**Speak Up-Kōrerotia**

**Caregivers and caregiving in Aotearoa**

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**Plains FM**

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**Sally**

E ngā mana,

E ngā reo,

E ngā hau e whā

Tēnā koutou katoa

Nau mai ki tēnei hōtaka, Speak Up-Kōrerotia.

Tune in as our guests ‘speak up’, sharing their unique and powerful experiences and opinions and may you also be inspired to speak up when the moment is right.

Today we're going to be talking about carers and caregivers and caregiving in Aotearoa. What are carers, what are caregivers, what kind of work do they do? What kind of human rights situations are they facing? It seems a really timely topic at the moment, I think, because we’ve seen some protests this year around the disability community and the downsizing of Whaikaha, the Ministry of Disabled Peoples, the rollout of Enabling Good Lives being paused, all sorts of issues that are putting the rights of the disability community – and by extension, the rights of their caregivers – into question. And so I'm really looking forward to jumping into this topic. I think it's a really important one and as we've already had on a kind of offline conversation, not one that gets much airtime.

We've got two guests with us today who are going to be sharing their expertise. And I'm super excited. You guys from quite come from quite different perspectives. So I think we'll have lots to kind of come to the middle wit.

But it would be lovely to hear a little bit more about you. What is it that drives you? What's your passions, and how you've come to the work that you're doing today? What is your mahi? Laurie, perhaps we'll start with you.

**Laurie**

You want me just to make a beginning? Okay? Well, when I was 32, I was working as a business journalist at various business publications. I wrote about it, and my partner lived up in the far North, and I would commute back and forth from Auckland, and one day we woke up, and he couldn't lift his arm. And I had no experience of understanding what a stroke was but obviously something was very wrong, and so like, like so many family carers, I was thrown into that role of, you know, protector, helper, and it was a very long journey to find out what had happened to my partner, and then what the implications of that were going to be for him and for me. And we didn't realise it, but our lives had really changed in that moment.

And I was surprised to discover that while there was a lot of focus on George, there was very little interest in or focus on me, and I didn't think that was fair, because caregiving is, you know, a very stressful, quite physically demanding role. And I thought my needs to be taken into account, too. So with another much older family care from Milton down South, we started Carers New Zealand, and it was the two of us. That was very small and informal for a long time. But today there are 80,000 people in our network people and organisations. Carers New Zealand is the national peak body for family whānau carers, and we're the Secretariat for the Carers Alliance, which began in 2004, and is now 60 national not-for-profits.

So I'm coming to the end of my, you know, what I can contribute to Carers. I mean, back then there was zero. There was not a brochure, there was no helpline, there was absolutely nothing and very little interest. I mean successive health ministers, and even some that became prime ministers, just did not think we needed to have a focus on family carers. So it's been a battle all the way along, and it remains a battle. You know, a lot of the challenges that we faced back in those early days are still our challenges. Those big things don't change. They need investment. They need focus. And they need leadership. And we're still fighting for that.

**Sally**

And so is Carers New Zealand an advocacy group?

**Laurie**

Yes, we do advocacy, I mean, largely through lobbying for progress and change for carers. We've got a campaign the Carers Alliance has been running for quite a while at wecare.nz. We've got a petition arguing for a home in government for carers in their own right. They are a large population of, we think, about a million New Zealanders, two-thirds of whom are women, most in middle age or older. Almost 90% of family cares are workforce age and they really struggle to keep working and earning. I was a lucky one, because nobody in New Zealand really wanted to be an IT e-commerce journalist back then and I was able to work from home so I was able to pay my mortgage, and some of the extra care costs that we had, and I didn't wind up on that slippery slope of, you know, needing public assistance and not being able to save or earn.

So it's something I'm really passionate about. I think we need to look at that in New Zealand, because more and more is being expected of family carers, especially in these times of high cost of living. Housing costs, transport costs, service uncertainties, funding uncertainties. I mean, we need people to do this more than ever, and they want to do it. But it is not fair that their needs aren't looked at, too.

**Sally**

Great. You touched on so many themes that I'm sure we'll pull out more as we go through again. Tyrone?

**Tyrone**

Yeah, awesome. So my background is quite a bit different. So I've been involved with mental health kind of support work and that kind of includes managing daily routines, socialisation, and a lot of the kind of challenging tasks that caregivers would face in their role. And then also for the last two, three, years. I've been involved with this research project with Dr. Shinya Uekusa, and we're looking at caregivers, informal caregivers, and their experiences of caregiving during the COVID-19 pandemic. So quite recent and quite relevant. And it's been, yeah, awesome to hear people's stories. And I think Laurie mentioned a lot of the things that we've heard from our participants while doing this research as well.

**Sally**

So just as we get started, I'm going to pick up on something. Tyrone, you mentioned ‘informal caregivers’ and Laurie, you mentioned ‘family carers’. A discussion about terminology seems a really good place to start: carers and caregivers – are we talking about the same thing and informal, formal, family, unpaid, paid? What's all the terminology here?

**Laurie**

A lot of people don't like that word ‘carer’. But we call people who do this role. Family carers. You're supporting someone in your family, whānau or a friend. It's a role we can all expect to have in our lives at least once, especially with an aging population, or we may need support from someone in our family. So there's the paid support workforce, we care about them, because if they're sustainable, then we're sustainable. But our community is the family whānau carers.

**Tyrone**

Yeah. Very kind of similar definition, I suppose, coming from us. It's about kind of the close family members and the family that are caregiving typically tends to be for kind of spouses, partners, parents, dealing with kind of health decline and stuff like that. But it's really interesting if you dig into the research that each country kind of has different ways of defining.

**Laurie**

It's a lightning rod word, ‘carer’. A lot of people don't like the word ‘carer’, including some people who are what we would call a family carer. But our response to that is that feedback from carers over the years is we *are* family members. We do this role out of love and duty. But it is more than being a family member. More is asked of us.

And the young ones, especially, have driven that over the years. There is a global care movement, the International Association of Carer Organisations, and we all have adopted that word carer. And it's a word of activism to pursue progress, recognition, and valuing of the estimated 1 billion people in the world who have this role.

**Sally**

Well, that's huge, isn't it?

**Tyrone**

Yeah, it's really interesting you bring that up, because something we kind of found is we, you know, label the study as a caregiver study, and we have people contact us saying, “Well, I'm not a caregiver. I'm looking after my spouse. It's what I'm expected to do, or, you know, I do it because I love them. I'm not a caregiver.” But in fact, they are; like you said, they're going above and beyond what a family member would do to care for a loved one.

**Sally**

So what kind of work do carers, caregivers, family carers, tend to do?

**Tyrone**

Caregivers kind of do a bit of everything, right, because they are family members, typically, or close family friends. So they're kind of often involved in a lot of the daily routine stuff managing, I suppose, medications, meals, kind of daily cares, as well as you know, doing the normal household kind of duties as well. And it can be quite challenging as well, because not all care is equal, you know. Care that requires more kind of physical… sometimes it's dealing with mental declines, particularly with kind of Alzheimer's and dementia with memory can be quite difficult to manage. So yeah, it's interesting. So it involves quite a quite a range of things. And I, from the research that we've done. It sounds like the kind of mental health side of it is quite difficult to deal with.

**Laurie**

It's a really diverse community like you can be thrown into that role overnight, like I was. That's very common. It can happen with a diagnosis, so you might need to provide more support over time. It might be for a short time, it might be for a lifetime. And the growing trend in our research is with the aging population and more care being delivered in the community we're now seeing, not just a sandwich generation of caring in families but a club sandwich, you know, that's coming through in our research that many, many carers now support more than one family member – and more than 40% have disabilities themselves – but they are supporting one or more others who needs their help.

**Sally**

And you mentioned there's a gender disparity there, and you've mentioned there's a high percentage with a disability as well. Do you notice other trends among the caring population?

**Laurie**

Well, there is a trend that young people are carers – young carers, we call them – and they're the most invisible carers of all, and in New Zealand census has found about 80,000 of them only in the 15 to 24 age group. We think there's a very high number, based on over overseas experience of Under 15s who may be in a very intensive, even a primary, caring role for someone in their family. So we need to look at them more and understand their needs and focus on them. They're also, you know, obviously, there's a diverse range of ethnicities, Māori, Pacific, a growing Asian population in New Zealand. We've got new settlers and refugees – and we don't know enough about who they are. We're trying to draw that out in our own research. But we need to do more work there, because probably if it's hard enough to find support if you're an English-speaking New Zealander, it's probably much harder for others who don't have English as a first language.

**Sally**

I'm sure that's definitely true. My research is with multilingual communities and I'd back that up entirely. And how do you know these kinds of numbers. How do you get a sense of how many carers there are in New Zealand?

**Laurie**

We don't have enough data, but the Census does ask two questions – and has done since 2001 – about whether you provide care for someone living with you in your in your home, or in another location. And so that has identified it's now up past the 500,000 mark in the latest census. We've just been looking at those numbers. But based on global demographic data from all the carer peak bodies, you know, one in four-to-five of most populations have some caregiving responsibilities for someone who's frail, unwell, or may have a health condition or a disability. And so that would equate to, you know, a million-plus Kiwis. So that's the figure we use.

**Sally**

And so quite comparable to the number of people with a disability, which I believe is also about 25% of the population.

**Laurie**

Yes, and I mean, I suppose I identify as a disabled person, too. I mean, my mother took an injection when she was pregnant with me that causes can cause disabilities. physical disabilities, and reproductive disabilities. So I have a hearing impairment, and I have other invisible disabilities. But they didn't change my life in the way that caregiving did. I'm very passionate about the need for valuing and recognizing and supporting family carers.

**Sally**

Laurie, one of the things that I believe Carers New Zealand does is the State of Caring report. Is that something you produce?

**Laurie**

Yes, having evidence is really important. It's how you can make your arguments for progress and change, so everybody does that. And Tyrone, you know that's great that you've done that research to shed light on this experience during COVID-19, which continues. State of Caring is a comprehensive survey, can take up to an hour to finish it. It's only online. We did our first one right in the COVID era. So it was… you know, we weren't able to have any face-to-face meetings or gather some data that we hoped to in person, but it's meant to look at who carers are and how they are faring over time. We based ours on one that Carers UK has done in the United Kingdo for many years, and you're able to track trends, and how people are doing and what they do, and the contributions they make, and their physical and mental health over time. So we've got the second one open at the moment, and we'll be closing that in March hopefully. I think the first one had more than 1,600 responses, and we're hoping for a bit more than that this time. Synergy the research company does the analysis and the reporting. So it'll be really interesting to compare this second one with what we learned in the first one. And then we want to repeat it every two years.

**Sally**

That's great. And I guess, Tyrone, is a question for you as well: How do you reach out to people to encourage them to take part in these sorts of research projects?

**Tyrone**

So for the particular research project that I was involved with, it's a cross collaboration between the University of Canterbury and Massey University in Palmerston North, and they run the Health and Age research team out of Palmerston North campus. And they're like Laurie, they do a big survey – I think it's every two, three years from memory – as well. So they've built up a nice database of participants that we were able to tap into and use, which was awesome for us.

But yeah, I think it's quite difficult, because caregiving can be quite full on so asking these people to kind of give up their time when they've already got so much on their plate, can be challenging and trying to capture, you know, different age groups, ethnicities, and diverse backgrounds can be very difficult. And I think it's why the kind of survey that Laurie's doing is great, because, yeah, they're capturing quite a lot of voices in one survey.

**Sally**

And also it's open for a nice long period of time. That's good.

**Laurie**

Some would say too long. But you know, in March this year, Whaikaha announced those funding changes. And, you know some of the funding and support avenues that were available for disabled people and family carers were curtailed, and that caused a lot of distress that continues with us. So we didn't want to say, “Carers, would you complete a one-hour online survey for us?” So we kind of have stretched out the period state of caring is open, recognising the reality of those pressures. But at the same time it has activated family carers to want to speak out, to make a difference. They struggle to march in the streets or attend rallies, or, you know, wave placards at Parliament. They're often invisibly doing this work of caring, and so they can't, you know, join active protest always – although we have seen some of that recently – so they know that they know that completing a survey or taking steps like signing a petition does actually support having a collective voice and there is a lot of passion amongst carers of all ages, everywhere in New Zealand at the moment to want to do that. So this week, for example, we had 250 people coming into State of Caring, which was our biggest week since we opened the survey. And that's really nice, really nice to see, because you need that large, collective voice, so that you can be listened to.

**Sally**

Yeah, really great.

**Tyrone**

I think it kind of shows caregivers’ willingness, and want to make change as well.

**Laurie**

I think there's also a desire. Certainly it was one for those of us who started the carer movement is, you don't want people to have to go through what you did. You want progress and change so that it's easier for the ones who come after you. And you know there has been progress. It's not like there's been no progress over all these years. It's just that when new governments come in, you know, this has been said to us, “What's the low hanging fruit? What support can we give? That doesn't cost a lot of money, or won't take a lot of time” and we're kind of tired of that, because true change does cost money, and it does take leadership and commitment. So you know, we're hope we're trying to drive more of that, because otherwise what you've got is a demographic change where younger people tell us “We want to make the choice to provide care for someone we love but if we don't get support, we're not going to be able to do that.” So we're moving from the stiff upper lip generation who will do things, no matter what, and expect very little, to generations “saying, We want this role, but it has to be valued and recognised and supported.”

That is why the Carers Alliance is seeking a place in government for this large population of New Zealanders in their own right, not tacked on to the end of other populations, which will always be the priority for investment and progress and change, especially at the moment. Look at the headlines in health and disability. I mean, it's… carers are another thing, and they're not going to be prioritised unless we fight for that.

**Sally**

I’d like to now look at the human rights challenges that especially face caregivers and there are so many of them. We’ve touched on quite a lot already, but if we could pull this apart a bit, that would be great.

**Laurie**

Where to start?! Tyrone, do you want to talk about what you saw?

**Tyrone**

Yeah. So we'll kind of start, I suppose, with COVID-19. So what we kind of found is that we focused on older caregivers, and they were actually a lot more reliant and adaptable and able to cope with caregiving challenges faced during COVID than kind of the social norms let us believe. And a really interesting comment that we had quite a few caregivers make was, it's kind of young mothers and younger caregivers that would struggle as opposed to older caregivers. They felt they had the life experience that they could, you know, adapt and use to manage caregiving during COVID. But it's maybe the younger caregivers that have less life experience that would have struggled more, which I thought was kind of really interesting. I don't know if you have any kind of comments around that, Laurie, you're more familiar with younger caregivers?

**Laurie**

That’s probably true of the carers that you interviewed. For example, we're looking at with concern at elderly male caregivers who are one of the fastest growing populations of killers in the world. And I use that term because they, you know… You see all these cases around the world, and we've had them here in New Zealand, too, of men killing or trying to kill their wives of many years, their spouses, and then either successfully or trying to kill themselves as well. Elder homicide, suicide. And it's described by our coroners and the media as an act of compassion or a mercy killing. But actually, it's a mental health issue. Things are changing, you know the maybe the elderly male care has had a changing health diagnosis themselves, or their wife has had that, or they're not coping with the caring role, and they see this as the way out. And often there may have been a conversation years ago, saying, “If I'm like that, I don't want to live,” you know, and that's used in court cases as justification for what's happened. But actually, often these are extreme acts of violence, and the woman has not had an opportunity to change her mind or to say, “Yes, I want to be shot in the head, or smothered or beaten to death.”

I mean, we need to look at these things because we have an aging population and often caregiving in the state system is referred to as natural support. The Government would like carers to do as much free, natural support as possible, but there isn't anything natural about what is being asked of carers in modern times. You know, it's not just helping with a meal or taking someone to the doctor. It can be invasive procedures. It can be, you know, 24/7, full-on caring, and the fastest growing population of carers is older people, older people caring for each other, or very elderly carers. And I think we have to do some research – Tyrone, maybe that's something you can take back to your team – but we need to look at the impacts and supports needed by this unique population of people, which is quite elderly carers at home, and particularly men.

**Tyrone**

It's great that you kind of brought up those mental health challenges because quite often what we saw was the idea of caregivers locking themselves down for longer because of immunocompromised care recipients, I suppose, and that kind of almost a fear factor to keep that person they caregiving for safe. And that kind of played in into worrying a lot of kind of hypothetical situations for caregivers. You know, they didn't need – or the caregivers we interviewed didn't need – medical support as such during the pandemic, but it was a conversation or a concern about what if we need it? How do we go about getting it? Do we take the care recipient to hospital? What if they get COIVD while we're there? So yeah, you can kind of see how all these little decisions lead to kind of that big picture, and how that can be overwhelming and kind of cause anxiety for caregivers.

**Laurie**

And also, I mean, people who have significant support needs and their you know, their family care who might be their spouse, or it might be their parent, or whatever, they're already quite isolated and often lonely. Like, State of Caring found that about 70% of carers said they were lonely or isolated. Two-thirds experience depression and anxiety – that's a lot more than the general population. More than 40% get injured in their role.

You know, caring, caring does have its own health risks for carers, and that the mental health stress is a real thing. I try and talk about it because it was a reality for me, like I lived in the far North, I didn't leave home for 5 years, I didn't access respite – that took an enormous toll on me in my thirties. I can't even imagine what it would be like now. But I developed a real social anxiety and I had to have a lot of counselling to be able to speak in even small groups of people I know. And I still have it, you know, this is 30-odd years later. You know, the impacts can last for a lifetime, and I think that's what even we as caregivers don't understand. I often hear carers say, “Yes, I have this terrible anxiety, or I feel isolated. But you know, when I'm not a carer anymore, then it's I'm going to spring back like a rubber band, and it's all going to be fine.” And I think my message to carers is: It might not happen.

And in the older population, caregiving is an independent mortality risk. I've known – you know, so many faces crowding my mind as we talk about this conversations – where someone says, “Well, I'm going to do this, you know, my wife won't live forever. She's got this terrible condition, and then things will be fine for me” but carers can die first. And I think that that's why they do need to think about their own wellbeing and having respite. And even if the person they support says, “I don't want anyone but you to provide my care, or I don't want to go to a facility” you have to, so you can have some respite as a family carer. You have to really think about that, because the realities for you can be life-threatening in an older age, but also it can have lifetime impacts. You know, my example has been a reality of that.

**Tyrone**

Yeah, it's great that you bring that up kind of, I suppose, pushback from care recipients. The caregiver has gone. They found support workers to come in for a couple of hours to give them a break, and the whole time they're there the care recipient is calling up the caregiver rather than asking the support that's available. And something that was really interesting for our research, as well, was that idea of being immunocompromised, the care recipient being immunocompromised, and how do you get support? How do you get that break, that respite? Because they don't particularly want somebody to physically come in because it opens up that risk. It becomes, you know, more prominent. So yeah, I guess, yeah, something that's quite challenging that's come out is, how do we support caregivers when those kind of traditional physical supports and way of doing things aren't ideal anymore and we want to isolate and social distance?

**Laurie**

Yes, and those realities are still with us, I mean, COVID hasn't disappeared. There's a lot of COVID in the community at the moment, so that concern about somebody who's immunocompromised, or what if the carer gets very sick with COVID? That that's still a reality in our community and will be ongoing, I mean, COVID isn't going to go away along with the other challenges. But during COVID-19, we saw that that trend during the lockdowns, and we created a website called wecare.kiwi, and that was so anyone who was living on their own or had concerns could contact us. We made use of IHC's police-vetted volunteers around the country, and we would give practical help however we could. And what we found is mostly what people needed was someone to listen to say, I'm scared of this, or what if that happens? It was a reassurance, vent for people. It's not active at the moment, because a lot of the anxiety has receded. But we see it here at Carers New Zealand, with our own Helpline. People are still anxious about that.

So I think we need to learn the lessons of COVID-19. There was very little support for carers. They didn't get, you know, any claps. Or we kept saying to the political leaders, why doesn't someone say, “Thank you, family carers. You're doing more than ever services are disrupted. You're being asked to provide more support than ever.” But it didn't happen. And what we've said, is, we need to learn the lessons of COVID-19, so that we do better in any future event. And also the long tail of COVID, not just the instances of COVID, but the fatigue and burnout and realities of what happened to people however many years now, you know, three, four, years, they didn't stop caring after COVID. They carried on, and a lot of people in the first State of Caring report said they had not had any respite for a long period, and that is even more true now and we're really worried about the long tail of COVID on top of, you know, already the sparse support that cares had pre that, and post the lockdowns.

**Tyrone**

Yeah. One thing we've kind of that come up in our research was caregivers weren't really aware to go for support and not too sure why, that is. They quite vividly remember a lot of stuff around COVID, and what to do if you get COVID, and to call this line if you've got COVID, but nothing specifically for caregivers during that time. So that was kind of really, really interesting. And the other thing they commented on was around respite – and this is more of a long-term issue – that was there before the pandemic during the pandemic, and to a degree still now, is the time that it takes them to, you know, secure funding to then find a respite service, and all the paperwork and kind of red tape that goes along with that they fill in order to get the support. It's taking more time and work than the break they get from the support. So yeah, it's another challenge jumping through all the hoops in order to get that support can be difficult for caregivers as well.

**Laurie**

You're right, Tyrone. It's messy. But we have to figure it out because people aren't machines, and they're going to have wellbeing impacts themselves or not be able to keep caring unless we look out for them too. Now respite. The respite system in New Zealand is very fractured and broken, and not enough has been invested in it, and it means different things to different people. So you saw this in March, where the only state support most carers get is a thing called the Care Support Subsidy, and it's about $80 a day that you can use to buy something that will give you a break from caring – now that could be, you know, a night in a rest home, they tend to cost more than $80 a night, so you have to top that up. You know, there've been lots of barriers to using care support, but in COVID, people were able to use it more flexibly. They were able to use it as a budget, and we thought that was good, because that allowed people to have choices about how they could access breaks and rest. Then in March, in the Whaikaha world we saw, you know, carers are having massages, they're having their hair done, they're having their nails done, they're buying things, we don't think that's a good use of state money. So that was all closed down. What that has meant is, people are, now again, we've gone back to the 1980s, very restricted in their choices about how they can use – let's face it – that tiny bit of money to have a break. So we've asked the government to repackage care support as a budget, just release that money to people. It's typically less than $3,000 a year if you're a primary carer. Give that money to people so they can make the respite choices that work for them if they live in a rural area there may not be a facility that's suitable for respite. There may be there may not be workers easily available that you can use to pay care, support. So if there's one thing we can achieve in 2025, we really hope that we can just unbundle care support. So whatever age you are, if you're a primary carer across health and disability, that money can flow to you to make respite choices with higher needs. There are a lot of challenges with respite, and there just needs to be commitment to improving the system so people can have breaks because people cannot care and they will have wellbeing impacts if they cannot have respite, and our system is dysfunctional.

**Sally**

How about some of the other challenges like we touched on it right at the start, like the inability to work a full-time job and make money whilst also having, in many cases, a full-time caring role and trying to balance that and the financial implications of all of this.

**Laurie**

Did that come up in your research, Tyrone? It must have been worse during COVID.

**Tyrone**

Yes, so, interestingly enough, it wasn't during COVID but kind of after the pandemic or the lockdowns stopped that people started to feel that kind of financial burden. But a lot of caregivers are not working, is what we found. They're quite often involved in some forms of volunteering to give themselves a bit of a break and have some time away from their care recipients. And yeah, those that were working, their hours often got cut down because of COVID or stopped completely, and that did create a financial burden for them during those kind of lockdown periods especially when, you know, they've got to be able to afford medications and some medications to subsidised, some aren't. So it's a lot of stress for caregivers to manage. And I know we've had a couple of stories about people own their own businesses, you know, going under because of them having to caregive and COVID kind of impacting that part of their life.

**Laurie**

Yes, we had been working on a program to encourage employers to be flexible, because one in eight of every workplace is a carer. And so we wanted to build stronger relationships with employers, so they would understand the need for flexibility by carers, the ones they already employ, and then to have an open door hiring policy for flexible roles for any new vacancies. And it was a strange time but we launched our Carewise program as COVID started in New Zealand, so not an ideal time where employers already had quite a few challenges of helping staff work from home and so on. That program was catalysed with some funding from MSD Industry Partnerships and we worked with Business New Zealand, and others, and although it was a strange time, you know we now have got, you know, 150 plus employers in that program at 600 locations, employing more than 100,000 staff. We help them develop their intranet so carers know what support is available. They have lunch and learns so we can talk to them about some of the realities and pressures, and we also have for the last two years learned a lot about carers who are not able to work for whatever reason.

Most carers do want to work, they've got hopes and dreams, you know. State of Caring showed often a carer will work until 75, because they haven't been able to save enough money to retire, and so that lifelong financial anxiety is a reality for so many carers. And we've worked with some great employers who have hired family carers into flexible jobs. And it's an area… This is work that will never be done. But I just take my hat off to MSD Industry Partnerships for, you know, paving the way for Carewise to be a program available to support employers to understand and assist their staff who are carers. And then you know, just everything. All those employers that we've worked with who are genuine. They see people's lives coming to work with them; they really get that. We have an aging population, and if they want to retain these staff who may be carers, then then they want to be flexible and help to do that wherever possible.

So yeah, it's a movable feast, but a really important one for New Zealand, because we did an analysis of the Census labour participation data with Infometrics and it's great. The two leads who worked on that report were very familiar with caring themselves and they broke all the data apart, and the annual economic value of caring in Aotearoa is at least 17.6 billion dollars. So it's a huge economic contribution and priceless social and family value. That economic data is really important and stacking up any government and public investment in the viability of carers as a workforce. It's not just a nice thing to do to support carers, it's a smart thing to do, and we need to do it better. The work the unpaid mahi aroha is incredibly value valuable to New Zealand and to our economy. And you don't want to grind people down so they just have a life of, you know, feeling unvalued and economic misery. New Zealand doesn't like that. We can do better than that. So that's a driving thing that we want to achieve at Carers New Zealand but also the Carers Alliance. So in the calls to action in our wecare.nz campaign, we've got the petition. We want a home in government for carers so they can be looked at and supported in their own right, but also true progress for mental, physical, and financial wellbeing.

**Tyrone**

Yeah, and the financial one’s really important, and something that come out of our study. I was lucky enough to be involved with some of the interviews for Māori participants and some of the data analysis around that, which is great. But there's a cultural expectation for them to care for their kaumātua so kind of managing that. And we've had some participants state that they've given up their jobs in order to do it, because it's what's it is expected of them, that’s how it works sort of thing, So kind of really interesting that I guess cultural needs that they have or expectation to care, and how that impacts them financially if they're not able to work while doing that.

**Laurie**

Absolutely.

**Sally**

I did want to ask if there were sort of any systemic barriers that that crop up. And I wonder about systemic racism, rural/urban divide. I'm sure there's probably quite a lot of structural barriers that come into play with many of these roles?

**Laurie**

Did you look at that Tyrone?

**Tyrone**

Yeah. So for our particular study, a lot of caregivers felt they didn't need to access health systems during the pandemic; there were some that did and had quite kind of severe needs but for the most part, none of our participants felt there was any kind of racism or different treatment because of their ethnicity. However, in other aspects of their life outside of caregiving and outside of COVID, they have experienced those things. So it's definitely there but it's not something that popped up in this study specifically.

As for kind of the rural and urban: our rural participants often made comments that they would have found it easier than urban areas because they're used to not having access to all the supports that you can find in urban areas. And simple things like when they went for walks they had their own land so they're not bumping into people, you know, there's not that risk of getting COVID or sick from somebody else. And kind of that they're a tight knit community that often relies on their neighbours to help out and that didn't change during COVID as in the urban areas I guess a lot of those supports shut down. Caregivers didn't want to access that physical nature of support because of the potential risks, so they probably felt a bit more isolated than what our rural participants did.

And with that as well, something else that kind of come up is this idea of internet and what support can we offer online as respite, something we could do online, which often for kind of those rural areas? Then the network isn't that secure and can cause problems. So even if it was a viable option, it probably wouldn't work for those more rurally isolated.

**Laurie**

Yes, I would agree with all of that, Tyrone. And we saw that, too, through our helpline, and so on. I do think there is systemic racism, just from feedback we get through our helpline, and I certainly witnessed it in those early caring days myself, but that was a long time ago. You hope there's been progress and change since then. But I wonder, you know, access to supports, that's probably another area that could use more research in terms of urban rural. I mean, geography is a reality, isn't it, that you're probably not going to have the same kinds of services in rural areas that you might have in urban areas but I think it's a bit of a myth that the services in urban areas are fantastic. You know. I think there isn't enough, and there aren't things that are age-appropriate for younger disabled people to have to, you know, live in aged residential care, or have respite in aged residential care. I mean, that’s an unhappy situation everywhere. I think there is a postcode lottery in terms of what you can access in different areas.

And I think one good thing that has come out of the Whaikaha changes in March is there is a lot of scrutiny on who's getting what, where. And we're only a small country and there should be consistency and transparency and equity. I had a meeting last week with a bunch of providers in Whaikaha, and I felt somewhat reassured at the data they're gathering and the picture that they're building. So perhaps out of all of this chaos, you know, we might see some progress and a more sustainable sector but it's causing a lot of human unhappiness in the meantime.

**Tyrone**

And we have kind of lots of comments about, can the health system cope with cope with everything that was happening with COVID? And obviously for caregivers – when that caregiver is somebody that's older, as well – there's that concern what happens if they get sick. So yeah, I think that's a very good point that even the urban areas struggle with supports as well for caregivers.

**Laurie**

I think the lesson of COVID is, you know, in a time like that everything is disrupted, including the usual support services and the people that provide them and we are increasingly reliant on our families, our whānau, if we have that – not everyone has that – our neighbours, our communities. And Sam Johnson from Student Volunteer Army, he always says we need to figure this out when there isn't a crisis. We need to all have a plan ourselves. We need each other when times are tough. And I think certainly for family carers, I would also like, in any future horrible event, to think that we could do better for them, you know, because not just leave them to it and assume they're going to cope, and everything will be fine. The supports that they needed, including at the least acknowledging the more that they were doing at the least that we will, that they will not be invisible and unrecognised and lacking in support.

**Tyrone**

Yeah, I think that's important. I think it was mentioned earlier that caregivers want that kind of reinsurance, or somebody that they can vent to and I think when we ask caregivers what could be done to better support them, specifically caregiving during the pandemic, that was something that come out, you know, like somebody to say you're doing a good job. Because it's difficult. And when you don't have the support – and yeah, caregivers often relied on family members which, because of social, distancing rules and stuff kind of created that divide of whether family members can come over to support, can't they? – and I think there was a bit of confusion about that which this study found, that caregivers felt that improved throughout the pandemic, but was still an issue. So yeah, I guess kind of how do we provide them with the supports they need and validate the work they're doing while, you know, isolating and social distancing. It's quite a challenging task to be able to manage something like that.

**Laurie**

It's human nature, isn't it, like there will be future events – whether they're natural disasters or other pandemics, or whatever it will be – this will happen again in time. But I feel like we have not done enough in New Zealand to really unpick the lessons of COVID-19 so that we can even put even simple plans in place of what will happen next. I mean, at the time the Government did respond very well to bringing community leaders and organisations like ours together. We met every week, and we talked about what we were hearing and experiencing, and what would help and make a difference, but it just probably wasn't visible enough in what happened. We need to move faster. We need to message better, and we should be planning for that now, not scrabbling it all together again, like we did back then.

**Tyrone**

I think that's an important thing you've kind of made is that idea of being prepared. And it's something that our caregivers commented on as well, is that COVID was a shock to the world. It wasn't something that we thought would happen. It wasn't something that we could prepare for. It was something that we kind of just had to cope with in the moment. And, like you said, those conversations have been had so hopefully looking to the future there will be something a bit more kind of set up to help us manage and support the caregivers in those situations.

Another thing that we kind of found was caregivers didn't feel they needed to access supports or network with kind of potential support agencies and stuff like that until there's an issue that arises where they need that support. So how do we kind of get caregivers involved and build up their networks with organisations and supports when they feel that they don't need it, but tomorrow they might need it. It’s kind of an interesting idea to think about.

**Laurie**: Well, Kiwis are interesting. Like we found they're early adopters of the Internet. They want to be able to find things and move in and out when they want it. They don't necessarily want to come to meetings and talk about how hard life is, or you know they're quite pragmatic in what they want. But we did find after COVID there was a craving for face-to-face engagement and so we have been hosting these 50 meetings around the country just to listen, really, and say, “How are you feeling? Are you getting the support you need? Do you know what is needed in your community for carers? And really, it's such simple things. It's, you know, feeling that someone cares about them, too, you know, like just receiving information builds a sense of community for them. So like the things that we do, we do complex advocacy where needed, but a lot of it is listening. A lot of it is providing information like our magazine, our info packs, our e-newsletters, our Facebook community, just where people can check in with each other, help each other receive information. Probably the information we develop isn't something you would find in mainstream media always. So yeah, it's not rocket science things; it's those little human things – and I think that intensified during COVID. And now there is a craving to think, “Oh I have become quite isolated, what am I going to do to reach out? How will I make some new friends?” We did launch, we called it a discovery portal at weconnect.nz and that's to help you find things in your community or online that allow you to befriend, find activities, outings, learning opportunities, respite. That was a COVID response but it's become an ongoing service for us, because that need for connection is always there.

**Sally**

It sounds to me listening in that COVID has provided almost a spotlight on many of the issues that carers face all the time, and hopefully provides a really good opportunity to pick up on what this has illuminated, and build on it, moving forward. Just any final words as we wrap up?

**Laurie**

Well, you always want a pathway into the future for a thing, because there is a lot that needs to improve for carers. And so we were a bit concerned with the change of government that the Care Strategy might not continue. The last Action Plan finished in December 2023, and we've had to circle the wagons again with the new government, but they do seem committed to wanting to continue with having progress for carers. We hope it can move faster and with a bit more shoulder to the wheel for carers in areas like respite, a fair payment system for carers supporting carers to be able to participate in paid work alongside their caring role, looking at their overall, physical and mental wellbeing, possibly recognition, legislation. So we have got runway, which I'm happy to report. But you know, it is work that will never be done, and if ever a large community of New Zealanders deserved that attention and investment, it is family carers.

**Tyrone**

Yeah, I think one of the big things we found is caregivers quite often relied on their local GP as their go-to way of getting support, information, anything they need to help with their caregiving. And obviously with a lot of those services not running in person and it being kind of phone call-based, it was a bit difficult and the stress that was on the health system, they weren't as freely as available as they otherwise normally would have been. But it's great to have seen some learning from COVID, and some things come out. So I know navigating wellness, Third Age Health have produced a kind of booklet that is available at GP Centers and it has a whole lot of things, simple things, such as how to clean wounds or wrap them, and moving to a kind of more severe problems as well. So it's good to see that there is ideas coming out of COVID on how to better help support caregivers but yeah, like, Laurie said, more kind of needs to be done and developed in order to support them.

**Laurie**

And Tyrone, just from your research, I mean, we did a caring and lockdown forgotten families during COVID-19. We did a report that about 600-odd carers gave input into which we've shared with government, you know, hopefully, some lessons in there for to inform, heaven forbid, future events… But if you could summarise, what's one thing that we could do, that was a lesson of your research for COVID-19 that we should not lose?

**Tyrone**

I think one thing that come out is the socialness of humans, and that face-to-face is really important and when we think about supports, we're quite often thinking about, what can we do in the pandemic where socialisation is a thing? But we also need those supports that have a humanness to them, where there is that face-to-face, or physical touch is quite important in some cultures as well. So incorporating, I suppose, how do we find that balance between supporting caregivers from a distance but also having that in person support that face-to-face, that friendliness, that human connection. I think that's probably the main important thing that's come out of our research is maintaining that human connection.

**Laurie**

I would agree with that. I mean, you know that we all can't do everything, but we can do something. So what are the some things we can do for ourselves in our communities? And then what are some things that government with its resources can do? We've continued that conversation post-COVID. We took over the Secretariat role for the Let's End Loneliness Coalition because it's such a problem in our community. And a group of NGOs had created this about five years ago, led by Age Concern, and we've been hosting some conversations in the Waikato in the community and we're now continuing that in South Auckland. Loneliness is a growing issue, and it's a reality after COVID-19. So what makes us feel lonely? What can we do about it? How can our community's help? And people have been willing to be very vulnerable in sharing their thoughts about that. And that's some future research that we're doing with Matthew Parsons and the Healthy Aging Institute with Waikato University, MSD, Carers New Zealand and others. It's a continuing conversation, isn't it. That's what research is, isn't it? It's little lights along the path to try and make life better for people, you know, understand ourselves and make life better. And so I've really enjoyed the chat, and hearing some of your insights, Tyrone, and thank you, Sally, for putting it together.

**Sally**

Sure. Thank you both for contributing your time and your wealth of experience and expertise.