

Caring In Lockdown

Forgotten families during COVID-19

July 2020



Report Contents

About this research, Profile of carers, Acknowledgements	3
Introduction	4
Executive summary.....	5
Rising levels of care	6
Changes in the amount of care provided	6
Reasons for providing more care.....	6
Caring changes.....	7
Financial pressures.....	8
Increased costs.....	8
Are you spending more money?.....	8
Employment situation and impact on working carers	9
Employment before COVID-19	9
Worries and fears.....	10
Practical issues for carers.....	11
Food and other supplies.....	11
Technology	12
Personal Protective Equipment.....	12
Government guidance / Information	13
What now for carers?	14
Respite.....	14
Recommendations	16
Summary	17
Longer term.....	17
Short-term.....	18



Caring In Lockdown records the experiences of nearly 700 New Zealand family, whānau and aiga carers, finding that the COVID-19 outbreak is having a profound impact on carers' lives.



About this research

Carers NZ and the NZ Carers Alliance carried out an online survey between Thursday 14 and Monday 25 May 2020. A total of 676 carers responded to the survey, which was time-consuming to complete (more than 15 minutes). Not all respondents completed every question, but every question had a response from at least 520 carers. Most questions were accompanied by comments, giving rich insights about the issues facing carers through COVID-19 that cannot be gleaned from the numbers alone.

Profile of carers

Of carers responding to the survey:

- 29% live in Northland and Auckland; 17% in the Waikato, Bay of Plenty and Gisborne; 21% in the MidCentral region; and 33% in the South Island.
- 90% identify as female and 8% as male. The remaining 2% preferred to self-identify or not say.
- 82% describe their ethnicity as New Zealand European / Pakeha and 7% as Māori.
- There were very small numbers of carers from other ethnic groups with no group exceeding 1%.
- For 6% English was nominated as their second language.
- Most respondents (71%) care for one person, 20% for two people and 8% for three or more people.
- The age group(s) of the person cared for divided approximately into thirds: 29% under 18 years, 37% between ages 16 to 64, and 35% over the age of 65. 9% of the people cared for were over 85.
- The majority of respondents were long-term carers. 35% have been caring for 15 years or more, 20% for between 10 to 14 years, and 4% for less than one year. 3% have been caring since the beginning of the COVID-19 outbreak.
- Over half of carers (54%) considered themselves to have their own health condition or disability. This is significant and more than twice the number of those responding to Carers UK's recent COVID-19 survey who considered themselves to have a disability (23%).



Acknowledgements

We thank Carers UK for allowing us to modify its *Behind Closed Doors* COVID-19 survey, undertaken in April 2020, and its subsequent excellent report. We added some questions and deleted others. While NZ and the UK differ significantly in our experience of and response to the COVID-19 pandemic, we share a concern for the additional burden experienced by family carers, and the generally invisible nature of their unpaid work over this difficult time.

We thank family carers who spent on average 15+ minutes completing the survey so their collective lived experiences during COVID-19 could be recorded. Significant decisions and changes were made during this period that have impacted carers and their families and whānau – it is important to capture these for their historical context, as well as for lessons that may improve recognition, information, support, and services for family carers in future emergencies. This survey is also a reminder that when policy decisions are made suddenly, the ripples are felt deeply by those they affect – in this case, by family carers.

We acknowledge also the not for profit, community, and government networks that shared our survey link. These partnerships allowed us to reach a broad population of carers, ensuring a high number of responses in a short period.

Carers NZ and the Carers Alliance acknowledge too Danette Wilson for her editorial and design work on *Caring In Lockdown*.

Introduction

As New Zealand emerges from the COVID-19 pandemic, we are fortunate to not still be battling a widespread virus outbreak.

On the heels of this relief is concern, mostly economic, about business recovery, jobs, and how to help the vulnerable recover from COVID-19's frightening life realities.

For Carers NZ and the Carers Alliance of almost 50 national not for profits, there is also concern about the invisibility of family carers during the outbreak, and its lessons and consequences.

In NZ successive governments have, since the Carers Alliance was formed in 2004, attempted to improve visibility and assistance for carers through a Carers' Strategy and a series of five year Action Plans.

The most recent Plan includes, for the first time, strategic focus on NZ's still evolving payment regime for carers, support for working age carers, and a unified respite system to sustain carer wellbeing.

All of these areas are important for carers, and the COVID-19 experience demonstrates how much work is needed to ensure carers aren't taken for granted - left to get on with caring as a lower priority than the 'real' workforce, service provision, and other usual areas of focus.

The NZ Census has recorded almost half a million carers for family and whānau who are frail, unwell, or have a long-term health condition or disability.

This report highlights how they came through the COVID-19 crisis, providing essential care and support behind closed doors, often with little outside help.

Almost 700 carers completed the survey and their feedback is shared here to shed light on the hidden issues of caring during the coronavirus pandemic.

Our report provides powerful evidence of the difficulties carers face and their worries for the future.

The sudden halt of respite and household management services, support worker visits, and other help meant that carers had to immediately step up when COVID-19 struck, filling gaps due to workforce shortages and service changes almost overnight.

As you will read in carers' own words, they were already providing substantial care before COVID-19. Now, as normal life resumes, with a cautious eye on a resurgence of cases and concerns about weaknesses in New Zealand's border security, the impacts of weeks of caring are clear in this report.

Many carers have been juggling paid work at home

with home schooling a disabled child or caring for a fragile spouse or parent during lockdown.

The employment of many carers, as in the general population, has been affected by COVID-19, adding to financial worries that existed before the pandemic.

Caring In Lockdown is a portrait of carers themselves: most middle aged women, many caring for two or more people, many self-caring for their own chronic condition or disability whilst supporting others.

This glimpse of carers – of people giving so much but receiving little recognition or support themselves – reinforces the importance of the Government's *Mahi Aroha* Carers' Strategy Action Plan for 2019-2023.

Launched at Parliament in December 2019, *Mahi Aroha* commits to recognising, valuing, and celebrating carers in a range of action areas to which 11 government Ministers pledged their support.

During the COVID crisis many of these good intentions fell away, with carers not receiving basic information to keep themselves and vulnerable family and whānau members safe.

Key policy changes were implemented suddenly, without consultation or good information about how to access support in new ways at one of the trickiest times ever for carers.

None of us could anticipate the changed landscape of COVID-19. Carers came through as carers typically do – they did a difficult, often 24/7 role for weeks with little support or information, reinforcing the priceless social and family values carers are known for.

What would we do without them?

The COVID-19 crisis needs to be a turning point in how we treat carers. It has never been more important that government leaders, their agencies, services, employers, and all of us who care about Aotearoa New Zealand take action to support carers and those they care for.

Carers NZ and the Carers Alliance will continue to fight for carers' rights now and in the future, as we have done together for so many years.

A question we must ask as we review carers' responses to this survey is – who is listening?

Laurie Hilsen, Carers NZ CEO
Catherine Hall, Alliance Co-Chair
Janine Stewart, Alliance Co-Chair

Executive Summary

Caring In Lockdown records the experiences of nearly 700 family carers, finding that the COVID-19 outbreak is having a profound impact on carers' lives.

Many of those who completed the survey were providing very high levels of care, or juggling care in complex circumstances. Not only have many provided more care than before, they are suffering financially and are worried about the future. For many, their concerns and anxieties existed pre COVID-19; the pandemic has amplified these.

- 64% of carers provided more care during COVID-19.
- Of those providing more care, 51% did so as a result of services being reduced or closed.
- 50% of all carers have provided more help with emotional support, motivation or keeping an eye on the person they care for during the pandemic.
- 76% of carers have spent more money - 64% on food and 46% on household bills.
- 25% of carers worry about their financial situation longer term.
- The COVID-19 lockdown had an impact on working carers: 18% had given up work because of their caring responsibilities before the pandemic, while during lockdown 16% had either lost their jobs or were unable to work because of Alert Level rules.
- 66% of carers worried about what would happen to those they support should they become ill themselves or not be able to continue caring for other reasons.
- 37% of carers reported feeling overwhelmed and worried about burning out.
- Nearly one third of carers assist more than one person and over half (54%) considered themselves to have a health condition or disability of their own.



64%

of family carers
provided more
care due to the
coronavirus outbreak

54%

of carers have a
health condition or
disability themselves;
28% care for two or
more people

51%

are providing more
care due to services
reducing or closing

Carers NZ and the Carers Alliance call on the Government to restore health and disability supports with urgency, and ensure a range of flexible respite options are available to sustain carers after the COVID-19 lockdown. We further urgently call for quality information for carers in crucial areas such as respite, flexible funding, payment for carers, and how to access wellbeing supports such as counselling, COVID testing, and PPE. In addition, we call for a scan of gaps for carers during the pandemic to ensure better readiness for this important workforce in the months ahead, and to address system weaknesses so carers can be better recognised and supported in future emergencies.

Rising levels of care

Before the COVID-19 outbreak, carers were already providing substantial amounts of care, with a conservative annual economic value of at least \$10 billion.¹ The COVID-19 outbreak, and the lockdown requirements of Alert Levels 4 and 3, significantly increased the pressure on carers, with most changing the amounts and types of care they provided for many weeks.

COVID impacts on caring

Two thirds of people (64%) said they spent more time caring for someone during COVID-19 than previously. When asked to state the hours per week of caring pre and post COVID-19, most found this difficult to quantify. Respondents were asked to identify the reason or reasons for their increased caring. Over half (51%) said they were providing more care as a result of services having reduced, paused or stopped. The closure of schools and demands of online schooling were identified by many as a reason for significantly increased care levels. Deteriorating physical and mental health as a result of the lockdown were among the 'other' reasons cited for increased care levels.

Reasons for providing more care since the COVID-19 outbreak

Reasons for providing more care	%
Because services have been reduced, paused or stopped	51%
Because I am worried about paid health and social care staff having contact with the person I care for	18%
Because paid health and social care staff reduced personal care hours	9%
Because my paid working arrangement changed, so I have more time for caring	11%
I am providing more care for other reasons	19%

Around one fifth (21%) of carers provided the same level of care during the COVID-19 lockdown.

"Nothing has changed. I continue as I did before."

"The amount of care is constant."

"Because the person I care for hasn't been at school and is also doing shortened hours now school has returned. The paid support carer was stood down for safety."

"We usually have a carer for three hours a day five days a week. She has been paused with full pay during lockdown."

"My carers were not keen to help during Levels 4 or 3. I was also not keen for them to come as my child with special needs is vulnerable to COVID-19."

"Our carer had health problems that meant she had to stay at home."

"My employer was closed for eight weeks, as was my son's, so we were home together 24 hours seven days a week, often in trying circumstances for us both."

"I am providing more care as I am working from home as well as schooling due to child being at home."

"I am providing more care because my son's difficulties have increased along with his anxieties and OCD routines."

"My partner is fearful and anxious and needs considerably more emotional support. Also, I am organising everything because he is unwell. Lockdown is relentless."

A small number (4%) provided less care because they were following government advice to reduce face to face contact or because they were no longer spending as much time with the person they care for.

"I have spent less time during COVID-19 because I don't drive the person I care for to all the appointments she previously had (hairdresser, medical appointments, hospital, shopping, aged care club etc)."

"I cannot do as much for my friend now because I can't visit her in the retirement village."

¹ Infometrics, *The economic value and impacts of informal care in New Zealand*, 2014.

Before the COVID-19 outbreak, Carers NZ and the Carers Alliance had already raised concerns about high and unsustainable levels of care provided by many families.²

Our last round of consultation for the Carers' Strategy showed many carers and families at breaking point due to an underfunded care system.

The situation has clearly been worsened by this crisis, requiring urgent attention to the need for support and respite to sustain carers.

Changes to types of care

For many carers, the kinds of care they provided changed due to shifting circumstances, services or the needs of the person they care for during COVID-19.

Carers were asked if they were providing more of any of the following types of care and were able to select more than one option.

Half (50%) of carers said they provided more emotional or motivational support or checking in on someone either in person, on the phone or online.

"His needs for care, physically and emotionally, have quadrupled and more."

"Emotional and mental support has increased."

"Making sure there is some exercise and interaction rather than being (24/7) on the laptop."

"A lot, lot, lot more physical exercise."

"High level medical care, personal care and personal cleaning etc."

"Support with technology for online Zumba classes and social time with friends."

"Preparing every meal, and searching and ordering activity and craft materials that he would usually find himself when out shopping or be provided by his day programme."

"Encouragement, cooking, practical support. It is only

when you do all these things for a long time that you realise how draining it is."

Almost half (48%) were more involved in helping with exercise.

Are you providing more of the following types of care since the COVID-19 outbreak?

Type of care	%
Emotional support, motivation or checking in with someone in person, by phone or online	50%
Helping with exercise	48%
Personal care (e.g. dressing, bathing, washing, shaving, cutting nails, helping with eating, using the toilet)	36%
Practical help at a distance (e.g. arranging food and medicine deliveries)	31%
Arranging or coordinating care and support, medical appointments and other help	24%
Help with moving around	23%
Help with paperwork / financial matters	22%
Help with medications	20%
Help with medical care (e.g. giving injections, changing dressings)	12%

Many carers spoke of the exhaustion of providing constant care, including mental wellbeing support for the person they care for.

Comments from carers also show that the halt or closure of regular services added to their stress levels, removing usual opportunities for respite from caring and potentially impacting their own wellbeing.

50%

of carers provided more help with emotional support, motivation or keeping an eye on or checking in with the person they care for

71%

of carers provided more help with exercise and moving around, to help the person they care for stay mobile through the pandemic

² Synergia, Respite in New Zealand: We must do better, 2019.

Financial pressures

Many carers already faced difficult financial situations due to their caring responsibilities. Infometrics analysis of Census labour force participation and household income found that caring can result in a sharp reduction in income due to earning 10% less on average than non-caring New Zealanders, along with the extra costs of caring.³ These pressures can have lifetime economic impacts for carers who may leave paid work altogether, cannot easily contribute to KiwiSaver or save for retirement, who leave the paid workforce before retirement age, and / or if the person they care for has had to give up work due to illness, injury or disability.

The COVID-19 pandemic is likely to have a lasting impact on many people's finances, affecting jobs and income levels alongside changes in lifestyle. The true impacts will be played out over the next months. The current unemployment rate is at 4.2% for the first quarter of the year and is expected to rise sharply to between 8% and 10% by the end of the year. Our survey confirms finances are a concern for many carers, with 25% saying they are worried about their financial situation.

Increased costs

Most carers have seen an increase in costs since the COVID-19 outbreak. 76% said they were spending more. The biggest increases were for food and household bills. Cleaning products and hand sanitiser feature prominently as a reason for an increase in household costs. Carers also reported difficulties accessing cheaper food lines and having to resort to more expensive options. More time at home increased costs for phone bills, online entertainment and activities to keep families occupied.

"I have shut off power to my hot water cylinder to afford costs and more stored food such as canned foods which are expensive but can be relied on. I have bought cleaning and hand sanitiser, gloves and masks which cost a bit."

"Bought device to keep child connected at school."

"Had to purchase face masks and hand cleansers online which were much more expensive than in the supermarket where they were not available."

Are you spending more money on any of the following things since the start of the COVID-19 pandemic?

Are you spending more money?	%
I am spending more on food (because of getting food deliveries, fewer choices about what to buy etc)	64%
I am spending more on household bills	46%
I am spending more on technology and internet to stay connected	29%
I am spending more on personal care and pharmacy items (e.g. continence supplies)	16%
I am spending more on support	10%
I am spending more on equipment	9%
I am spending more on something else	6%
No I am not spending more on anything	24%

76%

of carers have spent more (64% on food, 46% on household bills)

29%

of carers have spent more on technology to stay connected during the pandemic

24%

only 24% of carers said they have not spend more on anything

"I am spending more on support workers."

"Have to use my own money to pay for breaks as my carer support worker won't come back til level two."

"Spending more on incontinence products."

"Not spending anymore because I am not going anywhere."

"Spending more being at home but saving bus fares to and from work and petrol."

³ Infometrics, *The economic value and impacts of informal care in New Zealand*, 2014.

Employment situation and impact on working carers

Infometrics' analysis of Census data and labour force participation found that working carers were already struggling to juggle the pressures of working and caring, trying hard to balance providing practical and emotional support, managing appointments, and keeping an eye on the person they care for alongside paid work.⁴ Its analysis found that carers typically earned 10% less than non-caring New Zealanders so they could manage this juggle. Before the COVID-19 outbreak, only 39% of survey respondents described themselves as being in paid employment either as a full- or part-time employee, or self-employed on a full- or part-time basis.

Employment before COVID-19

Pre-COVID employment situation	%
Retired	21%
Government paid carer	13%
Employed (employee full- or part-time, self-employed full- or part-time)	39%
Unable to participate because I am caring	8%
Looking after the house / family / dependents full-time	11%
Unable to work due to own illness	4%
Other (student, looking for work)	4%

The impacts of COVID-19 continue as New Zealand returns to work, school, and ordinary life. Many businesses and industry sectors are likely to struggle to operate at a sustainable level in the months ahead. Total retail sales fell by 3.9% in March 2020, the biggest fall on record in both percentage and dollar terms.⁵ Business closures are expected, and the unemployment rate is anticipated to reach around 10% by year end.

Our survey shows that the crisis has already had a significant impact on working carers' jobs. Carers who were in paid work pre COVID-19 were asked about their current working situation. Bearing in mind that only 39% of survey respondents were in paid employment before the pandemic, of these 16% reported either having lost their job or being unable to work during lockdown because they were deemed vulnerable (over 70 years) or due to social distancing rules. 18% said they had given up work because of their caring responsibilities.

A stark finding of this survey is the high vulnerability of carers who struggle to keep working, earning, and saving for retirement at the best of times. This ability deteriorated during the COVID-19 outbreak and remains a significant worry for carers, with long-term risks for their financial wellbeing. Some employers were able to continue operating and to support alternative working arrangements. 33% of carers worked from home during COVID-19, though managing caring and working from home was a challenge. Self-employed carers had a particularly difficult time with dramatic reductions in income and stress about what the future holds.

Current employment situation	%
I am working from home	33%
I have given up work because of caring	18%
I am an essential worker, so I am still going to work as normal	14%
I am unable to work because I am over 70 years	10%
My work hours have been reduced	9%
I have been granted paid leave	6%
I am unable to work because of social distancing	3%
I have been asked to reduce my wages	2%
I have been unable to work due to illness	2%
I have been asked to work unpaid	1%
I have lost my job	1%

"I have had to suspend my business and do shortened hours thanks to the lockdown. It has caused me lots of stress to keep my business running while also full-time caring for my disabled son. I work very long hours to compensate so I am permanently tired."

"I am an essential work but took leave under Level 4 and thankfully got paid the wage subsidy."

"I haven't given up totally but have had to reduce my working hours by at least 50% as my son cannot go to any of his activities or day programmes because of lockdown and now at Level 2 the day programme still has not opened."

"Working from home, reduced pay."

"I work from home as an essential family carer. I have continued to be paid and am very grateful for this."

⁴ Infometrics, *The economic value and impacts of informal care in New Zealand*, 2014.

⁵ Statistics NZ

Worries and fears

Caring for someone can be challenging, and many previous New Zealand and international research reports have highlighted the impacts on carers' physical and mental health.

Alongside the usual stresses of ensuring the person they care for is well looked after, the COVID-19 outbreak added extra pressures.

Most prominent of these is carers' need to maintain their own health to be able to continue caring.

Carers were asked to respond to a number of statements about their wellbeing during the COVID-19 pandemic.

What worries carers	%
I worry about what will happen to those I care for if I become ill	66%
I feel overwhelmed and worry that I am burning out or at risk of burnout due to caring	37%
I worry about the impact COVID-19 has on the person I care for	27%
I have been caring 24/7 without help since the COVID-19 lockdown and my wellbeing is being affected	26%
I am worried about my financial situation	25%
I am experiencing depression or anxiety resulting from the COVID-19 situation	22%
I worry about my own safety when caring	14%
I worry about being able to care safely due to lack of knowledge, information or equipment	7%



46%

of carers' paid work was adversely impacted by COVID-19

66%

of carers worry about what will happen to the person they support if they become ill

37%

worry they are burning out or at risk of burnout due to caring

26%

say their wellbeing is affected due to 24/7 caring without help during the lockdown

33%

of carers' worked from home during the pandemic, juggling work with caring

18%

of carers' have given up their paid work to care during the pandemic

Alongside the usual stresses of ensuring the person they care for is well looked after, the COVID-19 outbreak added extra pressures.

Practical issues for carers

The COVID-19 lockdown substantially disrupted access to staple household items and other essential supplies. Not only were stocks limited but shopping was a restricted activity for many. The practical difficulties of accessing what they needed for their household and to provide safe care was a significant additional stress for carers.

Have you been able to access the supplies you needed during the COVID-19 outbreak?

	Good Access	Some Problems	Big Problems
Food	65%	30%	5%
Medication	77%	21%	3%
Money from your bank account	86%	12%	3%
Cleaning products	47%	38%	15%
Personal care items	67%	27%	6%

Food and other supplies

35% of carers had problems accessing basic food necessities. Problems were both supply and cost.

"At one point we were starving as the lines at the supermarket were so long, and meat seemed expensive or was non-existent."

"Found internet shopping impossible in first week – no spaces – so went myself to the local supermarket which is far more expensive."



Access to cleaning products was especially problematic, with over half of respondents (53%) experiencing problems. For people with compromised health, this was an added stress.

"Our daughter has an insulin pump and in the early days getting sanitiser to help clean her hands after washing prior to change was hard. But now sorted. All those with coronavirus worries swamped out normal users."

Almost a quarter of carers (24%) had problems accessing essential medical supplies.

"Have not had good access to medical supplies from hospital e.g. spare feeding buttons / tubes."

"Direct access to doctor ceased, so weekly anaesthesia injections ceased. Long awaited appointments for DHB referrals were cancelled, leaving most of us in distress."

Some carers also shared positive stories of local businesses, neighbours, friends and community groups helping them to access necessary supplies. There were stories of banks and power suppliers ringing in to see people were okay.



Technology

	Good Access	Some Problems	Big Problems	No Access	N/A
Mobile phone	67%	7%	1%	2%	23%
Smart phone	75%	10%	2%	2%	11%
iPads and tablets with internet access	64%	10%	4%	4%	18%
Computers with internet access	73%	11%	4%	2%	9%
Internet data	78%	15%	4%	1%	2%

Carers were asked about how they accessed different types of technology and the internet during COVID-19. More than 64% reported good access, substantially higher than the 53% in Carers UK's *Behind Closed Doors* report.

While technology was a lifesaver for many, almost one fifth of carers experienced problems with internet data and access which comprised their efforts to shop, learn and stay connected. For many, costs were also an issue.

"My digital device is now so old it won't access websites for the most part ... there are times I have run out of calling minutes on my plan ... it's a struggle to afford more all the time."

"We live rurally; no support or data cap increases, and internet is very expensive."

"Had problems being able to cope with video appointments."

Personal protective equipment

A key concern throughout the COVID-19 outbreak was access to personal protective equipment (PPE) for care workers coming into the house, for family carers themselves, and for those they support. Just over half (55%) said they had access to PPE. But

access was not without difficulties. For many it was late and not supplied until Level 2.

Others resorted to making their own PPE or buying it at high cost, sometimes having to settle for a lesser quality.

Notably almost half of carers (45%) did not have access to PPE despite high risk or vulnerability. This remained a source of anxiety for family carers at all COVID-19 risk levels.

Adding to this anxiety has been conflicting and contradictory advice given about whether PPE was necessary and in what circumstances.

Over half of those who used PPE said they were given no information on its proper use.

Some were frustrated in their attempts to get information from official channels and others resorted to online posts and YouTube.

"The Healthline people were in complete denial about community transmission and just didn't give any information at all as they dismissed my worries."

"Online posts showed my family and I how to use PPE correctly."

"Overall the digital world has been a lifesaver, keeping us connected with the silent world of lockdown."

78%

of carers had good access to internet data during lockdown to stay in touch

75%

had good access to smart phones and 64% had good access to devices

1%

had no access to internet data - though most had good access to data and devices

45%

of carers had no access to PPE; 51% had no information about proper use

Government guidance / information

Respondents were asked how satisfied they have been with the information and / or assistance they received from a specific list of organisations during the COVID-19 outbreak. Responses reflected local experiences with government and non-government agencies.

On top was the Ministry of Health with 64% of respondents either satisfied or very satisfied. This may reflect the daily reassuring and comprehensive briefing provided by Director General of Health Dr Ashley Bloomfield. Regular, open and respectful general communication is likely to be remembered as one of the key features of New Zealand's management of its COVID experience.

The next highest level of satisfaction was accorded to the networks of community groups and non-government organisations who provided practical assistance, made regular phone calls and generally did what they could to help out.

A number made specific mention of Facebook groups as providing the most useful information and helping to filter and translate what was important to families.

District Health Boards were at the bottom of the list, with one in four either dissatisfied or very dissatisfied. This is perhaps not surprising given DHBs' primary focus was on COVID-19 preparedness. However, for people with complex health needs, the cancellation of DHB appointments and difficulties accessing supplies increased stress levels for carers and those they assist.

"Blind Foundation and Brain Injury checked up on us – not one single government agency did."



A number of carers said Facebook groups provided the most useful information, helping to filter and translate what was important to carers.

"Family doctor has been amazing during the whole lockdown – ringing daily to check on everyone."

"Wellington Down Syndrome Association provided the best information, with updates and a selection of activities members could use."

"Facebook groups have been good at filtering the overwhelming information."

"Had a phone call from our power supplier (TrustPower) to see if we were okay."

"At the start, even before the pandemic, the Healthline was not returning my calls even though I left two messages to please ring me, both the COVID-19 Healthline and the ordinary Healthline. I was sick and really needed help and information, and nobody ever rang me back."

What now for carers?

With many carers under a significant amount of pressure and worried about the future, the reinstatement of care and support services at the earliest opportunity must be a priority. It is also now more urgent that progress be made to address the issues and implementation of key actions outlined in *Mahi Aroha*⁶, the Carers' Strategy Action Plan for 2019-2023.

Carers were asked what would help their wellbeing post-lockdown. The responses are not surprising and mirror issues raised before COVID-19. Much of what we have learned through the survey is not new and cannot be attributed to the COVID outbreak. The pandemic has exacerbated or intensified the challenges that have already been well documented for carers.

Respite

Top of the list by a considerable margin is respite, with over half saying this would help maintain their wellbeing as New Zealand moved out of COVID-19 lockdown.

Respondents were asked how long it was since they last had a break. One in five (20%) said that within their bubble the caring role was shared so a break had not been necessary. Providing breaks 'within the bubble' worked for some families, but for others it did not provide necessary relief from caring. For some, a break was simply being able to get out for walk or to ring / text a friend.

A significant wellbeing risk for carers emerging from the pandemic lockdown is that almost half (46%) of survey respondents said they had not had a break for more than eight weeks.

At the time of writing this report, no systemic plan across health and disability was in place specifically to address carers' need for respite after their weeks of intensive caring during the COVID-19 lockdown.

We believe ensuring that such planning happens is an important lesson of COVID-19 to inform future emergencies – whilst now looking at carers' respite options with urgency to help them recover from the stresses they have experienced through the pandemic.

⁶ *Mahi Aroha*, the NZ Carers' Strategy, 2019.

⁷ *Synergia, Respite in New Zealand: We must do better*, 2019.

What would help you post-lockdown?	%
Respite / break from caring	55%
More clear/ specific government advice for carers	39%
Increased financial support	38%
More help with contingency planning in case you aren't able to provide care	37%
A rise in benefits	29%
More advice and information and benefit entitlement	24%
Someone to talk to	24%
More information and support from your DHB	22%
PPE for workers and / or for family carers and those they support	22%
More frequent testing of people with symptoms	20%
More support from your GP or medical practice	17%
More support in community eg; from local volunteer	15%
Paid leave	10%
More support from community pharmacies	7%
Something else	8%

55%

of carers would value
respite or a break
from caring after
lockdown

10%

of carers would like
extra paid leave to
recover from work /
care stresses

38%

of carers say they
need increased
financial support

39%

would value clearer
government advice
for carers

"Although the Ministry of Health let me use my partner for respite ... it's not the same as normal respite and might as well have not happened."

"Although our bubbles shared the care, we were also juggling full-time work and a toddler. We cared for six weeks within our bubble and everyone does feel exhausted."

"I was at absolutely breaking point from being a single mum, trying to work full-time, care for my non-verbal child with special needs and her little sister, while also trying to home school them for six weeks before I was able to drive from Wellington to Hamilton to take them to their grandparents to finally get a break. It was a very, very long time."

55%

of carers said that a break from caring would help them maintain or increase their wellbeing post lockdown

46%

of carers had not had a break for more than eight weeks at the time they completed the survey - they are tired



Caring can be challenging and impact on all aspects of life from health and wellbeing to employment and finances.



Caring can be challenging, and impact on all aspects of life from health and wellbeing to employment and finances.

Carers are under even more pressure in the wake of COVID-19, providing more care than before while also managing concerns about work, education, respite, resumption of usual services, and keeping themselves and those they care for safe and well.

The invisibility of carers identified by *Caring In Lockdown* highlights the need for this large population of New Zealanders to be heard and supported in their own right - no longer as an afterthought within system silos such as disability, health of older people, or mental health. This approach over many years has not served carers.

We call for a strategic agreement with the Government to directly recognise and assist family, whānau, and aiga carers as a large and unique population, as happens in countries such as Australia and the United Kingdom.

This will help to avoid the problems of the current system which, despite the good intentions of the *Mahi Aroha Carers' Strategy*, allows the invisibility of carers to continue.

The experiences of carers during COVID-19 show that we need to do more for carers. We need to do better.



Recommendations

Our recommendations after analysing *Caring In Lockdown* have been broken into those that must be addressed now and those requiring action over time.

Feedback from carers for this report underscores what Carers NZ and the Carers Alliance learned during our support for carers through the COVID-19 lockdown.

From the beginning of the pandemic, we have placed a high value on information and advice to carers. Where possible we have helped them navigate the challenges of COVID-19 and access supports.

We quickly raised issues with relevant government agencies on behalf of carers, highlighting concerns being raised through our helpline, social media, community networks, and communication channels.

New Zealand's lockdown was an intensive period for everyone. Carers were confused about sudden changes to key funding streams and policies, and some carers required urgent escalation to health authorities, needs assessment services, and emergency services.

We responded with *wecare.kiwi*, an online and 0800 service that allowed carers and vulnerable people to register for free advice and check-ins from community and not for profit organisations.

Despite these relationships, ensuring that carers' voices were heard during the pandemic was not easy. Little information was available when, without notice, for example, the Ministry of Health made significant changes to Funded Family Care, the hard-won government payment on the brink of major publicly announced changes as COVID-19 took hold in New Zealand.

Eligibility of FFC was due to broaden in the April to June 2020 period to include spouses and others who were previously not able to access the payment (parents of children under 18 with high support needs, for example).

We spent much of the COVID-19 lockdown unable



to answer carers' questions about such important changes. As we write this report, many questions remain for us and for carers about this important policy shift.

New Zealand's chaotic response to other areas such as access to Personal Protective Equipment left carers vulnerable, whilst doing their best to provide an essential 24/7 service for at-risk family members.

The lack of government clarity, consistency, and information for carers is a lesson of COVID-19.

General announcements and updates have been praised for keeping the population informed about key developments during the pandemic. But carers need more. They need their own focus, so they can care well at the best of times, and during emergencies such as COVID-19.

We have been fortunate in New Zealand.

We have so far escaped the worst of the global pandemic: widespread infections, a high death toll, and long-term lockdowns. Now we have an opportunity to review gaps in our COVID-19 response for the whole population, and for carers.

Given the important role of family carers as an emergency response workforce - the last bastion of care in pandemics and disasters - we owe it to them, to those they support, and to our country to think more about carers while we have a chance to put right current system weaknesses for them and the vulnerable.

Our recommendations highlight how we can do this in the immediate future, and going forward.

Summary of short-term recommendations

We call on the Government and its agencies to implement these recommendations with urgency:

- Take steps to increase awareness and recognition of the role of family, whānau, and aiga carers so they are more visible, better understood, and better supported through COVID-19 and beyond.
- Ensure carers are treated as a large and unique population of New Zealanders for whom supports can no longer be afterthoughts within other populations e.g. health of older people, disability, mental health, and long-term chronic conditions.
- Place a high priority on guidance, information, and advice for carers as they continue to navigate the challenges of COVID-19.
- Ensure information and support is available for Māori, Pacific, Asian and new settler carers.
- Invest in mental health and wellbeing supports for carers, and a flexible, seamless respite system to help them recover and cope going forward. Ensure they know what their options are for respite - they are tired.
- Urgent residential respite is needed for some carers. There is an opportunity to work out how this will be managed in each DHB and for DSS and to develop guidelines for how that will work. We can't have a repeat of the weeks of lockdown where respite just stopped.
- Ensure carers know how to access food, PPE, medicines / supplies, internet data, available funding, and COVID-19 testing.
- Support working age carers through long-term social investment in programmes like CareWise.
- Protect carers from burnout and over-caring.
- Evaluate New Zealand's support for carers during the pandemic, to identify what has worked well and what has not. Learn from these experiences to help carers prepare for ongoing COVID-19 challenges, to fill gaps in information and support, and to prepare for future emergencies that will rely on the resilience of New Zealand's family, whānau, and aiga carers.



Longer term at the end of this crisis the Government and its agencies must:

- Further improve recognition of the role of carers and review and invest in additional support, including financial support through full delivery of the Actions specified in *Mahi Aroha*, the Carers' Strategy and its Action Plan for 2019-2023.
- Improve carers' rights to take time off to juggle work and care, and improve leave provisions for working age carers as a highly vulnerable workforce.
- Ensure that the role and needs of carers are fully considered in COVID-19 recovery plans and that they are represented in their own right as a large, unique population in system change as outlined in the New Zealand Health and Disability System Review.

Short-term recommendations

We call for these urgent steps to support, celebrate, and sustain New Zealand's family, whānau, and aiga carers:

Increase awareness and recognition of family carers and celebrate their vital role.

Carers often say they feel invisible and the results of our COVID-19 survey, and scrutiny of media reports during New Zealand's COVID-19 outbreak, found this to be true. Debates about safety and wellbeing have primarily focused on the formal workforce. This is understandable, but family carers matter, too. They also faced risks from the lack of PPE and, out of concern for a vulnerable member of their family or whānau, many halted visits from workers or attendance at services well before the lockdown. Carers have provided an unstinting 24/7 service for New Zealand's most vulnerable, and their lives have been significantly impacted by COVID-19. New Zealand's leaders and government agencies should promote the important role of family carers regularly in key communications, briefings, and media statements.

Ensure carers are supported as a large and unique population of New Zealanders - not merely an adjunct to other populations e.g. disability, mental health, older people, chronic conditions etc. The experiences of COVID-19 show the need for carers to have their own voice in decision-making that affects them. Sudden changes to flagship policy such as Funded Family Care during the lockdown shows the degree to which important changes can happen without enough thought for carers. Major shifts in health and disability have been flagged in the recently released New Zealand Health and Disability System Review report. We call on the Government to ensure carers have their own status and voice in this work from its earliest stages. We welcome the report as an opportunity to directly recognise carers' role, needs, and mahi aroha.

Learn from COVID-19 the importance of early guidance and information for carers.

Unprecedented amounts of information have been distributed across the population since the COVID-19 outbreak, but there has been little specifically for carers. Family, whānau, and aiga carers are a unique workforce. They are our country's largest

workforce. They need information just for them in simple language that is easily accessible online and in the community. They need to know how to access supports and services, how to access and use PPE, how to care for a vulnerable person at home (often without outside help); how to access food and supplies when these are limited; who to call if they are worried; how to secure and use funding including flexible new options like those introduced during COVID-19 (many carers didn't know about these options, so couldn't use them). New Zealand has a second chance to close the information gap for carers. This should be developed for family carers with urgency across health, disability, and social services as they continue to navigate the unknowns of COVID-19. An information plan should be made to swing into action at early stages of future emergencies, ensuring this frontline workforce is prepared, supported, and sustained. Better information for carers is one of the things carers say will help them as New Zealand recovers from COVID-19.

Ensure information and support is available for Māori, Pacific, Asian and new settler carers.

This survey had almost 700 responses from carers but less than 10% of were from Māori whānau carers and those of other ethnicities. How did the broad population of carers other than those who are Pakeha or NZ European fare during the COVID-19 outbreak? How can they be better prepared or supported should the pandemic continue, or in future emergencies? We need to know more about these carers. The Government can help by supporting the first major annual survey of carers to track issues of particular interest and concern to carers who are Māori, Pacific, Asian, or of other ethnicities. This could be done through the work of *Mahi Aroha*, the Carers' Strategy, and its governance and working groups.

Invest in mental health and wellbeing support, and a flexible, seamless respite system for carers. As this report highlights, many carers have not had a break from their role since before lockdown. They moved quickly to protect vulnerable people when the threat of COVID-19 surfaced, reducing worker visits and closing their doors to safeguard those with fragile health. Now carers are weary. More than ever they need a nationwide respite system that is flexible, accessible, responsive, open for business and that functions well.

They need information about respite options in their communities, including services that are no longer available due to COVID-19, and alternative services. They need respite funding to be flexible so they can make choices that work for them in a post-COVID world of changed or fewer respite services. We call on the Government to continue permanently the flexible Carer Support funding introduced during COVID-19 across ages and caring situations. We ask that information for carers about these changes be developed in partnership with Carers NZ and the Carers Alliance so carers understand their options for respite. 54% of carers say they have a health condition or disability of their own. Many support more than one person. Although carers have come through COVID-19 well, we now need to support their mental and physical wellbeing so they can recover from the impacts of the pandemic. The New Zealand Government and its agencies should ensure wellbeing support and information is available to carers so they understand how to access help; if services do not have sufficient resources to provide carers with the wellbeing support they need, including additional respite, Government must provide this funding. This is especially important for carers of people who have high and complex support needs across the system, including ACC. Increased funding for mental health and wellbeing services should explicitly include carers.

Review respite arrangements for all carers across DHBs and disability to ensure options for breaks are available to carers, and that planning is done to ensure respite is available now and if there are further Covid-19 outbreaks.

The pandemic reinforced longstanding pressures and challenges with respite.⁸ Fixing these issues for all carer populations would go a long way to ensuring these problems are avoided in the future. Strengthen action and commitment to a seamless, functioning respite system in New Zealand, as outlined in the Carers' Strategy Action Plan.

Ensure carers can access food, PPE, medicines / supplies, internet data, funding, and COVID-19 testing.

Our survey found that while most carers came through COVID-19 with good access to most things, some reported problems. This is especially concerning in areas such as food, medicines, essential medical supplies, and PPE for those who need it. As family carers are the last front line of healthcare - delivered in the home and

often 24/7 - ensuring they can care sustainably is an important investment. This report calls for an urgent evaluation of how those in caring roles can access what they need to get through COVID-19 and future emergencies.

Support working age carers through long term investment in programmes like CareWise.

The vulnerability of working carers is a major finding of this report. Almost 90% of carers are of workforce age, and a high number of these vulnerable workers are women. Even before COVID-19, many carers completing this survey had to leave paid employment to care for at least one dependent person. 46% of those who completed the survey say their paid work has been adversely affected by COVID-19. We call for ongoing investment in CareWise and other programmes to build a country of carer friendly workplaces, deliver employer education about how to support the 1 in 8 staff who are carers, and provide direct information and support to working age carers.

Protect carers from over-caring.

New Zealand has taken its carers for granted during COVID-19 and allowed them to over-care without sufficient information, recognition, or prioritisation. As New Zealand emerges from the initial impacts of COVID-19, let's do more - let's do better - for carers. As they recover from the immediate threats of COVID-19 let's nurture them through the provision of good information, by recognising their contributions, by ensuring they know how to access wellbeing / respite programmes and funding, and by helping them prepare for what may yet come with COVID-19. Let's help them understand that even though it sometimes feels that way, caring for a vulnerable person isn't all up to them - because New Zealand cares about them, too. As an outcome of this report, let's truly value carers and their mahi aroha.

Evaluate New Zealand's support for carers during the pandemic, and address gaps.

Identify what has worked well and what has not. Learn from these experiences to help carers prepare for ongoing COVID-19 challenges, to fill gaps in information and support, and to prepare for future emergencies that will rely on the resilience of New Zealand's family, whānau, and aiga carers. This work could be done through the of *Mahi Aroha* governance and working groups, in partnership with the carer movement.

⁸ Synergia, *Respite in New Zealand: We must do better*, 2019.



Caring In Lockdown

Forgotten families during Covid-19

July 2020

If you are a carer looking for information and guidance, please visit our website, www.carers.net.nz or get in touch with our advice team by emailing centre@carers.net.nz or phoning our helpline on 0800 777 797 during business hours.

Across New Zealand today almost half a million people are carers, supporting a friend or family member who is frail, unwell, or has a disability, chronic condition, or mental health condition.

Caring will touch all of us during our lives, whether we become a carer or need care ourselves.

While caring can be a rewarding experience, it can also impact on a person's wellbeing, finances, work, and relationships.

Carers NZ is here to listen, and give expert information and tailored advice.

We champion the rights of carers in partnership with the Carers Alliance of almost 50 national not for profits, and together support carers in finding ways to manage at home, at work, or in their community.

We're here to make life better for carers.