, but actually I threw myself

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into a situation of risk in a profession where that risk should never really have been in existence. And like Ian, I've taken a big hit on my pension, like Kathryn there's no such thing as death in service for me now if I die, that's it, and there's nothing I can do to boost my protection for my family. Yeah, I don't have any easy answers.

**Lord Russell**

Yeah, thank you very much. I'm just conscious of time, Heather could I ask you to be very brief and just say realistically what would you hope for?

**Heather Jones**

I would definitely really agree with Dr Eleanor that we threw ourselves literally into the line of fire and trusted that people would do right by us and that isn't the case at all. So I call on the Government to do something to help protect our jobs, we are valuable, we've proved that enough over our careers, please help us now, do not throw us away, we are not worthless, we are not useless, we still have value. Sorry.

**Lord Russell**

Yeah, thank you very much. No, thank you very much. Kathryn anything to add?

**Kathryn Harries**

No, I think I agree with the others, I think the Government do need to look at financial support, potentially compensating frontline staff with Long Covid, we have done our part and we've been injured and if you were in the Army you'd be entitled to pay-outs if you got injured and so I agree with the others, I think something needs to be done.

**Lord Russell**

Thank you very much, and finally Ian, anything to add?

**Ian Archbold**

Not to add really, it's just the same sort of feelings, I mean obviously again and I've said it a couple of times, I'm very fortunate and I'm not too far off retirement neither, so but there are people a lot younger than me who are faced with losing their jobs, who have lost their jobs and for me that's unacceptable, if it's Covid and it's Long Covid and especially if we're going down the route that it's

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been contracted at work in the first place, I think it's unfair and there should be protection for people's jobs and then you know also there is the financial side of it and I think the majority it affects us financially in various ways and for me as I said if I do have to take my retirement in the next few months I'm going to lose out financially quite significantly and I think it's unfair and the only way sort of that you can be comforted and supported is financially for what you've lost because the actual Long Covid, nobody knows what it is, why it is, my Consultant said that to me and I agree with him, so it's just the actual real hard facts and the real impact that it's having on people and I think the vast majority of that boils down to financially.

### **Lord Russell**

Thank you very much, Philippa back to you.

### **Philippa Whitford MP**

OK, thank you very much and if I can thank our four witnesses, Heather, Kathryn, Ian, and Eleanor for your very moving and powerful testimony, that has been really helpful. You're very welcome to stay and hear the second session, I appreciate that that may not be something that you feel able to do, but you are very welcome.

We're now moving on to listen to some of the bodies that you know we may be calling on to support you, but equally who face challenges relating both to Covid and Long Covid, so if I can introduce our witnesses and thank the second panellists. We have Danny Mortimer who is Chief Executive of NHS Employers and Deputy Chief Executive of the NHS Confederation. We have Quinn Roache who is Policy Officer at the TUC who have done recent surveys looking at the impact of Long Covid. And we have Paula Cole who is Partner at TLT Solicitors but has 25 years' experience in employment law and I thank all three of you for attending this panel to give your evidence. So, having listened particularly to the last evidence from our witnesses who have suffered Long Covid, I'm going to ask you all what protections you think should be in place to support those living with it. Now I recognise particularly for yourself Danny that you know the NHS has really been in the spotlight throughout the Covid pandemic, both in remodelling itself, in looking after people in the acute circumstances, in delivering vaccines which obviously people have really appreciated the NHS as never before, but it does put you under a spotlight, so if I can start with you what protections do you think we need to have for people who've been these frontline key workers looking after the rest of us through the pandemic?

### **Daniel Mortimer**

Thank you Philippa and thank you, it's nice to see you and your colleagues again. And I did catch the end of the evidence from colleagues and it is very moving and it very much tallies with what members are telling us and the issues we've been talking about with our trade unions. It may be helpful just to remind the committee that the arrangement we have in the NHS at the moment is that at the beginning of the pandemic we did put in place an agreement with our trade unions, a set of arrangements which Ian I think touched on which were about fundamentally were motivated by infection prevention and control, making sure people didn't attend work if they had Covid or were

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being asked to isolate, and those enhanced arrangements which don't count against someone's sick pay entitlement, don't count towards their sickness absence record are still in place. The were only ever intended to be temporary but you know clearly our expectations about how long the pandemic would impact us as it has have had to be constantly re-evaluated.

I think where we find ourselves now is very much we do have in place some arrangements and again I think Ian set them out very clearly that we've always had for people in terms of accessing their pensions if they're permanently not able to work and that involves enhancements to pensions if there is that sort of permanent inability to work in any role. We do have a very generous sick pay scheme relative to other sectors of the economy and we also have some temporary allowances that allow people to phase back into work.

What we're faced with, and I'm sure other colleagues on the panel will talk about this, is just employers now wanting to have more certainty and more guidance in terms of the conversations they're having with staff. There are a range of circumstances, I think the default very much is about people who want to come back to work in some kind of form, we are absolutely looking at how we can redeploy and protect people's earnings for periods of time in that, but at the moment there isn't the certainty in terms of both Covid and Long Covid actually, in terms of their impact on people. And I think we'd all appreciate, my members would appreciate, more guidance and if there are to be enhancements to the benefits that we offer staff or if there are to be enhancements to economy-wide compensation schemes, I know the committee have called for something previously modelled on the military scheme, then we would really like that for people like Ian and other colleagues to be implemented sooner rather than later.

**Philippa Whitford MP**

So that's really a call to Government both to give you a level playing field of guidance and to come up if you like with that support for you to then support your frontline staff.

**Daniel Mortimer**

Indeed.

**Philippa Whitford MP**

OK thank you very much. If I can come to you Quin, what would you feel from obviously the TUC covers a much wider industry, what are you seeing?

**Quinn Roache**

Thank you. A real pleasure to be invited to talk to you about the evidence we've gathered, but before I even start I just want to reflect on two things. One thing that Eleanor said she said that she felt like she had been 'battle injured' and Heather Jones a second ago said she felt like she was in 'the line of

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fire', and I don't mean to continue this kind of war metaphor that we're hearing but I've been thinking about the number of people who have contracted Long Covid and what that means and for me I think there's a clear link of having Long Covid and being disabled, and I can't think of another event that has disabled as many people, because we have around two million people who have been disabled by this. The only thing I can think of is World War One and so I think it is an apt metaphor that we're looking at here.

But what needs to change, what does the Government need to do to support people who have Long Covid, I think the first thing that I would say is that they need to extend the protections of the Equality Act explicitly and immediately to cover these groups of people, the Government can define any condition as a disability and that would therefore give anyone who has Long Covid the protections of the Act immediately. It would do something else as well though, it would mean that the Government, people who have Long Covid must be considered by the Public [inaudible 1:04:55.4] so the Government would have to consider people with Long Covid when making decisions, making policy decisions which isn't something we can say is immediately apparent in their decision making processes at the moment, so it would be good for workers and good for the Government to consider it. I think we need to increase statutory sick pay to the living wage of around £330 per week, you know with this many people being off ill with Long Covid for different periods of time it's so important that they can live.

Universal Credit needs an overhaul and I won't go into depth, we know it's not working, it needs to work. And we also think another thing that would be helpful is a day one right to flexible working, so I think what we've heard from Heather and Eleanor and Ian is that the fluctuating nature of the condition that they have of Long Covid and actually having access to flexible working and flexible phased returns is so important, it came up time and time again when we speak to people who have Long Covid and in our evidence, so we need to get a day one right to flexible working and to get flexible working to work for us.

### **Philippa Whitford MP**

Thank you very much. And if I can come to you Paula?

### **Paula Cole**

Thank you, the point which Heather made in relation to the process which her school had taken her through really resonated with me because it is a situation that many employers across lots of different sectors are dealing with and trying to address and the problems of Long Covid and illnesses of this nature for both employers and employees is a difficulty in knowing exactly what they're dealing with. So I would very much echo Danny's point about there being a need for more guidance and more support for employers across many, many sectors. Obviously not just the NHS, but across a number of different sectors in terms of having clear guidance and in terms of knowing what they're doing and knowing how they need to progress, because as we've heard this morning every case is different, every sort of individual presents differently and for many employers trying to sort of plan their workforce, deal with the issues arising and treat fairly individuals who are going through such difficult situations is a really difficult position for them. So I think the point has been touched on in terms of

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categorising this illness as a sort of industrial disease would help and address a lot of the issues and concerns because without that individuals in the situation are, like many individuals in our society, dealing with long-term health conditions in the workplace and yes they have protections from unfair dismissal, leaving aside the question of whether or not this should be a disability under the Equality Act, and employers have to go through what can often be a very long and complex process, but it's also a difficult process for both the employer and the employee. So I think there's much more that can be done to give clarity for both employers and individuals in this situation.

**Philippa Whitford MP**

Yeah, I think that's the thing, I mean obviously this is on a huge scale as Quinn talked about and relatively new and hugely varied condition, while we've obviously seen many other post-viral syndromes, they are all different and even within Long Covid obviously a huge range. Thank you very much. If I can bring Susan, Baroness Masham in to ask her question.

**Baroness Masham**

We are hearing how a diagnosis of Long Covid impacts on a person's ability to get life insurance, what should be done about this? In the field of disability I find that everything seems much more expensive. Could we first have Danny please?

**Daniel Mortimer**

Thank you Baroness Masham. There have been discussions I know with the Association of British Insurers during the pandemic, particularly led by my trade union colleagues because we also had examples of people who had had a positive Covid test who were struggling to get access to insurance products and a very helpful agreement was reached with the ABI led by the BMA in particular. But clearly, again, we return to this point about clarity, we return to this point about in the absence of clarity our colleagues in the insurance sector are perhaps making decisions that are not in the best interests of their industry longer term and we need to have more clarity about Long Covid and what it means, its status relative to other long-term conditions that people have to live with and that insurance companies do have to treat. You do raise a second and more important point that as a, on behalf of our members caring for the community, and there perhaps is something overdue in terms of access to financial products for disabled communities because there is I think quite a lot of evidence that there's a broader issue here in terms of how that industry treats members of the community who have disabilities. But again, the primary point in terms of Long Covid is around clarity and guidance and insurers can adapt in the light of that.

**Baroness Masham**

Even with holiday insurance, that seems to be more expensive.

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**Daniel Mortimer**

Indeed, there's a whole set of things I know, this is a longer standing issue that you and others have campaigned about now for some time.

**Baroness Masham**

Thank you so much, now we have Quinn.

**Quinn Roache**

Thank you very much, I don't have anything to add I think we've covered it quite well.

**Baroness Masham**

Thank you very much. And Paula.

**Paula Cole**

Just one very small point to add, some employers do offer some impairment [ph 1:10:57.7] health insurance but it's certainly not universal across the organisations that I work for, it can be an expensive benefit for employers to provide, even before Long Covid, leaving aside those issues and unfortunately not many employers spend the money to make that investment in their workforce. So, it's a situation where greater investment in that area I'm sure would reap more benefits.

**Baroness Masham**

And do you find that some people can't get life insurance?

**Paula Cole**

So as far as I'm aware the issue tends to be more around income protection insurance rather than life insurance [inaudible 1:11:35.7] Long Covid is not perceived by the insurance industry as a life-shortening disease but obviously it has a clear impact on their ability to work and to earn income, so the issues which I see are very much around income protection and impairment health insurance kind of arrangements.

**Baroness Masham**

Thank you so much, back to Philippa.

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### **Phillipa Whitford MP**

Thanks very much, so then to clarify Paula that obviously would impact people's ability in taking out things like a mortgage where income protection would be central to that, which obviously is very important in people's life choices. If we can come to Baroness Brinton now, thank you.

### **Baroness Brinton**

Yes, thank you very much. Danny, you referred to the complexities of issues between someone who has Covid-19 versus someone who has Long Covid and we heard from Eleanor that whilst some parts of the NHS has been good at recognising that Covid-19 and its direct illness is outside the ordinary sickness scheme, that's not true consistently for Long Covid, and is it right that Long Covid is treated differently to Covid-19?

### **Daniel Mortimer**

So I think it is important to stress of course that general practice has a different status to the people I represent in the NHS, it is a ... general practitioners by and large are independent contractors working in a partnership and there are different arrangements. For the people that my members employ, people employed in the statutory NHS we have a temporary scheme which is still in place which has no time limits on the amount of pay that someone can claim if they're absent from work due to Covid, so I think in practice the distinction between Covid and Long Covid isn't there in financial terms for many people but it's an ambiguity because the scheme wasn't originally envisaged to include Long Covid, it was envisaged to, as I said as an infection prevention and control measure. So that is part of the clarification that's needed as we move forward and that's the first point.

I think the second point then is that there is also some need for clarification about how Long Covid if it does have a permanent and long-term effect how it is dealt with in terms of ill health retirement and is the guidance clear for occupational health colleagues there in terms of making those assessments. I think the third thing is that in practice and I'm sure Paula and Quinn will touch on this for other industries as well, managers are having conversations with employees on a case by case basis and seeing what is possible, how can people return to work flexibly as you mentioned in your questioning, can people be redeployed to other roles where actually their health isn't compromised or could be managed that little bit more easily. And I think it's important to say that even with the kind of guidance and clarity that Quinn has called for and the TUC have called for, those individual assessments are still really important, we can't have a blanket ... our understanding of Long Covid from what our members tell us is that individual circumstances, the individual impact varies enormously so that case by case judgement about what's possible, what's in the best interests of the individual longer term, even with the clarity which as I said before I do think is important, that individual assessment is still going to be really important to make.

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### **Baroness Brinton**

Thank you, that's very helpful, I wonder Quinn if I could come to you next and as Daniel referred just now perhaps broaden it to outside the NHS too and whether there should be formal guidance for organisations, not least the education sector given Heather's evidence.

### **Quinn Roache**

I think that's a really good question. I just wanted to quickly reflect on what our survey found, so we had a survey out and we have 3,500 people say they had Covid and 3,300 people tell us they had Long Covid and in that group one in six told us they had used so much sick leave that they had triggered absence management policies as a result of their Long Covid and one in 11 had used all their entitlement and had been warned that there would be negative consequences if they took more leave. So this is a real serious point for us and a real serious issue. And so what we believe is that Long Covid should be treated as a disability, I mentioned earlier, and we believe that absence linked to disability or in this case Long Covid, it should be recorded separately and not trigger absence management policies. I think that's where we would go with this, we don't want workers who have an impairment to be managed out of work because of that impairment, we want them to be supported to stay in work and if we think about Heather's story from earlier or Eleanor's story, that would have kept them in work or maintained their position, they wouldn't be going through the stress that they're currently going through if their sickness absence was recorded somewhere else. And this is a policy that we've had for actually quite a while for disabled workers in general and we think it should absolutely be applied in this instance as well.

### **Baroness Brinton**

Thank you very much. And Paula?

### **Paula Cole**

The vast majority of employers that I work with treat Long Covid and the symptoms that individuals present with in exactly the same way as they treat anybody else who presents with a similar disease and whether or not they're presenting with ME or CFS or any of those other diseases that can wax and wane if you like, they are treated as individuals in exactly the same way. So in those circumstances as we've heard from Heather, as I said before it resonated because that's the kind of process which many employers are dealing with and they're trying to address the issues on individuals presenting with Long Covid sickness absence or an intermittent absence, whether or not they're able to report for work or whether they're simply not able to make it into work. So against that context they're not recording absence separately, they are dealing with it according to their normal sick pay provisions, whether that be company sick pay or if that has been [inaudible 1:17:53.8] exhausted it then goes to SSP. So in many cases it is they are following a procedure and they are following the normal standard practices which are endorsed by employment tribunals but it can result in a situation where individuals

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are finding that they are either been threatened with losing their jobs, ultimately losing their jobs when they get to the end of that process if they're not able to return to work.

The point which Danny made is part of that process involves doing it right, talk to the individual about their circumstances, what they can do and what the company can do to assist them in either returning to work or remaining in work as part of that process. But it is very much an individual conversation.

**Baroness Brinton**

Paula, thank you very much. Back to you Philippa.

**Philippa Whitford MP**

Thanks very much Sal. Just coming to Barbara now, Barbara Keeley.

**Barbara Keeley MP**

Thanks. Quinn, earlier you said the Government should extend the Equality Act to cover Long Covid, is it the case, it sounds as if it is, that Long Covid isn't already a disability for the purposes of the Act and if it was extended what protections would that bring? I think you touched on one particular aspect but if you could just help us with that.

**Quinn Roache**

Absolutely, so I think that's one of our main recommendations when we looked at the evidence of the 3,500 people who responded, so we think currently in order to be covered by the disability provisions of the Equality Act workers with Long Covid would have to take an employment tribunal and on a case by case basis prove their condition would have a substantial and long-term effect on their ability to carry out their day to day activities and those are kind of the tests in the Equality Act to show that you are disabled by the Equality Act. And what we think is that taking an employment tribunal is a real burden or hurdle for anyone, let alone someone who has Long Covid who might be experiencing fatigue or brain fog. And so we're worried that, and we think that unless and until there's more medical evidence that Long Covid is likely to last longer than 12 months this is the route employees will have to go through and they might not be covered by the Act, so we think that during this time they could, employees or workers could face discrimination and job loss and we don't think that's right based on the fact that the most ... the biggest group of people who would seem to have Long Covid are key workers, workers from health and social care, workers from education, workers who kept the country going during the pandemic, so that's why we think that the Government should use their power to specify that Long Covid is a disability under the Equality Act. And the great thing about that is that they don't necessarily have to amend the Equality Act, they can amend the regulation using secondary legislation so it can be a quick fix and that quick fix could protect a lot of workers from a lot of negative discriminatory cases. And also of course it has the added benefit of making sure the

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Government consider workers with Long Covid and Long Covid in any decision making processes they go through a policy making decisions they take.

**Barbara Keeley MP**

Thank you and Paula do you have anything to add to that?

**Paula Cole**

Yes, as Quinn just said there are currently three disease families which are deemed disabilities under the Equality Act, that's cancer, HIV and MS. So from the point of diagnosis and the point of saying this is a cancer diagnosis they are protected under the Equality Act from that point. It doesn't matter what kind of cancer it is, it doesn't matter whether, to use a broader definition of the Equality Act the cancer is having a substantial adverse effect on their ability to carry out day to day activities, they have that protection from day one of the diagnosis. At the moment that's a very small list and if an individual doesn't fall within that list, if their illness is as I mentioned before ME and CFS, then those situations they come within a broad definition and it is very much individual tests which a tribunal as Quinn said would determine following an application to the employment tribunal. So again it's a question of has it lasted or is it likely to last 12 months or more and in this context Long Covid, we may well find in due course, and I think we're a long way from getting any tribunal guidance on this, it is likely to fall within the definition but it is still very much a case by case basis.

So one issue I have is to differentiate Long Covid from other similar diseases, whether they be ME or CFS and to put individuals with Long Covid in the box of the sort of three and it may be actually better for Government to look more broadly at the definition of what falls within the category deemed disabilities, because I think it may create a sense of unfairness within the workplace if individuals are managing long-term conditions and then seeing individuals with Long Covid being treated differently. And it maybe it happens already in the context of cancer or MS for example but actually maybe a more holistic approach would be more appropriate to look at more generally rather than just adding on Long Covid to that list of deemed disabilities.

**Barbara Keeley MP**

And what specific entitlements would, you know how would the situation change, would it change dramatically for the people that we've heard?

**Paula Cole**

It does, for those individuals who are disabled under the Equality Act it does give them significant amount of protection in legal terms. The most practical protection it gives is there is a legal duty, a positive duty on employers to make reasonable adjustments to accommodate an individual in the workplace, either to return and to remain in workplace. And that is very much a positive duty and that's something which on a day to day basis we engaged with employers because it has a real

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difference. Now they may do it anyway as I mentioned before in the context of a capability procedure, but to have that legal duty on them to address those issues does have a big impact and is of the most benefit to individuals. The other rights it gives them is protection from direct disability discrimination, protection from discrimination arising from their disability which in many respects is a broader protection because it can cover things like absence arising from their disability and also it protects them from harassment and victimisation which in the workplace tends to be of less a concern for individuals who are suffering disability, but the key protections in this the duty to make adjustments and protection from discrimination arising from their disability.

**Barbara Keeley MP**

Thanks very much, back to you Chair.

**Philippa Whitford MP**

Thanks very much and if we come to Baroness Finlay now, Ilora.

**Baroness Finlay**

Thank you very much indeed, I mean I think this is almost first part is a yes/no and the second is a question about other precedents. So, if Covid is prescribed as an occupational disease would that mean that Long Covid is automatically included, so that's the first one and secondly is this is viewed as a death or illness in the line of duty, does that make any difference to the way that it should be managed in terms of the employers and I'm thinking about firemen, police, army, others who may sustain some life-changing event which has been sustained in the line of their duty. I think possibly I'd quite like to go to Paula first and then come to Danny Mortimer.

**Paula Cole**

So, in terms then of occupational disease, I want you to remember of course is that individuals can suffer from Long Covid regardless of where they've caught Covid, whether it be in the workplace, and what we've heard today the experiences of individuals catching Covid, primarily at a time when there was inadequate PPE in place and so very much it is a workplace illness. And I mentioned before that my preference would be not necessarily to single out Long Covid as a deemed disability, partly because that doesn't recognise the fact those individuals have caught Covid through their workplace. So my view is that to address that concern it would be better for this to be an industrial disease if you like, to be categorised and described in that way because that would then recognise the fact that this was caught at the workplace and employers have a duty of care to protect their individuals and as Covid has developed we've seen many employers undertaking risk assessments, making sure they're putting those further protections in place, but in the early days of the pandemic those protections weren't in place and the stories we've heard today very much emanate the situation where the protections weren't in place, there was a consequence of doing their job and protecting [inaudible 1:27:11.3] more

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generally, the individuals impaired from have caught Covid and are suffering consequences. So I think that would be better addressed by being categorised as an industrial disease.

**Baroness Finlay**

Can I go to Daniel and then to Quinn?

**Daniel Mortimer**

So I think Paula makes really important points both in answer to this question and the previous one about other, many other conditions that aren't amongst the three that are designated under the Act as disabilities. I think it is important to stress that my members and I think you've heard some evidence of this, do seek to make reasonable adjustments, do do that without any, many conditions being designated as a disability. What we do have in the NHS at the moment are three benefits that people receive, one is a sick pay scheme that is relatively generous compared to many other workers that Quinn would be representing, and the second is payment of what's called a temporary injury allowance which allows people to kind of have a phased return to work, and the third is if people aren't able to work in the longer term a two-tiered ill health retirement scheme for pensions. We don't have in the NHS the kind of permanent injury scheme that the military have for example, I appreciate it is very complicated but does exist.

I think it is an interesting question about whether Long Covid, given healthcare workers do appear to have had a higher risk of contracting Covid and therefore Long Covid, whether there would need to be access to such a scheme, but I do think it's important that we focus on trying to, as a health service we focus on trying to help people get better and to manage their conditions, we help our employers and employers elsewhere in the economy make the reasonable adjustments that they need to make in order to get people back to work to offer that kind of flexibility. But, this is a difficult thing to express particularly hearing the kind of moving accounts from people, there may well be situations and circumstances, individuals, where it is not possible for them to work at all and in the NHS we can provide access to the pension scheme, it's not a full pension as you've heard described but it is a fairly generous enhancement to the pension, again relevant to many other sectors, but we are aware that what we have is not necessarily available in most other parts of the economy.

**Baroness Finlay**

And just before I go to Quinn, can I ask you what the impact is on the total workforce, because we know that there's a shortage of healthcare professionals in just about all the different branches of the professions, we know that with them off sick that's a problem and we know the load on the NHS is absolutely massive at the moment, and actually it seems to have really taken off again and had relatively little publicity around it.

**Daniel Mortimer**

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Absolutely Baroness Finlay and you know we're experiencing winter in July at the moment which is a quite remarkable turn of events. We have, I mean the evidence that we've seen, we've seen reported is that about 90% of NHS staff, 90-95% of NHS staff who've had Covid have been off work for three weeks or less and it's about 95-98% have been off work for three months or less. We're a massive employer so that couple of per cent who've had the experience that's been described to you earlier today is still a significant number of people. I do think part of the key lies in investment in treatment, it does lie in the kind of education Eleanor talked about in terms of clinicians, it lies in learning the examples of some of the other long-term illnesses and conditions that Paula has touched on and it will be about, and we've got lots of examples of this happening already in NHS organisations, and it's about providing support to people. Fantastic schemes I've come across in Liverpool and Belfast and Chesterfield in terms of trying to provide support to people using occupational therapists and occupational health departments to get people into work and to keep them there, but there's still clearly a lot of work for us all to do to better treat and support people who've got Long Covid.

### **Baroness Finlay**

And Quinn?

### **Quinn Roache**

Thank you very much. I actually failed to mention that we have actually recommended that Long Covid, or workers with Long Covid have access to disablement benefit earlier, so that is one of the things we are calling for and that's based on the fact that in 2020 alone there were over 4,500 outbreaks of Covid in workplaces and that number excludes care homes, hospitals and educations and prisons, so we think there's a very clear link between catching Covid and being at work and we know that several other states have already done so, and when we look at the evidence, you know our evidence from the survey 80% of those who had Long Covid were key workers, a third of them were from education and roughly a third came from health and social care, so we do want to see that group of individuals have access to this benefit. I think that what we know is that you know it will be offered in certain sectors and you know we would support that but we would obviously like anyone who has contracted Long Covid at work to have access to this benefit.

So that's kind of our stance on that but I did want to just touch on something that Paula said earlier which I thought was important to come back on. She's absolutely right, there are three deemed disabilities within the Act, the Equality Act 2010 and we actually think being in a pandemic and hopefully a once in a century event where two million people might have contracted Long Covid and might need protection that it would be a moment where the Government could consider amending that and deeming this a disability. And I take on board her point that some people with say energy limiting impairments might, it might cause frustration, so actually what we did was we spoke to groups who have energy limiting impairments to understand what their thoughts were around us deeming Long Covid a disability and what they said to us is great, that might mean that people start to understand our condition which is really poorly dealt with by employers. So I just thought it was important to kind of reflect on that and I think the other thing that we've heard a couple of times is that employers go above and beyond, they treat people who have Long Covid or their employees with

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Long Covid well, like they were disabled, and that's really great and I really applaud best practice, but that's no way to run a country and that's no way to set the law, it means people have varying practice and varying levels of protection, so I would much prefer to have something clear that protected everybody than something that relied on employers' good will. I just wanted to make those points.

**Baroness Finlay**

Fine, thank you very much and I think Philippa I could pass back to you, thank you.

**Philippa Whitford MP**

That's lovely, just Lord Russell to finish off again, thanks very much Simon.

**Lord Russell**

Right, very quickly, thank you Philippa. So Danny if I could ask you first of all, I mean the umbrella question which we've touched on in various ways is you know what can and should the Government be doing more of, but it does occur to me that all the time we're talking about Long Covid I'm just wondering in actually understanding what it really is, this is an international problem, it's not a UK problem, all over the World scientists and medics are looking at this trying to understand it, trying to codify it, how far along do you feel we are in an understanding of what Long Covid really is and if you like how to categorise it and deal with it. And given where you feel we are along that curve, what do you think realistically the Government should be focusing on and prioritising to help as many people as possible but also to look towards the future. Danny.

**Daniel Mortimer**

I should stress I'm not a clinician, so others on the panel are far more expert than I am. Clearly what we do get told by clinicians is that we're still, they're still understanding the extent of the impact of Covid for the longer term. What we have seen, the first point to make is what we have seen is some investment in specialist service provision for Long Covid and that's been very welcome. I think what ... we've still got further to go there, the Government have still got further to go there. There is a really important need to respond to the demand that we're seeing outside the specialist services that are being set up in primary care for services like occupational therapy and some of the other physical therapies as well as mental health therapies as well because of the impact that Long Covid has there, and I think that's a really important set of steps that the Government need to take to invest in helping people get back to work and the others, with respect to the TUC I think that there's a risk that the debate becomes about compensating people and the designation as a disability and so on, what we see is a need to invest in research and in services that help manage this for the longer term.

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Having said that we would in the, whilst we're still developing the understanding I think there is a need for interim guidance, I've not ... I've talked about that before, I think there is need there and I think there is a need for some adjustment for us in the health service from some of the temporary measures that we've had over the last 18 months into something that takes us through this next phase which may be the next couple of years whilst Government policy and science catches up with understanding Long Covid. And we are really keen to work with our trade union colleagues to try and agree that kind of guidance and to recommend that to the Government.

**Lord Russell**

Quinn, that neatly leads onto you please.

**Quinn Roache**

Thank you. I think you know I am also not a clinician so I don't really have a lot of evidence behind what Long Covid is, how it is contracted, but all I can say is that when we ran our survey we asked about 21 of the most common symptoms of Long Covid and on average each person had nine of them, so you know it's a collection of symptoms, people on average have a huge number of them and it's really concerning. What should the Government prioritise to help workers and people who have Long Covid I think that's ... I've said it before and I'll quickly say it again and I think ensure the Equality Act protections extend to people who have Long Covid, we need to increase and expand statutory sick pay to the living wage, that will help workers who have Long Covid and are off sick, we need a Universal Credit system that is fit for purpose, a day one right for flexible working, all of these things will help and I think getting access to the Equality Act protections and reasonable adjustments is fundamental because it also means then that they have the right to reasonable adjustments as Paula pointed out, like working from home and different flexible working types, so I think that would be really key and if the Government could do that that would help a lot of people. Thanks.

**Lord Russell**

Thank you Quinn. Paula, to you lastly and would you like to comment on Danny's suggestion that clarification quite urgently in terms of clearer guidelines would be very helpful?

**Paula Cole**

Yes, I would very much endorse that point, that was one of the first things I was going to say is that it would be very valuable to many employers. As I said before, it is a difficult situation for both the employer and the employee so having some more clear guidance and support is essential and the other follow up point I'd make is that more access to more support, the more investment in occupational health services to enable and support employers to help people stay in the workplace, to keep people in the workplace, so I think that would be side by side with the guidance that I think would be key at a very practical step that can be taken.

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**Lord Russell**

Thank you very much. Philippa back to you.

**Philippa Whitford MP**

Thanks very much. Paula could I just come back to you, obviously we heard Eleanor's story earlier and Danny has more talked about the big NHS organisations, Trust employers, but obviously general practices are individual businesses with different practice agreements and there is this tendency that kind of as we heard for Eleanor after six months you're out, do you think that the Government should be looking at providing not just the guidance to that but the support directly, I mean primary care is the foundation right across the pyramid of the NHS, if it gets into difficulties the whole thing comes crashing down. So do you think Government would maybe consider looking at both the guidance to the independent contractors that GPs are, but also to protect them. Or do you think some of these things we're talking about, making it a disability, making it an industrial injury would apply in general practice and therefore would have dealt with Eleanor's situation?

**Paula Cole**

I think the answer to your final question is yes, very much so, because the Equality Act doesn't just cover employees, it covers workers, whether they be contract workers, or partners in a partnership which I suspect is what GP practices are very much, so within that category if it was broadened out so that she had the protection of the Equality Act it would have addressed the concerns that she's had and difficulties that she has raised. I suppose one point which I haven't dealt with and it's probably a slightly academic point is regardless of whether or not individuals are protected under the Equality Act, what we do know is that Long Covid does affect certain groups within our society and there is therefore some suggestion that those individuals could bring indirect discrimination claims. Now I recognise that tribunal claims as Quinn said before taking tribunal claims is not an easy step for anyone to take, never mind someone who is suffering from the difficult concept Long Covid presents with, but it will potentially present an option aside from the Equality Act issue, but it's by no means a quick fix or an easy fix. So in that context it very much would have helped the doctor had that been covered by the Equality Act it would have addressed her concerns.

**Philippa Whitford MP**

OK thank you very much and sorry for adding ...

**Paula Cole**

I hope I've answered your question.

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**Philippa Whitford MP**

... at the end. I again am sorry we've overrun but we've had such fantastic evidence both from our first and second panel, I already thanked our witnesses from the first panel, but if I can thank Paula, Quinn and Daniel for engaging with us and for giving us such useful information. So thanks to all of you and take care, thank you.