**Special Series: Living with COVID**

**Interview with Summer Foundation UpSkill Lead, Linda Hughes**

**George Taleporos:** Hi and welcome to Reasonable & Necessary, Australia’s premier series on everything you’ve ever wanted to know about the National Disability Insurance Scheme, brought to you by the Summer Foundation. I'm your host, Dr. George Taleporos, and in this episode of our special series on COVID-19 we talk to Upskill Lead, Linda Hughes about the importance of planning ahead in order to stay safe as Australia opens up. Check it out.

Hey, Linda. Welcome to the show. Great to have you on.

**Linda:** Thanks, George. Thanks for inviting me.

**George:** Now, I know that a lot of people watching know you and love you but for the people who don’t know you, can you just introduce yourself?

**Linda:** Yeah. So, my name is Linda Hughes. I work for Summer Foundation, I’m the UpSskill lead. So, my role is to train support coordinators and allied health professionals. We really recognise the important role, the vital role that allied health professionals and support coordinators play in ensuring that people with disabilities live well and are included in the community. I’ve also been in the disability sector or disability community for quite some time. I’m the parent of a 29-year-old man who’s got complex support needs and that drew me to being involved in advocacy and working and being involved in the sector for some time, particularly around wanting to achieve good outcomes for people with complex health needs or complex support needs generally.

**George:** You do some fantastic work. I know that you’ve been very active around trying to address issues related to COVID and people with disabilities. Can you tell us a bit about that and especially as we move towards a COVID normal, what does that look like for your family?

**Linda:** It’s really - I think that COVID has created a high level of anxiety for a lot of people but particularly for people who have got complex health needs or people who have got family members with complex health needs, so we really - I think COVID normal for us is not too different from lockdown in many ways. It almost feels like a constant risk assessment of, “How safe is this? What’s the options here? What protections, what protections, what precautions can we take to ensure that we don’t bring COVID into our family and particularly to my son?” So, it’s - COVID normal, it feels like just a constant level of risk assessment to be honest around -

**George:** It does, doesn’t it?

**Linda:** - what’s safe and what’s not safe and what strategies can we use to minimise the risks?

**George:** So, what have you been doing up until now?

**Linda:** So, I suppose we’ve been really ensuring that mask wearing, PPE, the use of PPE - I think my son, as I mentioned, he has complex health needs and disability and requires people to be in close proximity so the idea of social isolating is really difficult in terms of getting the support he needs but certainly having a tight team of support workers, having the team really well educated and understanding the risks so that even in their personal life, they can ensure that they’re taking reasonable precautions in their daily life outside of work. So, of course, the good hand-washing, the good hygiene practices, generally having really, a high level of cross-infection control measures in place, and we have these in place generally but I suppose it’s just taking it to another level with COVID risks.

**George:** Now, we’re moving to a point where we’re going to have community transmission as a part of life. I’m really interested in having that conversation around what we do to plan for this and I know that you’ve done some thinking around what would happen in a situation where possibly, Jacob was exposed. Can you talk us through some of that planning?

**Linda:** So, I suppose there’s a couple of strategies really, it’s like prevent so you’ve got your cross-infection control measures, the things you do like social isolate or try and avoid crowded situations and enclosed situations so you’ve got prevent, then you’ve got kind of preparation for the what ifs? What if Jacob gets COVID? What if I get COVID? What if - and et cetera. So, there’s those sort of things there that you’ve got the plans in place just in case and I think that when we say that COVID is going to be - the thought is that COVID is going to be endemic, that it’s just going to be in the community everywhere, that it's a good process to have those practices in place.

One thing that I think is really important is a COVID companion or a hospital passport or there’s various names for these type of documents, having that prepared early so that if Jacob or generally if any person has to go to hospital, having a COVID passport or a hospital passport that you can hand to ED - it’s a good idea all the time but particularly now - that can provide the emergency department staff with some really important knowledge about the person. That includes things like what is the person typically like, do they need glasses on, do they need a hearing aid to communicate, if they’re deaf-blind, do they need a tactile interpreter? What helps keep a person feel safe and secure and minimise distress?

All those type of things can be included on this document, as well as things like who’s your doctor and what medications you’re on but it really starts to give the emergency department and hospital staff a good picture of a person and how to support them in a positive way in a hospital environment.

**George:** I like that one of the things that is really key is to think about what is it that people need to know so that the experience is one that reflects what my needs are? So, I’m really interested in how we can plan ahead with respect to this. You’ve talked about this COVID passport, so is there a document that people can download? How do they fill this out and get to having one that people will actually use and believe and implement?

**Linda:** Well, I think the first thing is it’s got to be done now. There’s no point doing it when someone’s on their way to hospital so it’s part of that pre-planning and preparedness. It’s called - there’s various names. One is called a COVID companion and that’s on the Australian Government website for COVID preparation for people with disability. There’s another called Julian’s key and that’s another type of hospital passport, and if you just Google ‘hospital passport’ - one more is called A to D, admission to discharge and that’s a really quite comprehensive document but it’s got the top 5 in that and that’s the top 5 things the ED needs to know when you turn up there. So, if you Google ‘hospital passport’ or have a look on the Australian Government’s COVID website, you’ll find these sort of documents there pretty easily.

**George:** That’s really helpful. I also think it gives you the opportunity to explore some of the complex issues that you might encounter when you are in hospital. So, for example if you need a support worker in hospital with you, you don’t want to have that argument when it’s all happening and when the oxygen is low and you’re about to go into a coma. You need to have that conversation early.

**Linda:** Yeah, I think that we’ve got to be thinking about this early and I think there’s a lot of barriers to people in the hospital environment. We certainly know that there’s barriers there and there’s some unconscious bias potentially, even amongst hospital staff. An unconscious bias is hard to address, because people aren’t conscious of it, so there’s issues there. So, having the information readily available, the idea is that putting an understanding of what a person really looks like day to day, as opposed to how they turn up when they’re in hospital, sometimes there might be some considerations like - part of that unconscious bias might be diagnostic overshadowing, and that’s where someone’s behaviour might be attributed, sorry, the signs of being unwell might be attributed to behaviour or attributed to their disability in some way, rather than actually considering that there’s something really, really wrong with this person.

So, having that documented, that “Normally, I’m like this.” We created a hospital passport a while ago for my son and it’s got photos of him doing things in it even so hospital staff can actually get a bit of a picture literally of what he looks like day-to-day and what he’s doing. So, again, that idea of conveying that information quickly so that hospital staff can get an idea that this person, where a person is.

**George:** Let’s take a step back then, how about the need to plan around a support worker being a primary contact or positive with COVID as well. I had this situation twice in the last month where I had a support worker say that their family member was exposed to COVID, so I was like, “Oh no, what do I do? I should’ve planned for this.” Have you thought about what to do?

**Linda:** Yeah, it’s always adapting. As I said before, it’s kind of like almost this constant risk assessment. It’s actually quite tiring to do all the time, going, “What are the chances?” Today, my son’s support worker called to say that he’s feeling unwell and he’s going for a COVID test so he’s self-isolating until he gets a result so that just means that we’ll play it real safe today and not go anywhere at all, not that we were going far anyway. But I think if he came back positive, we would very quickly be getting full PPE-ed up for any support for my son.

At the moment, we can go, “The chances are pretty unlikely. We know this support worker is very careful in what they do. They’re wearing PPE when they’re working with Jacob. They’re very careful in their personal life as well so the risks are quite low,” but nonetheless, we have to work through the next thing, “What if?” I don’t have any solid answers, George. It’s just so hard to think about but having the PPE - we’ve got more I suppose the high-level of PPE on hand if you need it.

**George:** And I think that it’s not about getting overly anxious about every single circumstance but to really think about, “These are the things that could happen. This is what I should do,” get prepared, get the necessary PPE and you need to get on with your life, right?

**Linda:** Yeah and I think the best thing we can do is have everyone vaccinated. That’s the best thing if you’ve got - my son is vaccinated, anyone who’s in contact with him is vaccinated and ideally, anyone who’s in contact with anyone who’s in contact with him is vaccinated as well, so it really reduces the risk of someone catching it and reduces the risk of them spreading the virus, so I guess that’s the number 1 safeguard. As we said before, we know that COVID is still going to spread through the community just because of the very nature of this Delta strand in particular, that we’ve got to have some other contingency plans in place.

**George:** The other thing is that things keep changing and developing and we now have access to these rapid antigen tests that you can now buy at your local supermarket and I picked up a pack before they sold out. What are your thoughts on using those tests?

**Linda:** I think this is really important. I think this is a way of really - they’re not like the PCR tests which are much more accurate but they’re pretty accurate. They’re good tests to really ensure that people who are coming to work with people with disability are not excreting the virus, don’t have COVID. So, I think they’re actually quite useful. I’d be really encouraging support providers, service providers to be considering using those with their staff, insisting on staff having testing, particularly if they are working with people who would be very vulnerable even when vaccinated, to COVID. So, I think this could potentially really save lives to be honest.

**George:** Yeah. What I’ve learnt though is that you should still go and get your standard PCR test if you have any symptoms and with the rapid antigen testing, they work well if you use them regularly. There was an article in the Lancet that said that if you use them 3 times a week, then you actually get a really good, accurate reading of whether that person has come into contact with the virus. So, I did a bit of research myself on that and I think that’s the key, doing your research and talk to your doctor about what will work in your situation. Are you going to use them in your family?

**Linda:** Yeah, so I think that we will be using them. We have to develop the protocol for it. I think that it would probably be every 3 days that support workers self-test and if they feel that they have been in a situation where their chance of exposure is higher, we’ll give them the option of putting their hand up for additional testing. I think one of the good things about them is that they’re pretty cheap. There comes just a really small, small cost in terms of - if you consider the cost of a support worker over an 8-hour shift, it’s a very small additional cost and a really important safeguard I think, alongside other PPE and other strategies that you use, not on its own, but certainly, I’d be certainly talking to people and advising people to talk to their doctor and consider using these.

**George:** Yeah, absolutely. Speak to your medical professional before making any decision on what’s the best approach. Before we go, Linda, do you have any final words of advice for our viewers?

**Linda:** Yeah, I just think that it’s really advisable to plan in advance. As I said, being prepared, having that list of what-ifs, it’s easier if you’ve thought about things in advance and you’ve got a plan of what you’re going to do next that makes it much easier when the plan is there and you go, “Okay, this scenario has happened and this is what I would do in that case,” so I’d really recommend people have those plans. Having a COVID passport or your hospital passport ready to go as well is a great idea too.

**George:** Great advice, Linda. Thanks for joining us today.

**Linda:** No worries, thanks for having me on.

The following websites were referenced in this episode:

Hospital Passport
[www.health.qld.gov.au/\_\_data/assets/…LHC-staple.pdf](https://gate.sc?url=https%3A%2F%2Fwww.health.qld.gov.au%2F__data%2Fassets%2Fpdf_file%2F0032%2F858362%2F3.-Julians-Key-Health-Passport-100gsm-LHC-staple.pdf&token=1cf2fc-1-1639636946020)

A2D Admission to discharge
[a2d.healthcare](https://gate.sc?url=http%3A%2F%2Fa2d.healthcare&token=af2b2-1-1639636946020)

Top 5 things for hospital staff to know
[a2d.healthcare/wp-content/upload…\_-Information.pdf](https://gate.sc?url=http%3A%2F%2Fa2d.healthcare%2Fwp-content%2Fuploads%2F2017%2F01%2FTOP-5_-Information.pdf&token=fe0f90-1-1639636946020)

Developmental Disability WA – My Hospital Passport
[ddwa.org.au/forms-to-help-you-p…assport-march-2020/](https://gate.sc?url=https%3A%2F%2Fddwa.org.au%2Fforms-to-help-you-prepare-for-an-emergency-hospital-visit%2Fhospital-passport-march-2020%2F&token=f9823c-1-1639636946020)