

Dementia Care Pathway



*The future
of Dementia Care for
Counties Manukau*

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FOREWORD

Dementia is a devastating disorder of later life, having a profound impact on the person afflicted and all their friends and family. With progressive and increasing disability caused by the condition, family members end up playing a central role in providing care for the person with dementia, particularly in the latter stages of the illness.

Dementia is a common condition in older people, in spite of which it is often poorly recognised and managed by the community and by health services generally. With the ageing of the population structure, the number of people suffering from the disorder is set to double in the next 15 to 20 years. Looking after those with dementia is expensive – the costs of care, including residential and private hospital care, and the costs imposed on families are significant and set to increase. To date there has been no single or coherent service providing care for those who suffer from dementia or supporting the families that care for them. Rather, people are often assessed and managed in a multitude of different services, and many families feel that they do not know who they should turn to in times of difficulty.

It has been the wish of many of those working with people with dementia and their families, to see the creation of a dedicated care pathway devoted to this illness. There is a recognition that clear and early diagnosis, long-term continuous management and, in particular, a commitment to providing support for those families who care for people with dementia, will make a big difference to the quality of care provided to all those with the illness. There is good evidence that good quality care improves the health of both those with dementia and their families; there is also evidence that this can be provided in a cost-effective manner.

We are privileged to have been the sponsors of the project set up to address the issues around providing such a Pathway. We are very grateful to all those who have contributed their time and expertise to the project and brought it through to this stage. We hope to see their efforts rewarded, and to see the implementation of a high quality dementia care service that will be available to all those people needing it in Counties Manukau.



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EXECUTIVE SUMMARY

Dementia is a clinical syndrome of increasing brain injury and impairment, which can be due to a wide variety of different disease pathologies. The most common cause is Alzheimer's disease, affecting over 50% of cases. Early symptoms (depending on cause) are commonly personality change and poor short term memory. However, as the illness progresses, cognitive deficits escalate with deterioration of language, visual and cognition skills and knowledge of how to complete ordinary daily tasks. Finally, people with dementia may struggle with even recognising members of their own family.

Dementia is frequently complicated by Behavioural or Psychological Symptoms of Dementia (BPSD), such as depression, psychosis, agitation or apathy. These symptoms are especially difficult for those families providing care to deal with. There is an increasing level of dependency as the illness progresses, which often leads to family members spending many hours each day caring for the person with dementia. The person often ultimately requires care in an Aged Residential Care (ARC) facility such as a rest home or private hospital. Dementia, if the underlying disease is able to run its course, will be fatal, but due to the age of onset, the person with dementia may die of some other or related intercurrent illness.

There have been numerous discussions between clinicians in Mental Health Services Older People (MSHOP) and Health of Older People (HOP) about the fragmented nature of care being provided for people with dementia. Currently people referred into CMDHB services with memory problems or dementia may be seen by either service depending on presenting symptoms, but frequently end up being seen by both services over time as the illness progresses, this is largely due to the high risk of physical health and mental health complications. The models of care are significantly different in the two services, but both operate as secondary care services with clients being discharged back to the care of their GP after (usually) a short period of care. Although many are also referred to Alzheimer's Auckland Charitable Trust (AACT) for follow-up, many clients do not make use of this service and the follow-up is often not intensive. Many of those who do make use of AACT do report benefits and appreciation for the support that they receive. However there is little real communication or collaboration between AACT, and either HOP and MHSOP in the CMDHB region.

“People with dementia and their families should receive assertive on-going care throughout the illness.”

It was our (MHSOP and HOP) shared view that people with dementia and their families should receive assertive ongoing care throughout the illness, and that this was more likely to produce significant improvements in the quality of care provided, as well as potential reductions in use of future Secondary Care services and Aged Residential Care (ARC). This could be achieved by developing a Dementia Care Pathway that describes the types of services and interventions available to people with dementia and their families.

This was the motivation leading to the development of a Dementia Care Pathway that would define the types of services and interventions that should be available to people with dementia and their families, for the duration of their journey through the disorder.

Given this context, CMDHB supported a project to develop a Dementia Care Pathway for the populations we serve. A Project Reference Group was established to provide input and guidance into the development of the Dementia Care Pathway, with the intention of designing a service which provides:

Key elements of the Dementia Care Pathway

- Referral and Triage phase
- Assessment and diagnosis phase
- Intensive Community Follow-up phase
- Ongoing Community Care
- Care provided to those in Residential Care
- Groups for people with dementia and their families/carers



We emphasise that the Dementia Care Pathway is about providing care to those people living in the community, suspected of, or suffering from dementia, and supporting their families. The Pathway is not claiming to provide community education, screening, workforce training or a specific General Hospital management service for those with dementia. It is also hoped that early detection and diagnosis of dementia will be an outcome, but the Pathway has not targeted this aim specifically. It is hoped that all of these will be provided in time, in a complementary manner.

Additionally, we describe the outcomes and specific benefits we expect will be achieved by fully implementing the Dementia Care Pathway. These are more fully outlined in the body of the document, and apply to both the person with dementia and the family caring for them. A proposed list of Pathway performance indicators is suggested. We also hope that, through the collecting of this information, the Pathway will be a source of information for future service planning.

Key Clinical Outcomes

- Becoming aware
- Living well
- Staying Healthy
- Being strong / Being smart
- Accepting Help
- Completing the journey



We acknowledge that it is important that any new development must be able to demonstrate cost effectiveness, in terms of increased efficiency, saving money, and/or providing a positive benefit to clients, their families, the communities and service provider.

We have reviewed the relevant literature, and have provided clear evidence that full implementation of the Dementia Pathway will ultimately prove to be a cost effective way of providing services in the future. This is described more fully in the body of the document, but expected benefits include:

- Delayed Admission and use of Aged Residential Care Services
- Shortened General Hospital Stays
- Reduced Inpatient Admissions
- Increased efficiency in use of clinical resources

We have calculated the required resources needed to fully implement the Dementia Care Pathway over a 5 year period. Our calculation of case-loads and Full Time Equivalent (FTE) staff requirements is based on a realistic assessment of numbers of clinical visits for each stage of the pathway and numbers of working hours in the year. We have attempted to define a relatively lean and efficient service, and realistically acknowledge this will need to be a phased and incremental approach given the current workforce capacity issues and funding constraints. However at Implementation of the Dementia Care Pathway, we have calculated that there are already a number of staff in existing services that could be re-deployed to the new Pathway. Our resource estimations build on this existing capacity, over a 3 staged approach:

Table 1: Calculation for New Resource requirements for the Dementia Care Pathway: Summary

Stage	Description	Existing FTEs available	Forecasted FTEs Required *
Stage One: Pre- Implementation	<ul style="list-style-type: none"> Business case and setting up Dementia service Preparation for Implementation Stage April 2012- March 2013 	Nil	3 FTEs
Stage Two: Implementation	<ul style="list-style-type: none"> Assumes 3 FTEs in Stage One are sustainable and funding ongoing Funding secured Staged implementation Existing staff re-deployed Year 1 - Commence service delivery By July 2013 	10.5 FTEs	7.4 FTEs
Stage Three: Caseload accumulation	<ul style="list-style-type: none"> Phased implementation and caseload growth over Years 2 - 5 Conservative estimate - this does not factor in the effects of demographic growth where we expect an approximate doubling of cases in CMDHB over the next 15 years 	Nil	13.6 FTEs
Calculated Totals		10.5FTEs	24 FTEs

* Dependant on outcome of Stage One and Two scoping exercise and MOC developments

Finally, whilst we have considered the full requirements to implement the Dementia Care Pathway, it is important to recognise there are a number of potential constraints and limitations that must be considered.

Although the evidence clearly suggests that the Pathway would be well received, and would enhance the care of people with dementia and their families, it is possible that we may not be able to fully meet expectations based on the current constrained fiscal environment, the potential for a high volume of referrals, high caseloads, workforce capacity and capability constraints, as well as the need to align infrastructure and systems to support the delivery of the Dementia Care Pathway. We are confident, however, that with thoughtful planning and a realistic timeframe for establishment during the pre-implementation phase, these potential risks and constraints can be mitigated.

We are excited that the Dementia Care Pathway has been endorsed in principle by CMDHB and now look forward to moving into the next phase of staged Implementation, Service delivery and Evaluation.

Chapter 1

THE DEMENTIA CARE PROJECT

Project Overview

Counties Manukau District Health Board commissioned a project to engage with the Clinical Heads from CMDHB Health of Older People Services (HOP) and Mental Health Services for Older People (MHSOP), and a range of community agencies, to agree an integrated continuum of care for clients with Dementia. The intention was to ensure a consistent approach, and access to specialist multi-disciplinary expertise from diagnosis through clinical management, and for ongoing, supportive care to clients and families. The recommendations from this project will inform both local implementation of the Pathway and also wider regionally consistent planning.

Dementia is a progressive clinical syndrome of increasing brain injury and impairment, which can be due to a wide variety of different disease pathologies. The most common cause is Alzheimer's disease, affecting over 50% of cases. But other causes include cerebral vascular disease, Lewy Body dementia, and the group of Fronto-Temporal dementias. Early symptoms (depending on cause) are commonly personality change and poor short term memory. However, as the illness progresses, cognitive deficits escalate with deterioration in the person's use of language, their visual and social skills, and their knowledge of how to complete ordinary daily tasks. Eventually, people with dementia may struggle with even recognising members of their own family.

Dementia is frequently complicated by Behavioural or Psychological Symptoms of Dementia (BPSD), such as depression, psychosis, agitation or apathy, especially in early and middle stages of the disorder. These symptoms are especially difficult for those families providing care to deal with. There is an increasing level of dependency as the illness progresses, which often leads to family members spending many hours each day caring for the person with dementia. The person often ends up requiring care in Aged Residential Care (ARC) facility, such as a rest home or private hospital.

From most causes Dementia is a fatal illness, but due to the late age of onset, the person with dementia may die of some other or related concurrent illness.

Local Context and Genesis of the Project

There have been numerous, often informal, discussions between clinicians in Mental Health Services for Older People (MHSOP) and Health of Older People (HOP) about the fragmented nature of care being provided for people with dementia and their families. There was agreement that the quality of care could be improved for those suffering from dementia. These discussions led to the writing of a proposal document about providing good quality dementia care, and which was one of the important prompts that led to this project being launched.

Currently people referred to CMDHB services with memory problems or dementia can be seen by either HOP or MHSOP depending on presenting symptoms. However many end up being seen by both services at different times as the illness progresses, largely due to the high risk of both physical health and mental health complications. The models of care are significantly different in the two services, but both operate as secondary care services with clients being discharged back to the care of their GP after (usually) a short period of care. Although many are also referred to Alzheimer's Auckland Charitable Trust (AACT) for follow-up, a large number of clients do not make use of this service and the follow-up is not often intensive. There is also a concern that some ethnic groups in particular do not make use of the AACT service. Many people and their families report benefits from attending the AACT programmes. However, in the Counties Manukau area there is little real communication or collaboration between AACT, and either HOP or MHSOP.

It was our shared view (and the starting point for this project) that people with dementia and their families should receive ongoing assertive care throughout the illness, and that this was likely to produce significant improvements in care as well as potential reductions in use of other Secondary Care services and Aged Residential Care (ARC). There was agreement in these discussions, that a Dementia service could be provided by a nursing-strong team with multi-disciplinary backup, and that this would be more efficient and accessible than a medical outpatient type service. There was also an agreed dissatisfaction with the commonly used Memory Clinic model¹ which is very much of the outpatient clinic type service, and often does not offer long-term care and assistance. (However it should be noted that Memory Clinics have continued to evolve and now come in a wide range of forms and models).

¹ Jolley, D., Benbow, S., Grizzell, M. (2006) Memory clinics.

National Context

Nationally and internationally there has been realisation that Dementia is a rapidly growing problem and that the numbers of likely cases are threatening to overwhelm older people's services and general health services in the future. There is also the recognition that the overall cost of health care is very high for people with dementia, and frequently entails years of home-based community services as well as time living in ARC. There is also recognition of the high and 'informal costs' imposed on the families caring for those with dementia.^{2 3}

The Minister of Health's "Letter of Expectations for District Health Boards and their subsidiary entities for the 2012/13 year"⁴ 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. Accordingly, the Northern Region Health Plan: Health of Older People Clinical Network has identified the development and implementation of a dementia care pathway in each DHB as one of the principal work streams to be completed over the next year. Some of the CMDHB Project Reference Group are members of the Clinical Network, and from an early stage there was a specific undertaking that the work completed by this project was to be made available across the region. This is in line with one of the Minister's other points of emphasis in his letter, that of seeing an increase in the level of regional cooperation.

The Ministry of Health's "*Mental Health and Addiction Services for Older People and Dementia Services: A Guideline for District Health Boards on an Integrated approach to Mental Health and Addiction Services for Older People and Dementia Services for People of any age*",⁵ for the first time, specifically included a clear statement that those suffering from dementia should be included within the potential client group for Mental Health and Addiction services in each DHB.

Additional National policy imperatives that have been considered in the development of this Dementia Care Pathway are *Better, Sooner, More Convenient*,⁶ *Whanau Ora*⁷ and the development of *Integrated Family Health Centres (IFHC)*.⁸ These are particularly relevant to the Pathway in respect of increasing integration across the primary and secondary sectors, as well as stronger community based services aimed at improved access, earlier intervention and promotion of seamless transitions in, through and across services.

² WHO (2012) Dementia A Public Health Priority

³ Alzheimer's New Zealand Incorporated (2008) Dementia Economic Impact Report 2008

⁴ Minister of Health (2011) Letter of Expectation for District Health Boards and their subsidiary entities for the 2012/13 year

⁵ Ministry of Health (2011) Mental Health and Addiction Services for Older People and Dementia Services: Guideline for district health boards on an integrated approach to mental and addiction services for older people and dementia services for people of any age

⁶ Ryal, T (2007) Better Sooner More Convenient – Health Discussion Paper

⁷ Ministry of Health ((2011) Whanau Ora: Transforming our Futures

⁸ Letford, K., Ashton, T (2010) Integrated Family Health Centers

The National Dementia Strategy: 2009

Three themed areas were seen as their focus of improving services, namely:

1. Increasing the awareness of dementia in the general population and amongst clinical staff,
2. Trying to improve early diagnosis and intervention for those with dementia, and
3. The provision of high quality care and support for those with dementia and their families.

Some of the areas of focus described in the strategy include:

- Effective memory services
- Continuity of care for people with dementia and their carers
- Information for people with dementia and their carers
- Improved care in general hospitals for people with dementia
- Improved end of life care planning
- Increasing public awareness of dementia
- Improved ARC facility level of care
- Workforce development
- Effective commissioning and audit



International Context

There has been considerable work completed around the world on the promotion and development of dementia services, as the significance of future demographic growth and the resultant impact on health costs has become increasingly apparent.⁹ Projects have, therefore, been completed around the world in the area of delivery of Dementia Care services to the escalating number of people with this group of illnesses. The most significant recent example has been the World Health Organisation's "Dementia: A Public Health Priority. There have been escalating amounts of research and review studies in the area of managing dementia, and there have also been important government-sponsored initiatives around the world, looking at improving the delivery of care for people with dementia and their families. The National Dementia Strategy¹⁰ in the United Kingdom is one of the prime examples of this work, and identified the principal areas of effort required to improve the wellbeing of those with dementia and their families.

⁹ Knapp, M., Prince, M (2007) Dementia UK (A report to the Alzheimer's society on the prevalence and economic cost of dementia in the UK produced by Kings College London and the London School of Economics

¹⁰ Department of Health (United Kingdom). (2009) Living well with dementia: A National Dementia Strategy.

“Projects have been completed around the world in the area of delivery of Dementia services to the escalating numbers of people with this group of illnesses.”



Following the publication of this strategy, local area health trusts have each put forward proposals to create such services in their own area. The Healthcare for London Dementia Services Guide¹¹ was a good example of this work, and has been an important source for our own work in this project. A further example is from Wales: 1000 Lives Plus: Improving Dementia Care.¹² Similar work has been completed in other countries such as Australia; for example, both New South Wales and Queensland have published dementia care plans. See, for example, the Queensland proposal¹³ which emphasises similar areas of intervention as the National Dementia Strategy in the UK.¹⁰

There has also been the development of evidence-based Guidelines internationally. Important examples of these include the American Psychiatric Association¹⁴ Practice Guideline for the Treatment of Patients with Alzheimer’s disease and Other Dementias, and the NICE-SCIE Guideline¹⁵ on supporting people with dementia and their carers in health and social care.

¹¹ Healthcare for London (2009) Dementia Services Guide

¹² 1000 Lives Plus (2010), ‘1000 Lives Plus - Improving Dementia Care’

¹³ Abbey, J., Palk, E., Carlson, L., Parker, D. (2008) Clinical Practice Guidelines and Care Pathways for People living with Dementia in the Community

¹⁴ American Psychiatric Association (2007) Practice Guideline for the Treatment of Alzheimer’s Disease and Other Dementias.

¹⁵ National Institute for Health and Clinical Excellence. (2007) A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care

The Project Approach

We wanted to ensure a range of perspectives were gained to inform the development of this Dementia Care Pathway. The approach followed is described below.

1. Project Reference Group

A Project Reference Group was established with representation from key stakeholders and service providers to provide input and guidance into the development of the Dementia Care Pathway (refer to Appendix One for Membership). This was also supported by a smaller Technical Advisory Group that regularly peer reviewed the development of the Dementia Care Pathway, and provided clinical input and advice.

2. Literature Review

National and International Literature was reviewed to gain an understanding of evidence-based best practice for Dementia Care services and this information is referenced throughout this document. Journal articles and published guidelines relating to the provision of dementia services were reviewed to inform the development of the Dementia Care Pathway. It has not been our intent to undertake a comprehensive review of all of the literature, but rather reference appropriate evidence as it is relevant to and has informed the development of this Pathway.

Some of the areas of particular interest for us were:

- Demographic data and future projections of demand
- Structure of dementia services and related guidelines
- Types of non-pharmacological interventions trialled in people with dementia and their families, and the benefits of these
- Benefits or otherwise of dementia medications
- Use of antipsychotic medications for people with dementia
- Evidence for cost and cost-effectiveness of dementia services



There is a significant and rapidly increasing literature in all of these areas; many of the important studies or guidelines that have been utilised are referenced in the text of this document.

3. Clinical Files

Clinical files were reviewed allowing us to identify the number of people with dementia currently accessing HOP and MHSOP services, in order to provide a robust rationale for the development of a dedicated Dementia Care Service. We initially attempted to ascertain the number of dementia referrals to the CMDHB services through diagnoses recorded by clinical coding. Unfortunately this did not prove to be an accurate or effective way of recording numbers of dementia cases. We therefore completed manual file reviews of sequential cases in both HOP medical outpatients and MHSOP, looking at how many referrals to these services received a diagnosis (or had clear symptoms) of dementia.

For those cases seen by MHSOP, an estimate was also made as to whether they would be suitable for a Dementia Care Pathway. Accordingly, those who resided in an ARC facility or who had moderate-to-severe Behavioural and Psychological Symptoms of Dementia (BPSD) were excluded. This file review did not necessarily capture all cases of dementia that might be referred to a Dementia Care Pathway. For those referrals to HOP, we did not include people seen by the Community Geriatric Nursing team. It also did not include people cared for by the inpatient services in either HOP or MHSOP who might have been seen as suitable for a Dementia Care Pathway following their discharge from that setting. It is likely that the numbers of cases identified is therefore slightly under-estimated.¹⁶

Additionally we completed a survey to assess the likely life expectancy of people with dementia following diagnosis by looking at the survival times following discharge of those HOP inpatients who received a diagnosis of dementia (from June 2005 to June 2007). From this survey we found that average survival time following discharge was 33 months with a median value of around 21 months. Although the results were informative, the sample is unlikely to be representative of a group of people referred to a Dementia Care Pathway from a community setting, who would be expected to have a longer life expectancy on average.

Workshops and Stakeholder Perspectives

Workshops were conducted with key clinical leaders from the provider services to inform the development of the Dementia Care Pathway. A significant amount of information was gained from the workshops about what was seen to be currently working well with regards to caring for people with dementia as well as input from key clinicians involved in delivering a range of services across the continuum (including NGOs, Primary and Secondary Care services), about how services responses could be improved to improve outcomes and experiences for people with dementia and their families/carers.

Stakeholder meetings, individual interviews and focus groups were also held over the course of this project to ensure we were informed of what is needed from consumer, family members and service provider's

¹⁶ Fisher, M., Thomson, R (2011) Data for CMDHB Dementia Pathway – Unpublished work

perspectives, and reflect these perspectives in the Dementia Care Pathway. This continues to be an ongoing activity. The information gained from one of these is outlined below.

Focus Group for Carers of People with Dementia

A focus group was held at the Age Concern Homestead, and attended by 11 people (family members or carers of people with dementia), recruited through Alzheimer's Auckland Charitable Trust (AACT) and Age Concern NZ.

The participants were provided with a brief overview of the proposed CMDHB Dementia Pathway project, and were asked the following questions:

1. *Do you know what services you need, and what are they?*
2. *What helped in regards to accessing these services?*
3. *What would you like to see improved?*
4. *How do you think the desired improvements can be achieved?*

There were a number of common themes that emerged from the focus group feedback. These are listed in the summary below.

Focus Group Feedback

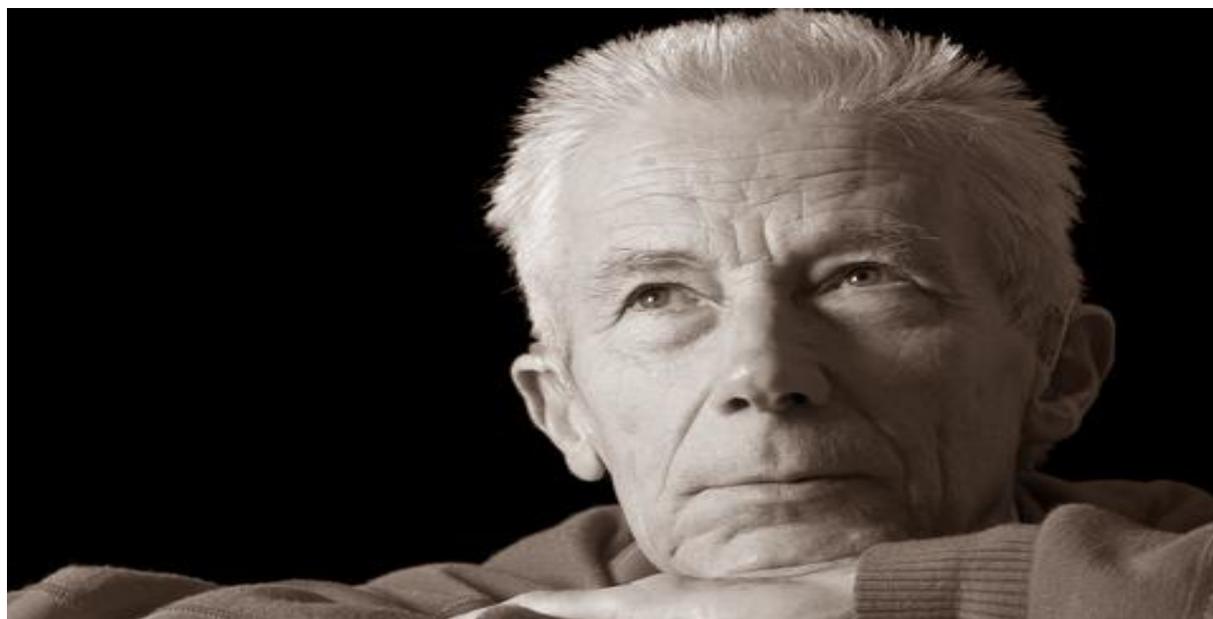
- That having dementia or “Alheimers” was stigmatising for people and their carers. This made it difficult to inform friends and family and to seek their help.
- “Memory issues” was thought to be a better name than Alzheimer’s.
- Participants felt the need for more than just assessment and diagnosis. There was a high level of gratitude for services such as NASC and AACT.
- Many families had difficulties identifying what services were available or should be accessed. People were keen to receive better support and guidance.
- Families and carers appreciated the involvement of clinical staff in the difficult decisions about issues such as driving. Families also expressed a desire to have access to clinical staff outside the assessment of the person with dementia. They described “feeling like a traitor” when talking about the person or being involved in decisions about entering care.
- Participants felt that continuity of care was very important. They described current services as being fragmented with “lots of different services being involved”. There was the experience that the service to where people were initially referred, led to quite different results. There was support for the idea of a single point of entry.
- People found dealing with the financial implications of care and engaging with WINZ challenging and confusing. They also described that some people with dementia were not funded for some of the support services.
- Participants felt that dealing with physical health issues was important, and were keen that clinical notes were somehow tagged, so that new clinical staff (such as in the General Hospital) would be made aware of the dementia. There was also a feeling that clinical information needed to be better shared between involved services.
- The importance of home-based care and respite services was emphasised. Options for younger people with dementia and those that are more active need to be better developed.
- Carers also described finding it difficult to meet their own needs, such as being able to go to appointments.
- Participants were keen to have more information and resource material about dementia. They agreed that being a carer can be exhausting and isolating. They emphasised the need for carer support groups and care for the person’s family. There was a feeling that this was particularly important in the early and middle phase of the illness, and less so at the point of entry into residential care. Carers described finding it “hard to see the way forward” in the middle phase of the disorder.
- Participants supported initiatives such as end of life planning and palliative care in dementia.
- Participants said that there were many positive and rewarding experiences from being a care-giver to someone with dementia, and that these should be shared.

These themes are in accordance with the experiences and wishes of families and carers from many qualitative studies across the world. An excellent summary of these is included in the “Interventions for Carers of People with Dementia” section of Dementia: A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care (2007).¹⁵

“Participants said that there were many positive and rewarding experiences from being a care-giver to someone with dementia, and that these should be shared.”

Chapter 2

THE COUNTIES MANUKAU LANDSCAPE



The following section describes the current Counties Manukau population with expected demographic changes, and also provides a high level overview of the existing services available for people with dementia and their families.

Current Population and Demographic Changes

Counties Manukau DHB currently has a population of those aged over 65 of nearly 50,000, with an estimated annual incidence of new cases of dementia of 989 people. The estimated total number of cases of dementia in the CMDHB area is around 2920. This does not include those cases with Mild Cognitive Impairment (MCI), who typically make up around 20% of referrals to a Memory service on average – that is, a further 33% of cases.¹⁷ These population figures are based on the work commissioned by Alzheimer’s New Zealand¹⁸ which looked at typical rates of dementia in the population in each age band. Work in the UK has also highlighted that many of the cases of dementia in the population are not recognised or given a formal diagnosis by the health care system. This applies to as many as one half or two thirds of cases.¹⁹

¹⁷ National Audit Office (2007) Improving services and support for people with dementia

¹⁸ Alzheimer’s New Zealand Incorporated (2008) Dementia Economic Impact Report 2008

¹⁹ Health Foundation (Matrix evidence) (2011) Spotlight on Dementia Care:- A Health Foundation improvement report

Table 2: Estimated Annual Incidence & Prevalence of Dementia in Counties Manukau

YEAR	POPULATION 65+	ESTIMATED INCIDENCE PER ANNUM	ESTIMATED TOTAL PREVALENCE
2011	50,000	989	2920
2026	91,110	1916	5723

There will be a dramatic demographic change in the next 15 to 20 years, driven by the ageing of the existing population in South Auckland and also by the on-going growth in housing in the area. By 2026 there is expected to be a total population aged over 65 years of 91,110 persons. This is estimated to effectively double both the incidence and prevalence of dementia in the area, to 1916 and 5723 persons respectively. The prevalence and incidence of dementia will actually increase faster than the growth of those aged over 65 in the population, because of the rapid increase in the numbers of those who are “very old” (who have high rates of dementia).²⁰

²¹

This growth is mirrored throughout the developed world; for example, in Australia the prevalence of people with dementia in 2040 is estimated to increase by 222% over 2010 levels.²² This same group calculated the increase in formal dementia care costs (those funded by health and social services) for this population would increase from \$5.0 Billion in 2010 to \$16.7 Billion over the same period. Globally, the largest increase in cases of dementia is likely to occur in the developing world.¹⁸

It is clear that any system providing care in the area of the health of older persons will need to meet rapidly increasing demands on clinical services during the next few decades.

²⁰ Jorm, A., Dear, K., Burgess, N. (2005) Projections of future numbers of dementia cases in Australia with and without prevention.

²¹ Henderson A, Jorm A. (1986) The problem of dementia in Australia.

²² Vickland, V., Werner, J., Morris, T., McDonnell, G., Draper, B., Low, L., Brodaty, H. (2011) Who pays and who benefits? How different models of shared responsibilities between formal and informal carers influence projections of costs of dementia management

Existing Contracted Providers in Counties Manukau area

Currently there are a number of services that are specifically tasked with assessing and managing those people who have dementia, as well as a large number of service providers who are required to provide care for those with dementia as part of a wider role, such as ARC or general hospital care.

Specialist Services for Dementia Care

The major providers in Counties Manukau who are contracted to specifically assess or manage people with dementia are:

- Health of Older People (HOP) services
- Mental Health Services for Older People (MHSOP)
- Alzheimer's Auckland Charitable Trust (AACT), and
- Specialised parts of the Aged Residential Care (ARC) sector, including Day Care programmes, Psychogeriatric Private Hospitals and Dementia Care facilities. (This also includes 12 beds at Parkhaven Private Hospital which are regional Mental Health-funded beds for those with dementia and profound behavioural issues).

A small number of people with dementia are initially seen in other mental or physical health care services, especially those who are in a younger age group or who have specific neurological illnesses such as Parkinson's disease.

HOP Medical Outpatients and MHSOP are both tasked specifically with the assessment and initial management of people in the community with Mild Cognitive Impairment (MCI) or dementia, or suspected of having these. HOP Medical Outpatients sees the majority of referrals where dementia is suspected or known. Those referred are seen in one of the outpatient clinics provided by HOP and are seen by a Geriatrician. HOP also provides a Community Geriatric Nursing service that undertakes assessments in people's homes or in Aged Residential Care facilities.

Currently, MHSOP receives those referrals for people where the dementia is complicated by Behavioural or Psychological Symptoms of Dementia (BPSD), or situations such as ongoing Elder Abuse. Many of these cases may have previously been diagnosed or seen in HOP Medical Outpatients. There are also a number of cases referred to MHSOP with symptoms of depression / anxiety or psychosis, but who turn out to have MCI or dementia after assessment or treatment of the presenting symptoms. MHSOP has 15 acute inpatient beds and some of these are inevitably occupied by people with dementia, usually those with significant BPSD.

A review of referrals to our respective services, suggested that HOP medical outpatients receives around 665 referrals per year querying memory problems or dementia (this represents around 47% of their total referrals). Mental Health Services for Older People receives around 1000 referrals per year in total, of whom it is estimated that around one eighth or 12.5% (n=125) have dementia or MCI, and who might be suitable for the proposed Dementia Care Pathway.

Table 3: Annual referrals to HOP & MHSOP teams for dementia or MCI

Service	Annual Dementia Referrals	% of total Annual referrals
HOP Medical Outpatients	665	47%
MHSOP Community Team	125	12.5%
Total	790	

In total, it is estimated that HOP and MHSOP services receive 790 referrals per year for dementia or memory problems.

Currently, in most cases of relatively uncomplicated dementia, the person will be discharged back to the follow-up of Primary Care after three to six months. They are usually referred to separate follow-up by **Alzheimer's Auckland Charitable Trust (AACT)**, although many people do not proceed with this option. AACT provides services across Auckland, and has a dedicated contract with CMDHB to provide information, education and ongoing support for both the person with dementia and their carers, family, friends and whaanau. They receive around 170 referrals per year and have a case-load of over 300. They provide a mix of individual and family work, education and groups.

HOP Funders contract with four **Day Care Providers** in CMDHB, who provide a service for those people who are living at home, are frail, elderly and/or have some form of dementia, and for those who are the primary carers for these people. Currently approximately 180 people are registered at a day care service, with attendance ranging from 1 day to 5 days per week. Access to day care services is uncapped and is based on assessed need. Current providers have capacity to cope with increasing numbers.

Where people with dementia require care in the **Aged Residential Care sector**, a small proportion is cared for in the various specialised Dementia facilities. These facilities are tasked with looking after those people with dementia with moderate to severe BPSD symptoms, and who could not therefore be safely cared for in ordinary ARC facilities. In total, the CMDHB area has 12 beds at Psychogeriatric Private Hospital level of care (with plans to develop a further 12 -15 beds in the near future) and 130 Dementia Care Rest Home beds for

those residents assessed as requiring specialised dementia care. There are also 12 mental health beds situated at Parkhaven Private Hospital which are regional Mental Health-funded beds for those with dementia and profound behavioural issues.

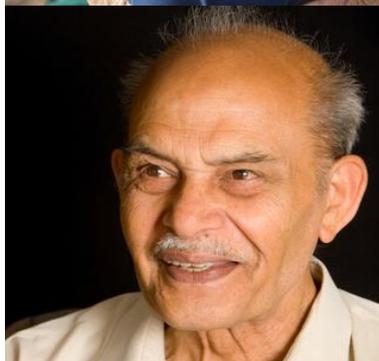
General Services Supporting Dementia Care

The Needs Assessment and Service Coordination teams (NASC) are integrally involved in making sure people with dementia have access to suitable community based care and assistance, and also approve people moving into residential care, where appropriate. Therefore, they are generally involved, in most cases, where someone has dementia, but they also see people with a vast array of other physical illnesses or disability. In keeping with this, all those independent contracted providers of community-based or home-based care are frequently providing services to people with dementia.



Primary care is a major source of assessment and care for those with dementia, but in general most GPs have only around 10 people with dementia on each of their case-loads,²³ and some of these are not ever recognised as having the disorder.^{24 25}

There are many services that provide care to people with dementia, but do not have a specific mandate for this. A high proportion of those living in the **Aged Residential Care** sector have dementia, especially at the Private Hospital level of care, where around 30 – 50% of residents²⁶ are estimated to have some form of dementia (as well as other medical problems).



All parts of the **Secondary Care** sector, but especially general medicine, have people under their care who have dementia.²⁷ In fact, in many cases people are first diagnosed with dementia when seen in outpatients or following admission to the DHB General Hospital. However it is also equally likely that their dementia goes unrecognised by the assessing or treating team.²⁸ As inpatients, people with dementia are demonstrated to have significantly longer general hospital stays.¹⁹

²³ Illife, S., Drennan, V (2001) Primary Care and Dementia – Bradford Dementia Group- good Practice Guides

²⁴ Millard, F., Baune, B (2008) Dementia – who cares? A comparison of community needs and primary care: a review of the use, efficacy and quality of measures

²⁵ Moise, P., Schwarzingler, M., Yong-Um, M and the Dementia Experts Group (2004) Dementia Care in 9 OECD Countries: A comparative analysis.

²⁶ Grant Thornton New Zealand (2010) Aged Residential Care Service Review

²⁷ Alzheimer's Society (2009) Counting the cost – Caring for people with dementia on hospital wards

²⁸ Walker, Z., Leek, C., D'Ath, O., Katona, C (1995) Psychiatric morbidity in elderly attenders at an accident and emergency department

In summary, the services that will be delivered by the proposed Dementia Care Pathway are currently provided by HOP Medical Outpatients, MHSOP community team and Alzheimer's Auckland Charitable Trust. Most of the other services described above would continue to provide care for people with dementia, independent of the pathway interventions.

“In total, it is estimated that HOP and MHSOP services receive 790 referrals per year for dementia or memory problems.”

Chapter 3

THE DEMENTIA CARE PATHWAY: THE MODEL

The section below describes the Dementia Care Pathway, including the Model of Service, underlying principles and key elements of the Dementia Care Pathway, as well as what is not expected to be provided as part of the Pathway.



Dementia Care Pathway versus Service

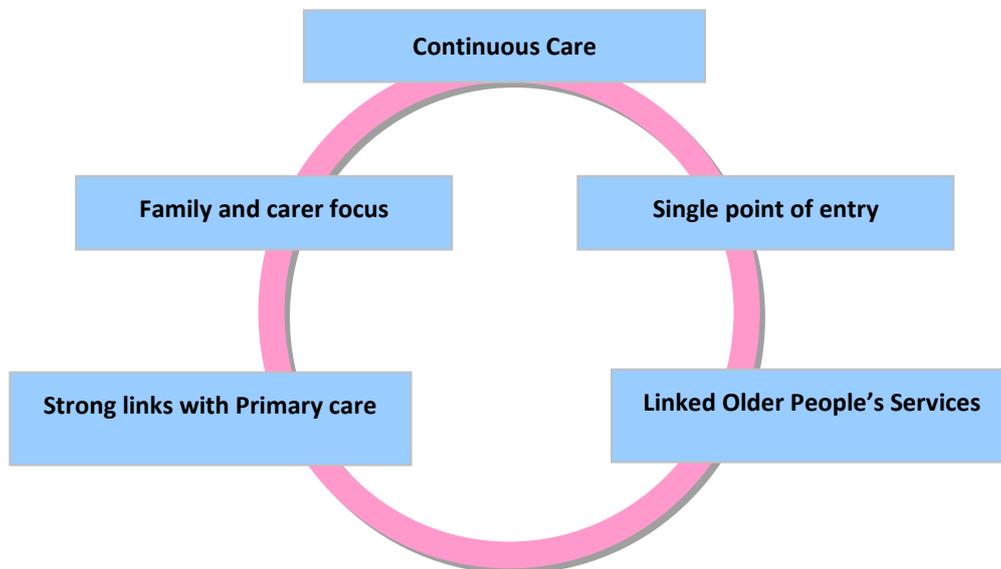
Throughout this paper we have talked about the Dementia Care Pathway rather than a service. We describe the progression of a person with dementia and their family through the stages of care, from the point of referral and assessment through to the end of their illness. The sequential steps of care and the staffing required to provide this are outlined, as well as many of the elements of the care. Implementation of the Pathway would require translation of these components into a workable service or combination of services.

It is our belief that fragmentation of the Dementia Care Pathway components would undermine the efficacy of the care provided to people with dementia and their families. We therefore recommend that oversight of the Dementia Care Pathway is the responsibility of one single provider, although there may be more than one team

operating under the same roof once the case-load grows and FTE numbers increase. It is our view that if the Pathway was to be provided by more than one provider, that the only feasible separation would be with one service tasked with providing the assessments, the Navigators and Multi disciplinary team's (MDT's), and a separate second service providing the group programmes. There is the potential to work collaboratively with other providers in a sub-contracting, joint venture or partnership arrangements. However there would need to be very strong liaison between the two services to ensure good continuity of care and to make sure that the services and messages provided were complementary rather than contradictory.

Model of Service: Key Principles

The following are the fundamental principles that underpin the delivery and operation of the Dementia Care Pathway.



1. Continuous Care

The fundamental difference between what is provided currently for most people with dementia and the Dementia Care Pathway is that care and follow-up will be on-going once the diagnosis is made. This is specifically with the aim of making sure that the entire family is supported through a long and complex illness. Because dementia is constantly evolving and BPSD is virtually inevitable at some point, it is critical to have services available to the person and their family throughout the illness, and that there is always someone they can call on for advice or intervention. There also needs to be a reasonable investment of time for each person, as there are many tasks and challenges that need to be worked through. There is increasing evidence for the benefits of having ongoing key-working or case management available to all people with dementia and their

families.²⁹ The reviews conducted by Brodaty et al³⁰ and Olazaran et al³¹ emphasise that effective services for people with dementia (and their families) require ongoing and available professional support, individually-tailored, structured, multi-component but flexible programmes, and that both the person with dementia and their families should be involved in the programmes.

2. Single Point of Entry

Currently people with dementia may be referred to and assessed by one or both of two different services (HOP & MHSOP), and then provided with follow-up by both Primary care and another service again, namely Alzheimer's Auckland. Certainly people with dementia may present for the first time with psychiatric complications, elder abuse or significant medical issues that need to be addressed, before ongoing care in a Dementia Care Pathway commences. Things may change from one week to the next. Many written referrals are also not entirely clear about the contribution of psychiatric or medical issues to the immediate presentation, and these are frequently only ascertained after a triage and assessment process. For all these reasons, it is easier for the referrers, the services involved, and for the person and their family, if all referrals are sent to the same point of entry or front door.

3. Linked Older People's Services

Behind the Single Point of Entry, it is proposed that there should be the three defined Older People's Services: Health of Older People, Mental Health Services for Older People and the Dementia Care Pathway. These three services should be strongly linked and co-located. Even though the service delivered may be domiciliary or locally based, the services themselves should be closely aligned and have strong connections with each other. Although it is hoped that there will be adequate skills in all three services to prevent unnecessary transfers of care amongst them, this will need to happen at times, and that is a reality in the health of older people.

People with dementia who are under the care of the Dementia Care Service may need to be seen by the other two services at specific points in their journey through their illness. Examples are those who may experience psychotic symptoms as part of their dementia and need the specialised care of MHSOP, or those who may, for example, suffer a stroke and need the benefits of specific rehabilitation following this under the care of HOP. By having these three services strongly linked, it is hoped that these transfers of care will be as smooth as possible, and liaison between the services will make sure that people's care is efficient and appropriate.

²⁹ Low, L., Yap, M., Brodaty, H. (2011) A systematic review of different models of home and community care services for older persons.

³⁰ Brodaty, H., Green, A., and Koschera, A. (2003) Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia

³¹ Olazaran, J., Reisberg, B., Clare, L., Cruz, I., Pena-Casanova, J., del Ser, T., Woods, B., Beck, C., Auer, S., Lai, C., Spector, A., Fazio, S., Bond, J., Kivipelto, M., Brodaty, H., Rojo, J., Collins, H., Teri, L., Mittelman, M., Orrell, M., Feldman, H., Muniz, R (2010) Nonpharmacological Therapies in Alzheimer's Disease: A Systematic Review of Efficacy

4. Strong links with Primary Care

The Dementia Care Pathway will deliberately seek to make sure that people and their families are engaged with their usual General Practitioner (GP), and will seek to involve the GP in the response to emerging physical and mental health issues. Maximising the person's physical health, preventing delirium, and managing vascular risk factors such as diabetes are an important part of living well with dementia and attempting to prevent both General Hospital and ARC admissions. As such, the Navigators, who are the core component of the clinical team, will actively seek to have a close working relationship with all the GPs who look after their clients. This will be assisted by the fact the Navigators are visiting people in their homes, meaning that visits to the local surgery when necessary will be possible. If people with dementia do not have families, then the Navigators will assist the person in making visits to see their family doctor.

It is not proposed that the Dementia Care service is sited in or part of the Primary Care service. This is for a number of reasons. GPs generally have a low case-load of people with dementia - each GP has roughly 10 people with dementia in their practice and may see 2 – 3 new cases per year.²³ Many of these cases are not recognised in Primary Care. Surveys have also shown that many GPs do not feel confident in the diagnosis or management of people with dementia, or do not have the clinical time available for these frequently time-consuming tasks.³² Nonetheless there is therefore merit in agreeing baseline screening processes as well as developing education and training options to address these issues.

A close working relationship with the person's GP will also be facilitated by Navigator case-loads being allocated on a geographical basis. Not only will this make the visiting of people and their families more efficient, it will allow for the development of a close working relationship between Navigators and local GPs.

The connection between the Dementia Care Pathway and GPs will be augmented by the development of links between GP and DHB computer systems, with GP access to Concerto, and the electronic referral system. GPs will receive regular updates on the progress of any person under the care of the Dementia Care Pathway, and it is intended that expert advice will be available at all times by phone or email between the Pathway and Primary Care.

The development of a Localities-based model of service development in the Counties Manukau DHB area is awaited with interest. It is hoped that the Dementia Pathway may evolve to fit in with this vision of future community based services provided by CMDHB. However the team providing the services under the auspices of the Dementia Pathway will initially be modest in size, and there will a tension between protecting the effectiveness of the multi-disciplinary team, and having a strong presence in all four localities. Collaborative

³² Todd, S., Passmore, P (2008) Alzheimer's disease – The Importance of Early Detection

Care models between Primary Care and a secondary care service, such as the Dementia Care Pathway, have been successful in the management of both depression and dementia in overseas settings.^{33 34}

“A family care-giver will spend 8.5 hours per week on average looking after someone with mild dementia, 25.0 hours per week caring for those with moderate dementia, and 41.5 hours per week looking after someone with severe dementia.”

5. Family and Carer focus

People with dementia rely on their families or friends for much of the care that they receive. Because of this, the Dementia Care Service will make sure that families and carers receive considerable support in this most challenging of tasks. Calculations of the amount of time spent by carers looking after the person with dementia highlights the degree of burden that they experience. Vickland et al²² calculated that a family care-giver will spend 8.5 hours per week on average looking after someone with mild dementia, 25.0 hours per week caring for those with moderate dementia, and 41.5 hours per week looking after someone with severe dementia.

There will be an emphasis on making sure that families and carers are prepared for the future of looking after the person, and have ready access to advice or interventions as required. Reviews of other similar pathways internationally show significant benefits in terms of mood and quality of life for families and carers. Learning skills and having respite and access to assistance, allows families and carers to look after the person with dementia for longer in their own environment.^{35 31} This is especially important for those



³³ Callahan, C., Boutsani, M., Unverzagt, F., Austrom, M., Damush, T., Perkins, A., Futz, B., Hui, S., Counsell, S., Hendrie, H (2006) Effectiveness of Collaborative Care for Older Adults with Alzheimer Disease in Primary Care – A Randomized Controlled Trial

³⁴ Callahan, C., Boustani, M., Weiner, M., Beck, R., Livingston, L., Kellmans, J., Willis, D., Hendrie, H (2011) Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home

³⁵ Nichols, O., Martindale-Adams, J.M, Burns, R., Graney, M., Zuber, J (2011) Translation of a Dementia Caregiver Support Program in a Health care System – REACH VA

groups or cultures who believe that the person with dementia should remain at home for the duration of the illness.

Because of the diverse population living in the Counties Manukau area, engaging successfully with people with dementia and their families will require a range of skills and flexibility with respect to dealing with different cultural groups.

Chapter 4

THE DEMENTIA CARE PATHWAY: THE PHASES



Eligibility for the Dementia Care Pathway

All people known or suspected of having dementia or Mild Cognitive Impairment, and who are residing in the community are eligible for inclusion in the Pathway. This eligibility is independent of the cause of the dementia or the stage of the illness. For example it will include those with typical dementias such as Alzheimer's disease, but will also accept those who may have dementia secondary to illnesses such as Huntington's disease or Parkinson's disease.

It is not intended that people with dementia who are living in Aged Residential Care (ARC) will be eligible. However people who may be living in Retirement Villages will be eligible for inclusion in the Dementia Care Pathway. Referrals will be accepted from all sources, including from the person themselves or their families.

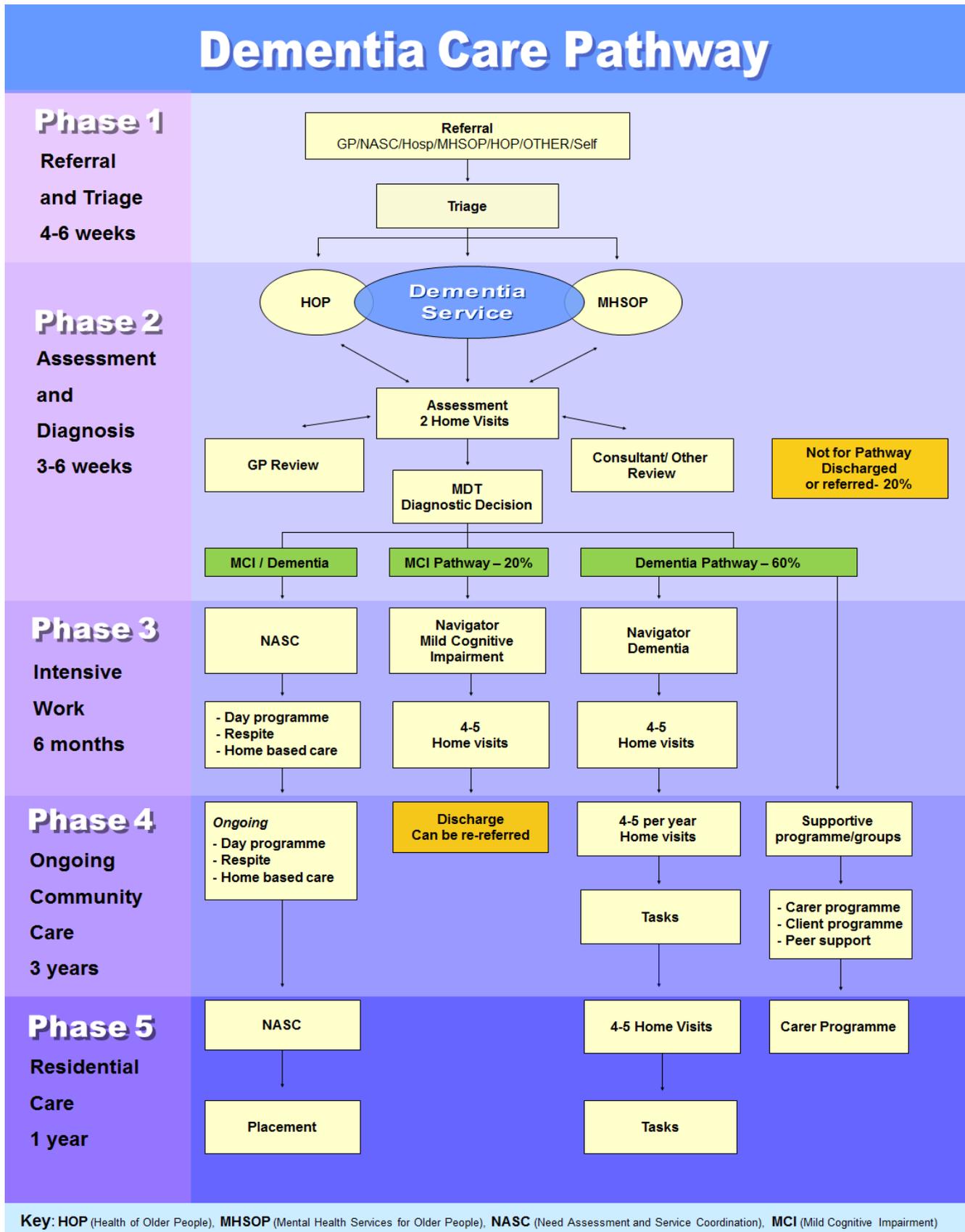
Because people with dementia may have significant medical or psychiatric issues at presentation, it is the intention that the triage process (see below) will direct referrals for assessment in the appropriate setting. Hence, some referrals will be initially directed to HOP Medical Outpatients, Community Geriatric Nurse assessment, or MHSOP Community Team rather than the Dementia Care Pathway.

The Croydon Memory Service reported that a specific dementia service with deliberately open eligibility criteria helped to attract referrals at an earlier stage of the illness.³⁶ This was supported by an assertive programme of education and visits to referrers such as Primary Care providers.

³⁶ Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., Murray, J. (2007) Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon memory service model.

Elements of the Pathway

The following flowchart shows the elements of the Dementia Care Pathway.



The Dementia Care Pathway Phases

Phase One - Referral and Triage

It is proposed that the existing Triage services in HOP and MHSOP should be combined, creating a “Single Front Door” for all referrals to the three older persons’ services. This is the type of recommended entry point in guidelines such as the UK National Dementia Strategy¹⁰ and UK Health Foundation Review of Dementia Care.¹⁹

The new combined triage service would have experienced clinical staff and there would be staff members able to deal with all and any type of referral. All referrals for people with dementia would come through this channel as well as all other referrals for physical and mental health services.

If a person was being referred for dementia or memory issues, then the Triage service would undertake a reasonable triage, which would entail ringing the person or their family, contacting the GP and some review of existing computerised medical records. This will ensure the person goes into correct service for the next phase of clinical assessment. Someone who has moderate psychiatric symptoms or unstable medical issues would be directed initially to MHSOP or HOP respectively. However it is hoped that most cases of early or uncomplicated dementia will be directed to the Dementia Care Pathway. These three linked services should be viewed as part of a complete and comprehensive Dementia service.

Those referrals for, say, bone density scanning or an inpatient ward review, which are amongst the various HOP services, will be managed by Triage in the same way as at present.

Some referrals to the pathway will be from either HOP or MHSOP, who hopefully will have brought those presenting issues under control. Because a comprehensive assessment will have been conducted in both those services, the person may be directed into the pathway but not require the full assessment process that would ordinarily be the first step.³⁷

If the person has not been referred by a GP, and has not had recent medical review or investigations, Triage will also be asked to organise and order some initial investigations such as blood tests and CT scan. This is to make the subsequent assessment more efficient. If the person referred has not had a recent medical review, Triage will ask the person to visit their GP for a physical examination and check-up. The GP will be contacted, alerting them to the request and asking for a report to be sent to the Triage Team.

³⁷ Stuck, A., Illife, S. (2012) Comprehensive geriatric assessment for older adults – Should be standard practice, according to a wealth of evidence .

Triage will send a letter to the person referred and their family notifying them of the result of triage and what will happen next. Some information about the Dementia Pathway will be sent also. Triage staff would have access to the various members of the MDTs in HOP, MHSOP, and the Dementia Care Pathway, for advice about suitability of referrals in those cases that might be equivocal. The Triage service would ideally be able to provide cover internally for leave or absence because it will be a larger service. However, it is possible that back-up cover for triage leave will need to come from either HOP or MHSOP on occasion.

Phase Two – Assessment and Diagnosis

When a person is referred to the Dementia Care Service, the first stage is for a thorough assessment to be carried out. This would be completed by the Dementia Care Service clinicians, principally experienced nursing staff. It is our view that experienced nurses are capable of completing a full and accurate assessment of dementia.^{38 39} It is critical that they are provided with back-up from the clinicians making up a full multi-disciplinary team. This is a model already employed in both HOP and MHSOP.

Each assessment would entail two domiciliary visits to meet the person and their family. These would typically occur around two or three weeks apart. A standardised assessment, as described in many of the guidelines, would be completed with appropriate cognitive, physical and psychiatric tests, and documentation of history. Physical investigations and some examination would be completed. A full social, legal and carer stress history would be taken. Driving and car usage would be investigated. There would be opportunity to discuss the person individually with any other member of the MDT after the first assessment visit, should there be any worrying features or specific areas of concern. If such features are present, then the second visit may include another member of the MDT such as a psychiatrist or social worker.

Following the two initial assessments, the details of the assessment would be presented to the full MDT for discussion and review. The majority of cases would be diagnosed formally at this meeting and a decision made about future management. In a modest proportion of cases, the MDT might decide that an assessment by one of the other members of the MDT would be useful, for example a Geriatrician, Psychiatrist, Social Worker or Psychologist. Following this, the person would again be discussed at the MDT, and diagnosis and management agreed. It is also likely that the person will be asked to attend their GP for review and management of their general health, especially if they have not been seen recently.

Following diagnosis there would be a further meeting with the person and their family at their home. Those people assessed as suffering from either MCI or dementia will be introduced at that meeting to a Navigator who would act as their key worker and be the main point of contact in their future care. Those without MCI or

³⁸ Trapp-Moen, B. Tvrev, M., Cook, G., Heyman, A., Fillenbaum, CG (2001) In-home assessment of dementia by nurses: experience using the CERAD evaluations. Consortium to Establish a Registry for Alzheimer's Disease

³⁹ Scherer, Y., Bruce, S., Montgomery, C., Balls, L (2008) A challenge in academia: meeting the healthcare needs of the growing number of older adults

dementia would also be seen; those that required referral to another service will be advised of this and their consent sought. The remainder will be referred back to Primary Care. Letters will be sent to all families and their GPs about the outcome of the assessment.

We have used the term ‘Key worker’ rather than Case Manager to describe the Navigators. This is a better description of their task which is to look after the person with dementia and their family, and be clinically responsible for their ongoing care. The Navigators will work with the person with dementia and their family, to ensure that they are supported and that the challenges of dementia can be anticipated and managed. The Navigators role does include (but is not limited to) coordinating and brokering access to services, which is what is sometimes meant by ‘Case Management’.⁴⁰

Community Follow-up

The Navigators will form the backbone of the Dementia Care Pathway service as far as on-going follow-up of the person and their family is concerned. The Navigators will largely be experienced senior (general and mental health) nursing staff and will be supported in this role by a MDT, including Geriatrician, Psychiatrist, Social Worker and Psychologist.⁴¹ The intention is for the person and their family to receive care and follow-up from the point of diagnosis until the end of their illness (or the point at which they withdraw from the service).

This is a component of the Dementia Care Pathway which is currently available to only a small proportion of people with dementia and their families, or only for a limited period of time. The Navigators will instead provide ongoing care until the end of the person’s illness or their death from other illnesses. This regular contact with the person and their family, plus the long-term availability of advice, support, extra visits and / or provision of reviews by Primary Care or Specialist team members, is what makes it possible for people and their carers to enjoy a longer period of time living in the community.

In a qualitative review of dementia case-management programmes around The Netherlands, there was an attempt to identify those factors that made for a successful implementation of such a service.⁴² The important factors identified included the expertise of the case managers, availability of MDT backup, investment in a strong provider network, support for the programme by local providers, and patients and care-givers having a low threshold for accessing support and care.

⁴⁰ Verkade, P., van Meijel, B., Brink, C., van Os-Medendorp, H., Koekkoek, B., Francke, A (2010) Delphi-research exploring essential components and preconditions for case management in people with dementia

⁴¹ Elliott, A., Burgio, L., Decoster, J. (2010) Enhancing Caregiver health: findings from the resources for enhancing Alzheimer’s caregivers health II intervention

⁴² Minkman, M., Ligthart, S., Huijsman, R. (2009) Integrated dementia care in The Netherlands: a multiple case study of case management programs.

The service provided by the Navigators will need to be flexible according to the needs of the person and their family, the stage of illness at presentation, the evolution of the dementia and its complications. Most importantly the Navigators will be available at short notice, by phone or visit, to the person and their family throughout the course of the illness.

The Navigators will have close links with the Primary Care providers for their case-load, and will also make sure that other Secondary Care providers are made aware of the dementia as required. Each Navigator will be supported in this work by the other members of the MDT⁴³ and the rest of their Navigator colleagues.

The Navigators role is divided into three phases:

Phase Three: The Intensive Work

This first phase is for a six-month period of 4 – 5 domiciliary visits, available to all those with MCI or dementia. The purpose of this phase is to ensure good engagement with the person and their family, support them through coming to terms with the diagnosis, and to make progress with those tasks that need to be addressed urgently such as a review of their medications, organising Enduring Powers of Attorney (EPOA) and commencing a trial of anti-dementia medications. It will also be the start of the conversations about the future of the illness and its care. For those with MCI, the person will be discharged from the Dementia Care Pathway back to Primary Care following this initial phase, which will be adapted to meet their needs.

Phase Four: Ongoing Community Care

The subsequent work with the Navigators will be limited to those who have dementia as a diagnosis. This second phase involves a period of follow-up of the person with dementia and their family in their home, with around 4 – 5 visits per year over an estimated period of time of around 3 years on average. There will also be phone contact with the person and availability should problems occur.

Phase Five: Aged Residential Care

Lastly, the Navigator will complete quarterly visits to the person, following their entry into Aged Residential Care, for an estimated period of one year on average.

⁴³ de Vries, K., Brooker, D., Porter, T (2010) Workforce Development for Dementia: Development of role, competencies and proposed training for; “ Primary care Liaison Worker” to support pathway to diagnosis of dementia.

Roles of the Navigator

In each of these phases the Navigators will have specific and evolving roles and tasks, including the following:

- Explaining the illness and supporting the person through their dementia
- Encouraging the person with dementia to continue with and enjoy their usual activities
- Supporting the families and carers, and checking for levels of carer stress
- Monitoring and intervening if elder abuse is an issue
- Monitoring the progression and complications of the dementia
- Providing resource material and other information
- Connecting the person and their family with appropriate care and support through NASC
- Assisting the person and their families with issues around EPOA and Driving safety
- Beginning and encouraging on-going discussion about End of Life Care
- Helping families to anticipate and manage future crises or behavioural problems
- Teaching or making family members/carers aware of ways of managing the challenges in this role
- Being available to assist families to manage these crises when they do occur, and arranging appropriate reviews where needed
- Encouraging physical wellness, exercise and regular Primary Care review
- Helping to review the need for medications such as antipsychotics
- Being an advocate for the active treatment of the dementia such as with cholinesterase inhibitors or similar
- Encouraging participation in available group activities provided within the Dementia Care Pathway
- Helping families with coping with decisions about placement and adjustment to this
- Liaising with affiliated services involved in the care of the person, including the General Hospital, and
- Finally, helping the person with dementia (and their family) to come to terms with living and dying with dignity.



Mild Cognitive Impairment

For those with MCI, the person and their family will receive an adapted programme for six months. Following this period, which will only cover a proportion of the above tasks, the person will be discharged from the service, but with a clear invitation to return should their symptoms worsen. People with MCI have a higher risk

of developing dementia in subsequent years than similarly aged peers, but the rate of conversion is uncertain from the literature and also depends on the diagnostic system used for the MCI.^{44 45} However, it is likely that the conversion rates are significantly lower than the often cited 10-15% per year on average, and that many people (up to 20-30%) with MCI actually improve or have stable symptoms. Accordingly, the Dementia Pathway will assist this group with tasks such as education, support, care services and legal issues such as Enduring Powers of Attorney through a modified intensive phase of work, and then be willing to have the person be re-referred should the MCI show signs of developing into dementia.

Groups for those with dementia and their families or Carers

The work of the Navigators needs to be complemented by a range of groups offered to those with dementia and their families or carers. These are offered for a number of reasons; to help with the efficiency of providing care, to reduce the sense of isolation of those with dementia and their families, to offer specific interventions, and lastly, because we know peer groups are a good way of sharing strategies for coping with things like difficult behaviours. Groups will be offered to all those who are in the Dementia Pathway, who have a diagnosed dementia. They will not be offered to those people with MCI.

Groups will be available following the phase of Intensive work by the Navigators, for the middle community period of 3 years on average. There will also be some peer support groups available for families or carers once the person with dementia has entered Aged Residential Care.³¹ Many of the programmes offered internationally which have been reviewed, have employed this combination of individual work with group attendance.⁴⁶

Currently there is a limited range and number of groups available in Counties Manukau and these are not well attended. This is partly because of logistical problems around transport, but also likely to be due to limited availability or promotion of these. There is also the clinical experience that many people and their families do not like attending “Alzheimer’s groups” because of the stigma attached to the title.

The Dementia Care Pathway hopes to offer a range of groups, in a number of different settings. It is hoped to have groups focussing on exercise, activities, challenging behaviours, living well, and maintaining mental health. It is also hoped that there will be the opportunity to deliver such a service to those ethnic groups and

⁴⁴ Ritchie, L., Tuokko, H. (2010) Patterns of cognitive decline, conversion rates, and predictive validity for three models of MCI.

⁴⁵ Mitchell, A., Shiri-Feshki, M. (2007) Temporal trends in the long term risk of progression of mild cognitive impairment: a pooled analysis.

⁴⁶ Mittelman, M., Haley, W., Clay, O., Roth, D (2006) Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease.

populations that do not currently use the service available. For example, in the Croydon Memory Service approaches were made to local temples or churches in an effort to engage people and their families with the service.³⁶ There will also be the opportunity to hold groups for those people with rarer presentations, such as early onset dementia. Some of these may ultimately be best organised on a regional basis by agreement with adjacent DHBs.

The groups provided need to be professionally run and based on good evidence. Hence it is proposed that a Psychologist be employed as supervisor of the group programmes. The psychologist can also serve as a trainer of those interested in running the groups.

Needs Assessment and Services Coordination (NASC)

NASC is already available to people with dementia and their families. It will be critical for the Dementia Care Pathway to have close links with NASC, and it is hoped that there will be staff from NASC, working alongside or embedded in the Dementia Care Pathway service, so that care needs can be promptly and efficiently met.

What is not provided by the Dementia Pathway

When our Dementia Care Pathway is compared with the service outline described in the UK National Dementia Strategy¹⁰ or Healthcare of London Dementia Service Guide,¹¹ it is clear that we are providing only a proportion of the services that they recommend. The Dementia Care Pathway does not provide for a specific service caring for people for dementia in a general hospital, provide information to the community as a whole about dementia, or specifically seek to do research. We have specifically not made it a mission to undertake community screening and the early identification of cases of dementia, as yet unidentified. It has yet to include workforce development or the training of those caring for people with dementia in ARC. We recognise that all these are important aspects that will enhance the provision of good quality of care for people with dementia. However we also recognise the funding limitations that would limit the implementation of the full combination of described services. We have therefore attempted to prioritise our Dementia Care Pathway by making our starting point the provision of a practical clinical service for those with dementia living in the community and their families.

We expect that these complementary pieces of work will become available over time as the Pathway develops and regional activities grow. There is work already commenced on the difficulties identifying and looking after people in a general hospital ward as one of the work streams of the Northern Clinical Network. Canterbury

DHB has also recently developed an impressive training package for staff working with people with dementia in ARC.

In summary, it is our belief that a good community-based Dementia Care Pathway, a General Hospital Pathway for those with Dementia and Delirium, and improved training in ARC are probably the places to start, and slowly work toward developing the full portfolio of dementia services over time.

Chapter 5

OUTCOME MEASURES FOR THE DEMENTIA CARE PATHWAY

A number of outcome measures will be developed and agreed to assist us to know whether the service is making a difference to people with dementia and their families and carers. These will be further developed and selected in the Pre-Implementation phase of the Dementia Care Pathway, so we can establish a baseline. Additionally, the agreed outcome measures will need to be linked to contractual monitoring and reporting requirements, such as the Key Performance Indicator (KPI) framework.

In this section we have outlined the key areas of improved clinical outcomes, for both people with dementia and their families, and then looked at some of the performance measures that might be included in the function of the Pathway.

Clinical Outcomes

This section describes the focus of the therapeutic interventions and clinical outcomes desired for both people with dementia and their families. The structure of the Dementia Care Pathway, and the tasks that Navigators will be asked to complete have already been described. This section summarises those efforts into achievable clinical outcomes, which it is hoped will guide development of groups of measurable performance outcomes for the service.



1. *Becoming Aware*

People with dementia and their families have often spent time before presentation puzzled by symptoms such as changes in behaviour or may have attributed noticeable forgetfulness to old age. These attitudes are often echoed by friends and even clinical staff. Therefore, the first critical task of the Dementia Care Pathway is to provide the people with dementia and their families with an accurate diagnosis following assessment. Furthermore, following that diagnosis, all those involved need educating about the illness and to have access to resource materials. They also need to be made aware of the future or potential course of the disorder, possible complications and how to access assistance. The range of services and availability of groups and home-based care packages, either now or for the future will be outlined.

The Pathway and its stages need to be explained to them. The need for Enduring Powers of Attorney and some of the other tasks will be commenced. The benefits of anti-dementia medications will be explained.

2. Living Well

Sometimes people with dementia feel the message they receive following diagnosis is “to go home and put your affairs in order”. This is, however, not the intention of the Dementia Care Pathway. People and their families will be encouraged to fully live their lives, even in the context of having dementia. There will be a specific recommendation to continue existing activities. People will be advised that they can enjoy a good quality of life and to be participants in the community to the extent that they are able. People with dementia will be encouraged to use their cognitive skills, and there is evidence that this can slow deterioration.⁴⁷ Families will be assisted in making the most of the time available to them with the person with dementia. The achievement of some of these goals will depend on the stage of dementia at the point of presentation, and disability from this and other illness. However it will always be an explicit clinical goal of the pathway.

3. Staying Healthy

Vascular dementia can be potentially slowed through management of risks factors (although clinical evidence for this is modest), and dementia of all types can be ameliorated by physical exercise. A complicating illness of any type will potentially cause Delirium and may lead to hospital admission. Those with dementia often do poorly in hospital, and it is hoped that some admissions may be prevented through attention to good health care in the community. Unnecessary medications can be a real risk in those with dementia or those frail due to illness or age. For all of these reasons, an important goal for the Dementia Care Pathway will be to keep people active and healthy, and engaged with their General Practitioner.

4. Being Strong, Being Smart

Families and carers of those with dementia often find the time spent providing care a rewarding and positive experience. But it can also be experienced as increasingly time-consuming and burdensome, and, all too often, is a lonely task. This is particularly so as the disorder progresses and the disability of the person with dementia increases. Families and carers need support and encouragement through this time. They need skills, advice and access to help through some of the difficult times. They also need access to those that have already negotiated the journey, through peer support groups. They will receive training and resource material about coping with difficult behaviours. They will be encouraged to employ non-pharmacological interventions to manage behaviour, but also guided such that they will seek medication and help, before difficult behaviours get out of control. They will also be specifically encouraged to look after themselves as well, both physically and

⁴⁷ Graff, M., Adang, E., Vernooij-Dassen, M., Dekker, J., Johnsson, L., Thisjssen M., Hoefnagels, W., Olde Rikkert, G (2009) Community occupational therapy for older patients: cost effectiveness study.

emotionally. The Dementia Care Pathway will have a critical role in making sure that families and carers receive the support that they deserve, in the hope that they may continue with this role for longer and experience more of the positives.

5. Accepting Help

Dementia is a progressive illness, and the dependency of the person with dementia grows with time. Both they and their families need practical assistance and respite at times, and will be directed to those services that offer these in the community. The Dementia Care Pathway, and through their close connections with both NASC and NGO providers, will ensure that people and their families anticipate this need and are accepting of suitable care as required. The pathway will also provide guidance through the often emotionally difficult times as families consider long-term care for their loved ones.

6. Completing the Journey

Dementia from most causes is a fatal illness. People with dementia and their families need to have started the conversation about this reality from early in their contact with the Dementia Care Pathway, and will be encouraged to continue these reflections throughout the journey with the illness. Advanced Care Planning by the person is possible, but frequently in dementia, the reality is that the family make decisions about end of life care. Families need to be confident in their decision making on behalf of their family member with dementia, and this will be a goal for the Dementia Care Pathway. Families need to be linked up with suitable services such as Palliative Care, when they have reached consensus that active care is no longer in the best interests of the person, nor in keeping with the likely wishes of that person. Whatever decision is made, the Dementia Care Pathway will have a role in helping people and their families through the final phase of the illness.

“The Dementia Care Pathway will have a role in helping people and their families through the final phases of the illness.”

Measured Outcomes

This is a preliminary list of measurable performance outcomes for the new Dementia Care Pathway:

- Time to assessment from referral and time to complete assessment process
- Attendance at groups (short-term vs long-term)
- Contacts with Navigators
- Crisis calls to service
- Care episodes in MHSOP and HOP
- Admissions to General Hospital and Length of Stay
- Number of GP consultations
- Time to entry into ARC
- Person with dementia quality of life measures (QoL)
- Measures of family / caregiver burden or mood
- Satisfaction with service
- Measures of BPSD
- Trial of anti-dementia medication and length of time for compliance
- Anti-psychotic medication usage
- Drop-out rates from service
- Life expectancy from time of diagnosis (time under care of the Pathway)
- Average time spent residing in ARC
- Staff satisfaction
- Case-loads and manageability of these.

Some of the outcome measures (e.g. life expectancy, average time spent in ARC) are included because of deficiencies in current knowledge. We have already commenced discussions about useful research projects and opportunities in this regards. We also intend to link in with the national Key Performance Indicator (KPI) project as part of a continuous quality and performance measurement.

Chapter 6

BENEFITS OF THE DEMENTIA CARE PATHWAY

This section describes the some of the clinical, emotional, social and legal benefits of a Dementia Care Pathway.

1. Emotional and Behavioural Benefits of the Pathway

There is strong evidence that provision of a Dementia Care Pathway including the components of assessment and diagnosis, community care and case management for people and their families, and a supportive group programme, makes a considerable difference to the well-being of both dementia sufferers and their care-givers. Reviews by Olazaran et al,³¹ Brodaty et al³⁰ and the comprehensive review by Goy et al⁴⁸ for the Department of Veterans Affairs show confirmed improvements in the mood and quality of life scores for both the person with dementia and their family. There is an experienced reduction in the sense of burden on the part of care-givers. There is generally a high level of expressed satisfaction with the services provided by such pathways. This was most profound for so-called multi-component pathways. However even simpler pathways, such as exercise programmes or case-management alone, also led to improvements in care-giver mood; the latter study also showed improvements in the behaviour of the person with dementia. Such programmes for people with dementia and their families are also recommended by international guidelines such as the American Psychiatric Association¹⁴ and NICE-SCIE guidelines.¹⁵

The REACH II structured multi-component care-giver skills programme, also sponsored by the Department of Veterans Affairs, demonstrated improvements in care-giver self-rated health, sleep quality, physical health and emotional health.⁴¹ Changes in a sense of burden and lower depression levels appeared to mediate these improvements. In this programme the intervention was a combination of nine in-home sessions and three telephone sessions over a period of six months.

In a three country randomised controlled study⁴⁹ of the benefits of adding psychosocial interventions for caregivers, where the person with dementia was receiving Donepezil (anti-dementia medication), established there was a significant improvement in the depression ratings of those care-givers receiving the psychosocial interventions (alongside the person with dementia receiving Donepezil), compared with controls group (where the person with dementia received Donepezil but there was no psychosocial intervention for the person and the care-giver). In this study the psychosocial intervention was five sessions of individual and family counselling

⁴⁸ Goy, E., Freeman, M., Kansagara, D. (2010) A systematic evidence review of interventions for non-professional caregivers of individuals with dementia.

⁴⁹ Mittelman, M., Brodaty, H., Wallen, A., Burns A. (2008) A 3 country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer's disease: effects of caregiver depression.

in the first three months of the programme and on-going ad hoc telephone counselling as required. Mood was significantly improved in those care-givers who received counselling and this continued to improve for the full two years of the study. By comparison, the care-givers in the control group showed a gradual deterioration in their mood over the same period. This demonstrates a significant improvement in outcome for care-givers receiving the sort of programme advocated by this pathway, without the huge inputs or investment of resources used in some Dementia Care Pathways.

2. Providing anti-dementia medications

There has been some reluctance to use these medications by clinical staff, as the benefits appear to be very modest, and frequently there is no immediate improvement in symptoms.⁵⁰ In New Zealand they were not fully funded for those with dementia until 2011.

A recent review⁵¹ showed that anticholinesterase medications such as Donepezil do lead to slowing of clinical worsening in people with dementia, especially those with Alzheimer's disease and Lewy Body Dementia. There were also improvements in behavioural problems associated with dementia such as apathy, hallucinations and depression.⁵⁰

Anti-dementia medications have been shown to lead to delays in ARC entry. Studies by Lopez et al⁵² and Geldmacher et al⁵³ showed delays of up to 9 – 12 months in ARC entry in those people taking anti-dementia medication. In the study by Lopez, people taking a combination of two different types of anti-dementia medication had an even greater delay in ARC placement, than those on anticholinesterases alone.⁵²

A Dementia Care Pathway will oversee and encourage the use of these medications, which are inconsistently used at present. The benefits of the medication will be explained to people with dementia and their families, and the medium to long-term benefits explained. Related to this, the use of medications to manage vascular risk factors, such as diabetes, hypertension and raised cholesterol, also has the potential to slow progression of Vascular dementia. This would be managed through liaison between the Dementia Care Service clinical staff and Primary Health Care.

There will be, in the future, the development of more successful medications to manage, slow progression, or ultimately prevent dementia, and the Dementia Care Service will be active in promoting those that offer significant benefits for people with dementia.

⁵⁰ Vernon, J., Goldberg, R., Dash, Y., Muralimohan, G (2007) Alzheimer's Disease and Cost-effectiveness Analyses: Ensuring Good Value for Money?

⁵¹ O'Brien, J., Burns, A. (2010) Clinical practice with anti-dementia drugs: a revised (second) consensus statement from the British Association for Psychopharmacology.

⁵² Lopez, O., Becker, J., Wahed, A. (2009) Long-term effects of the concomitant use of memantine with cholinesterase inhibitors in Alzheimer's disease.

⁵³ Geldmacher, D., Provenzano, G., McRae, T., Mastey, V., Ieni, J. (2003) Donepezil is associated with delayed Nursing Home Placement in patients with Alzheimer's disease.

3. Reducing risk from other medications

The risks of people with dementia taking other medications such as anti-psychotics (which raise the risks of falls and strokes) are well-documented.⁵⁴ People with dementia are sensitive to the side effects from all medications, especially those which have an action on the brain such as anti-depressants and sedatives. However people with dementia frequently suffer complications such as BPSD, and these classes of medication are used to manage these symptoms with some success. Guidelines locally such as those generated by the RANZCP Faculty of Old Age Psychiatry^{55 56} and overseas, advise clinicians using these medications judiciously and for the shortest period of time possible.^{57 58}

However it is a common scenario that people with dementia are prescribed these medications in the context of BPSD, delirium or the sleep disturbances that may accompany dementia.⁵⁹ This prescription is often commenced in hospital or by MHSOP (or in Primary Health Care), but the medications are frequently continued indefinitely following their discharge back to Primary Health Care.

A Dementia Care Service, which provides for ongoing care and supervision of people with dementia, would ensure that these medications are withdrawn cautiously three to six months after symptoms have settled. There would be regular liaison with a consistent approach, ready access to specialist multi-disciplinary expertise from diagnosis through clinical management, and for ongoing, supportive care to clients and families.

4. Enduring Powers of Attorney (EPOA)

People with dementia, as the disorder progresses, may lose the capacity to make decisions about their care or their finances. Consequently, they need to have someone identified to take over these responsibilities, when the time comes that they are no longer able to make these decisions for themselves. Appointing an Enduring Power of Attorney, which is later activated as needed, is the best way to organise this. Those situations where people with dementia have no EPOAs organised and are no longer competent to make decisions, require

⁵⁴ Huybrechts, K., Gerhard, T., Crystal, S., Olfson, M., Avorn, J., Levin, R., Lucas, J., Schneeweiss, S (2012) Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population based cohort study.

⁵⁵ Faculty of Psychiatry for Old Age - RANZCP (2009) Practice Guidelines – Antipsychotic medications as a treatment of behavioural and psychological treatments in dementia.

⁵⁶ Faculty of Psychiatry of Old Age (New Zealand) (2008) The Use of Antipsychotics in Residential Aged Care.

⁵⁷ American Psychiatric Association (2010) Guidelines for the Treatment of Patients with Alzheimer's Disease and Other Dementia's – Second Edition.

⁵⁸ Banerjee, S. (2009) The use of anti-psychotic medication for people with dementia: a time for action. A report for the Minister of State for Care Services.

⁵⁹ McLeery, J (2012) Antipsychotic prescribing in nursing homes – We need to understand why this practice continues despite the mortality risk.

family members to make an application to the court. Not only is this more time-consuming, due to delays in court hearings, it often leads to a hiatus where no one has authority to make decisions.

This is why it is one of the important early tasks following diagnosis to make sure that people with dementia organise the appointment of their EPOAs, if they are still able.

5. Connection with Community Services

People and their families need to be linked up with community services such as respite, home care assistance and day-care, according to need. It will be one of the roles of the Dementia Care Pathway to ensure that these services are available to all those being cared for by the Pathway. This, we hope, will be facilitated by having close links between the Pathway and NASC. The group programmes provided through the Dementia Care Pathway will also be a component of this care.

6. Driving

It is known that older people suffer as many deaths on the road (per kilometre driven) as do young and inexperienced drivers. This is partly due to the physical frailty of older people in accidents; however it is also due to natural changes in cognition such as a slowing of reaction times. All of these are exaggerated in those with dementia.

Many people with dementia stop driving in the early stages of the disorder. However, there are some that wish to continue driving, and may not understand the concerns of clinical staff or family about their driving safety. People with mild dementia may be able to drive safely, but many can no longer do this safely and are putting themselves and other drivers at risk. The safety of drivers can be a difficult assessment for clinicians to make, but it will be one of the fundamental roles of the Dementia Care Pathway. We will have to balance the wishes of those with dementia to remain independent against the safety of all road users.

“There is strong evidence that provision of a Dementia Care Pathway... makes a considerable difference to the well-being of both dementia sufferers and their care-givers.”

7. Early Diagnosis

It is hoped that the provision of a Dementia Care Pathway will lead to referral and diagnosis, at an earlier stage of the disorder than is currently the case. This will be through the promotion of the Pathway to referrers such as GPs. There are certainly benefits from early diagnosis, which is why it was one of the central aims of the UK National Dementia Strategy.¹⁰ However, it often requires considerable investment in promotion or education, in both the community itself and the referring groups. As such, it has not been an emphasis in this Dementia Care Pathway. Early diagnosis will also lead to longer periods of follow-up and community care, again putting a strain on the resources available. Nonetheless, it is certainly hoped that the existence of a dedicated Dementia Care Pathway will promote referral at an earlier stage of the disorder.

Chapter 7

COST EFFECTIVENESS OF THE DEMENTIA CARE PATHWAY



Cost effectiveness can be measured in relation to increased efficiency in terms of resources, saving money spent on care elsewhere in the system and providing a positive benefit to service users. It is within this context we have considered what is needed from the development of the Dementia Care Pathway.

We have reviewed some of the studies relating to the cost-effectiveness of Dementia Care Pathways initially, and then discussed possible ways in which savings in some of the related services might be made.

Cost-Effectiveness Studies and Reviews

Olazaran et al³¹ felt that non-pharmacological treatments of people with dementia and their families are cost effective, principally through delays in entry into ARC homes, that resource outlay was justified by virtue of the savings that followed. Brodaty et al³⁰ showed that four of seven studies that looked at delays in ARC placement as an outcome showed a significant delay from dementia care programmes. In contrast, the Department of Veterans Affairs⁴⁸ did not feel that the evidence regarding ARC placement delay was consistent for care-giver interventions; however they acknowledged the significant delays in ARC placements in studies using combined group and individual work, such as that by Mittelman et al⁴⁶ that led to a 557 day delay in placement for the treatment group.

A further three country study by Mittelman et al⁴⁹ showed that a short course of care-giver counselling and support, plus the prescription of an anti-dementia medication for the person with dementia, led to lower levels of depression in care-givers. The same study⁶⁰ also demonstrated a significant delay in time to ARC placement for those clients living in Australia. Fifty percent of the control group clients had entered ARC at conclusion of the study compared with 23% of clients where the caregivers had received the extra counselling and support. There was no significant difference in either the US or the UK groups. This was felt to be due to the relatively low levels of ARC entry in those countries (compared to Australia), and the relatively short period of intervention (limited to two years) compared with the original Mittelman study.⁴⁶

Banerjee and Wittenberg⁶¹ reviewed the cost effectiveness of the programme offered at their own Croydon Memory Service. They noted that previous reviews and studies had demonstrated delays of between 53 – 329 days in five different studies reviewed by Brodaty.³⁰ They also cited the intervention by Mittelman et al⁴⁶ which showed a delay to ARC placement of 557 days on average compared with the control group. This delay represents a 28% reduction in the use of ARC beds. They also noted that Challis et al⁶² had demonstrated a 6% delay in the use of ARC beds even in those clients with relatively advanced dementia at the time of the intervention.

The Croydon Memory Service³⁶ provides a thorough assessment and diagnosis service for people with dementia, and offers a six month follow-up programme (which can be compared to our intense community programme). It is largely targeted at those presenting relatively early and without major behavioural complications. It serves a population of around 50,000 elderly, approximately the same size as CMDHB, and

⁶⁰ Brodaty, H., Mittelman, M., Gibson, L., Seeher, K., Burns, A. (2009) The effects of counselling caregivers of people with Alzheimer's disease taking donepezil and country of residence on rates of admission to nursing homes and mortality.

⁶¹ Banerjee, S., Wittenberg, R (2009) *Clinical and cost effectiveness of services for early diagnosis and intervention in dementia.*

⁶² Challis, D., Von Abendorff, R., Brown, P., Chesterman, J., Hughes, J (2002) Care management, dementia care and specialist mental health services: an evaluation.

sees between 600 – 800 referrals per year. This service is complemented by parallel services from Community Mental Health Services and Social Services staff.

In Banerjee and Wittenberg's calculations, they did not attempt to assess reductions in General Hospital admissions but restricted themselves to the delays in entering ARC facilities. They costed their Memory Service at around 10 FTE (although that included management and administration staff) and estimated the necessary increase in staffing in their Community MHS at around 7.5 FTE and their Social Services at 7.0 FTE.⁶¹

They considered these costs against the savings from delayed ARC admission. In the UK two thirds of ARC beds are publicly funded. The savings increase quickly from about year 3 following the service initiation up to about year 6. They then increase more slowly according to demographic growth.⁶¹

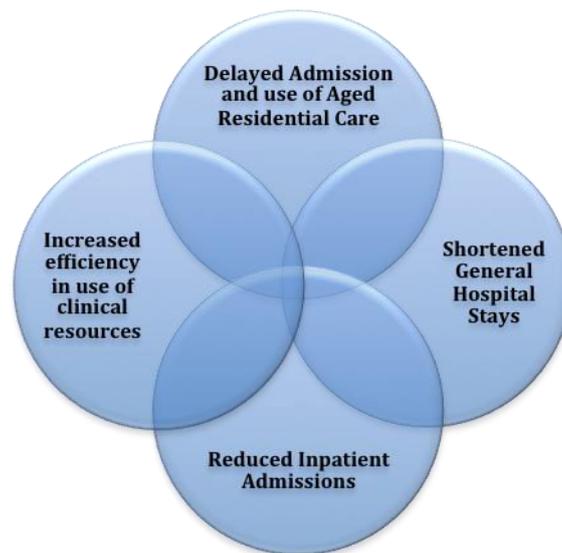
Banerjee and Wittenberg showed that a 20% reduction in ARC placements would be necessary to achieve savings in overall public spending. However they acknowledged that this did not take into consideration the marked improvement in Quality of Life (QoL) of those with dementia and their carers. It was their view that the Memory service would justify funding on the grounds of the combination of a 10% reduction in ARC admissions and that improved QoL.⁶¹

Banerjee and Wittenberg's model is one of the few attempts to calculate the Cost Effectiveness for a Dementia Care Pathway. The UK model of care is somewhat different from ours, and we have attempted to offer a leaner and more efficient provision of service with lower numbers of staff. The case for our Dementia Care Pathway is also strengthened by a slightly higher proportion of publically funded ARC beds in Counties Manukau – this is estimated to be around two thirds to three quarters of all those living in ARC facilities. The overall cost effectiveness would also be strengthened by the potential savings to General Hospital bed days.⁶¹

Vickland et al²² calculated the costs of providing dementia care in Australia showing that 61% of costs were funded and the rest were due to the costs incurred by the time commitment of informal carers, i.e. families of the people with dementia. They calculated that the total costs of care would more than triple by 2040. They also calculated the costs associated with two different clinical scenarios or interventions. In the first the assumed intervention would delay the onset of the dementia by two years, and in the second the assumed intervention would slow the progression of the illness by two years. They showed that the former scenario would reduce costs (compared with the intervention group based solely on demographic change) whereas the second scenario would increase costs due to people with dementia living longer.

For a Dementia Care Pathway to be strictly cost-effective, there will need to be equal or greater savings in the use of other services funded or provided by Counties Manukau DHB. The Dementia Care Pathway can also be viewed as cost-effective if it produces efficient and beneficial results in the outcomes of people's illnesses. This section describes the potential savings that may occur in the use of other funded services. It is proposed that these savings will come from the following areas.

“Dementia Care Pathways do lead to delays in the admission of people with dementia into Aged Residential Care.”



Delayed Admission and use of Aged Residential Care

Admission of people with dementia to ARC is often precipitated by carer burnout, behavioural problems and deteriorating functional levels such as in the area of continence. Carers and families struggle with providing round the clock care for the person with dementia, and currently many receive little assistance or have no one to turn to for help or advice in the management of building crises. The study by Banerjee et al⁶³ showed that having a live-in family member or carer delayed people with dementia from entering ARC placement, but those situations that were characterised by higher ratings of behavioural problems and lower family member/carers quality of life were also predictive of ARC placement.

⁶³ Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J., Mann A. (2003) Predictors of institutionalisation in people with dementia.

There is accumulating evidence that services that contribute to the Dementia Care Pathway do lead to delays in the admission of people with dementia into ARC. In the Mittleman study,⁴⁶ a combined programme of individual and group support led to delays in ARC entry of an average 557 days.

In Brodaty's review of dementia care programmes⁴⁶ four of seven studies that included this outcome measure, showed a significant delay in ARC placement. This was particularly evident in those studies where the programme involved both the person with dementia and their caregivers or families. This is because families are better prepared and more confident in their care of the person with dementia, they have quick access to advice, and their own levels of depression and anxiety are lower. Some of the crises are headed off before they escalate, and are anticipated by families.⁴⁶ There is also evidence that making sure that people with dementia are taking appropriate medication such as cholinesterase inhibitors may also contribute to delayed admission to ARC, as discussed above.

Shortened stays in the General Hospital

People with dementia have inpatient admissions around 50% longer than those without dementia.¹⁹ Some of this difference is not able to be reduced, but there is increasing evidence that if a person is known to have dementia and if they are managed in the General Hospital in a way that reduces the risks from superimposed delirium or falls, then inpatient stays can be shortened. Dementia is a major risk factor for superimposed delirium, and the combination leads to prolonged stays, higher mortality and a higher risk of being institutionalised following discharge.⁶⁴

Unfortunately at present many people with dementia are either not formally diagnosed as such, or their families are unable to communicate with General Hospital staff that their family member has dementia. Consequently the person's illness may well be complicated by delirium, falls or other injury, and their stay lengthened. Unfortunately delirium is often not identified as such by clinical staff, and this was found to be the case in an audit of admissions to the HOP ward at Waitemata DHB in September 2007, in the study completed by Bowen and Lin.⁶⁵

Delirium is common in elderly patients in the General Hospital, but is frequently unrecognised and mismanaged. There are recommended interventions in those with dementia to reduce the incidence of delirium, and these are demonstrated in studies. There is also evidence that early intervention in those with delirium can shorten the event and stay in hospital, and lead to reduced complications such as falls.^{66 67 68} . The Navigators would

⁶⁴ National Institute for Health and Clinical Excellence (2010) Delirium - Delirium: diagnosis, prevention and management. Nice Clinical Guideline 103

⁶⁵ Bowen, H., Lin, Y (2007) Personal Communication 2010

⁶⁶ Rathier, M., Baker, W (2005) A Review of Recent Clinical Trials and Guidelines on the Prevention and Management of Delirium in Hospitalized Older Patients Hospital Practise.

⁶⁷ Rathier, M., McElhaney, J. (2005) Delirium in elderly patients: How you can help. Psychiatric Times.

ensure that alerts are present on a person's clinical file, and that families and carers would be primed to inform General Hospital staff about dementia and delirium. They would also contact those staff themselves if needed.

Reduced Inpatient Admissions

It is expected that the service provided to the people with dementia and their families will ultimately reduce the number of hospital admissions. There is some evidence for this assertion; for example the review of studies of case-management of elderly people with illnesses including dementia showed reduced levels of hospital admissions and shorter inpatient admissions, than control groups.²⁹

There are a number of ways in which this might occur, as follows:

- Early intervention in some of the behavioural syndromes secondary to dementia may reduce a small number of admissions to the MHSOP inpatient unit
- On-going monitoring of the person's physical health, especially around cardiovascular risks and diabetes, including encouragement of regular Primary Health Care contacts, may reduce the need for some admissions
- Through regular contact with the Navigators, the person with dementia who may have been prescribed an antipsychotic for BPSD, will be on these medications in lower doses and for shorter periods of time. This should reduce the risks of stroke and injury from falls. This will also apply to other medications that may lead to similar risks
- Families caring for a person with dementia, who may be at breaking point emotionally, will turn to their Navigator for support, and avoid using hospital services such as the Emergency Department
- End of Life Planning or Advanced Care Planning, and the discussions around these topics throughout the illness between the person and their family, and the Navigator, may lead to a choice for people not to go to the General Hospital for the last phase of their illness. Instead they may be helped to die with dignity with their family, whether at home or in ARC.

It is proposed that the existence of the Dementia Care Pathway and the on-going care for those with dementia would lead to savings in the areas of care as described above. These benefits will not be immediate in most cases, and the benefits are likely to be experienced as a slowing in the rate of growth in both inpatient and ARC beds over the next 30 years rather than a reduction in the existing provision, particularly considering the changing demography of dementia.

⁶⁸ Inouye, S., Bogardus, S., Charpentier, P., Leo-Summers, I., Acampora, D., Holford, T. (1999) A multi-component intervention to reduce delirium in hospitalized older patients.

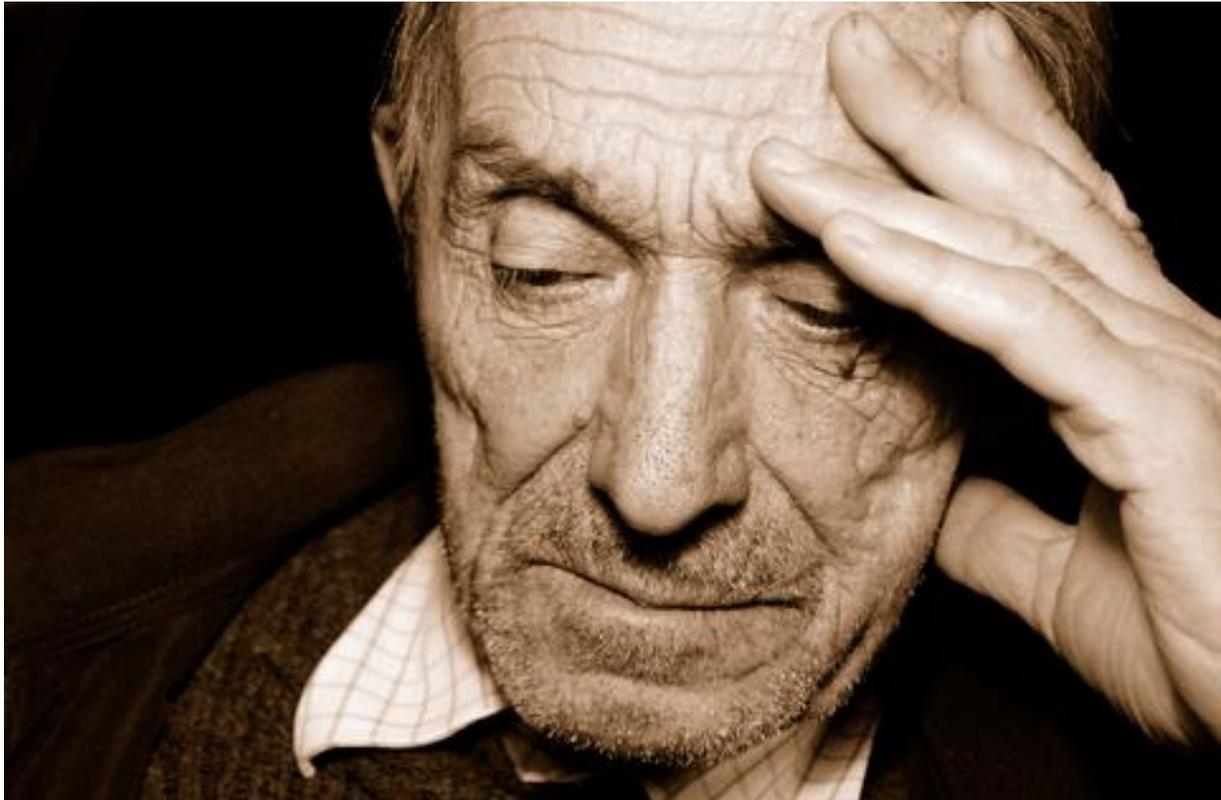
Increased Efficiency in use of Clinical Resources

Currently most people with dementia referred to CMDHB are assessed and followed up by Geriatricians based in outpatient clinics around the area. It is our belief that most people with dementia can be diagnosed and managed by experienced nurses, with the back-up of an MDT team. This should increase the economic efficiency of the service, and free up some consultant time in HOP services for other activities, including participation in the Dementia Service MDT.

Since 2007 HOP, MHSOP and Psychiatric Liaison Services have noticed a significant number of requests for Capacity Assessments. If Enduring Power of Attorney (EPOA) and other legal mechanisms are organised early, then these requests should diminish or be much less time consuming – therefore allowing for a more efficient use of clinical resources.

Chapter 8

RESOURCING THE DEMENTIA CARE PATHWAY



This section provides a summary of the Clinical FTE resourcing required to provide the Dementia Care Pathway in Counties Manukau. The full description of our calculations and assumptions in detail will be made available on request.

We have estimated the resourcing (in terms of Full Time Equivalent staff (FTE)) to provide the Dementia Care Pathway as described in previous sections. In making these estimates we have attempted to give an indication of those existing FTE that are already employed by the DHB (in HOP, MHSOP and AACT) in roles that support those clients currently referred to services with dementia. We have then calculated the extra FTE required in order to provide the full service as described by the Dementia Care Pathway.

We have used the existing population numbers to assess referrals numbers and looked at the accumulation of caseload over the entire pathway of around 4-5 years on average. We have therefore **not included the effects of demographic growth**: an approximate doubling of cases in the Counties Manukau DHB area over the next 15 years.

Following the calculation of resourcing, we have described the three steps of funding which would be used in implementing the service. These steps include:

- **Pre-Implementation:** This step would see the appointment of a small number of FTE to get the Pathway ready for implementation over the course of around one year.
- **Implementation:** We have identified the amount of new and existing resource needed at start-up (for the first year of activity). At this point the identified existing resource in current services would also be re-allocated where appropriate to the Dementia Care Pathway.
- **Case-load Accumulation:** This identifies the resource needed to accommodate the growth in our case-load by degree over the following four years of activity (at which point the total caseload should reach its equilibrium except for the effects of demographic growth).

Estimated annual referral numbers and Life Expectancy

We have used three sources of information to estimate annual referral numbers:

- The guidelines provided by NICE ¹⁵ on estimating a population benchmark for a Dementia Service
- The number of referrals to the Croydon Memory Clinic ³⁶ (which has a similar population base to CMDHB), and
- We have also reviewed actual referrals to MHSOP Community Teams and HOP Medical outpatient clinics to estimate the number of suitable dementia cases.

We have combined these sources to make an estimate of likely referrals to the Dementia Care Pathway, and the number of these referrals with dementia and / or Mild Cognitive Impairment (MCI).

We estimate that the Dementia Care Service will receive 850 referrals per year, and that of these, 510 (60%) will have dementia and 170 (20%) will have MCI.

The remaining 20% will not need the Dementia Care Pathway. Some of the cases with MCI will later develop dementia and will likely go through the referral and assessment process a second time. This may ultimately apply to 30 – 50% of MCI cases.

We have used our literature review to estimate the likely life expectancy of people diagnosed with Dementia. We have used a **mean life expectancy of 4.5 years** as a reasonable guide in our calculations. We believe this figure to be reasonable in view of our population and the figures from overseas. Unfortunately we do not have accurate figures locally. We have also estimated that, on average, clients will **spend around 1 year of this time in ARC**.

The life expectancy determines the accumulation of case-load in the service. We have taken the calculated life expectancy and expected number of new cases of dementia per year (510) to **estimate a total case-load after 5 years to be 2300 cases.**

Forecast for FTE Resourcing for each Pathway Stage

We have calculated these figures in two parts. For each phase of the Pathway we have firstly looked at the Nursing (or similar discipline) numbers, as this group will form the backbone of the service, in terms of clinical face-to-face hours and client numbers. We have then, secondly, addressed the requirement for other MDT members such as Geriatricians, Psychiatrists, Psychologists, Occupational Therapists and Social Workers.

We have then, in the summary, combined Pathway phases into the three resourcing steps: Pre-Implementation, Implementation and for Case-Load Accumulation.

Phase 1: Triage

We have proposed that the existing HOP and MHSOP Triages be combined into a single Triage service for Older Persons, and that people with possible dementia receive a formal triage process.

Phase 1: Triage

We therefore anticipate an overall increase in the amount of Triage time required, and this has been estimated at a total of 4.0 FTE. This implies **an increase in the existing resource by 1.0 FTE.**

Phase 2: Assessment Phase

The assessment will contain two home visits by individual assessment staff, reporting back to the MDT meeting and a follow-up visit to discuss the diagnosis and future management. All suitable referrals (N=850) will go through these stages.

Phase 2: Assessment and Diagnosis

With 850 clients per year, each taking up an estimated 6.0 hours of clinical time, the necessary resource will be 5100 clinical hours or 5.1 FTE.

In total, our estimate is there is the equivalent of around 1.0 FTE of existing Nursing time (and 1.5 FTE Geriatrician – which is considered under the Other MDT resource) already completing assessments on referrals of clients with dementia (in either HOP or MHSOP) who would be suitable for the Dementia Care Pathway.

As the Total FTE requirement is 5.1 Nursing FTE, this indicated the need for an extra 4.1 Nursing FTE for the Assessment phase as described in our model of the Dementia Care Pathway.

Phase 3: Intensive Community Follow-up.

Following assessment, there will be a phase of relatively intense work with those clients who have either dementia or MCI. We estimate that this will involve 4 - 5 visits on average by the Navigator over a period of six months.

Our assessment is that of the 850 referrals, there will be 510 clients with dementia and 170 clients with MCI. This is a six month programme therefore the calculation of resource has taken half of total annual need (680 clients) = 340 clients at any one time. The clinical time required per client is a total of 6.75 hours of Navigator time (1.5 hours x 4.5 visits).

Phase 3: Intensive Community Work

This suggests a recourse requirement for 680 clients per year of 2295 hours or around 2.3 FTE.

Again this assumes each FTE completes around 1000 Clinical hours per year.

Our review suggests that 2.0 FTE already exists in the three services HOP, MHSOP and AACT, and thus there is only **a need for an extra 0.3 FTE** to provide for the Intense Community work provided by the Navigators in the first six months following diagnosis.

Phase 4: Ongoing Community Work

Following the Intensive phase of work, the Navigators would provide ongoing follow-up of clients with dementia (but not MCI) and their families for a further three years (on average) whilst living in the community. We have assumed that Navigators would make quarterly visits complemented by an occasional extra visit (for example if people with dementia are admitted to hospital or have emergent illness of some kind). We have assumed an average of 4-5 visits per year, each of 1.5 hours duration.

This follow-up is only provided for those clients with dementia, and not for those with MCI. Therefore the number needing follow-up at the start of the first year is 510 clients and their families.

Phase 4: Ongoing Community Work

Our estimate of the necessary resource for these years is shown below: This is all new resource as this work is not being currently offered by existing services.

Year 1: 3442 hours= 3.5 FTE

Year 2: 3098 hours= 3.1 FTE

Year 3: 2788 hours= 2.8 FTE

Phase 5: Aged Residential Care.

We have proposed in the Dementia Care Pathway that the Navigators continue to visit quarterly for the client's placement in Aged Residential Care. We have used the same allowance of resource: 4.5 visits by the Navigator per year of 1.5 hours.

Phase 5:

Therefore the **necessary resource is 2509 hours of Nursing clinical time and equates to 2.5 FTE**. Again it is our belief that this service is not currently provided and that this would represent the additional FTE to provide Navigator follow-up in Aged Residential Care.

Phase 4 – 5: Supportive Programmes and Groups.

It is intended that the individual work of the Navigators with clients and their families is complemented by the provision of group work in the community. There will be a range of groups offered ranging from activities for clients, exercise programmes, carer support and education groups, peer support groups and possibly cognitive enhancement groups.

Groups and Programmes - Phases 4 – 5:

We estimate that the necessary resourcing would be around **6.5 FTE** to run the extended (doubled) group programme, representing an extra 4.5 FTE. 0.5 FTE of this would be for oversight of the peer groups following placement into Aged Residential Care. It is recommended that there also be 0.5 FTE Psychology time to provided planning, supervision and oversight of all the groups provided. This is included under the MDT calculations. Most of this extra FTE will be required during the Case-Load Accumulation step, over 4 years of service delivery.

Multi-Disciplinary Team

The calculations above have been used as the estimate of the Nursing FTE resourcing for each phase of the Dementia Care Pathway. However for the Pathway to operate professionally, efficiently and safely, a comprehensive MDT is needed to provide extra care when required and to provide advice and clinical backup for the nursing team.

MDT resourcing – Implementation Stage:

This would be the resource needing to be in place at the start of the service.

Geriatrician:	0.5 FTE
Psychiatrist:	0.5 FTE
Social Worker:	1.0 FTE
Psychologist / Occupational therapist:	0.5 FTE
Psychologist / Occupational therapist:	0.5 FTE (Planning & supervision of support groups)
Total:	3.0 FTE

MDT resourcing – Case-Load Accumulation Stage:

As the case-load increases with time due to ongoing care of clients, there would need to be further resourcing. (It is likely that as the staff numbers increased that there will ultimately be two teams operating across different geographical areas). This is the estimate of further MDT resourcing required for the Dementia Care Pathway over the next few years.

Geriatrician:	0.5 FTE
Psychiatrist:	0.5 FTE
Social Worker / Allied Health:	0.5 FTE
Total:	1.5 FTE

There is no MDT resourcing for the Pre-Implementation step. However it is anticipated that there will be a total of 0.4 FTE seconded resource from MHSOP and HOP, to assist in the development of the service. This time will make way for the recruited resource at Implementation.

Resourcing the Staged Implementation

In the preceding discussion we have provided the calculations of Nursing FTE through **each phase** of the Dementia Care Pathway, and separately the MDT requirements at Implementation and through Case-Load Accumulation.

Our intention is to now incorporate these together, in order to display the resourcing needed for the three funding steps: Pre-Implementation, Implementation and Case-Load Accumulation. These are discussed below, with an accompanying table summarising the resource at each step, and how much of this resource is existing and how much will need new funding.

Pre-Implementation

We believe that there should be a number of staff employed for approximately a period of one year to eighteen months, who should be tasked with preparing the ground for implementation of the service. This will include some of the following activities:

- Developing the service model to implement the Pathway
- Establishing operational guidelines
- Position descriptions created and recruiting of staff
- Developing resource material and training materials
- Agreeing documentation and templates
- Negotiating transfer of staff from current services
- Finding and securing suitable office space
- Negotiating working relationships with linked services, including Primary Health Care and AACT.

This group will continue with the service following implementation and will be critical to the smooth start to this important new service.

Pre-Implementation

We believe that this will require **3.0 FTE of new Funding**. We do not believe that these staff should be included amongst those that will move from existing services, as there will be no service provided for the first twelve months.

This will be supported by 0.4 FTE of Consultant time shared between HOP and MHSOP – which will be seconded, rather than appointed, for this step.

Implementation Resourcing

We recommend having an initial resourcing of the Dementia Care Pathway from the Triage phase to the end of the first year of the Navigators Community Ongoing care. Although this appears to over-allocate resource at Implementation, it provides the Pathway with some protection against being deluged with referrals and also allows for the team to learn how to work in this new way with people with Dementia and their families. We

also suggest that the existing resourcing of Support Groups be maintained (although this is already in place through AACT) and Psychologist supervision of these be resourced at start-up.

Implementation

The resource requirement for the Implementation step (on top of the 3.0 FTE Pre-Implementation resource) will be a total of 14.9 Nursing FTE and 3.0 other MDT FTE, a total resource of 17.9 FTE.

Given the existing resource within HOP / MHSOP / AACT (10.5 FTE), there **will be a need for an additional 7.4 FTE, of which 5.9 FTE will be Nursing and 1.5 FTE will be other MDT.**

Case Load Accumulation

The remainder of the resourcing would grow over the following four years in keeping with accumulated case-load numbers. As explained above, this is virtually all new resourcing rather than a mix of existing and new resourcing.

Case-Load Accumulation

This would amount to a growth of a further **12.1 Nursing FTE and 1.5 other MDT FTE: a total of an extra 13.6 FTE spread over the following three to four years.**

Summary of FTE Resourcing for the Dementia Care Pathway

The following table summarises the estimated resourcing for the Dementia Care Pathway through its different stages. The full resourcing for the Dementia Care Pathway is shown, as well as the contribution of existing FTEs from HOP, MHSOP and AACT. The final column shows the number of forecasted new FTE that will need to be funded in order to make the Dementia Care Pathway possible, and this is shown for each of the Implementation steps.

Table 4: Summary of Existing & Required Resourcing from the Dementia Care Pathway

Stage of Pathway	Necessary Nursing FTE	Other MDT Staffing	Existing FTE			Forecasted Extra FTE Needed
			HOP	MHSOP	AACT	
Pre-Implementation Total 1	3.0	(0.4)				3.0
Triage	4.0		2.0	1.0		1.0
Assessment	5.1		0	1.0		4.1
Community Intense	2.3		0.5	0.5	1.0	0.3
Community Ongoing – Year 1	3.5					3.5
Support groups	3.0	0.5			3.0	0.5
Other MDT –Start-up		2.5	1.5			1.0
Implementation Total 2	14.9	3.0	4.0	2.5	4.0	7.4

Stage of Pathway	Necessary Nursing FTE	Other MDT Staffing	Existing FTE			Forecasted Extra FTE Needed
			HOP	MHSOP	AACT	
Year 2	3.1		0	0	0	3.1
Year 3	2.8		0	0	0	2.8
Navigator - ARC	2.5		0	0	0	2.5
Support groups	3.7		0	0	0	3.7
Other MDT – Growth FTE		1.5				1.5
Caseload Accumulation Total 3	12.1	1.5	0	0	0	13.6

Full Pathway FTE Total 4	30.0	4.5	4.0	2.5	4.0	24.0
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Chapter 9

RISKS IN IMPLEMENTATION

This section attempts to identify some of the possible risks from implementation of a Dementia Care Pathway. Although the evidence suggests that such a Pathway would be well received and would enhance the care of those with dementia and their families, it is possible that the Pathway proposed may not meet these expectations. Some possible issues are discussed below.

The Dementia Care Pathway is overwhelmed with referrals

The creation of a new service and attendant publicity surrounding this may lead to a deluge of referrals to the Dementia Care Service. This is partly because many people with dementia living in the community are not identified formally as such in Primary Health Care. However the increased awareness about the new service may prompt a number of referrals of these cases. Both HOP and MHSOP will have high case loads of people with dementia that are being assessed and managed at the time of the implementation of the Pathway. This would amount to around six months of referrals to the Pathway. These people are likely to be referred to the Pathway on completion of this care, rather than back to Primary Health Care as is currently the case. It is also likely that referrals will be sent to the Pathway from General Hospital units and services. We have attempted to address this risk by including in our start up resourcing enough FTE to cope with a possible initial influx of referrals and the transfer of case-loads currently held in HOP and MHSOP.

The Dementia Care Pathway case loads are unrealistic

Our calculation of case-loads and FTE requirements is based on a realistic assessment of numbers of visits for each time period and numbers of working hours in the year. We have attempted to define a relatively lean and efficient service. However the Navigators (if they are not involved in the assessment process) would each carry case-loads of around 120 people with dementia and their families. This is a very high number of cases for a person to manage. The review of case managers in Holland suggested that appropriate case-loads would be around 50 – 60 people with dementia and their families. We are also familiar with the enormous variety of cases and family situations, which may involve lack of insight, rejection of diagnosis, elder abuse and dangerous behaviour, all of which may make the management of single case much more time-consuming than we have allowed for.

The Pathway has been designed such that the Navigators work is supplemented by work completed in groups, (as was the case in the Mittelman study).⁴⁶ This should help the Navigators manage their case-loads but will depend on the acceptance of group work by those with dementia and their families. The Navigators are also supported by a skilled MDT group who will be able to complete reviews of cases that are complex or challenging. We have also allowed for a 10% drop-out per year, and this is possibly an under-estimate

(although there is no evidence base to draw upon.) Complex cases, such as those involving elder abuse may be managed best in MHSOP, but this will have to be agreed. All of these factors may make the Navigators case-loads more easily managed - however there remains a risk that the case-loads of the Navigators will prove to be excessive.

Workforce recruitment and training

We believe that there will be strong interest by experienced staff in being involved in the implementation of a Dementia Care Pathway. However there are some roles such as that of Consultants or Psychologists that may be challenging to recruit into due to shortages of such staff in general. Most of workforce is likely to be recruited from existing HOP and MHSOP staff, or from those in similar roles. Most of these staff will be proficient at assessing and managing people with dementia and advising their families. However they are likely to be less familiar with tasks such as helping with Advanced Care Planning, and many will be uncertain about offering advice on funding or legal issues around application for Guardianship. Also, many staff will be less confident in advising families about managing behavioural problems. Clinical staff also tend to operate in a professional but relatively unstructured manner, whereas the role will come with some degree of making sure that a checklist of tasks is completed in all cases, but at the appropriate pace.

Many of these issues will be helped by having a strong MDT team. However there will remain a tension between having time to train new staff in these skills and needing to get staff up and running for the service. This will be especially important for those staff diverted from existing services into the Dementia Care Pathway. Those FTE cannot be “out of action” while having training for any duration, as they will have reduced the capacity in other services.

Referrals between older Peoples Health Services will be too high

It is anticipated that there will be a certain amount of transfer of care between the Dementia Care Service and the other two Older People’s services. This will certainly be a feature for those people with dementia initially dealt with by HOP or MHSOP, who will receive their ongoing care in the Pathway. There will also be some degree of movement from the Dementia Care Service into the other two services. This might occur because a person with dementia has a stroke and receives rehabilitation in one of the HOP inpatient wards. It may also occur because someone with dementia has escalating symptoms of BPSD that have not responded to the initial efforts of Pathway staff and GP. The existence of ongoing care for people with dementia and their families will ideally prevent some of these exchanges of care. However it is always a risk that having ongoing care will in itself act as a stimulus for extra episodes of care.

“The Navigators would each carry a case load of 120 people with dementia and their families.”

No alignment of infrastructure and systems

There is a risk that the three Older People's services and NASC will not be able to reconcile their documentation or computers. Transfer of care of people with dementia between the three services will inevitably occur. This will interrupt continuity of care, although if a person is under the care of the Dementia Care Service, then their Navigator will remain involved in their care even while treatment is taking place in either MHSOP or HOP. For the transfers of care to be as efficient as possible, the ideal would be that the documentation and computer systems of the three services and NASC would be similar, accessible and able to be reconciled. Given the plethora of different computer systems already in existence, there is a risk that having a further independent service will add to the complexity that already exists.

It will not be possible to co-locate services and NASC

At present HOP, NASC and MHSOP enjoy a close working relationship and are available promptly for consultation if requested by one of the other services. This working relationship is underpinned by their co-location in Building 31 at Middlemore Hospital. The proposal for the Dementia Care Service recommends that this service also join in this co-location with its sister services, to its ensure smooth operation and because the relationship with NASC, MHSOP and HOP will be one of the things that determines success. There is limited space within the building and co-location will be a challenge in the implementation of the full Dementia Care Pathway.

Contractual relationships with existing providers

The proposed Dementia Care Pathway is a significant change to current provision of the care for people with dementia. However there are implications for the existing services that provide some parts of this care at present. These services will effectively lose staff to the new Dementia Care Service and this will impact on HOP, MHSOP and AACT. The full implications of this will be further explored with the implementation phase of the Dementia Care Pathway as resources become available.

Chapter 10

SUMMARY

It is evident from our review of the literature and knowledge of the CMDHB population that there is a clear need to agree a definitive and consistent Dementia Care Pathway that reduces fragmentation of services and allows for a seamless and responsive experience for people with dementia and their families.

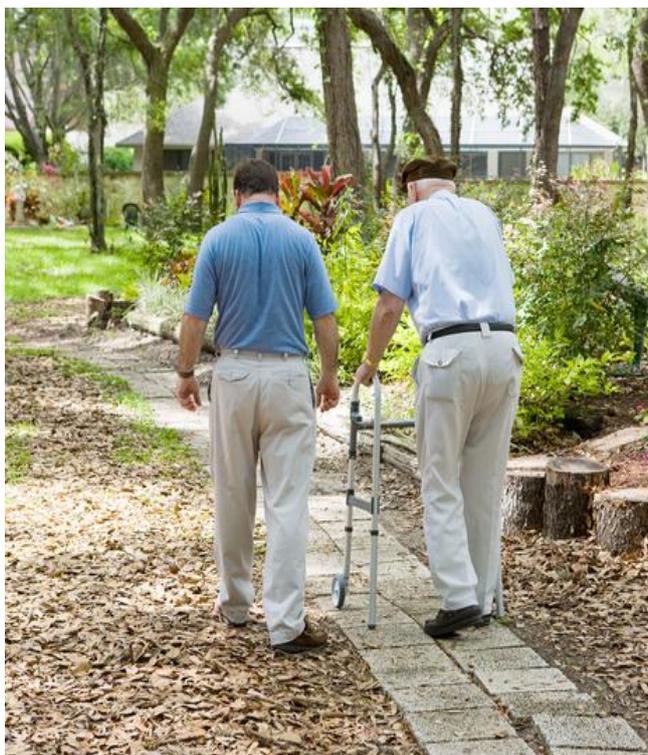
Currently people referred with dementia can be seen by either the MHSOP or HOP service, depending on presenting symptoms, but frequently end up being seen by both services over time as the illness progresses, largely due to the high risk of physical health and mental health complications. The models of care are significantly different in the two services, but both operate as

secondary care services with clients being discharged back to the care of their GP after (usually) a short period of care. Although many are also referred to Alzheimer's Auckland Charitable Trust (AACT) for follow-up, many clients do not make use of this service and the follow-up is not generally intensive.

This Dementia Care Pathway articulates our shared view that people with dementia and their families should receive ongoing care throughout the illness, and that this is more likely to produce significant improvements in care as well as potential reductions in use of Secondary Care services and Aged Residential Care (ARC).

The development of this Dementia Care Pathway is informed by international models and research, considering the national, regional and local context, as well as undertaking a comprehensive review of the numbers of clients currently accessing services and considered future growth in our rapidly ageing population. We have conducted workshops, met with key stakeholders and providers, and convened focus groups to ensure as many perspectives as possible are reflected in the Pathway.

With input and guidance from a Project Reference group made up with key stakeholder's in the sector, we have developed this Dementia Care Pathway, with the intention of ensuring a consistent approach, and access to



specialist multi-disciplinary expertise from diagnosis through clinical management, and for ongoing, supportive care to clients and families.

We have described a Dementia Care Pathway that is based on the resources and services that are currently in place, and described the increased resource requirements needed to fully implement the Pathway, reflective of the continuum of community and hospital based services as well as Primary Care.

The current population and demographic make-up of CMDHB has been considered, as well as services available in Counties Manukau for people with dementia and their families/carers. Based on this, and a review of best models of contemporary practice, we have developed a Dementia Care Pathway that describes the:

- Model of service
- Key Elements of the Pathway across the life journey in five distinct phases
- Composition of the Multi Disciplinary team (including roles, functions and estimated caseload numbers)
- Eligibility for the Dementia Care Pathway
- Estimated resourcing requirements over a five year period, and
- Outcomes and specific benefits we expect will be achieved by fully implementing the Dementia Care Pathway.

We have also recognised that it is important that any new development must be able to demonstrate cost effectiveness, in terms of increased efficiency, saving money, and providing a positive benefit to clients, their families, the broader community and service providers (across both the primary and secondary sector). By reviewing the relevant literature, we have provided clear evidence that full implementation of the Dementia Pathway will ultimately prove to be a more cost effective way of providing services in the future, with expected benefits such as:

- Delayed Admission and use of Aged Residential Care Services
- Shortened General Hospital Stays
- Reduced Inpatient Admissions
- Increased efficiency in use of clinical resources.

The Dementia Care Pathway, as we have described it, is a relatively lean and efficient service, and we acknowledge this will need to be a phased and incremental approach given the current workforce capacity issues and funding constraints.

At this point in time (June 2012), we have confirmed funding for some FTE to assist in the Pre-Implementation work for the Dementia Care Pathway.

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Appendix One

SPONSORS

Name	Role
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Deirdre Mulligan (Chair)	CMDHB	Project Manager – Dementia Pathway Project
Berta Nicoll	CMDHB	Programme Manager- Health of Older People
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Sue Thomson	CMDHB	Northern Regional Dementia Behavioural Support and Advisory Coordinator
Anne Williamson	East Health Trust PHO	ElderCare – Coordinator of services for Older People

Appendix Two

GLOSSARY OF ACRONYMS

AACT	Alzheimer's Auckland Charitable Trust (Counties Manukau Branch)
ARC	Aged Residential Care
BPSD	Behavioural or Psychological Symptoms of Dementia
CMDHB	Counties Manukau District Health Board
DHB	District Health Board
EPOA	Enduring Power of Attorney
FTE	Full Time Equivalent
GP	General Practitioner
HOP	Health of Older People
LOS	Length of Stay
MCI	Mild Cognitive Impairment
MDT	Multi-Disciplinary Team
MHSOP	Mental Health Services for Older People
NASC	Needs Assessment and Service Coordination
RANZCP	Royal Australian and New Zealand College of Psychiatrists
QoL	Quality of Life
UK	United Kingdom

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