



SYNERGIA

THE STATE OF CARING IN AOTEAROA

**A report for Carers NZ
and the Carers Alliance**

August 2022

Acknowledgements

We thank all of the people who took the time to respond to the *State of Caring* and *Respite and Time Out* surveys whose feedback forms the basis of this report. We also thank Carers NZ and not-for-profit members of the Carers Alliance for promoting the surveys through their networks.

We thank Carers UK for sharing its own *State of Caring* survey for adaptation and use in Aotearoa New Zealand.

Thank you also to Alzheimers NZ, IHC, and the Ministry of Social Development for partnering with Carers NZ and the Carers Alliance to fund this report.

We thank government agency participants in the *Mahi Aroha Carers' Strategy* governance and working groups for reviewing the survey and promoting it to family, whānau and āiga carers in their networks.

We thank too the many community organisations and social media networks who helped to promote the survey to family carers.

This joint work allowed the *State of Caring* survey to be widely shared across the country, resulting in a high response despite the disruptions of the COVID-19 pandemic. Without this generous participation, we would know little about the recent experiences of a large, unique population of New Zealanders: family, whānau and āiga carers.

Carers NZ and the Carers Alliance intend to repeat this survey every two years in order to build a picture over time of the lives and wellbeing of caregivers, and the realities of family caregiving. This initial report provides a foundation for this work now and in the years to come.



SYNERGIA

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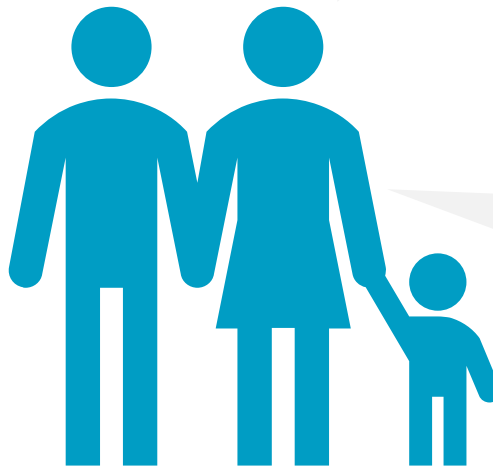


We lost all essential support / carers / school and routines.

Safety, e.g. mask wearing and whether carers are vaccinated, is an ongoing problem. We need more consistent policy.

There is very limited support, especially for mental health

If only we could turn back time, to when breaks were possible.



At times we had no one to provide respite because of the lockdowns.

I cannot afford to pay my bills and struggle financially.

The job of a carer is massive. I didn't realise till I became one. It's exhausting.

SECTION A

EXECUTIVE SUMMARY

OVERVIEW

This report summarises the findings from both the *State of Caring* and *Respite and Time Out* surveys undertaken by Carers NZ and the Carers Alliance in 2021. Over 1600 carers responded to the surveys.

For the purposes of this report and the surveys it summarises, carers are defined as being “individuals, family, whānau and āiga providing care for someone close to them who needs additional assistance with their everyday living because of a disability, health condition, illness or injury”.¹

Carers across New Zealand responded. They were of all ages, ethnicities and walks of life. These are their themes, their findings and their recommendations.

Key themes

The key themes summarised below are the result of analysing the 1600+ survey responses received. The richness and depth of the responses is significant. The following themes came through strongly in the responses. Additional evidence to support the themes is provided in the body of this report.

Caring significantly impacts wellbeing

Carers have rates of depression and/or anxiety that are much higher than in the general population, and many are not seeking support. Much of this anxiety and depression is due to the financial stresses that can come with caring.

Carers have very high levels of loneliness, very low life satisfaction, and low levels of physical health compared to the general population. Carers aged under 35 reported the lowest levels of physical health and the highest levels of depression and anxiety.

“DURING THE COVID LOCKDOWNS IT FELT LIKE THE GOVERNMENT DID NOT THINK ABOUT CARERS’ CONCERNS AND SITUATION AT ALL AND WE WERE NEGLECTED. CARERS WHO ARE MORE VULNERABLE WERE NOT GIVEN EXTRA SUPPORTS, EVEN WHEN THEY ASKED.”

¹ <https://www.health.govt.nz/our-work/carers-in-new-zealand#who>

Formal support for carers is lacking

The survey results highlight carers' common struggle to know what support is available and how to access it, with particular challenges around needs assessments and entitlements. Many carers indicated they are missing out or have missed out on supports that they should know about, which then negatively affects their wellbeing, relationships or finances. This can contribute to carers not feeling valued by the government and results in increased financial burden as they are paying out of pocket to meet care-related costs.

The internet is a key avenue for carers to access information and advice. There is varied use of other technologies such as remote monitoring alerts, medication management and telehealth.

Many carers are not planning for their own future because they are focused on caring or are unable to plan more generally (for retirement, for example). Only 7% of carer respondents have plans for their own future care needs.

Carers are not being included in existing processes for needs assessments and service coordination, and 86% of *State of Caring* respondents think that family, whānau and āiga carers should have their own targeted needs assessment. Any needs assessment or similar targeted support allocation process for carers needs to deliver supports that are available, accessible and well promoted to this population.

The challenges of juggling work, finances and caring are huge

Carers have lower rates of employment than the general population, with only 21% in full-time work and 23% in part-time work.

More telling is that 30% of carers indicated they are unable to undertake any paid work due to their caring responsibilities. Fifty percent of *State of Caring* respondents had to give up paid work to care, reduced their hours of paid work, or retained their hours of paid employment but with negative job impacts due to caring. Flexibility at work supports carers to juggle both work and caring.

Many carers (59%) said they cannot pay their bills without struggling financially, and 15% have been in debt because of caring, which makes New Zealand carers worse off financially than UK carers but under similar financial stress as Australian carers. Carers make ends meet in a variety of ways; it is a concern that 30% are cutting back on essential items such as food and heating for their whānau to best manage money and caregiving realities.

This financial stress is having a long-term impact, with 20% of carers not being able to save at all for retirement, 34% having their retirement plans negatively affected, and only 14% unaffected by financial strains.

Limited access to respite and time out options that work

Access to opportunities for breaks from caring (often called ‘respite’) has varied during the pandemic, with some carers being able to have breaks weekly or whenever they need them; 32% having breaks only a few times a year and 13% only being able to take breaks in emergencies. Access to quality options for respite was already an issue for many carers pre-pandemic, and COVID-19 has made this worse by reducing access to respite support and services. Carers’ wellbeing is being impacted by inadequate respite opportunities, with 48% struggling, really struggling, or needing emergency respite. Almost 90% of carers indicated they have had less or much less respite since the start of the pandemic in March 2020.

Suggestions for improvement included providing more flexibility with how funding can be used, more guidance on how funding works, and a competent, reliable workforce that can alleviate carers’ stress. Carers also indicated that increasing the availability of respite options and funding is important – especially over time as the ‘long-tail’ of pressure builds, leading to carer breakdown which in turn will cause significant financial burden for the government.

Recommendations

The survey feedback highlights the issues and challenges facing carers across New Zealand. In reviewing the feedback, there are potentially many recommendations that could be made – however, to provide focus and attention, the following 12 recommendations are made:

1. Fully implement the *Mahi Aroha Carers Strategy Action Plan’s* outcomes with vigour and use the data in this report and future evidence to identify useful actions for the next Action Plan.
2. Increase existing supports and provide new ones for carers – including making respite funding more flexible across the diverse population of carers and investing more into respite to improve carer wellbeing as a single vital way to safeguard and improve the wellbeing of this large population.
3. Provide more effective navigation support (particularly around respite) and improve the promotion of information available to carers about financial supports (including being paid to provide care), respite and wider

government assistance.

4. Improve and simplify financial supports to reduce barriers to financial assistance, such as changing spouses' inability to access the Supported Living Payment or family carers' inability to be fairly paid for the significant efforts they make in areas such as Individualised Funding (often at the expense of other paid work opportunities).
5. Formally recognise the role of carers and the value they provide to their whānau and the system by directing government departments to ensure plans and strategies specifically include focus and actions that relate to carers.
6. Prioritise the implementation of an approach to the appropriate consideration of carer needs in their own right and a process to ensure supports meet identified needs., with a specific focus on advance care and emergency planning.
7. Find a place in Government for carers, who too easily 'fall through the cracks' of existing structures, frameworks, and Ministries; this could take the form of a Minister/Ministry for Family Whānau and Aiga Carers and/or a Commissioner who has responsibilities for this large population of New Zealanders. We note that a similar approach is being mooted in Australia for the same reasons.
8. Ensure the evolving structures of government (Te Whatu Ora – Health NZ, Te Aka Whai Ora - Māori Health Authority, Whaikaha - Ministry of Disabled People, ACC etc) are meaningfully 'carer friendly' in important areas such as respite, information, financial support, wellbeing and support for carers who are Māori, Pacific, young, etc.
9. Identify measurable ways to support and improve carer wellbeing in areas such as employment, retirement planning, loneliness and social isolation, finances, and mental health; ensure programmes for wellbeing are adequately resourced and promoted.
10. Identify and implement supports for carers aged under 35 as a direct response to concerns highlighted in this report of the impact caring has on younger carers.
11. Support specific initiatives and programmes that assist working age carers, particularly women and young carers, whose earnings, life success, retirement savings, and financial wellbeing impact their ability to work, earn, save, and thrive.
12. Implement specific supports for carers impacted by the COVID-19 pandemic. These impacts were visible in the comments and data gathered for this report in 2021 and will have deepened since in areas such as respite, wellbeing, employment, finances, and access to support and services.

A WORD FROM THE AUTHORS

Over the last 20 years Synergia has completed over 1000 projects throughout New Zealand across all areas of the public sector. Whether it be mental health, wellbeing, education, disability, family violence or suicide prevention the needs of carers are often highlighted as an area of concern.

It is clear that the findings summarised in this report are not positive. As authors, we found many of the findings to be deeply concerning. In particular the levels of loneliness, the financial burden, and the general feeling of discontent with the system came through strongly and should be of concern.

Whilst this report adds more evidence to the debate, it doesn't really tell us anything new – which begs the question: what else is needed to drive action and change to better support carers? The societal and financial impacts are clear. The benefits of investing in carers makes societal and financial sense.

We hope this report helps in some way to drive real change with urgency and improvement of carers' lives across New Zealand.

“YOU GET TIRED OF FIGHTING FOR EVERYTHING SO GIVE UP ON YOUR OWN NEEDS FOR THE MORE PRESSING NEEDS OF THOSE YOU CARE FOR.”

SECTION B

THE SURVEYS AND PROCESS



OVERVIEW

This report presents the results of the 2021 *State of Caring* survey and the *Respite and Time Out Survey*. Both surveys were initiated by Carers NZ and the Carers Alliance of 50+ national not-for-profit organisations. It provides insight into the lives of family, whānau and āiga carers in New Zealand. It speaks to their wellbeing, the nature of their caring and how factors like recognition, access to supports and other factors impacted their lives during the COVID-19 pandemic. It covers their perceptions of support and how valued they felt, both by their whānau and by New Zealand's health and disability systems. The results of these surveys should be given careful consideration. These findings provide society and the government with valuable insights into the experiences of carers and those they support and can inform priorities and actions while New Zealand continues to grapple with the effects of COVID-19.

Carers provide significant economic value to New Zealand – an estimated \$16.8 billion per annum or 5.1% of Gross Domestic Product² – as well as priceless social and family value. We must listen to them, and we must support them. This report identifies concerns and ways to better assist and sustain New Zealand's 1 million plus family, whānau and āiga carers.

Process and methodology

The *State of Caring* survey collected responses between May and December 2021. It aimed for 1500+ responses from members of the public and achieved 1648 responses. It was advertised extensively to networks of families and people in caring roles via the not-for-profit and community sectors, government agencies, health and disability service providers, and social media. The *State of Caring* survey replicates similar surveys carried out in other countries, notably the United Kingdom³ and Australia, with appropriate changes for our Aotearoa context.

There were plans for face-to-face engagement with Māori and Pacific carers to better understand their role and experiences (as online surveys do not always reach these populations). Given COVID-19 restrictions on gathering, further work will be carried out to better understand these carers' experiences when this is possible. This report will be updated accordingly.

The *Respite and Time Out* survey collected 656 responses between November

² Draft report, Infometrics *Economic Value of Family Caregiving*, to be released in September 2022. The number updates data developed by Infometrics based on Census information in 2014-15.

³ [Carersuk.org/stateofcaring](https://carersuk.org/stateofcaring)

2021 and January 22, when parts of New Zealand were still in lockdown because of COVID-19. Respite support is invaluable to carers and those they care for, providing options to rest and have breaks from caring. Caring demands can be particularly high, and this can have a negative impact on carers' identity, wellbeing, workforce participation and social connection. Insights from this snap survey have been incorporated into the *State of Caring* report to identify the availability of respite during the pandemic and the impact of less opportunity for respite on carers and those they care for. At a time when all of New Zealand's population experienced some kind of restriction on socialising and public life, these findings provide a historically significant measure of carers' wellbeing and broader experiences during the COVID-19 pandemic.

This report

This report is structured to mirror Carers UK's own long-running two-yearly *State of Caring* survey, to support cross-country comparison. Each section of the report covers a different facet of caring that was asked about in the survey, and highlights specific groups of family, whānau and āiga carers where important. Comparisons to general population statistics are made where feasible.

Throughout the report, the term 'carer respondents' is used to name the people who participated in the survey. This is to reflect that the people who took part in the survey have family caregiving responsibilities, but that not all carers of Aotearoa in the broadest sense of the term are represented (e.g., parents, the support workforce, childminders, teachers, foster carers).

Respite and Time Out survey results are presented separately, as they are two separate respondent groups, but are included in this report to highlight the impacts of COVID-19 on carers and their access to respite and time out during the pandemic.

The surveys

***State of Caring* survey**

The *State of Caring* survey was completed by 1,648 carer respondents. This was an impressive response, encompassing surveys that were completed online and paper surveys that were submitted via post. All responses were analysed together.

To understand the experiences of different types of carers, a set of 'carer groups' was established to understand how experiences may have differed within the larger group of carers. Carer groups were easily developed using demographic questions. Respondents could endorse multiple ethnicities, but prioritised

ethnicity was used in the analysis. This means that any person who identified as Māori was counted as Māori, and any person who identified with a Pacific ethnicity (but not as Māori) was counted as Pacific. The table below summarises the numbers of respondents included in each carer groups – noting that people can be in more than one group.

CARER GROUP	NUMBER OF RESPONDENTS	PERCENTAGE OF ALL RESPONDENTS
Māori carers	168	10.2%
Pacific carers	53	3.2%
Rural carers	269	16.3%
Female carers	1390	84.3%
Carers aged under 35 years old	76	4.6%
Carers who have cared for five years or more	1065	64.6%
Carers for two or more people	352	21%
Carers of older people	818	49.6%

Respite and Time Out survey

The *Respite and Time Out* survey was completed by 656 carer respondents, of which 649 identified as a family carer.

SECTION C

**WHO IS CARING ACROSS
NEW ZEALAND?**



OVERVIEW

Albeit only a sample of New Zealand's wider caring population of a million-plus people, this survey has been completed by a significant number of family carers and is broadly representative of our country's diverse carer population. This section of the *State of Caring* report provides a demographic overview of New Zealand's carers, their wellbeing and how long they have provided support for someone in their family or whānau. It provides important context for other survey insights.

Who is a carer?

For the purposes of this document and the surveys it reports carers are defined as being individuals, family, whānau and āiga providing care for someone close to them who needs additional assistance with their everyday living because of a disability, health condition, illness or injury.⁴

As outlined in *Mahi Aroha: Carers' Strategy Action Plan 2019–2023*, it's also important to note that whilst “the term ‘carer’ is used internationally, we recognise that it may not resonate with everyone. Words such as ‘supporter’ or ‘manaakitanga’ may better describe the way a carer sees caring as a natural part of what they do for the people they love. In this document, the term ‘carer’ is used to describe the diversity of individuals, families, whānau and āiga who provide this support.”⁵

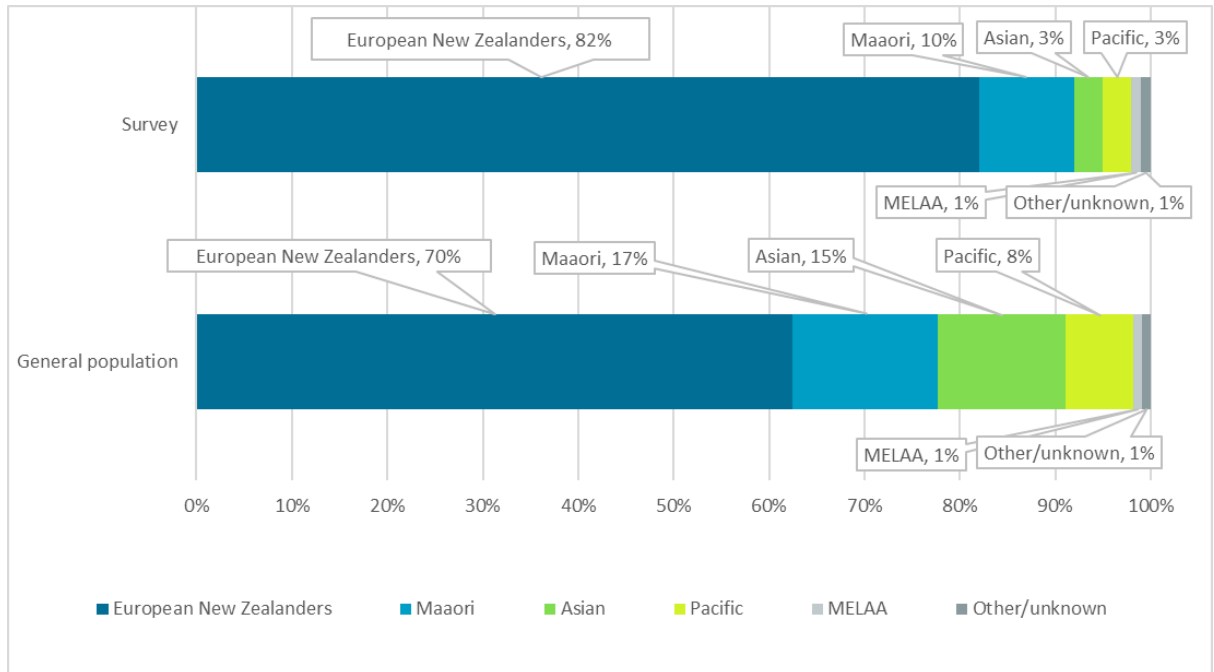
Demographics

We know that caring is not specific to one ethnicity or demographic, and while efforts were made to reach Māori and Pacific carers, the response rates from these populations were lower than those from other groups.

⁴ <https://www.health.govt.nz/our-work/carers-in-new-zealand#who>

⁵ Mahi Aroha Carers' Strategy Action Plan 2019–2023. Wellington 2019.

Figure 1: Ethnicity of survey respondents



Survey respondents were predominantly female (85%) and over the age of 35 (94%). Rural carers made up 16% of respondents.

Many respondents had a long history of caring, with 65% having been a carer for five years or more and 34% caring for one to four years.

Carers' own health conditions

A high number of survey respondents (52.5%) reported having their own disability or ongoing health condition such as arthritis, heart conditions or diabetes. This was fairly consistent across survey respondent cohorts but was highest for carers of two or more people (62.6%).

Respondents to the New Zealand survey were significantly more likely to report having a disability or health condition than respondents to Carers UK's *State of Caring* survey (in which only 24% of survey respondents indicated they had a disability).

Who do carers assist?

Carers can be supporting a single person or multiple people of a range of ages and with a range of conditions. 78% of New Zealand survey respondents assisted one person, while 22% cared for two or more. This is very similar to the UK's survey where 74% of respondents cared for one person.

Of the people receiving support from family, whānau and āiga carers:

- 18% had dementia/Alzheimers
- 25% had an intellectual disability
- 50% supported older members of their family, whānau or āiga.

18% are caring for people with dementia/Alzheimers	50% are caring for older people	25% are caring for people with intellectual disabilities
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Many types of help are provided by carers, with supporting leisure activities and outings, practical help, care coordination and emotional support being the most common types of support given (80–86% of survey respondents provide these types of care). Other main types of care provided include:

- help with paperwork or money matters (77%)
- personal care (71%)
- help with medication (63%)
- support with continence needs (54%).

SECTION D

THEMES



CARING SIGNIFICANTLY IMPACTS WELLBEING

Carers are people; people with their own wellbeing needs who happen to look after others as well as themselves. This section of the report provides an overview about family carers' physical and mental health, including factors such as loneliness and life satisfaction. Some comments indicated that carers experience such high demands from their caring role that they cannot fully experience what is happening for them. As one respondent mentioned: "I do not have time to experience anxiety or depression". Overall, there is significant room for improvement to support carers who experience anxiety, depression, loneliness, and other life satisfaction concerns.

Mental health and wellbeing

Carers report high levels of anxiety and depression

When asked about their mental health, 46.9% indicated good or very good mental health and 14.4% reported bad or very bad mental health.

In a follow-up question, however, 70% indicated very high levels of depression or anxiety – contrasting the initial result of 46.9% indicating good or very good mental health. That said, the 70% is significantly higher than the 20% estimated to experience a mental disorder in a 12-month period across Aotearoa's general population.⁶

A significant number of carers indicated they were not seeking support for their depression and/or anxiety. Of carers who experienced depression or anxiety, 48% had received therapy/treatment, and 52% had not. For those who did seek treatment, this was mainly paid for by themselves and not through any government-funded support or programmes.

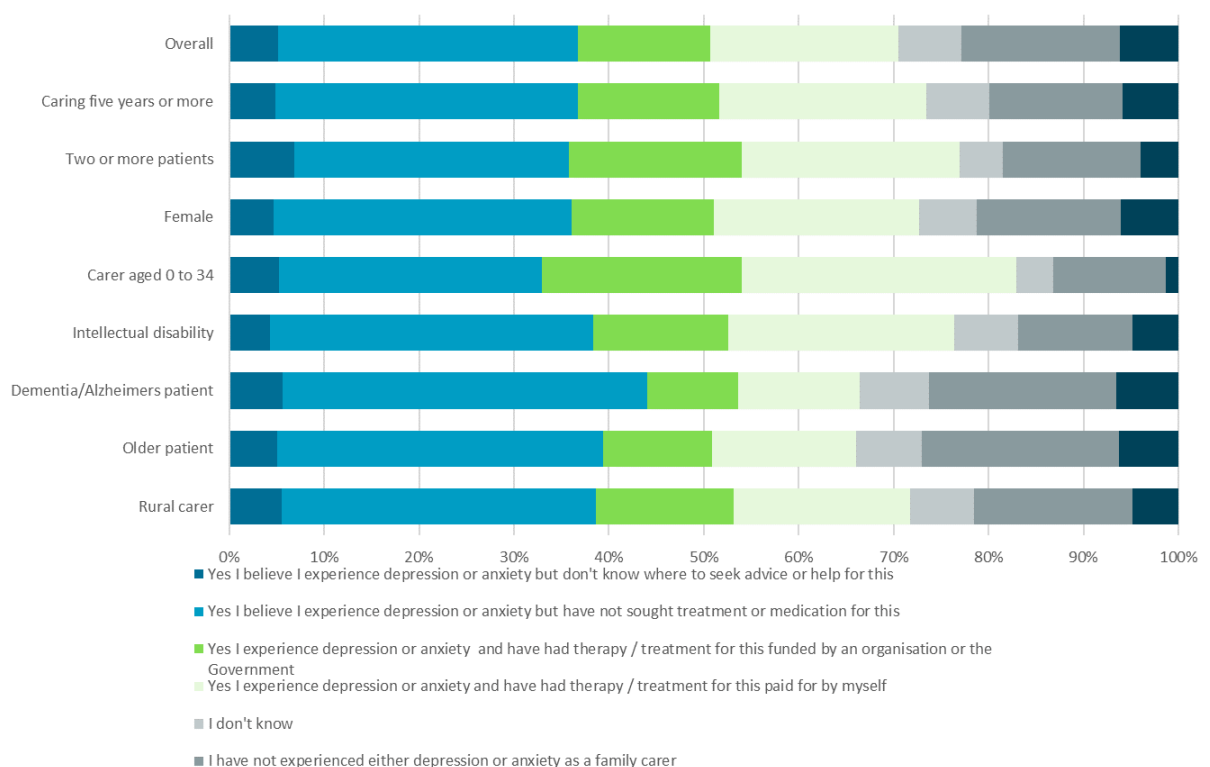
Female carers and young carers under the age of 35 reported the lowest levels of general mental health, at 50% and 46% respectively, and the highest levels of depression and anxiety, at 77% and 83% respectively. Mental health for those who care for older people and those with dementia was more positive than the overall rates.

⁶ <https://www.health.govt.nz/system/files/documents/publications/mental-health-survey-2006-12-month-prevalence.pdf>

Carers who identified as European reported the highest rates of depression and anxiety, with Māori, Pacific and MELAA carer rates being similar to the overall population rates.

Carers indicated their stress, frustration and tiredness can look like anxiety or depression, but if more financial resource was available, and therefore some stress, frustration and tiredness was alleviated, they would feel more at ease. Others who experienced serious emotional distress were unsure where to turn when they were unable to pay for mental health services themselves.

Figure 2: Depression and anxiety by carer group



Carers report high levels of loneliness and social isolation

Loneliness is very common amongst carers, with 66% of survey respondents saying they were sometimes or often/always lonely. This compares to 16% of the general population who identify as lonely.⁷ As a subpopulation, young carers under 35 experienced the highest rates of loneliness at 84%. Loneliness rated even more

⁷ <https://loneliness.org.nz/nz/facts/many-kiwis-feel-lonely/>

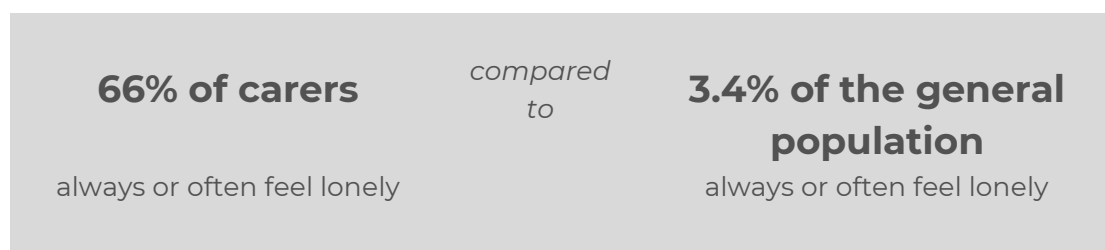
highly in the Carers UK *State of Caring* results, at 81% across all ages, and this could indicate that the samples of respondents differ in other ways.⁸

“I NO LONGER FEEL LIKE A MEMBER OF SOCIETY.”

New Zealand respondents indicated that having to give up typical activities in order to provide care contributed to their loneliness. Respondents said that not having time to participate in social activities made 42% feel lonely, while 31% had felt lonely because they were not comfortable talking to friends or whānau about caring. Additionally, 36% had felt lonely and socially isolated because they were not able to get out of the house.

“I HAD TO GIVE UP MY SOCIAL GROUPS, BUT THAT IS PART OF CARING.”

MELAA and Pacific carers reported higher rates of loneliness than other ethnicities, at 100% and 74% respectively, while feedback from other ethnicities was similar to the overall rate.



Only a third of carers are satisfied with their life. Carers' satisfaction with life is significantly lower than that of the general population. Overall, 33% of carers said they were satisfied or very satisfied with their life, while 36% were somewhat satisfied, and 31% somewhat unsatisfied or very unsatisfied. This is compared to an estimated 81.1% of the general population who feel satisfied or very satisfied with their life.⁹ This was consistent across carer groups, except for carers of people who have dementia and Alzheimers where a higher proportion (36.5%) of carer respondents identified that they are very unsatisfied or somewhat unsatisfied with life.

⁸ <https://loneliness.org.nz/nz/facts/many-kiwis-feel-lonely/>

⁹ <https://loneliness.org.nz/nz/facts/many-kiwis-feel-lonely/>



Physical health

The physical health of carers varied amongst carer respondents but overall was lower than that of the general population; some carer groups reported notably worse physical health than other groups. Overall, 48% of carers reported their physical health as good or very good, 38% as fair, and 14% as bad or very bad (significantly lower than the general population, where 88% of adults have reported excellent, very good or good physical health¹⁰). There was also variation between carer groups:

- Young carers aged under 35 and carers of people with intellectual disabilities reported the worst physical health, with 24% and 20%, respectively, reporting very bad or bad physical health.
- This was followed by carers looking after two or more people, 21.4% of whom reported very bad or bad physical health, compared to 12% for carers assisting one person.
- Higher rates of very bad or bad physical health were reported by carers who are Pacific (22%) or Māori (20%) compared to Asian (5%) or European (14%) carers.

¹⁰ <https://www.health.govt.nz/publication/annual-update-key-results-2020-21-new-zealand-health-survey>

FORMAL SUPPORT FOR CARERS IS LACKING

Carer respondents strongly identified a need for more practical support such as greater financial assistance and increased access to financial resources.

“NZ GOVERNMENT TAKES THE ROLE THAT WE PLAY AS PARENTS FOR GRANTED. THE STRESS ON THE ENTIRE WHĀNAU IS IMMENSE – ESPECIALLY SO FOR OTHER CHILDREN IN THE FAMILY. THERE NEEDS TO BE SIGNIFICANTLY MORE SUPPORT OFFERED AND EXPLAINED.”

Understanding what is available is difficult

Access to timely information about supports is generally challenging for carers. Without prior knowledge of the system, it can be hard for them to find and process information about available supports. Many feel they are 'learning as they go' without sufficient guidance. Written guidance is often jargon-filled; for many carers it feels 'all talk, no walk' by the Government and organisations with responsibilities to help carers. In times of crisis, carers don't have time to read lengthy reports to navigate what to do (carers' own suggestions for improvements include an 0800 crisis number for carers to use when needed).

Respondents indicated that it's difficult to:

- know what general help is available – 50%
- know about or access wellbeing supports – 34%
- learn about or access payments for caring – 31%
- access support for making decisions about how much help your family is eligible for or receives – 29%
- deal with needs assessments – 25%.

A specific resource covered in the survey is the government's *Guide for Carers*, one of few tools developed by the government specifically for carers. However, it's not enough to simply create such resources; significant promotion to carers is also needed, as 71% of carer respondents had not heard of the *Guide*. Of those who had viewed the *Guide for Carers* 4% found it helpful, 13% found it somewhat helpful, and 5% did not find it helpful.

“I HAVE FOUND SUPPORT IS SOMETIMES THERE IF YOU KNOW TO ASK FOR IT. HOWEVER IT’S NOT ALWAYS OFFERED AND IT’S DIFFICULT TO KNOW WHAT YOU DON’T KNOW!”

Carers are missing out on support

Carers do not always see themselves as ‘carers’, with lack of recognition causing 43% of survey respondents to miss out on practical support and 32% on financial support. This resulted in increased stress or anxiety for 80% of carers who had missed out on available support. Lack of awareness and self-identification as a carer put a strain on 59% of carer respondents’ relationships, and negatively impacted finances and physical health for 52% of respondents. For some carers, especially those caring for a child (even into adulthood), many wondered where routine parenting ends and caring begins.

Carers also expressed concerns about not being able to access supports because rules for their use were too restrictive, or because there was inadequate funding to provide necessary support.

“NASC WERE VERY RESTRICTIVE IN WHAT THEY COULD FUND, SHOWED NO FLEXIBILITY, AND HAD MORE REASONS NOT TO FUND THEN TO FUND. THEIR ANSWER TO EVERY QUESTION WAS ‘MINISTRY GUIDELINES DID NOT PERMIT THEM’ (TO OFFER FUNDING).”

Carers do not feel valued

This lack of support and recognition contributes to carers not feeling valued. Only 2% of carer respondents said they felt valued by the government, and only 27% felt valued by their family, whānau or āiga.

Carers who have cared for over five years (long-term carers) and carers aged under 35 felt less valued than other carer groups. Only 6% of long-term carers and 12% of younger carers felt valued by the government or their family, compared to more than 20% in all other groups. Carers of older people felt the most valued at 34%.

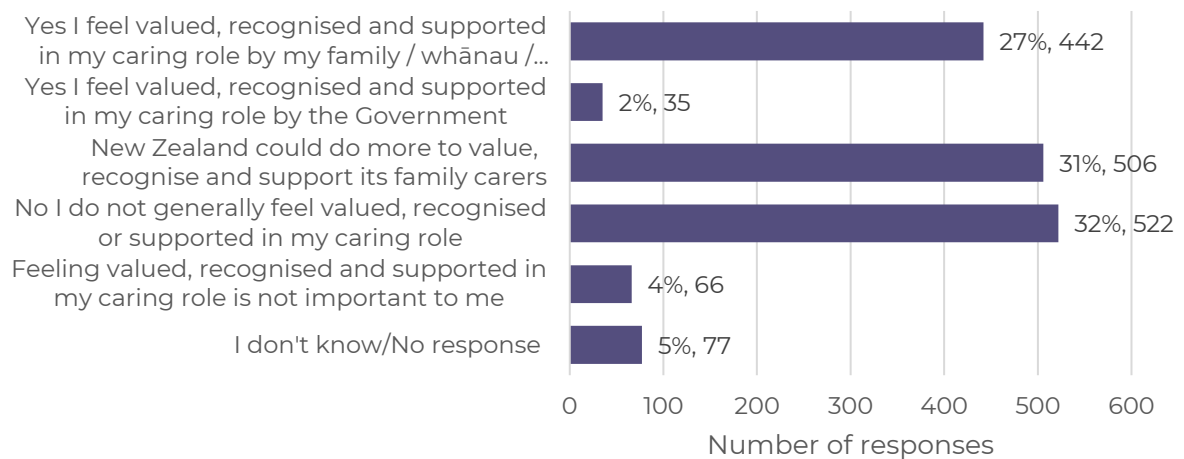
Of ethnicities, Asian and Pacific carers felt the most valued, with 40% and 38%, respectively, feeling valued by the Government or their family. Rates reported by

Māori and European carers were more in line with the overall group, with 32% and 28%, respectively, feeling valued by the Government or their family, whānau or āiga.

Although they felt valued more than other ethnicities, 42% of Pacific carer respondents (n=53) said that New Zealand could do more to value, recognise and support its family carers, which was higher than for other ethnicities.

“I FEEL RECOGNISED, VALUED AND SUPPORTED BY THE LOVED ONE I AM CARING FOR AND OCCASIONALLY BY INDIVIDUALS WITHIN GOVERNMENT AGENCIES, BUT NOT BY GOVERNMENT POLICY SETTINGS OR AT A NATIONAL GOVERNMENT LEVEL.”

Figure 3: Carers feeling valued



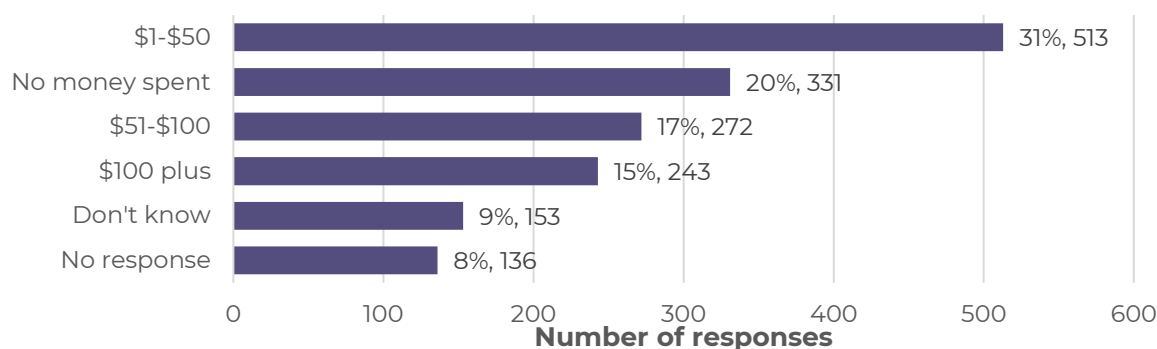
The financial cost of caring is not covered by available supports

Available supports can be used to pay for services, equipment or products to meet care-related needs. While 50% of carer respondents indicated they spent no money or under \$50 a week on care-related costs, 15% of carer respondents spent more than \$100 a week on these costs. Applying this number to survey respondents (n=1648) equates to a minimum of \$1,276,200 coming out of the pockets of family carers and their households each year. Extrapolating this to the 430,000 carers indicated by the New Zealand Census, the out-of-pocket costs increase to a staggering \$335 million per annum.

Carers under 35 years old had the highest proportion of paying over \$100 and between \$51-\$100 each week.

“WHENEVER WE HAVE ASKED ABOUT ASSISTANCE, THERE IS ALWAYS SOME TECHNICALITY THAT PREVENTS US FROM GETTING ANY FINANCIAL SUPPORT. YOU GET TIRED OF FIGHTING FOR EVERYTHING SO GIVE UP ON YOUR OWN NEEDS FOR THE MORE PRESSING NEEDS OF THOSE YOU CARE FOR.”

Figure 4: Carers' expenditure on caring needs



Access to technology

There is a range of technology available to support carers and those they assist.

Respondents identified some key access barriers to using technology: lack of technological knowledge or training, and lack of financial resource to pay for technology.

The internet is the main technology carers use. According to 80% of carer respondents, the internet is an important source of information and communication, and this was high across all carer groups. The internet is used by 39% of carer respondents to access online support groups and social media.

A small number of carers (1%) did not have access to the internet due to having no devices, not being able to afford it or by choice.

A range of other technology is supporting carers with more specific health and wellbeing needs. New Zealand carers accessed each type of technology at very

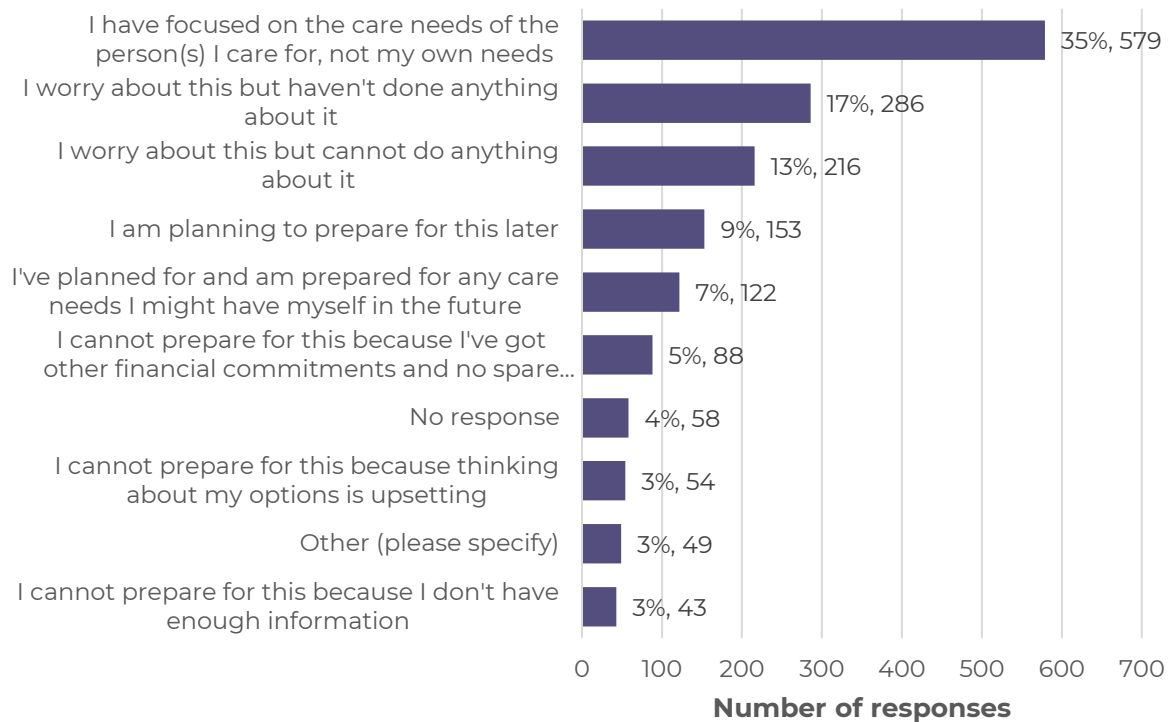
similar rates to respondents of the Carers UK *State of Caring* survey.

1. 25% accessed health services remotely for GP appointments or repeat prescriptions (27% in UK).
2. 17% used remote monitoring alerts such as fall detectors (19% in UK).
3. 11% used vital sign monitoring equipment (13% in UK).
4. 11% used medication management tools.
5. 6% used apps to help find support workers or other 'people' help.
6. 4% used apps for pain management, mood management or care coordination (4% in UK).

Planning for the future is difficult

Many carers are not planning for their own future – including 35% of carer respondents who focused on the needs of the person they care for rather than their own. Only 7% of carer respondents had planned for themselves and were prepared for their own future needs. A significant number of carers were either worried about planning for the future, or felt they were simply unable to do this planning.

Figure 5: Planning for the future



Carers and needs assessment

Carers are missing out on inclusion in needs assessment and service coordination support or having their own needs adequately reflected as a priority in the existing assessment system, and therefore are not receiving sufficient support for themselves. Of carer respondents, 46% did not feel the assessment process included their needs as a carer and they did not feel supported.

However, 37% felt the assessment process did include their needs as a carer and felt supported, while 7% had a delay of over three months before their whānau member had their needs assessment.

Carers under 35, carers of two or more people and carers of five years or more reported the highest levels of not feeling their needs were included in the assessment process, at 50%, 54%, and 49% respectively.

Any needs assessment process for carers needs to be holistic and comprehensive to properly identify necessary supports for those in caring roles. The current needs assessment process does not cover all aspects of caring:

- 51% of respondents did not have their ability to be paid for at least some of their care work considered in the needs assessment process, even though New Zealand now has a carer payment policy in place. All carers should be receiving information about how this works, to support their decision-making about their caring role.
- 41% of respondents felt that the emergency needs of the person they care for were inadequately considered in the needs assessment.
- 26% of respondents indicated equipment needed for mobility and support was the most thoroughly considered area in the needs assessment.

There is clear demand for a needs assessment for carers

86% of respondents indicated that a dedicated carers assessment that is undertaken alongside the current needs assessment process would be beneficial to carers. This sentiment was shared across all carer groups with only a small number indicating that this would not be beneficial.

Respondents stated that carers should have a unique needs assessment to assess their wellbeing, identify gaps in their caring knowledge and ensure they are well informed about available supports, including those just for family, whānau and āiga carers.

Any needs assessment needs to be followed up by supports that are readily available, and carers need to know how to access them.

“HONESTLY, THERE'S A LOT TO HANDLE AS A CARER, AND EVEN AFTER THREE YEARS I'M STILL LEARNING ABOUT THINGS THAT I AM ENTITLED TO.”

THE CHALLENGES OF JUGGLING WORK, FINANCES AND CARING

The caring population is diverse, with a broad range of employment and financial situations. Managing work, finances and caring responsibilities can be difficult for carers. Giving up paid employment reduces carer income at a time when carers are most likely to have more care-related expenses, which can impact their ability to plan and prepare for their own future and save for their retirement.

Carers are in a range of employment situations, but many can't participate in paid work. Almost half of carer respondents reported they worked in paid employment, but just 21% were in full-time work (including self-employment). A further 22% were in part-time employment. With almost 90% of carers being of workforce age, employment rates are very different for carers than for the general population.

Overall, 23% of carer respondents were retired and 30% were unable to work at all in paid employment, primarily due to needing to look after their home and assist those who rely on them.

A higher proportion of carers aged under 35 (36%) were unable to undertake paid work than those in other carer groups, although a higher proportion of young carers worked full-time (28% compared to 21% of carers overall). Carers who assist two or more people also had a higher proportion of respondents who were unable to undertake paid work due to their caring responsibilities.

Of Māori and MELAA carers, 32% and 26%, respectively, indicated they have had to give up work to provide care. The percentages for European, Pacific and Asian carers were 29%, 26% and 23%, respectively. Pacific and Asian carers were more likely to take up a less qualified job or turn down a promotion because of their caring responsibilities. Māori and Pacific carers reported higher rates of working the same hours but having their job negatively affected by caring commitments.

“I HAD TO GIVE UP MY CAREER, I HAVE ATTEMPTED SEVERAL DIFFERENT POSITIONS AND TAKEN ON OTHER ROLES TO MAKE MORE INCOME FOR MY FAMILY, BUT IT'S A CONSTANT STRUGGLE DUE TO THE HIGH NEEDS OF MY CHILDREN.”

Managing caring responsibilities and working is generally difficult, with around half of carer respondents having had to give up work to care or reduce their working hours to care or working the same hours but with negative job impacts.

Carer respondents identified that increased flexibility of work had allowed some to better juggle work with caring responsibilities, but in other cases one had to be given up for the other, or there was an impact on wellbeing; e.g., they were burnt out trying to do both.

Figure 6: Impact of care on work



Giving up work to care was the most common response across all carer groups, but carers of two or more people had the highest rate of leaving paid employment; 32% of these respondents had given up paid work to focus on caring for others.

Younger carers aged under 35 were more likely to be working the same hours but with caring responsibilities negatively affecting their work than carers overall, at 24% compared to 14%. This group also had the highest rates of poor mental health and loneliness, with 84% of respondents in this group indicating that they 'often/always' (34%) or 'sometimes' (50%) felt lonely.

The survey results paint a picture of high vulnerability among working age carers.

Many carers are struggling financially

Carers' employment situations vary, as does the need for paid work. Carers who have sufficient financial security are able to access extra supports or resources that they may need, but this is not the case for many carers.

There was a significant financial burden placed on some carers, with 59% of respondents indicating they could not pay their bills without struggling financially and 15% of carer respondents saying they were or had been in debt because of caring.

New Zealand carers are worse off than UK and Australian carers, with 39% of UK respondents struggling financially and 35% of Australian carers experiencing financial stress.

“CURRENTLY I AM WORKING AND CAN COVER BILLS. I AM GETTING STRETCHED AND TIRED AND FEEL I NEED TO GIVE UP WORK BUT I HAVE BEEN TOLD THAT THE PERSON I CARE FOR IS NOT SEVERELY AFFECTED ENOUGH FOR ME TO BE ELIGIBLE FOR ANY ASSISTANCE.”

Carers use a variety of methods to cope financially and cut back on expenses. Of carers who were struggling financially, 62% were trimming spending on hobbies and leisure activities, which in turn could impact their wellbeing. Additionally, 67% were cutting back on luxuries.

It is concerning that 30% of carers who were struggling financially were cutting back on essentials such as food and heating. This undoubtedly has negative effects on the health and wellbeing of these carers and their whānau, and contributes to the mental wellbeing strains carer respondents show in this survey.

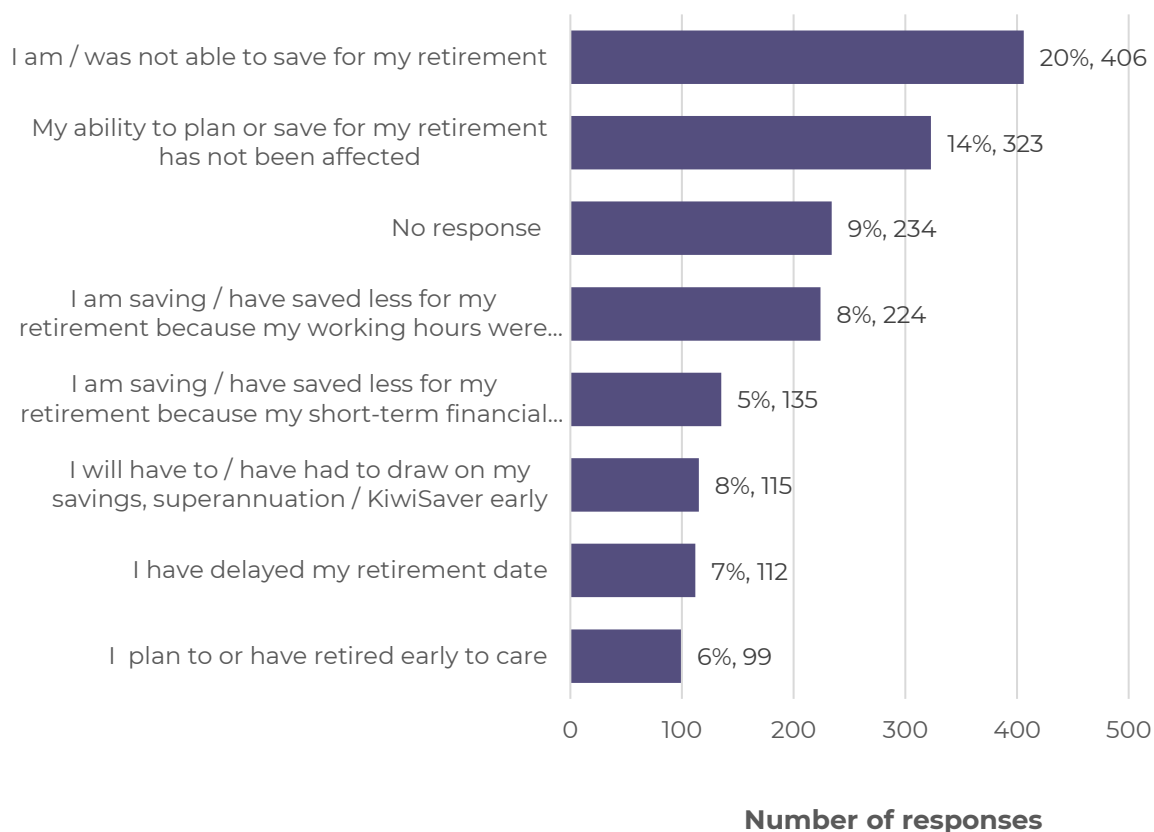
To make ends meet, carers turned to a range of sources, depending on their circumstances; 30% used credit cards, 20% used overdrafts from the bank, 21% borrowed from family, whānau or friends, and 8% took out loans from the bank. Savings were used by 43% of respondents to meet household shortfalls. For some carers this may be fine, but for others this could have long-term financial effects – especially regarding retirement.

Caring affects carers' retirement options

The financial impacts of caring are affecting family carers' retirement prospects – when they can retire and how they will pay for living costs in retirement. Twenty percent of carer respondents said they were not able to save for retirement at all and only 14% said caring had not affected their ability to plan or save for retirement.

Strains to plan or save for retirement result from carer respondents needing to give up paid work or cut back their earning due to care responsibilities, and/or paying extra costs to meet care-related needs, alongside the general financial struggles reported by care respondents.

Figure 7: Saving for retirement



LIMITED ACCESS TO RESPITE AND TIME OUT OPTIONS THAT WORK

This section of the report covers the results from the *Respite and Time Out* survey which sought to understand the impact the COVID-19 outbreak was having on respite access. Of all respondents, 656 shared their experiences of respite and time out in the survey.

Accessing respite was already an issue

Carers accessed respite (breaks from caring) at varying rates before the pandemic, with 12% having breaks whenever they needed to, and 13% only able to access breaks in emergencies. Concerningly, 24% of carers said they had not had a break for more than a year, and a further 18% had not had a break in over six months.

Figure 8: Taking time out or respite breaks prior to pandemic

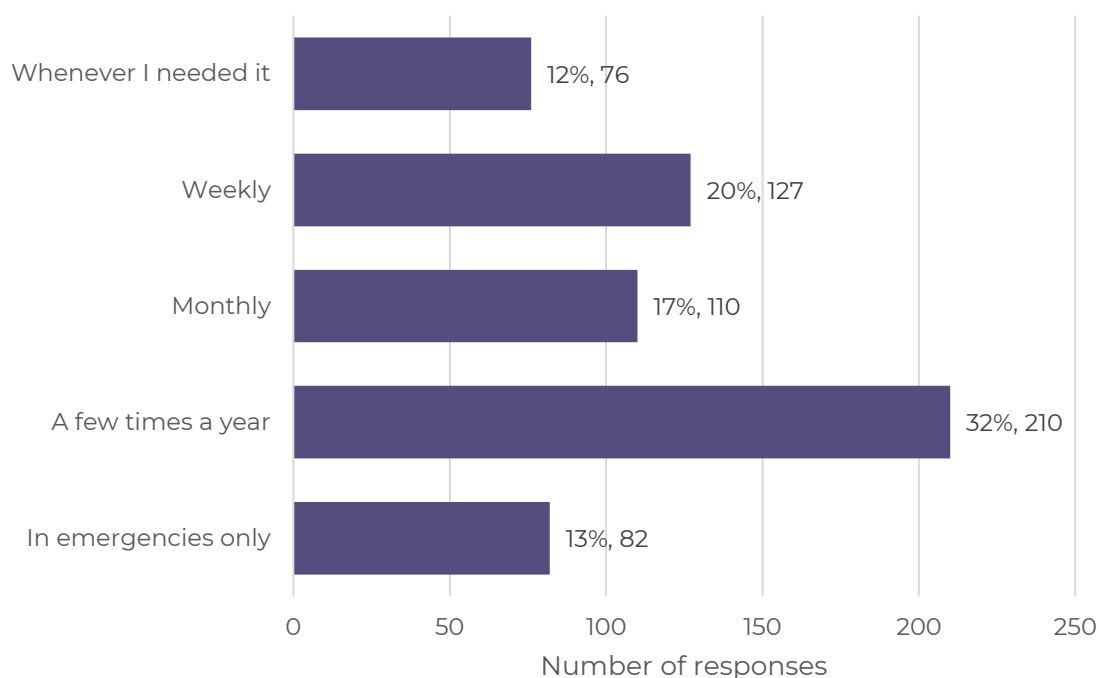
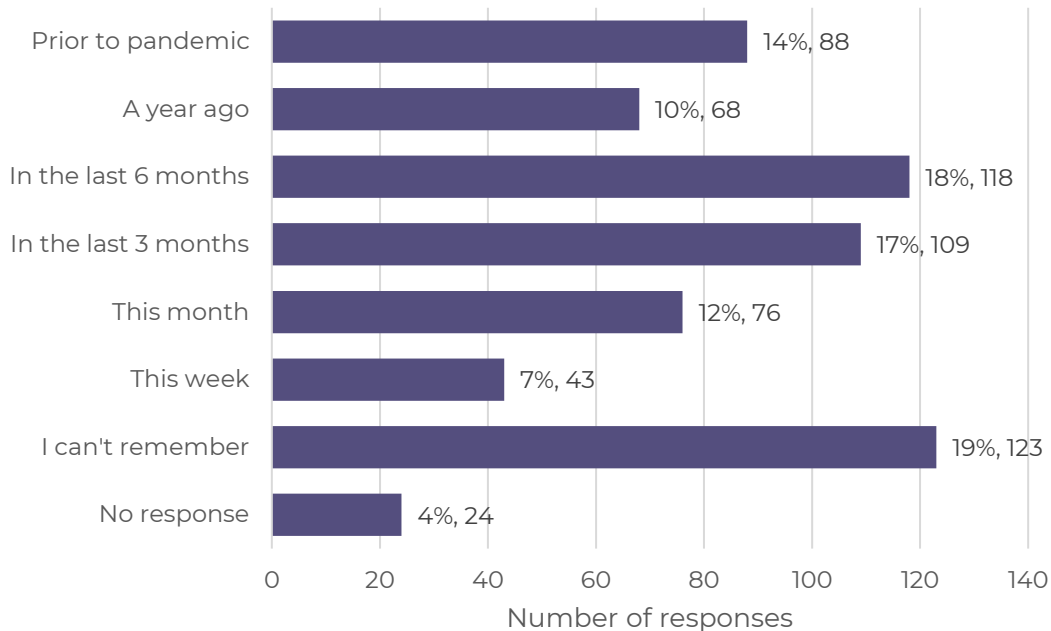


Figure 9: Length of time since respite break



Outside of the pandemic, financial cost, adequate care providers that are available locally, and logistical planning act as barriers for taking respite breaks. And for some, a lack of understanding of what respite is and how to access it is a further barrier. For many, the length of available respite is inadequate.

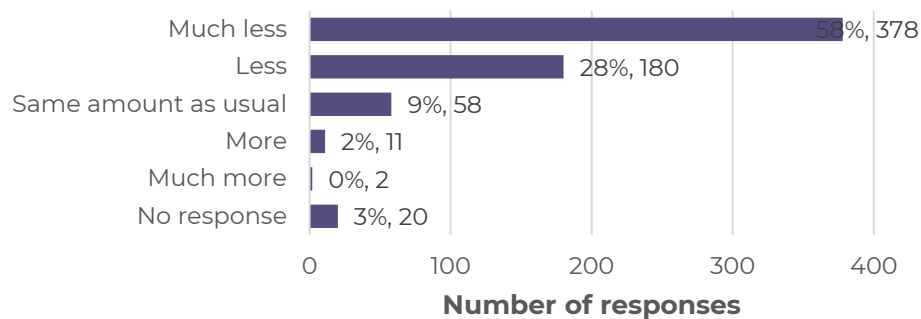
“I DON'T EVEN KNOW WHAT I COULD ASK FOR BECAUSE I DON'T KNOW WHAT RESPITE IS, I'VE NEVER HAD IT OR BEEN TOLD EXACTLY WHAT KIND OF RESPITE WE COULD GET.”

When the opportunity for respite becomes available, it is generally very short, for most only a few hours a week tops, and it can be difficult to fully recharge in such a short period of time. Carers say this has led to burnout in the long term.

COVID-19 reduced respite for carers

COVID-19 negatively impacted carers' ability to have time out or respite from their role, with 86% of carer respondents saying COVID-19 negatively affected opportunities for respite (Figure 10).

Figure 10: Ability to take breaks during the pandemic compared to pre-pandemic



The inability to travel to whānau and friends who provide regular support or to have relief carers travel to provide respite breaks, alongside cancelled support groups, day programmes, holiday programmes and other respite outlets, has meant that most carers have had less or much less respite since the pandemic began in March 2020.

"SUPPORT GROUPS HAVE BEEN CANCELLED, WHICH HAS BEEN DIFFICULT AS THAT IS ALSO RESPITE TIME FOR ME. MANY CARERS ARE FROM OUT OF TOWN BUT HAVEN'T BEEN ABLE TO TRAVEL TO PROVIDE SUPPORT."

COVID-19-related anxiety made it difficult for some carers to want to travel to take their usual respite breaks, especially with uncertainty around border restrictions. Before the pandemic, carers indicated they were able to take regular respite breaks, although some barriers were still an issue.

Lack of respite decreased carers' wellbeing

Lack of available respite due to COVID-19 has negatively impacted carers' wellbeing, which was already at concerning levels according to carer respondents in the *State of Caring* survey.

A significant portion of respite survey respondents felt burnt out because of a lack of breaks and added financial tension during the pandemic, and this decreased their physical and mental wellbeing. Almost half (46%) of respite survey

respondents indicated they were struggling or really struggling because of lack of respite, with a further 2% needing emergency respite. Many carers also said that despite the struggle, they felt that they needed to push through their burnout as this is their only option.

“MY FAMILY AND I ARE CONSTANTLY TIRED AND DRAINED. WHAT DOES ONE DO WHEN THERE'S NO ONE TO ‘CARE FOR THE CARER’?”

Suggestions for respite

Many carers felt they could not afford time off financially or emotionally. A variety of suggestions were provided by survey respondents to help mitigate this.

- More flexibility in where respite care funding can be spent, e.g., on technology to keep those being cared for engaged, supported and entertained, and to enhance studies/learning.
- More readily available knowledge on how respite funding works.
- An expanded, reliable and competent workforce to alleviate stress on individual carers and to be available in emergencies.
- Communications to carers who may need urgent or emergency respite, or an extended allocation of relief care funding due to increased pressures, service disruptions, lack of worker availability due to the pandemic etc.
- Additional respite capacity tailored for the pandemic, e.g., residential respite.
- Other suggestions include access to affordable accommodation, help with small household tasks, and accessible support groups.

CONCLUSION

The responses to the surveys and the analysis clearly show carers across New Zealand are struggling, do not feel valued and are under pressure. This report calls for urgent action to be taken with a focus on 12 key recommendations.

The survey feedback highlights the issues and challenges facing carers across New Zealand. In reviewing the feedback, there are potentially many recommendations that could be made – however, to provide focus and attention, the following 12 recommendations are made:

1. Fully implement the *Mahi Aroha Carers Strategy Action Plan's* outcomes with vigour and use the data in this report and future evidence to identify useful actions for the next Action Plan.
2. Increase existing supports and provide new ones for carers – including making respite funding more flexible across the diverse population of carers, and investing more into respite to improve carer wellbeing as a single vital way to safeguard and improve the wellbeing of this large population.
3. Provide more effective navigation support (particularly around respite) and improve the promotion of information available to carers about financial supports (including being paid to provide care), respite and wider government assistance.
4. Improve and simplify financial supports to reduce barriers to financial assistance, such as spouses' inability to access the Supported Living Payment or to be paid for the significant efforts they make in areas such as Individualised Funding (often at the expense of other paid work opportunities).
5. Formally recognise the role of carers and the value they provide to their whānau and the system by directing government departments to ensure plans and strategies specifically includes focus and actions that relate to carers.
6. Prioritise the implementation of an approach to the appropriate consideration of carer needs in their own right and a process to ensure supports are put in place to meet identified needs with a specific focus on advance care and emergency planning.
7. Find a place in Government for carers, who too easily 'fall through the cracks' of existing structures, frameworks, and Ministries; this could take the form of a Minister/Ministry for Family Whānau and Aiga Carers and/or a Commissioner who has responsibilities for this large population of New Zealanders. We note that a similar approach is being mooted in Australia for the same reasons.
8. Ensure the evolving structures of government (Te Whatu Ora – Health NZ, Te Aka Whai Ora - Māori Health Authority, Whaikaha - Ministry of Disabled

People, ACC etc) are meaningfully 'carer friendly' in important areas such as respite, information, financial support, wellbeing and support for carers who are Māori, Pacific, young, etc.

9. Identify measurable ways to support and improve carer wellbeing in areas such as employment, retirement planning, loneliness and social isolation, finances, and mental health; ensure programmes for wellbeing are adequately resourced and promoted.
10. Identify and implement supports for carers aged under 35 as a direct response to concerns highlighted in this report of the impact caring has on younger carers.
11. Support specific initiatives and programmes that assist working age carers, particularly women and young carers, whose earnings, life success, retirement savings, and financial wellbeing impact their ability to work, earn, save, and thrive.
12. Implement specific supports for carers impacted by the COVID-19 pandemic. These impacts were visible in the comments and data gathered for this report in 2021 and will have deepened since in areas such as respite, wellbeing, employment, finances, and access to support and services.

SECTION E

APPENDICES



QUOTES AND COMMENTS

Carers who completed the *State of Caring* survey shared thousands of comments, providing rich context about their experiences in a range of areas. Following are examples of common carer perspectives.

Recognition of the needs of carers

- “I have been looking after my son since he was a baby. He was 3-4 years old before we had some recognition that there were problems. Where does parenting stop and caring start?”
- “The job of a carer is massive. I didn't realise till I became one. It's exhausting.”
- “When I say I manage that is only if I don't have a social life.”
- “No needs assessment has been offered to us or followed through when I asked for one.”
- “I do not feel there is any consideration of what would happen should I get sick, or be unable to provide the bulk of the care required.”
- “Honestly, there's a lot to handle as a carer, and even after 3 years I'm still learning about things that I am entitled to.”
- “I feel recognised, valued and supported by my loved one I am caring for and occasionally by individuals within government agencies, but not by government policy settings or at a national government level.”
- “Where we live, which is where my husband and I both want to live, means considerable constraints on homecare support available, as only a limited number of homecare support people will travel out to our rural community.”
- “Being asked questions about my ability to care for myself, equipment needs for the family's future, and whether our house is big enough all requires change and large financial input. There is no one to provide that finance as far as I know so I'm not sure about the point of even asking the questions.”
- “I have saved my energy in asking for help at times because it is a battle. There is not enough funding.”
- “NASC were very restrictive in what they can fund, showed no flexibility, they had more reason not to fund than to fund. Their answer to every question was Ministry (of Health) guidelines did not permit them.”
- “Needs assessment was very much a box ticking exercise and completely about my son's needs.”
- “Needs assessment is one thing, but actual care given is another.”
- “Family carers need to be regularly supported so that they can look after their own mental and physical health needs.”
- “A lot of the care is put on the whānau and it can be stressful especially where you don't know what you are doing and how to help them properly.”
- “Time out is very important when the carer's ability to socialise is very compromised. Life can become very restricted.”

Finances and supports

- “I have found support is sometimes there if you know to ask for it. However it’s not offered and it’s difficult to know what you don’t know!”
- “We receive no financial support. I know so many people like me who have given up careers.”
- “We get money but have to find our own help.”
- “There is very limited support, especially for mental health.”
- “Lack of funding has reduced the number of visits the support services staff member can make.”
- “For the positive, our support carer’s hours were increased this year - which was wonderful.”
- “We do not receive ongoing support. Health requirements and assistance needs seesaw and generally we do not fit the current criteria.”
- “No change in amount of support, however quality is an ongoing problem/battle.”
- “Currently I am working and can cover bills. I am getting stretched and tired and feel I need to give up work but I have been told that the person I care for is not severely affected enough for me to be eligible for any assistance.”
- “There are a lot of supports and technologies we would like to get but can’t due to cost.”
- “I have always been a carer but whenever we have asked, but there is always some technicality that prevents us from getting financial support. You get tired of fighting for everything so give up on your own needs for the more pressing needs of those you care for.”
- “NZ govt takes the role that we play as parents for granted. The stress on the entire whānau is immense – especially so for other children in the family. There needs to be significantly more support offered and explained.”

Emergency preparedness

- “From what I can see talking to others in similar circumstances it’s not until an emergency occurs that this is addressed.”
- “I think it’s just assumed that they’d go into a care facility or hospital.”
- “This is something we try not to think of, as it hits close to home.”
- “Doesn’t matter what we plan, it will depend whether there’s a bed available with a service provider at the time.”
- “The admission could have been prevented if there was appropriate support for youth with mental health/anxiety issues, and if schools provided education appropriate for all children and not just ‘traditional’ needs.”
- “The public health system is poorly equipped and managed for intellectually disabled, nonverbal, patients.”
- “My other kids would just have to step up and help – hasn’t been discussed or planned.”
- “Family and friends would probably help but no plan in place.”

- “This is a major problem. I have had to put off care for myself on a number of occasions because I have been unable to find someone to adequately care for my wife while I am away.”

Technology and information access

- “Not much information support through the years in our small rural town.”
- “I did my own research and found it unhelpful and very confusing with multiple exclusions.”
- “Reading information doesn't help a person who is exhausted and in crisis. An 0800 crisis number would be more practical when you really need help and support.”
- “There's a lot of information that a carer has to sift through and you're not guaranteed to retain it all, let alone use it. It's a lot to handle.”
- “[Government's *Guide for Carers*] would be of no value without relevant additional support, especially financial.”
- “These technologies cost money either to buy or power to run it, and when needing to reduce living costs these are not possible.”
- “We have access to internet and mobile phones but are not tech savvy so don't know how to use, them except for basic use such as emails and making phone calls.”

Balancing work, life and care/mental health

- “I had to give up my career. I have attempted several different positions and taken on other roles to make more income for my family, but it's a constant struggle due to the high needs of my children.”
- “I have recently been housebound for five months but friends and carers dropping in have stopped me feeling too lonely. But I was suffering from being shut in.”
- “Feel more let down by the system than lonely or isolated but luckily I am proactive in seeking solutions. Not everyone has this skillset.”
- “I had to give up my social groups, but that is part of caring.”
- “I do not have time to experience anxiety or depression.”
- “I worried a lot for my partner, about his pain, about whether or not I was doing the right things.”
- “I no longer feel like a member of society.”
- “I feel completely invisible to be honest.”
- “I feel undervalued and ripped off.”

COVID-19

- “Safety, e.g. mask wearing and whether carers are vaccinated is an ongoing problem. We need more consistent policy.”
- “Regarding COVID itself I thought the information was good, but not for carers specifically.”



SYNERGIA

