



Northern Regional Dementia Work Group

Dementia Services Guide

June 2013

Authorship

This document was written by the Northern Regional Dementia Work stream Group. Others are welcome to make use of the document and material therein but the sources should be acknowledged.

Disclaimer

This document is a general guide to appropriate practice, to be followed subject to the clinician's judgment and the patient's preference in each individual case. The guideline is designed to provide information to assist decision-making and is based on the best evidence available at the time of development. Copies of the document can be downloaded on Healthpoint; log in and search on "Dementia Services Guide"

Table of contents

FOREWORD.....	4
EXECUTIVE SUMMARY.....	5
ABOUT THE NORTHERN REGION HEALTH PLAN: HEALTH OF OLDER PEOPLE, DEMENTIA WORKING GROUP.....	6
BACKGROUND TO THIS DOCUMENT	7
REGIONAL DEMOGRAPHICS.....	8
REGIONAL DEMENTIA SERVICES GUIDE.....	9
REGIONAL DEMENTIA SERVICES GUIDE.....	9
PRINCIPLES UNDERPINNING THE SERVICES GUIDE	10
PERSON CENTRED CARE:.....	11
<u>PATIENT JOURNEY ELEMENTS.....</u>	12
PREVENTION / HEALTH PROMOTION / AWARENESS.....	12
SCREENING	14
SUSPICION / INITIAL INVESTIGATIONS	15
ASSESSMENT / DIAGNOSIS.....	18
POST-DIAGNOSTIC INTERVENTIONS – MILD COGNITIVE IMPAIRMENT	23
POST-DIAGNOSTIC INTERVENTIONS – DEMENTIA	25
ONGOING COMMUNITY CARE – PERSON WITH DEMENTIA	28
ONGOING COMMUNITY CARE – FAMILY/WHANAU AND CARERS	30
PHYSICAL HEALTH CRISIS/ GENERAL HOSPITAL PRESENTATION.....	33
COMPLICATIONS OF DEMENTIA/ NON-COGNITIVE SYMPTOMS OF DEMENTIA	36
TRANSITION INTO AGED RESIDENTIAL CARE	39
ONGOING CARE IN AGED RESIDENTIAL CARE	42
END OF LIFE CARE	45
<u>SUPPORTIVE OR WHOLE POPULATION ELEMENTS.....</u>	48
COMMUNITY AWARENESS	48
WORKFORCE DEVELOPMENT AND TRAINING.....	51
RESEARCH /ELECTRONIC RESOURCES	53
IT AND DOCUMENTATION	54
GOVERNANCE: LOCAL – REGIONAL – NATIONAL	55
FINANCIAL: FUNDING AND COST ANALYSIS	58
FACILITIES DESIGN	60
LIST OF ACRONYMS:.....	62
REFERENCES:.....	63
APPENDIX 1	65
APPENDIX 2	77
APPENDIX 3	78

Foreword

Dementia is a devastating illness, and the growing population of people within the region either developing dementia or providing care to people with dementia is of considerable concern to us as health care providers. Dementia is an indiscriminate illness and it is unusual to find families or individuals not affected by this complex and progressive illness which robs many sufferers of their dignity. From a societal perspective many questions are being asked about our ability to manage this growing population as clinicians in the primary and secondary sectors, and across the NGO and community sectors.

In the later stages of dementia, the challenges are to assist with options for living arrangements and supports, which are the most appropriate to meet the needs of people with dementia. Another important issue is support for carers, who we know from the research, are more likely to develop physical and emotional problems due to the pressure of providing twenty-four hour care which can often be unrelenting.

Dementia has been identified as a key initiative in the Northern Region Health Plan for Health of Older People. A regional Dementia working group was established and their review of resources and a need to provide some consistency in approach to the development of Dementia Care Pathways highlighted the need for the development of both minimum standards and regional cooperation.

The Dementia Services Guide is the result of months of discussion, research and consultation, with the purpose of developing a document for health professionals and other people involved in the provision and/or planning of services to people with dementia in the Northern Region. We have been careful to ensure the Dementia Services Guide is consistent with the principles stated in the National Dementia Framework led by the Ministry of Health. Consultation commenced in January 2013 with clinicians, Ministry of Health, health care providers across the health spectrum, people with dementia and their carers. The latter group felt the vignettes accurately reflected their experience of dementia care as it is provided at this present time and were a useful way of illustrating the challenges of dementia.

I am grateful to those who have been involved in this project which hopes to provide a guide to health professionals throughout the journey of dementia and is completed by a section on supportive or whole population elements. We would like to thank all of those who generously gave up their time to provide input and advice in the creation of this document, and hope that it is utilised fully within the sector. I also wish to personally acknowledge Dr Richard Worrall and Sue Thomson, as their unwavering enthusiasm and focus has brought this guide to fruition.

Dr Alan Davis

Clinical Lead – Health of Older People Network – Northern Regional Alliance

Clinical Director - Health of Older People and Clinical Support – Northland District Health Board.

Executive Summary

The purpose of this document is to assist healthcare providers in the Northern Region in planning and developing a whole of system approach to supporting people with dementia, and their family/whanau and caregivers throughout the course of the illness. Fundamental to service design is empowerment of the person with dementia and their family/whanau. Because dementia follows a progressive course with changing care needs, involving multiple providers, innovative approaches to integration of care and sharing knowledge of the person's unique history and care needs are essential. A knowledgeable and skilled workforce will be a foundation to implementation of dementia assessment and care provision.

This document is aspirational, and aims to guide future service development. No Northern Region District Health Board provides all of the elements as described herein. This document focuses on what needs to be delivered rather than prescribing how implementation will occur. It is accepted that service models will be developed according to local population needs, resources, geography, and current skill mix. Governance structures at local, regional, and national level are required to facilitate implementation and prioritise elements for implementation as growth in funding allows.

The format of this document is designed to describe the entire component Elements, and set Standards for a fully-resourced Dementia Pathway. Some of the Elements describe the care and standards to be provided at each point in the journey of someone with Dementia. Supportive Elements are less concerned with individual care and more directed at making sure that the Pathway can operate effectively and efficiently, and that quality of care is ensured. Attempts are made to highlight innovative or exemplar service provision already occurring. Vignettes aim to illustrate in a simplified way the experience of people with dementia and their families. Key performance indicators (KPI's) are provided to support continuous quality improvement but are not considered an exhaustive list.

Models of dementia care are evolving rapidly and although effort has been made to represent current standards of care, it is hoped that this guide will be reviewed by the Dementia Workstream group bi - annually to maintain currency with changing practice.

About the Northern Region Health Plan: Health of Older People, Dementia Working Group

Established in 2012, this is a group of primary and secondary providers of specialist care to people with dementia and their carers, with representatives from throughout the Northern Region. The group seeks to increase access to services and help ensure that service provision is consistent, cohesive and supported by evidence

The work group's primary purpose has been to:

- Identify current service gaps and recognise opportunities for standardisation
- Develop Principles and Elements of Service Development
- Define a Model of Care
- Agree on elements of a comprehensive integrated pathway
- Share work produced and contribute to the National Pathway Framework Project
- Select priority areas of service provision, where regional consistency can be developed via evidence, debate, consensus, consultation, commissioning, implementation and review
- Provision of a mechanism in which local initiatives can be reviewed and advocacy can be provided.

Background to this document

As populations around the world age, the need to plan for supporting people affected by age-related conditions and in particular dementia is being recognised as a health priority.

Countries around the world have developed strategies in response to this issue, notably the UK Dementia Strategy (2009) the Healthcare for London Dementia Services Guide (2009) and the National Framework for Action on Dementia (2006). Increased awareness, early diagnosis and intervention, and high quality care and support throughout the course of this progressive illness are the common themes underlying these documents (Alzheimer's disease International summary).

In recognition of growing need, dementia care planning has been made a priority by the Minister of Health. The Minister of Health's "Letter of Expectations for District Health Boards and their subsidiary entities for the 2012/13 year" identified Health of Older People as a priority area for health services, focussing on improving the health and well-being of older people, especially those with dementia.

The Ministry has set out an expectation that District Health Boards (DHB) will develop and implement dementia care pathways by June 2013. Funding has been earmarked for Dementia Pathway development and DHB's are expected to report on use of this funding.

The Northern Region Health Older People Network includes a dementia work stream. This work stream has evaluated planning documents from international and national dementia initiatives and has developed this service guide for dementia service delivery in the Northern Region.

In parallel to the development of this document the Ministry of Health has been working with the DHBs and the National Dementia Cooperative to develop a Dementia Services Framework, and it is intended that this Services Guide will complement and enhance the guidance provided by the National Framework.

Regional Demographics

The number of people affected by dementia in New Zealand is projected to increase from 40,726 (1.0 % of the total population) in 2008 to 74, 821 (1.5%) in 2026, and 146699 (2.7%) by 2050. New cases in 2050 will comprise 0.8% of the population and number 44,376 nationally, suggesting in excess of 15000 new cases of dementia in the northern region per year (Dementia Economic Impact Report, Alzheimer's New Zealand 2008).

The Northern region has a projected 5 year growth rate of people over 65 of 21% in the period 2011-2016 and 37% for the period 2016-2021. Current figures for cases of dementia in the region area are not available, and diagnostic rates world wide are believed to include at best only 40% of possible cases.

Counties Manukau District Health Board (CMDHB) estimates a current prevalence of around 3000, and an annual incidence of around 1000 cases based on the Alzheimer's New Zealand Economic Impact report figures.

Waitemata District Health Board (WDHB), in a recent work by Bartholomew (2013) estimates prevalence at approximately 4,800 with an incidence of 1730+, with much larger numbers of old old, not accounted for in prevalence and incidence numbers likely to make these numbers an underestimate.

Auckland District Health Board estimates a current prevalence of as many as 4300 when the Aged Residential Care Population is taken into account.

Although ethnicity and age distribution demographics vary across the region it is estimated that in the Northern Region incidence was 5074 in 2011, increasing to 5541 in 2016 and increasing again in 2021 too 5916.

Based on total population prevalence for the Northern Region in 2011 was 11,300, and will increase to 14,083 in 2016. By 2021 prevalence will have reached 16,914, this is a 16% increase in prevalence over 10 years and a 49% increase in incidence over the same period of time.

Regional Dementia Services Guide

Vision:

A society in which people with dementia and their families and whanau remain accepted members of the community. This acceptance encourages people with dementia and their families and whanau to engage early with an integrated health and support system which recognises them as valued partners and supports them to achieve optimal wellbeing and quality of life throughout their journey with dementia.

Principles underpinning the Services Guide

Services will be supported to:

1. Support awareness of dementia and acceptance of, and respect for people with dementia.
2. Acknowledge the central role of the person affected by dementia, their carers and family/whanau.
3. Aim to empower and support people with dementia, family/whanau and everyone involved in dementia care, through effective communication and education.
4. Address needs across the entire journey of the person with dementia.
5. Focus on early recognition, health improvement and maintenance, optimising well being and independence.
6. Encourage recognition of individual variation in symptoms, disease progression and needs.
7. Support standardisation and consistency whilst recognising the need for local variation.
8. Ensure ease of access, responsiveness, efficiency and affordability.
9. Provide high quality evidence based care through developing and retaining a skilled workforce.
10. Be sensitive to social, cultural, economic context and location and meets Treaty of Waitangi obligations.
11. Ensure continuity of care throughout the journey of dementia through integration and flexible service provision.

Person Centred Care:

The principles of person-centred care are generally accepted as underpinning good practice in the field of dementia care(NICE -SCIE Guidance 42, 2006 Page 6).

The principles assert:

“...the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them”

“...the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia”

“...the importance of the perspective of the person with dementia (and) the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being”

(Brooker, D, 2004)

“A fourth principle emphasizes the imperative in dementia care to consider the needs of carers, whether family/whanau and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia. This is increasingly described as 'relationship-centered care”

(NICE –SCIE Guideline No 42, 2006. Page 6)

PATIENT JOURNEY ELEMENTS

Prevention / Health Promotion / Awareness

<p>Introduction</p>	<p>Dementia is a disease which is associated with stigma and fear. In both the general public and in health professionals a reluctance to acknowledge cognitive changes and lack of understanding of the disease may result in early cognitive symptoms being dismissed as normal aging.</p> <p>Cognitive decline has been found to be associated with a range of modifiable risk factors, and lifestyle changes and management of cardiovascular risk factors (such as smoking, lipids, hypertension, diabetes) and depression hold the greatest promise in reducing dementia prevalence. Destigmatisation, health promotion and prevention messages may help reduce rates of dementia and may promote earlier assessment.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Promote the benefit of prevention and or early diagnosis in delaying the development or progression of dementia related symptoms, accessing support and planning for the future. Promote the idea that “living well with dementia” is a realistic goal • Promote strategies and lifestyle changes which encourage the early identification of risk factors and signs of dementia • Promote strategies and lifestyle changes that may reduce or delay the onset of dementia • Promote cognitive, emotional, mental, and physical well being • Ensure responses to major alcohol reduction campaigns include such messages as the potential to develop alcohol related brain damage.
<p>Potential Providers</p>	<p>Alzheimer’s New Zealand (ANZCT) Ministry of Health All Healthcare Providers</p>
<p>KPIs</p>	<ul style="list-style-type: none"> ▪ Evidence of public national awareness campaign re

	<p>prevention that:</p> <ul style="list-style-type: none"> ○ Encourages maintenance and development of social and cultural links ○ Encourages continuing education ○ Encourages cognitive stimulation ○ Encourages physical exercise ▪ Evidence of strategies and promotional campaigns aimed at early identification and risk minimisation.
Local Initiatives	Alzheimer’s New Zealand “We Can Help” campaign

Christine decides to drop in to her elderly parents for breakfast. On arrival she smells smoke coming from the house. She finds her mother has put the Edmonds cook book in the toaster. She had seen the same thing on television the month before in the “We can help campaign”. After discussion with her distressed father, Christine and her parents meet with an Alzheimer’s Auckland Charitable Trust (AACT) representative the following week

Screening

Introduction	Universal screening of older people is not a required or evidence-based stage of the pathway. At this stage case finding (assessment when concerns or suspicions of cognitive impairment are raised) is the recommended approach. However there are opportunities for screening to occur in certain circumstances by agreement between providers. Cognitive screening could become part of driving licence renewal at ages 75 and above in Primary Care. Secondary Care inpatients or those in Emergency Department (ED) could have universal screening for confusion / dementia above an agreed age, by agreement.
Standards	Yet to be agreed
Potential Providers	Primary Care (Mandatory Driving Licence Renewal) Secondary Care (Patients over agreed age such as 75 or those with agreed presentations could be screened for Delirium or Dementia)
KPIs	<ul style="list-style-type: none"> ▪ Completion of agreed screening on identified population ▪ Engagement in screening may be improved with cultural and family /whanau support.
Local Initiatives	Auckland DHB Hospital Dementia Pathway

Elsie is 85 and suffers from Chronic Obstructive Pulmonary Disease (COPD) and hypertension. She is admitted to hospital after a fall at home and suffering a fractured humerus. Routine screening of people over 75 admitted to hospital is carried out using the GP COG. Elsie scored 6 on this test, and the nurse then asks further questions of Elsie's daughter as part of the informant interview. This reveals that Elsie has had memory problems developing over 2 years but has been more confused than usual in hospital.

- GP COG – The General Practitioners Assessment of Cognition
<http://www.gpcog.com.au/>

Suspicion / Initial Investigations

<p>Introduction</p>	<p>A person with dementia or their family/whanau may present with concerns about memory problems or behavioural change to their General Practitioner (GP), or their GP may have noticed a change in the person which might raise the suspicion of some cognitive impairment. Even if their GP does not feel confident to diagnose dementia, he or she should undertake some initial screening tests or investigations, and seek to exclude other possible causes.</p> <p>This section, therefore defines a sensible approach to a person with possible cognitive impairment, leading to the GP being able to refer to a specialist service if still concerned. Not all cases will require specialist referral.</p> <p>The same standards should be met in other services such as Secondary care when concerns about a person are raised, and a decision is being made about referral to an appropriate service.</p> <p>This standard is lower than that required to confirm a diagnosis of dementia, and is targeted at making sure referrals for specialist assessment are appropriate.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Evaluate and validate a suite of standardised screening and diagnostic assessment systems and tools (this may be done nationally / internationally) • Promote the benefit of early diagnosis in delaying the progression of dementia through education of healthcare providers including primary care • Assess existing dementia services in order to identify barriers to equity of access and consider recommendations for resolving these issues • Physical examination, (including neurological examination to exclude stroke or Parkinson’s disease) • Interview or contact with family/whanau member for collateral history • Use of appropriate screening tools such as <ul style="list-style-type: none"> ○ The General Practitioners Assessment of Cognition (GPCog) http://www.gpcog.com.au/ or ○ Montreal Cognitive Assessment (MoCA) < http://www.mocatest.org/ or ○ Rowland University Dementia Assessment Scale (RUDAS) <http://www.fightdementia.org.au/common/files/NAT/20110311_2011RUDASAdminScoringGuide.pdf> ○ Informant Questionnaire On Cognition in the Elderly

	<p>IQCODE http://www.mentalhealthwiki.org/Informant Questionnaire on Cognitive Decline in the Elderly %28IQCODE%29</p> <ul style="list-style-type: none"> • Inquiry about functional deficits and driving safety <ul style="list-style-type: none"> ○ The NZTA site for Medical fitness to drive for Medical Fitness http://www.nzta.govt.nz/resources/medical-aspects/docs/medical-aspects.pdf ○ The NZTA site for Occupational therapy driving assessments. http://www.nzaot.com/about-occupational-therapy/driving-assessments.php • Inquiry about other possible causes such as: <ul style="list-style-type: none"> ○ delirium http://www.hospitalelderlifeprogram.org/pdf/TheConfusionAssessmentMethod.pdf, The Confusion Assessment Method (CAM) ○ depression http://www.chcr.brown.edu/GDS_SHORT_FORM.PDF, ○ substance abuse http://www.kap.samhsa.gov/products/brochures/pdfs/Pocket_2.pdf, ○ or medication side effects • Request for blood tests and urine specimen to exclude thyroid, vitamin deficiencies or infection • Referral to specialist service if concern about mild cognitive impairment or dementia is confirmed • Multi disciplinary team meetings at regular intervals.
Potential Providers	<p>Primary Care services - including those in Aged Related Residential Care facilities (ARRC) Secondary Care services</p>
KPIs	<ul style="list-style-type: none"> ▪ Measurable evidence of primary care education in responding to people presenting with concerns about cognition ▪ Development of a suite of standardised tools in use in inpatient and community sectors e.g. http://www.dementia-assessment.com.au/measures.html ▪ Primary care clinicians are confident in an initial approach to people presenting with memory difficulties, and know when and where to refer (possible survey). <p>People with cognitive impairment and their carers report appropriate access to dementia care services regardless of where they live, their health status, their age, their cultural background, or financial and social circumstances.</p>
Local Initiatives	<p>Waitemata District Health Board Cognitive impairment pathway pilot.</p>

Ernie is 75 and has recently retired from his Accountancy practice. At a routine check-up Ernie's wife prompts him to mention to the general practitioner that his memory is not as good as it used to be, that he is having difficulty relaying phone messages to his wife, having difficulty remembering names when introducing people he knows quite well when at Probus Club, and is misplacing his wallet and glasses often. His wife has had no concerns about Ernie's driving.

The GP carries out a MoCA, physical examination and orders routine blood tests. He asks Ernie's wife to complete the IQCODE. The results suggest Ernie is developing memory problems greater than normal aging and Ernie is referred to the local memory service for further assessment.

- MoCA – Montreal Cognitive Assessments
<http://www.mocatest.org/>
- IQCODE - Informant Questionnaire on Cognitive Decline in the Elderly
<http://www.health.vic.gov.au/agedcare/downloads/pdf/iqcode.pdf>

Assessment / Diagnosis

<p>Introduction</p>	<p>People with Dementia require an assessment completed by an appropriately trained health practitioner, leading to a clear diagnosis. Diagnosis is the basis on which future care can be planned. This should include an assessment of dementia type, carer burden, needs assessment and presence of complications.</p> <p>This assessment may be entirely completed in Primary Care (with or without the input from a Dementia service) or any part of the Secondary Health Sector depending on the case and expertise available. The areas of Secondary Care with this expertise will commonly be General Hospital Inpatient Services, Health of Older People (HOP) and Mental Health Services for Older People (MHSOP). However the assessment may be completed by a specialist Dementia Service, following initial workup in Primary Care or some other setting. This is likely to be necessary for difficult cases or to ensure that the type of dementia is identified. The preferred setting in any one DHB will depend on local expertise and resourcing, but all people should have access to a specialist assessment if required.</p> <p>Assessment must lead to comprehensive care planning shared across healthcare providers.</p>
<p>Standards</p>	<p>Standards for the Assessment (for all providers)</p> <p>A comprehensive assessment must be completed. This may be completed over more than one session. This will include:</p> <ul style="list-style-type: none"> • Explanation of the assessment process and likely outcomes should be provided and consent obtained. • A full history from person with memory problems. Structured formats are recommended (NICE Clinical Guideline 42) Include description of time course and symptom progression • Collateral history from family/whanau or caregivers, including carer burden (NICE Clinical Guideline 42) eg IQCODE, care stress interventions. • Whanau ora assessments occur where appropriate http://www.tpk.govt.nz/en/in-focus/whanau-ora/ • Assessment of functioning including: <ul style="list-style-type: none"> ○ basic and instrumental Activities of Daily Living (ADLs) ○ http://www.abramsoncenter.org/pri/documents/iadl.pdf ○ driving competency <http://www.nzta.govt.nz/licence/medical/drivers.html>

	<ul style="list-style-type: none">○ risk and vulnerability● Review of risk factors including modifiable cardiovascular risk factors and complications of dementia such as Behavioural and Psychological Symptoms of Dementia (BPSD)● Medical history and medications including allergies should be obtained, as should history of alcohol or other substance abuse● Cognitive assessment using measures validated for diagnosis should be used, as well as measures of mood and functional ability e.g.<ul style="list-style-type: none">○ Montreal Cognitive Assessment MoCA, http://www.mocatest.org/○ Addenbrookes Cognitive Examination – Revised ACER http://www.stvincents.ie/dynamic/File/Addenbrookes_guide.pdf>○ Rowland Universal Dementia Assessment Guide RUDAS http://www.fightdementia.org.au/common/files/NAT/20110311_2011RUDASAdminScoringGuide.pdf● Assessment of social situation, care package, and powers of attorney. Enquiry about elder abuse and neglect. Some appreciation of legal competency should be gained. Cultural and spiritual identification should be ascertained. Where indicated assessment of decision making capacity is available● Clinical Judgement of risks to the person and family/whanau / carers● Physical examination including neurological and cardiovascular systems. Routine Blood tests should include Full Blood Count, Electrolytes, Renal function, Calcium, Liver Function tests, Vitamin B12 and Folate, fasting glucose and lipid profile. Consider Syphilis serology, Human immunodeficiency virus (HIV) on clinical grounds● Computed tomography (CT) / Magnetic Resonance Imaging (MRI) or Single Photon Emission Computed Tomography (SPECT) scan requested and performed within an acceptable time frame● Diagnosis should be made, incorporating history, history, cognitive testing investigations and imaging's and include specification of type of dementia (as far as this is possible)● Referrals or second opinions should be sought for those with specific presentations such as neurological symptoms , early onset of dementia, atypical presentations or rapidly progressive cognitive decline, suspected or confirmed Axis I mental disorder which may confound diagnosis● Diagnosis must be shared with person and their family/whanau● Diagnosis will be entered into computerised patient records,
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with alerts as appropriate. This should include a local register.

- Assessors will have skills to deal with all referrals including those people who are younger, have underlying learning disability or psychiatric or neurological disorder, or those from (Culturally and Linguistically Diverse Groups) CALD groups, with particular focus on Maori, Pacifica and Asian peoples.
- Develop single referral and assessment pathways to maximise sharing of assessment information between GPs, Secondary services and ARRC.
- Multi disciplinary team meetings at regular intervals.

If the service is being provided by a Specialised Dementia service or Memory clinic, then:

- Access to a single point of expert dementia care and advice
- The service should have a defined title and role with promotion
- There should be identified referral criteria and mechanism for referral
- There will be an efficient triage processes and prioritising of cases
- There should be defined response times for both triage and first appointment
- Clear instructions will be provided re appointments
- The case will be reviewed with the Multi-disciplinary team and where needed additional assessment by neuropsychologist, OT, SLT are available
- Written feedback will be provided to both the person and their family/whanau, and referrers
- Documentation will be comprehensive
- There will be staffing and resourcing to meet demand
- Help to find, organise and coordinate services from a range of local providers
- Multi disciplinary team meetings at regular intervals.

Where the Assessment is provided by a combination of services:

For example, by GP and Primary care practice nurse, supported by visiting Dementia Service Clinician:

- There will be a clear responsibility for tasks to be completed by each of the participants, including diagnosis and clinical decision making
- Clinical documentation will be accessible to all parties
- Response and process times will be defined
- Where Primary care diagnosis is occurring access to a decision

	<p>support tool eg Map of Medicine, NICE, or similar is recommended. This could be a opportunity for Regional or National</p> <ul style="list-style-type: none"> • Multi disciplinary team meetings at regular intervals • Available specialist advice /consultation: for example Gerontology Nurse Specialists – in some DHB’s review people presenting with cognitive issues who require work up of diagnosis at home or in aged residential care – this is in consultation with a Geriatrician.
Potential Providers	<p>Primary Care Secondary Care Providers Specialised Dementia Care Provider</p>
KPIs	<ul style="list-style-type: none"> ▪ Identified governance structure and articulated diagnostic pathway, elements of pathway correspond to above standards ▪ Number of GP referrals ▪ Number of GP’s using the service (for secondary services) ▪ Proportion of estimated population dementia prevalence ▪ Number of diagnoses and subtypes including MCI and Non dementia ▪ Ethnicity data is examined to evaluate access to service. ▪ Number of referrals without dementia ▪ Place of diagnosis ▪ Time from referral to assessment ▪ Number needing to see specialised dementia service ▪ Risks factors identified ▪ Presence of Complication rates ▪ Time from assessment to feedback letter to GP / referrer ▪ These standards will be incorporated into guidelines, protocols or computerised pathway guides ▪ Wait time for diagnostic imaging.
Local Initiatives	<p>Taranaki Primary Care Pathway Canterbury Dementia Pathway Guide Memory Clinics – multiple DHBs Counties Manukau Dementia Care Pathway – Memory Team</p>

Primary Health Care

Bob has moderate dementia with a progressive decline consistent with Alzheimer's disease. He attends his GPs after concerns are expressed by his family/whanau. His GP carries out a MoCA, and asks family/whanau to complete the IQCODE along with his history of decline diagnoses Alzheimer's Disease. The Practice Nurse organises blood tests and completes some screening tests such as cognitive testing and ADL's. A Clinical Nurse Specialist (CNS) from the local Dementia Service reviews Bob at the surgery. A CT scan is ordered through the DHB. The diagnosis is discussed at the surgery and the CNS meets with the person and their family/whanau to discuss this.

Result: Assessment Diagnosis and engagement with Specialist service.

Memory Clinic Diagnosis

Tui is referred to the local Dementia Service by her GP. He requests a specialist opinion, because of her young age (67) and because she has been experiencing hallucinations and falls. She is reviewed in memory clinic by a CNS, Geriatrician and Psychologist, over two appointments. Her family/whanau is interviewed separately. A feedback visit to her home is organised to discuss the diagnosis and plan ongoing treatment. Letters confirming her diagnosis are sent to Tui and her GP.

Result: Assessment and Diagnosis via Memory Clinic with referral back to Primary Health Care.

General Hospital Diagnosis

Rewi is admitted to the General Hospital following a stroke. He receives rehabilitation on the Geriatric ward, during which time it is recognised that he is confused. A full assessment is completed including CT Scan, while he remains an inpatient. After discussion with the Liaison Geriatrician, a diagnosis of Vascular Dementia is made.

Result: Assessment and Diagnosis.

Post-Diagnostic Interventions – Mild Cognitive Impairment

<p>Introduction</p>	<p>Mild Cognitive Impairment (MCI) is a brain disorder in which thinking abilities are mildly impaired. Individuals with mild cognitive impairment are able to function in everyday activities such as complex and instrumental ADLs, but have difficulty with memory – this can include, difficulty remembering the names of people they met recently, following a conversation, misplacing things. The individual may be aware of these difficulties and compensate by writing notes and using calendars. The diagnosis of MCI relies on the fact that the individual is able to perform all their usual activities successfully, without more assistance from others than they previously needed. In this regard, MCI is different from dementia.</p> <p>Some people with MCI develop a progressive decline in their thinking abilities over time and go on to develop a dementia. However many do not show any progression and some may even improve with time.</p> <p>When someone is diagnosed with MCI, they need to be offered a specific package of care, in anticipation of the possibility of future deterioration. This may be followed by discharge from the service (with re-referral if deterioration does occur) or regular reviews (such as annual check-ups).</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Education about MCI, including the possibility of future deterioration and dementia. Both the person and their family/whanau need to be involved • Whanau ora approach to care where appropriate http://www.tpk.govt.nz/en/in-focus/whanau-ora/ • Counselling about future signs and symptoms of dementia • Creation of MCI Future Care Plan • Education about healthy living and management of risk factors, including alcohol intake • Prompting for assessment in Primary Care for management of vascular disease risk • Contact with Primary Care to outline diagnosis • Appointment of Enduring Powers of Attorney (EPOA) • Review of driving risk • Advanced Care Plan (ACP) where appropriate • Review of medications

	<ul style="list-style-type: none"> • Review need for referral to Needs Assessment and Service Coordination (NASC) • Multi disciplinary team meetings at regular intervals.
Potential Providers	Specialised dementia service Primary care
KPIs	<ul style="list-style-type: none"> ▪ Number of people given verbal and written information about MCI ▪ Contacts with Primary Care – person ▪ Contacts with Primary Care – dementia service ▪ Number of people with advance care plans ▪ Number of people referred to Alzheimer’s society ▪ Number of people with EPOA ▪ Number of carer assessments completed ▪ Number provided with MCI future care plan.
Local Initiatives	Memory clinics

Ernie has been assessed by his local Memory assessment service and diagnosed with mild cognitive impairment, amnesic type. He and his wife are informed of the diagnosis, and given information about the condition, including the possibility that his memory problems will progress. After cognitive testing and driving questionnaires it is decided that Ernie is probably safe to continue driving, but it is explained that his fitness to drive will require regular review and he and his wife are made aware of red flags for concern about driving.

Review of his medication reveals that a sleeping tablet started during a recent hospital admission is no longer needed and sleep hygiene strategies are discussed.

Ernie already has EPOA set up. He is given information about advance care planning and it is agreed that this will be completed with his GP. Carer assessment reveals no major concerns for his wife at this time.

Post-Diagnostic Interventions – Dementia

<p>Introduction</p>	<p>Receiving a diagnosis of dementia is a stressful time for the person and their caregivers. At the same time having a name for what is going on, information and a plan for the future can provide some sense of relief in what has been a time of uncertainty.</p> <p>This is a time for all those involved in care to share in planning for the future.</p> <p>Given that there are a number of facets to post diagnosis care a structured way of recording and communicating what has been offered is advised.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Add to dementia register • Post-diagnostic support and counselling to the person with dementia and their carers. • Provide information about diagnosis, prognosis, treatment and available supports • Communicate with other healthcare professionals and share living well with dementia plan. • Clarify roles in ongoing care with primary care • Refer to support services: Alzheimer’s New Zealand, NASC services • Carers assessment: <ul style="list-style-type: none"> ○ Carers of Frail Older People - COPE Index (CI) • Book Annual reviews of physical state and prescribed medications • Review repeat prescriptions • Prescribe dementia medications if appropriate • Initiate living well with dementia plan: <ul style="list-style-type: none"> - This is me document - Capturing the diagnosis - Advice re legal matters EPOA, wills - Advance directives and advance care planning - Review of immediate safety/ self care issues • Consider work, income and dependents, driving, ADLs, vulnerability. <p>Service Development Opportunities</p> <ul style="list-style-type: none"> • Identification of GPs with special interests and the instigation of dedicated GP/Practice Nurse sessions • Promote access points, referral and assessment pathways and options for information to be available in other

	<p>languages</p> <ul style="list-style-type: none"> • Identify and promote the best ways to assist people with dementia, their families and carers to navigate the community care system • Continue supporting people with dementia to maintain and develop skills that enable them to remain connected to their communities for as long as possible • Identify and promote the best ways to assist people with dementia that are culturally appropriate and support equity of access to information and supports and equity of outcomes. • Identify and promote a range of responses to people with dementia that include not only medical and functional diagnosis, treatment care and support but innovative opportunities for people with dementia to remain connected to their communities • Multi disciplinary team meetings at regular intervals • Gerontology Nurse Specialists – in some DHB’s review management problems at home or in aged related residential care for people presenting with cognitive issues who require review of management.
Potential Providers	<p>Primary Care Memory Clinics Older People’s Health Services General Hospital Services Alzheimer’s Societies Mental Health Services for Older People (where person is a current patient)</p>
KPIs	<ul style="list-style-type: none"> ▪ Number of people given verbal and written information about dementia ▪ Number of people on dementia register/ number of people estimated to have dementia in target population ▪ Number of people with dementia diagnosis who have living well dementia plan ▪ Number of people with ACP’s ▪ Number of people referred to Alzheimer’s New Zealand ▪ Measure national prescriptions of drug use in people with dementia ▪ Number of people with EPOA ▪ Number of carer assessments completed ▪ Evidence of user friendly promotional material
Local Initiatives	<p>Memory Clinics Alzheimer’s NZ support services</p>

The point of diagnosis

Alice was a 52 year old nurse working in a general hospital. In recent years she had noticed increasing difficulty keeping up with younger staff members, she assumed it was just difference in training. However in the last few months she has become increasingly forgetful, had difficulty recalling what tasks she had to do during the day, and recently made 2 significant medication errors. At home she was less able to organise meals and found it impossible to assist her daughter with her school work. After much discussion her GP finally agreed that her behaviour was a concern and referred her to a Neurologist who diagnosed Alzheimer's Disease.

It was a relief to Alice, who had thought she was losing her mind. The Neurologist started her on Cognitive Enhancers and after discussions with her employer, Alice decided to leave nursing and stay at home to enjoy time with her husband and daughter.

Ongoing Community Care – Person with Dementia

<p>Introduction</p>	<p>Dementia is a progressive and evolving illness. It is viewed as necessary for the person with dementia to have regular follow-up, plus availability of services should crises occur. On-going support and guidance helps with the monitoring of the illness and its complications, and allows the families and carers access to advice quickly. There will also be on-going encouragement for the person in living well with dementia and coming to terms with the illness. It also allows for the timely interventions such as ceasing driving or activation of Enduring Powers of Attorney when necessary.</p> <p>On-going community care is frequently provided through a combination of home or clinic appointments with the family/whanau, and the availability of groups in the community.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Emergency support is available, which provides general and specialist advice, and physical and practical help • Patient information hub: - A service or information kit for each patient, carer and key worker, which includes all information on the patient, all relevant services and the agreed detailed care pathway is given to each patient/family/whanau dyad (this is both patient held and electronic records) • Medicine management and administration: advising patients and carers on basic medicines management and compliance is provided as a standard intervention • Practical assistance is offered within the home e.g. home help • Support is provided with everyday social activities – on a 1:1 basis or in group interventions. This should include activities and social engagements that patients and carers can do together • Care planning includes the patients needs and wishes • Care planning is agreed with the key worker/primary care team • Copy of the care plan sent to the 24/7 telephone and admin support system if this is available within the DHB, alternatively the development of a Northern Regional Support system may result in better information collection and support. • Copy given to patient and shared with support team • Advanced care and capacity planning is organised

	<ul style="list-style-type: none"> • Clinician engagement over prognosis involving continuous feedback • Unnecessary General Hospital admissions are avoided due to secondary service input • Identify and address the needs of older couples where one or both partners have dementia • Multi disciplinary team meetings at regular intervals.
Potential Providers	<p>Primary Care Specialised Dementia Services Alzheimer's Associations</p>
KPIs	<ul style="list-style-type: none"> ▪ Patient information packs are issued to every patient ▪ Numbers of people with a recorded diagnosis of dementia is reflected in prevalence data ▪ Number of people with dementia who have a living well with dementia care plan ▪ Number of alternative care options available e.g. <ul style="list-style-type: none"> - Transfer to acute hospital setting - End of life care ▪ Number of late stage dementia patients assessed for planned palliative care ▪ Number of people with dementia who receive a NASC assessment ▪ Number of scheduled visits to the person with dementia ▪ Percentage of these visits cancelled ▪ Numbers of calls out to crisis service ▪ Number of hospital admissions avoided ▪ Evidence that the needs of older couples where one or both have dementia have been identified and met.
Local Initiatives	

Ongoing Community Care – Family/whanau and Carers

<p>Introduction</p>	<p>Many people with dementia are able to maintain their lifestyle within the community with the support of families, carers, friends and the health services.</p> <p>However at present services are fragmented and carers often struggle with obtaining a diagnosis and accessing appropriate services and resources.</p> <p>Better services need to be available to all New Zealanders regardless of their location, culture differences or socio economic status</p> <p>Services need to value and respect the dignity of people with dementia as well as the significant role of both families and carers.</p> <p>We know that carers of people with dementia are at high risk of depression, poor physical health and social isolation. Early psychoeducation intervention, support and coordination of care can have positive effects.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Round the clock clinical and emotional support for patients and carers • Staff, carer and family/whanau training support to encourage trust • Development of peer support networks – facilitated by secondary service organisations • A named key worker who can be contacted quickly • Day programmes are available, accessible and affordable • Night care is available accessible and affordable • Out of hours support – providing rest and support for carers • Provide practical day to day support and hands on work • Access to specialist staff and advice on call 24 hours through a phone 0800 national system, supported by combined DHB /NGO resources • Promote counselling services and education and awareness programs to carers of people with dementia at all stages of the care pathway • Explore availability of advocacy services for carers and people with dementia including Health and Disability Advocacy Service etc • Develop flexible models of respite care (including culturally appropriate) in collaboration with local communities including care providers • Support the provision of care and support for people with dementia and their carers where “risk” of abuse is escalating

	<p>or where there is evidence of abuse occurring</p> <ul style="list-style-type: none"> • Identify health literacy needs for people with dementia and carers and develop strategies to promote health literacy based on best practise and available evidence.
Potential Providers	<p>Alzheimer’s New Zealander Secondary Providers e.g. NASC, MHSOA and OPH NGOs providing Home help, personal cares, respite and carer support</p>
KPIs	<ul style="list-style-type: none"> ▪ Family/whanau/Carer information packs are issued to family/whanau/carers ▪ Time from referral to completion of needs assessment ▪ Numbers of carers that have access to carer support and numbers of carers who use this support and types of use of this package ▪ Numbers of carers that have access to respite programme and numbers of carers who use this support and length of use, where and frequency ▪ Numbers of carers that have home help ▪ Numbers of carers that have personal care support ▪ Numbers of carers that are referred to Alzheimer’s New Zealand ▪ Numbers of carers that consequently take up Alzheimer’s New Zealand engagement ▪ Regular Carer forums held to discuss issues and needs of carers and appropriate support information disseminated to them. ▪ Evidence of ‘best practice’ respite care ▪ Carer surveys are completed annually and Families and Carers report satisfaction with service provided ▪ Evidence that management of high ‘risk ‘ circumstances has improved the safety and wellbeing of people with dementia and their carers ▪ Use of inteRAI for needs assessment service coordination nationally.
Local Initiatives	<p>CMDHB Dementia Service WDHB Primary Health Care pilot</p>

Coordinating Services

Helen, who was widowed, lived in her own home, and had been independently active for many years. Her GP diagnosed Dementia and referred her to OPH for an assessment of the impact of Dementia on her and her ability to remain at home alone in the future.

Initially she received supportive home visits from the MHSOA Community Mental Health Nurse (CMHN), who referred her to NASC. This service organised home help, so that she could continue shopping and could attend 3 monthly GP check ups.

Helen's daughter Tracey found it particularly difficult understanding her mother's illness and worried about her future. Tracey met with the MHSOA team, who suggested she engage with AACT. Tracey attended their Carer Education programme, and became actively involved with other carers.

Tracey took her mother to the Public Trust, who arranged EPOA for welfare and property management. Helen continued to live at home with the support of Home Help and later Personal Cares.

However eventually as her disease progressed, Tracey and her family/whanau suggested that Helen come and live with them in a small flat attached to their home. Helen continued to live in this supportive environment for a further two years; Tracey helped with meals, assisted with finances and was supported by AACT and Helen's CMHN.

The inclusion of carer support means that when Tracey and her family/whanau have needed a break, Helen has been able to go to the local rest home for a short stay.

Physical Health Crisis/ General Hospital Presentation

<p>Introduction</p>	<p>Physical Health problems are common in people with dementia, but the presence of dementia can complicate diagnosis and management.</p> <p>Failure to identify dementia and ensure the care needs of the person with dementia are met can compromise recovery of the index health problem and result in additional morbidity.</p> <p>Dementia is frequently complicated by Delirium when people become physically unwell. This adds to risk for the person while in hospital, and may lead to future deterioration in cognitive impairment if not managed effectively</p> <p>A move to the unfamiliar environment of the hospital can be unsettling for people with dementia.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Health care providers will screen for cognitive impairment in vulnerable populations such as hospitalised people aged over 75 using validated tools • A structured person centred approach to evaluating capabilities and support needs which involves the person with dementia and their family/whanau/ caregivers is recommended (for example the “This Is Me” document). Where this type of care planning has previously occurred the plan is available to hospital staff and the physical health crisis is considered a time for review of this plan. • Guidance and education for general hospital staff in caring for people with cognitive impairment in hospital should be available (e.g. Best Brain Care) • Guidance and education for general hospital staff in caring for people with Alcohol Related Cognitive Impairment and its medical co-morbidities, interventions and outcomes – including funding issues • Family/whanau involvement in care is supported. • Ongoing assessment for the presence of delirium complicating dementia, and managing any identified cause • Staff will be aware of and evaluate competency to consent to proposed medical treatments, and use appropriate legislation to support care provided. • Where dementia is newly diagnosed the standards for assessment / diagnosis will be met. • Evaluate reliability of dementia diagnosis coding in general

	<p>hospitals</p> <ul style="list-style-type: none"> • Hospital design and layout focuses on improved safety and orientation for people with dementia • Utilise hospital admission avoidance programs or failed discharge review processes where appropriate • Multi disciplinary team meetings at regular intervals.
Potential Providers	Primary Care, General Hospital, Emergency Medical Services, ARRC
KPIs	<ul style="list-style-type: none"> ▪ Number of ED admissions for people who have a diagnosis of dementia ▪ Number of ED admissions that don't result in admission to the main hospital ▪ Average length of stay ▪ Percentage of admissions for Dementia related issues ▪ Number of admissions for Delirium ▪ Percentage of admissions who are referred to MHSOA ▪ Percentage of admissions who are referred to Psych Liaison ▪ Availability and utilisation of local guidelines for identification of dementia and delirium in general hospital inpatients
Local Initiatives	Better Brain Care Pathway - Auckland DHB

Reducing hospital admissions:

Helen was receiving palliative care at her family/whanau home, being supported by CMDHB Dementia Service. She had end stage COPD, CHF and a vascular dementia. Her daughter rang the Dementia Service Navigator/Key worker in the evening because Helen had become increasingly confused, was resisting cares, which was unusual for her, and was newly incontinent.

The Navigator, who visited Helen and her family/whanau, was able to establish through electronic records, recent sudden change in behaviour and review of her previous medical history that Helen was delirious as a consequence of Urinary Tract Infection (UTI).

She called Helens General Practitioner who prescribed antibiotics. The Navigator arranged a short term increase in Helen's personal care hours.

Result: Helen returned to previous level of functioning, and hospital admission was avoided.

Post stroke delirium

Rewi is noted to be more confused than usual post stroke, is disoriented wanting to leave the ward and go to work. At first he doesn't recognise his wife. He is awake at night and disturbing other patient's sleep.

He is assessed by the medical team who diagnose a post stroke delirium and institute the best brain care management plan, and work with Rewi's family/whanau to complete the "this is me" document. This supports a personalised approach with reorientation, assistance with sleep routines including bringing in his favourite pyjamas, ensuring Rewi is supported with food and fluid intake. Family/whanau are supported to visit often and bring in his favourite music on an MP3 player which helps calm him.

Complications of Dementia/ Non-Cognitive Symptoms Of Dementia

Introduction	<p>Behavioural and Psychological Symptoms of Dementia (BPSD) occur in the majority of people with dementia at some point in their illness. These may include hallucinations or delusions, anxiety or depression, agitation, resistiveness with cares and aggression, wandering, apathy, and socially inappropriate behaviours. Some of these syndromes are more common in different types of dementia, emphasising the need for accurate diagnosis. As well as causing distress for the person with dementia, they are frequently a major cause of carer stress and may precipitate the decision to move the person into ARRC.</p> <p>Such behaviours also cause significant challenges in the aged residential care setting.</p> <p>Pharmacological treatments have historically been the first approach but typically have modest efficacy and are associated with risk /harm. There are also a number of non-pharmacological tools to manage these behaviours, and carers and families need training and guidance in employing these.</p>
Standards	<ul style="list-style-type: none"> • Specialist Assessment Teams are available to receive referrals for people with Behavioural and Psychological Symptoms (Usually Mental Health Services for Older People). • These services will have effective triage and crisis functions and linkages with referrers and other healthcare providers (including ARRC) • These services will support family/whanau and existing healthcare providers to manage the spectrum of complications of dementia • These services will carry out a comprehensive assessment which evaluates environmental, psychological (including depression), social and physical health (including pain) contributions to the current presentation • Gerontology Nurse Specialists – in some DHB’s review people at home or in aged related residential care who are presenting with cognitive issues which require review of management • Assessment will include a person centred focus which takes into account consideration of the person’s life history, personality, interests and preferences, family/whanau, and

	<p>recent transitions in care, and seeks to understand the message communicated by the behaviour</p> <ul style="list-style-type: none"> • Multi disciplinary and Multi team approach – primary carer and other teams • Education and ongoing support for carers (either family/whanau or in the ARRC setting) is a mainstay of management and includes engagement, support and education about appropriate techniques • Evidence based interventions will be available including <ul style="list-style-type: none"> ○ Carer education, Non-pharmacological approaches as an initial approach (which may include aromatherapy, personalised music, massage, multisensory stimulation, animal assisted therapy) (NICE Guidance) and pharmacological treatments (NICE Guidance) • Case management will be available as required • Legal and ethically responsibility - Consent is a cornerstone of care.
<p>Potential Providers</p>	<p>Informal carers Aged residential Care Primary Care Older People’s Health Services General Hospital and Liaison Psychiatry Services Mental Health Services for Older People</p>
<p>KPIs</p>	<ul style="list-style-type: none"> ▪ Number of transfers of care into specialised units Dementia Units (DU) / Psychogeriatric Unit (PG), Regional Mental Health Unit (RMHU) ▪ Injuries to staff ▪ Falls monitoring includes evaluation of antipsychotic and benzodiazepine prescription ▪ Evidence that MHSOP services routinely support non-pharmacological management of BPSD (Audit) ▪ Number of hospital admissions avoided ▪ Identify target symptoms or behaviours ▪ Rates of prescription of antipsychotics ▪ Target for reduction in prescriptions ▪ Target for mean duration of prescription of anti psychotics ▪ Evidence of time limited trials of antipsychotics ▪ Reduction of polypharmacy.
<p>Local Initiatives</p>	

Although Rewi's sleep cycle improves and other features of delirium resolve his memory does not improve back to normal. He is assessed by the occupational therapist who finds that he has perceptual difficulties and problems with sequencing elements of a simple task (making a cup of tea) he is diagnosed with a vascular dementia and the team follow the steps of diagnosis and support as above.

Rewi develops the belief that his wife has been unfaithful with a neighbour whilst he has been in hospital, and cannot be reassured by this. He is angry when she visits and threatens to "sort the neighbour out" when he gets out of hospital. He is assessed by the liaison psychiatry team and an antipsychotic is prescribed. Visits with family/whanau are encouraged, and a schedule is kept to remind Rewi of when his wife has visited. Family/whanau spend time reminiscing about favourite holidays in the past and staff have photos to support this reminiscence. Rewi's concerns abate over a week. Rewi has graduated leave with his wife and son prior to discharge.

Transition into Aged Residential Care

<p>Introduction</p>	<p>Many people with dementia end up moving into an ARRC facility. There are three major predictors of entry to residential care, dementia severity, the development of BPSD and the carer's health and burden of care. However, the move into ARRC is often a time of special difficulty for both the person with dementia and their families. The person is often reluctant to leave their home, and for many carers this is a time associated with feelings of guilt and having failed their loved one. There are also financial implications which impact on this time.</p> <p>This transition is the time when an ongoing relationship involving aged residential care staff, the person and their family/whanau begins and is an opportunity for development or review of person centred care plans in which care needs are understood and there is agreement about an individualised support plan.</p> <p>Residential care provides around the clock care and supervision to a large number of people with dementia when they or their families are no longer able to provide care. However some carers and residents identify issues of concern, including lack of stimulation, training, and inconsistent service provision.</p> <p>The person and their family/whanau need guidance and support through this time from specialised services, and may need assistance with making the decision about suitable placement.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Admission tracking and facilitated discharge to aged residential care from general hospital is available • ARRC providers will screen for cognitive problems and complications of dementia on admission • A person-centred support plan which takes into account the persons personal history, likes and dislikes, preferences, abilities and support needs is developed with the person with dementia and their caregiver/ family/whanau • In response to BPSD in residents clear pathways are designed to address:- <ul style="list-style-type: none"> - Management of physical care needs - Institution of behavioural and environmental management strategies - Psychological engagement - Care for the carer

	<ul style="list-style-type: none"> - Cautious use of psychotropic medication • Gerontology Nurse Specialists – in some DHB’s review management of people at home or in aged related residential care with cognitive issues . • Carers are supported in the transition of the person for whom they are caring throughout the care continuum including residential care • Regular Medication Review meetings between specialist services and ARRC • Multi disciplinary team meetings at regular intervals.
Potential Providers	<p>Specialised Dementia Service Alzheimer’s Association Aged Residential Care Sector NASC TBI Sector</p>
KPIs	<ul style="list-style-type: none"> ▪ Numbers of general hospital admissions avoided ▪ Numbers of psychotropic medications prescribed ▪ Numbers of falls ▪ Numbers of pressure areas ▪ Identify and target symptoms or behaviours ▪ Target for reduction in prescriptions ▪ Target for time spent on anti psychotics ▪ Reduce polypharmacy ▪ Time limited use of medication.
Local Initiatives	<p>BUPA Map of Life and My Day My Way Care Planning CMDHB Geriatrician medication reviews in ARRC</p>

Rewi’s cognitive impairment progresses. He has three times walked off from home thinking that it is time to go to work and on one occasion was nearly hit by a car. His wife June feels too anxious to sleep at night and she and her children decide that it is time for Rewi to go into secure dementia care.

Rewi’s Living well with dementia plan includes a “Living well with Dementia” section which includes information about Rewi, his life so far, likes and dislikes, things that tend to upset him and things which help calm him. Staff learn that Rewi was an accountant and still likes to do paperwork at a desk at home, that he enjoys music and gardening. This information helps staff to provide support what is a difficult time for Rewi who is often worried about where June is and tries to leave on three occasions. The mid afternoon seems to be the time Rewi worries most about June and so staff arrange for her to visit at that time.

June is encouraged to take time for herself and receives support from the Local Alzheimer’s’ support worker and another woman she met on the Carer’s course who has had similar experiences.

Family/whanau also bring in some of Rewi's favourite music on an MP3 player, photos and books for his room and a small desk where he can read the newspaper and do some paperwork in the mornings, or on days when he is more restless raking leaves in the garden.

Ongoing Care in Aged Residential Care

<p>Introduction</p>	<p>Cognitive impairment is common in Aged Residential Care residents, with rates typically around 70% (Opal Study). Complications of dementia are often the reason for admission to aged residential care. Aged residential care facilities must have a high level of expertise in supporting people with dementia and its complications, and must include family/whanau in ongoing support of the person with dementia.</p> <p>There are a number of models of care provision which can guide personalised, family/whanau oriented and socially inclusive and enabling care e.g. Person Centred Care, Eden Alternative, Spark of life.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Aged residential care providers will screen for cognitive problems and complications of dementia on an annual basis • Care is guided by a person-centred support plan which takes into account the persons personal history, likes and dislikes, preferences, abilities and support needs is developed with the person with dementia and their caregiver/family/whanau. • In response to BPSD in residents clear pathways are designed to consider:- <ul style="list-style-type: none"> - The personalised meaning of or message communicated by the behaviour - Management of physical care needs - Institution of behavioural and environmental management strategies - Psychological engagement - Care for the carer - Cautious use of psychotropic medication • Identify and initiate appropriate strategies to address the unmet needs of younger people with dementia living in residential care (e.g., peer relationships, occupation, physical exercise, sexuality). • Support the provision of care and support for people with dementia and their carers where “risk” of abuse is escalating or where there is evidence of abuse occurring • Identify and initiate appropriate strategies to address the unmet needs of people with dementia living in residential care who have extraordinary support needs:- <ul style="list-style-type: none"> ○ Alcohol dependence and dementia ○ Disability (physical or intellectual) and dementia

	<ul style="list-style-type: none"> ○ Traumatic Brain Injuries and dementia ○ Culturally and linguistically diverse backgrounds ● Multi disciplinary team meetings at regular intervals.
Potential Providers	<p>Aged Related Residential Care DHB Older People’s Health Services, Mental Health Services for Older People Education providers</p>
KPIs	<ul style="list-style-type: none"> ▪ Numbers of avoidable admissions to general hospital (e.g. such as admissions sent to hospital who would be better managed in residential care e.g. palliative care.) ▪ Numbers of dementia unit beds and or psychogeriatric beds are reflected in prevalence data ▪ Numbers of people with a recorded diagnosis of dementia is reflected in prevalence data ▪ Number of people with dementia who have a living well with dementia care plan which includes agreed individualised support for ADLS, activity and socialisation ▪ Numbers of psychotropic medications prescribed ▪ Target for reduction in prescriptions /polypharmacy ▪ Target for time spent on anti psychotics ▪ Time limited use of psychotropic medication ▪ Numbers of falls ▪ Numbers of pressure areas ▪ Hours of activities and diversional therapy provided in residential care setting calculated per resident ▪ Number of alternative care options available e.g. <ul style="list-style-type: none"> ○ Transfer to acute hospital setting ○ End of life care ▪ Number of late stage dementia patients assessed for planned palliative cares ▪ Number of ARRC services referring to MHSOA, OPH, Crisis teams ▪ Number of failed discharges of people with dementia from secondary services ▪ Number of referrals where service discontinued, by family/whanau or secondary provider ▪ Evidence that management of high ‘risk ‘ circumstances has improved the safety and wellbeing of people with dementia and their carers ▪ Carer surveys are completed annually.
Local Initiatives	<p>Walking in another’s Shoes programme (South Island New Zealand)</p>

Ngere is a Cook Island Maori woman in her late 80's has been living with her extended family for some years. She has a diagnosis of Alzheimer's disease. Cook Island Maori is her primary language, her family are New Zealand born pacific people, and do not speak her language fluently, or maintain many of the cultural norms e.g. diet, church and music.

With her increasing dementia, Ngere becomes harder to occupy, is repetitive in her conversation and actions, and intolerant of the young children who visit the family home regularly. She can not be left alone, because the family is on a busy road; however her family are either working or at university. When her nephew talks to her in her language he says she is worried she is becoming a burden.

The NASC worker is called and Ngere agrees to go to care in a rest home that has many pacific residents and staff. While the family feel guilty for having placed her in care, it becomes obvious that Ngere, enjoys the opportunity to talk to other Pacific people who are both residents and staff, the routine of the Resthome, and the weekly Pacific feasts that the rest home provides.

End of Life Care

<p>Introduction</p>	<p>Dementia is ultimately a fatal illness, although many people with dementia die of other connected or coincident medical problems. People with dementia deserve the opportunity to die with dignity, with their families and to have participated in a discussion about their choices in this regard. There needs to be an open and honest discussion between the person and their family/whanau, and clinicians about the prospects of further medical interventions improving quality of life for the person, and the point at which these are becoming less effective. These issues need to be discussed throughout the journey with dementia, with the goal of having some planning by the person and their family/whanau in respect of end of life care.</p> <p>This may include Advance Care Planning (ACP) or it may take the form of someone with Enduring Power of Attorney for Personal Care and Welfare knowing the person’s wishes and acting in accordance with these or the principles of “best interest” for that person.</p> <p>At present the role of Advanced Care Planning in End of Life Care for people with dementia remains an issue under discussion primarily because of the complex issues around capacity, where no firm decisions or projections of impact have been made.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Work with acute, community and residential care providers of palliative care to ensure people with dementia, their families and carers are included in decision making about how their services will be provided • Promote awareness of the need for “forward planning’ including Advanced Directives, to people with dementia, cares and families, community care and health services provided • Promote palliative care for people with dementia that is sensitive to the needs of different cultures or language. • Palliative care services provide education and training to <ul style="list-style-type: none"> ○ Aged residential care ○ Primary care ○ disability and mental health providers ○ Home support services • Palliative care services are educated in dementia and intellectual disability so they can better support the person with dementia and their family/whanau.

Earlier in Journey:

- There will be discussion with person and their family/whanau about the need for EOLC planning. There will be encouragement of this as an evolving conversation throughout the journey
- The person's capacity to understand the nature of the decisions and to communicate choice will be taken into account.
- Development of ACP as part of clinical and personal care plan
- EPOA or Welfare Guardian will be in place
- Carers such as Aged Residential Care will be informed about ACP documents or EOLC planning
- There will be knowledge of each patients specific wishes e.g. decisions around resuscitation
- Multi disciplinary team meetings at regular intervals.

Nearing the End:

- There will be discussions with person and their family/whanau about the point at which active interventions will no longer be sought. This will be guided by expert medical advice from Primary Care or medical staff
- Counselling will be provided around this decision
- A clear decision will be recorded and copy of ACP provided
- Following this, should the person become unwell, there will be a clear clinical decision about clinical management in accordance with principles of palliative care
- Validated palliative care pathways will be used
- Pain control and comfort will be goals of care
- Palliative care team will be asked to advise, or another clinician with these skills
- Family/whanau and friends will be provided with space and opportunity to spend time with person
- Families may be advised re funeral services if needed
- Families will be visited following the death of the person
- Families may be directed toward bereavement counselling or support as required (this may be part of the secondary service)
- Families and carers have opportunity to rate satisfaction with service provided
- Health and Support professionals are supported after the death
- Care coordination service informed
- Multi disciplinary team meetings at regular intervals

Potential Providers	<p>Primary Care Dementia Care Service Aged Residential Care Palliative Care Providers</p>
KPIs	<ul style="list-style-type: none"> ▪ Place of death ▪ Percentage of people dying in preferred place of death (for patient and carer) ▪ Percentage of people with ACP ▪ Percentage of people with EPOA / Welfare Guardian ▪ Supporting documentation with record of discussions about EOLC wishes and decision making with family/whanau ▪ Encourage and support role of the General Practitioner ▪ Involvement of Palliative Care clinician or equivalent ▪ Service providers up-skilled and supported to provide quality end of life care ▪ Carer/Family/whanau satisfaction questionnaire ▪ Information on 'forward planning' including advanced directives available through health networks and in the community ▪ Families are asked for structured feed back 6 months after the bereavement.
Local Initiatives	<p>Liverpool Care Plan Advance Care Planning New Zealand</p>

Mama Ngarangi came to live in New Zealand in the 1950's. A stroke 6 years ago led to her daughter and her family moving in with Mama and Papa, to provide better care for them both. Mama Ngarangi was physically compromised but the changes to her memory had only become significant in her last few years. One morning when her daughter went to help her out of bed, she found Mama to be unresponsive, cyanosed and with little tone in her right side. Aarii called the doctor, and then the ambulance. Mama Ngarangi went to Middlemore hospital where they diagnosed a massive CVA, and said Mama did not have long to live. The family asked if they could care for Mama at her own home. While the medical staff were initially not keen on this idea, a discussion with the specialist Dementia service and promises to support the family alongside Alzheimer's Auckland left the staff satisfied that family would be able to manage her care for what was expected to be only a short time, and that the Dementia Service would remain in regular contact.

Mama Ngarangi died 36 hours later with her family surrounding her and the Dementia Nurse Specialist and Alzheimer's Auckland Navigator present. A hospice support package had been arranged to further support Mama Ngarangi's family.

SUPPORTIVE OR WHOLE POPULATION ELEMENTS

Community Awareness

Introduction	One of the biggest obstacles to improving care and awareness of dementia in the community is the fear and stigma associated with the illness.
Standards	<ul style="list-style-type: none"> • Up to date information about dementia, treatment/care options is available to people with dementia, their families and caregivers and to all health professionals • Identify and support people with dementia as early as possible through dementia awareness programmes • Expand awareness, detection and referral for depression of people with dementia • Expand awareness, detection and management of dementia in the disability sector • Identify needs of younger people with dementia • Identify appropriate strategies to address the unmet needs of younger people with dementia • Promote awareness of the need for ‘forward planning’ to people with dementia, carers and families, residential care and other health providers • Implement culturally appropriate dementia awareness and risk reduction awareness programmes • Participate in national process to determine agreed key messages on dementia • Support Age Concern Elder Abuse Service in relation to the needs of people with dementia • National Awareness campaign <ul style="list-style-type: none"> – including websites that will hold local and national resources – maintain cognitive and mental health wellbeing through promotion of social cognitive, physical and learning activities – encouraging health lifestyle e.g. Heart Foundation – Advocacy Services for carers and people with dementia identified and promoted within the community – Key community awareness campaigns and

	<p>messages should engage Maori communities and be culturally appropriate, delivered in Te Reo if appropriate and delivered/disseminated through Marae, Churches and other Maori specific venues and through Maori media e.g. Maori TV, radio and other media</p> <ul style="list-style-type: none"> – Key community awareness campaigns and messages should engage Pacific Communities and be culturally appropriate, delivered in the main languages of the Pacific Community e.g. Tongan, Samoan, Cook Island Maori and delivered/disseminated through Pacific communities e.g. Church, Community Services and Pacific media, TV, radio and other media – Key community awareness campaigns and messages should engage Asian communities and be culturally appropriate, delivered in the main languages of Asian populations (Mandarin, Cantonese, Korean etc) and delivered/disseminated through ethnic communities and ethnic media – Specialist data needs to be available in Stats NZ level 2 Asian and MELAA categories and this demographic data included in national, regional and local reports – All Advocacy services need to use interpreters and information must be translated.
Potential Providers	<p>Alzheimer’s New Zealand All health professionals</p>
KPIs	<ul style="list-style-type: none"> ▪ Needs of people with dementia and their carers included in depression initiatives ▪ Information on ‘forward planning’ including advanced directives available through health service networks and in community ▪ Key community awareness messages established ▪ Evidence of culturally appropriate dementia awareness and risk reduction awareness programs. ▪ Evidence of strategies and promotional campaigns aimed at early identification and risk minimalisation ▪ Evidence that initiatives outlined by Aged Concern Elder Abuse prevention package have been implemented ▪ Collect specialist data – including numbers, time to assessment, and outcomes, regarding diagnosis and

	treatment of people with dual disabilities e.g. <ul style="list-style-type: none">○ Alcohol dependence and dementia○ Intellectual disability and dementia○ Traumatic Brain Injury and dementia○ Early onset○ Ethnicity specific
Local Initiatives	Alzheimer's Auckland Charitable Trust – Forget me not day, Awareness days, CEP training

Workforce Development and Training

<p>Introduction</p>	<p>The health workforce must become dementia competent. This will require training for all staff appropriate to their role. The service delivery model in each DHB will influence the level of training required. For example where the aim is the majority of diagnosis and management in primary care the primary care workforce is likely to need specific training.</p>
<p>Standards</p>	<ul style="list-style-type: none"> • Continuity of understanding and consistency of approach, including training, experience and skills, information, and understanding of each patient and their ongoing support • A highly trained dementia care workforce guided by a rigorous research base • Education and support to improved sector recognition, engagement and how to access support services • Assess level of competencies against prescribed training i.e. standards, accredited training and recommend strategies to maximise spread of competency across the community, DHB and NGO sectors • Instigate a workforce development strategy • Identify existing dementia training and development programmes • Develop and implement a sector-wide training and development strategy for working with people with dementia which includes:- <ul style="list-style-type: none"> ○ Baseline competencies ○ On line information and service guides ○ Access to supervision or mentoring ○ Information sharing forums on best practice ○ Performance criteria for ongoing staff development planning • Seek cooperation from ITO's including Universities to influence the design and delivery of training for relevant health, community care and aged care professionals with a specific focus on curricula related to dementia awareness and care • Support the development of a suite of nationally recognised dementia specific qualifications ranging from NCEA to Masters degree level • Identify incentives and barriers to recruitment and retention of workers in dementia care • Develop incentives for recruitment and retention of workers in dementia care

- Collaborate to provide joint training and development opportunities that foster linkages across residential care (NGO) and DHB settings
- Provide the residential care sector with regular dementia awareness and skill development training
- Maintain and raise awareness of elearning tools available to informal carers, the NGO sector and the DHBs e.g <http://www.networknorth.org.nz/e-resources/>
- The health workforce as well as being dementia competent also needs to be demonstrate culture competency in regards to Tangata Whenua. Specifically the workforce needs to know:
 - Core cultural competencies when working with Maori
 - Understand the role of family/whanau hapu/iwi for Maori
 - Have a commitment and understanding of the Treaty of Waitangi
 - Understand family / whanau responses to care of the older person with dementia
 - Understand historical injustice which has led to deprivation and social inequity
 - How to work with interpreters if need be
- The health workforce as well as being dementia competent also needs to be Pacific culturally competent specifically the workforce needs to know:
 - Core cultural competencies when working with Pacific cultures
 - Understand the role of family / fanau village/island and church in the Pacific community.
 - Understand the migrant journey, and the impact of birth in New Zealand for the Pacific older person
 - Understand the role of faith in the lives of older people from church
 - Understand family / fanau responses to care of the older person with dementia
 - How to work with interpreters if necessary
- The health workforce as well as being dementia competent also needs to be CALD culturally competent specifically the workforce needs to know:
 - <http://publications.nice.org.uk/dementia->

	<p>cg42/person-centred-care</p> <ul style="list-style-type: none"> ○ How to work with interpreters ○ Understand the migrant journey for the older person ○ Understand the role of faith in the lives of older people from CALD backgrounds ○ Understand family responses to care of the older person with dementia.
Potential Providers	<p>Alzheimer’s New Zealand Secondary Providers e.g. NASC, MHSOA and OPH ITO’s e.g. Career Force, Universities, Network North Coalition.</p>
KPIs	<ul style="list-style-type: none"> ▪ Baseline workforce competencies in the care of people with dementia identified ▪ Directory of training providers in-place and on- line for DHB and NGO agencies ▪ Implementation of a Training and Development Strategy ▪ Specialist competencies and training pathway identified. ▪ Evidence of inclusion of dementia awareness and care in relevant curricula. ▪ A suite of national dementia specific qualifications exists to meet the differing requirements of the workforce ▪ Evidence that the retention of staff in community, DHB and NGO staff are choosing to work in dementia care ▪ Evidence of joint professional development initiatives between DHB and NGO sectors ▪ Dementia awareness an skill level enhanced within ARRC sector as evidenced by:- <ul style="list-style-type: none"> ○ Types of complaints ○ Audits
Local Initiatives	<p>Network North Coalition http://www.networknorth.org.nz/e-resources/</p>

Research /electronic resources

Introduction	<p>Knowledge about dementia is rapidly expanding, and research covers a wide ranging number of fields. Increasing the accessibility of new knowledge and translation of this knowledge into clinical practice can be facilitated by the use of</p>
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	electronic resources.
Standards	<ul style="list-style-type: none"> • Increase the awareness of service provider networks that interact with people with dementia and their carers • Establish links between specialist dementia resource/information service with other dementia services e.g. advanced care planning • Promote and disseminate agreed key areas of research to key stakeholders and workforce • Identify and implement the most appropriate ways to enhance existing practice • Enhance existing practise based on research findings. • Raise awareness and encourage use of elearning tools for research dissemination and education upskilling of the workforce.
Potential Providers	All dementia service providers Te Pou, Ministry of Health, Network North Coalition
KPIs	<ul style="list-style-type: none"> ▪ Current dementia information disseminated actively ▪ Awareness resources developed ▪ Established knowledge exchange and transfer systems ▪ Data analysis, trends, outcome reports ▪ Linkages established between specialist dementia services and other key information services ▪ Evidence of promotion and dissemination of agreed key areas for future research ▪ Identify the extent to which practice guidelines and service models are based on research findings.
Local Initiatives	National Dementia Cooperative research action group. Network North Coalition http://www.networknorth.org.nz/e-resources/

IT and Documentation

Introduction	Information technology provides great opportunities for active involvement of people with dementia and their families in care planning, and the integration of care across multiple service providers and settings.
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	Information technology will also allow us to more accurately capture where and how people access services and what is provided when they do.
Standards	<ul style="list-style-type: none"> • Centralised scheduling of care • Electronic clinical records of all interventions for patients and carers • Accurate clinical outcome, admission prevention and key performance indicator data for providers and planners
Potential Providers	All healthcare providers
KPIs	<ul style="list-style-type: none"> ▪ Evidence of dementia data collection as per national standards ▪ Evidence of progress towards shared access to care plans
Local Initiatives	

Governance: Local – Regional – National

Introduction	<p>Local Governance of Dementia Care requires that there is leadership and oversight of the provision of dementia services to the local DHB population, across the various providers.</p> <p>Local governance is supported by a Regional process of governance to ensure the sharing of initiatives and comparison</p>
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	<p>of performance. It is also an opportunity to review ways of delivering dementia care in each locality to ensure that services are both effective and efficient. Regional governance may also support equity of access to more specialised services and training.</p> <p>There should also be a National governance process to ensure standards are updated, that dementia remains a priority for healthcare, and to review the roll-out of dementia care services across the country.</p>
<p>Standards</p>	<p>Local</p> <ul style="list-style-type: none"> • Identify service gaps and plan to ensure services can meet future need • Prioritise the creation of new initiatives • Plan delivery of services in a manner appropriate to the local population and geography • Key initiatives implemented with appropriate policy and funding support • Clarify roles and responsibilities • Develop dementia specific service models that are responsive to the needs of diverse groups and culturally appropriate • Allocate service provision to appropriate local providers <p>Regional</p> <ul style="list-style-type: none"> • Monitor local and regional trends and collect statistical information to inform service planning • Shared training and service development initiatives. • Coordinated contracting for Aged residential care and support services to meet regional needs, particularly for extraordinary needs groups (single sex facilities, facilities focused on a particular cultural group, young onset dementia and intellectual disability plus dementia). <p>National</p> <ul style="list-style-type: none"> • Establish dementia as a national health priority • Develop Dementia Care Pathways by June 2013 in all DHB's • DHB's will work in collaboration to develop Dementia Care Pathway Framework • Contribute to the National review of regulations regarding Driving • Identify barriers to access of care and support for people with special needs • Linkages to the National Dementia Cooperative Action

	<p>Groups</p> <ul style="list-style-type: none"> • Support the work of Advocacy groups to increase awareness about legislative changes that may affect Power of Attorney; the benefits of forward planning and advanced directives • Promote and disseminate dementia research findings to community care and health agencies to inform future planning, service management and delivery.
Potential Providers	DHB's, Ministry of Health
KPIs	<p>Local</p> <ul style="list-style-type: none"> ▪ Each DHB has developed an DHB dementia care pathway by June 2013 – which responds to identified DHB priorities ▪ Identify statistics on projected service demand and gaps <p>Regional</p> <ul style="list-style-type: none"> ▪ Develop regional dementia maps showing referral pathways ▪ Evidence of dementia specific service models that are responsive to the needs of diverse groups and culturally appropriate. ▪ Document and address service gaps and develop initiatives that improve responses to people with dementia and their carers. <p>National</p> <ul style="list-style-type: none"> ▪ Evidence of input and joint sign off on policies, plans and reports for local, regional and national initiatives ▪ Local, Regional and National linkages maintained ▪ Improved awareness of Power of Attorney and Advance Directives procedures amongst people with dementia, their families and carers. ▪ Evidence of promotion and dissemination of dementia research findings to community care and health agencies
Local Initiatives	

Financial: Funding and Cost analysis

Introduction

Caring for people with dementia is costly and will become even more critical as the NZ population ages – in 2008 the total financial cost was estimated at \$713 million.

	<p>Historically, models of mental health funding have not taken into account dementia. Despite this, around half of patients presenting to older age psychiatry services are affected by problems relating to dementia.</p> <p>The reliability of dementia diagnosis and data capture is one barrier to evaluation of the cost of dementia care especially in acute and primary care settings.</p>
<p>Standards</p>	<p>When looking at economic investment in dementia services effectiveness and cost effectiveness, should be reviewed, however may be limited to the little research undertaken to date with few cost effectiveness studies available.</p> <p>The potential for interventions in one service area to create savings in another should be considered. Examples from the available literature are listed below.</p> <ul style="list-style-type: none"> • Collaborative care models in primary mental health may be of particular benefit for older adults • Early provision of support at home can decrease institutionalisation by 22% • Even in complex cases, and where the control group is served by a highly skilled mental health team, case management can reduce admission to ARRC by 6% • Older peoples mental health services can help with behavioural disturbance, hallucinations and depression in dementia, reducing the need for ARRC • Carer support and counselling at diagnosis can reduce care home placement by up to 28% • Early diagnosis and intervention improves the quality of life of people with dementia • Cost effectiveness modelling of early diagnosis service is available (Banerjee, 2009) • Early intervention has positive effects on the quality of life of family/whanau cares
<p>Potential Providers</p>	<p>DHB Mental Health for Older People Services DHB Older People Services Funding and Planning in each of the District Health Boards</p>
<p>KPIs</p>	<ul style="list-style-type: none"> ▪ Identify the cohort of relevant patients and associated volumes <ul style="list-style-type: none"> ○ Under 65's, Over 65's, with intellectual disability, alcohol related cognitive impairment and traumatic brain injuries ▪ Identify the hospital admissions that relate to this

	<p>cohort of patients</p> <ul style="list-style-type: none"> ▪ Identify the aged residential care admissions related to this cohort of patients ▪ Identify the total cost savings for each patient on the DHB pathway ▪ Calculate the gross savings associated with transferring these patients on to a dementia care pathway.
Local Initiatives	

Facilities Design

Introduction	<p>The built environment has potential to enable or disable people with dementia, to encourage orientation and a sense of familiarity and meaningful activity, and to promote social models of care. All health care facilities should attempt to make adaptations to the needs of people with dementia, but this is of particular importance in units caring for older people, and all aged residential care facilities. Special consideration should be given to specialist secure dementia care units which</p>
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	cater for mobile residents with additional support needs arising from complications of their dementia.
Standards	<ul style="list-style-type: none"> • Audit standards include review of adaptation of facilities towards dementia friendly designs. • All new builds or retrofits make attempts to dementia design principles and use existing audit tools (Stirling/Hammondcare audit tool; Environmental Audit tool http://www.hammond.com.au/research/environment • Although all facilities should aim to provide the below features, particular attention should be paid in specialist dementia care units where a safe and secure homelike environment, domestic in scale with a garden area which is therapeutic which promotes activity, walking for purpose, and exposure to sunlight. Visual access and multiple types of orienting cues should also be considered. Personalising rooms will also promote orientation.
Potential Providers	<p>All healthcare facilities and aged residential care providers, architects and construction companies.</p> <p>All DHB Funding and Planning Aged Care Clinicians</p>
KPIs	<ul style="list-style-type: none"> ▪ Agreed national standards for health and residential care facilities likely to be caring for people with dementia. ▪ Commitment from Aged residential care providers to dementia friendly designs which are externally reviewed prior to building. ▪ Active dialogue and planning between ARRC providers and DHBs to build and contract facilities which meet the range of care needs of people with dementia and cater to specific populations (e.g. young onset dementia, single sex facilities, intellectual disabilities, and the range of levels of care rest home, private hospital, secure dementia care, psychogeriatric private hospital) ▪ All new build residential care facilities will be evaluated using a recognised audit tool.
Local Initiatives	

List of Acronyms:

AACT	Alzheimer's Auckland Charitable Trust
ACP	Advanced Care Planning
ADHB	Auckland District Health Board
AO	Alzhiemers Organisations
ARRC	Age Related Residential Care
BPSD	Behavioural and Psychological Symptoms of Dementia
CALD	Culturally and Linguistically Diverse Groups
CMDHB	Counties Manukau District Health Board

CMHN	Community Mental Health Nurse
CNS	Clinical Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disease
CT	Computed tomography
DHB	District Health Board
DU	Dementia Unit (ARRC)
ED	Emergency Department
EPOA	Enduring Power of Attorney
GP	General Practitioner
GPCog	General Practitioners Assessment of Cognition
HIV	Human immunodeficiency virus
HOP	Health of Older People
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
MCI	Mild Cognitive Impairment
MoCA	Montreal Cognitive Assessment
MHSOP	Mental Health Services for Older Adults
MMSE	Mini Mental Status Exam
MRI	Magnetic Resonance Imaging
NASC	Needs Assessment and Service Coordination
PGU	Psychogeriatric Unit (ARRC)
RMHU	Regional Mental Health Unit (ARRC)
SPECT	Single Photon Emission Computed Tomography

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This document was developed using some key international documents relating to Dementia Strategies and Guidelines for care, they include the following documents. Appendix 1 (which follows) is a list of recommended reading relating to the various elements of the Guide which may be useful in assisting the development of service provision.

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Appendix 1

Patient Journey Elements

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Appendix 2

DEMENTIA WORK STREAM MEMBERS

Name	Organisation	Position/Representations
Dr Alan Davis	Northland DHB NDSA	Clinical Director – Department of Medicine – NDHB Clinical Lead – Health of Older People Regional Network - NDSA
Dr Mark Fisher	CMDHB	Clinical Head – Mental Health Services for Older People (MSHOP)
Gina Langlands	BUPA	General Manager, Quality and Risk
Julie Martin	AACT	General Manager
Dr Terry Mitchell	ADHB	Geriatrician – Memory Clinic ADHB A+ Links Older Peoples Health ADHB
Chris Pegg	Northern DHB Support Agency	Programme Manager – Health of Older People
Dr Gavin Pilkington	WDHB	Clinical Head – Mental Health Services for Older People (MHSOP)
Sue Thomson	Northern DHB's	Northern Regional Dementia Behavioural Support and Advisory Coordinator
Anne Williamson	East Health Trust PHO	ElderCare – Coordinator of services for Older People
Dr Richard Worrall	ADHB	Clinical Head – Mental Health Services for Older People (MHSOP)

Appendix 3

Stake holder groups for people with dementia and their carers – 11 June 2012

The Ministry of Health ran focus groups for people with dementia and carers of people with dementia, these were held in Auckland and arranged by Alzheimer's Auckland, this was also an opportunity for the Northern Regional Dementia Work stream group to get feedback on their work in the last year.

Anne Foley represented the MOH Richard Worrall and Sue Thomson the Dementia Workstream. Five people attended focus group for people with dementia, including people with varying degrees of dementia and people with early onset dementia. Six people attended as carers of people with dementia, their partners were at varying stages of the illness. Only one couple were a dyad.

Anne Foley fed back to both groups that there were 50+ people on the Dementia Pathway Group and they had developed a Dementia Care framework based on international and national research, the experience and knowledge of the group's participants, and from the invaluable feedback of the participants in the Carers and People with Dementia groups. She was also clear that the concerns the two groups had shared, had been listened to, and in developing the framework attempts were made to address and acknowledge the issues raised.

Below is a summary of the discussions. Issues raised in the initial discussions are grouped together, included topic headings and then each issue is followed with today's discussions.

NAVIGATOR ROLE

Carers wanted one person to provide care who could support them through the health service, and asked to be included in clinical consultations.

Anne Foley fed back that there was general consensus that one key worker was the best option for care provision and that in the framework this had been called the Navigator. The navigator could be a nurse, a GP or someone from AACT, it would be the person who was most likely to be able to accompany and support a person throughout the journey of dementia.

Both the carers and people with dementia supported this idea.

STIGMA

- Both carers and people with dementia are aware of, and concerned about, the stigma associated with dementia and would like increased community awareness and normalisation

This was an area of considerable concern to people with dementia, and they talked of the loneliness and purposelessness of their lives now that they had a diagnosis. Three of the people with dementia had young children to care for, two of them by themselves.

When asked if the advertising campaign had made a difference there was no response, however two people had begun to tell people who wondered at their repeated loss of eftpos cards and problems at shops that they had Alzheimer's and the response had been polite and supportive.

Carers also had an issue with stigma and one carer reporting that a long term relationship with their GP had led to his unwillingness to tell the "bad news" that her partner had dementia.

SOCIALISATION

People with dementia and their carers expressed a wish to remain physically active and socially engaged, but noted there were problems with social isolation and lack of suitable activities for them in the community. Loneliness was a strong theme. Carers particularly noted the pressures families were placed under and a desire to socialise as families was a common wish.

People with dementia raised the ability to fill in their days with things to do as an issue; this was very difficult if these activities were to be interesting and purposeful.

Carers talked about issues with knowing what was available to support them and the person with dementia.

SUPPORT OF CARERS

There was acknowledgement that the carers role was difficult, they had little time to themselves and it was difficult to find their own life balance, coping and burnout were a constant, practical help was seen as essential.

Carers talked about the issues with looking after themselves. One man reported how he had developed hypertension while caring for his wife and when she went into care his blood pressure decreased significantly. They talked about how the emotional stress of caring was significant, draining and unrecognised.

RESPECT

People with dementia would like to be more respected as individuals and have their opinions sought.

Feedback was given to carers and people with dementia regarding how grateful we were to have their input and how their concerns had been included in the framework and that via the Regional Group we had attempted to address some of these concerns.

EARLY ONSET DEMENTIA

PwD with children still living at home would like see consideration of the issues their children are facing. Carers looking after people with early onset dementia would like the additional difficulties faced by these families addressed. Financial assistance for this group was also raised.

Three people with dementia had dependant children living at home with them; two of them were providing care by themselves. Two of these people with dementia were over 65. They discussed the issues of being able to provide supervision in a safe manner and the potential impact on there children of the illness – e.g. stigma

HOME BASED SUPPORT

Access to respite and activity programmes are helpful for both carer and person with dementia.

RESIDENTIAL CARE

- Attitude of some residential care providers is not helpful.
- Carers would like guidance and support to decide which aged care facility would be best for their family member as those that had been through this process had found it difficult finding anyone or any information that would help them make this decision.

Carers raised issues about the quality of staff and what level of education and training care staff had. We spoke to them about the present education offered in the ARRC sector – Dementia Units.

INFORMATION

Both groups wanted written information about dementia and suggestions on how to manage different situations. A “booklet” where all information they are given is kept, along with details of the services and health professionals was desired

INTEGRATED CARE

Both groups wanted integration of clinical notes so that there is a reduction in the number of times the person with dementia’s details and story needs to be repeated.

The Living Well with Dementia Plan was introduced to the carers and people with dementia liked the idea, however it seems unlikely that this document will be persisted with given the probable use of the Health Passport across the country.

Questions were asked by the Carers as to what plans for integration of notes etc on electronic platforms. Participants were informed that there are a number of initiatives being piloted which involve sharing of electronic records, some of these were with PHO's and DHBs, and some were within DHBs, their exact form is yet to be confirmed.

Carers were then read and provided with some selected narratives from the Dementia Services Guide these included:-

- Assessment

Primary Health Care

This was described by family as an accurate portrayal of Primary care contact.

- Post Diagnosis. Support in Dementia

Primary Health Care

Memory Clinic Diagnosis

General Hospital Diagnosis

There was unified agreement that the scenarios accurately portrayed their shared experiences.