



## Launch of the Dementia Economic Impact Report, Parliament, 22 July

An ageing population will impact on our health system and our country's economy.

Just how big is the problem in New Zealand now? How big will it be in another 20 years and what needs to be done to avoid the projected negative impacts? The Dementia Economic Impact Report sets out to answer these questions.

*Continued on page 3*



Terry Pratchett on the 'embuggerance of dementia'

*Page 12*

## Alzheimers NZ Awareness and Appeal Week



July 20 - 26

During Awareness Week...

- Alzheimer's New Zealand will be launching its Dementia Economic Impact Report in the Grand Hall at Parliament on 22nd July – *groundbreaking New Zealand research*
- Member Organisations across the country will be running special events in their local community during Awareness and Appeal Week – *find out how special they are for yourself*
- Alzheimer's New Zealand will distribute its Dementia Manifesto to politicians and public during July – *get one*
- businesses and organisations will be invited by Member Organisations to organise Cuppas for a Cause during Awareness and Appeal Week – *give it a go*
- throughout July, Progressive Enterprises will be donating to our cause from sales of Signature Range coffee, Woolworths Select teas, and Fresh Zone lamingtons – *thank you PE*
- Progressive Enterprises are again holding a national mufti day, this time during Awareness Week on Thursday 24th July – *more entertaining costumes*
- magazines and newspapers will be carrying stories about people living with dementia – *watch the media.*

# Chairperson's Report



As this issue goes to press, I am finding my way into the position to which I was entrusted. I was elected by the Board immediately after the AGM held recently in Wellington. I trust that the faith that Board has shown in my ability to lead the organisation is not misplaced.

I take over from Joy Simpson who has given so much to the organisation over the

years - not just in her recent role as chairperson, but over many years. She has my unstinting thanks for the way that she has led the organisation and for her vision of the future. It is a vision that my colleagues on the Board can develop over the coming years. Joy's dedicated service is a model for those who follow.

I need also to mention the work that Wendy Fleming, another outgoing Board Member, has done over many years. Wendy carries our banner at Alzheimer's Disease International and has been a stalwart advocate for Alzheimers New Zealand. In her time with the Board, Wendy has made a tremendous contribution. She will continue her dedicated work for people with dementia as Chairperson of the Alzheimers New Zealand Charitable Trust.

We wish both Joy and Wendy well in the future. Their wisdom and experience stays with us.

We also wish to welcome on board Bill Durham and Martin Brooks.

Bill has wide experience in the accounting field (including audit requirements), as well as being an experienced business and property owner. Over the years he has developed considerable understanding of human resources and governance. We look forward to having someone as dedicated as Bill working with us for our community.

Martin says he was "rather thrown into the experience of caring for a person with dementia" with first his uncle, then his father, developing Alzheimer's. Currently President of Alzheimers Canterbury, Martin's background includes being company director of an automotive repair organisation where he developed a sound knowledge of business practices. We look forward to Martin's passion for communication and cooperation becoming part of our community.

One outcome of the recent AGM was our collective certainty that we are all already clear about our mission and it has been motivating our every move for some time. If, as a Board, we can continue to "make life better for all those affected by dementia" in the coming year, then we will have done something worthwhile. I shall certainly work hard to see that we fulfil our mission.

A major discussion in workshops preceding the AGM was the question of how Member Organisations can move forward together as part of regional groupings. The potential benefits of such collaboration have been recognised by the participants in the workshop. The details are yet to emerge.

As with all new processes, however, we can expect that a number of issues will have to be dealt with, and the Board will need to consult widely if we are to be successful in continuing to do the best for those in our care.

I am confident that with free and open communication we can achieve this and the Board will be setting its sights on that achievement. Whatever we do and however we do it, I am confident we will not lose sight of the people we work for or our motivation to do the very best we can for people with dementia.

Thanks again to all of you for the work you do, and for your support of the Board and of Alzheimers New Zealand.

Bryan Bang  
Chairperson

## Welcome to the Board



Bill Durham



Martin Brooks

## National Director's Report



The very first Annual General Meeting of this organisation I attended was in November 1986. This meeting was held at the time of the inaugural ADARDS National Conference being hosted in conjunction with the 7th Geriatric Services Workshop in Christchurch. I didn't work for the Society at the time - I had agreed to take the minutes to assist a friend.

The feeling at that first meeting was of the organisation riding the crest of a wave - lots of hard work had been done in getting the foundations right and now they were ready to move. The first press release stated: "the new National Body will present a united front to raise Government and public awareness, stimulate and promote research into the disease, promote education and training of relevant personnel, particularly health care professionals and workers - all will ultimately benefit caregivers and sufferers throughout New Zealand".

Although the language may have changed, the message is the same today. Last month in Wellington I again felt that those attending an Alzheimers NZ AGM had a commitment

to take the next step, to cement our place in New Zealand as the only dementia-specific organisation in this country.

Regionalisation will provide an opportunity to align our organisation even further. It was a moment we recognised:

- we have a very clear mission statement
- Member Organisations are already working closely together
- we have a national office wanting to work with Member Organisations
- there is a willingness among all of us to promote and assist with achieving consistent and quality services in every Member Organisation.

I know the Board is excited about taking this goodwill forward and turning it into beneficial actions for us and all those we work with.

This is the last newsletter before Alzheimers Awareness and Appeal Week - 20 to 26th July 2008. I wish all Alzheimers NZ Member Organisations well for the events that you are planning. I hope the community is made more aware of dementia because of you. And I hope the community is generous to you - you all deserve it!

*Lucille*  
Lucille Ogston

## Launch of the Dementia Economic Impact Report

*Continued from page 1*

Long-term planning is required to provide sufficient quality services for people with dementia. This report's information and analysis is vital to provide direction for government agencies, DHBs, NGOs, community social networks, education and training institutions, businesses and planners of our country's future.

The brief for the Dementia Economic Impact Report was to provide prevalence and incidence projections, invest in anticipatory care and support for self-management, provide sufficient quality and cost-effective services, increase resources in line with demographic growth and support research into the causes, treatment and care of people with dementia.

The report will quantify the broad range of economic impacts including: health system expenditure, productivity losses, costs of care and the 'burden of disease' (the value of the loss of healthy life due to dementia).

Alzheimers New Zealand urges the Government to respond to this major challenge to the health sector and nation's economy.

Staff from Access Economics: the people behind the report



Katie Yates



Chris Roberts



Lynne Pezzullo

# The World in Brief...

## Alzheimers Scotland:

The Scottish government recently announced a three year health plan which commits £630,000 to addressing issues around dementia.

The Scottish Public Health Minister, Shona Robinson, announced the new health support package.

The Scottish Government is currently preparing a public awareness and information campaign.

## Alzheimers UK:

In the report *A Last Resort*, British MPs in the All Party Parliamentary Group (APPG) urged the British government to stop the over-prescription of anti-psychotic drugs to people with dementia.

The report puts forward a five-point plan for inclusion in the government's National Dementia Strategy, due out later this year.

The five points highlight the need for:

- specialist dementia training for all care home staff
- family involvement in decision-making around prescribing antipsychotics
- more pro-active support for care home staff from GPs, community psychiatric nurses and psychiatrists
- compulsory medical reviews every 12 weeks of people with dementia on antipsychotics
- a cost effectiveness review and national audit.

## France Alzheimer:

French President Nicolas Sarkozy recently announced a five-year plan for Alzheimer's Disease. The 1.6 billion plan establishes a new Alzheimer's research foundation, sets 44 measures to:

- improve the quality of life for people with dementia (at home and in care homes)
- improve diagnosis
- reduce stigma for those with dementia.

## European Commission:

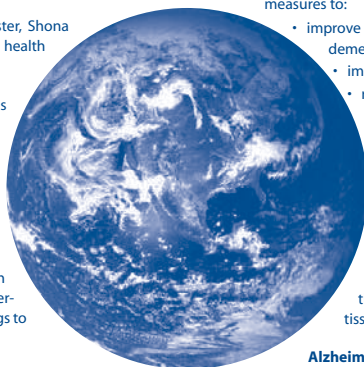
The European Commission has launched a consultation on specific rules concerning the authorisation, supervision and pharmacovigilance of advanced therapy medicinal products (gene therapy, somatic cell therapy and tissue engineering).

## Alzheimer Society of Canada:

At the start of this year, the Alzheimer Society of Canada launched Heads Up for Healthier Brains, a campaign encouraging people to take charge of their brain health and reduce the risk of developing dementia.

Features of the campaign include the role of families in maintaining a healthy lifestyle, and maintaining a healthy life after diagnosis.

The campaign, launched at a reception on Parliament Hill, was an opportunity for the Executive Director to ask politicians for a 'commitment to the thousands of their constituents living with Alzheimers and related diseases, by ensuring that dementia becomes a national health priority'.



## 11th Regional Conference Alzheimer's Disease International Taiwan June 13 – 15

We wish our Asia-Pacific neighbours good luck and know how valuable it will be to share developments from other countries and listen to highly regarded international speakers.

Lucille Ogston, National Director, will be attending the conference and the Alzheimer's Disease International University Day prior to the event. This is an excellent opportunity to showcase the progress New Zealand has been making in recent years in the area of dementia care and support and to promote the Alzheimers New Zealand 2010 Trans-Tasman Conference to be held in Wellington.

## What do people with dementia want?

Alzheimers New Zealand will be letting the Government know what people living with dementia want when it releases its Dementia Manifesto in late July.

Alzheimers NZ Chair, Bryan Bang, is enthusiastic about how the Dementia Manifesto has come together. "When we consulted our Member Organisations about their key issues, there were clear areas they wanted changes to happen in to make life better for people with dementia."

"They are working every day with people with dementia, their carers and families, so they know what is needed at the grass roots level. We will be asking all the political parties what they are going to do about the things that need to change."

Australia, Europe, Scotland and a number of other countries have presented their governments with manifestos containing the needs of people living with dementia. They have been successful in achieving policy and funding that recognises the seriousness of the issues.

The survey of Member Organisations identified three key areas of concern:

- there are already not enough appropriate services for people with dementia;
- health professionals and care workers need more specialised education and training in dementia;
- the needs of family carers are not being met.

These are complex issues that need to be worked through to provide appropriate services for a person with dementia - both in the community and within residential care facilities.

Many issues have already received considerable attention from the Government. For example, the Ageing in Place policy can assist older people to live at home longer, but when it comes to providing services for people with dementia, agencies often lack understanding about what is needed.

As Lucille Ogston, National Director, Alzheimers NZ says: "There is no point in delivering Meals on Wheels, if the person forgets to eat it. Something more needs to be both understood and provided. Then there is the ongoing problem of whether there are sufficient care workers to deliver basic home care - especially in rural areas - so this is not just a matter of funding training or additional services, but also of workforce recruitment and development."

Alzheimers New Zealand is also looking for improvements within residential care facilities. In particular it wants the specialised nature of dementia care to be recognised. Lack of specialised knowledge of dementia affects the type of programmes provided for people with dementia and the component of training in dementia that is part of staff qualifications.



*Sue Brewster and Keith Knowles look pleased with their work after a workshop on what Alzheimers NZ offers our communities.*

Not only is there a need for specialised knowledge in dementia, but there is a need to cater to special groups with dementia. For example, more people are being diagnosed with early onset dementia earlier - some as young as 50 years - but there are no appropriate services for someone their age.

As Lucille says: "Would you want to stay in a residential care unit where people are twice your age? However, the problem can't be solved by just building a residential care unit specialising in early onset dementia. The ideal place for care is within the community a person lives, so that family and friends can visit them. We need to be able to provide different choices and models of care for a person - from their own home through to residential care."

The Government has put significant work into provision of respite care, but it remains a hot issue for carers.

*Continued on page 9*

## Cuppa for a Cause<sup>®</sup>

Cuppa for a Cause is one of our annual fundraising campaigns that also aims to raise awareness about dementia. Here's how.

Typically, the wording of promotions around Cuppa for a Cause say something like: "You may also know that the most common form of dementia, Alzheimer's Disease, progressively impairs memory. But do you know that this means being unable to do simple things like make a cup of tea?"

Many people worry about their memory, so it's often a useful starting point to discuss the difference between forgetting something and being unable to do something. We suggest that people host a Cuppa for a Cause in workplaces, clubs, or social groups, because we find that in a group of more than 10, nearly everyone knows someone with dementia. For those that don't, it helps to make it real when they hear the stories of someone who does.

These occasions can also be an opportunity to find out more information about dementia. The Cuppa packs sent out by local Alzheimers Member Organisations often include their local press clippings, Alzheimers NZ information sheets, or a timetable of activities for the local group along with the traditional poster and balloons for hosts.

Never organised a Cuppa for a Cause? Give it a go! Call 0800 004 001 and your local Alzheimers organisation will help you do it.

Not able to host a cuppa and still want to do something for people with dementia? Call 0900 41234 to make a donation. Every dollar counts.



## Progressive Enterprises

Thank you for your continued support:



- To do - July:*
- buy the special discounted products in Progressive Enterprise stores in July*
  - make a donation during Awareness Week when you see our people with the blue flower outside the stores*
  - Enjoy your cuppa!*

Progressive Enterprises are supporting our Awareness and Appeal Week for the second year.

Running with our Cuppa for a Cause campaign, Foodtown, Woolworths, and Countdown are donating 25 cents from any Signature Range coffee or Woolworths Select tea you buy in July. What's more, this year, Fresh Zone Lamingtons have been added to this campaign. So have a cuppa and don't feel guilty about having a lamington!

Staff will once again be participating in the PE National Mufti Day on Thursday 24th July. Last year's mufti day not only provided many opportunities to raise awareness of dementia issues across New Zealand, but the gold coin donations from staff were dedicated to directly funding awareness.

# Carer's Strategy and Five-year Action Plan 2008



*Dr Jean Gilmour, Senior Lecturer at Massey University, has research interests in the experiences and care of people with dementia and is Convener of the Research Advisory Committee for the Alzheimers New Zealand Charitable Trust. We asked Jean to comment on what the Strategy might offer to carers of people with dementia and to point to further actions that can be taken to ensure the potential of the Strategy is realised.*

Alzheimers New Zealand organisations around the country have worked hard for decades advocating for quality carer support. More recently,

Alzheimers New Zealand provided input into the development of the Carer's Strategy through the Carer's Alliance.

The Carers' Strategy and Five-year Action Plan 2008 marks a new government focus on carers and their health needs. This Strategy can now be used for leverage for more comprehensive services. The Government vision is that New Zealand society will value all those who support others with daily living needs.

## What does the Strategy offer?

The Strategy contains five priority areas identified through public consultation.

The priorities are to:

- provide information to carers
- protect the health and wellbeing of carers

- enable carers to have a break
- provide financial support for carers
- provide training and pathways to employment for carers.

The Ministry of Social Development will 'scope' a national centre to develop information about locating respite care and resources for carers. A more efficient system of accessing respite care would be a great relief for many families. However, the use of the term 'scope' is concerning since this is not a clear commitment.

The health and wellbeing of carers is a key issue for Alzheimers organisations for the 2008 election. It is not yet clear how useful this second area of the strategy will be for carers of people with dementia. Alzheimers organisations will need to take all consultative opportunities that occur during the development of ACC's generic programme for informal carers about well being and learning.

The Ministry of Health will be contributing to carer wellbeing and health through updating training requirements for informal carers caring for people with disabilities and by...

*Continued on page 9*

## Member Organisations

During Awareness and Appeal Week, Member Organisations around the country will be running special awareness events in their local community.

Throughout the year, our Member Organisations provide much-needed support services for those with dementia, their families and caregivers.

We can tell you that they provide services such as education programmes, community worker support, day activities, memory groups and support groups for carers. What we can't convey in this short space is how appreciated our organisations are, how special the people we work with are, and how our organisation is unique in the very long-term relationships that it builds.

To find out what is happening in your area during Awareness Week or on a regular basis, free phone 0800-004-001 to be put through to your local Alzheimers organisation. Get involved and find out more!



## Jackie's Story



*Thank you to Mike for having the courage to share his journey with us as a husband of a lovely lady with Alzheimers and the effect it had on his own health and their family. It is only when those affected have the courage to speak out to the public that awareness is truly made.*

Jackie and her family first became known to our organisation 6 years ago. Jackie was a 55 year old woman who was living at home with husband Mike. This delightful and attractive intelligent lady was just like so many of us. A wife, mother, grandmother who had worked in many areas during her life. She was once involved in the community of Waikite Valley where she lived and worked on the family farm with her husband Mike and their three children.

Jackie was the kind of person that most of us would like to have as a friend, good company, great sense of humour, warm, kind, and family orientated.

Changes in Jackie were first noticed by her husband and other family members in her early 50's, her personality began to change slowly and she appeared frustrated, anxious and depressed. In fact depression was diagnosed and she was treated for that. However, as time went by it was obvious that there were other things happening to Jackie and further investigations were made. Alzheimer's disease was diagnosed, Jackie was still very aware at this stage with insight into what this meant for her and her family. She accepted this with courage and dignity and tried to take a positive attitude Mike and Jackie had been married for 34

years at that stage and had known each other since they were teenagers. It was devastating news.

Mike cared for Jackie at home for several years aided by community providers. Mike was still working full time at this stage and had to make significant changes in his working lifestyle so that he could care for her. Jackie commenced day care at a local resthome and this continued until she went into full time care. This was a difficult decision for Mike to make but the situation at home was becoming unsafe and at times very stressful. Jackie could not be left alone so the decision was made with love and courage, for her to move into a specialised unit in November 2005. There are no words to describe the heartbreak and sadness surrounding this final transition. Only those who have walked this path and lost a partner in this way or from illness can relate to it.

Jackie was happy most of the time, enjoyed going out for coffee, still laughed a lot and yes, shed a few tears at times like the rest of us in moments of frustration, or maybe having a 'bad day'. She still enjoyed having her hair done and loved to eat her favourite food at local cafes.

Jackie had been in full time residential care for 2 years and 4 months when she finally passed away earlier this year. The last six months of her life were very stressful on the family and close friends. Jackie no longer recognised many people, needed full nursing care and was unable to communicate verbally, feed or care for herself and spent most of the time sitting on the floor in her room. She responded to kindness in the way of hugs and touch and, yes, still always enjoyed chocolate.

No one has any immunity to this cruel disease. It affects people from all walks of life. If you have any concerns about anyone close to you please do not hesitate to contact your local Alzheimers NZ organisation.



### Alzheimers New Zealand Board Elected Members for 2008-2009

Bryan Bang (Chair), Eileen Smith (Vice-Chair),  
Derek Barlow, Martin Brooks, Kate Clark,  
Bill Durham, and Verna Schofield

Co-opted: Joy Simpson

# Carer's Strategy and Five-year Action Plan 2008

*Continued from page 7*

improving support for carers of people with mental illness or addiction issues.

Alzheimers New Zealand is working with the Ministry of Health on the development of a framework for nationally consistent mental health, addiction and dementia services for older people. The September Alzheimers News will feature an interview with representatives from the Ministry of Health on this area.

The third priority area, about enabling carers to have a break, is of particular interest since it has the potential to improve respite availability. The Ministry of Health is responsible for: improving access to the Carer Support Subsidy for respite care, increasing age-appropriate residential respite care in a number of regions, and helping with recruiting relief carers. Availability and flexibility of respite are key areas of concern to Alzheimers Member Organisations. Carers of people with dementia need a wider range of options for respite care including what are sometimes called "wakeovers" where carers stay overnight in the family home.

The Ministry of Social Development leads the provision of financial support for carers by working towards improving income support for carers with major caregiving

responsibilities and developing a Carers Allowance proposal. All movement in reducing the economic impact of dementia on families will be a welcome initiative.

Finally, the Department of Labour will work on providing training and pathways to employment for carers. This area recognises carer needs in the workplace such as flexible work conditions and the possibility of additional leave.

Alzheimers New Zealand's Dementia Economic Impact Report to be released in July should provide useful data to support the proposed income support initiatives and employment options.

## Constructive possibilities

In conclusion, there are some constructive possibilities in this new policy document for carers of people with dementia. But the steps in the implementation of the policy are undeveloped and Alzheimers New Zealand organisations have a key role in providing expert advice to ensure carers of people with dementia benefit fully from the proposed initiatives.

The Strategy can be downloaded from <http://www.msd.govt.nz/work-areas/cross-sectoral-work/carers-strategy/index.html>

## What do people with dementia want?

*Continued from page 5*

Said one carer: "I have a big family event coming up in Australia, so I ring around to find respite. I'm in a rural area where the chances of getting a bed locally are next to nothing, so I'm expecting there's going to be all the logistics of getting Bill to somewhere out of the district."

"Then I get on the phone and they say to me 'ring back closer to the time and we'll let you know if we have anything'. But I have to book the ticket – I don't want to know three days before!"

Lucille Ogston said: "The stress associated with inability to plan ahead has been found by researchers to be a major reason carers decide it is time a person enters residential care. Carers need to be able to plan ahead like the rest of us."

Finally, it was apparent in discussions with Alzheimers organisations that they saw an urgent need for more New Zealand-based research. In particular they wanted evaluations of the types of programmes and activities that might enable people in the early stages of dementia to retain quality of life for a long as possible within the context of New Zealand's health sector.

It's clear there are many issues and no easy solutions – but we need to find these soon.



*Member Organisations' staff, Board members and people with dementia hard at work on what they want the government to hear.*

# Medical fitness to drive: LTNZ

## Role of the doctor

While they are advocates for their patients, doctors and registered optometrists have statutory duties to report medically unfit drivers to the Director under certain conditions eg if they consider, on the grounds of public safety, that a patient is medically unfit to drive and they believe that the patient will continue to drive despite being advised not to drive.

## Role of the Director of Land Transport

The Director is required to issue driver licences in accordance with the law which specifies that drivers have to be medically fit to drive. The Director manages medical fitness issues for those licence holders who have to provide regular medical certificates due to their age, the types of licence classes or endorsements they hold, and those who have an identified medical condition that may affect their ability to drive safely.

In law, the Director is responsible for making decisions about whether a licence should be suspended or revoked on medical grounds, or whether conditions should be placed on a licence, and is legally accountable for them. However, these decisions are usually made in consultation with the licence holder's doctor, optometrist or other relevant health practitioner. Decisions about suspending or revoking a licence are made very carefully by the Director who recognises the need to balance the licence holder's desire to retain their driver licence against the risks to public safety if they are allowed to continue driving.

The Director applies the medical standards outlined in Medical Aspects of Fitness to Drive. This is a guideline for medical practitioners, optometrists and occupational therapists that sets out the medical standards for driving for both private and professional drivers. The guideline was developed in consultation with the medical fraternity.

The Director must have reasonable grounds to suspend/ revoke or place conditions on a licence, on medical fitness criteria. A licence holder has a right of appeal, to the District Court, about decisions made by the Director regarding their licence. Very few decisions made by the Director against a licence on medical fitness grounds have been overturned, on appeal, by the District Court.

## Role of the LTNZ Medical Team

The Medical Team at the Transport Registry Centre of Land Transport NZ who manage medical fitness to drive on behalf of the Director regularly discuss medical fitness issues with an individual licence holder's doctor or other health practitioner. In some cases, medical fitness issues can be resolved earlier and with less distress to the patient by the doctor contacting the Medical Team directly to discuss any concerns they have about a patient's fitness to drive.

The Medical Team welcomes inquiries from medical and other health practitioners who have concerns about a patient's medical fitness to drive. They can call the Medical Team by phone on 0800 822 422 ext 8089 during normal business hours.

## Formal reporting

There may still be occasions in which a doctor or optometrist will be required to formally report a medically unfit driver to the Director. This sets in motion a formal process to review the person's medical fitness to drive. There are checks and balances in this process to ensure that the licence holder is made aware of the review and is treated with fairness and consideration.

*This information was provided by LTNZ.*

Did you know that drivers over 75 years make up 4.5% of total licence holders but are involved in less than 2% of accidents causing injury or death?



## Driving policy statement

*Every individual has the right to mobility. A person has a right to drive if they can do it without risking the safety of their passengers, other road users and pedestrians, and themselves.*

*A diagnosis of dementia is a warning sign that a person will not be competent to drive at some stage in the future. A diagnosis does not determine whether a person should drive at that moment. Ongoing assessments are needed for this.*

Alzheimer's Australia

## What are the warning signs?

Often, it is a family member, neighbour, or friend, who becomes aware of the safety hazards. If a person with dementia experiences one or more of the following problems, it may be time to limit or stop driving.

Does the person:

- get lost while driving in a familiar location?
- get confused when there is a detour or they have to take an unfamiliar road?
- fail to observe traffic signals or give them?
- fail to stay in the correct lane or have trouble doing lane changes or motorway exiting?
- drive too slowly? (this doesn't mean all slow drivers have dementia)
- know the difference between left and right?
- need a navigator?
- become angry or frustrated while driving?
- get confused when stopping?
- make poor decisions or fail to anticipate dangerous situations?
- find it stressful to drive in heavy traffic, for long distances, or at night-time?

*Adapted by Alzheimers NZ from the Alzheimers US Home Safety for People with Alzheimer's Disease.*

## What should a carer do?

It's important to take up the issue as early as possible, while the person with dementia can still make decisions about their driving future, such as selling their vehicle.

Being unable to drive can represent a tremendous loss of independence, freedom, and identity. For someone in the early stages of dementia this may be the moment when they have to confront what it means to have dementia.

If you believe a person is no longer driving safely, you must get help. Speak first to the person's doctor. They may be able to arrange a driving assessment.

Discuss your concerns with family members. Involve others who can assist in talking this issue through – for example, workers from your local Alzheimers organisation and NASC workers.

You can assist the person's transition from driver to passenger if you:

- work to limit the driving in steps, rather than all at once
- initiate discussions about driving and transportation needs early and often
- address the social needs of driving as well as discussing the alternatives
- offer to drive for the person or arrange outings that do not require the car to be driven by them
- support past routines when you investigate public transport
- find out about community buses or hospital transport arrangements for appointments
- accompany the person while they get used to new types of transport and continue to assess whether they need support.

*Adapted from: Land Transport New Zealand Factsheet 23*

*A woman told her husband that she thought drivers had become ruder and more dangerous, as they often tooted her and made gestures. When her husband saw her driving one day, he realised she was driving very dangerously and other drivers had to take action to avoid accidents with her. Because of her dementia, she did not understand that she was the one making mistakes.*

Alzheimer's Australia

## Terry Pratchett on the 'embuggerance' of dementia



In December last year, Terry Pratchett, who has sold more than 55 million copies of his books, announced that he had the 'embuggerance' of dementia.

Within hours of this announcement being made on his artist's website, he received more than 60,000 messages. In typical style he said: "Most of them were readers and

well-wishers. Some of them wanted to sell me snake oil and I'm not necessarily going to dismiss all of these, as I have never found a rusty snake."

In April this year he spoke of his future: I want to go on writing! Admittedly, that means I have to stay alive. You can't write books when you are dead, unless your name is L. Ron Hubbard."

On Alzheimers Terry says: "It's a nasty disease, surrounded by shadows and small, largely unseen tragedies. People don't know what to say unless they have had it in the family."

On being asked why he announced that he had Alzheimer's, his response was: why shouldn't I? I remember when people died "of a long illness" now we call cancer by its name, and as every wizard knows, once you have a thing's real name you have the first step to its taming."

Speaking at an Alzheimers research conference in April this year about his hopes for answers from Alzheimer research, he said: "Say it will be soon - there's nearly as many of us as there are cancer sufferers, and it looks as if the number of people with the disease will double within a generation. And in most cases alongside the sufferer you will find a spouse, suffering as much. It's a shock and a shame, then, to find out that funding for research is three per cent of that which goes to find cancer cures. Perhaps that is why, for example, that I know three people who have successfully survived brain tumours but no-one who has beaten Alzheimer's???"

"I'd like a chance to die like my father did - of cancer, at 86. Remember, I'm speaking as a man with Alzheimer's, which strips away your living self a bit at a time. Before he went to spend his last two weeks in a hospice he was bustling around the house, fixing things. He talked to us right up to the last few days, knowing who we were and who he was. Right now, I envy him. And there are thousands like me, except that they don't get heard."

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## When a person has been told not to drive

The person with dementia may not understand why they can't drive. Work as a team across family and professionals, to deliver the same message. A letter from the doctor or licensing authority, may help the person accept the decision.

It is usually best to avoid a rational discussion or argument. It can help to empathise with the feelings of loss but respond with the same short message eg 'the doctor believes it is safer not to drive'.

When dementia impairs driving and the person with continues to insist on driving, what can you do?

As a last resort:

- hide the car keys, or substitute another set of keys that doesn't fit the car if needed
- do not leave a person with dementia alone in a parked car
- sell the car or keep it out of sight
- have a mechanic install a "kill switch" or alarm system that disengages the fuel line to prevent the car from starting
- place a large note under the car hood requesting that any mechanic call you before doing work requested by the person with dementia.

# Wanting to go home

**Ann, a Social Worker who speaks with carers of people with dementia, says:**

“One of the things that carers find hardest is dealing with that moment in the visit when the person says ‘I want to go home’. All sorts of feelings rise up for the carer. It helps to be prepared, to know that it will not help to explain why it’s not possible. Many times what the person is actually saying is they miss who they were before and the people they know and love. Often when the carer says ‘I miss you too’ and holds their hand, that is all that needs to be said.”

**Jan, a residential care Manager says:**

“People with dementia often say they want to go home. When I listen to them, I find it is not so much that they want to go back to a place they have lived – even if that is the direction they have headed in – but more that they are searching for the ‘home of the heart’, the place where they are loved, where they most have a sense of belonging. We need to work with families to make this happen – so they belong here and receive the love of their families.”

**Jane Verity from Spark of Life says:**

“We need to ask ourselves: What does home represent to me? Our answers are most likely to be emotional representations of home and this is also true for people with dementia.”

“It is unlikely that they are actually thinking of the physical home that they are either living in right now or have left in order to move to a residential care facility.”

“Some people with strong religious connections may think of home as going home to God. They can be indirectly saying that they wish to die. Others may be searching for emotional fulfillment of wounded or unfulfilled needs.”

## Free information sheet on wandering

Alzheimer New Zealand has a free information sheet on wandering. It covers:

- Reasons for wandering
- What may help stop a person wandering
- What to do if a person goes missing and
- How to respond when the person is found.

You can download from the Alzheimers NZ website or order a hard copy from your local Alzheimers NZ organisation.

**Free call: 0800-004-001 [www.alzheimers.co.nz](http://www.alzheimers.co.nz)**

## What’s behind ‘I want to go home’?

There are many reasons for a person with dementia to say they ‘want to go home’.

They may:

- be unable to recognise home as home because of memory loss or changes in perception
- have recently moved to a new and unfamiliar place
- be depressed, stressed or bored
- feel insecure or frightened about changes
- be searching for a place from their childhood that no longer exists
- be looking for a time when life was more comfortable
- be looking for a person who is now dead.

## Responding to ‘I want to go home’

Here are some strategies from the book *Understanding Difficult Behaviors*:

### Home context:

- respond to emotion (eg ‘are you feeling scared?’) and offer reassurance (eg ‘Don’t worry. I will take care of you. Everyone will look after you.’)
- redirect the person’s attention (eg go for a walk, listen to music, look at photos).

### Day care context:

- have family members write a note saying what they are doing (eg “I am going to lunch with Ann and will be here to pick you up 2.30pm. Have a nice time. I love you. Your daughter Jan.”)
- ask the person to help the staff in some way (eg set table, sort laundry)
- if the person can read, leave a brief biography of memorable events with the person.

### Residential care context:

- set up a ‘visitor’s book’ for the person that you and the family write in to reassure the person they are loved, visited, not forgotten, and ask staff to reinforce this by reading it with or to the person
- if the person wants to go home at night time, suggest they stay a night and go home in the morning.

# The debate about tracking devices

A number of countries continue to debate the use of assistive technologies, such as tracking devices to locate people with dementia.

In New Zealand we are yet to have such a debate. However, Alzheimers New Zealand believes it is in the interest of carers of all people living with dementia to carefully consider the issues involved.

Tracking technologies are often put forward as addressing the needs of both carers and people with dementia. But in real life situations, this balance can be difficult to achieve.

The values of safety and freedom are laden with emotion for all those involved and ethics around consent are highlighted. Tracking devices work for some but are not the answer for everyone. Think about and talk through the issues.

## Pros and cons of tracking devices

While tracking devices work well for many they are not the answer for some.

Here are the pros and cons at a glance:

- ✓ retains independence for longer
- ✗ loss of privacy with monitoring
- ✓ reduces the need for some restrictions
- ✗ is not a substitute for care
- ✓ reduces the risk of harm
- ✗ cannot prevent danger
- ✓ eases worry of carer
- ✗ can provide a false sense of security.

## Here are some views on the debate

**Lucille Ogston, National Director of Alzheimers NZ:**

"The first question I always have when people start to talk about using a device is: 'Why is the person wandering? What is behind it?' It's vital to consider the causes before leaping into a solution. My second question would be: Does this particular situation really call for the technology? Will using the device give the person with dementia more independence? There's a fine line between the lack of autonomy that comes with wearing a device and the lack of freedom that comes with being locked in the house."



*Mayor of Wellington Kerry Prendergast,*

**Kerry Prendergast, Mayor of Wellington:**

"I know from personal experience that it's very frightening for families to think of a loved one who has dementia going wandering. It's also tempting to look to technology to put your mind at ease. However, there are many factors to take into account before choosing this option. How great is the risk? Have you sought independent advice? What other options are available?"

"Once you've weighed up the options, if technology such as pendants and the like is the best option, it can really help reassure many carers and family members. Just make sure you do your homework first."

**Dr McShane (psychiatrist and developer of a tracking device used in Britain)**

"It would be a mistake to think all patients with dementia as being the same. Some will be able to make decisions about using a tracking device, others won't. We haven't come up with a panacea, but we have something that might be a practical solution for some people."

**Russell Tucker, Assistant Search & Rescue Coordinator from the Tasman Police District:**

"There should be a thorough assessment before a person is provided with a pendant. Discussions need to take place with the family and caregiver or rest home, a representative from the Alzheimers society and the person's GP."

## Using the 'Wandatrax' system

Russell Tucker, Assistant Search & Rescue Coordinator from the Tasman Police District uses the Wandatrax system in conjunction with volunteer search and rescue groups.

Russell says: "It is important to remember that this device does not stop people getting lost or going missing. However, it does have the potential to enable them to be found more quickly than would be expected in the normal search and rescue operation."



The Search and Rescue's advice on the best way to ensure potential search / rescue problems are mitigated is to:

- have a sound search pre-plan in place that does not rest on tracking devices
- involve your community in all aspects of this pre-plan
- consult and liaise with medical experts such as hospital geriatricians and community experts such as Alzheimers organisations and community mental health groups
- consult rest homes, schools, and caregiver groups on what pre-plan they have in place for potential wanderers
- take every opportunity to educate a community in the processes involved in a town or urban search
- use a tracking system for potential wanderers.

### How the 'Wandatrax' works

The tracking device in the hands of a trained operator should in normal circumstances be able to locate a pendant wearer up to 900 metres away. Russell says: "It operates on a radio frequency and therefore it will have other forms of interference at times – for example it is severely limited in snow and hail storms, but over all it is a very beneficial device."

### Graham and the Wandatrax

Penelope looks after her husband Graham who is in his early sixties, has a dementia which severely affects his ability to speak. He is physically very active, and part of his daily routine is to go for long walks by himself, sometimes for up to two hours.

Although he is familiar with the streets around his home, there is always the risk of his getting lost and being unable to ask for directions because of his difficulty with communicating.

For some time now he has been wearing a Wandatrax pendant, which he puts on every morning as a routine part of getting dressed. This has not been needed as yet, but gives Penelope great reassurance that should Graham become disoriented he can be found within a very short time, almost certainly less than an hour.

## Wandering Issues

### When you find them...

It's very easy to let the person who has wandered know how worried you have been. But although it's understandable, it is not good for them – they need reassurance, not a telling off. They are likely to have been frightened too and may still be confused. The best approach is to make no fuss and walk alongside them, gradually moving them towards home. Or if you have found them while driving, offer them a lift.

*Taken from the Alzheimers New Zealand information sheet on wandering.*

### When is it safe to leave a person with dementia alone?

Most carers worry about when it is safe to leave a person with dementia alone. Here are some things to consider.

Does the person:

- recognise dangerous situations?
- know how to use a phone in an emergency or know how to get help?
- stay content at home or wander or get disoriented?
- become confused or unpredictable under stress?
- have significant changes of mood when left alone for any length of time?
- try to do activities at home that they used to do but now are unsafe without some supervision?
- forget they should not drive and get in the car?

## How can I make our home safe?

Here are some safety tips to reduce the risk of wandering:

- Disguise the exit by placing locks on exit doors out of direct sight (ie high, low, or on the opposite side from the expected one), by painting the lock the same colour as the door, or wallpapering the door to match adjoining walls.
- Consider double locks that require a key. Keep a key for yourself and hide one near the door for emergency exit purposes.
- Divert the attention away from the door by: placing small scenic posters on the door; attaching removable gates, curtains, or brightly colored streamers across the door.
- Place STOP, DO NOT ENTER, or CLOSED signs in strategic areas on doors.
- Reduce clues that symbolise departure, such as shoes, keys, suitcases, coats, or hats.
- Consider securing the yard with fencing and a locked gate.

And as a final safety measure in case none of these things work, place labels in garments to aid in identification when a

person is found and make sure you have recent photos or a home-video on hand to assist police.

*Adapted from the US National Institute of Ageing and Alzheimers Disease Education and Referral Centre.*



## Residential Care: managing wandering

People with dementia may appear to move about in an aimless way (hence the term 'wandering') but the behaviour is often based on understandable reasons, such as human need, avoiding something in the environment, physical discomfort or psychological distress. When this is the case, what is happening is a form of communication.

For example, residents may be communicating:

- a need to have food, fluid, toileting, exercise, physical stimulation or companionship
- a need to get away from loud sound, confusing visual stimuli, too many other people, or the discomfort of unfamiliar surroundings
- physical and mental disturbances such as pain, infection, incontinence, depression, anxiety, or delusions that need to be addressed.

Lucille Ogston, National Director of Alzheimers NZ, says:

"People wander for a number of reasons. They might be looking for someone or something from their past. They might have forgotten where they were going or what they were doing, or be disoriented about the time of day. They might be fulfilling a need – such as keeping occupied, or they might simply be continuing a lifelong habit of walking long distances.

It's important to know the person and build a picture of where they are likely to go before the first incident happens."

Within a residential care facility, wandering can be both helpful and unhelpful.

It is helpful when it provides stimulation and social contact or increases mobility. These have the physical and mental benefits of preserving strength, maintaining skin circulation, preventing constipation and feeling in a good mood.

It is unhelpful when it leads to a resident entering unsafe areas, including other residents' rooms, or leaving the facility altogether.

Wandering can lead to physical problems such as dehydration, weight loss, excessive fatigue, injury, agitation or, in a worst case scenario, death.

What can a residential care provider do about wandering? What is considered best practice? There are few empirical studies evaluating interventions for wandering. The US Alzheimer's Association found the most successful interventions were those in accord with general principles of effective care practices.

Best practice relies on careful individual assessment of the resident's abilities and needs to develop care plans that address the particular causes of that resident's wandering. It also involves consideration of environmental factors.

When a person is wandering, staff need to discuss why it is happening. For example, if it routinely happens during a shift change, establish a specific routine to build security and decrease stress. If it is triggered by needing to go to the toilet, reschedule toileting according to the person's patterns and provide cues to help the resident find the bathroom quickly.

Staff can determine whether wandering is a risk or a benefit by assessing a range of individual risk factors including:

- history and patterns of wandering: life history of past occupation, daily activities, sleep patterns, leisure activity interests, toileting routines
- cognitive function, vision, hearing, and mobility
- medical conditions that may contribute to wandering, such as pain, infections, night time urinary frequency and urgency, constipation
- medication history
- psychological conditions such as depression or anxiety, patterns of socialising
- life history or daily routine that might lead a resident to attempt activities that might result in falls.

A wandering care plan ideally promotes a person's choice, mobility and safety. Involving the family in planning is useful for staff to understand previous patterns of behaviour and successful intervention strategies.

For a person who has newly arrived, staff can play a key role in establishing a sense of security through supporting consistent relationships. Some care facilities recommend hosting specific welcome activities for a person moving into care. They may also involve the person in identified interest activities with others who also enjoy them.

It is important for the wanderer to be kept comfortable and healthy. The following tips for health are taken from Understanding Difficult Behaviors:

- weigh weekly to make sure the person is not losing too much weight
- ensure fluid intake is sufficient
- provide comfortable clothing
- check often for blisters or swelling
- get the person to rest every couple of hours for half an hour with feet elevated to prevent swelling.

Staff need to know what is expected of them when a person goes missing and how to act when they find them. All facilities should be prepared for the event of a person leaving the facility.

Basic preparation includes:

- keeping photographs and former addresses of residents in a secure location
- accounting for residents at agreed on intervals (eg meals and shift changes)

- having a sign-out process for when residents are taken out
- keeping phone numbers of nearby bus terminals, train stations, taxi services in case the search needs to move beyond the residence and immediate surrounding areas.
- having an agreed procedure for notifying local police and family.

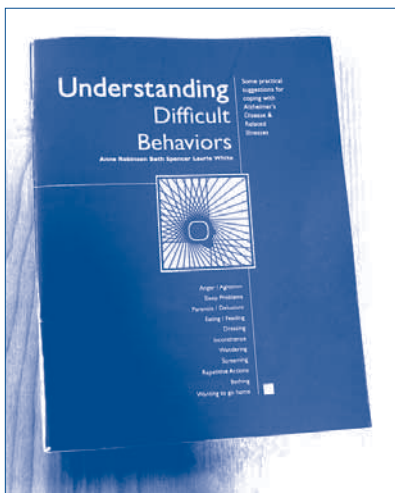
Attention to the environment can also reduce unsafe wandering:

- making the place homelike by reducing institutional sounds such as paging systems
- creating indoor and outdoor pathways free of obstructions
- having pathways without shadows or pools of bright light
- eliminating glare on windows eg covering with blinds
- making transitions from pathways onto grass smooth and even
- providing substitute activities eg dancing, exercises
- using memory boxes to cue residents to their room
- using large visual signs for bathrooms.

Further details can be found in the United States journal *Alzheimer's Care Today* 2008 Jan-March 2008.



## Book Review



**Understanding Difficult Behaviors**, Anne Robinson, Beth Spencer and Laurie White (2007 2nd ed) Eastern Michigan University, Ypsilanti, Michigan: Paperback, 73 pages.

This very practical manual for understanding behaviours associated with Alzheimers Disease and Related Illnesses is a must-have for anybody involved in caring for someone with dementia.

Not only is the design of the book down-to-earth with an easy to follow format and a larger print but it's very practical. If one coping strategy fails, you try the next.

The book considers a wide range of behaviours such as hallucinations, incontinence, repetitive actions and wanting to go home. Each chapter begins with an explanation of why the behaviour occurs, possible causes eg environmental, task-related or communication problems. This is followed by a list of coping strategies, some of which have been based on conversations with families.

At the back of this book there is a large reference section including book titles, resource material eg. videos, websites, fact sheets, journals and mail order catalogues.

**Understanding Difficult Behaviors** is available from [www.emich.edu/alzheimers](http://www.emich.edu/alzheimers) or through **Alzheimers New Zealand** at \$35 each.

*Reviewed by Lucille Ogston, National Director with 17 years experience in the dementia field.*

## A visit to Alzheimer's Society UK

Alzheimer's Society moved to a new office in the lovely St Katharine's Docks area of London last November. Their new library / knowledge centre has recently opened. I visited on 8th May and was shown around by head librarian Janet Baylis.

There are over 10,000 items in the library- books, reports, journals, DVDs, videos etc - and space to study (if you can stop looking at the fantastic view). The Alzheimer's UK website has also been updated and is very user-friendly - just go to [www.alzheimers.org.uk](http://www.alzheimers.org.uk) click on researchers and professionals or load <http://www.alzheimers.org.uk/dementiacatalogue> . Over 50% of the items are available on line.

If you are in London and want to visit the resource room, it is only 15 minutes walk from Tower Bridge. You need to make an appointment with Janet to be shown around. The contact email is [mailto:knowledgecentre@alzheimers.org.uk](mailto:mailto:knowledgecentre@alzheimers.org.uk) or phone 02074233575.

*Submitted by Chris Perkins, member of the Alzheimers NZ medical advisory team, who has just returned from her visit to the UK.*



## Famous people with Alzheimer's

Famous Alzheimer's sufferers include former Prime Minister Harold Wilson, U.S. President Ronald Reagan, Irish novelist Iris Murdoch, 1940s movie star Rita Hayworth, Hawaii 5-0 star Jack Lord, The Ten Commandments actor Charlton Heston, Star Trek actor James Doohan, Death Wish star Charles Bronson and American boxing legend Sugar Ray Robinson.

## We would like to thank our sponsors:



- Worldwide there are an estimated 29.8 million people with dementia - an estimated 33,000 of whom reside in New Zealand. International estimates indicate that the number of people with dementia will rise 75% by 2031.
- Dementia ranks as the fourth leading cause of death among those 65 years and over. In Australia, it affects the lives of nearly one million who care for a family member or friend with dementia and is the second largest cause of disability burden after depression.
- The UK currently spends £17 billion on its 700,000 people with dementia.



## Alzheimer's New Zealand

*Making life better for all people affected by dementia*  
Kia piki te ora mo ngā tāngata mate pōrewarewa

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