

Disability Done Different: Episode 10

Rod Harris on...MND and living for each day

Podcast transcript

Audio Length: 00:28:04
Hosts: Roland & Evie Naufal
Guest: Rod Harris

Intro

Maia: This is Maia Thomas; I am the DSC podcast producer and I just wanted to give you a quick rundown of DSC as an organisation before we get started. DSC is a team of 33 people across Australia, all working together to bring specialised training and consulting expertise to providers in the disability sector. Our focus is on helping providers to survive and thrive in the NDIS. Our purpose is better outcomes for people with disability.

Dialogue over intro jingle:

Evie: All right, here's what's going to happen now.
Roland: Hello, and welcome to our podcast.
Evie: We are DSC. Your turn, you're the boss. Disability Done Different, Candid Conversations.
Roland: Disability done different.
Evie: I hope you're ready because we're starting.

Start of Interview

- Evie:** Hello, and welcome to Disability Done Different, Candid Conversations. My name is Evie Naufal. I am the host of this program. [Laughter].
- Roland:** No, she's not.
- Evie:** I'm joined in the studio by my assistant and dad Roland Naufal. [Laughter], and our producer Maia Thomas.
- Maia:** Hi.
- Roland:** Our guest today is Rod Harris.
- Rod:** Welcome, thanks.
- Evie:** [Laughter].
- Roland:** I think I'm meant to say welcome.
- Evie:** Yes, you just got welcomed by the guest.
- Roland:** Yes, well, he thinks I'm an assistant, so it stands to reason he would welcome me. Rod Harris I've known for a very long time. A lot of people have known him for a very long time because he's been 25 years CEO of Motor Neurone Disease Victoria, MND Victoria. Before that, with Para Quad, he's done some consulting, which he probably doesn't put on his C.V. because most people don't.
- Evie:** Do you want to start again without slagging off consultants? [Laughter].
- Roland:** I was doing it deliberately.
- Evie:** Were you?
- Roland:** Yes.
- Evie:** Okay.
- Roland:** You can leave that in, as well. We're going to talk to Rod about a lot of stuff. Principally, a lot of interesting stuff. Let's start deep and meaningful, Rod. Motor Neurone Disease tell us a little bit about it.
- Rod:** Well, it's a rotten disease, first described in the late 1860s by a neurologist called Shak O. Essentially, it's a progressive, degenerative neurological condition that takes away your ability to walk, to talk, to breathe, and to swallow. Or as I like to describe it, you lose your ability to hug, to hold, to kiss, and caress. It's terminal. It has an average life expectancy of about 27 months post-diagnosis. It's a series of losses. People lose their ability to do various things that we all take for granted. Walking, as I said, talking. You wouldn't be sitting here participating in this discussion if you've had Motor Neurone Disease for many, many months. The progression of loss is continual, and carers and family members are experiencing grief at every loss, as a person declines in their capacity.
- Evie:** We did want to go deep fast.
- Roland:** We did.
- Evie:** There's a fairly popular study that says when somebody acquires a disability and somebody wins the lottery, about a year later, they're both about as happy as they were

before that happened. It sounds like that doesn't happen with MND because of the way that it changes?

Rod: No, I don't think that that's right. I think what happens is with MND, as people are adjusting and acclimatising to their losses, they actually find new and different meaning in their lives. They gain greater value from some of the simpler things in life that they're still able to engage with and enjoy. I think that any loss actually helps you appreciate what remains. It's about that quality of life as you are living it, not what was it or what might it be, but it's about today. Living today.

Roland: I don't want to get too woo-woo, but I've dealt a bit on the fringes of palliative care and people dying as well. I found a number of the people work in palliative care, I just met some of the most wonderful people I'd ever met. Do you think that's because the sector attracts those people, or do you think the experience of being around so much grief and death is a really positive personal experience?

Rod: Yes, well, I think it's both. I think the people who seek out roles in palliative care. My wife works for a palliative care provider, they want to do that work. There's a spiritual, psychological, physical benefit of working in an area that you want to work in. I think also people learn about themselves and about others, so grow in that role and become more positive about the work that they're doing. Look, I have my criticisms of palliative care.

Often, people continue to talk about it as an end-of-life service, I'm working hard to try and change that, to a quality of life service. People have got to be able to live well until they die, like I've said before. People want to live well until they die. I think as palliative care is refocusing itself and it is now starting to talk about living well, so we're going to get more people engaged in palliative care. As to whether it attracts or creates people, I think it does both.

Roland: You're old enough to remember the slogan after the Whitlam government got sacked, which was: Maintain the rage. In my dealings with you over the years, you've been angry with me more than a couple of times. Anger has formed part of your persona, is it part of your way of coping? Is it your advocacy? Talk to us about anger.

Evie: Why are you so mad all the time?

Roland: [Laughter].

Rod: My anger is a part of the bag of tricks that I need to use to convey the importance of what I'm trying to say. You and others have heard me stand up at a lot of conferences recently talking about the fact that our national disability organisation has abandoned people over the age of 65. I will keep expressing outrage and rage about that, because it's not all about the national disability insurance scheme. Some people acquire disability over the age of 65. Where are they going? What are they supported by?

Roland: Quick background, Evie, what's Rod talking about?

- Rod:** That NDIS participants need to be aged under the age of 65 at the time that they become an NDIS participant.
- Roland:** Otherwise, they have to become part of the aged-care system.
- Rod:** Aged care has currently 126,000 people waiting for places.
- Roland:** Help me with this one too, Rod, the largest home that we currently think is okay for people with disability is 5. A lot of people are saying that's an institution, that's too big. When I was working in aged care, we were building 120-bed nursing homes, institutions. It always strikes me that all the young people in nursing homes movement, which I have a huge amount of time for, says: We should not have young people in nursing homes because they're horrible places that institutionalise people. We shouldn't have old people in nursing homes that are horrible places that institutionalise people. How can we work with such a divide in our attitudes towards one group of people up to 65 and then post-65?
- Rod:** I think partially it's because of the way we've always divided money and responsibility in government. States looked after people with disability, supposedly, and the Conwell looked after the aged. The introduction of the NDIS and the co-ag agreements separating responsibility failed to take account of people who were living with disability who were in aged care services, and there were many. It also failed to take into account that not all people who acquire a disability over the age of 65 are frail and demented. Some of them are still active members of the community and unfortunately, they have a disability. If there's no question about, do you need assistive technology to access your community and your support groups? If we want people to live longer at home, whether they have a disability, or when they have a disability and they're older, we've got to help them maintain the relationships that they've always had within their community and their friendship circles and their activity circles.
- Roland:** Do you have any frameworks? Are you a fan of circles of support, or is there anything that you could recommend to people who are trying to understand what you're talking about and trying to do it better?
- Rod:** I think circles of support work for some people. I think the NDIS has actually hit the nail on the head to the extent that it talks about addressing unmet needs created by disability. We should be looking at that for aged care, as well. What are the needs of the person who wants to stay in their home for longer at whatever age, 80/90, it doesn't really matter? Can we deliver it?
- I think aged care is doomed in terms of the fact that the aged care budget and the number of people it supports is purely a calculation, dollars divided by numbers of people equals an amount of money. Whereas, the NDIS has actually projected a budget based on assessed need and how much it would cost to address that need. That's reasonable and necessary. I'm a strong supporter of reasonable and necessary.

- Roland:** With the NDIS, we've heard from other people that the complex people with higher and more complex needs are really missing out. Some of the people you work with surely fit that category, is that what you're saying?
- Rod:** Well, I would first say that people with MND have never been as well off as they are under the NDIS.
- Roland:** Okay.
- Rod:** We have more clients receiving more services than they would have ever received under the older state-funded packages of care. What I would say is that the creation of the NDIS has been built around everybody being the same. Unfortunately, people aren't all the same. There are people with different needs, MND is one, with rapid progression and ending in death. There are many others who need to have a different stream of assessment and evaluation and planning to make sure they get the services that they need. It's not like funding a day program at X dollars, or a swimming class for Y dollars, or an accommodation support where you can just put that in place, and it addresses the needs of a whole range of people.
- We've been very successful, though, in negotiating with the NDIS to create a basic plan, a model plan for someone with MND that addresses their needs today, as well as their prospective needs for the next 12 months. By doing that, we're attempting to reduce legislative appeals to the administrative appeals tribunal or whoever. We're trying to reduce the number of plan reviews that go in place. We're also trying to reduce the number of re-planning exercises as people progress. That has been reasonably successful.
- We still have planners in the NDIS that don't like and want to exercise their own judgement. We've seen planners overriding decisions of therapists when that planner is not a therapist. In the moment, we've got that in place. For example, someone with Motor Neurone Disease who needs assistive technology can have and purchase a bundle of equipment through the NDIS from MND associations that will supply all the equipment that they need for 12 months.
- Evie:** How does that work? You mentioned before that the average life expectancy post-diagnosis is only 27 months. A lot must change in those 12 months. How can you possibly plan 12 months ahead in such a rapidly changing disease?
- Rod:** When we've had 25 years of experience that I've seen.
- Evie:** It's fairly predictable?
- Rod:** We've got a fair idea of how people will progress and what they'll need through that progression. What changes is the time that that takes. By building a 12-month plan, we project where people are going to be up to as far as their assistive technology or personal care needs, their communication devices, perhaps transport, whatever it might be, to ensure that we can cover the bulk of them. Yes, if an individual move away from that trajectory as we've seen it, they can go back in and we can help in identifying

that change and go back into NDIS to get another plan. In the mind, a 12-month plan works really well.

Roland: Can I ask a question, because you and I have had numerous contacts over decades around information services reaching people with a disability with the message that we need to reach them with? You know this better than I do, but often the services, the cohort specific services, so down syndrome association, Motor Neurone Disease association, cerebral palsy association. Those organisations I don't want to name anyone in particular, but a lot of them in general have difficulty accessing their client population and getting them active members or active users of the situation. You're involved in disability information Victoria, we competed for that tender many years ago. It was a total flop in reaching people with disability with the information they need. On your website, you say you've got a 95 percent market penetration with MND to be clinical and almost cruel about it with a 3-year turnover with the people with whom you're working with. That's three times as hard as working with people who are with services for longer. Hopefully, some public servants are listening and some people that are trying to provide information services. How do we successfully provide information to people with disability?

Rod: Well, for starters, I don't think you can take a one brush takes all. For Motor Neurone Disease, we'd look at information as being a two-phase process. First phase is general information that you can read, you can get off the website, someone can hand you a brochure. You might get it off any source. The second phase is making that relevant to the individual. That requires me talking to you face-to-face, where I can see your living circumstances and build that information into a relevant tool for you.

Roland: How do you find me?

Rod: Well, in MND, we've got a reputation for finding nearly everybody.

Roland: How?

Rod: Well, we've built up a reputation.

Roland: A brand that people recognise.

Evie: People are coming to you.

Rod: People are coming to us. More importantly, the vast majority of our referrals come directly from health professionals and neurologists.

Roland: They're not going to do that if they don't trust you.

Rod: Correct. We've had to build a relationship based on doing. When we say will we do X, we'll do X. We don't stuff around and take time to do stuff. I think part of the issues and what makes MND easier, if there is such a term, is that we know we have to work quickly. We have to get information into people and then help them assimilate it for their circumstances quickly, because they are progressing as we're talking to them.

Roland: You don't stuff around?

Rod: We don't stuff around.

- Roland:** Evie, I wonder if you could just quote the Sally thing about reliability?
- Evie:** Sally Coddington who is one of our consultants, she is a parent of a child with a disability, and she talks about the marketing messages that a lot of service providers have, which is around: We'll help you live your best life and achieve all of your dreams and you'll be so independent. It's very high-level stuff. Her thing is: Well, if you can't show up when you say you're going to show up. If I have to have a cancelled shift every other week and I can't count on you to pick up my daughter from school when you say you're going to, then don't even start the conversation with me about goals and dreams and aspirations. If I'm still scared about what's going to happen this afternoon when you show up, we can't begin that expansive conversation.
- Roland:** I think the same has to be true for health professionals, too. They're not going to refer to an information service, a support service, any kind of service, unless they're confident the person they're referring them too will get some reliability. Often, they don't.
- Rod:** They do from us. I think that is partially because one of the key services that we provide is assistive technology. Now, the major provider of assistive technology in this state, apart from paying for it yourself, is SWEP. The history of...
- Roland:** The State-wide Equipment Program.
- Rod:** The State-Wide Equipment Program in the disability arena is not great. Not great is a good way to describe it. Generally, slow. Complicated by a number of factors. It's not fully funded, so people have got to contribute. They've got to find money. There's slow prescription process which involves trial. Then it's for complex equipment, it's about ordering, purchasing, and supplying, which slows everything down.
- If someone wants an electric wheelchair, you could probably guesstimate that someone is going to take through the state-wide program six to nine months. If it's in our stock, four days, it's in their hands. I think when we talk about getting referrals from allied health professionals, our equipment service stands as our frontline service. In terms of referrals from neurologists, they know we will, our goal is to see every person nearly diagnosed within two weeks of that diagnosis. No matter where they are.
- Roland:** That's so cool, Rod.
- Evie:** DSC late last year, we put a call out looking for providers who we could give some awards to because we get a lot of bad news in the sector and we wanted to really have some good news stories. We put the call out and asked the sector to nominate providers who were doing things a little bit differently. We gave our award in the category of NDIS organisational transition to MND New South Wales. The MND association of New South Wales. They were recommended by an occupational therapist, I think she was, who worked for a partner organisation who said that MND New South Wales had made her job so much easier that the advocacy that they'd been

doing for their participants was phenomenal and most of all, they'd created an equipment loan pool.

We know that for many people with MND, the equipment needs that they have change very quickly, they're also fairly expensive. When it comes time to go to the planning meeting and justify why a ten-thousand-dollar piece of equipment is needed for three/six/twelve months, that can be a very difficult conversation. We understand that MND New South Wales has created an equipment pool to get over firstly the conversation that has to happen to convince the planner to fund it, but secondly, as you've just pointed out, the time barriers that are usually at play when it has to go through that formal planning purchase process.

Rod: We've been operating an equipment loan service as MND New South Wales have for about 37 years.

Evie: Okay.

Rod: This is not something new. When MND organisations first formed, they sat down and said, what do our people need? The first thing they needed was information because there was nothing. When I was interviewed for my job, I went to the library and there was nothing between motorcycle and motor vehicle. It wasn't well-known. Information was crucial to start with. The second thing people wanted was assistive technology. I've got a wheelchair that's no longer being used, would someone else like it? That grew into a loan model, which under the marketized environment of the NDIS, we've converted to a hire model. Our hire model in Victoria, for example, supplying disability aids and equipment to probably about 400 people.

Roland: What sort of stuff?

Rod: You name it, we've probably got it except for communication devices.

Roland: We set up a tent, you were one of our competitors.

Rod: We were glad you won.

Roland: We set up this equipment recycling scheme. What we ended up with was a whole lot of broken shit that we had to dump and store. We lost a lot of money doing it. What were we doing wrong?

Rod: For starters, you were collecting equipment from people who used it for years and years and years. When it was no good for them anymore, they gave it back to you. State-Wide Equipment Program or PADP, program of aides for disabled people would then buy them a new one. We can get ten years out of an electric wheelchair, but that might be eight different users.

Roland: Wow, we're not seeing that anywhere else.

Rod: No. Well, it's happening in other states within MND.

Roland: Yes.

Rod: Not anywhere else.

Roland: It's working.

- Evie:** The other part of this story that I've heard is that the NDIA has been very responsive, that it's a bit unusual to have this kind of equipment pool, how it goes into plans, it's not totally traditional. That the NDIA have actually been very active partners in working with organisations to make this work. What I'm hearing from what you're saying and from what we've heard about the success of that MND New South Wales model is that there's something about MND and the way that it rapidly progresses, that means you can't really afford to not do a good job, to not get things done right away. What I'm wondering is, is there any way to replicate that model in other sectors?
- Roland:** I want to make this a double-barrelled or an even more complex question because most people from outside the disability sector and I think a very significant portion of the younger policy makers in the current disability sector do not understand their heterogeneity of the sector. That two people with Motor Neurone Disease might have quite different needs, but they're certainly going to have very different needs to a young person with cerebral palsy, a person with mental health issues. I think we're missing a lot of the nuances. You touched on them before when you said, well, you can't take a single brush to these issues. Can we answer Evie's question, can we replicate that and do it better, but can you also acknowledge the heterogeneity as you go?
- Rod:** Look, the model that we're using in MND New South Wales and other MND associations including Victoria is based on the fact that people only use equipment for a relatively short time. To recover equipment and refurbish it, it has to be fundamentally sound to start with and not worn out.
- Roland:** Not customised either.
- Rod:** Not customised.
- Evie:** I guess where I'm coming from is not just about the equipment pool, but just the nature of the organisation, of having the urgency to respond and then the capability to do so. Short of making everybody else's disability needs more urgent, which they are, frankly, they're just not changing as fast as many others.
- Rod:** I think that urgency has a price. That price is not being met by the nation disability insurance scheme in terms of ally rates for service. Also, there's the complexity of families wanting to be in control of what's happening, that takes time. Education and support of families takes time. I think that the notion of a single-brush service is never going to work, as I said before. You've got to look at, what are the unmet needs of the person and how can they be addresses.
- Roland:** Rod, I want to finish with a question and it's probably a bit of an angsty one for me, personally, but you would have had the opportunity to have bailed from a smaller information support and advocacy organisation and jump into a big CEO role, which is what I did. I still sometimes look back and did, that was the happiest I ever was, why

did I choose that career path. Why didn't you ever go for the bigger salary? Let's also finish with, what are you most proud of in your 25 years with MND Victoria?

Rod: First off, don't think because people run small organisations they're working on low salaries.

Roland: Okay, cool. Your jobs are just being advertised? Is it closed?

Rod: Exactly. It has.

Roland: Sorry, too late, guys.

Rod: Why didn't I leap? I have to be honest, when I started at MND, I was undergoing some employment rehabilitation to get myself back into disability and back into organisations. I thought, three years, I'll jump and find something better. My board was smarter than me. Within three years, they'd sent me overseas for a couple of weeks to look at MND services in England. The following year, they sent me to our international conference. They were so convincing about how good I was, which I didn't feel good, at working with this field, I traded in a significant pay rise in return for them sending me to the international conference every year in the future. They supported me to go on the board of the international organisation. They supported me to be the chairman of the international organisation. They, in a word, sucked me in. I'm so glad that they did because I have learned more about myself and about people. I've met some of the best people in the world.

Roland: You're most proud of?

Rod: What I'm most proud of? Look, I think I'm most proud of taking an organisation that was on the cusp of going out of business to one now that can withstand the ups and downs of the NDIS and can keep delivering services for people with Motor Neurone Disease. We've done that where not exceeding 20 of government funding of our total budget, by actually trying to reduce the amount of money we've got from government, because that leaves us powerful. No one can tell us what to do.

Roland: Well, thank you for being a great guest, Rod Harris.

Rod: Thank you for having me.

Evie: Thanks, Rod.

End of Interview

Outro

- Roland:** You've been listening to the podcast from Disability Services Consulting. Evie, do we do consulting?
- Evie:** I don't know. [Laughter].
- Roland:** We get that question a lot; do you do consulting? It's like, Disability Services Consulting.
- Evie:** And training.
- Roland:** And training. We do a lot of consulting and training. We'd love to hear from you. If you like our podcast, you'll probably like our consulting and training even more.
- Evie:** You can subscribe to our podcast by following the link in the show notes, or on our website: disabilityservicesconsulting.com.au. We also publish a stellar newsletter if I do say so myself.
- Roland:** It is pretty wonderful.
- Evie:** Stop it.

End of Audio