



Caring for New Zealand Carers

Your Life
Your Work
Your Say

He Atawhai i te Hunga Ngākau Oha o Aotearoa

.....
A CONSULTATION DOCUMENT FOR THE DEVELOPMENT OF A CARERS' STRATEGY FOR NEW ZEALAND
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Foreword from the Minister for Disability Issues and Minister for Senior Citizens

Hundreds of thousands of people in this country support a friend, family or whānau member to live with the dignity, independence and security which the rest of us take for granted. They are hidden heroes who form an invaluable weave in the fabric of our society and communities. Unpaid carers, however, often tell me their work is undervalued and not recognised, and that they have fewer opportunities than other people to participate to the extent that they would wish in work, education and other social activities.

Every carer I have met has been an inspiration to me, and having listened to their stories I know we must and will do more in the years to come to help them. The development of a Carers' Strategy and this consultation document is a first step towards this goal. *Caring for New Zealand Carers* opens up the public debate on the development of a Carers' Strategy. It has been produced in partnership with the Carers Alliance, a network of 43 non-government organisations (NGOs) supporting unpaid carers. The Government has worked with the Carers Alliance to develop a vision, principles and key themes to improve the lives of carers.

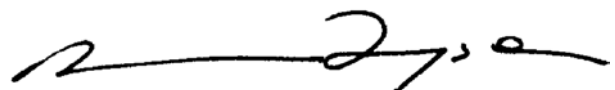
The Carers' Strategy will be finalised in 2008 and will incorporate feedback from this consultation. The Strategy will sit alongside other government programmes such as the New Zealand Disability Strategy and the New Zealand Positive Ageing Strategy.

I would like to thank the individuals and groups in the carers' sector whose work has contributed to *Caring for New Zealand Carers* and who have promoted the development of a New Zealand Carers' Strategy. I would also like to acknowledge those carers who generously allowed us to share their stories in this document.

In addition I would like to recognise the work of the Hon David Benson-Pope, Minister for Social Development and Employment, in supporting the development of a Carers' Strategy.

Caring affects every one of us and there is a high chance that we may all need support or be carers in the future. *Caring for New Zealand Carers* offers you an opportunity to have your say on what the Carers' Strategy should include and how it should be implemented.

I encourage you to respond.



Ruth Dyson
Minister for Disability Issues and Minister
for Senior Citizens



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Introduction

Carers need caring. Most of them need high quality, reliable and responsive support from statutory or voluntary services. Many need help from their employer. Carers have many of the same needs as the rest of the population – such as the need to maintain their own health and wellbeing – but, especially for those who care for a large number of hours each week, carers have less opportunity to get what they need.

SOURCE: UK CARERS' STRATEGY, 1999

Many New Zealanders are supporting others. Their effort, understanding and compassion helps other people to live with dignity and to participate in society. Carers need to be properly recognised and helped to do this so that we can all enjoy the sort of New Zealand society we want to live in.

Unpaid carers are people who assist a friend, family or whānau member who because of ill health, disability, mental illness, addiction or old age, cannot manage the tasks involved in everyday living without help and support.¹ Carers cross the diversity of New Zealand society, varying in age, ethnicity, culture, characteristics and outlooks.

¹ This description is based on the National Health Committee, *How Should We Care for the Carers*, 1998. By unpaid carers we mean informal carers who do not have an employment contract for their caring role. Informal carers on income support, such as Domestic Purposes Benefit – Care of Sick or Infirm, and informal carers receiving ACC wages are included within the Strategy.

The Government is working in partnership with the Carers Alliance, a network of 43 non-government organisations (NGOs), to identify priorities for unpaid carers.² The Carers Alliance and the Government suggest working towards a vision where:

New Zealand is a society that recognises and values family, whānau and other informal carers. Carers have the choices and opportunities to participate to the extent that they would wish in work, education and in other social activities. Carers' voices are heard in decision-making that affects them.

The aim of this consultation is to seek feedback on the vision and principles for unpaid carers, the issues they face, and the immediate priorities in deciding how services should change in the future. A Carers' Strategy will be published in April 2008.

² A list of the Carers Alliance members is provided in Appendix B.



The Carers' Strategy is part of wider progress to improve the choices parents and other informal carers are making about ways to balance paid work, their caring responsibilities and other aspects of their lives.³ The Strategy will also work towards reducing disparities for Māori and Pacific carers and those from ethnic minorities and will consider how support can be most appropriate to these carers and whānau.

³ Caring for Adults is one of six key areas of activity identified in *Choices for Living Caring and Working, A Ten-year Plan to Improve the Caring and Employment Choices Available to Parents and Carers*, announced by the Prime Minister in August 2006.

Have your say

Have your say on what the Government should do to help unpaid carers. We are seeking feedback from a wide range of individuals, families and groups who provide unpaid assistance to people with support needs. Feedback is sought in particular from:

- carers
- the families, whānau and aiga⁴ of carers
- people receiving support from family, whānau and other informal carers, including ACC claimants
- the wider public, who may be carers in the future
- employers, unions and other workplace organisations
- health professionals such as general practitioners, practice nurses, occupational therapists, physiotherapists, nutritionists and social workers
- formal or professional carers
- non-government organisations, such as organisations supporting carers, people with disabilities, mental health needs and illness
- advocacy organisations
- disability support services
- mental health community services
- health of older people support services
- funders and purchasers, including District Health Boards
- researchers
- other interested parties.

This document contains information on the work of family, whānau and other informal carers and some of the issues they face, and examples of initiatives which may help them. There are a number of questions in this document seeking your response. More information on how to respond can be found at the back of the document.

⁴ Aiga is a term many Pacific peoples use to describe their extended family.

Who are carers?

At the time of the 2006 Census approximately 420,000 New Zealanders reported providing support for an individual with ill health or a disability within the previous four weeks (Statistics New Zealand, 2006).⁵ Unpaid carers in New Zealand cross a wide spectrum of ages, cultures, ethnicities, characteristics, backgrounds and outlooks. What they have in common is a shared belief in helping others to have a good quality of life.

Support can be provided in the home, in the workplace, in educational settings, or at social activities. Approximately 47% of carers are supporting someone outside their household, 38% are helping someone inside their household, and 15% are supporting people inside and outside the carer's home (Statistics New Zealand, 2006). Often somebody requiring assistance may have a number of people who help them: for example, an older retired woman might be caring for her husband with the help of her son.

An unpaid caring role may involve personal care (such as dressing, toileting and bathing), physical and mobility tasks (such as help with getting out of bed, doing physiotherapy, and transportation), safety and protection (such as providing a safe home environment),

practical household tasks (such as cooking and housework), administrative tasks (such as paying bills, arranging appointments), emotional support (such as encouragement and reassurance), spiritual support, and advocacy.

The relationship between the carer and the person they help is often based on love, kinship or friendship, and usually exists before the need for support. Most people, given the choice, would continue to help the person as it is something they do out of a sense of love or responsibility. The majority do not see themselves as carers but as relatives or close friends of the person who needs support. However this can mean that some people do not feel that they have any choice in helping others, and that the caring role is imposed on them without warning or time for preparation.

I believe you can never get over a thing like this, but you learn to deal with it in a way that does not affect your life as much. No one signs on for anything like this when they have babies, but to think of never having him would be a fate worse than death. I would never want to change the past because then maybe my son would have a different personality, and I love him just the way he is.

⁵ This figure may underestimate the number of carers as it does not include carers under the age of 15 or some carers of older people who associate health problems in later life with being old as opposed to ill health or disability. The figure may overestimate the number of carers as the question includes one-off caring responsibilities, rather than ongoing issues.

It is sometimes hard to distinguish between caring and ordinary parenting or support for family, whānau and friends. This is especially true when the level of involvement rises gradually over time and a carer may not be fully aware of the increasing demands.

Women are more likely to be carers than men. Around 63% of carers in New Zealand are women (Statistics New Zealand, 2006). International research has shown women are also more likely to be the main carers and provide assistance for more hours (Goodhead and McDonald, 2007).

Thirty-eight percent of carers in New Zealand are between 45 and 64 years old, with a further 31% between the ages of 30 and 44. Twelve percent of carers are 65 or older (Statistics New Zealand, 2006).

Māori and Pacific peoples are more likely to provide unpaid support (Statistics New Zealand, 2001). Generally Māori and Pacific peoples face complex caring responsibilities, particularly in the 15-44 age group. The younger average age of Māori and Pacific carers, higher rates of severe disability, and larger households make it more likely that they are caring for more than one person and across more than one generation.

The most common source of help for those being supported is from a family member. Help with household tasks, such as heavy housework and meal preparation, was most commonly given by a spouse or partner, followed by daughters, sons and parents. After family, the next most frequent sources of help were paid individuals and voluntary organisations (Ministry of Health, 2004).

Many New Zealand carers identify themselves as unemployed and may be interested in paid employment if suitable jobs are available. Around 73% of people aged 25-64 who provided unpaid support to a sick or disabled person outside their household in the previous four weeks at the time of the 2001 Census, were also in paid employment.

Around two-thirds of these were employed full-time (Statistics New Zealand, 2001).

Current support available to carers

There are currently a range of government-funded support services available to some carers in New Zealand. These include income support⁶, carer support and respite care, ACC payments, home modifications and equipment assistance, home-based support services, a range of ad hoc education, information and support programmes, and a small number of individualised funding packages.

The Government has also published a number of plans to indirectly improve support for carers, such as the New Zealand Disability Strategy (2001) and the Positive Ageing Strategy (2001). Existing plans provide a foundation for better recognition and help for carers. The intention is that the Carers' Strategy will focus explicitly on the role of informal carers and will build on this past work. The Carers' Strategy will also align with the Review of Long-term Disability Supports being led by the Office for Disability Issues, work on the interface of disability support and care and protection provided by Child, Youth and Family, and other work in government affecting carers and the people they assist.

What are the current challenges for carers?

Providing support can be emotionally rewarding for carers. Carers can also experience many barriers to participating to the extent that they would wish in paid work, education, family or whānau life and in other social activities.

Just as attitudes can be barriers to disabled people or elderly people participating in the community, carers too can suffer from a lack of understanding about the nature and value of the work they do and the impacts this may have on their life.

⁶ Eg, Domestic Purposes Benefit – care of sick or infirm provides income support for people who are caring full-time at home for someone other than their partner who would have to receive hospital care if they were not being cared for at home. Child Disability Allowance is a non-taxable allowance that is available to the principal carer of a dependent child who has a serious disability.



The so-called gateways end up becoming gatekeepers. Finding help is like a treasure hunt, and no one is accountable. You have to be so persistent, but many carers give up. They don't have the energy to keep knocking on doors. My best sources of support have been other carers. We understand how carers think and feel because we are carers.

SOURCE: CARERS NZ

Due to the demands of providing support, carers are at a higher risk of stress, depression, isolation and increased health issues. There are often increased financial, emotional, social, cultural and spiritual burdens on carers, their families and whānau. Often unpaid carers cannot participate fully in the workforce due to their caring commitments. This can have short- and long-term economic impacts on the family or whānau and the carer. When carers suffer because of inadequate assistance, so do the people they support.

The Carers' Strategy will help to respond to changes in New Zealand society. For example, the shift away from institutional care (meaning that many families now provide help in the home environment and may require a range of assistance to do this), as well as future challenges in assisting New Zealanders (particularly as the population ages and the traditional networks of support change).

What are the benefits of supporting carers?

Caring should be something that people can do with pride and feel supported to do. Supporting carers helps develop strong healthy families that are able to assist their members to reach their full potential. Improving choices in employment and education will help address skill shortages within the economy, improve productivity levels and help carers to secure their future incomes and resources for retirement.

Vision and principles

The suggested vision for carers is that:

New Zealand is a society that recognises and values family, whānau and other informal carers. Carers have the choices and opportunities to participate to the extent that they would wish in work, education and in other social activities. Carers' voices are heard in decision-making that affects them.

The six principles below add more detail to the vision. They are based on principles developed by the Carers Alliance (see Appendix A).

The principles are to:

1. **recognise and value** the essential contribution of family, whānau and other informal carers to New Zealand's families, communities, society and economy
2. ensure that carers have the **choices and opportunities** they need to achieve a good quality of life in health, social and economic wellbeing, and can balance their caring role with participation in employment, education, and family, whānau, social and community life
3. recognise, value and support the **diversity of needs** of carers and those they support, including cultural diversity, stage of life, environment, impairment and other areas of diversity
4. ensure that support for family, whānau and other informal carers enables carers to carry out their role with **integrity, respect and as little stress** as possible
5. encourage information, supports and resources that are proactive, high-quality and customer-focused and **empower** carers
6. recognise and respect that the life choices and needs of carers and those they support are **integral to each other**.

Question 1: Do you think the vision and principles recognise carers' needs sufficiently? If not how would you change them? (You could include comments here if you think there are any aspects missing, disagree with any of the above principles, or feel that some principles are especially important.)

Themes

To guide the development of the Carers' Strategy we propose grouping the issues facing carers into eight themes.

1. **Recognition:** the Government, employers, support services and communities recognise and value the contribution of carers and reflect this in their interactions and approaches with them.
2. **Health and wellbeing:** the health and wellbeing of carers is proactively and successfully supported.
3. **Education, employment and financial support:** financial support that recognises the additional costs of caring both now and in the future, and works alongside initiatives to give carers more choices and opportunities to enter, progress or stay in education or employment.
4. **Information and planning for caring:** timely, co-ordinated and accurate information and planning to help carers make informed decisions based on their unique family life and carer perspectives, and have more control over their own lives.
5. **Provision of professional and social supports:** an adequate range of quality, co-ordinated and professional services and supports tailored to individual circumstances.
6. **Young carers:** supporting children and young people to pursue education and personal development during and after their time in a caring role.
7. **Māori carers:** ensuring that the strategy is able to respond to the cultural, social and spiritual needs of Māori.
8. **Pacific carers and other ethnic minority groups:** ensuring that the Strategy is able to respond to the cultural and ethnic diversity of New Zealand.

Question 2: Which themes require immediate attention and which themes are important but long-term in nature? (You could include comments here if you think there are any themes missing or any themes you disagree with, or if you believe that some areas are especially important and want to explain why through your own story.)

Recognition

This section looks at why carers should be better recognised and how this might be achieved.

Caring can be for a short time or a lifetime and anyone can be called on to be a carer. It can provide many benefits, such as the satisfaction of fulfilling what a carer may see as the natural

role of a relative or friend. However the carer may make many sacrifices which go beyond the reciprocity of everyday life, by giving up more than he/she wishes to. If carers did not make these sacrifices, the cost to communities and the Government would be much higher.

When my daughter returns home she requires 100% of my time and attention to ensure her safety and to give her the best possible quality of life I can. Even taking a shower or going to the toilet requires careful planning.

SOURCE: CARERS NZ

Providing assistance for those who need it is a collective responsibility that is shared by the Government, family, whānau, friends, communities and society. However many carers often feel that other people, whether in the community or in the workplace, do not understand or recognise the role and impact of caring. This can lead to extra stress and barriers to receiving the advice and support carers need.

I worked full-time and had a company car, but Dad's health went downhill, and after a year of trying my best, I had to choose between Dad or my job. So I resigned and haven't had any income from a job since last year.

SOURCE: CARERS NZ

Examples of how carers could be better recognised and valued

- More formal structures could be set up to better represent carers' interests to the Government. More funding could be made available for New Zealand research into carers' needs. An annual carers' award could be used to raise public awareness of the role of caring.

- Initiatives to improve recognition of carers' individual needs could be implemented. More advocacy services could be made available to help carers' represent their interests to others. A voluntary registration scheme could be set up, with discounts available from businesses and other services such as transport.

Question 3: Do you think that carers are effectively recognised and valued at the moment? If not what would help carers feel more recognised and valued? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Health and wellbeing

This section considers how the health and wellbeing of carers may be compromised in their caring role and how this might be addressed.

A number of carers find that their health and wellbeing suffers due to their caring role (Carpinter et al, 2000): for example they may suffer from back problems or experience increased stress, anxiety or depression. International research has found that stress is a commonly reported issue for carers and can be caused by worry over financial and legal matters, the quality of paid services being provided, and increased social isolation and loneliness (Goodhead and McDonald, 2007). It is important to the carer, to the person being supported and to society that carers' health and wellbeing is protected. If a carer is unable to continue caring, alternative arrangements can be distressing for them, their wider family or whānau, and the person being cared for.

A few years ago I had the flu, but had to keep caring for my daughter as there was no one else. In the end I was hospitalised as it turned into viral meningitis.

SOURCE: CARERS NZ

Improving choices to participate in family, whānau, social and community life can help to improve carers' wellbeing. Services which help carers take a break or help them participate in social activities are a vital part of this.

The caring relationship can, however, be complex and depends on the dynamic between the carer and the recipient. It should be recognised that at times abusive relationships may develop either from the carer or to the carer, and extra support may be needed in this situation.

There can also be issues when carers themselves have disabilities, mental health issues or chronic health issues, as different support systems may be involved and responsibilities are not always clear.

Older New Zealanders with a caring role may need particular assistance to manage their health and wellbeing.

Living a long life should be something to be celebrated, but if you're an older carer, it can feel like a time of 'grey peril'! My husband has Alzheimer's and it's exhausting. He can be verbally abusive and has hit me several times. He prowls around the house at night. I don't get enough sleep and with all of the caring tasks I do feel my own health is at risk.

SOURCE: CARERS NZ

Ideas to improve the health and wellbeing of carers

- Initiatives for proactively maintaining the wellness of carers could be developed. For example, ensuring that carers and whānau have the information they need before the person they will be supporting leaves the hospital (where there is a hospital admission).
- Carers could be made more aware of existing services available to them, such as mental health services. More supports, for example early counselling or better links to

support networks, could be provided to help carers through key transitions, such as the start and end of caring.

- Initiatives could be developed to help carers pursue activities that help them maintain social networks, such as leisure activities or employment.

Question 4: What could be done to help carers protect their health and wellbeing? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Education, employment and financial support

This section considers the barriers faced by carers in accessing education and training, finding quality employment, and achieving long-term financial security.

Education and skills development for employment

Participating in ongoing education not only helps carers enter and progress in employment, but may also help them manage their caring responsibilities and engage in other social activities. However carers may find that their ability to participate in education and training is reduced, interrupted or stopped altogether given the demands of their caring role.

I love architecture and would love to study, but my caring commitments are very time consuming. I'm now 28 and feel I am starting things much later than other young people. I worry about this.

SOURCE: CARERS NZ

Employment

Since the 1980s there has been a significant growth in the proportion of unpaid carers in paid employment (New Zealand Government, 2006).

Many carers welcome the opportunity to combine care with paid employment, but more support may be needed for those providing high levels of assistance. Paid employment, whether full-time, part-time or self-employed:

- provides financial independence
- gives an external focus and source of satisfaction separate from caring
- helps maintain social networks and friendships, which may enhance the carer's wellbeing
- promotes self-esteem
- assists with the additional costs of caring
- can offer the person cared for assurance that the carer has security and satisfaction from paid work.

Often carers have to take jobs that pay less than they would like, are less interesting, and/or offer less training and career development (Gendall and Fawthorpe, 2006). Carers may also find that workplace arrangements, such as core working hours and shift work, are inflexible. Some employers have responded to this by offering quality flexible working arrangements, including part-time work and the option to work from home. However such arrangements are not always readily available and it can be difficult to meet the needs of everyone.

Many carers feel unable to discuss their concerns with their employer, they may view their employer and fellow employees as unsympathetic or unaware of their caring needs, or they may feel that they are marginalised and undervalued in the workplace.

Self-employment can be helpful to some carers as it may provide additional flexibility to help them balance their caring commitments with earning an income.

I am very fortunate to now be able to work part-time, which constitutes the only “normal” part of my life. As I fast approach 60 and have no savings for retirement, I do realise how seriously disadvantaged our family has been due to my caring responsibilities. The unpredictability of my daughter's health and well-being precluded any opportunities to provide for my children as I had always dreamed. This is probably the most difficult problem to come to terms with.

SOURCE: CARERS NZ

Financial support

Research has found that there are often significant and multiple costs from caring (Goodhead and McDonald, 2007). Depending on the circumstances these may include increased heating costs, medical costs, transport costs and home modifications. Carers may also choose to reduce or cease paid employment to provide more support to their friend, family or whānau member.

Improving the choices carers have to balance care with education or work can improve their financial security. Carers on income support generally experience multiple disadvantages in returning to employment, as most are over 45, have been out of the workforce for over a year, and have little or no other income (Ministry of Social Development administrative data, 2004). As a group they may particularly benefit from support to increase their social participation, part-time employment, and help them make a transition to sustainable long-term employment once their caring responsibilities allow.

Caring may also affect how well-off carers are in retirement. They may be less able to build up savings during their working life and may find that any savings they do have are eroded by additional personal and medical care expenses.

Examples of how education, employment and financial support for carers could be improved

- More work with employers to promote quality flexible work arrangements and other workplace supports for carers (for instance a minor change, such as providing access to a telephone, can be a significant help). Work could be progressed to improve opportunities for carers to take time off work to meet their caring responsibilities.
- More support and information could be given to carers to re-enter education or employment when their circumstances allow. There could be better flexibility of educational provision through distance learning or e-learning.
- More research could be undertaken to find how we can better address income barriers and other disincentives currently faced by carers wishing to balance their caring responsibilities with employment.

Question 5: If carers need help to enter or progress in education or employment when their circumstances allow; what type of support should be provided? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Question 6: How can the Government support employers to provide as much flexibility in the workplace as possible for carers? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Question 7: What do employers need to do to help carers balance paid work and caring? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Information and planning for caring

This section explores how to provide information to help carers in their caring role.

Sometimes a person's support needs increase gradually, perhaps as they grow older. At other times the change may be sudden and unexpected, for instance if a person is injured following a road accident or with the diagnosis of an illness such as cancer. For any carer new to the role there may be a confusing range of new systems, information and supports to understand and negotiate. Improving information for carers will empower carers, help them find the best supports for their family or whānau, and educate them on how to protect their physical and emotional health.

It was confusing trying to negotiate the mental health system, while at the same time, frantically educating ourselves about Schizophrenia; reading information, attending support groups, talking endlessly to people, both health professionals and carers, and trying desperately to understand. To a person who has never had any contact with mental illness this is a minefield and a very difficult concept to grasp.

SOURCE: CARERS NZ

Research into carers' needs suggests that information should be accessible and provided in a range of formats and places to recognise carers' diversity (Goodhead and McDonald, 2007). Suggestions from carers on topics to cover include:

- what support services are locally available, such as respite care, transport services and communication aids
- how to find out if they are eligible for help
- how to cope with any medical and personal needs

- whether further education or learning opportunities may be useful and are available
- what support groups are available locally, nationally and within their own family, whānau and friendship groups
- the likely progression of the condition of the person they are caring for, and how the person's behaviour may change
- the rights of the carer and the person being supported.

Carers have also said that information on planning is useful. This includes how to plan with support services to help a carer deal with a crisis, pursue activities outside caring, and ensure they do not provide support beyond their coping ability, putting their own health and wellbeing at risk.

Examples of how information and planning could be improved

- Moving towards a one-stop information shop for carers. This could include a face-to-face service, a website, or freely accessible carer information packs. For example, in Australia Carer Resource Centres are provided in each State capital, and work in partnership with Carers Australia to provide information and advice for carers, including where to go for help of any kind.
- Information could be made available at a wide variety of places for example, schools, youth radio, services for refugees and churches.
- A programme to upskill and empower carers through information could be developed. For example, the United Kingdom has recently launched an "Expert Carers" programme to provide learning for carers to better self-manage their health and the health of those they care for.

Question 8: What type of information is needed by carers and what are the best

ways to provide information and advice to them? (You could include how information should be provided, such as through leaflets or phone lines, or where information should be provided, such as through health services or post offices.)

Question 9: How could carers be helped to plan for themselves and the person they support? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Provision of professional and social supports

This section considers how health and other support services should be delivered to help carers and the people they assist.

Carers have said that poor and unreliable services can be a problem to being supported. Carers have asked for services to be offered on the basis of the needs of the recipient and the carer and the wider family or whānau to be taken as a whole, rather than with each addressed in isolation (Bray et al, 2005). This includes delivering services in ways that:

- are focused around the carer and those they support, rather than around government agencies
- provide help when and where the carer and the person they support needs it
- allow for short, frequent care relief to be provided, if required, in a location appropriate to the needs of the carer and the person they support
- do not expect the family or whānau to always be available for back-up
- prevent and help with crisis management
- are consistent and fair



- are culturally appropriate, for example, by working with the family or whānau
- recognise the needs of carers and their family or whānau
- are stable and reliable
- have eligibility criteria that are easy to understand.

While government agencies have to account for taxpayer money, there is so much paperwork and so many reviews. The reality is that most of us are severely financially and socially disadvantaged either by illness or disability, or by supporting family members with health needs. The last thing we need is a punitive approach.

SOURCE: CARERS NZ

Helping carers take a break

Respite care and carer support are very important for carers to allow them to take a break. Research indicates that, to be effective, these services need to be of a high standard, flexible, reliable, accessible, culturally appropriate, and not constrained by financial support needs (Goodhead and McDonald, 2007).

It needs to be recognised that many carers support more than one person with health needs in their family. Assessment looks at the person requiring support, often in isolation of the needs of the whole family. I think this results in more bureaucracy, more cost, and not necessarily the best services. Why can't assessments look at the wider needs of the whole family or whānau, including multiple care situations?

SOURCE: CARERS NZ

Relationships between carers and health professionals

Many carers would like more support, recognition and information from health, mental health and disability sector professionals. Common issues are that health professionals do not recognise carers as important members of the care 'team', and do not consistently refer carers to useful services. Research has found that being treated respectfully, being listened to and being believed by professional carers are important elements in the process of establishing trust with professional staff and carers (Goodhead and McDonald, 2007).

Witnessing the incremental loss of the person you were expecting to share so many years of life in the future with – to bit by bit let go of your dreams, to take over the shared tasks and responsibilities up until the last ones of feeding and toileting your loved one – is an enormous emotional, mental and spiritual challenge... It's made harder by the fact that I have to constantly come out and explain that we are gay to all the people we have to deal with. I've had to be an educator as well as a carer.

SOURCE: CARERS NZ

Ideas to improve the delivery of support services and interaction with health professionals

- Carers could be more included in support and service planning at the right level, including hospital discharge planning. For example, by providing information packs, or having a discussion with a health professional on the likely course of events and the initial development of a long-term support plan (including a crisis response plan).

- Awareness about carers' issues could be a larger part of health professionals' training to increase the likelihood of implementing carer-focused systems.

Question 10: What changes could be made to improve support services for carers? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Young carers

This section focuses on young carers because the issues they face are often different to those of adult carers, for example the difficulties of remaining engaged in education (particularly at senior secondary school and initial tertiary institutions) and the experience (or perception) of social exclusion by their friends. The Government does not expect any child or young person under the age of 18 to undertake a full-time caring role; however young people⁷ may be helping to support family members or one of their extended whānau.

Young carers will often gain diverse and rich life experiences from their caring role which can benefit them in later life. However their caring role may make it difficult to keep up with school work or to make transitions from school into tertiary education or employment, or they may have fewer opportunities to play, socialise and make friends.

I've been helping to care for my aunt and grandmother since I was 11. When I was younger I would get up every day at 5am and help them to wash and dress and make them breakfast. At night it would be similar tasks. Sometimes they would have trouble sleeping, so I would keep them company, sometimes until 3am. As a young carer I just wanted to be recognised and

heard. My friends didn't understand why I couldn't do things with them, or felt down or tired sometimes.

SOURCE: CARERS NZ

Ideas to improve support for young carers are:

- greater identification and recognition of young carers by health professionals, schools and communities
- flexible support options within the education system
- support with education and/or career planning before and/or after caring ends
- age-appropriate camps and befriending opportunities.

Question 11: What other challenges do young carers face and what are the best ways to support them? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Māori carers

Research has found that Māori carers often have poorer outcomes than other New Zealanders, and may need focused policies to support them (Goodhead and McDonald, 2007). The needs of Māori carers must be considered within the broader context of whānau and their wellbeing. The carer, the person being supported and whānau are seen as one "unit". When considering who to assist it is essential to take into account the needs of the whole whānau and to offer help to carers as well.

Whānau care is diverse by nature and facilitates more than just practical care. Whānau care enhances the emotional wellbeing of the whānau and is about ensuring a person with a disability maintains a sense of purpose,

⁷ A young carer can be up to 30 years old.

independence, dignity, health and connectedness with whānau, hapū and community across a person’s lifespan.

SOURCE: NIKORA, 2004

Māori cultural concepts will influence understandings of caring. This may include expectations that whānau members will be available to provide support (Goodhead and McDonald, 2007). However this may not always be the case. How Māori carers and whānau access and receive information and support is an important consideration. There is a strong emphasis on the spoken word.

We don’t ask for much different than everyone else but there are a couple of things; like realising for big meetings the whole family wants to be there and that the whole family includes cousins, nieces and nephews; that we need hospital staff to understand.

SOURCE: NIKORA, 2004

Question 12: What other challenges do Māori and whānau carers face, and what are the best ways to support them? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Pacific carers and carers from other ethnic minorities

Pacific people in New Zealand are ethnically and culturally diverse. However, like Māori carers, Pacific carers need to be considered within their family or aiga and their particular cultural context. Research has found that language and difficulty in obtaining information were significant barriers to Pacific people accessing health and support systems (Goodhead and McDonald, 2007). Financial pressures are common. Traditionally the extended family and community have been

responsible for assisting those with a disability or other health support needs, but in New Zealand Pacific people are often isolated from that wider support network. In addition, culturally it may be difficult to acknowledge the need for help or to accept a support worker into the home. Other ethnic minority groups may face similar challenges.

Question 13: What other challenges do Pacific carers and carers from other ethnic minorities face, and what are the best ways to support them? (Please provide a reason for your answer if you are able to do so. You could comment on what currently works and what does not work.)

Other groups of carers

Carers come from many different backgrounds and there may be other groups of carers who are also particularly disadvantaged in their caring role.

Question 14: Are there any other groups of carers who may be particularly disadvantaged in their caring role, and how could they be better supported? (For example refugees, rural carers and gay, lesbian and bisexual partners in caring roles.)

Information on how to respond

The closing date for feedback is **14 September 2007**. You can provide feedback by:

- using the online feedback form at www.msd.govt.nz/work-areas/cross-sectoral-work/carers-strategy
- emailing carersstrategy@msd.govt.nz
- writing to: Carers' Strategy Consultation, Ministry of Social Development, PO Box 1556, Wellington.

If you have any questions or require any further information please contact the Ministry of Social Development at carersstrategy@msd.govt.nz

The Ministry of Social Development and the Carers Alliance, will be holding a range of events to gather feedback throughout the consultation period. Details of these events are available at: www.msd.govt.nz/work-areas/cross-sectoral-work/carers-strategy

A summary of questions is below. You might like to use these questions as a way of organising and presenting your feedback. Please feel free to make any additional comments or to use a different format if you want. You do not have to answer questions or provide personal information if you do not wish to. Any information you do provide will only be

considered by the Ministry and the Carers' Strategy Steering Group⁸ in developing a Carers' Strategy.

Your submission may be requested by an individual or organisation under the Official Information Act 1982. If this happens, the Ministry of Social Development will release your submission to the person or organisation who requested it. If you are an individual please mark on your submission whether you would like your personal details to be removed if a request is made. Your personal details are your name and contact details and other information that may identify you.

In your feedback it would be helpful if you could include the following:

- your name and address or email address
- whether you are responding as an individual or an organisation
- how many people have had an input into your feedback.

If you are responding as an **individual** it would be helpful if you could include:

- your main interest in the Carers' Strategy (for example, as an unpaid carer of an adult, child or youth with support needs,

⁸ The Carers Strategy Steering Group comprises of representatives from the Carers Alliance and senior officials from the Ministry of Health, Department of Labour, Ministry of Social Development, Office for Disability Issues, Office for Senior Citizens, Accident Compensation Corporation and the Department of the Prime Minister and Cabinet.

as someone who is supported by a carer, or as an interested member of the public)

- your ethnicity (NZ Māori, NZ European, Pacific Island, Asian or other)
- your age (you may wish to use an age bracket such as under 14, 15-24, 25-44, 45-64, 65-74 or over 75).

If you are an **organisation** it would be helpful if you could state:

- the name of the organisation
- your position in the organisation
- your main interest in the Carers' Strategy (for example, as a representative or advocate for carers, as an organisation assisting people with support needs or assisting a population group, as an employer, or as a service provider).

If none of these categories apply it would be helpful if you could describe your interest in the Carers' Strategy.

Summary of questions

Please provide reasons for your answers if you are able to. You may wish to do this by sharing your own story with positive or negative experiences, or by commenting on what currently works and what does not work.

Question 1: Do you think the vision and principles recognise carers' needs sufficiently? If not how would you change them? (You could include comments here if you think there are any aspects missing, if you disagree with any of the above principles, or if you feel that some principles are especially important.)

Question 2: Which themes require immediate attention and which themes are important but long-term in nature? (You could include comments here if you think there are any themes missing or any themes you disagree with, or if you believe that some areas are especially important and want to explain why through your own story.)

Question 3: Do you think that carers are effectively recognised and valued at the moment; if not what would help carers feel more recognised and valued?

Question 4: What could be done to help carers protect their health and wellbeing?

Question 5: If carers need help to enter or progress in education or employment when their circumstances allow; what type of support should be provided?

Question 6: How can the Government support employers to provide as much flexibility in the workplace as possible for carers?

Question 7: What do employers need to do to help carers balance paid work and caring?

Question 8: What type of information is needed by carers and what are the best ways to provide information and advice to them?

Question 9: How could carers be helped to plan for themselves and the person they provide support?

Question 10: What changes could be made to improve support services for carers?

Question 11: What other challenges do young carers face, and what are the best ways to support them?

Question 12: What other challenges do Māori and whānau carers face, and what are the best ways to support them?

Question 13: What other challenges do Pacific carers and carers from other ethnic minorities face, and what are the best ways to support them?

Question 14: Are there any other groups of carers who may be particularly disadvantaged in their caring role, and how could they be better supported? (For example, ethnic minorities, refugees, rural carers, and gay, lesbian and bisexual partners in caring roles.)

Thank you for your participation

Sources

Bray A, Moss J, Forrester K and McConnochie K, *Evaluation of the Complex Carers Group Project*, Donald Beasley Institute, Dunedin, 2005.

Canadian Caregiver Coalition, *Framework for a Canadian Caregiving Strategy*, Canada, 2005.

Carer quotes: Sourced from the Issues Registers of Carers NZ, 2005-2007.

Carers Australia and National Centre for Social and Economic Modelling, *Who's Going To Care? Informal Care and an Ageing Population*, University of Canberra, 2004.

Carers New Zealand, Ministry of Health and Children's Issues Centre, *Young Carers Report*, New Zealand, 2007.

Carpinter A, Irwin C and Rogers G, *Just surviving: talking with parents of children with very high disability support needs about how they get by*, Health Funding Authority and Department of Child, Youth and Family, 2000.

Carpinter A and Harrington C, *The Best of Care? An Independent Review of Issues at the Interface of Disability Support and Care and Protection*, Department of Child, Youth and Family, 2006.

Department of Health, *Caring about Carers, A National Strategy for Carers*, United Kingdom, 1999.

Evercare and National Alliance for Caregiving, *Caregivers in Decline, A Close-up Look at the Health Risks of Caring for a Loved One*, United States of America, 2006.

Gendall K and Fawthorpe L, *Decisions about Caring and Working: A Qualitative Study*, Department of Labour, New Zealand, 2006.

Goodhead A and McDonald J, *Informal Caregivers Literature Review: A Report for the National Health Committee*, Victoria University, Wellington, 2007.

Ministry of Health, *Health of Older People Strategy*, New Zealand, 2002.

Ministry of Health, *Living with Disability in New Zealand, A descriptive analysis of results from the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities*, New Zealand, 2004.

Ministry of Health, *The New Zealand Disability Strategy*, New Zealand, 2001.

Ministry of Social Policy, *The New Zealand Positive Ageing Strategy*, New Zealand, 2001.

National Health Committee, *How Should We Care for the Carers*, New Zealand, 1998.

New Zealand Government, *Choices for Living Caring and Working, A Ten-year Plan to Improve the Caring and Employment Choices Available to Parents and Carers*, 2006.

Nikora L, Karapu R et al, *Disabled Māori and Disability Support Options*, University of Waikato, 2004.

Palairt Law, New Zealand Carers Alliance and Carers New Zealand, *Family Carers: A Review of New Zealand Legislation and Related Strategies*, New Zealand, 2006.

Scottish Executive, *Strategy for Carers in Scotland*, 1999.

Statistics New Zealand, *2001 Census Population and Dwelling Statistics*, New Zealand, 2001.

Statistics New Zealand, *2006 Census Population and Dwelling Statistics*, New Zealand, 2006.

Taskforce on Care Costs, *Where to now? 2006 Final report*, Australia, 2006.

The Carers Association, *Towards a Family Care Strategy*, Ireland, 2006.

Appendix A

Guiding Principles of the New Zealand Carers Alliance, April 2006

- **Leadership and Recognition:** Family carers play an essential role in the country's health and social systems. This role needs to be recognised and valued.
- **Information and Education:** Carers should receive appropriate, up to date information and education so they can care safely, and act as effective advocates for themselves, their wider family, and the person(s) they support.
- **Public Services:** Public Services should be timely, co-ordinated, high quality and sustainable.
- **Assessment and Reviews:** Carers and their families should be able to access assessment and appropriate reviews when needed to ensure they receive the support they are entitled to.
- **Proactive Help:** Carers should receive proactive help to effectively meet the financial, physical and emotional challenges of their caregiving role.
- **Workplace:** Ensure quality and flexible work practices so carers can participate in the workforce while continuing in their caring role. Carers also may need assistance to return to the workforce when caring ceases.
- **Diversity:** The diversity of needs of carers should be recognised within public services and society.
- **Tangata Whenua:** The perspectives of Māori whānau and family carers will be recognised, valued and supported.
- **Other Cultures' Perspectives:** Carers' cultural perspectives will be recognised, valued, and supported.
- **Younger Carers:** Children and young people who are carers will be appropriately recognised and supported.
- **Partnership:** Assistance for carers should complement the support, recognition and services provided to the people they support.

Appendix B

Carers Alliance participants are: Access to Medicines Coalition, Age Concern, Allergy NZ, Alzheimer's NZ, ANZMES, Aotearoa Māori Whānau Carers Network, Autism NZ, BALANCE NZ, Brain Injury Association, Cancer Society, Carers NZ, CCS, Cerebral Palsy Society, Complex Carers Group, Cystic Fibrosis Association, Epilepsy NZ, Foster Care NZ, Grandparents Raising Grandchildren, Head Injury Society, Heart Children, Hospice NZ, IHC, Kidney Kids, Lysosomal Diseases NZ, MS Society, Muscular Dystrophy Association, Neurological Alliance, NZ Down Syndrome Association, NZ Federation of Disability Information Centres, NZ Lesbian and Gay Carers Support Network, NZ Organisation of Rare Disorders, NZ Spinal Trust, Parent to Parent, Parents of Vision Impaired, Parkinson's NZ, Rescare NZ, SAMS, Schizophrenia NZ, St John, Stroke Foundation, The Phobic Trust of NZ, TOA Pacific and Young Carers NZ.



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Te Manatū Whakahiato Ora

