



**Caring for New Zealand Carers
He Atawhai I te Hunga Ngakau Oha o Aotearoa**

Your Life, Your Work, Your Say

A discussion document with recommendations for
the Government's five year Action Plan

Submitted by Carers NZ and the NZ Carers Alliance

September 2007

Background Information

Carers NZ was established informally by carers in 1993 and became a national charitable trust in 1998.

Today the Trust, which is governed by a Board of Trustees, has a stakeholder network of more than 14,000 individual carers, organisations, and supporters.

It acts as New Zealand's peak body for family carers, operating as a 'network of networks' partnering with, and freely providing information to, other organisations which support carers.

Carers NZ is funded through information and advice contracts with the Ministry of Health, whose early support was pivotal to developing the diverse stakeholder network that now exists in New Zealand. We acknowledge its leadership.

This network now awaits the ongoing strategic 'across government' to ensure enduring outcomes for New Zealand's family.

Practical Partnerships

Carers NZ has close ties to carer peak bodies in Australia, the United Kingdom, Canada, and the United States.

Increasingly the international peak bodies for carers are working collaboratively to share resources and expertise for the benefit of carers in their own countries.

These relationships have been of enormous benefit to New Zealand in recent years, allowing Carers NZ to swiftly and affordably adapt carer initiatives that have worked well elsewhere.

An example is the New Zealand Carers Alliance, formed by Carers NZ in November 2004 to create a collaborative framework for non-government organisations to achieve a unified non-profit voice for family, whanau, and aiga carers.

The Carers Alliance was developed on the advice of Carers UK, which shared the Terms of Reference for its own Alliance, and has given ongoing guidance to the New Zealand coalition.

Carers NZ is the Secretariat for the NZ Carers Alliance, which now has over 40 national NGO participants, and an elected chair and executive committee.

All Carers Alliance participants are national NGOs for whom supporting carers is a primary activity.

The Alliance's interests are broad and strategic; Carers NZ is its over-arching legal entity and the generic expert body for carers across society, undertaking the deep building work needed to achieve the strategic aims of the Carers Alliance.

Further NGO sector unity will be achieved in 2008 with the formation of the NZ Coalition of Regional Carer Networks.

Some of these networks have been catalysed by carers themselves; others are being developed by professional and community groups. Service providers such as Guardian Healthcare Group and Presbyterian Support are also establishing carer support groups as a way to build stronger partnerships with families, with whom relationships often begin through services such as respite and Carer Support.

Currently regional support networks for carers exist in isolation, and many new networks are emerging to deliver information, advice, and 'on the ground' support to carers in rural/regional New Zealand.

There is a wish by these networks to have representation in the NZ Carers Alliance and to participate in a collaborative framework for learning and sharing purposes. Regional groups affiliated to national Alliance NGOs are represented by their national body, though the new coalition provides opportunities for any regional group to meet with others for information, learning and sharing purposes.

As with the Carers Alliance, Carers NZ will establish and act as ongoing Secretariat for the new regional coalition, which will meet twice per annum. The Carers Alliance may in the future include a voted representative from the regional coalition in its national structure; this will be decided by the Alliance executive.

Specific communities of carers are developing their own national networks, which in some cases currently reside within Carers NZ's legal umbrella. Others are evolving legal and funding structures of their own to support carers within their areas of interest.

The partnerships add richness to New Zealand's fast-developing carer movement and provide opportunities to deliver support to Maori (the Aotearoa Maori Whanau Carer Network), Pacific aiga carers (an emerging national 'network of networks'), and via the Complex Carers Group (supporting parents of children and young people with high and complex needs), Young Carers NZ (which has a national policy, awareness raising and information focus for young carers), and the new Lesbian and Gay Carer Support Network (established at the Carers' Summit in April 2007).

Carers NZ is also working with appropriate NGOs to better support carers who are immigrants and refugees, one of the last remaining communities of interest for which strategic help for carers has yet to manifest in New Zealand. It may be that a number of NGOs supporting immigrant and refugee populations build a coalition to support carers from those communities during the Carers' Strategy Action Plan timeframe. We will foster such relationships to ensure this can happen.

Strategic Partnerships with Others

More broadly, Carers NZ has developed working alliances with professional and government organisations which commonly interact with family carers (examples include the NZ Continence Association, St John, ACC, Public Trust, Open Polytechnic, District Health Boards, several PHOs, and Work & Income).

Various government consultations have found that information, advice, and support for family carers is splintered among many sources across society, and government.

Work to overcome this concern has been underway for a number of years.

The Carers' Strategy Action Plan provides an opportunity to accelerate the free availability of credible, consistent information all carers need, regardless of their age, culture, geographic location, or the condition/needs of the person(s) they support.

This document presents suggestions to achieve a unified, efficient multi-stakeholder framework through which every New Zealand carer can receive this support. Our proposed 'create once, share many times' model builds on partnerships with regional, national, and other carer support networks that have evolved in the last three years.

Recommendations in this document relate to generic information and supports for carers. They sit outside of specific areas of help (support for those caring for someone with cancer, for

example, or areas where families need specialist support e.g. autism, Parkinson's, cystic fibrosis etc), which are the focus of NGOs dedicated to these areas. Equally, this submission does not address the specific needs of Maori or Pacific carers; these are being addressed by the new national bodies supporting those carers.

Foundations for Progress

Because New Zealand is a small nation, there is an opportunity to achieve speedy progress for general supports for carers in priority areas for the Carers' Strategy Action Plan.

Carers NZ and the Carers Alliance have considered how existing relationships and resources might be built upon to deliver sound outcomes for family carers, with development, ownership, delivery, maintenance and funding of initiatives shared where possible by multi-stakeholders including NGOs, government, industry and professional associations, existing services and (where appropriate) the private sector.

While some areas of the Action Plan must reside within government (e.g. development and funding of an effective respite system for families, modifying benefits and eligibility criteria in areas where this might be needed, reducing paperwork to ease carer burdens, and consideration of a fair way to financially recognise carers), others can be achieved through the "shared ownership and outcomes" framework proposed in this document.

Part of the success factor in implementing the Carer Strategy will be to apply carer specific knowledge, expertise and empathy (akin to mental health, youth justice etc) before any contracting is initiated from the Action Plan. This can be achieved through an agreed process, i.e.

- Government officials accepting the need for and seeking carer insight when designing key service contracts;
- Carers NZ being consulted as the peak or expert body for carer issues, as happens in Australia and the United Kingdom; and being recognised and respected financially for providing advice when this is needed by the wide range of agencies who use its knowledge as New Zealand's sole NGO to focus on the generic role/needs of family carers; and bringing together as needed the broad experience and advice of Alliance organisations, regional groups etc.
- Accepting that additional training will be required for some agencies taking on roles for general population initiatives designed to support carers and their families.

Dovetailing with Existing Work

The Carers' Strategy is being introduced at a time of intense development activity within Carers NZ, the Carers Alliance, and the overall health sector.

Many initiatives and partnerships are already in place, particularly in the areas of information, young carers, caring and employment, carer learning, and recognition for carers/valuing the caring role.

The Carers Alliance, for example, intends to follow the lead of other countries to promote carer awareness, in partnership with Carers NZ, during a Family Care Celebration week. Participating Alliance NGOs can be involved in various ways. The first Celebration week is planned for 2008, appropriately coinciding with an historic year for New Zealand carers (the introduction of the Carers' Strategy and its Action Plan). Its role will increasingly focus on broad social and strategic messages to government, services, and society about caring.

At an operating level, Carers NZ is today an important “hub” for NGOs, community groups, government, service providers, and individual families in the area of carer information, and collaborative initiatives which reduce silo activity. Underpinning these partnerships is a shared goal to make it easier for carers to find help at different stages of their journey.

It is a strategic imperative for both Carers NZ and the Carers Alliance that public-NGO unity be achieved for carers during the Action Plan timeframe.

This model has been successfully piloted with MSD during the Carers’ Strategy consultation period, and should be continued and built upon to ensure enduring, efficient, strategic outcomes for carers

Development of the Action Plan should not happen in isolation of work that is already in progress.

Rather, there is an opportunity for the Government to more actively partner with, and fairly contribute to, these outcomes for carers.

Acknowledgement

New Zealand is relying on its family carers as never before, and for families to meet this challenge, those in caring situations must be supported, recognised, and protected from the sometimes adverse consequences of having to care too much.

We believe the Carers’ Strategy will deliver measurable improvements for families with caring responsibilities from 2008 to 2013, and acknowledge the Government for proactively caring for its carers.

Carers NZ and the Carers Alliance offer our expertise, global partnerships, and the strength of our network to ensure this happens.

Carer Strategy Submission

1. Collaborative Partnership
1. Agreement with the Government
2. Operational Carer Hub in Wellington
3. Having a Break/Respite
4. Information & Distribution
5. Carer Wellness
6. Employment & Caring
7. Carer Learning
8. Training for Professionals
9. Emergency Planning
10. Migration to Long-Term Care
11. Financial Support for Carers
12. Young Carers

Carers' Strategy Discussion/Recommendations

Ongoing NGO/Government Collaboration

We seek a formal ongoing partnership between Carers NZ/Carers Alliance and the Government (MSD) for the five year Action Plan period to develop;

Policy relating to family carers;

Accountable service specifications for providers of key supports to family carers;

Monitoring and reporting of outcomes from the Action Plan.

Operational Centre or "Feeder" Hub

Principles

There should be multiple gateways for generic carer information, advice, and support (no wrong door).

There should be less replication of information and similar services for carers across government (create once, share freely many times).

In a small nation there is a need for generic carer expertise on one hand (at least one Centre or 'hub'), and on the other to make best use of existing community support gateways for carers (Disability Information Centres, Citizens Advice Bureaux, Heartland Centres, chemists, medical practices, hospitals, churches, carer support groups etc).

A 'feeder' hub based in Wellington will ensure that support gateways, NGOs, help agencies, health services, and individual carers do not have to treasure hunt for information, advice, and support. The hub will bring the Alliance, regional/rural groups, relevant government and other stakeholders together so they can efficiently develop, sign off, distribute and update key resources of value to all carers. It would also be a training hub for services and organisations which interact with carers, seeding expertise and knowledge about carers and their role deeply into communities across the country. Currently this capacity does not exist.

A hub approach will deliver to all stakeholders, especially carers, information and support that is accurate, consistent, credible, of general interest to all carers, and freely available to anyone that wants it, in formats of their choice (print, web, face to face).

There needs to be constant upskilling/awareness raising of general carer needs to all stakeholders involved in supporting family/whanau carers. Today's splintered, siloed support system fails carers, but could be quickly improved with this 'hub and spoke' approach.

In a small nation, it would be wasteful to establish multiple regional Carer Information Centres like those found in Britain and Australia. The proposed approach is, in the first instance, economic, strategic, and adds to rather than competes with any existing gateway through which family carers might choose to receive centrally developed information, advice and support.

The approach also supports the capacity of the carer movement, ensuring this is available at a central level for policy development, consultation (e.g. a viable Carers Alliance, liaison with diverse networks and the regional coalition etc).

The hub would become the central point through which carer information and other national initiatives could be developed and distributed via a diffuse web of stakeholders (government, NGOs, professions/industry, private sector).

The hub would share information, advice and support with, and refer carers and other stakeholders to, developing networks (Maori, Pacific, young carers, Complex Carers Group, lesbian and gay support network etc).

In time it could provide a platform to coordinate and improve telephone and 0800 advice for carers, perhaps in partnership with existing services such as Healthline.

In the first instance, simply collating existing 0800 services (health, NGO and general) would be helpful for carers seeking specific support, without having to treasure hunt for this information. This could be an early Action Plan outcome, with a one page, attractive, graphical resource disseminated widely by the hub and its stakeholders. It could be freely available in PDF and Word formats at NGO websites (create once, share many times), at the national carer information channel (www.carers.net.nz), and perhaps at the front of every telephone book. For the latter, Carers NZ and the Carers Alliance could approach the publisher and make a case that printing this information (supplied and updated by the hub) is a valuable free public service. It is an example of how multi-stakeholder collaboration (public, NGO, private) can deliver nationally strategic outcomes, and consistent carer information, at low cost.

Later in the Action Plan period, an evaluation could be undertaken to determine whether the 'one stop' 0800 guide has met the referral needs of most carers, or whether a dedicated 0800 carer line is warranted. The value of such lines has relied in other countries on the knowledge and experience of the national peak body for carers. Should such a service proceed in New Zealand, liaison with Carers Australia and Carers UK would be useful to identify development priorities, service options if a generic provider is used, etc.

In the meantime, existing 0800 services should receive formal learning about family carers and what types of support and information are available, so they can refer carer callers to these sources of help (create once, refer many times). They can refer complex carer inquiries to the hub for referral/resolution if needed. Carers NZ and other Alliance NGOs field many such calls every week.

Breaks/Respite

Principles

Family carers often have intensive support roles which prevent them from fully participating in family and social life and/or the paid workforce. Without regular breaks (respite) they are vulnerable to their own physical and mental problems, are unable to earn to support their families, are at risk of abusing the person they support, and can become isolated from friends, family, and their community.

Carers can have breaks in many ways but their options are not always clear. The national shortage of care workers (relievers) means that even if carers are eligible for considerable state support, it is not always possible to have breaks because trained relief care is unavailable.

Family carers, as New Zealand's biggest health workforce, are one of the country's most important sources of care worker 'on the job' training. The turnover of care workers is high, and family carers can find themselves repetitively training a series of respite workers, which adds to feelings of stress.

While the Government cannot magically overcome the shortage of paid workers – a problem for other nations too -- there is much it can do in the Carers' Strategy Action Plan to ensure that carers:

(a) are aware at an early stage of respite options including day programs, school holiday programs, after school care options etc ('here are all the ways you can have a break'),

(b) know how to find and access these (with state funding, or by paying privately),

(c) understand the mental and physical health risks of not having regular breaks, especially from intensive caring situations,

(d) how to find care workers in their area and self-navigate to find solutions, and

(e) what to do if there is an emergency.

(f) Often carers cannot afford to have breaks away from the family home during respite periods (overnight, weekends etc). Ensuring that carers know about affordable places to have a break (on their own or with their family member(s)) is another way to help even those on low incomes have a holiday.

A respite system for New Zealand

In its Action Plan, the Government could develop an efficient national/regional respite system that allows carers to easily learn about ways they can have a break; who does what; how they access relief care; and who pays.

The system would be developed by scanning current options (public and private for all ages) and developing information resources that are widely shared (create once, share/refer many times). It would look at how some DHBs, for example, are developing regional respite systems.

Gaps would be identified (skills and facilities, especially for families with high/complex long-term needs, younger people, and those living in rural areas).

The respite system would seek detailed input (focus groups etc) from carers about how respite could work better for them.

Later in the Action Plan period could there be a national respite booking system that puts the onus of finding respite on professionals/services, so carers don't have to expend energy on this tiring task, and/or make available an online booking system like wotif.com that allows families to self-navigate what out-of-home respite options are available for the date(s) they want to take a break. Australia does this via a dedicated 0800 service.

Fund more beds/facilities and dedicated respite for all ages. Address respite gaps in rural areas. Build teams of emergency relief carers where there is high need.

There is a clear shortage of respite beds/facilities in New Zealand, especially for younger people. The Carers' Strategy Action Plan could fund extra capacity in a staged process over the five year timeframe.

Beds should not simply be funded in isolation.

There is also a need for an over-arching quality framework for respite services, and independent monitoring and comparisons about services. This information should be transparently available to the community so families can feel they have choice in service provision, access to services of the highest quality, etc. Currently respite is offered on a 'take it or leave it' basis, with poor choice

for families. Given the importance of respite for families, and growing reliance on community/family care, this is unfair.

Emergency Respite

Teams of highly trained relief workers could be available to at-risk families to deliver in-home respite. Existing agencies or organisations like St John could be funded to have such teams in place to respond to emergencies; deliver short-term, quality, in-home respite for people with very high needs so their carers can have a break (for a few hours or a few days); or recover from their own or another family health emergency.

Demystify Carer Support and respite. Ensure national consistency and fairness. Give families more choice about who can be paid to provide this support.

Remove the confusing description of respite or support 'days' and replace it with language carers can easily understand (X hours at X per hour and you can decide how to use it).

Allocation of respite and Carer Support is not nationally consistent; families with the same needs receive different allocations in different parts of the country. Standardise allocations so the system is fair for all New Zealanders. Make decision-making about who gets what more transparent.

Funding for Carer Support and respite

The existing Carer Support rate is not keeping pace with daily charges of facilities, or workers' hourly rates. Families are having to pay top ups and often can't afford to do this, so are not getting sufficient respite. This trend threatens the sustainability of family/community care.

Relax Carer Support criteria

There is a strong wish to allow Carer Support and respite payments to be made to family/whanau/aiga members. Given the national shortage of trained care workers, family members must often step in anyway; their work, unpaid leave from paid employment etc, is not being fairly recognised at the moment. A review of who can receive payments is urgently needed. Its basis should not be the few who might abuse the system, but fairness and what is right for the greatest number of carers and their families. This is a fundamental support for all carers, so bottlenecks and disparities cause widespread tension.

Paid work is a break for many carers

Currently family carers are not allowed to use Carer Support to pay for alternative care so they can participate in paid employment, as this is not regarded as a 'break'. Is it the Government's role to police how carers decide to use respite funding? For many carers, workforce participation is a vital way to have a break, providing opportunities for personal fulfilment, development of new skills, interaction with colleagues and society, and earning resources to support their family. Giving carers, who often feel constrained by their role, the freedom to decide how to use their respite/Carer Support funding is a pragmatic and useful way to support families, and carers' own health and wellbeing.

In-Home Versus Out of Home Respite

Every family is unique and should be free to decide what option(s) work best for them. High quality, reliable, nationally consistent and age-appropriate options should be available within a systemic respite framework to give families flexibility and choice about where and how to use respite.

Taxation

The Government needs to clarify or disseminate information about the tax status of Carer Support payments. It is a grey area for carers.

In Development

A Respite Locator is in development for print and web dissemination so carers can self-identify options in their area.

A directory of low cost respite/holiday options for carers and/or their families is in development so carers know where to go and who to contact to arrange a break.

Carer Information and Distribution

Principles

Carers need nationally consistent, accurate, credible information about common issues, developed from their perspective, and they need to know how to access different kinds of support at different stages of their caring journey.

Carers like to receive information and support from many sources, in different formats, at different times of the day. Not all carers like to receive information through personal visits (by a professional, for example) or to attend support groups. Some don't have Internet access.

There should be no wrong door or way for carers to find the same quality, consistent information about generic issues and available supports. (Create once, freely share many times, in choice of formats.)

Existing sources of general carer information include the MoH funded resource www.carers.net.nz, *Family Care NZ* magazine, Emergency Care Planning Tools, information sheets about common carer topics, an advisory booklet about subsidies and benefits of interest to carers (produced with Work & Income), and other resources in development with partners such as the NZ Continence Association. These resources have all been created once and are freely available across the NGO and professional sectors, and via Alliance NGOs, regional carer groups, etc.

Develop, Own, Share, Disseminate ... and Update

Build on information resources and support, expand and promote existing national resources.

Ensure that key government agencies such as Work & Income, Health, ACC, Child Youth and Family, Justice, Labour, Education, SPARC, Transport, Housing etc participate in and contribute to information channels for carers. In some cases these agencies are also information distribution gateways (Heartland Centres, for example); how can they be strategically involved to disseminate carer information?

The suggested hub model provides a platform for Carers NZ, Alliance NGOs, professional bodies, government agencies, and other interested stakeholders to share ownership, development and dissemination of generic carer information.

This approach will reduce silo activity and ensure that carers receive authoritative basic information that is freely available through many gateways across the country.

Carer Wellness

Principles

All of the Carers' Strategy themes support carer wellness. Availability of trained workers, respite, information, financial supports etc all contribute to a carer's ability to maintain their physical and mental health, and continue safely in their caring role. Improvements in these areas within the Action Plan will support overall carer wellness, help to preserve family relationships, and reduce stress.

A survey undertaken by Carers NZ last year found that of 123 carer respondents, over 90% said depression was an issue for them. Many of these carers take prescription medication to cope with their depression; others use exercise, medication, and natural therapies/remedies to restore or maintain their mental health.

The Carers' Strategy Priorities Survey 2007 also found that carers' own wellbeing was a vital priority for many carers.

Carers have made suggestions at consultation meetings and in the survey about ways the Action Plan could support carer wellness.

Free Counselling for Carers

There are multiple providers of free or low cost or government subsidised counselling in New Zealand. None of these specifically focus on the concerns of family carers. It is difficult for carers to know who provides counselling services and what they cost.

Knowing where to go for help, and that many other carers have these issues too, is an important way to support carer wellness.

We believe that carers should have access, on an assessed basis, to government-supported counselling. This has worked well in Australia, where a free carer counselling program has been in place since 2003. Counselling is delivered by qualified professionals in person, by phone, or via the Internet.

Carers who meet the assessment criteria (they are typically long-term carers of someone with higher needs) receive six to 10 free counselling sessions. Those with ongoing counselling needs may receive extra free help. All providers of carer counselling undergo training from Carers Australia or the state association so there is national consistency regarding the aims of the program, and so counsellors understand common carer issues. This program is available for free adaptation for New Zealand. An evaluation of the program is also available for review by New Zealand officials.

Stocktake What counselling programs currently exist in New Zealand (via Work & Income, Justice, Relationship Services, etc); eligibility criteria; cost. Promote this information widely.

Carer Perspective Overlay Train existing counselling services to meet the concerns/needs of family carers and ensure national consistency across services.

Gaps If these are significant and carers do not have easy, fair access to free counselling, the Government could fund a pilot program for higher needs carers and at-risk communities such as young carers. This could be reviewed/evaluated during the Action Plan period with recommendations for future action(s). Draw on Australia's proven and successful program.

Public education about carer wellness. Carers often neglect their own health, so ensuring that public health educators target carers as a large at-risk group for breast and cervical screening, prostate cancer awareness, depression etc would be beneficial. Encourage PHOs, medical

practices, and carer support networks to host carer wellness events where basic checks can happen (this was very popular at our Carers' Summit and would take little coordination at a community level).

Self-navigate information for respite/holiday options. Support groups directory. Other self-navigate information. Carers' ability to quickly find simple information about inexpensive holiday/respite accommodation and where to find different kinds of help supports their physical and mental wellness.

Accessing services and supports, assistance with emergency care planning, and planning for long-term care when this is needed. Fewer forms and over-frequent assessments. Perhaps a certificate of entitlement for people with ongoing health/disability needs which can be created once and used many times (for mobility parking permit, Disability Allowance, other entitlements), and updated every three to five years rather than annually. Helping carers to understand that if they are no longer coping or abusing their family member, it is time to look at formal care, and how to recognise the signs.

Discretionary payment or funds would allow carers to self-choose how to maintain wellness, particularly those with long-term and/or high caring commitments. Often carers use massage, swimming, gym visits etc as stress relievers and find this brief, low cost approach to 'time out' sustains them, even if longer term problems (lack of trained workers, for example) cannot be easily resolved. Analyse such funds in Australia to determine whether they could usefully be trialled in New Zealand.

Employment and Caring

Principles

A majority of New Zealand carers are of workforce age (15 to 64).

Often carers must retire early, work part-time, change jobs or professions, or make a decision not to participate in paid employment if they have substantial support commitments for a family member.

Some carers are unable to participate in the workforce for many years, losing skills and confidence, and wondering how to re-enter paid employment when their caring time has ended. Others may need to retrain to find work that better complements their caring situation.

Typically carers are able to juggle their paid work with caring, but may not be aware of important sources of information and support. Early knowledge can help carers to quickly access help when it's needed, without compromising their paid employment.

Young carers are at risk if caring has disrupted their education and/or early employment opportunities. They may need extra help to build confidence, identify work options, and access programs to help them gain employment skills.

Employers for Carers and ACE (Action for Carers in Employment), United Kingdom

Over the past year Carers NZ has met with employer groups, unions, and relevant government agencies to build support for a multi-stakeholder adaptation of the UK's successful employment information programs.

Carers UK and the leaders of the ACE initiative are supporting this work.

In addition, Carers NZ has agreed to work closely with Carers Australia to (a) use the UK programs as best practice examples of directions for our countries or (b) adapt the information programs for transtasman use.

The programs bring together government, employer, NGO and private sector sponsor stakeholders to deliver helpful information to working carers, and also to employers who want to better support carers in their workplaces.

Carers NZ intends to support Carers Australia's plan to host a major employer/government Summit in Australia next year, and to promote the event here. Together we may bring a global human relations expert employed by BT to New Zealand and Australia to talk about caring and employment, and the importance of multi-stakeholder support for carers in this area. This will raise public and employer awareness about issues for working carers, and highlight ways everyone can manage better.

A transtasman partnership between industry organisations, unions, government, Carers NZ, and Carers Australia may be useful. UK leaders in this area are also keen to help.

Workplace based support for carers

Giving working carers the opportunity to learn about important supports such as needs assessment, home modifications and equipment, respite and Carer Support, continence services, what to do in care emergencies etc ... can help them to prepare for situations that might otherwise disrupt their employment. Trialling get-togethers for carers in larger workplaces, and developing an information section of *Family Care NZ* devoted to employment issues for carers, are ways to support working carers. Meeting colleagues who are carers may also achieve peer support in the workplace.

Innovative public policy

Explore legislation and initiatives that work well in other countries. What would work well here?

Work with Business NZ, human resource managers, unions, groups of carers to identify workplace options for supporting carers, leave flexibility or sharing etc.

Collate employment and education information re assistance available for carers who want to work or study. Make this widely available in a single information resource, disseminate online, promote via Carers Alliance etc.

1. Job placement, employment and training programs
2. Coaching/life planning services
3. Distance study
4. Funding/subsidies for learning, upskilling etc
5. Self-employment programs, grants, subsidies etc from the carer perspective: how do these work for carers?
6. Transition to work advice for young carers
7. Work re-entry advice/programs

Build on paid parental leave or investigate medically approved 'time out' for carers dealing with an intensive care situation, or an ongoing family emergency, a systemic approach that works well in countries like the United States.

Carer Learning

Principles

Family carers are New Zealand's biggest health workforce.

They receive no nationally consistent learning so they can safely support someone with health or disability needs at home.

They are at high risk of care-related injuries.

Build on what exists

The existing MoH-funded informal carer training program is the only avenue for carer focused learning in New Zealand. It does not, however, deliver nationally consistent health learning for carers. It could be complemented by, or replaced with, a framework that ensures consistent outcomes identified by the suggested hub partnership with strong input from NGOs, carers, services such as St John (already a partner in this area), the Continence Association, professionals, funders, and overseas bodies that already deliver carer learning.

All providers of carer training funded by the Government should be required to freely share the resources they develop for courses (some regard this as competitive intellectual capital even though development has been publicly funded); and to disseminate the generic carer information produced during the Action Plan period as a way to ensure early national outcomes and consistency for existing carer training contracts (this happens informally but is not required, and is therefore not consistent).

Discharge and transition planners should be required to deliver basic ABC learning to new carers and a framework for this should be formally agreed upon. This should happen as a matter of course when families with health and disability needs are discharged back into the community.

Key frontline services (hospitals, rehab providers) should be required to deliver this learning/framework as part of their existing publicly funded service, and delivery needs should be formally supported and monitored.

More formal development is required to deliver consistent learning to support safe caring in the home. Focus groups could gather input from carers about what they should learn at different stages of their journey, and the best way to receive this learning.

Achieving a flexible learning framework for family carers is important given the national shortage of trained paid care workers; the escalating support commitments of carers who, when paid workers are not reliable or not available, meet this shortfall; and the role of carers as frontline trainers of paid staff coming into their homes.

The Carers Alliance and Carers NZ, like carer peak bodies in other nations, do not support a 'qualification' for family carers. We believe this undermines the sanctity of family relationships and could lead to over-reliance on families to undertake an escalating menu of health care tasks. Family carers may find it increasingly difficult in such a scenario to say 'no' to performing care duties ('they do it, why won't you?'). We also believe that training family carers to be quasi health professionals undermines the skills of highly valued care partners such as nurses. In the first instance carers are spouses, lovers, parents, children, siblings, and friends. There is a need to protect family relationships that are already often under strain.

Family carers who wish to undertake formal care learning for employment purposes already have opportunities to do so. There are government-funded options to seek care worker skills which are recognised by employers, and these could be promoted to family carers.

We recommend that carer learning options focus on helping families deal safely with common home-based health and disability tasks/needs, and that carers have a choice about how to receive this learning (at events, in print, on the web) to suit individual preferences.

Training for Professionals

Principles

Often those who interact frequently with family carers in their jobs do not understand carers' needs, or why they are often highly stressed.

Not being heard is a frequent complaint of carers (this is evident in the Strategy priorities survey results) ... even though they often have considerable knowledge and are a vital part of any support 'team' especially for family members who have high needs.

Ensuring that professionals and frontline government workers receive formal carer awareness training is an important way to achieve improved recognition and support for all carers.

Accountability, sensitivity

Adapt carer awareness training programs from those operating in Australia and the UK.

Require NASCs and staff at key government agencies such as Work & Income to receive face to face, print or computer-based learning about caring.

Adapt resources to raise awareness of carer needs/perspective among GPs and frontline health providers. Distribute/promote these to health professionals.

Specific training for professionals and agencies may be needed for:

- Those who frequently deal with carers of people with high needs.
- Those supporting carers of older people.
- Those supporting Maori whanau carers.
- Those supporting carers from Pacific and other cultures.
- Those supporting lesbian and gay carers (residential providers and hospitals, for example).

Emergency Planning

Principles

Carers often worry about emergencies, their own and those of the person they support.

Carers may feel indispensable and that if they have an accident, become ill, or die suddenly, their family member will suffer too.

This kind of psychological stress erodes carer wellness.

Knowing what to do

If a carer has an emergency, are NASCs required to respond to inquiries in person? How is emergency care planning coordinated? What should carers do if they have an emergency, and what help can they expect in what timeframe?

Collate and make this information freely available via the hub and its stakeholders (create once, share many times). Ensure that services are accountable for this important task (is it currently seen as optional, or a luxury for which services have no time?).

Emergency Care Planning Tools: These exist and need updating. Make them available and promote them widely. (Create once, share freely many times.)

Also promote existing care planning resources such as Age Concern's inexpensive Life Tube, which costs just \$3 and is recognised by all emergency services.

Encourage carers and those they support to have up to date wills, enduring powers of attorney, and other important planning documentation (this is done with Public Trust in every issue of *Family Care*, for example).

Encourage families to have regular meetings to openly discuss how they would cope in different emergency scenarios. This will help them to 'swing into action' if an emergency does happen.

Promote emergency supports such as medical alarms, first aid training, home first aid kits, Healthline, Medic Alert, Dr Global etc. as options for families considering emergency planning.

The preferences and needs of every family are different, but if they have a menu of options and know how to access them, what they cost etc, they can self-choose what would best work for them.

Develop information with emergency services such as fire, St John etc about how families should cope with common emergency scenarios and widely share this information.

Encourage support groups to make emergency planning (completing the Tools, talking about options, etc) the focus of at least one meeting each year.

Rural carers need tailored advice as in emergencies there may be extra delays receiving help, the need for family members to travel to receive treatment or support etc.

Help to Migrate To Long-term Care When This is Needed

Principles

Families need guidance so they can plan for transition points such as moving to long term care when needed (a young person leaving the family home to go flatting or to residential care, an older person needing to go into formal care, or a person with illness needing advanced nursing such as in a hospice).

Making these choices can be difficult and emotional for the whole family. Knowing about options can help.

Sometimes carers keep caring for too long, to the detriment of their wellbeing, and that of the person they support.

Knowing when it's time for transition

Information, advice, support and public education is needed to help carers and their family members accept formal care when the time comes.

Vulnerable groups, such as older men in 24/7 caring roles, are at risk of homicide-suicide to avoid formal care for a spouse. Cases in New Zealand have been classified as euthanasias. In fact, this is a global mental health issue for older men.

Helping all carers feel that it's okay to say they are no longer coping, and can no longer care at home, is an important public health message.

Carers NZ is establishing, with private providers and other stakeholders, a Families Association to deliver targeted information, advice and support to carers whose family member has moved to long-term care. Alliance NGOs will be invited to participate and information will be freely available to groups and individual families.

Financial Support For Carers

Principles

Financial recognition is important to many family carers and has come through strongly in the Carers' Strategy consultation process and the Priorities Survey.

Although the issue of a payment for carers was not included in the scope of the Carers' Strategy, perhaps existing work undertaken by the Office for Disability Issues could be woven into the Action Plan.

It is difficult to envisage a Carers' Strategy without this happening, given the importance to carers of financial issues, and their common feelings of powerlessness over their long-term financial futures, mixed ability to participate in paid work, and the disparity between carers' dependence on benefits which does not reflect the contribution they make to New Zealand social and family life or (as unpaid workers) its economy.

Fairness and balance for carers

There are various ways better financial recognition for carers might be achieved.

Enrolling 24/7 carers in KiwiSaver and helping them to save for retirement, recognising that many are unable to do this if they cannot participate in paid employment.

Providing a non-means tested weekly payment. This could be available to all carers whose family member needs over 20 hours of personal care a week for at least 12 months, with some care being provided each day. In Australia such a payment is made for up to two adults who receive daily care and attention, or any number of children with health/disability needs. The carer does not need to live with the person who needs over 20 hours of support per week. Australia has offered to help New Zealand cost this if the option is of interest.

Providing a living minimum wage to family carers who support someone with very high needs. This is a small number of New Zealanders who provide significant levels of care, for prolonged periods (often for a lifetime). Such carers are likely to live in poverty and suffer care-related health problems. This payment should continue for a period of weeks (in Australia the period is 14 weeks) after the supported person's death, to give carers a respectful period of adjustment. In some cases a lump sum bereavement payment is also made.

Investigating and possibly adapting Australia's range of supports for those who need special help in a crisis (Lump Advance Payment, Crisis Payment, Special Benefit, Disaster Relief Payment, Emergency Relief which provides grants to community and charitable organisations to provide assistance to individuals and families in financial crisis).

Giving family carers in 24/7 situations Community Service Cards in their own right, or extending the Government's SuperGold Card for 24/7 carers so they can access future discounts for things like council rates, and power and phone services.

Giving family carers an allowance on a par with the Disability Allowance, recognising that they too often pay for household health and disability costs. This also balances the trend for such costs, in the community care era, to be devolved from the public system to households, many of which cannot afford to pay for continence supplies, extra medical visits, pharmacy items, etc. Lack of funds to purchase these essential items is highly stressful for carers and those they support.

And/or establish an Assistance Scheme for families that need to buy continence aids, travel to medical appointments, are frequent users of taxis or shuttles, etc. Such a Scheme exists in Australia.

Discuss with Local Government NZ options for rates discounts for carers, who contribute so much to community and family life in New Zealand.

We do not believe that tax breaks or incentives or deductions for health and disability items is a fair way to support all carers ... as often carers are on very low incomes anyway ... but it may be helpful for some carers. It would be cumbersome and costly for the Government to monitor/administer.

Increasing Carer Support rates is a way to financially help carers, who must 'top up' daily shortfalls to access care at residential facilities or fund relief care by the hour.

The asset testing threshold has not kept pace with escalating home values and is a growing concern for couples. Most New Zealand homes are now valued at considerably more than the current \$170,000 threshold. Caring partners or spouses face an extra stress when planning for long-term care as their home may not be exempt from asset testing when it is time for formal care. On one hand asset testing thresholds are increasing at the rate of \$10,000 per annum; on the other, home values continue to rise at a faster rate. Carers may worry that they will not be able to keep their home when a partner enters formal care, and may try to continue providing care for financial reasons when it is no longer safe to do so.

Ensuring prompt assessments for people who have had a serious injury, stroke, or other life-altering health situation will result in faster access to necessary equipment and home modifications. This will relieve financial stress for families, who often pay for these things after becoming frustrated by delays. Prompt assessments will also ensure safer living environments for people who need equipment and home modifications, and reduce injury risks for them and for their carers.

Young Carers

Principles

Over 8% of 15 to 24 year old New Zealanders support an ill or disabled person living with them or in another location (NZ Census). It is not known how many under 15s provide care for an ill or disabled family member.

Currently young carers are an afterthought in health service planning and delivery in New Zealand.

The Carers' Strategy provides an opportunity to recognise young carers; provide them with age-appropriate support; and formally include them in services such as needs assessment.

At a policy level, Young Carers NZ was developed several years ago with funding support from CYF, the Children's Commissioner, and the HDC. There is now a national database of young carers, NGOs, researchers, interested health stakeholders, professionals, educators etc who wish to more formally support young carers.

Relationships have been forged with young carer movements in Australia and the United Kingdom, and links are being built with other emerging young carer networks in Canada and the United States.

Representatives of Young Carers NZ have attended global conferences, and the group has its own presence in the national Carers Alliance.

Appropriate action for young carers

Global mentors have recommended that a national reference group be formed to bring key stakeholders together several times a year to guide strategic developments for Young Carers NZ.

They have recommended that the existing Young Carers NZ website (within www.carers.net.nz) become a standalone resource for young carers so they have their own 'place' online.

Adaptation for New Zealand dissemination Jenny Frank's best practice guide for professionals who work with and support young carers (*Making It Work, Young Carers Initiative, UK*).

Young Carers NZ requires its own full-time coordinator to link disparate sources of information and support, strengthen relationships (aka the hub concept) with regional young carer groups where these exist and national organisations such as Parent to Parent which offers camps and programs for siblings. The coordinator can also build on existing global linkages for sharing purposes, collect global research (more of this is being published here and overseas), etc.

Regional young carer meetings across New Zealand during Years One to Three of the Carers' Strategy Action Plan, so young carers can meet one another, and consider how they would like to be supported ongoing.

A free information pack/resource for wide distribution to young people (adapted from existing resources in Australia and the UK). This initiative is already underway, with multi-stakeholder interest from public and private funders.

Engagement with the Ministry of Education, the Ministry of Youth Development, the Families Commission etc to ensure that government plays its role in strengthening awareness of, and supports for, children and young people in caring situations.

Lesbian and Gay Carers

Principles

Lesbian and gay carers experience discrimination by some services and there is low awareness of their culture and perspective.

Lesbian and gay carers can feel doubly vulnerable and isolated, and are seeking opportunities to share information, advice and support.

Making services and professionals aware of the needs/perspective of lesbian and gay carers is a way to improve service quality for this community.

Supporting global mentoring from similar networks will support the development of the New Zealand network.

Support options

The NZ Lesbian and Gay Carer Support Network intends to adapt information resources for professionals developed by a similar body in the UK.

A national network for gay and lesbian carers has been formed and is building membership and awareness.

The network is represented in the NZ Carers Alliance and will have a presence at the revamped www.carers.net.nz

Social awareness of lesbian and gay carers is being achieved through publicity and articles in *Family Care NZ*.

Rural Carers

Principles

Carers who live in rural areas have extra stresses (transport, access to workers, increased isolation from community and medical supports etc).

They also face extra costs.

Knowing where to receive support and information in rural areas is especially important.

Options for rural carers

Ensure they are aware of available information, advice and support (national and rural).

Rural Women and other rural networks are natural dissemination gateways for carer information. These relationships are in place.

Mentor rural support groups for carers which may be online (Skype etc) if face to face meetings aren't an option.

Host information and support events in rural/regional places and promote these well in advance so carers and local services/professionals are aware of and have access to information resources.

Ensure rural carers are aware of important services such as the 24 hour Healthline.

Redress transport funding disparities for workers so this is not an extra responsibility/stress for rural carers.

Examine options to reduce the social isolation rural carers often experience.

Ensure that rural/regional carers have easy access to information about whanau accommodation, shuttle services etc so they know what is available if their family has to travel/be away from home, know about costs, and who pays for what.

Emergency discretionary funding for families should be available so they can deal with health crises without this being a significant extra burden at times of stress.

Promote services like St John's Emergency Room Befriending service which provides people with information, advice and support if they arrive at hospital alone, to streamline access to whanau accommodation etc. The service is not available everywhere but offers important support at times of high stress at 16 hospitals across the country (and hopefully more during the Action Plan timeframe). It is a free community service funded through charitable donations.

Other Issues

Needs assessment and service coordination is an area of high stress for carers. The individualised nature of NASC means it is not transparent, consistent, or accountable to families. If families have emergencies, or are unhappy with coordination of services, and a NASC is unresponsive, this can be disempowering and have long-term repercussions.

Carers often feel their needs and views are not heard during this important process. Young carers can feel disenfranchised by assessment and that their concerns or issues are peripheral, even though they might be an important source of support within the family.

The Carers' Strategy provides an opportunity to review assessment processes from the carer perspective to ensure this important gateway for many kinds of support is meaningful for the whole family.

Reviewing of NASC from the wider family perspective may lead to innovative ways to ensure assessment and service coordination is more efficient, less bureaucratic, leads to improved relationships, etc.

All frontline NASC staff including administration personnel who engage with carers should be required to undergo carer perspective training. Carers are their clients too.

Advocacy services are geared to meet common needs.

As with some government agencies (CYF etc) greater specialisation is needed so public advocacy services can manage complex disability cases.

Often these fall back on NGOs who spend considerable time and resources working with families to resolve concerns, or ensure these are heard (the devil is always in the detail, and the system is not geared for detail leading to resolution).

Those working in advocacy roles should be required to undergo carer awareness training.

At a general level, Carers NZ is developing a self-advocacy toolkit adapted from a Canadian resource, with partnership and input from HDC. This will be freely available to Alliance NGOs and others who want to help carers be better self advocates.

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