

So...podcast – Episode 13 Social Isolation is Not New to Us

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John: Greetings. John McKenna, So...podcast. On Thursday the 26th of March 2020 I recorded an episode which I called "Coronavirus – Disability Peer Support".

It was one of those episodes where I invited people with disabilities to share messages with me and the world about their own energy at the moment when thinking about the coronavirus, with a particular focus on their strategies and how robust they're feeling. And we got some fantastic messages which I'm going to share with you. The name of the podcast episode is called "Social Isolation is Not New to Us."

When determining and creating that headline, I thought hard and I thought, "Okay, not everybody is isolated or feel isolated," but when I really reflected, even as myself, as a person with a physical disability, I have had times where I've felt isolated, and I'm sure if people with disability look back on their life, depending on their disability type, at different parts, have had some forms of feeling isolated. It could be because of communication challenges, it could be because of the built environment, also people's attitude can really make people feel isolated. I do hope you enjoy this episode.

I'd like to remind everybody that it's available on our website, <u>www.johnmckenna.com.au</u>, also I would really welcome your feedback via email to <u>letstalk@sopodcast.com.au</u>. I really enjoyed this particular episode, and the thing that made me quite emotional actually when listening to it and doing it was the diverse range of people who all had a diverse range of disabilities. And every message that you're about to hear is very unique; not only is it unique, but it's powerful and I'm feeling confident that when you listen, you're going to come away with a different perspective on thinking about the word "isolation".



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I really hope you enjoy, and please do send your feedback after you've listened.

Thanks.

Tish: Hi, my name's Tish Peiris, I've an acquired brain injury that I got in 1994 as a result of a motor vehicle accident whilst I was doing an internship at the *"Sunday Times"* in Colombo.

Having a brain injury is the worst thing that's happened to me, and I've managed to do two masters degrees since leaving school. I need to go to the gym about three or four times a week for my balance and mental health, and it's been personally diabolical that the gyms are shut. I bought a skipping rope for some cardiovascular fitness, but have since figured out that I can't actually jump anymore, so now I go to the park and walk around about three times, and then I walk up and down my fire stairs. I live on the sixth floor in a sevenfloor building. I'm careful to wash my hands straight away afterwards though, because I need to hold the rails. And you can also do free yoga on the internet, and you could just use your towel and your dressing gown rope for stretches. I do sit-ups and leg-lifts every single night before I go to bed. You don't have to be amazingly fit; there's a girl with an intellectual disability that's just started in my gym who was way more flexible than I am.

I understand that these are very difficult times, and I live on my own; I'm selfisolating from my family. My sister's come back from New York, and my brother's children have just come back from America, so I understand, and I just want everyone to be really, really strong at this time.

Thanks. Bye.

Tricia: Hi, I'm Tricia Malowney, and I had polio when I was four months' old. I use callipers and crutches. And I'm in Melbourne, Australia.

I am working from home, which is really good for me as I'm still able to work, so not everybody can do that but I can. I think that for me, it's really good that



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I'm able to help people adjust to the way they're working, that we're all in this together, and that we will come through this really well out the other side. I have my own home, so I'm lucky that I have somewhere safe to live, and that I'm able to walk in my garden.

What we are doing, and what we are finding is that people are supporting each other, so people are saying, "This is what's working for me. This isn't what's working for me," and we're sharing our ideas together, and I think that that's really important for all of us. For me, I'm able to hold meetings using Zoom, so I'm able still to talk to people, but for those who can't work from home, I'm still keeping in contact with them anyway because I think that's really important to do as well.

Everywhere around the world the issues are the same for people with disabilities; we all share that strength and resilience that we have, we're very adaptable, we're able to change the way we work to suit everybody. And so for me, my message for everybody is: Stay strong. We'll get through this, and we'll get through this together, but we'll come out stronger on the other side, and the rest of society will realise that the things that they're doing now are things that we've been doing for a long time.

Thanks very much everybody.

Linda: Hello from the Land Down Under. This is Linda Blaik from Geelong, Victoria, Australia. I'm a person with a disability; I'm totally blind. And I just want to give a little bit of positivity.

> What I've been doing in the lockdown system is thinking of ways of cheering other people up, checking on people to see if they're okay, writing a few poems just to send to friends, and last weekend I delivered 18 packages around Geelong, well, a taxi driver delivered them, I didn't, and people were very appreciative of that.



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My situation is that I have a guide dog, and another positive that has come out of it, somebody has kindly been taking my dog for a run at an oval because he can't get out; he's wondering what's going on.

I think the main positivity that has come from this is that I've been able to clean my office. Now, my office is called the Magpie Nest; I'm a Collingwood supporter, that's the AFL football team here in Victoria, and for months it's been an absolute mess. Well, it's all decorated now and going very well, and looks like a Magpie Nest rather than a tip. The other thing that I've been doing is I'm a Donny Osmond fan, and my Donny Osmond room is now set up with all, lots of different dolls, memorabilia, new photos, blankets, just things that I've collected over the many years.

And you're just trying to keep sane, I suppose. I'm a person who likes to go out every day. I am quite a busy person, but have found that the second week in isolation is a lot better than the first week; I think we do get used to things, and I feel that I'm doing rather well.

So that's my message to everybody, and I hope you all stay safe.

Justin: Hi, my name is Justin. I'm from Perth, Western Australia. I have intellectual disability, and I'm proud to be disability.

One thing I'm going to say is be positive, be active, and don't worry about the coronavirus; we'll get through it. We will get there. Just be positive, just keep calm and don't freak out; we'll all get there.

Yenn: Hi there, I'm Yenn Purkis, I'm calling from Canberra in the ACT. I'm a person who is autistic, and I also have schizoaffective disorder, which is a mental illness. And I'm a very proud autistic person, so I should say that.

Some of the things we've been doing that I've been involved in to sort of support people in this difficult time is lots of online messaging and chats and things like that. On the weekend I was part of a chat for Women with Disabilities ACT, and we were talking through Zoom, and there were about 10



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of us talking through Zoom, and it was a great way to stay engaged and keep in touch, given the situation. And I facilitate a women's group for autistic women, and that's also going to be a Zoom meeting, and that's tomorrow night, so really making use of the technology in order to live well and then all just stay connected, so staying connected is really important.

And as people with disabilities, we often do use online means and things like that in order to stay in touch, and this is just an opportunity to do that, I suppose. And I found that a great way of staying in contact with people.

So, stay strong everyone; we can do this together. We're very resilient already, and so this is an opportunity to be resilient into the future, and to support one another, so thank you.

Bye.

Brandon: My name is Brandon Tomlin. I work as a communication access mentor with Scope Australia. We work with businesses all over Australia to build communication access as part of their customer service.

Communication access is where everyone can get their message across, and people have communication resources available, and the knowledge and skills to communicate effectively with anyone, regardless of how they communicate. Now, more than ever, communication access is vital.

I have a disability called cerebral palsy; it affects my movement and speech. It doesn't affect my intelligence. I communicate by using my eyes to spell out words on a board with letters. This means that I need to be face to face with a person in front of me. Obviously in these current times this is not always possible. I also use an electronic communication device that produces what I like to call "my voice". That's what you are listening to now. This helps me to communicate in this now digital world.

At the moment I am feeling okay, but there is a lot of information out there in the media which is causing people to panic. I wish that the world would stay



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calm as we learn how to manage this; it's about having a balance between being informed, keeping safe, and staying calm. What helps me to stay calm is making sure that I find reputable sources of information, and I base my decisions on this, for example, listening to a well-informed radio program.

One of the things that has changed for me is how I work; where I used to go into the office, I now work remotely from home. Communication access has been vital, and planning for communication access is even more important in this time to ensure that everyone can connect remotely, not just in person. Thank goodness for technology. Access to the right technology is important. I set up my computer and webcam so I can see my team and vice versa. I join in team meetings and training this way using online meeting spaces such as Zoom. I also make sure I have remote access to my work server, and my mobile phone handy to communicate by text messages, email or video. I am no stranger to alternative forms of communication and to find ways to communicate using methods other than speech. But now more than ever, everyone is needing to embrace alternative methods of communication to stay engaged, productive and connected.

I hope this helps you to see what is possible in times like this.

Lyn: Hi, my name is Lyn. I have a physical disability, so I'm in a power wheelchair. I have arthrogryposis multiplex congenital. I know most of you probably wouldn't have a clue that that is, but there you go, there's only a few of us, so we're all unique in our disabilities.

I'd like to say that in this time of crisis, I suppose you could say that, we're getting by. Look, I'm knitting, I love my books. Thank goodness for Netflix. I think we just have to stay positive, and most of us who have a disability, we know what it's like, we are tougher than the majority of people out there. And I guess we all have to stick together with this thing. We'll get by. Look, there's no problems there; I know we'll all come through the other end, and honestly, I really think our earth is going to appreciate this: no cars on the road, things like that.



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I think it's going to be a great opportunity to see what it's like out the other side when we all come through this, and I know we will because we are strong Australians. I am an Australia, sorry, I should have said that earlier. I live in Geelong, Down Under, in good old Aussie.

And look, we're all in the same boat, and I think it's just fantastic how we can pull through. I just want to say, I'm really pleased to be on this podcast with, thank you John for inviting me. I think we have to stay positive, and of course, naturally stay safe. I have carers every day, and look, without them I think I'd be more isolated. I do have a husband, but you know what husbands are like, or wives sometimes; they get on your nerves. And I think the girls that come in, for me, they've been really positive too, and I think that helps your mental healthiness as well.

I think my time is up, so I'd better say goodbye. Thank you very much.

Jenny: Hi, my name is Jenny, and I'm from Melbourne, Australia. I'm a full-time carer for my 21 year old grandson, Chris. I've cared for Chris since he was two years old.

Chris is autistic, non-verbal with complex needs, so I am essentially the voice that he can put across so that other people can understand what he wants and needs. Chris is normally a very social being, and would be usually out and about in the community, but with the restrictions that are now on, we've had to become quite creative about how we're going to structure our day and make things work for us. And hopefully, some of the things that we're doing might also help for you.

We've thought outside of the square a little bit; getting outside and being active I think is really crucial in this time as well, not just for your health and wellbeing, but for your mental health as well, so we've come up with things like washing the car, simple, vacuuming the car, things that we do weekly anyway, but we can do at home; playing totem tennis, playing soccer, gardening, staining the outdoor table and chairs are something again outside. Make a game of washing your hands, sing loud and be proud while doing it.



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Chris has the Coles mini shopping items, and we've set up a shop and a trolley with his communication device to ask him to buy things, identify what they are, and pay for them. We've got a pocket money game, and that's teaching him about money and how to use it. We're Zooming live videos, his weekly speech and behaviour sessions, and we are Facetiming our family members and playing games with each other; it's really important to keep in touch. Use the tools that we have to stay connected.

Be safe, stay safe out there, and good luck everyone.

- Heather: Hi everybody, my name's Heather. I live in Victoria, Australia, and I'm deaf and blind. I use sign language. You can hear a man's voice at the moment; he's my interpreter. When I heard about the coronavirus it stopped me from travelling on train and taxi, and other forms of transport. I used to visit friends and go to a gym, and go swimming, but now I'm stuck. It's very difficult. But, what I do, I try and think positively. I have to change my plans, set up a new routine, and I've brought a lot of things with me, like board games, a computer, a phone with a braille display. I've brought gym equipment, and a box of clay for pottery. I've also got a braille book from Vision Australia. I love my cat also, whose name's Champagne. I'm here, and I'm slowly settling in to a new environment. It's new for me. At times it's frustrating, losing my way, but I try and speak openly with my sister to make sure that everything is smooth around me. I've stayed in contact with friends, family and colleagues on SMS, email, Messenger, etc, etc. Sometimes I'll go for a walk with my sister; we go walking through the countryside looking at the green hills. We try and take different routes each time. It's very relaxing. I want to say thank you, be safe and look after yourselves. Thank you.
- Sammy: Hi, I'm Sammy McCombe. I'm from Melbourne, Australia, and I have oculocutaneous albinism, which is a condition that effects the amount of pigmentation in the eyes, hair and skin.

I'm 15 years of age, living with impaired vision and severe sun sensitivity, which can prove an issue in a country like Australia where the sun, and weather in general can be so very unforgiving. Personally, I hate summer; all



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my friends are out at the beach in their bikini's, while I'm living it all through a phone screen. Yes, I could go out with them, but if I were, I think I'd probably spend more of my time putting sunscreen on and avoiding sun stroke than actually enjoying the time with my friends, so often times it's just easier for me to stay home.

I think that everybody is an understanding of that concept now that we're all isolating ourselves for COVID-19. I guess I've just been experiencing it longer. Through my isolating, I've worked out that in summer if I spend too much time looking at my phone I get depressed. If I can accomplish just one thing each day it makes me feel more satisfied with being at home, so I always try to stay productive. My ways of doing this include spending time in the kitchen baking, cleaning my room, believe it or not, chasing my younger brother around the house with a wooden spoon threatening to take him down, even though he is bigger than me now which I can tell you probably would not work in my favour. I also like zoning out to music, singing to defer my teenage attitude. I'm also pretty academic, so with all this time now on my hands, I've managed to put some of it towards getting ahead in maths, which though in the process may drive me slightly up the wall, but the satisfaction of completing the work afterwards definitely makes it all worth it.

Finding something to keep yourself occupied in these times is the key, in my opinion. Now, your own outlets may differ from mine, but my tip for you in these hard times for our world, is to explore your own interests. Try something new; pull out that board game, play a game of cards, crack open a puzzle that you know you'll never finish. And if you're into art, purchase a reference journal, you won't regret it. Write a book. Just do something with your time, because at the end of this, you'll want to look back and think, "Wow, look what I've learnt."

Thank you.

Luke: Hi guys, I'm Luke from Melbourne, Australia. I have cerebral palsy.



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What I'm doing to fight the coronavirus is to just sanitise your wheelchairs. What I'm doing also is getting the same support workers, getting them to wash their hands and gloves up, but also to be positive.

I've been able to set up, because we're in quarantine at the moment, so I've been able to set up virtual get-togethers, virtual drink parties, so it's just all about staying positive, and we can do this. I mean, people with disabilities, we're resilient. We can stand up and we can work together to, it may be dangerous but it's not the end of the world. We've got to be positive and we've got to work together, because it will end.

I think we need to stand up, and we need to just embrace each other, and just say, "At the moment, yes, it is pretty awkward for people with disabilities, but in wheelchairs and everyone else, everyone else around the world, let's just stand together and let's just work this out," because it will go back to normal.

Thank you very much.

Bronwyn: Hi, my name's Bronwyn King, and I'm a support coordinator in Melbourne, Australia. My role is to support people with disabilities, to link into supports and services to meet their goals and needs, so it's a real privilege to be a part of this podcast and be able to share some ideas to the wider community.

> The first section I would like to talk about is some ideas for those that receive funding for their supports. With so many skilled professionals being currently unable to work in their normal jobs, we're able to tap into their skillsets and develop and produce some really amazing person-centred programs. So far, we've been worked with chefs, teachers and personal trainers to deliver educational programs via online interfaces, and continue to support people with fitness programs. Support workers are also continuing to provide support via phone calls and video conferencing, which is proving to be really effective in keeping people socially connected.



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The Australian government is also promoting the use of telehealth to keep people connected with their essential therapies. Although it's early days, the feedback has been really positive.

In terms of community supports, the social media platforms are proving to be an amazing opportunity for people to connect with members of their local community. We're really seeing people of all walks of life banding together to support each other. Some of these sites you might find could be the Good Karam Network, the Kindness Pandemic, and local community pages on Facebook.

We're also seeing some great innovative and online activities that people of all abilities can tap into. Some great ones we've seen so far are virtual Disneyland rides, virtual museum and zoo tours, Auslan courses, online DJ-ing, Storyline online, and the options are just endless.

In closing, I feel it's really important that we all keep supporting each other, regardless of who we are, where we live, or what we may or may not have in common. The kindness and compassion we all show is what will be remembered after this crisis.

John: I trust everybody enjoyed listening to those messages. It was an experience that I'll never forget, and it was really fun making the podcast.

I want to do a few thank yous, especially for this episode, because it was quite challenging using technology such as mobile phones. There are two great people who played a big role in making this all happen: Xinxin and Jian, my support team So...podcast, thank you, a big thank you.

Another organisation who has helped in all my episodes are people from OutScribe Transcription Services; they have transcribed all of my episodes. Their link is on the website. Why they are so important is because they do accurate transcription so that people have the option to download transcription, and also look at captioning on the YouTube clip. So thank you,



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