

# Hey Minister, a 'Penny' for your thoughts?

## What happened to "caring for the carers?"

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In March 2022, National MP for Invercargill Penny Simmonds wrote a column in the Southland Times with the title “who will care for the carers needing respite?”

**The Southland Times**  
31 Mar 2022

News

# Who cares for the carers needing respite?

Society

[+1 more](#) Penny Simmonds MP for Invercargill



Southern people caring for family members who have health conditions, disabilities, or who

Across the country, this is a significant group with at least a million New Zealanders providing care for someone in their family. For many it is a seven-day-a-week role.

These carers are given limited recognition or support, despite their unpaid work being worth an estimated \$10 billion annually – about \$10,000 per carer per year. The work they do is essential, involves long hours

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Simmonds, a parent of an adult daughter with Down Syndrome had a point. We were in the throes of Covid restrictions, and for disabled people and their whānau/carers, it was a very stressful time. Rules around masks in public places, access to healthcare, vaccines and in-home support, the social isolation, loss of important routines - not to mention a pandemic to deal with, was incredibly difficult!

In her column, she was critical of the Labour governments lack of understanding and urgency in making important supports (like respite) easily available to disabled people and their whānau.

“As the National Party’s Disability Spokesperson, I’ve been working hard to achieve improvements for carers and to get a commitment from the Government on the provision for extra support.”

She goes on to explain the capped daily rate we are given to pay carers, worker shortages, made life extra stressful for carers who were already coping with so much.

Simmonds had sought clarification from the (then) Minister of Disability Issues Carmel Sepuloni, and Minister of Health Andrew Little, but was disappointed in their lack of response:

“It [also] makes a mockery of the stress that many families are under and serves to undermine any hope that those with sick or disabled dependents might have that this Government is ready to address their concerns.”

“...more help is needed for the carers in our community - we cannot ignore their plight because we simply cannot do without them.”

Let's just let that last sentence sink in a while. We *cannot ignore* carers because we *need them* BECAUSE we as a society rely on them to pick up the slack of an underfunded and inequitable health system.

For those of us who are parents and carers, where do the two roles merge? We parent unconditionally, because they are our child and we love them. Disabled or not, parents care for their child, they clothe, bathe, feed and nurture them because it is expected. Whether we are dressing them when they are a helpless newborn, or as an adult, our love is what motivates us to keep going.

Parents can also be carers, I see these roles as mutually exclusive, but parents become the carer as well, and that's just accepted. We do it willingly because we are parents and the ones who know our child's needs most intuitively.

Nobody questions this because it's easier to see parents as 'inspirational' hardworking super-mums and dads. And sometimes our role as parent suffers as a result of the pressures of being a carer on top of that.

We plug up the support gaps from the health and education systems, often at the cost of our careers, relationships and health. The joy of parenting is spread thin over tasks like home visits, paperwork, school meetings and research because we all believe the narrative that 'only special parents are gifted special children.' So we just get on with it.

### *The NASC'y business of Needs Assessments*

To access support in the form of funding, we have a Needs Assessment, where a stranger comes into our home, forces us to list all of our child's challenges, and what the worst day possible looks like for them, as well as verbalising our own weaknesses. It is a very disempowering experience, and as nice as the assessor is, it is draining.

We are approved an annual budget, which comes in the form of units if you use Carer Support, or a \$\$\$ amount if you use Individualised Funding. There is a list of criteria for claims that you must follow. There is paperwork, lord, there is paperwork! Carer Support claims were the only times I would send an actual letter through snail mail, and hope that it reaches the destination in one piece.

We changed to IF on the promise that the rules were more flexible, and claims could be made through an online portal. I didn't realise that if I wanted to have a professional carer, I was essentially becoming an employer, responsible for recruitment, payroll, KiwiSaver and other entitlements and tax. It's too much. My brain doesn't work well with numbers, and being responsible for paying someone makes me break out into a cold sweat just thinking of it.

Thankfully it was during the period Minister Simmonds mentions above, that we were given more flexible guidelines for purchasing. Nothing ridiculous - sensory items like fidget toys and a weighted blanket, things that my daughter had an interest in like gardening, annual pass to the zoo for her and a support person, LEGO, monthly subs to Spotify and Disney that she could access on her device, a contribution towards a MacBook. These were all things that made her life full and interesting, and could use independently or with a support person, so I got an opportunity for respite.

I've never claimed for a manicure, haircut or massage, but I don't judge anyone who has. It's the act of self care that we are in such need of. And the physical act of sitting still, even for a 45 minute appointment, is a rest. So let's not go there.

Surely these are more cost effective ways to access respite than what it might cost to the health system if carers physical and mental wellbeing are being impacted now and in the future.

Maybe Nicola Willis will repurpose all those unspent disability and respite \$\$'s into mental health services because I fear this is the direction many of us are heading in.

I'm disappointed that a Minister of Disability Issues can make comments that denigrate and shame parents and carers, with all she knows - as a representative of her community, and as a parent and carer with disabled whānau. Talk about punching down!

She has not only caused upset and anger, but has lost the trust of many in the disability community. The way she threw Whaikaha (the ministry of Disabled People) and our community under the bus is very unbecoming for a Member of

Parliament. Exactly who is she representing now? Not me, not my daughter, not the disability community in Southland either.

The past seven days have been full of tears, I can't recall one day I hadn't cried into my breakfast coffee last week.

I don't expect much from this government. We have a house, which I guess puts us in the bracket of 'squeezed middle.' Yet all the things that were helpful to us as a family of four with one income have been, or are about to be taken away. Free prescriptions are a huge help when GP charges continue to rise, and I am on four different medications. Free and half price public transport for myself and two school aged children have also saved us approximately \$20 a fortnight. That's the difference between a 3L of milk and some bread that is always in short supply in my house!

So we have kept our funding budget, but it's nigh impossible to spend now, and all the things I use it for like subscriptions for my daughters Spotify and Disney that she uses every day, will have to be reassessed. If I pay for these things out of my own pocket, then something else will have to be cut. I'm really hoping it's not, but the weekly speech language therapy sessions will have to be considered.

*[Yes, you read that right SLT doesn't qualify for funding, it never has - as its within school hours, this should be able to be funded and provided by a Ministry of Education Therapy team. Despite the fact my daughter has been in college 2 years and we are yet to hear from a MoE SLT 🙄 ]*

So when you hear the govt saying "we haven't cut funding," please keep that in mind. Technically they have not, but they've made it a hell of a lot harder to use our approved funding. We can no longer provide the supports that made our disabled loved ones lives full and happy.

We, parents, caregivers and disabled people are being forced to make cruel cuts ourselves, slashing our own supports and respite, capping our own opportunities - while the funding approved just sits there, guarded by government, whaikaha and providers gatekeepers.

I won't speak for disabled people, that's not my place. But as a parent and carer, this particular week has felt heavy and burdensome. That's no reflection on our role, nor our loved one's disability - it's the world around us that makes things so tiring and impossible. That's what we need the occasional opportunity for respite from.

Penny Simmonds should remember that the next time she's punching down on us.

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