**TRANSCRIPT**

Reasonable and Necessary with Dr George: Making Sense of the NDIS podcast

**Series 4 – Staying safe during COVID-19**

**EPISODE 1: 3 APRIL 2020**

Q: Hi, listeners, and welcome to Reasonable and Necessary, Australia’s premier podcast series on everything you ever wanted to know about the National Disability Insurance Scheme.

I’m your host, Dr. George Taleporos, and this is the first episode in our series dedicated to Coronavirus.

We know that this is a very tough time for all of us and in order to get through it, we need to support each other.

This series is all about learning from one another and talking about what we are all doing to make it through.

We’re going to chat to people with disabilities, support coordinators, advocates and other guests about how we are doing our best to be prepared and to be safe.

Just remember that if you’re looking for medical advice, please talk to your doctor for that.

You can also call the National Coronavirus Information Line on 1800 020 080.

So let’s get in to it.

Joining me now is NDIS participant and freelance photographer Jarrod Sandell-Hay to talk to us about how he is juggling support workers, supplies, and social distancing. Hi, Jared, how are you?

A: I’m good, how are you?

Q: I’m doing well, how have you adjusted to the Coronavirus?

A: Well, I don’t know how you measure it, but I guess we’re doing okay, we’re still here and in these times, I think that’s the main thing, yeah. It came on like everybody, it came on quite quickly, so me and my wife, we run a photography business and about 4 weeks ago we were booking jobs about once every 2 or 3 days and now that’s all stopped and we haven’t had any cancellations, but we’ve had a couple of postponements and nobody’s booking us, so no deposits are coming in, so no money’s coming in and then on top of that, there’s the whole disability stuff. So we’re both wheelchair users and we’re both NDIS participants, so we have to manage that as well and then there’s also the equipment and the stuff we use because of our disabilities and where we can find it and we can’t, and then on top of that, there’s the whole how do we feed ourselves? Where do we get the food from? Do we go outside? Do we not go outside, so we’re making decisions day by day and it’s costing a lot more money than it would normally because obviously, things like takeaway stuff and sometimes we can only find drugs or wipes or whatever at convenience stores and convenience stores are often much higher priced than the supermarket. So it’s not great, but I guess we’re not in the worst situation.

Q: So you have a lot of financial pressures from what I’m hearing in terms of your incomes and in terms of your incomes going down, and having the need for support workers, you also have expenses there, don’t you, that are related to your support. I’d like to focus a bit on the support worker situation, a lot, well, we’ve all been told to socially isolate, but that’s not as easy for people like us, is it?

A: No, it actually costs more money, more funding now if we wouldn’t self isolate, so I have the support worker come in to help me get up and pretty much put me to bed and a little bit throughout the day and I rely on those hours. I rely on their support, so you have to manage who’s coming in and who’s coming out, you don’t often know where they’ve been until they come and tell you that day and the rate of infection in New South Wales where I am is quite high, it’s the highest in all of the country, it’s almost 3 times as high as the infection rate in Victoria, so that’s a bit concerning. We do organise the workers, but we’re going to stick with our current situation where we pretty much have 2 workers swapping between the 2 of them and one of them does all of my night shifts and some of the weekend and the other one does all of the week day, morning shifts.

Q: So you’ve obviously had to rearrange some of your support services and what I’m hearing is that one way that you tried to reduce the risk is by reducing the number of support workers who come in to your house.

A: Yeah, which is smart, but also very dangerous because if one of those support workers gets sick or can’t come or whatever, then I have to invite new people in to our house and that’s the scariest thing. It’s scary on the best occasions, but when we have what’s going at the moment where we want to not vet support workers, but try and work out what their daily routine is to make sure that they’re not bringing anything in to our home and we’re not bringing anything in to their home because that’s also important. We don’t want to infect other disabled people who they might be looking after and where we’re being infected by anyone else who they might be looking after, so we’re hoping that the Prime Minister says in 6 months, from a disabled person’s point of view, I daresay we will still be doing this in 18 months’ time just because of the extra little precautions. So hopefully, in 18 months’ time, those support workers will still be in place until this dies down.

Q: And I think the reality is that we don’t know how long this will take and we also need to recognise that there are risks with certain approaches to this. So for example, if I reduce the number of support workers, yes, I will have fewer people who A, will possibly have the Coronavirus and be in my home and B, less people in my house may have the virus, too, however, on the other side of that, if I have less support workers, I then may find that if someone is unwell, I don’t have the backup support.

A: Yeah, and one of the things I want to stress and I haven’t seen much media around this is that we’re not just worried about getting Coronavirus, we’re worried about getting other types of flus and sicknesses and we’re worried about getting hurt or needing to go to hospital, especially when the peak comes. At the time of where we’re recording this, the peak is not here yet, so when the peak comes and if our hospital system gets full and we have to go to hospital or wherever and they’re at capacity already, what does that mean for us? If I’m going to hospital, I’m still going to need support in the hospital and then it becomes a nightmare, so I have to work out how you manage support workers coming in to hospital. What’s the plan? So one of the main decisions that we’re taking for our health is our goal not to need to go to a doctor or hospital in the next 6 months.

Q: Absolutely, we need to stay well at home and we know what often happens to people with disabilities in the health system then.

A: On the best of days.

Q: Absolutely, on the best of days, hospitals are quite difficult places to be if you have a disability and we’ve seen that in a range of inquiries and Royal Commissions that have looked at this.

A: It becomes how do we stay healthy in our places of living and what do we need to do?

Q: Jarrod, tell me, are you currently planning on using personal protective equipment such as masks and things that currently are unavailable?

A: So, I’ve always had a pretty open relationship with my support workers around conversations about what to do and what not to do. I’ve moved up a step when it comes to what I’ve asked my support workers to do. Before this, they were only using gloves when it came to personal care, but now they’ve moved to a stage where I’ve asked my support workers to use gloves when they’re handling anything to do with me - so putting me in my wheelchair, helping me in the shower or wherever, so whenever they’re touching me, they’re touching me through a glove and then when it comes to masks, one of my support workers, I’m quite happy with this, one of my support workers does wear masks throughout the shift and it’s their choice. Once she started wearing the mask, I’d encourage her to keep wearing it because there’s no point going backwards and forwards between taking off the mask and putting it on in my point of view and that’s a good way to attract infections because if anyone gets sick, then we know we can almost pinpoint where it comes from then, we need to be careful. Moving forward, though, if it gets and if it looks like it’s going the way it’s going and we do need to protect ourselves more, I have no idea where we’re going to source these masks from. I’ve only recently stocked up on gloves, so where I keep the gloves for a little while, but what happens the next time I decide to go to the supermarket which I probably shouldn’t be going to and they have no gloves, where do people go now? I don’t think this is a priority when it comes to when people are talking about it in the media or the news, they’re talking about nurses and doctors on the front line which I agree they are the most important, but prevention is always the best way to go and if people don’t protect themselves in here, we’re going to add to the high demand of hospitals if we’re not careful.

Q: And you really made a very important plan and that is that we need to stay out of hospitals and we need personal equipment in our homes in order to do that and what I’m concerned about is that we’re hearing messages about how important it is to stay 1.5 metres away from other people and the people who need personal assistance in order to do that, so it’s important that the government provides the support we need to stop the need to go in to hospital and I’m really keen to see some initiatives that provide everything that we need in our homes, so we don’t need to go to supermarkets or that we don’t need to go to hospitals because that’s the only way that we’re going to get through this if we stay in our homes and have the support in place that’s provided safely.

A: Yeah, up until now, the government have been pretty good at securing support worker safeguards and now the support agencies who provide the support, they’ve been well looked after which is important too, because if they don’t feel secure, then they’re not going to come here, but then it goes both ways. You need to support the NDIS participant and the people who are on the DSP and you are paying a little bit more for food deliveries or fast food or wherever, this is a new cost to us that are not just one off costs, they’re ongoing.

Q: They certainly are. Jarrod, do you have any words of advice and we’re not here to give people I guess a set of instructions on what to do.

A: No, I don’t think there is a right way or a wrong way to do things, I think the dignity of this still applies and that’s still very important and people will know what to do in their own circumstance. One of the things that I’ve changed in my behaviour is I’ve been avoiding big supermarkets. I’m in a privileged position of being able to go out myself in my electric wheelchair, but we’ve been avoiding big supermarkets. I’ve been evaluating the places I go by building size. If it’s a small building, I go in to it, if it’s a smaller shopping centre, I’m likely to go there and I’m likely to go there late at night till around 9.30 or 10 o’clock just before they close, that’s when there are fewer people but then that’s also not very good for me because if it gets cold in winter, I’m going to be going to the shops late at night in the cold, it’s not going to be great. I go to shops if we need something on the day late at night and then we do a big shop online about once a week, but that still doesn’t mean we get everything. On more day-to-day stuff, just keep every conversation with support workers trying to see how they feel, trying to reassure them and keep your home and their workplace as clean as possible and try and make it so it’s not only about you, but it’s about their safety. If you provide a good workplace, then they’re likely to keep working as long as possible for them.

Q: It’s very good advice and I just want to end though by talking about something that I think is really key at this time and that is mental health and for people, even though we’re socially, well, I prefer the term physically isolated, I don’t think that we should be socially isolating. I think that we need to make more of an effort more than ever to be social. Have you put in place any strategies to make sure that while you’re physically isolating that you’re not socially isolating?

A: Well, on the broader question of mental health, what I need to do to stay relatively of good mental health, I do a few things, I’m one of those people who love information and the more information I get about Coronavirus, the better. I find that some people are not always in to that, they don’t want to talk about it, they don’t want to think about it, they just want to try and live their life like they were living before this as much as they can and that’s perfectly okay, so I do that. But I also check in with my circle of friends, the ones who I always talk to. I guess moving from Melbourne to the Central Coast, I’ve been doing that, anyway, especially with my Melbourne friends and now with my Central Coast friends, I’ve been doing it more with them. So it’s about checking in, it’s about them, they ask if I’m okay, if they can do anything for me and I return the favour and it’s just about showing you can do amazing things with your friends or with your iPhones and just maybe check in with that person or your friends and check in for a while and you never know, you might have something, you might reimagine a friendship or something. But I find that another thing that’s really important is humour. If you can make light of some of the stuff, whether it is the hairdressing or rugby league or toilet paper, if you can make jokes about some of the lighter stuff, obviously, you have to pick your timing, but the humour is very important. But we all go through different cycles of emotions and it won’t be long until I look in my house and I’m like, I’m so sick of these walls, I just want to go out and see my grandparents, or my friends or somebody you haven’t seen and the idea of not seeing them for another 6 months is heartbreaking, so you have a bit of a cry or be down for half a day or a day or even a week and then you wake up, you see something funny on Facebook and you post it and one of your friends will comment on it and you just feel connected with each other and if we all do that, I think we will be able to balance each other out.

Q: Absolutely, we need to stay connected, I think that’s critical and we need to be really grateful that we’ve got the technology that we have, the fact that we can be in the same room with someone. I said to a friend earlier in New York and I didn’t have to leave the house and that’s a pretty awesome thing that we can do.

A: Yeah, and it doesn’t have to be one-on-one either, it can be in a group, you don’t want to go drinking, but you can open up a bottle of wine and have a conversation over the phone and it might not be the same atmosphere, but it’s still valuable and I’ve been saying this for years, but social media has always been undervalued in general I think.

Q: It certainly is and we need to use it for good and not for evil as they say. Jarrod, thank you for joining us and I think that we will, everyone listening will have hopefully benefited from hearing this conversation.

A: No worries, thanks for having me on.

Q: Stay safe.

A: You, too, wash your hands.

Q: Wash your hands, people.

A: Or get somebody to help you wash your hands.

Q: Or if you don’t have hands, wash your stumps. On that note, see you Jarrod.

A: See you, George.

Q: That’s all we have time for on today’s episode of Reasonable and Necessary, brought to you by the Summer Foundation.

Check out our Facebook page for previous podcasts and transcripts.

We also love hearing from you, so please leave your comments and suggestions for future episodes.

Remember for the most up-to-date info, on the Coronavirus, call the Coronavirus helpline 1800 020 080 or visit health.gov.au.  
We hope that you enjoyed the show and that you stay tuned for more episodes.

Until next time, stay well and reasonable and please, please remember to wash your hands.

END OF TRANSCRIPT