

## **All-Party Group on Coronavirus - Oral Evidence Session 2**

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### **Layla Moran MP**

I am delighted to have you guys with us, thank you so much Claire, Jake and Robin for joining us. In the session that we are running today we are gonna be doing you guys, obviously long-Covid, we've also got Andrew Gwynne who also suffers from long-Covid himself, he's here with us and I'm delighted that he's been able to join us. Please feel that this is ... while some of these sessions can be very formal we're very aware that you know you guys are not used to being in front of Parliamentarians talking about such things, so we're gonna have it as informal and you know, we just want this as an opportunity to make sure that your voices are heard, but we do have lots of questions from Parliamentarians to you, so my ask is try and keep what is a very complex thing as brief as possible so that we can get through them all. And the view at the end is to then generate a list of recommendations so that we can really push on this on your behalf to Government. So, Tom, are we live already or are we going to go live now?

### **Tom Brufatto**

We're live.

### **Layla Moran MP**

We're live, fantastic, alright well in which case I will get started properly. So, first of all welcome so much Claire, Jake and Robin for joining the All-Party Group on Coronavirus, in today's inquiry we will be focusing on you guys for the first hour on long-Covid, the issues around it, what is it, and what is it that we can usefully do to advocate on your behalf and gain better understanding of what this is and at 12:30 we will then be having a further session with Bereaved Families for Justice, so I will leave the introductions for them later. So just to introduce Claire, Jake and Robin, Claire founded the Long-Covid Support Group on Facebook which I understand has almost 15,000 members which is extraordinary, Claire herself suffers from long-Covid, members of this Facebook group are also here which is Jake and Robin, Jake is a Staff grade Doctor in anaesthetics and intensive care medicine and was in good health prior to contracting Covid-19 and Robin currently writes and works on various projects linked to the global fund to fight AIDS, TB and malaria and gender equality and she's had Covid-19 symptoms since the 3<sup>rd</sup> of May. So perhaps I can start by asking Claire then Jake then Robin what has your experience been of long-Covid, what is it to you and what does it mean for those who perhaps don't know what it is, Claire.

### **Claire Hastie**

I think it can be best characterised as something that can attack any system in your body, so my personal experience I started on 17<sup>th</sup> of March with the mildest of sore throats, barely noticeable but straight away I isolated and kept my children out of school because it was the week before the schools closed and I carried on working. Then Mother's Day, Sunday, I felt like I'd been hit by a bus, my chest was tight, I could hardly breathe, I was frozen to the core for several weeks, so the opposite of what the Government recognised symptom is fever, I was absolutely frozen. I had heart pain, chest pain,

you name it, I had it and then over the weeks it progresses, so sometimes you might find neurological symptoms develop, cardiac, respiratory, other people have gastrointestinal symptoms, you cannot characterise it by symptoms alone.

**Jake Suett**

From my point of view I'd been working in close ... sorry to interrupt, I'd been working closely with patients with Covid on the intensive care, I'd been involved in intubating three the week before I became unwell, I started off with a sore throat and just feeling a bit tired, but by day ten I had a dry cough, was very short of breath, fevers and since then I've sort of had chest pain, palpitations as well, those symptoms have just gradually improved over the last few months, I'm much better than I was but I'm still very impaired on those symptoms even now.

**Layla Moran MP**

Thank you, and Robin.

**Robin Gorna**

Thank you, so I developed Covid later than the others, I had moved from lovely Brighton to London for family reasons and I was writing a lot about Covid because I work in global health and I was filling in the Tim Spector app and started to notice I had a sore throat over a period of time and then I was violently sick on the 3<sup>rd</sup> of May and thought I had food poisoning and I was working on a very intense global health project with a number of doctors who'd been working in Covid and suddenly found all the classic symptoms kicking in and shortness of breath, extreme exhaustion, persistent coughing, not able to get up and bed-bound for a couple of weeks, although I continued to work. I tried very hard to get a test, I wasn't able to get a test. I spent a long time trying to get help from my GP but because I'd moved from Brighton to London I spent a few days trying to get a GP in London to take me on and none of them would accept me until finally I hit on a fantastic surgery in Hackney where all of the GPs had had Covid themselves and having known a huge amount about Covid before I became ill I expected to be better in two weeks and was quite anxious when I wasn't better, especially as I'd come to London because my mother has cancer and so I was very worried about having to leave the house and now I continue to have on-going problems like the others, mainly palpitations but I also have extreme difficulty walking, not as bad as Claire who I understand is now in a wheelchair, but I find that even if I go out for a ten minute walk then I'm stuck in the house for another week afterwards and I used to walk for a couple of hours a day during lockdown, it was one of my great pleasures. So, I'm still trying very hard to work part-time but my energy levels are utterly shot.

**Layla Moran MP**

Thank you, so perhaps back to Claire, what is lifelike now, are you able to work, you're in a wheelchair, how did that come about?

**Claire Hastie**

I've been using a wheelchair for a month now, I had been bedridden for several weeks at the beginning, only able to sort of shuffle to the toilet and possibly downstairs for one meal a day where I was lying on a sofa so that my kids didn't feel entirely abandoned. They've been having to care for

me because I'm a single parent, so they've been doing all the cooking and washing since March, they are 16-year-old and 11-year-old twin boys. A month ago my Mum came to fetch me, she didn't want me in the house on my own when the kids went to stay with my ex, she drove a nine-hour round trip and we stopped off at a motorway services to go to the loo and my body just did not want me to walk, you don't realise how far away the toilets in a services are and I was shuffling, I could barely move, I was pausing for breath every three paces, people were staring at me and asking me if I was OK and ever since then my thighs have been seized up with lactic acid, so I borrowed a wheelchair and I'm lucky to have a downstairs loo, I've actually got a mattress on the floor which I don't know if you can see, there's my mattress and my wheelchair in the background, I use my mattress as a daybed because I only go upstairs once a day at bedtime to limit what might be too much for my body, but at the moment there's no signs of improvement with my legs but I'm optimistic that at some point they'll sort themselves out.

### **Layla Moran MP**

And Claire what interaction have you had with your doctors over this, are there things that they can ... have they been trying to improve your symptoms or are they just hoping it's going to go away at the moment?

### **Claire Hastie**

I'm very grateful to my GP who from the beginning has treated me like a grown-up and acknowledged that I'd had awful symptoms but said we simply don't know. Many people in our group to this day are being told by their GPs that it's caused by anxiety and is all in their heads. It can cause anxiety but is not caused by anxiety. So, I've been very vocal to my GP, but the science needs to catch up with us. Collectively we know more, it sounds arrogant and I don't mean it to but collectively we know more about what it feels like and symptoms and what possibly might help here and there, or we've even got a few hypotheses as to what avenues to explore with research as to where there might be some correlation if not causation, so I've got an appointment after this to go to the Covid Clinic in my local hospital for the first time, I'm grateful to live in a big city, most people don't have access to those and frankly I'm going with low expectations, I'm expecting to be able to tell them more about it from my knowledge from having 15,000 ... we went past 15,000 group members this morning, than I expect to get from them, because I think they might give me rehab which involves exercise and we know that a lot of us are exercise intolerant and that is what's caused me to not be able to walk. So, yes.

### **Layla Moran MP**

Well thank you, we'll come back to the research point in a moment because we really do want to explore that but I just wanted to give an opportunity to Jake and then Robin to say what is life like for you now and what are you able to do or not do compared to before.

### **Jake Suett**

Thankfully I've been able to manage to look after myself, my sort of activities of daily life, throughout but just about, I've kind of been on the border of that at some points earlier on. I can walk for about 30 minutes now but I get short of breath and I get chest pain and that's very different for me, I was doing 12-hour shifts in ICU, it's a high pressure situation, you have to be able to be active, I was going

to the gym three times a week regularly and now a flight of stairs or a food shop is about what I can manage before I have to stop, so it's quite significant.

**Layla Moran MP**

And has this, are you back at work or not able to be?

**Jake Suett**

I haven't been able to go back, as I say if I'm on my feet for more than an hour the shortness of breath comes back, the chest pain comes back, I've tried a couple of times, I have gone back a couple of times to try and it just isn't happening.

**Layla Moran MP**

Yeah, thank you Jake, and Robin?

**Robin Gorna**

So, I worked for myself and I lost a lot of my work at the beginning of Covid because I work internationally so all of the things to do with travel were cancelled. What I find now is that when I have, as I do at the moment, work I can do it but I work very intensely and I cannot do anything other than the work and I'm realising that I have a real brain fog, my processing skills are much slower so something that would usually take me 20 minutes might take me two hours to work, and it's a very difficult challenge because I love what I do, I'm very proud of what I do and I don't want to stop, but when I'm working I literally can't do anything else, answer a phone call, answer an email. Friends are having to shop for me again because the last time I tried to go out and do that for myself I just relapsed, and I wasn't able to leave the house. Also I've developed what someone thinks is reactive arthritis, I'm on quite a lot of heavy painkillers and so I walk with a limp and other people I know with long-Covid have had the same situation where a sort of previously small injury now recurs and you know like the others have said breathlessness and I have headaches all day, I was someone who never used to take any kind of paracetamol or ibuprofen and I pop them all day long. So, I'm pretty functionally housebound which is very strange as I was someone who previously would jump a plane to work three times a week and fly all over the world and was known for having really annoying levels of energy.

**Claire Hastie**

I forgot to say I used to cycle 13 miles a day on my commute and now I can't even walk 13 metres, so.

**Layla Moran MP**

Philippa, I know has some questions on research and so on, Philippa Whitford.

**Philippa Whitford MP**

Thank you Layla, I mean obviously there are people trying to pigeon hole this as if it's like post-viral syndrome, like ME, other things, but it's clear that Covid is a disease unlike anything we've had and that long-Covid is a sequela of that unlike anything we've had. So, we now hear about research being set up and I wanted to know whether either you as individuals or the Facebook group are aware of the UK wide research that's been set up from the National Institute of Health Research into long-Covid because obviously both treatment and management, we're gonna have to understand it more. If I could start with Claire and then Jake and Robin.

**Claire Hastie**

Yes, we are aware of it. Various researchers are starting to get in touch with us more. One of my fellow admins in the group works in the area of patient involvement and public engagement in research so she's set up a separate sister Facebook group dedicated for us to interact with researchers but I think Jake's got some thoughts about the nationwide initiative that I think you're talking about.

**Philippa Whitford MP**

OK, Jake.

**Jake Suett**

So, the study that I'm most aware of is the PHOSP-Covid study, the one that's gonna be run out of Leicester, so obviously that's very welcome but that's really only involving hospitalised patients and there's a study that's come out from the Netherlands from their Lung Foundation which shows that the severity of symptoms is no different between the hospitalised and the non-hospitalised cohort, once you get into this long-Covid area. So, I think really where the evidence gap is gonna be missing here at the moment is by capturing what happens to the non-hospitalised cohort and making sure that we're not finding that there's a different disease feeder type if you like, there might be a different immune response in these long-Covid patients and if we're not capturing that cohort in studies we're never gonna get to the bottom of the mechanism of what's causing these symptoms. And as you say I think we have to keep an open mind at the moment about what this is, I don't think it's suitable to say that this is something that is similar to anything that's ever existed before. We know that patients with SARS were left with long-term consequences after 2003 SARS, so really, we shouldn't be too surprised if there is a new syndrome after this, we need to find out what the underlying mechanisms are in my opinion.

**Philippa Whitford MP**

Yeah, I mean obviously the Dutch study, Andrew was talking about it earlier at our pre-meeting showed a quarter of sufferers regardless of you know being in hospital or a degree of severity of the original symptoms seemed to be ending up with long-Covid, and I know a German study I think it was that suggested that they were carrying out cardiac MRIs and finding changes even in asymptomatic patients and we know that from lung CT there were people who were actually ending up diagnosed by a lung CT when their test had proven negative. So, I would agree, I think we need a much wider ... now whether that will be a separate study. Do you think, I mean one of the distinctive things in the UK, it's hard to know did that contribute to severity or even to our very striking loss of patients, but obviously there was a high proportion of people who stayed at home and who stayed at home even

when they had become quite ill because that was the message initially. Do you think that we've got maybe three cohorts, the very mild symptoms, severe symptoms but never admitted to hospital and then obviously those who were ventilated or in intensive care?

**Jake Suett**

I think, you know, as a doctor I try to avoid jumping to conclusions, but I think that's certainly a feasible hypothesis. I was at home and I thought I was going to die for three days, I was so short of breath and I do think that probably under normal circumstances there is a large group of people that would have been potentially admitted and therefore they would potentially be included in those studies now as well. So, I think yeah, there's a real possibility that there are several different cohorts and different processes going on in this group.

**Philippa Whitford MP**

And is your group feeding into PHOSP-Covid to ask them to widen it or to propose to the Research Institute that there should be either a widening of the study or a separate study?

**Jake Suett**

I've certainly written myself and I think other people have written to their MPs to make the case that non-hospitalised patients need to be involved, we've informally been in touch with some people, some researchers that have shown an interest in what's happening, but I don't think this is being dealt with adequately from a top-down perspective, you know I think it needs to be much clearer from the top that the non-hospitalised cohort is a significant group.

**Philippa Whitford MP**

Obviously this would be the National Institute rather than MPs, so can I, before I go to Robin can I just ask you Claire whether your group has been in touch with the academics at Leicester University to propose that they either create a second cohort or widen the study?

**Claire Hastie**

We haven't formally and that's a very good point, and I think the point that Jake made about us talking to researchers is it comes down to funding because the 8.4 million for the PHOSP study I understand in the world of research is a drop in the ocean, so it's all going to come down to that and one thing I would like to add as well to what you said earlier Philippa is the bar for admission was incredibly high, I've been to A&E five times, I was told, each time was on the advice of either 111 or a GP, you know I didn't just take myself off and there were times when I was practically crawling through the door because I was passing out and they said oh your SATS are fine, your oxygen levels are fine and they'd send me home and they said only come back if your lips turn blue or your chest pain becomes unbearable, well I think frankly people may well have died as a result of that. We have stories in our group of paramedics telling that to people when they'd called an ambulance at home as well, so the bar was set incredibly high. I've heard informally and probably rumours that actually it was based on your oxygen levels and it's not that I particularly wanted to be admitted because frankly they wouldn't have known how to treat me anyway because again what I said before the science needs to catch up with what's happening, but yeah there will be lots of people who ... well there's a question as to

whether if we had had oxygen earlier or whatever might that have nipped in the bud whatever we're now experiencing. And just one other thing before I let go is I also wanted to make the point that this is not a linear recovery, I'm sure we'll come upon it, it relapses and remits but not only that is that you can develop quite alarming symptoms way down the line, so I'm 20 weeks yesterday, middle of March I caught it, we've got people in our group who've had it the same length of time as me, there's a doctor who posted two days ago to say she's lost the vision in one of her eyes, she doesn't know if that's temporary or permanent or what's caused it. We had several people posting yesterday to say has anyone else developed incontinence at 20 weeks, so they're urinating all over their carpets because they can't get to the toilet and this is developing four and a half months or whatever down the line. We've got people who have got suspected TIAs, with mini-strokes and we go for all our scans because we know that some people have risks of strokes or pulmonary embolism, lung clots but often our scans thankfully ... it's good that they come back normal for lots of us but equally it's a bit perplexing because then you just get discharged because the medical professional understandably doesn't know what to do with us, so I can't emphasize enough the importance of getting to the bottom of what causes this.

### **Philippa Whitford MP**

I mean obviously one of the things was when it started and we didn't know much it was being treated as a respiratory illness whereas as time goes on we realise it attacks all the fine blood vessels in the body and therefore attacks every single organ. If I can just come finally to you Robin, I don't know whether you have views on research or your willingness to be involved in research?

### **Robin Gorna**

I have a lot of views on research, so my story is that I've been involved in the response to HIV and AIDS since the mid-80s and so part of how I became involved with Claire and Jake is because I'm very concerned about the lack of adequate attention on research and as I mentioned before I worked principally at a global level and I think some of the things I'd want to say is that obviously there is research which is quite community based, so you mentioned the Dutch study, there was also a study very early on by Body Politic and that really mirrors a lot of what we saw in the early days of AIDS. Having been involved in treatment activism around AIDS in the 80s and 90s one of the things that I know is that describing the natural history is so important and can take ... I think it took us nearly 15 years in HIV to describe the natural history in women for example, so I think what you've just been saying about multi-organ disease is so important and it's part of why we get quite frustrated when we're told we have post-viral fatigue because it is clearly affecting my brain, I clearly have issues that concern me on many, many different organs. I worry terribly that the Tim Spector study isn't fully funded by Government and I do think as a recommendation that's something hugely important, for many of us it's been part of our syndromic management, it's been part of our awareness of becoming ill, you know and it's such an important tool both for research and also in a strange way for patient management and so I recommend it to anyone who reaches out to me and says they suspect they have Covid, I encourage them to fill in the app to monitor their symptoms. So, I think the natural history is hugely important, I also think as we look at treatment there are some hypotheses that like with HIV, caused by a virus but a syndromic condition, that the virus will do different things to different organs over time and with something that is only seven months old we cannot possibly know what it will do to our bodies in three or four years' time and Claire I must say being on the Facebook group can often be very alarming when I see people six weeks ahead of myself developing appalling symptoms, but we really do need a concerted effort. And one other thing just to say on this is I think you know as you say very correctly the fact that we weren't hospitalised, the fact that we were actually actively prevented from seeking medical care, I think that's one of the most shocking things. I was

tremendously fortunate because I have so many great friends who are doctors and I had round the clock medical care from people on different continents using the algorithms in Malaysia which has had a very successful response, South Africa and other places helping me, telling me to buy a pulse oximeter, telling me when I should and shouldn't call an ambulance, which I never did because I felt in safe hands. But living alone, it was terrifying, especially as my SATS often went below 94 which was the cut-off point and they taught me exercises to try and stay healthy. So, I think, you know, it's a really alarming approach by Government to tell people to stay at home and then to give sub-optimal care you know by telephone, hopefully that's something that will improve as we understand this better and I've been very blessed with great GPs, so nothing to criticise there but I hear horror stories from others. Two final things I just want to touch on, there's a thing called ACT-A, the ACT-Accelerator that WHO and other global health bodies are involved in, I know UK Government is playing an active role in it and I think that international collaboration is absolutely critical, but I want to make a really, really strong plea that those of us who are living with long-Covid and have experienced what this condition is all about need to be central to that and central to research, because researchers, policy makers need to hear, which you are doing, from our lived experience. And my final point is may I gently encourage you not to use the term sufferers about us, I do suffer many days but I'm a person front and foremost so I'd love you to start to talk about us as people living with Covid which is what we're trying very hard to do and it might seem a trivial point but we are trying to live as well as we can with it, so a gentle encouragement on that front.

#### **Philippa Whitford MP**

Thanks for that Robin, the one thing that I think all three of you highlight is the fact that young people are still thinking too much that they are immune from this, people talk about the loss of people with Covid is elderly, frail people and all three of you are exemplars of the huge ramifications of younger people who could catch this.

#### **Layla Moran MP**

Thank you, Philippa. Yes, sorry Claire.

#### **Claire Hastie**

If I may but in, I don't feel very young anymore, I'm 48 but I have three children with long-Covid, so I've got 11-year old twins as I say and my 16-year old, they have all had it, one of them is yet to recover, one took four months to recover, children can get this and you may have seen there was an article in Forbes about two or three days ago, Forbes magazine that gave some shocking reports of research, there was one done in Chicago at a paediatric hospital that showed that children under five, so toddlers and pre-schoolers, have ten to 100 times the amount of virus in their naso-pharynx, back of throat, than adults do, ten to 100 times, and children aged five to 17 have the same amount as adults do and if you come across a toddler ever you know that when they're at sort of nursery school they catch every cold going, they're always coughing and sneezing and kissing each other and dribbling and what have you. So, that needs to be absolutely front and centre of any plans about whether we reopen schools or not because the public does not realise being fit and healthy and active is absolutely no defence against this, as I say I used to cycle 13 miles, our group has got ... I think it's one of our hypotheses to check in fact as to whether people who are super-fit might be more prone to it because there are marathon runners, there are triathletes, we've got competitive rowers, there's one marathon runner who was doing sub-three hour runs, he was prepared for the London Marathon, he'd never been as fit, now he can't exercise at all without causing a huge relapse, so I can't emphasize



enough the importance, you know it could be you, it could be any of us getting this and I don't want to scaremonger but actually maybe yes I do.

**Robin Gorna**

May I just make a really tiny point on that, I know you want to move on but one of the things that really troubles me is this binary conversation, you die or you get flu, you know and I think as politicians and Government has as really critical role particularly around prevention in helping people to see ... I wouldn't wish this on anyone, I'm very glad I didn't end up in hospital, I'm extremely pleased I'm alive, my son also who's in his early-20s had Covid and he, we think, doesn't have long-Covid although he has some strange symptoms suddenly kicking in 18 weeks later and you know this is a nasty illness and I think we need to try and help young people understand, they do need to get on with their lives, we do need to encourage them to get on with their lives but this isn't a picnic.

**Layla Moran MP**

Jake and then I've got a quick follow up for Claire and then I'm going to Barbara Keeley after that, Jake.

**Jake Suett**

Just to tie in with the research and Robin's point about the fact that it's not binary, Dr Alwan has recently written a piece in the British Medical Journal and this sentence basically sums up what we've just been talking about that "death is not the only thing to count in this pandemic and we must count lives changed, we still know very little about Covid-19 but we do know that we cannot fight what we do not measure." And I think that sort of sums it up that if we don't measure this group with studies and epidemiological studies, we just actually don't know how many and what is happening to this group.

**Layla Moran MP**

Thank you, just a quick question from me to Claire or any of you, in your group of 15,000 how many are reporting children with long-Covid?

**Claire Hastie**

It's not something we've actually asked explicitly but it's not uncommon and I know that some research is looking at genes as a potential factor and maybe that is the case, but yes, it's not uncommon for children to be affected.

**Layla Moran MP**

Thank you very much, Barbara Keeley.

**Barbara Keeley MP**

Thanks Layla, I guess this follows on from Jake's point really about counting lives that have changed, but I think it's important that we as MPs on the APPG do understand how your lives have changed and how that might impact you going forward and you've touched on this in your earlier responses to Layla talking about becoming exercise intolerant for one thing, that seems like an important thing and Jake not being able to go back to his 12-hour shifts and not being able to travel for work or commute as you had been doing. Can you talk us through the impact on your day to day life and how you're starting to feel this will affect you going forward because these are things as Jake has said that should be measured because it's not binary, that's such an important point that you're making, but you know what are the impacts that we should know about and how do you think that will affect you in terms of employment and looking after children and whatever else, family life.

**Claire Hastie**

Maybe I'll start, my children are still looking after me, my ex has taken them away and I'm gonna be joining them tomorrow because I've got a hospital appointment afterwards, but in the meantime my friend has come to stay with me for a few days because I can't easily manage, if the doorbell goes I can't easily get to the door, I've still got friends who've been shopping for me over the months, now I'm able to get an internet shop more readily but I can't leave the house, I cannot leave the house unless someone takes me in a wheelchair, so I can't do my shopping. Cognitively I feel I'm very exhausted and I get brain fog, I could do some work but I'd need to sleep and rest in between, but Robin touched upon some of the patient led research that's happened, there's a guy in our group, he's the marathon runner I talked about actually, **Jez Mediger**, he's done some amazing research himself across the different Facebook groups and the Body Politic group on Slack and his findings show that 80% of people, and his sample size was 1800 so it's a lot bigger than a lot of the sample sizes you see in medical journals coming out, 80% of people feel unable to work to their normal capacity. We've got people in our group who've been told, or think that they'll never work again, if they've got a physical job, so one is a Pilates instructor for example, she doesn't know if and when she'll ever be able to work again in her chosen field of work. People are being pressured back by employers who understandably don't understand this, and they also think oh if you've had a negative test you must be fine, get back to work on Monday. We had a poor lady, she's a plumber, she fits wet rooms which is a very physical job and wet rooms are largely used by elderly and vulnerable people so she's, we don't think we're infectious anymore but we don't frankly know that, so she was told oh you've had a negative antibody test get back to work on Monday but we know that there are huge flaws with these tests and depending on when they're taken, the antibodies or T-cells that they might be looking for, never mind the reliability of the tests themselves, so it's absolutely vital that there's no discrimination based on whether you have a positive test result or not, it's vital that employers understand the relapsing and remitting nature because we've had people who start going back to work but then my fellow admin, she did two weeks of full time work from home thinking she felt fine and then whoosh, she had a relapse and she's back just as bad as she was in the acute phase and has been signed off for another month, well we've got people who've just started new jobs and they're having to do this and it's incredibly difficult.

**Barbara Keeley MP**

Thanks Claire.

**Layla Moran MP**

Thank you very much.

**Barbara Keeley MP**

Do Jake and Robin want to add to that?

**Jake Suett**

Yeah I would say from my point of view I've definitely improved from where I was, I wouldn't have been able to catch my breath enough to have this conversation with you four months ago, I thought I was dead to be honest and so I have improved over four months, I'm not completely stuck but my recovery does seem to have flattened off now and I'm still a long way from where I was. I refuse to give up, you know I'm getting out and doing what I can and I'm gonna keep trying to get back to work eventually but the thought has crossed my mind, is this what life is gonna be like now and I can just about do my shopping, go for a 20-30 minute walk, but life's not easy.

**Barbara Keeley MP**

OK, I appreciate this is a difficult question to answer, and Robin?

**Robin Gorna**

Yeah, it's very difficult, I think there are probably two or three areas that I would highlight. I live alone, I've always been very good at living alone and I recognise that everyone goes through this because of lockdown but as Claire touched on, we do have questions about whether we're still infectious and again I'm one of these awkward people who knows a little bit too much because of my work in HIV and I have questions as to whether, as we discovered in HIV, viraemia can alter and that when you become sick again maybe you might become infectious again. I've been asked through the app to get tested six or seven times, I've tried repeatedly, for some reason the system just spits me back out again, I've tried calling 111, so I've never been able to get a test, I was told to drive and get a test, well I tried driving the other day and after 20 minutes that was not gonna happen for me. And so, I would like to know if I'm shedding virus, in the end I actually paid to get tested so that I could see my mother after she finished her radiotherapy treatments, the only reason I'm in London is because she developed cancer and ironically I've seen her twice since March and obviously at a very safe distance, so that's pretty rough and it's rough that there's just a couple of friends who come and see me because they're the ones that help with shopping and because they also know a great deal about HIV we can talk and think about what it might mean and what the balance of probability is about that. So that's really hard and I do my very best in terms of my mental health, but I think everyone has concerns about that and the isolation that's caused around it. Financially it's a massive, massive hit, I've been rejected by Universal Credit because I operate through a small business, I receive £500 furlough a month, I used to be in very senior roles and I got paid for consultancies that I did last year and so Universal Credit said well tough, they didn't take account of the fact that I've had to borrow money to live this year from family members and now, you know it's very hard to know what work I will have sufficient energy for and it's difficult saying this because I love the work that I do and I'm trying very hard to do some work, but it takes every bit of energy out of me and I also don't want to be in a position where people think I don't have capacity to work. But, truthfully, I'm not sure how much

capacity I have and none of the Government safety nets do not catch me, so I'm selling my house, that's the only way I can [inaudible 0:44:21.9].

**Barbara Keeley MP**

Layla, I've just got a follow up question.

**Layla Moran MP**

We need to move on. Quickly.

**Barbara Keeley MP**

A very quick one. Just about support because Claire you're now having to use a wheelchair and hopefully things will improve for you but have you or will you be approaching social care in your local authority for any sort of support?

**Claire Hastie**

The answer is I haven't had the energy to even think about what to do. What I would love to happen at some point is if someone could send me an easy form to fill in for how I might possibly get a Blue Badge if things don't recover, you know maybe collectively I think we ought to consider about a way of getting us on the shielding list for any future spikes in infection because I'm really afraid that people in our group are being forced back to work in an office or work on a building site or whatever they do, whereas I think if they were on the shielding list they would be protected and at least be able to work from home, so I think there is certainly mechanisms like that that would be very, very helpful and also our eligibility for, is it called PIP, I mean I don't understand the world of disability, I actually ... I've only cried three or four times during this and one of ... well a couple of, I cried with relief to have woken up the next morning a couple of times when I thought I wasn't going to and then one thing that really set me off ... I'm gonna cry again now, was setting up ... sorry, was filling in the forms for my kids' secondary school and it asked if my kids have caring responsibilities and I just don't know how to answer that because they do now and I had to fill in a form at the same time that asks if I'm disabled under the Disability Act and I thought, I don't know if I'm disabled. Sorry, I shouldn't get emotional.

**Layla Moran MP**

No, thank you Claire, thank you, this is really difficult and just sorry to say we've only got about 17 minutes left so I'll pass now to Caroline Lucas and then Andrew Gwynne. Caroline.

**Caroline Lucas MP**

Thanks Layla and thanks to all of you so much for sharing so much with us, I mean I can imagine just how painful it is and Claire you know I just think you're amazing so thank you for hanging in there and sharing everything with us. I wanted to ask a little bit more about from your perspective what might make it easier from both the employment perspective but also from support from Universal Credit or anything else and maybe not necessarily only from your own experience but what you know is true through colleagues in the Facebook group and so forth. But as you've already touched on I should

imagine it's hugely difficult making the case to employers, particularly if you haven't got a positive test that there's something wrong and that really worries me because obviously what we've heard, you know absolutely so powerfully there is something massively wrong and that's partly for us politicians to work out, but I wondered if you had any ideas about what could help you in relationships where those are had with employers to make the case. Is it about a massive education of GPs, so that they can properly advocate on your behalf and say that, you know you might well not have a positive Covid test but you are seriously ill, is there anything else that you could imagine that could help this? Jake, thank you.

**Jake Suett**

I think one thing that I would start with as a reply is to talk about testing in general as you say, I think it's really important to just remember that during peak incidents of infections testing wasn't widespread and that's just the way it was, you know that's not a criticism per se, but therefore if a fraction of those cases go on to have persisting symptoms we shouldn't be surprised that the majority of people with persisting symptoms don't have a positive test result. And we also know that timing of those tests is important and even if they're taken at the right time there's still a very high false negative rate. There's obviously then the use of antibody tests, but again if you look at the Cochrane Review into antibody tests in general they've been assessed in hospitalised patients, we're not clear on ... well there's studies that show not everybody makes antibodies full stop and there's questions around the timing of those and the sensitivities of those. So, I think one thing that would be really helpful would be to establish a greater public understanding of the limitations of testing, but also to make sure that a clinical diagnosis is sufficient to access these types of support services as you mentioned. Whether or not that's clinical services or support with employment and so on.

**Caroline Lucas MP**

That's really helpful thank you, I don't know if Robin or Claire had anything else to add?

**Robin Gorna**

Just a couple of things to bounce off that, I think in terms of testing you know there are certain moments in public health strategy when testing is the cornerstone, but testing isn't the answer and again in HIV, sorry to bang on about it but it's what I know best, it took us a good decade to get really reliable antigen and antibody tests and so I think we shouldn't be surprised if our tests are imprecise right now and I do really worry when I hear, like I was listening to Radio 4 yesterday, approaches which are all about testing in the morning and going to work with a test, I mean let's not over think testing, testing is a pathway to care and without care, and we don't have any care available to us, I think we need to be really moderate around the world of testing as a prevention strategy. I think the other thing is again, I want to keep going back to this public discourse, I keep yelling at the radio when all the messages about Covid assume we don't have it, you know thousands of us have Covid in the UK and so we need to become a little bit more sensitive in the way we're talking about this because it's not gonna help employers to understand, and I find it really ironic that on the days when I am able to go out and I'm wearing my mask and if I chat to a shop person and say I've had Covid they might jump out the way, even though I'm a very safe distance, there's a huge amount of stigma around it and lack of public understanding. And the final thing I'd say on Universal Credit is I only found out last night that for three months I get the full sum of zero pounds and I spoke to someone at quite some length about it trying to explain this is money for work I did last year, I've been sick since May, all my work disappeared in February, my clients have only just paid me, tough. You know so there needs to be a

bit more sensitivity, I've can't even imagine that I've had to apply for Universal Credit, it's not the kind of life that I've had the good fortune to live, so something in the system has to be more flexible and understanding and again when we listen to stories about freelancers and small business owners who've been so horribly affected by Covid, let's not lose sight of the fact that some of them have it too, it's not that their businesses have been closed because of the restrictions.

**Caroline Lucas MP**

Thank you that's a really good point, Claire did you want to say anything?

**Claire Hastie**

Just to amplify what you already said Caroline about the importance of GPs having guidelines and I think this goes back to what I said before about some people still being told it's anxiety or being given existing labels, oh it's ME, oh it's pericarditis, that might just be a fraction of the symptoms that the person has on that day and they may develop more down the line, so both from the point of view of GPs, at least showing understanding even if they say we can't treat you, at least being acknowledged and recognised. But then what you said Caroline about getting GPs based on symptoms rather than test results to be able to sign people off work, that would be a big help as well, but as I say there's only so much you can do that before you run out of road presumably.

**Layla Moran MP**

Thank you, Claire, Andrew Gwynn.

**Andrew Gwynne MP**

Thank you and can I thank all three of you for giving us your personal experiences, I'm at week 18 of this now and everything you've described pretty much mirrors my own experiences, the brain fog, the sheer exhaustion, the sweats, I mean I feel like I've run the London Marathon when I've done just a basic task around the house and so thank you for explaining that. What I would like to explore is what you think the Government's response to long-Covid should be. One of the things that I'm really worried about, I know my own limitations, I sometimes struggle just to ask a single Parliamentary question by Zoom and then I'll spend the rest of the day in bed trying to recover from that ordeal, is as the economy is switched back on and there is an expectation by employers that people go back to work, the lack of understanding by employers towards long-Covid, I know that I wouldn't physically be able to do my job as a Member of Parliament if I was demanded to go into London. If I had to work in a factory or in public services, in a hospital or in an office that would just floor me. It's that lack of understanding, so what more does the Government need to do to make employers aware of this and also to build into the social security system an awareness of this as well, because if you have to have a work capability assessment, trying to explain a whole range of conditions is difficult enough, trying to explain long-Covid to these people would be near impossible, so what do you think needs to be done? Jake.

**Jake Suett**

I'll have a start with an answer, I think one of the things is about how it's communicated, so how we've spoken about the fact that it's not binary and actually that kind of feeds into both prevention of other

people joining us, you know I see young people playing basketball and things like that in the park, and I think people have been given the impression that if they are young and fit and well that this can't affect them, so I think a change in communication would help both prevent more cases but also help to deal with those issues that you're talking about, about working logistics and employers. The other things I think the Government needs to do, focus on research in the non-hospitalised cohort as we've touched on and then the other thing I would just address is the NHS Your Covid Recovery, obviously that's welcome that it's been recognised that there's a problem but I think we need improved clinical services as well, because that website seems to be very focused on exercise and rehabilitation type things when actually as we've touched on earlier there are 78% of patients in that cardiac/MRI study had signs of cardiac involvement, 60% had myocarditis, exercising with myocarditis is dangerous, so it's all very well to have that NHS Your Covid Recovery app but there needs to be, if people are struggling with the advice in that they need to then have a clinical service that they can access with access to sort of a multi-disciplinary team and investigations to rule out pathology, so I think it's communication, research and improved clinical services from my point of view.

**Layla Moran MP**

OK, thank you very much. I am going to go now to Baroness Finlay if she's there.

**Baroness Finlay**

Yes, I am. Thank you very much indeed. And thank you for your sharing openly your experiences. I've been concerned that the NHS app makes it sound as if a little bit of exercise and you'll get going again and you've already alluded to that, I just wondered how many of you are actually involved in on-going longitudinal research studies because, that involve not only scanning but also metabolic studies because there are great similarities with true ME and I'm not talking about post-viral chronic fatigue but this brain fog, this being completely laid out after undertaking any activity mirrors really severe ME where there are definite metabolic disturbances but they're terribly under-recognised and I worry that all those areas of research are just not being undertaken in a long-term epidemiological way. Thank you.

**Claire Hastie**

Jake, I don't know if you know of any, but I don't know of any.

**Jake Suett**

I can say to you that I'm not involved in any longitudinal studies apart from submitting my data into the Tim Spector Covid-19.

**Baroness Finlay**

The ZOE app, yes.

**Jake Suett**

I would agree with you, I think ME sounds to me as though it needs to be researched more as well, but I think you know the findings that we're finding on cardiac MRI for example don't fit in with that, but I think that all of this post-viral phenomena need to be studied because we're gonna learn from each other anyway, so completely agree with you, I think any research would be welcome.

**Baroness Finlay**

My worry is that unless we have on-going epidemiological research which collects the thousands of cases we're not gonna get advice then which is appropriately tailored and certainly my own god-daughter is like you, completely felled months afterwards and struggled and could never get past the outside door of A&E when she was desperately sick and I worry about what she's thrombosed off actually.

**Jake Suett**

Yeah, agreed.

**Layla Moran MP**

Thank you, Baroness Finlay. Well, we are nearing the end of our session before we're about to be joined by bereaved families but in the final few minutes that we have I wanted to ask Claire then Jake then Robin just for any final burning issues that you feel that we perhaps didn't cover, so Claire is there anything that we've not quite covered that we maybe need to have a further evidence on or look into?

**Claire Hastie**

I think we've covered a lot of ground; I think if I understand correctly you already do plan to speak to people on a follow-up session, people like epidemiologists and Dr Alwan who was mentioned before. One thing I just wanted to observe through all this is that we've been going through the biggest health challenge of our lives and yet we have been having to work very hard to achieve rehab, research recognition, our little slogan, we've got a slogan, we've got our longcovid.org website, we're launching an advert this evening because we think well if the Government isn't going to communicate it then we blooming well will, so any help with any unsold advertising space would be gratefully received. There's a documentary on tonight on BBC1 nine o'clock which is going to touch upon long-Covid so we're trying to do a launch at 8pm of our new advert in partnership with the UK Sepsis Trust, I didn't want to be doing any of this, I wanted to be resting, recovering, spending time with my kids.

**Layla Moran MP**

Thank you, Jake.

**Jake Suett**

It sounds like you've got a very good grasp of the issues actually, I would reiterate the importance of research that involves people who were not hospitalised, I would emphasise the importance of proper



clinical services in addition to the website and rule out pathology and to help raise awareness of what pathology people have in this group, and I would re-emphasise the limitations of testing and the fact that we cannot rely on that as a way of ruling out Covid at least.

**Layla Moran MP**

Thank you, and Robin.

**Robin Gorna**

Yeah, I think you really have covered a huge amount of issues and thank you very much for them. I think that the couple of points I just want to underscore at the end are I would love to be part of longitudinal research because we failed so dreadfully as a country, we have thousands of us, so please can we find a way to capture that learning. The other thing I would say is in many other patient conditions, patient advocacy groups are funded and supported to do this kind of work that Claire is doing in her part-time for free and I think you really need to invest in supporting people with Covid to learn from each other because that's where we're getting the most support at the moment. And the final thing is just to improve dramatically the types of communication that are coming out, much of it is really offensive and dismisses the fact that so many of us have Covid, so we've got to get it right in the way that we absolutely stop more people from getting this horrible condition, but also respect that we are part of the solution and we need to be in the middle of it.

**Layla Moran MP**

Claire.

**Claire Hastie**

One final point, we've talked about the Covid symptom study app a few times by King's College London, I really would emphasise that everybody should be downloading that and using it especially if you're well, because what happens is it literally takes a second, do it when you're brushing your teeth, if you're well, this is my dream to click on the button that says I feel physically normal and it takes you two seconds, you can do it for all your kids, elderly relatives and then the day that you report a relevant symptom in the app it automatically sends you for a test, so I would urge everybody in the public, especially as the schools reopen and lockdown eases to do that, but I also wanted to encourage you if you're not already planning to, to talk to Tim Spector and his colleagues from the app because he believes from his data that there are somewhere between 200,000 and 500,000 people who report symptoms for 30 days or more, that is a big number and we are important to the economy, you know I used to have a really senior role advising some of the biggest companies in the world on some of their biggest strategic decisions, it doesn't matter what you do frankly I don't want to seem arrogant but we are important to society, we are the types of people who never sit down, we volunteer, we work hard, we contribute to society and there's a lot of us and we need help.

**Robin Gorna**

And one tiny point, please let GPs send people for tests, don't do it all through this blasted website, my GPs, both my Brighton GP and now my London GP want me to get tested but they're not allowed to order that test, that's crazy.

**Layla Moran MP**

Thank you so much, well I'm so sorry to say we've run out of time but Claire, Jake and Robin this has been illuminating, alarming, but hopefully very useful for everyone listening and certainly very eye-opening for me. There is a lot here that we will be taking away and there is a lot that you've given us in terms of a steer for recommendations and we will be fast tracking those recommendations to Government as quickly as possible so that we can ensure that your voices are heard, but I just want to say enormous thank you for sharing your stories, it's clearly a very difficult thing to be going through, you are incredible people, what you are doing for yourself and your families but also all those 15,000 who are part of the group and all the thousands of others who might well be affected by this now or in the future, so thank you so much for being part of this today. We will continue to be in touch, it's not the end, it's the beginning of hopefully a continued conversation with you and thank you ever so much. You are very welcome to stay for the next session if you wish otherwise if you feel that now is the time to rest or go and do something else, don't feel obliged but thank you so much for your time, it is massively appreciated by all of us, thank you.

**Jake Suett**

Thank you very much.

**Claire Hastie**

Thank you for the opportunity.

**Robin Gorna**

Excellent questions.

**Layla Moran MP**

Thank you. OK, we are now going to take just a ten second break while I change my papers and we are expecting Jo Goodman, hello Jo. Lovely to see you, thank you for coming. Charlie Williams, is Charlie here yet? I can't see Charlie. Kathryn de Prudhoe is here, lovely to see you, have I pronounced your last name correctly?

**Kathryn de Prudhoe**

It's de Prudhoe.

**Layla Moran MP**

De Prudhoe, thank you. And Hannah Brady is also here.

**Hannah Brady**

Hello, thanks for inviting me.

**Layla Moran MP**

Hello, thank you so much. So, I didn't see, unless I'm missing them, Charlie.

**Jo Goodman**

I saw his name was there, so he might have dropped out and he'll be coming back in again.

**Layla Moran MP**

Might have dropped out, I think it would be nice if we can just ... ah there he is, fantastic. I'll just let him connect. Charlie are you there and are you able to put your video on?

**Charlie Williams**

Putting my video on at the moment, my apologies.

**Layla Moran MP**

No, thank you Charlie, we can go with sound if it's not stable enough.

**Charlie Williams**

I'll continue trying but please proceed.

**Layla Moran MP**

OK, we'll get going. Well first of all thank you all for joining us, this All-Party Parliamentary Group on Coronavirus and we're delighted to have you with us and we very much appreciate that this is obviously a very difficult thing for you guys to speak to and I'm sure it's not every day that you get to be quizzed by a group of MPs but actually the point of this is to make sure that your voices are heard and we will then after this session and through all the evidence that you've submitted ... and it's worth noting for those who don't know, we had hundreds of submissions from bereaved families when we did the call to evidence and you know some of them very, very personal and very, very difficult to read. So Jo, Charlie, Kathryn and Hannah are from the Bereaved Families for Justice group, Covid-19 Bereaved Families for Justice is a group of 1,450 family members, if that's correct, who have lost loved ones as a result of the pandemic and you I understand have all lost your fathers to Covid-19 and I wonder if I could start by asking you all in turn, I'll start with Jo and then do Kathryn and then Hannah and then Charlie, could you tell us the story of your father and your loved one, when did they get it and what happened.

### **Jo Goodman**

Yeah, thank you very much for this opportunity. I don't know how well you can see this, but this is my Dad Stuart, my Dad was in the shielding category, he was 72, he had heart failure, mild asthma and he was undergoing diagnosis for cancer. This photo was actually taken a week before he passed away and it shows him holding the first copies of his first published book that he'd just received, so I just wanted to use that to illustrate the fact that despite his health issues he still had a huge amount to live for. Although at that point there was no instruction for those who'd later be told to shield, to do so, and as far as I can tell there was no differentiation in advice to that group at that point, my Dad did begin isolating a week or so prior to lockdown. However, he had a scheduled hospital appointment to receive his cancer diagnosis on the 18<sup>th</sup> of March and it's there that we think it's most likely that he contracted Covid-19. So, he was in a crowded waiting room full of vulnerable patients, there was no social distancing and staff weren't provided with any PPE whatsoever, this is five days before lockdown. He began his chemotherapy treatment the following week on the first full day of lockdown and a few days later he started to develop symptoms. He was taken into hospital and diagnosed with Covid-19 which as you can imagine was an absolutely devastating thing to hear knowing how vulnerable he was. We were told that there was very little that could be done for him because of his underlying health condition, so he wasn't eligible for a ventilator or anything like that so all that could be done was to make him as comfortable as possible. He passed away a few days later on the 2<sup>nd</sup> of April and he received his shielding letter nine days after he died. As you can imagine after he passed away, we were absolutely devastated, we as a family felt that too little had been done by the Government and too late to protect my Dad and people like him. I became involved with setting up the Covid-19 Bereaved Families for Justice group with an aim of bringing families together and ensuring that we have a voice, so thank you for allowing us to use that voice today. At the top of our agenda is obviously we can't bring our loved ones back but what we really think is important is that we raise our voices to protect those that are still at risk and so what we're calling for is for the Government to initiate a statutory public inquiry into the handling of the pandemic with an urgent immediate phase looking at what needs to be rectified immediately. I have to say over the past few weeks I've had an unnerving sense of déjà vu, it's taken me back to March with case numbers rising but at the same time the messaging seeming to be encouraging people to get out there, shielding advice being lifted and I'm very concerned that the level of risk isn't being appropriately communicated and vulnerable people still aren't being protected as they should be. I feel that at the start of the pandemic the Government was very much caught asleep at the wheel and I'm not entirely convinced that the Government has fully woken up yet and so we're calling for really urgent action to be taken to ensure that others are protected and people don't need to go through the same needless loss as us. Thank you.

### **Layla Moran MP**

Thank you very much Jo and thank you for sharing your story. Kathryn, would you be willing to share us yours?

### **Kathryn de Prudhoe**

I don't know how well you can see this, this is my Dad, **Tony Clay**. He was incubating Covid-19 when that photograph was taken playing with my son, that was the last time we saw him. He died 23 days later in hospital. He was 60 years old; he was fit and active and he had no underlying health conditions that we knew of. He flew to the UK from his home in rural France on the 13<sup>th</sup> of March, my Mum had come to the UK a few weeks earlier with cases on the rise in Europe they decided UK seemed like a safer place to be, so he joined her here. He caught Covid-19 somewhere between leaving his home in

France and the UK going into lockdown on the 23<sup>rd</sup> of March. Ironically, the village he came from in France still has zero cases of Covid-19. He had flu-like symptoms for two weeks, during the second week my Mum became concerned, she called both 111 and the GP, both diagnosed moderate symptoms over the phone, advised him to stay at home, drink fluids and take paracetamol. When he finally made it into hospital it was too late to save him, despite receiving excellent care at the **LG** he died from multiple organ failure after three days in intensive care. In mid-March the public health message was that people under 70 without underlying health conditions would suffer a mild illness. That clearly wasn't accurate. My Dad was on a low dose of blood pressure medication and he had a family history of heart disease and it appears now that they were risk factors, he was unaware of. He may be one of thousands if not millions of people that ought to have been shielding at the time when community transmission was rampant. I believe that with clearer messaging, more honest communication about who was at risk and earlier lockdown, travel restrictions, border controls, test, track and trace and a health service that was equipped to attend to people other than the most critically ill, my Dad would still be alive. I believe these lessons need to be learned and acted upon now ahead of a second wave. My story also has a professional element, I'm a psychotherapist and I have grave concerns about the psychological impact of Covid-19 bereavement on many of the members of our group, Covid-19 bereavements are really traumatic, both in the nature of the death and the complex circumstances surrounding them caused by lockdown and the social distancing measures that were in place. And as a result of that the grief is very complex too. There was already a huge funding gap in mental health services before Covid-19 with really long NHS waiting lists, many third sector counselling services relying on trainees and volunteers to meet demand. Grief is a difficult process at the best of times but this grief is complex, some relatives in our group are also suffering from post-traumatic stress due to the circumstances of their bereavements, these complex mental health issues need specialist support, this is a need that cannot be addressed with the goodwill of volunteers and trainees, thank you.

#### **Layla Moran MP**

Thank you so much Kathryn. Hannah, are you able to tell us your story?

#### **Hannah Brady**

Thank you. My name is Hannah Brady, I'm 24 years old and I'm from Wigan, my Dad was Sean Brady, he was only 55 when he died from Covid-19 on the 16<sup>th</sup> of May. Dad contracted Covid before lockdown and he spent 45 nights in hospital, 42 of those were in ICU, ventilated, sedated and alone without his daughters by his side. Covid destroyed his lungs, it led to kidney failure, heart failure, pancreatitis and suspected brain damage. The only help we as his daughters could give him as a thank you for your 24 and 22 years of love and dedication to us was to consent to and be present when his ventilator was switched off to give him peace after it became clear he could never recover. Dad was a key worker and he was so proud to be considered one, he worked in food production at HJ Heinz, in his spare time he went to the gym three times a week. Dad had no underlying health conditions, he didn't drink, he didn't smoke, and he was not obese. His last day off sick was over 20 years ago. Dad had a lot of reasons to live, his daughters, his family, his community, his charity work, but he only needed one reason to die, the Government's sluggish response to the threat of Covid-19 to our country. If our Government had taken heed of the WHO declaring Covid-19 a global pandemic emergency on the 13<sup>th</sup> of March, a lockdown even one week sooner than the 23<sup>rd</sup> of March, Covid would have been far less prevalent in our society and our NHS staff and key workers like my Dad would have been sent to work without it costing so many of them their lives. We should also have quarantined all those returning to the UK from abroad when it became clear in early March what Spain, Italy, France, Portugal and Germany were experiencing, the warnings were there we just didn't listen. My only aim in telling my

Dad's story is to better highlight the failures of the Government's response to the first wave of this pandemic so that lives can be saved in the coming second winter wave. I am using my grief, grief that has come to me and my sister more than 30 years too soon, and I am subjecting myself to online abuse and trolling that Covid is a hoax, Covid is a lie, that I should be hanged for questioning our Government, so that bereaved families are no longer ignored. We have a wealth of insight into the nightmare of contracting, suffering with, dying from and grieving because of Covid. Covid-19 Bereaved Families for Justice have been willing to share our stories and experiences for months, but until today in this meeting we have been actively ignored by those who could listen and make a difference. Thank you.

**Layla Moran MP**

Thank you so much Hannah for sharing your story. Charlie has managed to get his video on which is wonderful, Charlie would you be willing to share your story? Oh, we've got video, but we've lost sound. Unfortunately, not. Now you're on mute but I think you do have sound.

**Charlie Williams**

Can you hear me now?

**Layla Moran MP**

We do, thank you Charlie. So please tell us your story.

**Charlie Williams**

Thank you, my father, **Hermita** Williams was 85 years old, he was living in a care home for several years quite happily although he was bed-bound. The 16<sup>th</sup> of April, Thursday 16<sup>th</sup> of April we received a phone call to say our father's condition had deteriorated within the care home. He had a chest infection and urine infection we're told. I asked if I could go to see my father, we were told there was a lockdown at the time, and they are receiving patients from a local hospital and have transformed the first floor into an isolation unit. We were shocked and quite devastated to hear this. Friday the 17<sup>th</sup> the doctor called us and asked us if we want our father to go into the hospital or remain at the care home. We asked would our father be guaranteed a hospital bed and we were told no, we made a decision for my father to stay at the care home for that reason and also so he was amongst familiar faces that he's known for years. I also asked the doctor is there any Covid-19 patients in the care home, the doctor told me yes, when the Care Manager told me no. Monday the 20<sup>th</sup> of April, again I asked if my father can be tested for Covid-19 and we were told once again there is no facilities for testing, but we'll make further calls. My father died a few hours later, after I made that phone call.

**Layla Moran MP**

Thank you so much for sharing your story Charlie and of course so utterly devastated for your losses but hopefully this session will allow us to explore some of the ways it might have been prevented and how we can better support you. We have a number of MPs who will now ask questions, because there's four of you if we come to every single one every time we may not get through them, so my only ask is try and keep it short or if someone's said something that you agree with there's no need to repeat it. So, thank you in advance for your brevity. Sharon Hodgson.

**Sharon Hodgson MP**

Thank you so much Layla and thank you to Jo, Kathryn, Hannah and Charlie for being so brave in sharing your stories with us today, we do really appreciate it and want to extend our deepest condolences to you and your families. I want to ask if you believe that this awful loss of your fathers that you've all suffered could have been prevented and I know Hannah touched on the lockdown perhaps if it had even been a week sooner do you all agree that if lockdown had been sooner this, your loss, could have been prevented?

**Jo Goodman**

Absolutely, I think most of us believe that our fathers contracted it prior to lockdown, I think possibly with the exception of Charlie and almost immediately before lockdown at the time that cases were rises exponentially and I think even cases that were post lockdown there were many, many more because the number of cases at the point of lockdown was so high, so absolutely.

**Kathryn de Prudhoe**

Yeah, my Dad as I've already said flew into the UK on the 13<sup>th</sup> of March, that was the day after the Government decided to stop doing any testing in the community because the virus was already so widespread, but we weren't informed of that and he unknowingly flew into a country that was already you know rampant with Covid-19 and spent ten days going about his business as normal because he didn't know that he was at risk, and it's absolutely patent that he caught Covid-19 in that space of ten days.

**Hannah Brady**

Yeah, I'll just add that the Covid-19 Genomics UK Consortium has estimated that Covid entered the UK from abroad about 1,300 times, 0.1% of those cases were from China and yet we quarantined everybody coming back from China for 14 days. 33.6% of them, so a third, were from Spain and they were most likely British holidaymakers returning to the UK. That's quite a personal one for me because my Dad knew of, and told me about, people he knew who to prevent them missing out on a summer holiday booked last minute holidays for early and mid-March, one guy was proud that he'd snook out and snook into the country, no test and trace, no quarantine for him, back into the community, back out into work within hours of him reaching the UK.

**Charlie Williams**

Yes, so to add to that in my father's case I believe if we had locked down earlier as a country it would have saved absolutely thousands of lives. If the staff in the care home had PPE initially, again it would have saved many, many lives within the care home. If the hospital patients were not transferred to my father's care home, again it would have saved thousands of lives and to this day I cannot believe our Government did that, especially when we made several hospitals across the country, you know for this very eventuality, but yet most of the hospitals that were made in nine days were left there empty while 25,000 patients from hospitals were sent into our care homes across the country. I mean it's, you know, beyond belief.

**Sharon Hodgson MP**

Thank you so much.

**Layla Moran MP**

I'll now come to Barbara Keeley.

**Barbara Keeley MP**

Thank you, Layla and thank you Jo, Charlie, Kathryn and Hannah for sharing your stories, I think it's very important that we understand your experience. Kathryn talked earlier about Covid bereavements being traumatic and the grief being complex but I do think it's very important that we understand that but first let me ask you what impact did lockdown have on your bereavement and what support has been available to you, or would you like to see available, I think Kathryn's touched on that but maybe she'd like to expand and maybe others would like to comment too.

**Kathryn de Prudhoe**

OK, if I talk from a personal perspective first and then from a professional perspective and what I see happening with our group members. So, when we got the call to say my Dad, that they were withdrawing the life support from my Dad I was sat outside my Mum's caravan where she's been living since March because she can't get back to France, on a camping chair, and when that call came to say that he'd died we sat three metres apart on camping chairs and we had to continue to do that for two weeks because she was self-isolating, so she spent the first 11 days after her husband died alone. We haven't had any support from the Government, my Mum, husband and I are all paying for private therapy. My children are struggling, they're six and eight. My son, his Grandad was his best friend and he cries three, four times a week for his Grandad. My daughter is crippled with anxiety, she didn't leave the house for weeks after my Dad died because she is so afraid of catching the virus. How can I tell her there's nothing to be afraid of? They need the routine and structure of school and their friends and specialist help to process their trauma. My Mum's friends and neighbours are selling her belongings and readying her house for sale in France so that she can buy a new place in England because we're so afraid of her travelling back to France. Many are not as lucky as we are, family members have watched their loved ones die slow agonising deaths, some have said goodbye on phone calls, video calls, while others like us weren't able to say goodbye at all. Relatives haven't been able to see their loved ones in hospital or funeral homes after they'd died because of infection risks, social distancing measures left people like my Mum self-isolating immediately after being bereaved and most people haven't been able to access their usual support networks of family and friends. Funeral restrictions have deprived us of the basic fundamental part of the grieving process. In normal circumstances 10-20% of people experience bereavement difficulties that persist over time rather than diminish, post Covid-19 that figure is expected to be much higher, with a much higher number of people needing professional mental health support to process that bereavement and grief.

**Barbara Keeley MP**

Thank you, Kathryn.



**Jo Goodman**

Yeah I mean I'd echo a lot of what Kathryn said, I mean I've never lost a parent before so I can't compare this but it does feel deeply traumatic and I think we were some of the lucky ones in that we were able to see my Dad in hospital, very, very many of our group members didn't have that privilege but having said that I have that memory ingrained in my mind of the look in my Dad's eyes, just the look of fear as he was gasping for breath and that will never ever leave me. Due to the restrictions we've not been able to, you know you talk to people on the phone, video call, it's not the same, you can't have a hug, I didn't see my Uncle who was my Dad's brother until yesterday and he wasn't able to see his own brother's grave until four months after he passed away. So, I think we're only just beginning to understand how traumatic all of this is, as well as the fact that as Kathryn says all of us are experiencing very high levels of anxiety about our own families, about watching other people who may be under-estimating the level of risk, so yeah I think it's hugely traumatic and there seems to be very little support available. There's also the sense that the Government doesn't necessarily want to engage with bereaved families and the scale of loss that's been experienced by us as a country because it feels like that would be acknowledging that we do have a huge death toll and there are a huge number of people struggling.

**Barbara Keeley MP**

Thank you, Jo, thank you. Do Hannah or Charlie have anything they want to add?

**Hannah Brady**

I'll just add that like Kathryn I've had to access private support because there's nothing available specifically for Covid grief and normal bereavement services have such a pre-existing backlog and Covid-19 bereavement will put such a strain on that sector. To put it in plain terms I'm 24 years old, I've held my sister's hand and watched my Dad die, I had to watch his lips go from blue to white, I had to watch his eyes tear up and think does he know what's happening, does he know that he's dying right now? I live in a constant state of anxiety that either I or a family member will die, I've made a will, I'm 24 years old, I've made a will, I can't stand people leaving the house with the fear that they'll never come back, I had to sit for 42 days ringing the hospital four times a day to check if my Dad was still alive. We have experienced a loss of control that we could not help our loved ones, we're trying to now by giving evidence to this APPG and trying to ask the Government to listen to us, apart from that we have no other way of dealing with our grief and we do need Covid specific professional support.

**Barbara Keeley MP**

Thank you, Hannah. Charlie.

**Charlie Williams**

I'd like to echo what everyone has said from our group of over 1,000 bereaved families, I last saw my father via video, that was the last time I saw him. We have so many traumatic stories within our group and none of us are getting support from the Government as bereaved families whatsoever, we are literally trying to help and support each other. We've reached out to the Government several times by writing letters to him and he's pretty much ignored this, I mean we haven't even received a condolence from our Government, we received a two-line reply acknowledging our letter with no

condolences. You know we find this shocking; we've got so much information to give in order to save lives before the second wave and we hope this Government will please listen to us.

**Barbara Keeley MP**

Thank you all, I know it's very difficult to talk about such difficult bereavements but thank you.

**Layla Moran MP**

Philippa Whitford.

**Philippa Whitford MP**

Thanks very much, just to follow on from what you were talking about particularly Kathryn and Hannah talking about having to access private mental health support, have any of you been able to access voluntary groups that are near you that help with bereavement support, there's ones like Good Life, Good Death, Good Grief are there any of those or do you feel that they are all simply overwhelmed by the sheer need?

**Kathryn de Prudhoe**

I reached out to two local hospices about a week or so after my Dad died, they had helplines operating, they only operate between ten and four on weekdays and unfortunately I can't, you know, confine my need to those times. I eventually contacted Cruise; they had a four to six week waiting list. But I'm also because I'm a therapist myself I'm also very aware that majority of those services run with trainees and volunteers who are not necessarily experienced and skilled to handle the level of trauma that people who've been bereaved by Covid have experienced. This needs to be met with very specialist help. We, as a group, reached out to an organisation called the National Bereavement Partnership and they have managed to secure some funding for time limited, eight to ten sessions, of paid counselling for 150 people. Well it's something but it's not nearly enough and I also feel very strongly that we as a group of bereaved families should not be the ones having to go out and seek this stuff. It should be provided to us.

**Philippa Whitford MP**

Do you think obviously, I mean obviously losing a parent or a loved one is traumatic for everyone but there are certain kinds of loss that are particularly difficult, do you think the not being able to be with your loved one on that journey to be seeing them, the way you would if they were ill with something else, you'd be at their bedside frequently, do you think that that is a particular component with Covid which clearly is not common in any other circumstance.

**Kathryn de Prudhoe**

I do, I mean a huge, I mean a huge part of processing grief is acceptance and how difficult is it to accept that a person has died when the last time you saw them, they looked like that.

**Philippa Whitford MP**

I wonder if Hannah or Jo or anyone else would like to add anything about voluntary groups they may have looked at or any other avenues that are open to families?

**Jo Goodman**

Yeah, I was just gonna add so my family we've been able to access some support through our Jewish community which again is a volunteer run service. So, we've had that, but that's because of you know particular access through a particular community that's not available to everyone, so it's very much not standardised. I was just gonna add in terms of the trauma I think that the other thing that's very, very difficult to deal with is that this isn't the death that was in the plan for these people, so people have said to me you know oh your Dad would probably have died of cancer anyway which I mean other than just being quite cruel, the thing I find really difficult is he never got the chance to see if he could fight the cancer, we never got that ... we were, my brother and myself were isolating away from him in order to move back home so we were fully intending to be here with him through his chemo, to support him, to make sure he knew he was loved, record his stories, you know make sure that we did that end of life stuff if that was the way it could have gone, but that was robbed from us. I mean it felt like this just swooped in and took him, you know it was two and a half days from when he was diagnosed to when we lost him and although we were able to go to the hospital I have genuinely no idea how I was able to sit at his bedside and speak, because even thinking of it now just, yeah you can probably tell it's incredibly difficult.

**Philippa Whitford MP**

I mean my own background, medical background is as a breast cancer surgeon, so I've been involved in end of life projects during the pandemic and that's always been the one thing that cancer patients often have the time and the chance to say goodbye and that, both from the family side but also from the patient side seems to be one of the particular things from Covid that people have not had that chance to you know to prepare or to tell people that they love them, and I wonder just ... you know I think that seems to be a very particular component. If I can ask you as I go further to Hannah and Charlie also is, what's the one thing you really need from Government most urgently to come forward with, Hannah and Charlie you haven't had the chance to comment yet.

**Hannah Brady**

Are you speaking as a bereavement?

**Philippa Whitford MP**

I'll start with yourself Hannah.

**Hannah Brady**

Yeah, of course, we need Covid specific bereavement access setting up and it needs to be there urgently. People are dealing with depression, anxiety, post-traumatic stress disorder, immense feelings of guilt that they couldn't help their loved ones, a sense of shock, that is just unprecedented, and it needs an unprecedented response. In the same way that this country found money to prop up

the economy which was outstanding from Rishi Sunak, we need to find the money and the time to prop up this country's mental health or we will face a mental health crisis, so we need specific Covid-19 treatment for mental health now.

**Philippa Whitford MP**

Charlie.

**Charlie Williams**

Basically, we need an urgent rapid independent public inquiry to sort out all the various issues, we need urgent protection and guidelines for the black, Asian and minority ethnic community who are suffering in mass numbers, this is an absolute emergency. We need an inquiry into the 111 service who we know from our members are actually, believe it or not, are responsible for many, many deaths that many people do not know about within the Government and also in particular the black, Asian and minority ethnic community also when it comes to giving advice on the 111 service things like asking a black person are your lips blue, came out quite significantly in our group. With a black person you cannot tell if their lips are blue, that one question alone is responsible for several deaths within the BAME community and the wider community as well, take a paracetamol, stay at home, so many deaths we've got from this within our group of over 1,000 bereaved families. It's an urgent inquiry that is needed absolutely now, before the second wave it's absolutely needed now. Also, testing in care homes, I went through this with my father, I asked for a whole week, my father never got tested, I actually had to get my father tested while he was deceased because I was fighting to get my father tested while he was alive but I was determined, I carried on fighting with the coroners and the pathologists to test my father for Covid-19 while deceased, I got my MP involved and they agreed to test my father while he was deceased and we changed the death certificate from suspected Covid-19 to Covid-19, my father died from. There's still a problem with testing in our care homes to this very day. You may be aware of the reports by one of our biggest care home providers of hundreds of care homes across the country, there is now a gap of five weeks where there'll be no testing in our care homes as we speak due to lack of products. This is an on-going thing as we speak, and this is one of the reasons of many we absolutely need this independent rapid public inquiry which our group is calling for immediately.

**Philippa Whitford MP**

OK thanks Charlie. Jo and Hannah obviously you gave us quite vivid descriptions of your experience but if I could just have quite briefly first Jo and then Kathryn, what is the one thing that you would ask from Government now, Jo first and then Kathryn.

**Jo Goodman**

Yeah, so I think as Charlie said we really need the Government to engage with bereaved families, we believe that we have a huge amount of information about what we believe led to the loss of our loved ones, some of those are quite well-documented, so delays to locking down and so on, but others are quite specific, so as Charlie mentioned there's a huge amount of people in our group who had experiences where the 111 service were telling people to stay at home despite the fact that their symptoms were clearly extremely severe and I think as someone mentioned in their previous session, you know these were the kinds of symptoms where ordinarily absolutely people would have been

admitted to hospitals and we're left with this situation where it feels like there was more focus on ensuring the NHS wasn't overwhelmed than there was on actually saving lives. So, these empty beds were sitting there while people were in care homes or in their homes passing away with no medical intervention other than paracetamol and bed rest.

**Philippa Whitford MP**

So, your request would be the same as Charlie's really, an inquiry to understand.

**Jo Goodman**

Yeah and the model that we refer to on that is the Taylor Review that happened immediately after Hillsborough, so obviously the full understanding of what went wrong at Hillsborough took a long time, but within a matter of months the Taylor Review looked at very urgent, critical issues around safety in football stadiums and made changes in advance of the next season. So that's the kind of approach we're looking at and we want that to be Judge led and have access to all of the evidence and witnesses that it would need to make sure it could make proper judgements.

**Philippa Whitford MP**

OK and finally to yourself Kathryn, what's the one thing you would ask for?

**Kathryn de Prudhoe**

I guess it's a Government funded network of trauma informed counsellors and therapists to provide specialist support through a tiered approach of helplines, support groups and one-to-one therapies for those who need it, including children.

**Philippa Whitford MP**

Thank you all very much.

**Layla Moran MP**

Thank you so much all. So Munira Wilson.

**Munira Wilson MP**

Thanks Layla and thank you to all of you and I'm so sorry for your loss, thank you for sharing so bravely with us today. Charlie, I wanted to ask you a couple of questions of clarification with regards to your father's care home if I may. You talked about being told, I'm horrified to hear, that there was a short of isolation area for people who had been discharged from hospital at your father's care home. To your knowledge, were any of these individuals tested prior to discharge from hospital into the care home?

**Charlie Williams**

Not to my knowledge, I was told by the Care Manager over a phone call they've transformed the first floor into an isolation unit and they're receiving patients from a local hospital to isolate at my father's care home. We were told the patients had recovered from Covid-19 and are going to be isolating at my father's care home. We were absolutely shocked and horrified by this.

**Munira Wilson MP**

OK but you don't know if they were tested just prior to discharge.

**Charlie Williams**

I do not know if they were tested or not.

**Munira Wilson MP**

You also referenced inadequate PPE so again specifically in your father's care home did you, were they short of PPE, did you find them at times you know doing things which they shouldn't have been without requisite PPE, did they mention to you about lack of access to PPE?

**Charlie Williams**

Absolutely, initially they had no PPE whatsoever. I spoke to one of the care staff myself, but I'd actually known her since I was ten years old, when I spoke to her she was at home and not at work, she was at home, what she told me was in fear of her life because they had no PPE at the care home whatsoever and I was in touch with my MP at the time and I told my local MP this as well and she told me yes, you're right Charlie there was no PPE at this care home initially, but she actually sorted it out and got on the PPE eventually, but initially there was no PPE.

**Munira Wilson MP**

And finally you talked about getting a call asking you whether your father should be sent to hospital or kept at the care home and apologies if you referred to this and I missed it, I'm struggling to understand why that wasn't a medical decision, why that was given to you and did you ever get any sense that other patients who perhaps should have been sent to hospital weren't being sent to hospital because of their age for instance.

**Charlie Williams**

I mean the whole situation was quite bizarre but, you know, we received that call from an on-call doctor asking us as a family would we want our father to go to hospital or remain at the care home and after a number of questions, in particular would our father receive a bed, could you guarantee our father will receive a bed if we agree for him to go to the hospital and she told us no, and we didn't really want to be in a position where our father is left on a stretcher in a corridor and potentially passing away, so we made a family decision for him to stay at the care home, whereas at least with familiar members of staff what he's known for decades they all treated him as family.

**Jo Goodman**

Just to follow up on that we do certainly have group members whose loved ones were in care homes who were trying to get them admitted to hospital and were told that they weren't admitting patients from care homes into hospital and there are a lot of people who are concerned about whether their loved ones were able to access the treatment even to make them comfortable, or whether things like blanket do not resuscitate orders were applied to care homes or to specific demographics, potentially without assessment of the individual case and certainly in some cases it seems that the communication was fairly poor around that.

**Munira Wilson MP**

Sorry, can I just follow up on that, so where group members have said that they were told their relatives could not be sent to hospital, do we know where that decision, where that triage was coming from, was that the care home managers or was that a GP attached to the care home, was that hospital protocol?

**Jo Goodman**

I'm not entirely clear on that, but I believe that in some ... and I've seen a news report which I think some of our members contributed to which suggested that care homes were trying to push for their residents to be admitted to hospital and weren't able to achieve that in some cases.

**Layla Moran MP**

I'll bring in Barbara Keeley very quickly and then back to Munira for the completion, Barbara Keeley.

**Barbara Keeley MP**

Well just a follow up question on that particular aspect to Charlie and to Jo, you were asked that question Charlie I mean it's effectively the doctor putting to you a question about what turned out to be end of life care isn't it, you know where do you want that care to be delivered. Is that something that later you know in terms of your grief and your bereavement you've reflected upon because you know it doesn't sound as if that was handled the way it should be, I know these are difficult times but I just wondered what was the impact on you, because I've had issues with constituents with the same problem and I know that it's a difficulty that you go over these things again and again and again, you know so if you could talk about that more.

**Charlie Williams**

Yeah, well you know I'm not a medically qualified person, I'm not a doctor and it seems as though a decision that should have been made by a doctor was put to our family to make, where it really should have been a trained medical person to make such a decision and not a family.

**Barbara Keeley MP**

But the difficulty seems to be that there was no guarantee of a bed and you were effectively deciding between care in a care home where your father knew the staff and he'd been cared there for a while with what was potentially a trolley situation or a corridor situation, I mean just I wonder what impact that's had on you since, is that something that you've reflected on?

**Charlie Williams**

You know, the whole thing is absolutely horrendous, this whole episode has literally ripped our family apart and I do mean ripped our family apart, like I could never explain to you.

**Barbara Keeley MP**

I'm really sorry about that and you know to Jo for the other members of your group I think this is something that if there's an inquiry really has to be got to the bottom of. Thank you.

**Layla Moran MP**

Back to Munira Wilson.

**Munira Wilson MP**

Thanks, a number of you spoke about how there should have been swifter action sooner, I just wanted to ask you about what the Government is doing now and its current advice on isolation and returning to work and whether you feel there is enough clarity in that advice and the messages coming from Government and that's open to any of you.

**Kathryn de Prudhoe**

I'd like to come in with something there. I've referred to this already which was you know my Dad had no idea he was at risk, you know he took the lowest dose of blood pressure medication that you could take and had regular medicals throughout his working life and never, you know, a heart problem had never been detected but there was a family history. I wonder how many millions of people in the country are in similar situations where they think that they're not at risk until it's too late. I also feel really concerned about the fact that you know the borders are open and people are travelling to Europe and back for holidays at the moment given what happened to my Dad. We don't know where or when he caught the virus in those ten days, but it could easily have been in an airport or on an aeroplane, on a train, in a supermarket. He could have caught it from me, you know we all had the virus and I don't want anybody else to be left feeling the things that we feel which was if only he hadn't got on that plane, if only I hadn't seen him that day, I don't want anybody else to go through those things.

**Hannah Brady**

I will say that the advice that was out there from the beginning and the advice that's out there now, not only is incorrect it's not clear enough, so an example of incorrect advice that was given was that



Covid-19 positive patients should isolate for seven days and not the WHO recommended minimum of ten days, now that's been amended last week and that's a hugely positive step, but that wasn't in place from the start of this pandemic. Secondly the advice that we're getting simply is not clear enough, an example of that, I'm from Manchester where 2.2 million people were placed into a more intense lockdown last week via Twitter at half past nine at night, that is simply not good enough. If you want the public to engage in complying with a lockdown you need to respect them, and you need to communicate with them in a way that everybody can access. I have friends who were working on the Friday when we were locked down from midnight on the Thursday, they had no idea if they were allowed to go into work, they had no idea what furlough scheme extension would be in place, if they could take their children to their parents for childcare. We are being put into earlier local lockdowns which is positive, but the Government advice still is not being communicated clearly and you will never get the public on board unless you communicate with them on a community level.

### **Jo Goodman**

I think the other thing just to add on that is that the symptoms that are communicated aren't always the symptoms that our group members' loved ones displayed, so I think there's definitely a question as to whether people aren't isolating because they don't have a cough for example or they don't have a fever but they have other symptoms, so I think there's definitely concern there as to whether people are actually registering the full breadth of symptoms that are indicative of Covid.

### **Hannah Brady**

I'll just come in again with that one sorry Jo, my Dad became symptomatic on the 24<sup>th</sup> of March with stomach problems that he attributed to food poisoning, so he continued to go to work, go to use public transport and go to the shops until the 2<sup>nd</sup> of April and that's when his breathlessness emerged, so that's over a week of him being symptomatic, potentially shedding a huge viral load in major locations, major transport hubs and still the Government message is if you've got a high temperature, if you've got a persistent cough or you're breathless isolate, but apart from that no other symptoms are mentioned.

### **Charlie Williams**

Also, I'd like to add to that also the black, Asian and minority ethnic community in particular the Bangladesh community and the black community in particular are on the front line of many of our services across the country and they're amongst our most vulnerable, particularly when it comes to jobs and using public transport, only today amongst many of the reports there's another report out today by Runnymede Trust saying the high risk of the BAME community it is absolutely urgent we have this rapid independent public inquiry, you know for all of us and in particular the BAME community who are at urgent vital risk as we speak. And we need to protect these people who are on the front line of many of our critical services across this country, they need protection.

### **Layla Moran MP**

Thank you, Charlie, I'll now go to Baroness Finlay.

**Baroness Finlay**

Thank you very much indeed and thank you for having the courage to share as clearly as you all have. I'm very concerned at what you're saying about 111 and I'm very concerned about the lack of bereavement services. The difficulty is that it takes the time to train people and so in relation to bereavement services I wonder whether within your larger group people have been able to access hospice bereavement services because the hospices did receive additional funding at the onset of this to maintain their viability and whether they have broadened and who you feel should coordinate national bereavement services, because we need a lead. And on 111, whether within your group you've been able to collate the type of misinformation that you've just highlighted, particularly relating to the BAME community, that's an obvious one of the colour of your lips, but I think there are lots of others, the lack of gastro-intestinal symptoms in particular and the fact that these are not being communicated to the public at large, so the public at large don't realise how serious this disease is. Thank you.

**Kathryn de Prudhoe**

I'll pick up the first part. I'm not aware of others in the group accessing local hospice support, I don't know about that, I know that I tried originally, you know within a week or two of my Dad dying and as I said they had a helpline and it was manned but it was available for six hours a day during the week, so there are things like that available but they're limited, it was also very clear to me as an experienced therapist that I was speaking to somebody who was fairly inexperienced and couldn't do a lot more than just listen, they didn't have trauma training. You talk about the national service, there are thousands of private therapists up and down the country with trauma training, experience of dealing with trauma and bereavement and they are under-utilised. They're a fairly mobile service in that you know we can work from home like this on Zoom, it would need someone to coordinate it and I'm not entirely sure how that would work, but I'm sure that there are people in professional bodies like the BACP who would have a take on how that could be managed.

**Layla Moran MP**

And to the symptoms or the fake, the bad advice.

**Jo Goodman**

I'm happy on the 111 to come in on that, we did actually have a group meeting regarding this with people who've experienced it and we did collate, sorry I'm looking at my notes here but so the kind of issues coming through were difficulty getting through, some people really couldn't get through on the phone and in some cases were handed to teams in different parts of the country who weren't adequately connected up with local services to ensure that people had a smooth experience. Fixed call scripts that led to people being told to stay at home despite the fact that they were in extreme you know agony in a lot of cases, you know people who because they were able to speak on the phone they were not considered to be adequately breathless and because they ... so quite a few people said they heard their loved ones on the phone and they just said yes three times and then they were told no, you stay at home despite being in the worst condition of their lives and communicating the level of distress they were in. A lot of people were very concerned that risk factors weren't taken into account, so people had symptoms but they were also mentioning you know this person has heart disease, this person has respiratory issues, so it was quite clear that they were likely to be at an elevated level of vulnerability but it doesn't appear that that was taken into account. And then yeah in terms of inclusivity whether those scripts are inclusive of BAME communities as Charlie mentioned

around blue lips, but also in terms of language barriers, so whether if English wasn't their first language whether they were able to communicate their symptoms in a way that was adequate to ensure they got help, so briefly those are the kinds of issues that have been coming out.

**Layla Moran MP**

Thank you very much Jo, Jo would you be willing to write to us if there are more that therefore we've got the full gamut of evidence. Now, everyone I'm so sorry to say that we have to draw the session to a close, just before I do however, I was struck by what Charlie was saying that you'd sent a letter, presumably was it to the Prime Minister, Charlie?

**Charlie Williams**

Indeed, yes.

**Layla Moran MP**

When was that sent?

**Charlie Williams**

It was from Jo.

**Layla Moran MP**

It was from Jo, when was that sent Jo?

**Jo Goodman**

We wrote to the Prime Minister three times beginning on the 11<sup>th</sup> of June asking for him to meet with bereaved families and also to Matt Hancock calling for a public inquiry and also calling for them to meet with us and hear our experiences. At first we only received a two line acknowledgment and we eventually received a letter that said they are unable to meet with us due to the current pandemic which obviously given what we want to meet with them about and the fact that they're able to meet with cycling groups and other groups it feels as though we're being swept under the carpet.

**Layla Moran MP**

So, Jo, if you had a message for the Prime Minister if he were listening what would you say?

**Jo Goodman**

I'd say speak to us, you know we really do want to ensure that other people don't go through this and we think it's really important that bereaved families' voices are heard.

**Layla Moran MP**

Thank you so much all, we'll all that's left for me to do is to say again thank you for sharing your stories, you're so brave and it's been an incredibly moving session, but I also hope it's started to highlight some of the issues that have yet to see the light of day in terms of public engagement on them, so many journalists I know are watching, we will be making sure we're collating all the evidence that you're giving to us and in the capacity of the APPG writing into Government to do our best to push them to hear your voices. We are holding our own inquiry into this now in order to do exactly what you have asked to try and avert whatever can be averted before a second wave, but you're absolutely right that this is not the Judge-led independent inquiry where they can force people to come in front of them, so we will also continue to be pushing for that as soon as possible. And thank you all for taking the time so Jo and Kathryn and Hannah and Charlie, again massive condolences and thank you so much for coming today, your time is enormously appreciated. Well that brings the session to a close for everybody, I thank everyone who's been watching, I thank all the parliamentarians who have so ably asked questions and we will be back next Wednesday for an evidence session, information will go up on the March for Change APPG website. Thank you very much everybody, take care and stay safe.