



## National Dementia Strategy 2010 – 2015

### Executive Summary

New Zealand has a rapidly ageing population which brings with it an increasing number of people with dementia. As the number of people with dementia continues to increase so does the human, social and economic cost that is related to it. According to the Alzheimers New Zealand 2008 Dementia Economic Impact Report, by 2026, over 74,000 New Zealanders will have dementia and by 2050 this number will rise to over 146,000. This follows the worldwide trend, where dementia is doubling every 20 years. The total financial cost of dementia in New Zealand in 2008 was estimated at \$712.9 million. Dementia has no cure.

As a response to this rise, Alzheimers New Zealand has developed a National Dementia Strategy and an action plan to ensure the needs of people with dementia are recognised and supported. This has been developed in consultation with the sector, the dementia community, and our local Alzheimers organisations.

There is an urgent need to commit to the funding of, resourcing and implementation of a National Dementia Strategy. In doing so, we can better meet the needs of people with dementia, their families/whānau/carers and others involved in their lives, such as service providers, medical health professionals and community organisations working in the dementia community.

The National Dementia Strategy promotes and encourages collaboration between sectors and organisations. To meet the increasing needs of people with dementia and families/whānau/carers and to ensure services are effective, efficient and cost-effective, it is vital that cross-sector collaboration is undertaken. The strategy requires ownership and commitment, engagement and partnership from people with dementia and their families/whānau/carers, central and local Government, District Health Boards, NGO's, health service providers, clinicians, health professionals and community organisations to ensure it achieves maximum benefits and long term outcomes for all people coping with the disease.

As a society, New Zealanders have always shown a willingness and need to provide care for those who require it. The National Dementia Strategy is a reflection of that willingness and need. Alzheimers New Zealand will play a vital role in ensuring the voice of people with dementia and their families/whānau/carers will continue to be heard as the strategy progresses.

The National Dementia Strategy is a living document. The accompanying action plan will be regularly updated over time to ensure the strategy is implemented and monitored.

The National Dementia Strategy strategic goals are as follows:

- 1) Recognise dementia as a national health priority
- 2) Increase public awareness of dementia
- 3) Provide access to affordable and appropriate medication
- 4) Improve early diagnosis and management of dementia
- 5) Provide appropriate services to all people with dementia
- 6) Provide support to family/whānau/carers of people with dementia
- 7) Develop the workforce to deliver quality dementia care
- 8) Increase dementia research and the evaluation of dementia practices.

# Strategic Goal 1: Dementia – A National Health Priority

With New Zealand's ageing population there will be an increasing demand on services for people with dementia. It is urgent that the New Zealand Government officially recognises dementia as a national health priority.

## Objective 1.1

The New Zealand Government officially recognises dementia as a national health priority

**Timeframe:** End 2011

### Action 1.1

- i) The Government provides funding to ensure the implementation of the National Dementia Strategy

# Strategic Goal 2: Increase Public Awareness

There is a need to build public awareness about dementia and the services and support available for people with dementia, their families/whānau/carers. A publicly funded campaign would raise community awareness about dementia, assist in de-stigmatising dementia, gain recognition of the skills needed for dementia care, gain support for the person with dementia and their families/whānau/carer and inform the public on service available for people with dementia and their families/whānau/carers.

## Objective 2.1

Increase public awareness of dementia and support services available to people with dementia and their family/whānau/carers through a publicly funded national information campaign

**Timeframe:** Campaign to take place in 2012

### Action 2.1

- i) Government will manage a national public information campaign in collaboration with key stakeholders in dementia care to raise awareness about dementia, the support services available to people with dementia, their families/whānau/carers and the skills needed for dementia care. The campaign will help to de-stigmatise dementia

# Strategic Goal 3: Access to Affordable and Appropriate Medication

Medication available for dementia can be effective in delaying memory loss and slowing the progress of dementia. Subsidising the medication ensures that it is available to all people that need it and not restricted to those that can afford to pay for the medication.

## Objective 3.1

Government to subsidise dementia medication so that it is affordable and accessible to all that need it

**Timeframe:** Dementia medication to be subsidised by end of 2010

### Action 3.1

- i) Advocate central government and Pharmac to subsidise dementia medication

# Strategic Goal 4:

## Early Diagnosis and Management

An early diagnosis increases the time available for future planning and time to identify and manage appropriate treatments. Early diagnosis allows the person with dementia to be involved in decisions about future care, care options and to plan for dealing with personal and financial affairs. Early diagnosis also enables families/whānau/carers to prepare for future caregiving. Resources need to be provided for health professionals to diagnose early and to undertake ongoing assessments and support self management. It is recognised that medical health professionals require more sensitive diagnostic tools to achieve early assessments. Timely access to specialist and referrals to community support services are vital for advance planning and can delay entry into residential care.

### Objective 4.1

Educate and train General Practitioners to assist in detecting and diagnosing early stages of dementia via the development of new resources

**Timeframe:** Resources and toolkits available from June 2012; Standards-based training programme to be available June 2012

#### Action 4.1

- i) Provide information packs and resources specific to GP's developed in collaboration with government agencies and medical health professionals
- ii) Provide a standards-based training programme for dementia-accredited General Practitioners
- iii) Include in the 2012 national public information campaign will be information to educate and inform health professionals on diagnosing and providing dementia support

### Objective 4.2

Provide General Practitioners with a robust diagnostic tool that can assist them in an early diagnosis of dementia

**Timeframe:** Diagnostic tool available February 2013

#### Action 4.2

- i) Develop a robust diagnostic tool for early diagnosis in collaboration with medical health professionals and Alzheimers New Zealand
- ii) Have the diagnostic tool available to General Practitioners

### Objective 4.3

Educate and train medical health professionals on dementia

**Timeframe:** Training programme available from June 2012

#### Action 4.3

- i) Provide a standards-based training programme in dementia for medical health professionals e.g. medical students, nursing staff and allied health professionals at under-graduate level

### Objective 4.4

Provide intervention guidelines to support dementia diagnosis and monitoring for medical health professionals

**Timeframe:** Guidelines available June 2012

#### Action 4.4

- i) Provide intervention guidelines to support dementia diagnosis and monitoring

# Strategic Goal 5: Appropriate Services

More people with dementia means increased demand on community support services, respite care services, residential care facilities and medical health professionals. There is a need to fully develop a continuum of quality care services from home, community, residential and palliative that is appropriate. To achieve maximum benefits, collaboration must involve government agencies, community organisations, mental health professionals, service providers, Māori, Pacific, Asian and other community and ethnic organisations. A range of services is needed to accommodate the cultural needs and the changing needs of people with dementia and their carers. To ensure the health and safety of people with dementia and their families/whānau/carers there must be access to age-appropriate respite care options.

## Objective 5.1

Provide a policy document on the ethics and treatment of care for people with dementia for use by service providers to enable a high standard of care for people with dementia

**Timeframe:** Policy document completed by December 2011

### Action 5.1

- i) Develop a policy document in collaboration with key stakeholders on the ethics and treatment of people with dementia
- ii) Have the document available to all service providers

## Objective 5.2

Develop best dementia care practices for use by DHB's, Primary Healthcare organisations and service providers

**Timeframe:** Dementia best care practices completed by December 2011

### Action 5.2

- i) Develop best dementia care practice document in collaboration with Alzheimers NZ, DHB's, government agencies and other key community organisations
- ii) Have the document available to all service providers

## Objective 5.3

Identify the number of respite services that could be made available in New Zealand to accommodate the varied and changing needs of people with dementia and their families/whānau/carers

**Timeframe:** Report completed by June 2011

### Action 5.3

- i) Undertake study on dementia specific home support and different models of respite care that will identify the impact of home support services and effects for people with dementia
- ii) A report is to be generated from the results of the study and used to identify appropriate respite models of care that could be implemented in New Zealand

## Objective 5.4

Identify and establish early on-set dementia programmes nationwide to accommodate the under 65 years age group

**Timeframe:** Identification of programmes completed by June 2011; Establishment to begin June 2012

### Action 5.4

- i) Identify programmes that are appropriate for under 65's
- ii) Alzheimers New Zealand to scope the establishment of identified programmes in collaboration with government agencies and other key community organisations.

## Objective 5.5

Establish best palliative care service guidelines specific to people with dementia for use by service providers and care facilities

**Timeframe:** *Guidelines to be completed by June 2012*

### Action 5.5

- i) Establish a working group with government agencies, key community organisations and medical health professionals to develop guidelines for specialist palliative care services

# Strategic Goal 6:

## Family/Whānau/Carers Support

The family and carers of people with dementia play a vital role in providing quality of life and care. Carers need to be educated, trained resourced and supported to enable them to continue their role for as long as they can. If carers are not supported, then the downstream costs to the health system would be significant.

### Objective 6.1

Collaborate with government to provide financial support and resources for family and carers of people with dementia

**Timeframe:** 2010 – ongoing

#### Action 6.1

- i) Advocate for and support the continued implementation of the government's NZ Carers Strategy introduced in 2009

### Objective 6.2

Inform and educate families/whānau/carers of people with dementia on how to provide care and access support

**Timeframe:** Information packs and resources completed June 2011; Development of standardised information and educational programmes are completed June 2012

#### Action 6.2

- i) Develop information packs and resources specific to families/whānau/carers in collaboration with government agencies and key community organisations
- ii) Distribute information packs and resources through other community organisations, PHO's, service providers and DHB's
- iii) Include in the 2012 national public information campaign will be information specific to families/whānau/carers
- iv) Develop standardised information and educational programmes for families/whānau/carers
- v) Ensure that information and educational programmes can be audited

### Objective 6.3

Provide guidelines for families/whānau/carers and resource programmes on dementia care

**Timeframe:** Guidelines completed June 2011

#### Action 6.3

- i) Develop guidelines for families/whānau/carers on dementia care specific to families/whānau/carers

# Strategic Goal 7: Workforce Development

The rise in numbers of people with dementia will increase the need for health workforce capacity. Dementia knowledge is specialised and workforce capability will need addressing. To ensure capability, the dementia workforce needs to hold, or work toward nationally-recognised qualifications to deliver dementia care. A process for upskilling the general health workforce in dementia best practice standards is also required. Recognition of a service structure for Māori, Pacific and Asian communities with dementia begins with research if an effective and efficient service structure is to be developed.

## Objective 7.1

National minimum standards developed for dementia-specific training of all staff involved in caring for people with dementia

**Timeframe:** National standards to be completed end 2012

### Action 7.1

- i) Identify and collaborate with a tertiary provider to develop/identify a qualification that can be used for informal carers to obtain formal training on dementia care by end 2010
- ii) Develop a formal training programme by end 2011
- iii) Begin implementation of the training programme 2012

## Objective 7.2

Ascertain and evaluate the workforce requirements for future capabilities for Māori working in dementia care

**Timeframe:** Evaluation to be completed end 2012

### Action 7.2

- i) Undertake a study of workforce development for Māori working in dementia care that includes working conditions and recognition of culturally based skills for dementia care

## Objective 7.3

Ascertain and evaluate the workforce requirements for future capabilities for other ethnic groups working in dementia care e.g. Pacific, Asian

**Timeframe:** Evaluation to be completed end 2012

### Action 7.3

- i) Undertake a study of workforce development for other ethnic groups working in dementia care that includes working conditions, issues of immigration, working conditions and recognition of culturally based skills for dementia care

## Objective 7.4

Educate and train service providers to provide a high standard of service to people with dementia and their families/whānau/carers via the development of new resources

**Timeframe:** Resources and tool kits available from February 2012

### Action 7.4

- i) Provide information packs and resources specific to service providers (developed in collaboration with government agencies) for distribution to service providers
- ii) Include in the 2012 national public information campaign, will be information specific to service providers on providing quality dementia support and care



# Strategic Goal 8: Dementia Research

A greater investment into research is needed to improve the quality of dementia care practices. Research into New Zealand based service models and care pathways all contribute to reducing risks, delaying onset and slowing progression of dementia. Effective policy and planning for projected service provision requires ongoing collection of accurate population-based data. Recognition of a service structure for Māori, Pacific and Asian communities for people with dementia and people working in dementia care begins with research if an effective and efficient service structure is to be developed.

## Objective 8.1

Update the existing 2008 Dementia Economic Impact Report

**Timeframe:** Completed by end of 2011

### Action 8.1

- i) Commission research for the 2008 Dementia Economic Impact Report to be updated

## Objective 8.2

Development of a national statistics database on the incidence of dementia

**Timeframe:** Collation of national statistics to begin 2011

### Action 8.2

- i) National statistics on the incidence of dementia is collected so that long-term planning can be undertaken

## Objective 8.3

Identifying community day programmes as part of a partial respite solution

**Timeframe:** Evaluation completed end 2011

### Action 8.3

- i) Evaluate the role of day programmes as part of community support and respite care needs to identify the outcomes for people with dementia and their carers

## Objective 8.4

Identify living models for dementia care in supported housing settings

**Timeframe:** Feasibility study completed end 2012

### Action 8.4

- i) A feasibility study on supported living models to identify the conditions and support needed for dementia care in supported housing settings (e.g. cluster housing)