



A collective voice for New Zealand's 430,000+ family, whānau, and aiga carers

## Briefing for Incoming Ministers November 2020

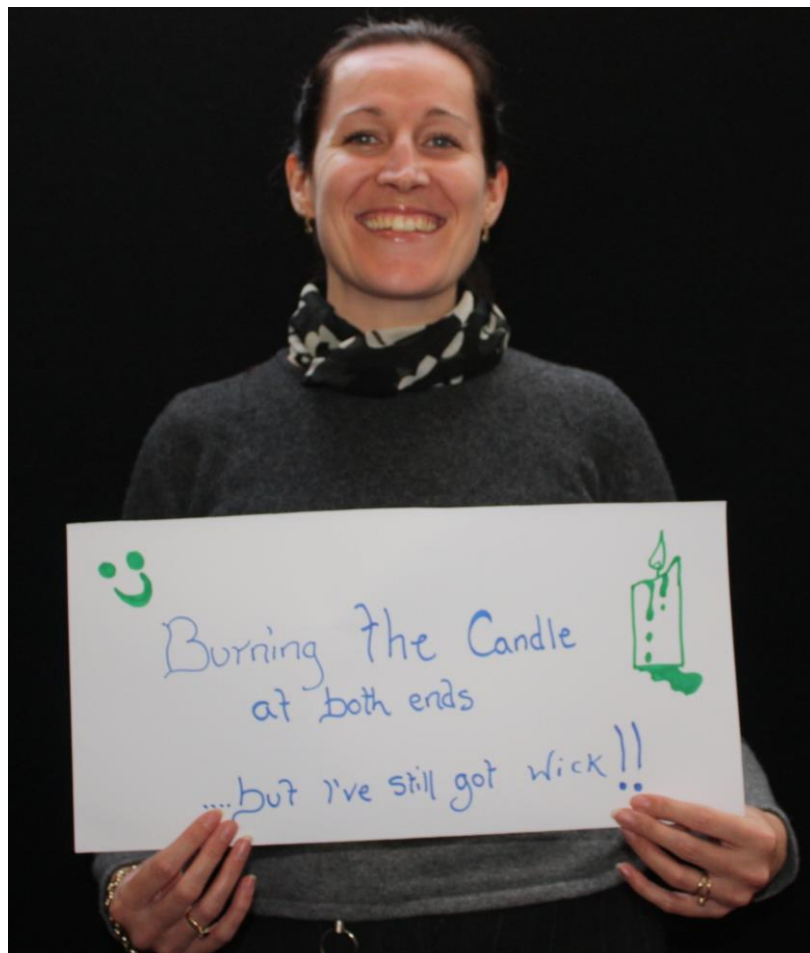
*Valuing the invaluable*



The Prime Minister Jacinda Ardern and then Associate Health Minister Julie Anne Genter, with John and Tim Forman at the August 2019 announcement about long-awaited changes to carer payment policy.

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## Valuing the invaluable: 430,000+ family, whānau, and aiga carers

### Our vision for a New Zealand that respects, values, and supports carers

We believe we need to change the way we recognise and support carers so they can continue to care, while living a fulfilling life beyond their caring role. *Our vision is of a society that respects, values, and supports carers.* We remain committed to working with government in partnership to advance our work of recent years through *Mahi Aroha, the Carers' Strategy* and its Action Plan for 2019-2023. We look forward to meeting with you to discuss the matters raised in this Briefing.



Rotary sponsored flight for international day of support for young carers, 2018. 8% of young New Zealanders aged 15-24 have caring responsibilities. Carers NZ is gathering data to learn more about New Zealand's most invisible carers - the unknown number of under 15s who are carers.

## Family carers: a precious resource

- Census 2018 found more than 430,000 New Zealanders who care for a member of their family, whānau or aiga in their home or in another location – at least 1 in 10 New Zealanders.
- Based on global demographics, we believe the true number to be in excess of 1 million – nearly 1 in 5 of the population – supporting someone who is unwell or has a disability or chronic condition.
- Caring can be for a short time or for a lifetime. We can all expect to give or receive family care during our lives; with advancing age, many will provide care for friends and family members multiple times.
- In 2015, economics agency Infometrics placed a median economic value on carers' unpaid work at \$10.8 billion per annum. This work is currently being updated based on 2018 Census data.
- Almost 90% of carers are working age (15 to 65) but only 63% are able to participate in part- or full-time employment. Of necessity, they are more likely than other New Zealanders to work part-time. Carers earn, on average, 10% less than non-caring New Zealanders.
- Two thirds of carers are women. Over-reliance on the unpaid work of women is unfair and impacts on their wellbeing and life opportunities, including paid work and ability to save for retirement. They are also disadvantaged by outmoded public policy (women caring for spouses, for example, cannot receive the Supported Living Payment).
- 54% of carers have their own disability or chronic condition while caring for at least one other member of their family, whānau, or aiga. 20% care for more than one person.
- 40% are injured in their role; two thirds experience depression or an anxiety disorder, an unaddressed wellbeing risk for this large population of New Zealanders.
- Demographic ageing, growing dependence on home-based care delivery, advancing complexity of support needs, escalating housing and living costs, and increasing reliance on 'natural supports' to shield government budgets have not been met with meaningful support for carers, despite the good intentions of successive Carers' Strategy Action Plans and other government policies and strategies meant to improve outcomes for carers.
- These trends have created inequities for carers in areas such as carer payment, support procurement, emerging flexible funding models, ability to participate in paid work, genuine valuing of women's unpaid work, and respite, to name a few.
- We need New Zealanders to feel able to make the choice to care for those who are unwell, injured, or have an ongoing palliative or chronic condition or disability, but we are not caring well enough for our carers. Outcomes are shallow, slow, and easily sidelined by competing social, health, disability and aged care demands.
- Upcoming health system changes provide an opportunity to improve this – to support carers as a large, unique, and essential population of New Zealanders whose work has profound economic value, and priceless social and family value. But the recent Health and Disability System Review Report barely mentioned carers, who risk being ignored again as this important work of the new government advances.

**This Briefing highlights key issues and current work underway for carers, and areas where we can meaningfully support New Zealand's large and growing carer population in partnership with the Government. It reinforces our commitment to *Mahi Aroha* Carers' Strategy outcomes in priority areas that are important to carers.**

## Priorities for Incoming Ministers

Following are the most urgent priorities for carers

### 1. Ensure that the *Mahi Aroha Carers' Strategy Action Plan 2019-2023* is fully implemented, and enhanced to sustain carers through the pandemic.

We have worked with the Government for more than three years to consult with carers, identify their wishes and priorities, and articulate these in *Mahi Aroha*. We have supported the Government by investing in research about key priorities such as carer payment, respite, flexible funding models, and continence, and shared this research to support aligned actions in *Mahi Aroha*. 11 Ministers with portfolio responsibilities for carers committed to *Mahi Aroha* and its actions. We offer our continued support and investment to work alongside government to respect, value and support carers in the upcoming term of government through our shared work to sustain *Mahi Aroha*. All recommendations in this Briefing fall out of our joint commitment to *Mahi Aroha* and the values that have underpinned our government partnerships for carers since 2007.

### 2. Prepare carers for potential ongoing impacts of the Covid-19 pandemic and future pandemics.

No one could anticipate Covid-19; we all worked together to get through. New Zealand has been fortunate to escape a major outbreak and the ongoing consequences experienced in other countries. This includes having to urgently inform and support large new populations of carers thrown into this role as a consequence of Covid-19; in the United Kingdom, for example, the carer population has doubled since February 2020. *New Zealand's health and disability system is not prepared for a sudden, substantial increase in the carer population*. Responses across the system in the first Covid-19 lockdown (and subsequently) were too slow to help carers adapt to service disruptions and closures, and information for carers was not seen as a priority – they were bombarded with general information that was not targeted for them, creating stress and confusion. Parts of the system, such as DHBs, remain ill equipped to inform and support carers.

#### We recommend that:

- Key government agencies (Health, District Health Boards, Social Development, Education, and ACC) work with Carers NZ and the Alliance to review current pandemic information for carers to refine what is available so this can be quickly shared should Covid-19 resurge in New Zealand.
- Ensure this information is kept current and added to as a readiness response for carers – the country's largest health, disability, and aged care workforce, the last defence for New Zealand's most vulnerable in a wide scale health event like Covid-19.
- Ensure the information is well promoted across family and carer networks, in all age groups and locations, and that a communications plan is jointly developed to cover if/then scenarios.
- Carers are tired and need respite after a difficult pandemic year; a functioning, well-resourced respite system is more important than ever. *See Priority 5 recommendations*, which are urgent as a sustainability response for carers through Covid-19.
- Continue with flexible respite rules for Carer Support in disability and urgently extend these to DHB-funded Carer Support; ensure additional funding is available for allocations to be fully available to carers so they can sustain themselves through Covid-19 and beyond. *See Priority 5 recommendations*.
- Ensure carers are a high priority when the Covid-19 vaccine is available. Carers protect the most vulnerable and are an essential frontline workforce. Investing in their wellbeing with early vaccination is a pragmatic step to offset future outbreaks and sustain carer readiness.
- DHB websites need good, current information for carers so they know how to enter the health and disability system and are aware of who to talk to and how to access supports, including options for payment. Currently *no DHB website* has adequate information for carers - generally, or as a Covid readiness measure. A collective response is needed with urgency.

### 3. Continue to work with Carers NZ and the Alliance in an equal partnership that respects, values and supports carers and the carer movement, building on the foundation of past Action Plans.

The Labour Government of 2008 valued the expertise of the carer movement and demonstrated this by ensuring we jointly ‘held the pen’ when crafting the original Carers’ Strategy and its first Action Plan. Our expertise and contributions of time and access to networks were tangibly recognised through joint work programmes, provision of travel contributions and funding our work to support the Strategy, and robust dialogue that allowed us to push policy boundaries while sometimes agreeing to disagree. Thank you for continuing to work with us in this shared spirit of partnership during the upcoming term of government.

#### We recommend that:

- Carers be seen by government as a large, important, and vulnerable population in their own right – not tagged onto existing populations (older people, disability, mental health, long-term chronic conditions) which results in their interests being marginalised due to other health, disability, mental health, and aged care population pressures. This is a major perspective shift for us and for you.
- A Minister for Family Carers be appointed, as happens in peer nations, to ensure focus on the role and support needs of this large population. The Ministerial role could be added to an existing relevant portfolio to give carers targeted status within government.
- The caring population be embedded as a distinct population in the emerging work of the Health and Disability System Review, with representatives of the carer movement in key panels and consultation networks to ensure the carer perspective is included and valued from the start of this major system change.
- In Health, that this status be tangibly recognised and valued through a direct leadership relationship between the Minister of Health, the Director General of Health, Carers NZ, and the Carers Alliance.
- A senior manager with delegation and decision-making authority be appointed as strategic and operations ‘lead’ for carer matters within Health, Education, ACC, MBIE, and MSD. These agencies cross areas of most impact to carers: respite and support, education, serious injury and injury prevention, employment, income and financial support, wellbeing, and welfare reform. Such roles would demonstrate the intent of government to respect, value and support carers deeply within its agencies, long-term.
- The strong mandate given by voters to this government result in decisive action to ensure the needs assessment process no longer over-relies on ‘natural supports’ across Health and ACC. The biggest step you could take to recognise, value and support carers is to acknowledge their *mahi aroha*, which has grown in scale, duration and complexity with longer lifespans and greater dependence on community-based care at a time when carers in contemporary society must often choose between paid work and family care. Define a new social contract that recognises modern pressures, values the work of women, and does not overburden families who can no longer manage with poor practical and financial supports to save the public purse.
- Our quarterly meetings with the Minister of Social Development that consider progress and action points for *Mahi Aroha* the Carers’ Strategy and Action Plan for 2021-2023 also be attended by the Minister of Health. This will ensure efficiency of engagement with the carer movement and officials of relevant agencies, and support the progress of key *Mahi Aroha* actions. We note that Minister Sepuloni is also the Minister for ACC, which complements alignment of agencies accountable for *Mahi Aroha* actions at these meetings.

#### 4. Ensure emerging flexible funding and carer payment models are fair, transparent, accountable, sustainable, and well promoted, with a straightforward path for independently reviewed decisions/allocations.

##### We recommend that:

- The Ministry of Health consult with Carers NZ, the Carers Alliance, and carers about the transition from FFC to IF during the first Covid-19 lockdown for transparency, learnings to inform future development, and to rebuild good faith lost with the sudden shift from FFC to IF without consultation with the carer movement. We are unclear about Health's intent for paid family care, despite our 15 years of work relating to this issue, and its inclusion in the *Mahi Aroha* Action Plan. MoH has not been accountable enough for this crucial issue to us, to carers and, perhaps, to Ministers; nor have Ministers been accountable enough about payment planning for the hardest working family carers.
- Family carers who act as unpaid coordinators for IF/flexible funding budget holders be eligible for payment – their work underpins the success of IF and current rules preventing payment is discriminatory on the basis of family status, and for the majority of carers who are women.
- Carers NZ and the Carers Alliance be included by MoH in future development of IF and flexible funding practices, information development, and planning.
- Carers NZ and the Carers Alliance be included in the development work of emerging funding models such as Mana Whaikaha and Flexible Disability Support, or their variants, providing cohesion of this work with the strategic aims of *Mahi Aroha*. Currently the carer movement has 'afterthought' involvement in this work – the carer movement should have similar leadership status to DPOs.
- The evolving and apparently growing importance of IF and its evolution as a funding mechanism for personal budgets be supported with independent information developed in partnership with sector leaders that allows people to understand service charges, government contributions, and how to make host choices as a healthy outcome of IF market development. Availability of such information has not kept pace with decision-making and implementations that affect carers, and is of variable quality/detail among hosts, resulting in low transparency for consumers.
- This information be widely promoted and easily found/available, and kept up to date as an MoH leadership responsibility.
- Newer host services receive innovation investment to offset the unintended consequence of the IF market's continued domination by a large state-facilitated incumbent, broadening and enriching host offerings, levelling the playing field, and giving people good information to support flexibility, choice, and control in this growing service area. If the government makes new markets, such as flexible funding and carer payment within the IF host model, it must own its responsibility for sound policy judgment, transparent procurement, and consumer protections.
- Appoint a representative of Carers NZ to a new panel that adjudicates allocations of carer payments. People should be able to challenge allocation decisions in a fair, transparent, accountable process that is nationally consistent for similar needs. We understand this mechanism no longer exists for FFC and it should be urgently reinstated. The current vacuum places an inappropriate and unfair burden on NASCs to adjudicate decisions amongst themselves, resulting in a lottery effect over supports for New Zealand's most vulnerable households.
- This independent process is also required for needs assessment allocations – NASC allocation peer reviews within its own provider network are, we find, not always fair to families with similar support needs. This was reinforced during Covid-19 lockdowns. If the system works better for everyone, it will be more efficient, cost less, enliven cross-sector collaboration, and give every chance of fairest outcomes for those in most need.

## 5. Ensure that New Zealand's respite system is functional and sustainably resourced to support carer wellbeing.

### We recommend that:

- Recommendations in our Synergia report *Respite in New Zealand: We Must Do Better* be advanced to help carers get the breaks they need. There has been little discussion with government about this report or its important recommendations since we shared it many months ago.
- Flexible rules currently in place for Carer Support in disability continue ongoing, with appropriate resourcing so all carers can utilise their full allocation.
- This flexibility be implemented across the system encompassing DHB-funded Carer Support for older people, mental health, long-term chronic conditions etc. Covid-19 flexibility for the disability community has not been available to carers funded via their DHB, creating an unfair (unintended) disparity for carers unable to use Carer Support allocations during the pandemic. The disparity should be resolved with urgency.
- New Zealand's fractured respite system be continuously improved and better resourced, as discussed with Minister Sepuloni at Ministerial meetings for *Mahi Aroha* and as highlighted in our report.
- An outcome of *Mahi Aroha* be a quality, sustainable respite system across all caring populations, one that offers true choice and flexibility, nationwide availability, meets diverse needs, and is accessible within available funding without the need for top-ups (which not everyone can afford, creating equity barriers for the most vulnerable carers).
- The Dementia Strategy and all its recommendations including those calling for respite improvements be fully implemented. Carers of people with dementia are one of the fastest growing carer populations in New Zealand and access to respite is an important way to sustain them.

## 6. Ensure that New Zealand's continence support and products system be fair, transparent, and accountable across the country, with access to diagnosis, treatment, learning, and support for all ages.

### We recommend that:

- Government consider the wide-ranging continence support recommendations in our report, *Understanding Continence in New Zealand*.
- Government ensure that Health and Disability System changes sustain diagnostic expertise, treatments, and population access to suitable products for the growing number of New Zealanders who have bowel and/or bladder continence needs; this support also sustains carers, reducing stress and relationship impacts due to managing continence at home and preventing formal care entry.
- Ensure that Continence NZ's free helpline and DHB continence diagnostic, treatment, and support services be resourced to meet rising community demand for these services in our ageing population.
- Invest in research to understand the costs and environmental impacts of continence product disposal in the community; health and safety risks for disposal service staff who handle waste products; and the environmental impacts of cleaning reusable products at home for a rising user population.
- Develop learning and advisory tools to help New Zealanders understand the costs and environmental impacts of continence management at home, so they can help to minimise the impacts.
- Contracted suppliers of bulk continence products be required to contribute to public learning about continence decision-making and environmental impacts through a 'Kiwi share' arrangement – if you win a supply contract above X value, X \$ will be applied to support the Continence Helpline, public education and information resources, and environment protection/awareness programmes, through a partnership between government, suppliers, and NGOs supporting disabled people, older people, and carers. Such support is poorly funded by current suppliers of lucrative government continence contracts; they have public good obligations that should be embedded into procurement processes.



Our Briefing reinforces our commitment to work with you and the wider incoming Government to recognise, support, and value family carers. We look forward to advancing our mahi aroha with you on behalf of carers. The work we do together builds on 25 years of collective effort by carers, the carer movement, supporting organisations, government, mentors and friends. Thank you for listening to carers, and for working with us to make life better for 430,000+ New Zealanders.

*NZ carer movement mentor Helen Kelly, NZCTU, Carers Alliance We Care Campaign, 2012*



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## APPENDIX 1

### Carers NZ and the Carers Alliance

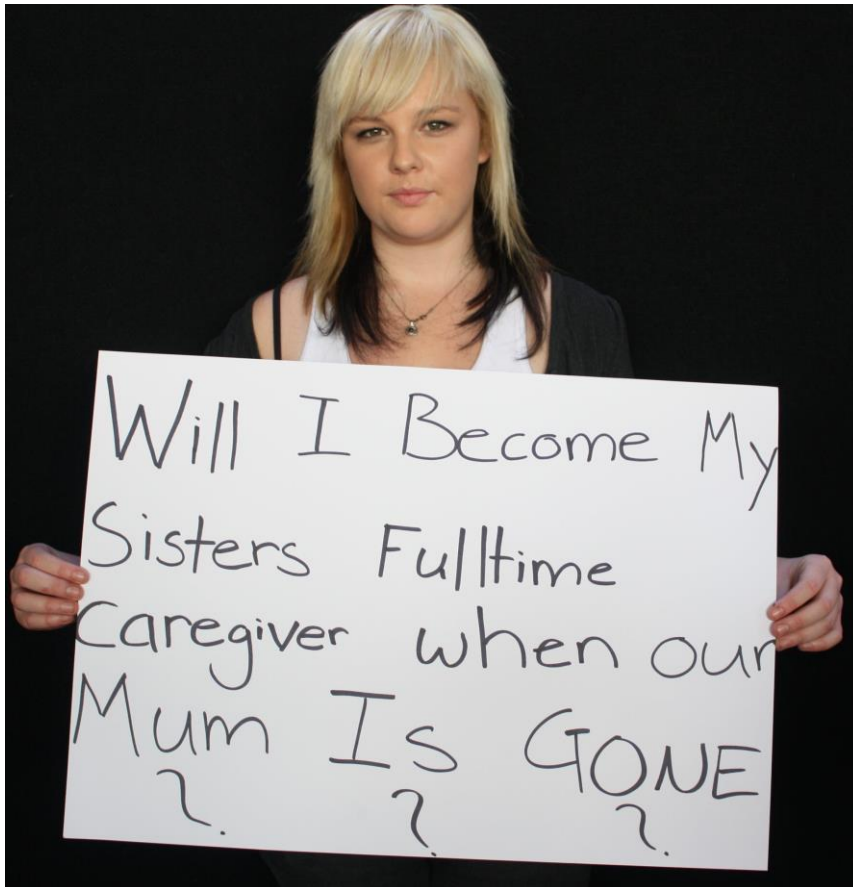
Carers NZ was created by and for carers in the mid-1990s and is today a national charitable Trust supporting a network of more than 50,000 carers and community organisations. Its national Resource Centre, based in Auckland, provides free information, advice and support to carers via its 0800 helpline, website, and social media community of 15,000 Friends. It acts as the legal umbrella for an emerging young carers network and is the ongoing Secretariat for the Carers Alliance of 47 national not for profits. Carers NZ is also New Zealand's representative on the International Association of Carer Organizations, a global carer peak body network which shares expertise and policy innovation, supports emerging carer peak bodies, and advocates for carer interests with the World Health Organization, the United Nations, and other international leadership entities.

The Carers Alliance was established in 2004 with a call at its first meeting to the then Labour-led government for a Carers' Strategy for Aotearoa. The original Carers' Strategy and its first five year Action Plan were launched in 2008. Alliance members' interests cross specific diseases and conditions, mental health, support for older people, young carers, Maori whānau carers, Pacific aiga carers, and others whose interests encompass the wellbeing of carers. Carers Alliance participants have in common a wish to improve policy and meaningful supports for carers as a key population within their memberships.

Since 2007 Carers NZ and the Carers Alliance have worked in partnership with successive governments to progress key issues for carers and ensure these are included in Carers' Strategy Action Plans. The most recent *Mahi Aroha Carers' Strategy Action Plan* was launched in December 2019. We work closely with the Strategy's cross government Governance and Working Groups to monitor the Plan's implementation and outcomes. These include actions critical to carers, such as fair respite and payment systems, and support to keep working and earning.

### Carers Alliance Organisations

Age Concern | Allergy NZ | Alzheimers NZ | Anxiety NZ Trust | Arthritis NZ | Associated NZ ME Society (ANZMES) | Autism NZ | Balance NZ | Blind Low Vision NZ | Cancer Society NZ | Carers NZ | CCS Disability | Cerebral Palsy Society of NZ Inc | Complex Care Group | Continence NZ | Cystic Fibrosis NZ | Dementia NZ | Diabetes NZ | Epilepsy | Fragile X NZ | Grandparents Raising Grandchildren | Head Injury Society | HeartKids | Hospice NZ | IHC New Zealand | Kidney Kids of NZ | Lysosomal Diseases NZ | Motor Neurone Disease Association NZ | Multiple Sclerosis NZ | Muscular Dystrophy Association | NZ Down Syndrome Association | NZ Federation of Disability Information Centres | NZ Foundation for Conductive Education | NZ Spinal Trust | Parent To Parent | Parents of Vision Impaired | Parkinsons NZ | Rare Disorders NZ | Rescare NZ | Retina NZ | Stroke Foundation | Student Volunteer Army | Supporting Families In Mental Illness | The Angelman Network | TOA Pacific | Vaka Tautua | Whānau Workshops/SAMS | Young Carers NZ



**Carers NZ and the Carers Alliance work to support and advocate for the interests of the 430,000+ people in New Zealand who provide mostly unpaid support for ill, older, or disabled family members or friends.**

**We will continue to fight for increased recognition and support for all carers, and to ensure they have a voice.**

**Our mission is to make life better for carers by delivering lasting change.**

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