



Mahi Aroha

Caring for the Carers

**Discussion document on the proposed
Carers' Strategy Action Plan**
2019 - 2023



MINISTRY OF SOCIAL
DEVELOPMENT
TE MANATŪ WHAKAHIAITO ORA



New Zealand Government

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Minister's Foreword

Carers are an essential and valuable part of Aotearoa New Zealand. They contribute to our country's economic sustainability, as well as playing a major role in improving individual wellbeing and community cohesion.

This Government is committed to supporting everyone who is able to be earning, learning, caring or volunteering. The Carers' Strategy Action Plan is an important part of this, and provides a framework to support people who are caring for a person who has a disability, health condition, illness or injury and needs additional assistance with their everyday living.

This Action Plan is taking a wellbeing approach and has two main aims: improving the wellbeing of carers, and ensuring the care role is sustainable.

This year's Action Plan will continue to contribute to the vision and direction of the Carers' Strategy. This strategy was introduced in 2008 to improve the choices of parents and other informal carers so they could better balance their paid work, their caring responsibilities, and other aspects of their lives. The release of the Carers' Strategy was a first step in recognising, valuing and supporting the people, families and whānau who care for someone with a disability, health condition, illness or injury.

Since 2008, there have been two Action Plans, which have contributed to achieving the vision of the Carers' Strategy. We have accomplished a lot over the past 10 years to support people to undertake a care role. We have worked to ensure that carers are becoming more recognised for the important mahi they do.

While a lot has been achieved, we know there is more we can do. Our goal has been to develop a more ambitious Action Plan, which focuses on supporting carers to do what they do best.

Since the beginning of the Carers' Strategy, we have worked in partnership with the Carers Alliance to ensure that the Action Plan reflects the views of carers. This partnership has been a great example of what we can achieve when we work together. We now invite all New Zealanders to be involved, so that Aotearoa New Zealand is a place where carers are valued and supported.

We want to make sure that we get this Action Plan right. To do that, we need your help. We want to hear from carers, the people they care for, and the organisations who support carers. Your input will help us to create an Action Plan that works for you, your family and whānau, and your community.



Hon Carmel Sepuloni
Minister for Social Development



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Introduction

We want to hear from you

It is important that the new Action Plan reflects what matters most to carers so that we focus our efforts on actions that will make a meaningful difference. In order to do this, we need your feedback to make sure we have got this right. We want to hear from people who are caring, as well as the people they care for, and the organisations that support carers.

This discussion document outlines a draft Action Plan. Each action area includes questions to prompt your thinking about the actions, and space for you to write your thoughts. The ‘Have your say’ section at the end of the document outlines the different ways that you can tell us what you think about the proposed actions.

In addition, we are also interested in hearing what the term ‘carer’ means to you, your whānau and wider community groups. You can find out more about the previous Action Plans by visiting www.msd.govt.nz/carers.

The Carers’ Strategy Action Plan is for all carers

This Action Plan is for anyone who carers for a friend, family, whānau or aiga member with a disability, health condition, illness or injury who needs help with everyday living.

The term ‘carer’ might not work for everyone. Words like ‘supporter’ or ‘manakitanga’ might better describe what you do, or you might see caring as a natural part of what you do for the people you love. Carer is the term used to describe the diversity of individuals, families and whānau who provide this support.



One in ten New Zealanders provide care.
There are over 430,000 carers in New Zealand.
Of these, two thirds are women, and at least
40,000 are young carers.

More people will need to provide care as our population ages

The demand for care is growing both here and internationally. We know that most people would prefer to be cared for in their own homes and communities rather than in residential or institutional settings.

An Action Plan that recognises, values, and supports carers is an investment in New Zealand's future

As more people take on caring roles, it is important that we are investing in support for carers. While the interests of carers and the people they care for are closely related, support is usually focused on the person needing care.

The demands of care often mean that carers have fewer opportunities than people without caring responsibilities to participate in education, paid work, and social and community activities. Over time this can have a negative impact on wellbeing and your ability to continue to provide care. It can also have wider impacts on your and your family's finances and social connectedness.



The new Action Plan responds to what carers told us is most important to them

In October last year, we held a series of workshops and an online survey to hear people's ideas about what we could do to better support carers. We also reviewed the existing evidence about carers' experiences, including looking at the feedback from the previous two Action Plans. This draft Action Plan seeks to reflect what we have heard.

Caring can be rewarding, but it also has challenges

We know that caring can be a really positive and rewarding experience. Carers have told us that providing care can bring them closer to loved ones and can give them a new sense of purpose and identity.

However, we also know that caring can sometimes be hard. Some of the challenges we heard about include:

- “I find it hard to access supports and services – information could be more centralised”
- “I find that services are not always culturally appropriate”
- “I have to keep re-telling my story to different people”
- “I am struggling to manage the financial costs of care”
- “I feel overwhelmed and at the end of my tether – I need a break”
- “I am unable to pursue my own interests – such as travel, work or study”
- “I have my own health concerns and worry what will happen to the person I care for if something happens to me”

It is important to us that our efforts are focused on addressing these challenges. This means that carers are able to take a break, look after their own health needs, and spend time with their friends and family. In turn, this helps to support the wellbeing of the wider family, whānau and community.

Some groups of carers face additional challenges

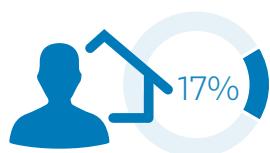
Caring is not the same for everyone. The experience and impact of caring can reflect culture, age or gender.

Many carers experience social isolation, difficulties balancing work and caring, and a lack of support. Some carers face additional challenges as a result of not wanting to ask for help, perceived shame and stigma, and services not respecting cultural norms.

This Action Plan is for all carers. It has an additional focus on four target population groups; Māori, Pacific, younger (25 years and younger) and older (65 years and older) carers.

Māori carers

Māori women are more likely to be carers than women in other population groups, and are also typically younger than other carers. Māori communities have higher rates of multiple and long-term health conditions. Māori carers are more likely to be managing their own health condition(s) as well as their care role(s). Māori may not see themselves as carers, with the role considered a normal part of whānau responsibility. Māori carers may have also had negative experiences with services, which may not be culturally appropriate or responsive to the needs of caring whānau. This can influence whether, or how, they access support.



Māori make up 15% of general population and
17% of the carer population.

Pacific carers

Like Māori carers, Pacific carers are often younger than the general carer population. Care is typically provided within families. Services may not be culturally appropriate or responsive to the needs of Pacific carers and those they are caring for. Negative experiences with services may mean Pacific carers feel reluctant to access support. Pacific communities tend to have poorer health than the general population, with carers having to deal with their own health conditions.



Pacific people make up 7% of NZ's general population, and
7% of the carer population.

Younger carers

Young carers may not want to draw attention to themselves. Caring can impact on their participation in school and study, and the usual things kids do. This can have impact on their opportunities in later life.



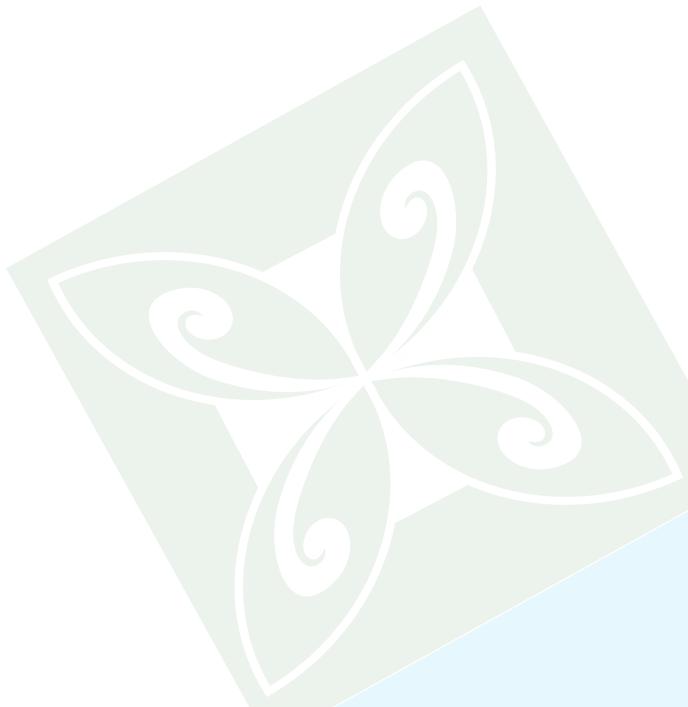
Approximately **9% of carers**
are **aged between 15-24**.

Older carers

Older carers are particularly vulnerable to social isolation. They may be managing their own health conditions, as well as dealing with the demands of being a carer.



Approximately **16% of carers**
are **aged 65 and over**.



Ensuring a Te Ao Māori perspective through our work

In keeping with our Crown obligations to Te Tiriti o Waitangi we have used Te Ao Māori frameworks to help guide this Action Plan. A whānau centred approach will inform the implementation of the Action Plan.

Supporting Pacific carers

To ensure the Action Plan represents Pacific carers' voices, including how we measure outcomes for Pacific peoples, we will be guided by the Lalanga Fou and Kapasa frameworks and tools. These will help bring to life Pacific peoples' values, knowledge, and experiences through the engagement process and for future actions relating to Pacific carers.

This Action Plan links to other work underway

This Action Plan links to, and complements, a number of other strategies and cross-government work, including:

- Government response to the Whānau Ora Review: Tipu Matoro ki Te Ao and the Whānau Ora Outcomes Framework (Te Puni Kōkiri)
- Better Later Life Strategy – He Oranga Kaumātua 2019-2034 (Office for Seniors)
- Healthy Ageing Strategy 2016 (Ministry of Health)
- New Zealand Disability Strategy (Office for Disability Issues)
- Transforming Respite: Disability Support Services Respite Strategy 2017 - 2022 (Ministry of Health)
- He Korowai Oranga – Māori Health Strategy (2002) (Ministry of Health)
- ‘Ala Mo’ui: Pathways to Pacific Health and Wellbeing 2014 – 2018 (Ministry of Health)
- New Zealand Framework for Dementia Care 2013 (Ministry of Health)
- Health and Disability System Review
- Government’s response to He Ara Oranga, Report of the Government Inquiry into Mental Health and Addiction
- Overhaul of the welfare system (Ministry of Social Development)
- Child and Youth Wellbeing Strategy (Department of the Prime Minister and Cabinet)
- Lalanga Fou Report (Ministry for Pacific Peoples) (particularly Goal 3 and sub-goal 2).

Four areas for action

Recognising

Recognising carers and their contributions

New Zealand's carers are often not recognised for the important work that they do. This can make it hard for carers, because their role might not always be acknowledged by health professionals, by their employers or by their teachers. It can mean that they feel undervalued.

During targeted engagement, carers told us that:

“Caregiving can be perceived by others as “not a real job”. I want to be valued by having my role recognised as real work...”

“I think caregivers are very forgotten people.”



Carers spend an estimated average of
30 hours per week providing care.

Action 1:

Exploring mechanisms, including legislation, to better recognise carers and their particular needs

- » **Lead:** Ministry of Social Development
- » **Supporting:** Carers Alliance
- » **Work to begin:** Year 1 (2019)

Work will be undertaken to identify ways carers can be better recognised and supported through mechanisms such as legislation, policy, in communities, workplaces and schools.

Action 2:

Develop a national campaign to raise awareness of carers, including a National Carers Day

- » **Lead:** Ministry of Social Development
- » **Supporting:** Carers Alliance
- » **Work to begin:** Year 3 (2021)

Promoting the value and contribution of carers and caring aims to increase awareness and positive attitudes towards carers across the community. This action would explore the idea of a National Carers Day, alongside a social media campaign, to increase awareness of carers and what they do. Our aim is for carers to feel they are valued by their community and that their caring role is recognised by the Government.

Action 3:

Better understand the needs of carers, particularly younger, older, Māori, and Pacific carers, as well as other hidden carers by creating a carer research fund

- » **Lead:** Ministry of Social Development
- » **Supporting:** Te Puni Kōkiri, Ministry for Pacific Peoples, Ministry of Youth Development, Ministry for Women, Statistics New Zealand, Ministry of Education, Office for Seniors, and the Carers Alliance
- » **Work to begin:** Year 1 (2019) We need to ensure that services respond to the needs of carers, families, whānau and aiga.

More research is needed on the needs of carers, particularly Māori, Pacific, younger or older carers. We also need to know more about those who don't identify with the term 'carer'. Research on carers will take into account the changing priorities and demographics of New Zealanders. This includes ensuring a kaupapa Māori approach in commissioning new research.

This action will also include looking into key barriers, and impacts of current care leave entitlements for carers who work. Research will inform investment in, and design of services and support in the future.

Action 4:

Improve information about carers by modifying existing data collection tools

- » **Lead:** Carers Alliance and Ministry of Social Development
- » **Supporting:** Ministry of Health, Te Puni Kōkiri, Ministry for Pacific Peoples, Ministry for Women, Statistics New Zealand, Ministry of Education, Office for Seniors, Tertiary Education Commission, and the Ministry of Youth Development
- » **Work to begin:** Year 1 – 3 (2019 – 2021)

This action aims to build a robust and accurate supply of information on carers, which can inform how services and supports are provided to carers. This work will explore opportunities to improve information collected through the Census, the General Social Survey and the Health Survey.

This action will also include supporting work to identify young carers through a survey tool in a New Zealand context (Multidimensional Assessment of Caring Activities).

Action 5:

Better support to include the voices of young carers in policy development, including through re-establishing a Young Carers Advisory Board

- » **Lead:** Carers Alliance
- » **Supporting:** Ministry of Social Development, Ministry of Education, Te Puni Kōkiri, and Ministry for Pacific Peoples
- » **Work to begin:** Year 2 (2020)

The voices of young carers are important to inform how the government can better support those in a care role, as well as their family and whānau. Re-establishing a Young Carers Advisory Board will help to ensure young carers are well represented. Nominations to reflect a broad range of views will be sought, including through Te Puni Kōkiri's Rangatahi Leadership Group.

What do you think?

- Overall, what do you think of the actions in this section of the draft Action Plan?
- Would you like anything in this section to be changed or improved?
- Is there anything else that you think might be more important than these actions to help identify and recognise carers?

Feel free to take notes and write your thoughts below.



Navigating

Ensuring carers receive supports and services

It can be hard to know where to go to find out about what support services are available. Actions in this area aim to support carers to access the assistance that they are entitled to.

Carers have told us that:

“It has been a struggle to find our way through the system...”

“There are a lot of people needing information and not knowing where to go to get it.”

“The biggest thing for me has been that no one tells you what’s available or who to ask for help or advice.”

Action 6:

Working with carers, people receiving care, and relevant sectors and agencies to explore the benefit of a national approach to managing continence

- » **Lead:** Ministry of Health
- » **Supporting:** Carers Alliance and District Health Boards
- » **Work to begin:** TBC

Incontinence (bladder and bowel) is a common health problem and is both an under-reported and growing issue, particularly within New Zealand’s ageing population. Managing continence is a priority concern for the many people who experience difficulties with it, as well as for their carers.

Apart from the stress and stigma that are often associated with incontinence, the costs of incontinence are a significant burden to people, the health system, and society as a whole. This includes productivity impacts (eg, time off or not being able to work), the cost of products, formal care, and environmental effects (ie, disposal). Access to continence services and equity of outcomes varies between population groups.

An intersectoral approach may be needed to identify priorities for this action. The report on continence commissioned by the Carers Alliance¹ will help inform work on this action.

¹ Understanding continence in New Zealand: A report for the New Zealand Carers Alliance, December 2018

Action 7:

Strengthen navigation across all parts of the care and support system (including health, welfare and ACC) to ensure carers receive available assistance

- » **Lead:** Ministry of Health, Accident Compensation Corporation (ACC), and Ministry of Social Development
- » **Supporting:** Te Puni Kōkiri
- » **Work to begin:** TBC

Finding your way around services and supports in health, welfare, ACC and other areas can be very complicated. This action is intended to help make it easier for carers to access the support that is available.

Action 8:

Improving engagement between people needing care, their carers, and supporting agencies

- » **Lead:** Ministry of Health, Ministry of Social Development, and Accident Compensation Corporation
- » **Supporting:** Te Puni Kōkiri, Ministry for Pacific Peoples, Carers Alliance, and Tertiary Education Commission
- » **Work to begin:** TBC

Carers can feel left out of discussions about the people they care for and get tired of having to repeat information to different people and services. Involving carers in a person's needs assessment, care planning and delivery is an important part of the care process.

The Ministry of Health is working on improvements in information sharing through the National Health Information Platform (NHIP). These improvements will improve access to information by people, their carers, health and disability providers, and other supporting agencies.

In addition, professionals who work with carers do not always have all the information about the care role, and the other services available to carers. This action involves identifying the key touch points for carers (for example GP visits) and developing resources and support for relevant professionals. It aims to enable professionals to recognise people who are in a caring role and enable them to respond appropriately to their carer related needs.

This action also seeks to connect government services with community providers that have a more direct role in supporting individuals and families.

This work will also align with the Accessibility Action programme that the Ministry of Social Development is leading.

Action 9:

Identifying whānau centred tools and initiatives that provide culturally responsive approaches for Māori carers and their whānau

- » **Lead:** Te Puni Kōkiri and Ministry of Social Development
- » **Supporting:** Ministry of Health, Ministry for Pacific Peoples, and Accident Compensation Corporation
- » **Work to begin:** Year 2 (2020)

This action will look at culturally appropriate ways for carers and their whānau to be supported in their care role and access suitable services and supports across the health, welfare and ACC systems, as well as at a community level.

Action 10:

Improve the quality, accessibility and equity of access to services across New Zealand to enable carers to take a break (including the Flexible Disability Respite Budgets – I Choose)

- » **Lead:** Ministry of Health, District Health Boards, and Accident Compensation Corporation
- » **Supporting:** N/A
- » **Work to begin:** TBC

This action will address the difficulty carers and their friends, family and whānau have in accessing ways to take a break that meets their needs. This means making sure services are affordable, easily available, high quality, generally and culturally appropriate.

Taking a break is important for carers' health and wellbeing, and could help address issues of social isolation and loneliness.

What do you think?

- Overall, what do you think of the actions in this section of the draft Action Plan?
- Would you like anything in this section to be changed or improved?
- Is there anything else that you think might be more important than these actions to help carers access services?

Feel free to take notes and write your thoughts below.

Supporting

Caring for carers – supporting wellbeing and building skills

This section focuses on the supports that government offers to carers. Actions aim to increase the level of support, improve access to information and training, and access to financial supports.

During targeted engagement, carers told us that:

“We live in poverty and I have no hope of bettering our situation.”

“I think the carer’s benefit needs to be reviewed, especially when all other costs have increased.”

“I am constantly tired.”



The prevalence of mental health problems among carers
is 20% higher than among non-carers (OECD).

Action 11:

Helping carers to access relevant information about the care role through improved language, formats, and accessible tools

- » **Lead:** Ministry of Social Development, Ministry of Health, and Carers Alliance
- » **Supporting:** Te Puni Kōkiri, Ministry of Pacific Peoples, Office for Ethnic Communities, Accident Compensation Corporation, Office for Disability Issues, and Office for Seniors
- » **Work to begin:** Year 2-3 (2020 or 2021)

Carers have told us that information can be confusing and difficult to access, or does not address their needs. This action will ensure that information provision is accessible, relevant and simple for carers who are trying to find out more about the care role, and what services they are eligible for. It is important that information is provided in a range of languages and formats, and that the information is culturally appropriate.

This action includes enhancing online care planning tools, including with a Te Ao Māori and Pacific perspective.

Action 12:

Update *A Guide for Carers* to ensure it is relevant for the different carer groups

- » **Lead:** Ministry of Social Development
- » **Supporting:** Ministry of Health, and the Carers Alliance
- » **Work to begin:** Year 1 (2019) This action involves updating the current *A Guide for Carers* to ensure that information is relevant, accurate and up-to-date.

The Guide is a resource for people supporting friends, family, whānau and aiga who need help with everyday living because of a health condition, disability or injury. It includes information on a range of services and supports, including financial and non-financial help, health and wellbeing, taking a break.

To see the current Guide go to:

<https://www.msd.govt.nz/what-we-can-do/community/carers/>

Action 13:

Development of pathways to support young carers and their family and whānau to access the support they need

- » **Lead:** Oranga Tamariki — Ministry for Children, Ministry of Social Development
- » **Supporting:** Ministry of Health, Ministry of Education, and Te Puni Kōkiri
- » **Work to begin:** Year 2 (2020)

This action will help to understand the needs of young carers and identify opportunities to support them and their families, whānau and aiga.

Action 14:

Develop and implement initiatives to preserve and grow social networks, supports and connections for older carers and carers of older people

- » **Lead:** Coalition to End Loneliness, and the Ministry of Social Development
- » **Supporting:** Office for Seniors, Ministry of Health, and Te Puni Kōkiri
- » **Work to begin:** Year 2 (2020)

We heard that social isolation can be a problem and undermine the wellbeing for older carers.

This action will develop and implement initiatives to preserve and grow social networks, supports and connections for older carers and carers for older people. This work aligns with the outcome areas in the Better Later Life Strategy – He Oranga Kaumātua 2019 – 2034.

Action 15:

Responding to the Mental Health and Addiction Inquiry recommendations for families and whānau carers of people requiring mental health and addiction support

- » **Lead:** Ministry of Health
- » **Supporting:** Ministry of Social Development, and Te Puni Kōkiri
- » **Work to begin:** TBC

He Ara Oranga, Report of the Government Inquiry into Mental Health and Addiction has three recommendations for families and whānau carers of people requiring mental health and addiction support:

- guidance on sharing information and partnering with families and whānau
- integration of guidance in workforce training, contracts, standards, guidelines, and accountability arrangements
- review support to families and whānau and propose supports to enhance access, affordability and options.

Action 16:

Funded Family Care policy change

- » **Lead:** Ministry of Health
- » **Supporting:** District Health Boards
- » **Work to begin:** TBC

Funded Family Care (FFC) policies allow eligible disabled people to choose to have their resident family member provide the support services otherwise provided by a state funded care and support worker. The Ministry of Health Disability Support Services and District Health Boards have FFC policies. In September 2018, the Government announced the intention to change FFC to make it fairer for family carers and those being cared for. This included the intention to repeal Part 4A of the New Zealand Public Health and Disability Act 2000. Engagement on FFC included eligibility and pay rates for carers and supports the need for change.



Action 17:

Review policy settings for financial supports for carers

- » **Lead:** Accident Compensation Corporation (ACC), Ministry of Health, and Ministry of Social Development
- » **Supporting:** N/A
- » **Work to begin:** TBC

This action will review policy settings in the medium to long-term, to ensure a coherent set of financial supports for carers. These currently include:

- ACC's attendant care policy including natural supports consideration
- The Ministry of Health's Disability Support Services Individualised Funding
- Supported Living Payment Carer

The objective is for it to be easy for carers to find out about, and to access financial support.

Action 18:

Consider a carer payment to support carer wellbeing

- » **Lead:** Ministry of Social Development
- » **Supporting:** Ministry of Health, and the Carers Alliance
- » **Work to begin:** TBC

While carers are currently able to get payments for caring, these payments are not expressly targeted at improving carer wellbeing. The potential Carer Payment could be similar to Australia's Carer Supplement, which is paid yearly. Carers could choose how to spend it, for example taking a break or buying a gym membership.

What do you think?

- Overall, what do you think of the actions in this section of the draft Action Plan?
- Would you like anything in this section to be changed or improved?
- Is there anything else that you think might be more important than these actions to support carers in their care role?

Feel free to take notes and write your thoughts below.

Balancing

Supporting paid work, study and other opportunities

Actions in this section aim to better support those carers who want to manage paid employment, study, and other commitments with caring. We also recognise that caring is a potential employment pathway and this focus area includes actions intended to support carers to follow this pathway if desired.

During targeted engagement, carers told us that:

“I am struggling to attend work for the required time and using all leave available to attend medical appointments for the person I care for. Having to take leave without pay is also affecting the family.”

“I can’t commit to anything. I never know day to day if she will manage to make it to school. If she does make it, I am on alert to rush and pick her up....”



three years

Carers' careers tend to be
three years shorter than those of non-carers.

Action 19:

Launch the Carers New Zealand CareWise initiative, including work to expand promotion of flexible working arrangements

- » **Lead:** Carers Alliance
- » **Supporting:** Ministry of Social Development, Ministry of Health, and Ministry for Women
- » **Work to begin:** Year 1 (2019)

This action includes reviewing human resource policies and procedures so carers are identified and recognised in workplaces. It will expand on existing work to promote flexible working. We know that many carers want to undertake other activities alongside their caring role, but sometimes their employers or teachers may not understand. Supporting employers to have carer-friendly policies, including communication, skill transition, and promotion of flexible working conditions for carers, will enable carers to manage their care role with employment, education or other training.

Action 20:

Developing carer skills and learning through formal training programmes that credit care experience, and to support further training or employment opportunities

- » **Lead:** Ministry of Social Development and the Carers Alliance
- » **Supporting:** Ministry of Health, and Tertiary Education Commission
- » **Work to begin:** TBC

This action includes exploring how carers can access alternative types of learning and training, including working with Tertiary Education Organisations to develop learning modules (microcredentials).

These modules may be related to specific care skills, but could also seek to formally recognise skills that are broadly relevant to the workplace. This creates an opportunity to improve and future-proof the employability of carers.



What do you think?

- Overall, what do you think of the actions in this section of the draft Action Plan?
- Would you like anything in this section to be changed or improved?
- Is there anything else that you think might be more important than these actions to help carers balance caring with other responsibilities?

Feel free to take notes and write your thoughts below.

Have your say

We would value your feedback on the draft Action Plan.

You can do this by:

- attending a workshop
- completing the online survey
- sending us a written submission.

Closing date for submissions is 16 August 2019.

Attend a workshop

Workshops will also be held around the country in July and August 2019. For information about these please go online to <https://careforcarers.nz/>

If you would like to attend a workshop, please register your interest at this address:
<https://careforcarers.nz/>

Complete the online survey

The online survey will be available at www.msd.govt.nz/carers on 1 July.

Send us your submission

Email us your submission at carers.strategy@msd.govt.nz

You can also post your submission to us at:

Ministry of Social Development
P O Box 1556
Wellington 6140
New Zealand

Submissions close 16 August 2019.



Publishing submissions

We will publish a summary of the submissions we receive on the Ministry of Social Development website. This may include quotes from your submission but will not include information that would identify you personally.

You may also ask for your details to be withheld if your submission is requested under the Official Information Act.

