Hayley Wolters: Opening Address

Tēnā koutou katoa,

Ko Hayley Wolters toku ingoa.

Before I begin I'd like to acknowledge that powerful introduction and to note that all of us are hear today because we're responding to a need – whether it's a desire for knowledge, for tools, for advice for lived experience to inform equitable policy – we're here because we're all in some way shape or form, the people who can make change happen – that is something to have front of mind before we start today.

I'd also like to acknowledge that lived experience has been centered, not sidelined as part of the planning for today – thank you to the organisers for being conscious of the knowledge and experience we bring to this forum and structuring the agenda accordingly.

If you'd told me at the beginning of 2020, that 3 years later I'd be talking to a very large group of people about my experience having a big scary virus making headlines around the world during the same period we spent locked in our houses while watching celebrities sing John Lennon's *Imagine* to each other - that would have been a very interesting thing for you to say.

And yet, here we are.

I am somebody who has lived experience of Long Covid, and I'm going to talk about experience of what that looks like – and to tell you what that looks like. I'm coming back a little bit later today to tell you what it could like look to be a supportive employer, courtesy of recommendations from Long Covid Support Aotearoa – I look forward to that conversation.

I got sick in March 2020. Specifically, I began to get symptoms on the same day that Prime Minister Jacinda Arden announced we were going into lockdown. Which – just as an aside, that exact time is the very worst time to start to get symptoms from a mystery virus that is sweeping the world – I don't recommend that approach.

So, with everyone suddenly locked in their houses, two days later, at midnight, I was sitting wedged in a corner of my bed, and I was desperately trying to breathe. I feel like I was sucking air through a straw. I felt like my lungs were filled with thousands of crawling ants, and every ant was on fire. Every time I lay down, I could not get enough air.

I stayed awake the whole night, because I thought I would die if I lay down, I thought I would die if I fell sleep. I didn't call an ambulance because I knew there was something really wrong with me, and I was absolutely terrified that if someone came into my house to help me, I would pass this thing on to them. So I stayed upright and awake, and I wrote a goodbye letter to my sister on the notes app of my phone – because I wasn't sure that I'd make it.

That remains the worst night of my life. Clearly I survived, but I didn't get better

What was working like?

For months, I really struggled. I was relapsing – every time I tried to "push through" I triggered a full blown replay of my initial symptom – this is very common for Long Covid. I struggled to walk up a hill – going for my usual run was completely out of the question, off the table.

I had heart palpitations, chills, that came and went, headaches, and crushing and I will say that word again – crushing fatigue. No two experiences of Covid are the same. The effects of Covid are neurological, cardiovascular, immunological, systemic – it can hit every organ. Long Covid affects 1 in 10 people at a minimum. You might not know, but two months plus is Long Covid, under 2 months can be ongoing post-viral symptoms – what I have just described can hit anyone recovering from Covid, before it turns into Long Covid. It's important that is widely understood and important to keep in mind as we move through day.

I genuinely consider 18 months of debilitating symptoms to be lucky because Long Covid is no joke – I am privileged to know many people 3 years later who are still battling every day. For me, I consider myself 90% recovered with enough ongoing symptoms that a reinfection, could compromise my health more than it already is.

The greatest gift that I was given was that my boss, when I went to her and said, hey, I've read about this thing on Facebook and I think I have it" – that's an interesting conversation to have - she did not kick me out of the building, but listened, and we worked on a plan together.

At the time I was remote working by default, but it really helped to be able to take meetings in my pajames (the camera off), I was able to work at night - My sleeping patterns, for months, were out of whack – I was working at 3 am some days because that's when I was awake.

We all talk about meetings that could have been emails, and how exhausting a back to back day can be. One – one - meeting could exhaust me for the rest of the day - I was able to talk to my colleagues about structuring my time based on the symptoms I felt on the day – because no two days are the same. I felt supported and not judged in doing that.

Something I still struggle with is my great love; writing. I will often write down the word I mean but spell it incorrectly. I will write things like progress, when I mean process. I try to double check everything, but it does make for interesting reading sometimes. This is a small example but an important point – I lend no less value to the role I have, but that now looks a little bit different – space was created for that to be the case.

The experience that I had being supported by my boss – her compassion, willingness to listen and adapt my work responsibilities to the situation – that will stay with me the rest of my life.

I also acknowledge that not everyone has the same type of job – I have the privilege of being able to work from my laptop – policy needs to consider the breadth of different kinds of worl.

I also have the privilege of being able to advocate for myself – as leader in my day job who manages people – I need to say clearly that there will be people we manage who need us to advocate for them. It should be noted I have the privilege of having supportive boss – it should be the case that a supportive boss is a bonus which is backed by policy.

Because everyone has the right to be heard and supported with as much empathy and integrity as **I** experienced.

That brings me to what next.

Modelling suggests, taking into account previous waves, that over 400,000 people in Aotearoa have Long Covid now. **At 400,000 there is an unequivocal, undeniable need for policy.**

I would confidently say that every single one of you has someone with Long Covid in your workforce as your colleague, as someone you work alongside. If you don't know anyone, it's not because you don’t have anyone – it is they don’t **trust** that you will support them or don’t know **how** you will support them.

We are yet to grapple with what Covid makes us now. Author Suzanna Arundhati Roy wrote that “the pandemic is a portal.” I firmly believe that we can’t go back to Kansas, and what is required now is leadership, and new ways of thinking. We do have a new reality now and the many amazing speakers today are going to undeniably, unequivocally demonstrate that.

Thank you for stepping up and acknowledging we are through that portal by your presence here today – we may be on the other side of the portal, but not the pandemic. You are well ahead of the inevitable curve by being in this room.

Leadership requires vision and the acknowledgement that shifts needs to happen based on data, evidence, reality. The long-term health of your workforce is a vision to hold and plan for now.

Finally to the people who have experienced long covid who I know are in the audience today – I see you, I hear you, I am so glad and grateful to know you - and I know there are enough brilliant minds in the room today – your voices included - to create some meaningful change.

Nga mihi nui ki a koe. Thank you,