

Leaders Comment

We asked the leaders of all political parties to tell us how they will support family, whanau, and aiga carers if they are part of the next government.

Carers are an invisible and vulnerable community of Kiwis.

We hope the leaders' feedback about carers and caring will help with your 2011 voting decision!

The leaders of all major New Zealand political parties were sent the same questions. All parties responded to our questions:

- ? How will you and your party, if part of the next government after November 2011, recognise and support New Zealand's 420,000+ family carers?
- ? Before the last general election all political parties promised to support the implementation of the 2008 Carers' Strategy and its first five year Action Plan. Are you satisfied that your party has delivered on its promise, and will you continue to build on the foundation actions of the 2008 Carers' Strategy to ensure ongoing progress for carers if you are part of the new government after the 2011 general election?

Thank you for contributing your party's response to our election special for family carers, those they support, and older people.

We ask that the party leader respond to this request, as caring crosses all government agencies, and is a broad social issue not confined to, for example, health.

Sincerely,

Carers New Zealand and the NZ Carers Alliance of 45 national not for profits

ACT PARTY Leader Dr Don Brash

Thank you very much for giving the ACT Party the opportunity to talk about the important role carers play in the lives of many New Zealanders. I agree with the 2008 Carers Strategy that those who take time out of their lives to care for people, often family members, who are elderly or disabled, are truly the unsung heroes of our community.



ACT is yet to finalise its health policy for the 2011 election. It will be released in due course, but in the meantime I can outline the general principles that ACT adheres to when looking at health.

ACT believes it is vital for individuals and families to be the first support network for people when they need assistance. Families know their loved ones far better than the state or other agencies do, so when they can provide their own care it is often better than anything anyone else could provide. This is no doubt why many people who need care choose to stay in their own home to be looked after by their family.

ACT also believes in choice and personal responsibility in health care. Individuals should be able to make their

own decisions about the kind of care they receive, not be forced to use the care provided by the state system.

ACT supports a system where people save towards funding the cost of their own health care and purchase their own health insurance. This would be feasible where there is a much lower tax burden, so people could keep more of their own money. So when someone gets sick, they are able to use their savings and insurance to pay for the treatment they want. Under this system, those who want to stay at home when they are elderly or afflicted by illness or disability would be able to make the choice for themselves to use their money to pay a family member or anyone they choose to help look after them. This system is far better for the person in need of care as they would be empowered to make the choice to stay at home or to enter a care facility – their money would go where they chose.

Such a system would also greatly benefit carers. Carers often make significant

personal and financial sacrifices to look after another person. Under a system of choice, those people would have the ability to pay carers for their time as they would be able to spend their own health money where they wish.

The sad reality is that, under a health system run by a state monopoly, people have little control of their own health care and people like family carers miss out.

Providing choice in health care is the most effective way of supporting our volunteer carers. When the government makes all the health care decisions, many people always miss out and one of those groups is carers. When people can choose for themselves, they can direct their health money to the areas they think are best for them – and many New Zealanders choose to be looked after by their own families.



"ACT SUPPORTS A SYSTEM WHERE PEOPLE SAVE TOWARDS FUNDING THE COST OF THEIR OWN HEALTH CARE AND PURCHASE THEIR OWN HEALTH INSURANCE ... FEASIBLE WITH A MUCH LOWER TAX BURDEN ..."

GREEN PARTY Co-Leader Metiria Turei

Valuing the often unpaid and informal work of caring is a core Green Party principle.



Our policies are written with this principle in mind, and our health, disability and income support policies contain specific measures to recognise and support New Zealand's 420,000+ family carers.

Central to the Green Party's approach is improving financial support for carers. We support the provision of benefits to single parents, partners of beneficiaries whose primary responsibility is caring for dependents, and those who care for impaired adults, without the imposition of a work-test. We would also reform work-test requirements for those currently on work-tested benefits, to take into account the valuable contribution of voluntary work, including caring.

For those caring for disabled children, we would review the Child Disability Allowance with a view to increasing the levels, in acknowledgement of the extra financial needs associated with raising a child with special needs.

We would increase funding, personal support and training for family carers, home help, and personal carers across the board. For paid carers, we would immediately increase the minimum wage to \$15 an hour.

We believe these policies are very consistent with the 2008 Carers' Strategy, and continue to support the Strategy and advocate for progress towards its implementation.

From outside Government, we have been an effective voice for carers, and for those with impairments. A key achievement in the current Parliamentary term has been the Government's adoption of our proposal to establish a full-time Disability Commissioner within the Human Rights Commission, a proposal that started life a member's bill by Green MP Catherine Delahunty. While the new Commissioner will focus primarily on the rights of disabled people, we believe a Commissioner dedicated to disability issues can only be positive for

advancing care-work issues as well.

Catherine Delahunty has also been actively supporting the right of family members who care for disabled adults to be paid for the important work that they do. As readers will no doubt be aware, nine families have been engaged in court action since 2009 seeking the right to be paid for the care of disabled family members. Their case was upheld by the Human Rights Review Tribunal and the High Court, but the Ministry of Health has filed for a hearing at the Court of Appeal.

The Greens support individualised funding for all people living with impairments and their families who wish to choose this option, and we support the plaintiff families in this court case in their call for innovative solutions for disabled care. Disabled people must be supported to make independent choices, and when that means family members caring for disabled relatives, they should be paid for this work, just like a contract carer.

Catherine held a successful forum on the right to pay family members in Parliament in March 2011. Plaintiff Cliff Robinson spoke at the forum, along with representatives from the Human Rights Commission and the Carers' Alliance.

Since then, Catherine has continued to point out the injustice of the Ministry of Health spending over a million dollars to fight these already exhausted and vulnerable families through the courts.

Finally, we have recently launched an online project which explores the value of unpaid work in a compassionate economy. We asked a number of prominent women to share their visions of a compassionate

economy, and several wrote about the importance of valuing care work and other unpaid activities. These contributes can be viewed online at www.greens.org.nz/compassionateeconomy

Whether in Government or not, the Green Party will build on our successes and continue to work towards our vision of a smart, green, compassionate economy that works for everyone.

Other points of Green Party policy that may be of interest to carers:

- Promote team-managed, home-based primary care for at-risk disabled and older people.
- Require all service providers to document that families/whanau and other significant people in the lives of people with or recovering from mental illness have provided input into treatment planning.
- Increase aged care sector funding, particularly the funding for residential care and home support.
- Promote team-managed, home-based primary care for at-risk older patients.
- Significantly increase funding for the aged and disability care sector.
- Work to develop services that enable older people, and those receiving palliative care, to stay in their homes for as long as possible and for as long as they choose.



"WE WOULD INCREASE FUNDING, PERSONAL SUPPORT AND TRAINING FOR FAMILY CARERS, HOME HELP, AND PERSONAL CARERS ACROSS THE BOARD. FOR PAID CARERS, WE WOULD IMMEDIATELY INCREASE THE MINIMUM WAGE TO \$15 AN HOUR. ... FOR THOSE CARING FOR DISABLED CHILDREN, WE WOULD REVIEW THE CHILD DISABILITY ALLOWANCE WITH A VIEW TO INCREASING THE LEVELS ..."

LABOUR PARTY Leader Phil Goff

In April 2008, the Labour-led government published the New Zealand Carers' Strategy, a major step towards valuing the immense contribution of carers to New Zealand.



The Carers' Strategy was developed in a partnership between government agencies and the New Zealand Carers Alliance.

We believe carers play an important role in assisting friends and family members who need help with everyday living because of ill health, disability or old age. Improving support for informal carers is important for developing strong, healthy families, and meeting future challenges of providing care.

The National Government has neglected family carers.

The Carers' Strategy has lost momentum because of budget constraints, restructurings, and health spending that is focused on facilities rather than community supports.

Further to that, much debate remains around the Solicitor General's decision to appeal a High Court ruling that parents

caring for disabled adult children were eligible for financial support.

The High Court has backed a Human Rights Tribunal ruling which found a Ministry of Health policy to pay carers only if they were not related to the patient was discriminatory.

Labour does not support the Solicitor General's decision but will watch with interest the Court's final ruling to see whether the Government will be required to comply with it.

We will not pursue any further court action if elected and will work with carers and their representatives to formulate a solution so that they are fairly compensated for the work that they do and for the sacrifices they make.

Another issue which the Government has refused to address has been Aged Care. In Opposition, Labour and the Greens worked with Grey Power to undertake an Inquiry into Aged Care, *What the Future Holds for Older New Zealanders*.

As a priority, after the election we will establish a working party to address the recommendations from this Inquiry in a way that reflects the fiscal constraints New Zealand now faces.

A key recommendation addressed

by the report is around investigating appropriate remuneration and respite care for family carers, and home based respite care for dementia sufferers.

Labour plans to build on the Carers' Strategy and review the work that has already been done to ensure its five year Action Plan is being implemented and achieved. Labour will be proactive about policies to ensure that New Zealand and New Zealanders cope well with the challenges of ageing and caring in the coming decades.

We will work in close partnership with the not for profit sector to support carers across age groups and caring situations.

Labour recognises the importance of developing training programmes to ensure that family carers who give support to ill, elderly, and disabled loved ones can do so safely.

We will also ensure that carers' valuable skills are recognised in their role as New Zealand's biggest health workforce.

A lack of career path for employees in the caring and support workforce results in difficulties in recruitment, retention and employee job satisfaction.

We will encourage and support employers to recognise carers' skills and investigate ways to support them into employment.

Labour will also work with Carers NZ, Business NZ and employers to ensure that carers have helpful information, advice and opportunities for flexible work so they can remain in paid employment.

"LABOUR WILL BE PROACTIVE ABOUT POLICIES TO ENSURE THAT NEW ZEALAND AND NEW ZEALANDERS COPE WELL WITH THE CHALLENGES OF AGEING AND CARING IN THE COMING DECADES. WE WILL WORK IN CLOSE PARTNERSHIP WITH THE NOT FOR PROFIT SECTOR TO SUPPORT CARERS ACROSS AGE GROUPS AND CARING SITUATIONS."



MANA PARTY Leader Hone Harawira

The biggest problem facing families today is the cost of living. When families struggle to pay their grocery bill, rent and power then something is seriously wrong.



Wage and salary earners already work longer hours than comparable countries but are still fighting to make ends meet. Most are worse off than their parents and our society is less stable with large and growing social problems. This is disgraceful in a land of plenty. Inequality is increasing dramatically. Most

are feeling the pinch while the richest 150 New Zealanders last year increased their wealth by \$7 billion.

Mana would lower taxes for wage and salary earners and increase taxes on unearned income. We would abolish GST completely and make the first \$15,000 earned tax free. This would be paid for with a proper capital gains tax, a Hone Heke tax on financial transactions, and a progressive taxation system which targets high and unearned income rather than wages and salaries.



"MANA WOULD LOWER TAXES FOR WAGE AND SALARY EARNERS AND INCREASE TAXES ON UNEARNED INCOME. WE WOULD ABOLISH GST COMPLETELY AND MAKE THE FIRST \$15,000 EARNED TAX FREE."

HAVE YOUR SAY ON ELECTION DAY!

Voters who are unable to get to a polling place on Election Day can vote in advance or apply to cast a special declaration vote.

Advance voting makes it easy for anyone who can't get to a polling place on election day, starting Wednesday, 9 November, until the day before election day. Information about where, when and how to vote in advance will be available online at www.elections.org.nz or Freephone 0800 36 76 56 from 2 November.

Information on advance voting will also be in your EasyVote pack, received about a week before election day. Voters who can't get to an advance polling place or a polling place on election day, who enrol after 26 October, are on the unpublished electoral roll, or who vote outside their electorate, will need to cast a special declaration vote. Special declaration

voting papers are available from advance polling places, polling places or returning officers from the Wednesday 9 November, and on election day. Returning Officers can issue special declaration voting papers by post to anyone who can't get to a polling place or advance polling place. Before election day you can complete and post the application for special declaration voting papers to your returning officer; or ask someone else to complete the application for special declaration voting papers and take it to your returning officer or advance voting place; or apply by fax, email or telephone to your local returning officer.

On election day you can ask another person to apply to collect your voting papers for you from a polling place. All voting papers must be returned to a polling place by 7pm on Election Day, Saturday 26 November.

HAVE A VOICE AND A SAY!

Please help us to build a united voice for carers, those they support, and elderly New Zealanders. You can have a voice and a say in the We Care! campaign by:

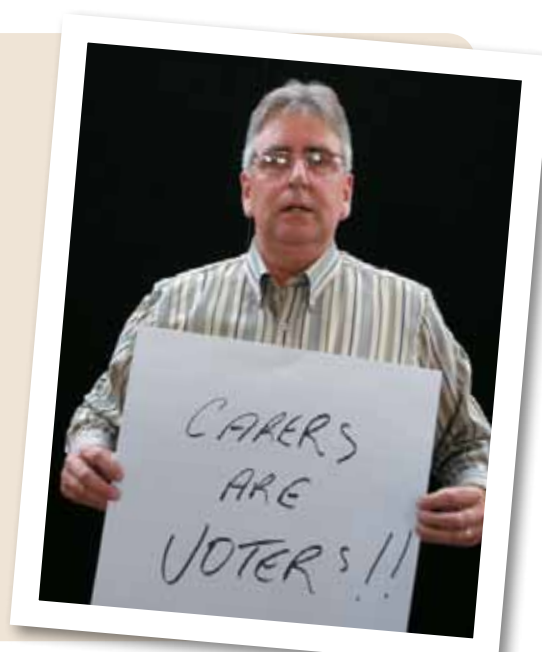
1 Distributing campaign postcards asking the Prime Minister to take a direct interest in the role and welfare of carers. Request cards by phoning 0800 777 797!

2 Visiting www.facebook.com/WeCareNZ and 'Liking' the campaign. More than 14,600 Kiwi Friends so far!

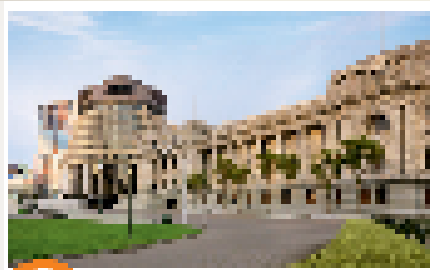
3 Visiting www.wecare.org.nz It takes just a few seconds to send our campaign email to the Prime Minister!

4 At the website, you can also upload a photo message like those you'll see at the site. It's easy! Just write your name on a piece of paper, take a photo, and upload it! Or, send your picture to us to upload: sara@carers.net.nz

5 Arrange a meeting with your local MP and ask how they will support carers, caring, and older people after the election.



VOTING ON ELECTION DAY IS EASY



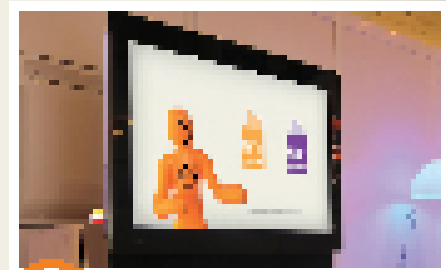
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Find out how to vote on Election Day. You can call 1-800-368-6848 or visit www.elections.ca for more information. You can also visit your local election office for more information.



2

Make sure you understand the instructions on the ballot paper. You can ask for help if you need it.



3

Follow the instructions on the ballot paper. You can ask for help if you need it. You can also ask for help from a family member or friend.



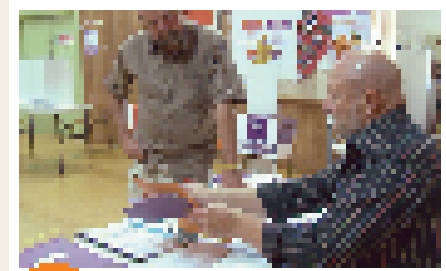
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Make sure you understand the instructions on the ballot paper. You can ask for help if you need it. You can also ask for help from a family member or friend.



5

The sign will tell you where to go.



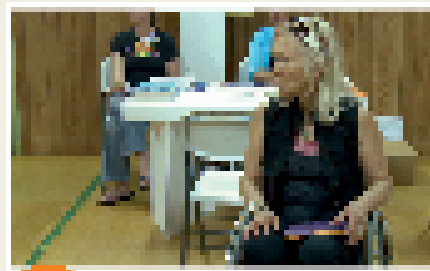
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The sign will tell you where to go. You can ask for help if you need it.



7

You can ask for help if you need it. You can also ask for help from a family member or friend.



8

You can ask for help if you need it. You can also ask for help from a family member or friend.



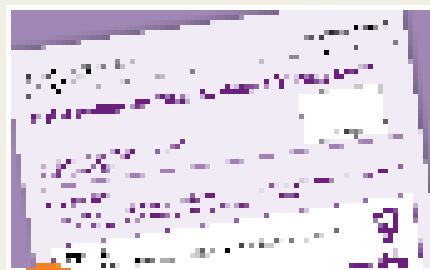
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You can ask for help if you need it. You can also ask for help from a family member or friend.



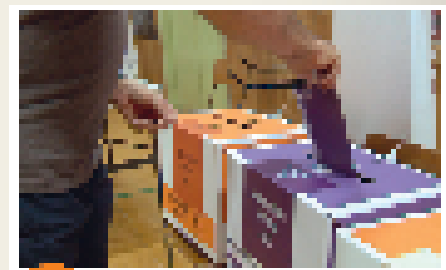
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You can ask for help if you need it. You can also ask for help from a family member or friend.



11

You can ask for help if you need it. You can also ask for help from a family member or friend.



12

You can ask for help if you need it. You can also ask for help from a family member or friend.



**YOU'VE VOTED!
THAT WAS EASY!**

For more information, visit www.elections.ca or call 1-800-368-6848.



1-800-368-6848



www.elections.ca

ELECTIONS
2025

1-800-368-6848
www.elections.ca

MAORI PARTY Co-Leader Tariana Turia

Tena koe i runga i nga tini ahuatanga o te wa

The Maori Party believes that carers are doing New Zealand a great service in

supporting the person they care for in their daily life and enabling them to stay closely connected to their family and community, despite the huge pressure they may be under because of ill health, ageing, or disability.

The Maori Party will continue to support family carers as we believe their role is fundamental to the wellbeing of whanau and families.

The Co-Leader of the Maori Party, Hon Tariana Turia, in her role as Associate Minister of Social Development and Employment, was appointed the Minister responsible for the Carers' Strategy.

One of her first priorities was to launch *A Guide for Carers: He Aratohu ma nga kaitiaki*, which was released in September 2009.

The Maori Party is also aware that despite the support and assistance that is available from government and non-government agencies, there is often a disconnect with the carers which results in support and assistance being under-utilised.

A Maori Party initiative in Budget 2009 saw the Government expand access to income support for carers, and to produce information for people looking after their relatives who are sick or disabled.

Tariana Turia was concerned that those who are caring for friends and relatives may not necessarily be aware of the specific support that is available, including the Domestic Purposes Benefit – Care of Sick or Infirm – which is a particular form of income support from Work and Income available for people



"THE MAORI PARTY WILL CONTINUE TO SUPPORT FAMILY CARERS AS WE BELIEVE THEIR ROLE IS FUNDAMENTAL TO THE WELLBEING OF WHANAU AND FAMILIES. ... CARERS ARE DOING A GREAT SERVICE IN SUPPORTING THE PERSON THEY CARE FOR ..."

with significant caring responsibilities.

As a result of her direction, Work and Income regional health and disability advisors have been instructed to promote this support, to ensure that carers who can get financial help do in fact receive it. Subsequent to that direction, events sponsored by the Ministry of Social Development were established to promote DPB – Care of the Sick or Infirm.

Another priority initiated by Tariana in her role as Minister, was to work with health sector groups and medical practitioners to improve their understanding about financial assistance available for carers. Associated with this, was her support for a carer wellbeing and learning programme including ACC injury prevention for carers through regular excerpts in the Family Care magazine.

She also established a Ministry of Health Review to improve training programmes for informal carers. Over the next year, the Ministry of Health will review respite care with a view to improving the design, purchase and delivery of respite services.

Another area where the Maori Party has been successful is in support for people with disabilities. The 2011 budget secured an extra \$130m, mainly for training which will help our people who live with disabilities to live more independently and it will also bring more carers who are qualified.

They will be able to provide some well-earned relief for our carers who work so hard now. Other areas of disability support that received extra annual funding in this

year's Budget included \$1.5m for respite for carers to be able to take a short break.

The Maori Party will continue to support the good progress being made to implement the New Zealand Carers' Strategy and Five Year Action Plan and is committed to ensuring that we continue to work with the Carers' Alliance to develop better supports and information for New Zealand's wonderful community of carers.

Finally, the Maori Party would like to see family members able to access funding for looking after relatives. The Maori Party supports whanau-based and home-based care options for older people and people with disabilities or ill-health to choose to remain in their homes, connected to their family and social networks.

The current rules do not allow family members to be paid for caring for a relative which we believe is inconsistent with the values of whānau ora – manaakitanga, kotahitanga, whānautanga.

We, as a nation, must demonstrate our labour of love in rewarding the expertise of caregivers and take actions which demonstrate that we value the wellbeing of our older, disabled and ill New Zealanders.



WE CARE! CAMPAIGN MILESTONES

Launched 23 May, 2011 at Auckland's Aotea Centre
50,000 postcards addressed to Prime Minister John Key have been distributed, seeking his direct interest in the welfare and needs of family carers
540 emails have been sent to the Prime Minister at www.wecare.org.nz by family carers and supporters

Every New Zealand Member of Parliament has received a letter seeking their support for the 2008 Carers' Strategy and full implementation of its Action Plan
We hope you will add your voice to ours. Have a say in the We Care! campaign! *Learn more on page 25.*

NATIONAL PARTY Leader John Key

As Prime Minister, I strongly value the contribution that family carers make to our communities.



I have nothing but admiration for those of you who dedicate time to looking after people who are ill, elderly, or living with a disability. You do a great and valuable job. Your contribution was clearly on display in Christchurch in the aftermath of the earthquakes. Although many carers faced damage to their homes and considerable difficulty getting around due to dangerous conditions and road closures, they still went out of their way to look after the people who relied on them. I know that the people of Canterbury are very grateful for the support and dedication that the carers' community showed during this difficult time. The National-led government is delivering on its promise to provide better, sooner, more convenient health care to the people of New Zealand. An important part of

that is our work to improve the quality of care for people with disabilities and their carers. I understand that recognising and supporting people who choose to care for their family members is an important issue for New Zealanders. The Government is updating training programmes for informal carers, making respite care for them more flexible and reliable, and increasing residential respite services for older people.

This year the Government provided an extra \$4 million a year for respite services for people with dementia. That comes on top of \$5 million increased funding a year to improve the availability of respite care for older people. The extra money is estimated to fund 6600 more respite bed days, and people and their carers now have greater choice as to whether that respite bed is in a rest home, at home, or in community respite care.

The Government realises that people with disabilities and their families want to have more choices about how they use taxpayer funded support. Therefore, we are working with the disability sector to develop a new, more flexible model of support. We are also

improving liaison, education, and training for carers looking after people with a mental illness, and we've established a community-based crisis respite service to give patients and carers a break where needed. The Government is also working towards greater support for people with cancer and their carers. This work that we are doing to improve the quality of care for people with disabilities and their carers is supported by other work we are doing in the public health service, such as introducing spot audits in rest homes. This Government has made good progress, and we are full of enthusiasm for the work ahead. As carers, you play a vital role by supporting people in their daily lives and helping them to stay connected to their family and community.

I want to thank you for everything you do to help the ill, elderly, and people with disabilities in their communities.



NEW ZEALAND FIRST Leader Winston Peters

Thank you for your letter requesting our answers to some important questions regarding carers and in particular the 2008 Carers' Strategy.



In regards to your first question, and a promise to support the Strategy in 2008 by those who were voted into government, as you can appreciate we were unfortunate to have missed being part of government for the past term. But we are working towards rectifying this at the 2011 election. We believe we have a lot to offer all New Zealanders. We understand that there are a substantial number of people caring for the vulnerable in our society, and it is a role that is taken for granted by governments and society in general. It is imperative that people who suffer from mental illness, disability, the elderly and those who suffer from addiction are well cared for; we understand that family are often in the best position to do this. We have a growing population of people who are aged, and

care for these people is very important to the New Zealand First party. From your website we understand that in 2006 there were more than 420,000 people supporting those who require ongoing care. This is a substantial number of New Zealanders whose contributions to the health and welfare of others often go unrecognised. It is not an easy role, caring and attending to another person's physical and mental wellbeing. As a party we fully appreciate that it is important that those who are part of government support carers to have appropriate training, opportunities for breaks, and to receive fair and equitable financial support. We are well aware of the costs of residential or rest home care, which often far exceed the cost of care provided by family or caregivers. We are unable to predict how New Zealanders will vote this coming election but hope they will see the benefits of having the New Zealand First party part of the governance of this country. We have always been a party concerned with the health and welfare of all New Zealanders and, with free health care for under 6's and the benefits of a Super Gold card for our over 65's, we see

this as going some way towards helping vulnerable New Zealanders. To do more, we must have New Zealanders provide us with their party vote. We would fully support any policies that enable our most vulnerable to lead productive lives and to experience a good quality of life. We support the Carers' Strategy and would endeavour to work and collaborate with groups and organisations who are working hard to make things better for New Zealanders regardless of their circumstances. Carers NZ's four principles of recognising diversity, being proactive, enabling carers and being inclusive are sound principles that would have our full support. We therefore encourage your supporters to give us their party vote so we can benefit all New Zealanders and work with Carers NZ in its crusade to support carers, who in turn support our elderly, disabled and mentally ill citizens.



UNITEDFUTURE Leader Peter Dunne

Aged Care

It is UnitedFuture policy to:



1. Ensure that there are sufficient community nurses and other welfare agencies so that people can be treated at home where possible.
2. Ensure that funding for the aged care sector covers staffing costs in both residential services and in-home care, to improve certainty and transparency, and quality of care.
3. Provide better incentives for the nursing, rehabilitation and treatment of the elderly in non-medical institutions, such as rest homes, at home and in retirement villages.
4. Support pay parity between nursing staff across all nursing sectors.
5. Re-assess the way in which the government funds aged care services, as part of a broader inquiry into future health care costs.
6. Ensure that hospices are properly funded so that high quality compassionate palliative care is available.
7. Develop apprenticeship-style training for caregivers, allowing them to acquire qualifications while working in residential or home care environments, to ensure that they can develop a career path in this field.
8. Investigate the introduction of a carer's allowance for those who stay at home to look after elderly relatives, from the starting point of providing a limited period of paid leave for those who take time off work to care for their parents in the final stages of their life.
9. Ensure adequate funding for the aged care sector to cover staffing costs in both residential services and in-home care, to improve certainty, transparency, and quality of care.

Disabled Care

UnitedFuture supports the intentions and direction of the NZ Disability Strategy, but believes that there is an unacceptable gap between policy and practise in many service areas.

Workforce

Society should not just be judged by how it treats its most vulnerable members, but also by how it treats those who support and care for them. It is UnitedFuture Policy to:

1. Ensure wage rates are included as part of all government contracts with providers; the starting rate should be \$18/hr.
2. Introduce a "Caregivers Allowance" for those currently providing unpaid support.
3. Ensure that appropriate respite care is available in every region.
4. Intensify workforce planning so that greater certainty is gained around issues of:
 - Scopes of practise
 - Qualifications and Training
 - Assistance for voluntary agencies (like RDA) to train volunteers
5. Fund regular evaluations and up-dates of training content by the Industry Training Organisation, including input from clients.
6. Ensure that ongoing staff training is part of government contracts.
7. Develop compulsory content for all participants in Teacher Education regarding teaching students with disabilities.

Funding Disabled Care

It is UnitedFuture Policy to:

1. Develop individualised packages of support.
2. Increase the flexibility between household management funds and personal care funds.
3. Extend contract times to allow sufficient time for planning and service development in a sustainable way.

4. Increase Ongoing and Reviewable Resourcing Schemes (ORRS) funding to schools by 10% and ensure that it is not pruned if a student makes academic progress but remains disabled.
5. Allow bulk funding for services separate from benefit income.
6. Create a separate funding stream for workforce including wages so that wage increases can be tagged separately from general operations funding to Providers.
7. Establish a health levy (or National Insurance Scheme) to provide a designated fund to address the disparity between trauma-based (ACC) and non-trauma based impairment.

Caring for Children with Disabilities

UnitedFuture understands that parenting children and young people with disabilities brings many strains and stresses; these are complex areas but we will:

1. Introduce a Caregivers Allowance for those currently providing unpaid support;
2. Ensure that sufficient and appropriate respite care is available in every region;
3. Establish advocacy services so that parents have more energy to give to parenting rather than chasing entitlements;
4. Ensure that meaningful consultation occurs with carers and clients when services are audited;
5. Address workforce planning, pay rates and qualification issues for people in this sector.



"UNITEDFUTURE UNDERSTANDS THAT PARENTING CHILDREN AND YOUNG PEOPLE WITH DISABILITIES BRINGS MANY STRAINS AND STRESSES; THESE ARE COMPLEX AREAS BUT WE WILL INTRODUCE A CAREGIVERS ALLOWANCE FOR THOSE CURRENTLY PROVIDING UNPAID SUPPORT ..."



*Dear Prime Minister and party leaders,
I hope you will read my story about caring
for my elderly father, a World War II veteran.
I wrote it to support the We Care! campaign.
I'm sure my experiences will be familiar to
thousands of other Kiwis caring for ageing
parents. Thank you for listening.*

ROSEY DUNCAN, NELSON

My Dad was a busy and productive man who worked hard and led a full life.

Nicknamed The Mighty Atom by friends due to his energetic 'up and do' attitude, Dad served as a Flying Officer in the RNZAF during WWII (524 Squadron).

His post-war passions were rugby and pig hunting. He was also a fiendish tennis player, and spent any other spare time riding his Army Indian motorcycle or bush-bashing his way to some remote location.

Dad spent 35 years as a school teacher, raised a family of four children, and simultaneously farmed a hundred head of sheep, combining his work and family duties with drenching, lambing, shearing, dagging, and haymaking.

Like all veterans who had served their country, my Dad deserved to be well cared for as old age crept up on him.

Supporting Dad

Dad was 70 and I was 30 when Mum died.

I began to spend more time with Dad, a few hours most weeks, to keep him company and attend to chores that Dad had relied on Mum to do: household cleaning, ensuring bills were paid on time, and helping with shopping.

Then, as dementia crept in, I began to accompany Dad on visits to the doctor. Whenever the doc asked how he was, Dad would reply "good, thank you"; it was up to me to ensure that he described his true health situation to the doctor.

After 10 years of gradually increasing needs, Dad suffered the first of several spinal fractures due to severe osteoporosis. I can't imagine how excruciating it must be to have a fracture in your spine.

Around this time Dad also failed his driving test. Although he tried to be stoic, Dad became much less mobile, and I started taking him for drives so he could have a change of scenery.

When I accompanied him to have his cataracts removed, Dad was unable to self-administer the eye drops, so I arranged a roster of people to help

... myself, neighbours, and a nearby community worker.

I spent uncounted hours cooking meals for Dad and putting them in his freezer, visiting almost daily to ensure something was thawing for him to heat and eat each evening. Later, I organised for Meals on Wheels to be delivered.

As Dad's other needs increased, I could no longer find time to do his household chores. Frugal though he was, I managed to convince him to pay for a weekly cleaner. However, I now had to provide a task list for the cleaner, check that everything had been done, and purchase the required cleaning items, as Dad could not manage those tasks.

Changes

One afternoon I visited Dad and found him dressed, but kneeling beside his bed. He had been there all day, unable to get up. The doctor diagnosed congestive heart failure.

I now felt that Dad needed someone to visit him at least once a day, so arranged various services to do this, with people from his church making occasional weekend visits. I also visited Dad several times per week.

A geriatric assessment meant Dad qualified for some in-home care, and a helper came twice weekly to assist with showering. Dad hadn't been showering properly for some time, preferring a splash in the sink instead. I was concerned about his personal hygiene and potential infections, as well as safety in the shower, so it was a relief to get this help.

I managed Dad's medication routine, organising his daily pills and checking that he took them. The cleaner and shower helper were also instructed to check this as part of their routines.

With the cleaner, Meals on Wheels, the shower assistance, and visits from church friends, Dad had regular visitors, but keeping everything organised certainly required a juggling act on my part.

In addition were irritating little things to deal with, like telephone companies





changing his toll services, and having to tell them to leave Dad alone. Other administrative tasks fell to me as Dad's Power of Attorney.

After awhile, I no longer felt able to go on holiday or to be away from Dad for longer than three days.

If he needed to use the toilet, Dad had four options: ring the bell for assistance (he couldn't remember that he had that option); wait and hold on (impossible); pee in his incontinence pad (probably the most regular option); or go to the toilet with my assistance when I was present.

Advocacy

When Dad was 83, he agreed to move to supported accommodation.

My partner and my sister, who was visiting from the United Kingdom, helped to pack up Dad's home of 20 years, label his clothing, and transfer his belongings to his new abode.

At first Dad occupied an apartment in an aged care facility, paying for 'rest home care'. However, this was not fully provided to apartment dwellers, and I regularly needed to advocate on Dad's behalf.

At meal times there was simply an announcement on the intercom system; if residents did not attend, they did not eat!

If Dad was ill his meal was delivered to his apartment, but it was just left on the bench; no one ensured that Dad ate it, even though he was unable to balance a tray on his lap.

At night Dad regularly fell out of bed, but staff said management did not permit them to assist between midnight and 5am.

Dad soon became very ill and was

transferred to the hospital where, with appropriate care, he quickly recovered. My sister and I were angered and saddened by this neglect. Fortunately we were able to find a vacancy and relocate Dad to another aged care facility, which had a smaller room but a more caring manager and a higher ratio of staff.

Staff too busy

Nonetheless, Dad still needed my assistance whenever I visited.

I explained to staff that if Dad made a very quiet prolonged noise while exhaling, it meant his back was extremely sore (by now he had suffered several spinal fractures). I would request a heat pack and rub his back at these times, but I think heat packs were only provided if I asked for them; the staff were too busy, and Dad's expression of pain was barely perceptible.

It was especially distressing to arrive for visits to find Dad lying in a saturated incontinence pad. Staff applied a toileting routine, but sometimes Dad couldn't wait.

I often took Dad to the toilet during my visits, as it seemed more straightforward than ringing the bell and waiting for the staff to do it.

If Dad needed to visit the dentist, I would have to arrange a wheelchair taxi and accompany him so he did not become disoriented.

If Dad was too hot or cold, I would help him to remove or put on clothing, as he could not do so without help.

I don't think most of the facility's staff were aware that Dad was unable to cut his own fingernails; it was me that did that.

Dad suffered from constipation, and I worried that his diet did not include much fresh fruit, so I would regularly shop for Dad to try to ensure he always had a supply of fruit (and some sweet treats). Later on, I had to remind him to eat the fruit while I visited.

I also worried that Dad was bored. His low to medium level of dementia meant he wasn't able to hold a conversation easily or read a book or newspaper, but because I knew him and his past, I was able to keep

him engaged in a conversation.

I brought photographs to look at with Dad while he reminisced and answered my questions.

Other days I took Dad for drives, or for walks in the wheelchair around the neighbourhood (staff did not have time to do this). If Dad needed anything that wasn't available at the facility, I would buy it. If anything needed mending, I would mend it.

Caring for carers

I worked part-time so I could devote extra time to Dad and ensure that he was comfortable and not in pain.

I never resented supporting Dad in any of these ways, although it was time and energy-consuming, and my partner and I sacrificed other activities and potential income.

It did seem inconsistent, however, that state funding is available to some types of carers and caring, but not to others.

In our ageing society, ensuring fair access to funding and other kinds of help will allow families to make the choice to care, as I did for my Dad.

Ways to help family carers could include access to free training, adequate assistance with tasks such as showering (Dad only received showering assistance twice a week, which wasn't enough), night respite (someone who can stay on watch overnight), and an 0800 service to help carers learn about and access the support they need. And instead of a benefit, perhaps there could be a system whereby 'family elected carers' could become 'temporary employees' of organisations that provide state funded care.

These are my suggestions; no doubt carers have many other ideas to ensure available resources are fairly shared. **FC**

