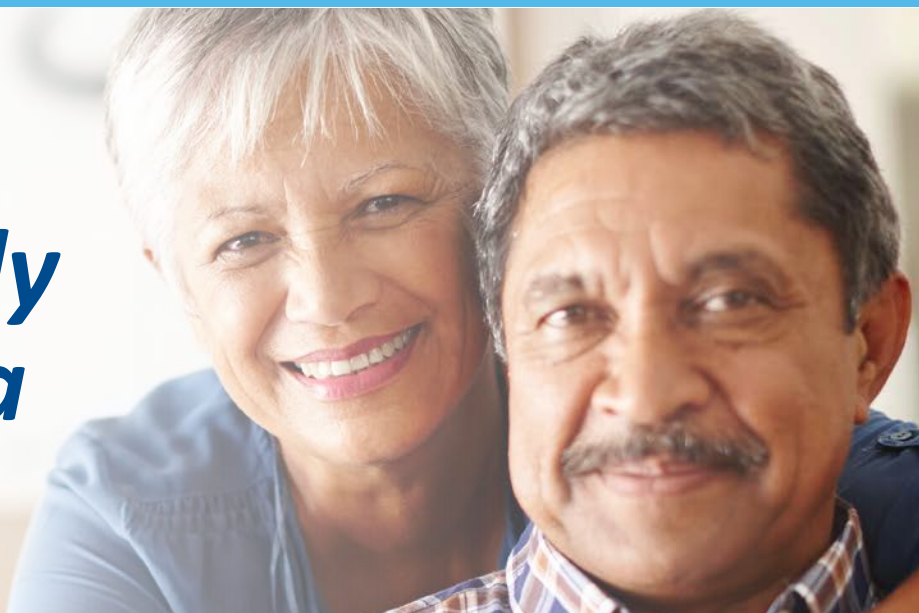


Govt urged to act quickly on dementia challenge



The New Zealand Framework for Dementia Care must be implemented urgently and in full, Alzheimers NZ has told the new Labour-led Government.

Releasing the organisation's official Briefing to the Incoming Health Minister, Hon Dr David Clark, Chief Executive, Catherine Hall, urged the Government to act now to implement the Framework.

She said it must be implemented in full because it outlines sensible and urgently-needed steps that will mitigate some of the long-term impacts dementia will have on New Zealand society. The Framework was prepared by the National Government in 2013.

The recommendations in Alzheimers NZ's briefing to the incoming Minister (BIM) focus on providing

enhanced support for people living with dementia.

The recommendations involve four key initiatives that are outlined in the Framework and which Alzheimers NZ wants to see funded in Budget 2018. These are:

- Extend existing health promotion approaches to obesity, diabetes, and cardio-vascular disease to include middle aged and older adults by including information that will reduce the risk or delay the onset of dementia.
- Create the 'navigation services' outlined in the Framework.
- Provide 12 months of post-diagnostic support for people diagnosed with dementia, and their family / whānau and care partners.
- Produce high quality hard copy information to support people diagnosed with dementia, and their family / whānau.

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Other measures Alzheimers NZ wants in place include:

- Promoting and creating a dementia-friendly New Zealand, including through a national public awareness programme.
- Ensuring care partners can take planned breaks and support their own health by having access to a range of respite care options.
- Following the WHO recommendation to “collect and use the necessary data on epidemiology, care and resources relating to dementia [in New Zealand] in order to implement relevant policies and plans”.

The Alzheimers NZ BIM also proposed that Government works alongside non-government organisations to fully implement the Dementia Framework.

The rationale, according to Catherine, is that, while Government funding is needed, the NGO sector brings additional funds, volunteers, solutions, and community knowledge and contacts that will be vital to provide services ‘on the ground’.

“This is an international problem, and other countries are actively focussed on tackling the issue with a range of initiatives.

“New Zealand, however, is lagging well behind and we need to act now or, as a country, we will face major personal, societal and fiscal impacts.”

Alzheimers NZ aims to brief the Government in more detail on these issues in the new year.

A full copy of the BIM is available on the Alzheimers NZ website (www.alzheimers.org.nz).

A message from our Chief Executive

2018 promises the launch of some exciting projects.

As you read this I will have recently returned from an event in Rotorua where I presented four Bupa retirement villages and care homes with certificates that recognised their new status as accredited Dementia-friendly organisations.

We congratulate Bupa on this achievement and look forward to more organisations joining our Dementia-friendly Recognition Programme in 2018.

Recently, we published our Briefing to the Incoming Minister (BIM), Dr David Clark, see our lead story. Our BIM was an extensive document that provided the new Minister with a detailed oversight of the dementia challenge facing New Zealand now and in coming years.

In it, we explained that, as a country, we cannot afford to do nothing about this issue, and we offered several recommendations about what should be done. For more information on our BIM, visit www.alzheimers.org.nz for a copy.

The last month has been occupied by our planning for 2018, and the biggest challenge for me as Chief Executive has been curbing the unbridled enthusiasm of our very keen team for ‘taking on the world’ with a range of big picture projects.

As is always the case, we have prioritised the projects and activities that we feel will best deliver for people living with dementia and their care partners, and we are excited about getting stuck in again in January.

The first initiative to get out of the blocks in 2018 will be the launch of our Dementia Friends programme, the

aim of which is to enrol Kiwis – as the name suggests – as Dementia Friends. This will involve educating them about dementia and its impacts, and supporting them to be more dementia-aware and more supportive to those who may be affected by dementia.

Watch this space for more information on the programme that we believe will help significantly to lift awareness of dementia and reduce any stigma attached to it.

Alongside our Dementia Friends programme is our campaign to recruit more business organisations into our Dementia-friendly Recognition Programme, and the work we are doing with our Member organisations to roll out our finalised Services and Standards model.

This model has now been well trialled and will go a long way towards ensuring all the community support services provided by Members of Alzheimers NZ are consistent and targeted specifically to the needs of people with dementia and their care partners.

So, while 2017 has been busy and productive, 2018 promises to be no less so.

But before we hit the ground running we will all take a well-deserved break – we wish all our readers a safe and restful holiday season.



Happy holidays
Catherine Hall
Chief Executive

Dealing with a diagnosis of dementia

Everyone has their own way of adjusting to a loved one's diagnosis of dementia.

The diagnosis itself can provoke a whole range of difficult emotions, including shock, anger, fear and denial.

As time goes by, everyone finds their own way to adjust, often finding in themselves an inner strength and resources they didn't know they had.

John's* initial response to his wife Muriel's* diagnosis of vascular dementia was a shock. Muriel had experienced post-natal depression after the birth of their last child and was prone to anxiety. But an increase in anxiety and forgetfulness in later years had started to signal that something else was wrong.

Once the diagnosis was made, John says "My biggest challenge was coming to terms with the grief and loss of starting to lose the person I knew as my wife".

John gathered useful information from his local Alzheimers organisation, and then took things a step further. Believing that he had to change his own attitude to dementia, he enrolled in an online course on 'Understanding Dementia' run by the University of Tasmania.

The course was an eye-opener for John, as he realised that many of the things he was doing were upsetting for Muriel. He became more accepting and started to see the crucial difference between the person and the condition.

John now feels better able to support Muriel who still lives at home, six years on from her diagnosis.

"It is getting more difficult and requires lots of commitment and tenacity, but my education about dementia has helped us enormously", he says.

*names have been changed

If dementia or Alzheimer's disease is diagnosed in a partner or family member:

- **Allow yourself to feel the way you are feeling** - anger, guilt, grief and fear are all perfectly normal responses.
- **Share your feelings** - talk with friends, family and whānau.
- **Remember it's OK to cry** - tears can make you feel better.
- **It's still OK to laugh!** - Laughing releases 'feel good' chemicals in your body.
- **Write it down** - it may help to record things in a diary or journal.
- **Get out and still enjoy life** - do something you enjoy and focus on how good you feel.
- **Take care of yourself** - exercise like walking relieves stress, and remember to eat a healthy balanced diet and get some good sleep.
- **Be prepared** - make lists of questions you have before medical appointments with your family member.
- **Don't be afraid to speak up** - especially about anything you don't understand in medical appointments.
- **Ask for help** - start by contacting your local Alzheimers organisation who are there to support you and give you information about living with dementia.

More dementia-friendly awards for Bupa



From left: Clare Jordon, Manager, Liston Heights Retirement Village, Jennie Arvidson, Manager, The Gardens Retirement Village, Catherine Hall, Chief Executive, Alzheimers NZ, Noku Sibanda, Manager, Redwood Care Home, Lyn Walker, Manager, Redwood Retirement Village.

Four more Bupa retirement villages and care homes have been officially awarded dementia-friendly status by Alzheimers NZ.

Three Bupa sites in Rotorua received awards in late November - Redwood Retirement Village, Redwood Care Home and The Gardens Retirement Village.

The company's Liston Heights Retirement Village in Taupo was also accredited dementia-friendly.

This brings to five the number of Bupa sites that are now dementia-friendly; Bupa Fergusson Retirement Village in Upper Hutt has previously been awarded dementia-friendly status, as has Westpac nationwide.

Alzheimers NZ's Dementia-friendly Recognition Programme recognises organisations that make special efforts to cater to people living with dementia.

To be recognised as dementia-friendly, organisations must meet a range of carefully selected criteria,

across seven standards that form the Recognition Programme.

Bupa Dementia Care Advisor Beth McDougall says achieving dementia-friendly status fits with Bupa's purpose of longer, healthier, happier lives.

Bupa is planning further dementia-friendly initiatives.

Alzheimers NZ Chief Executive, Catherine Hall, praised the efforts of Bupa and encouraged others to follow their lead.

"We estimate there will be over 170,000 people living with dementia by 2050 and they need to be supported with very real, tangible and practical support.

"That is why we created this Dementia-friendly Recognition Programme – to assist organisations to provide that support, as effectively and efficiently as possible.

"We celebrate Bupa's achievement as an important step along the path of making the whole country more aware of dementia and what's

required to support people living with the condition."

Catherine called on the government to follow Bupa's example and do its bit to achieve a dementia-friendly New Zealand by implementing the New Zealand Framework for Dementia Care.

"Neither we, nor the government, can afford to do nothing about what will be a major healthcare problem for our country.

"Every organisation has a responsibility to meet the needs of its customers and because four in five people in New Zealand are affected by dementia in some way, dementia is everyone's business."



Alzheimers Northland to pilot an innovative support system for carers



Community advisory, staff Alzheimers Northland - Maria Nicol, Teresa Urganhart, Viv Hollis, Ria Leef-Smith, Sue Peake, Pip Cotching, Margaret Salmon.

Alzheimers Northland has been asked by their local DHB to lead a six-month pilot, looking at a new, innovative way to request and deliver carer support services for people living with dementia and their families.

Originally designed for the disability sector, MyCare is a professional provider of care services throughout the country. It connects those needing assistance with a community of able helpers, via an online platform.

Kevin Salmon of Alzheimers Northland is grateful for the opportunity to pilot the programme.

"Alzheimers Northland sees MyCare as a great way to provide the sort of services that carers really want, delivered by people they have chosen and a time that suits them. And it is paid for by our DHB.

"This is one of the key benefits for us. It is not asking for new money, and it is a more efficient way of delivering services that have already been approved by our DHB.

"Northland is lucky. We have a DHB that is always looking to improve."

According to Kevin, a designated MyCare coordinator will work with families to arrange and monitor the quality of services they receive and assist in managing their finances. They will also provide the reporting and audit requirements for the DHB.

"The question is, why are services not delivered like this already?" Kevin asks. "We often hear about claiming back carer support funding. The MyCare programme may be a solution."

Alzheimers Northland and the Northland DHB are hoping to prove that receiving a high-quality service does not need to be more expensive.

The pilot is set to begin in January 2018. To find out more about MyCare, go to www.mycare.co.nz



Kevin Salmon, Alzheimers Northland General Manager

Big ups to Rangitoto College



Fundraising and charitable donations come in all sizes and forms, but a recent donation by students at Auckland's Rangitoto College was certainly unexpected.

The donation boosted Alzheimers NZ's coffers by \$2591.60, money that was collected by the college students following a school mufti day for which everyone brings to school a gold coin.

Jill Clare, who works in the school's finance department, said the students themselves decide to which organisations they donate the mufti day proceeds.

"It's great that young people of this age (13-18 years old) are thinking about dementia and are so aware of the need to do something about it," she said.

"It just shows you how widespread the condition is now."

Rangitoto has approximately 3000 students, so the collection, and the donation, was a great achievement.

Alzheimers NZ Chief Executive, Catherine Hall, welcomed the donation.

"Every little bit counts and helps us to better support New Zealanders affected by dementia. And with so many New Zealanders likely to be affected by the condition – it affects about four out of five Kiwis – we need all the support we can get.

"So thank you, Rangitoto College. You just played a useful part in supporting thousands and thousands of your fellow Kiwis. Well done!"

Alzheimers Marlborough - first to be audited under the new Services and Standards

Alzheimers Marlborough will be the first Alzheimers NZ member organisation to have their services audited against the standards providing a pathway to becoming an accredited provider of Alzheimers NZ Services and Standards.

The new Alzheimers NZ Services and Standards model specifies the range and quality of services that should be offered by Alzheimers organisations nationwide.

Manager of Alzheimers Marlborough, Diane Tolley, believes the new model will assist in ensuring those living with dementia will get the service they need and deserve. "Standards are so important. The

availability of more nationally consistent services that are quality assured is a fundamental right for all people living with dementia."

Diane says the first step in the process, which they began in July 2017, was to self-review their organisation against the expectations of the Services and Standards model.

"Being involved in the introductory phase of the Services and Standards is providing us the opportunity to reflect on current service delivery and experiences.

"It has affirmed that we are on the right track in terms of our current goals for a service where people living with dementia are at the centre of what we do.

"It's about making sure services are consistently of a high quality, and that people living with dementia have a say in how services are delivered."

Alzheimers Marlborough has already begun work in two key areas. Education around reducing the risk of dementia and living well with dementia, along with encouraging more input from our clients.

"Being involved in the introductory stage of the Services and Standards has been a really positive experience for us. Not only have we been able to contribute our ideas and perspectives, but it has informed our planning for the future delivery of services."

Save the date!

Major Alzheimers NZ conference coming in 2018

After the success of the 2016 Conference, Alzheimers NZ is excited to announce our next conference will be held in Auckland on 25 – 28 October 2018!

All the details are still being worked through, but the goal is to make it bigger and better than our 2016 event – so make sure you don't miss out!

Keep an eye out on our website www.alzheimers.org.nz and our Facebook page facebook.com/alzheimersnewzealand/ for more details.



Enjoying the festive season this Christmas

This time of year is about family, friends, and enjoying the lovely weather. Like most of us, you will be making plans to celebrate the festive season.

However, for some, the festive season can be a confusing and difficult time. Usual routines can be disrupted. The social activities, travel to arrange, or family to visit, can be overwhelming.

Here are a few tips from Alzheimers NZ on how people affected by dementia can better enjoy the festive season:

- Ask others to host, so you can relax and enjoy yourself. This is a wonderful opportunity for others to do something practical and get involved.
- Plan ahead. If you're going somewhere unfamiliar, ask your host to put labels or pictures on doors. For example, the toilet and kitchen.
- Factor in rest and quiet times during the festivities. If the house becomes too busy, ask your host for a quiet room without TV or other noise.
- If travelling, plan for enough time, so you don't need to rush.
- If possible, get involved with preparations for the occasion. Offer to peel the spuds or help in other ways. Many hands may make light work.
- You may find that you need more time than others to respond or participate in activities. Remind your friends and family to slow down if necessary. Sharing in traditions, like singing carols, is a great way to include everyone.

Be prepared to break with traditions that no longer work for you and your friends and family. Try to fit meals and celebrations around usual routines.

Festive times are occasions to share memories, and enjoy friends and families. Bring out the old photo albums, and have a laugh together!

Remember, you're not alone. You can contact your local Alzheimers organisation for support or information on 0800 004 001 or visit www.alzheimers.org.nz.



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