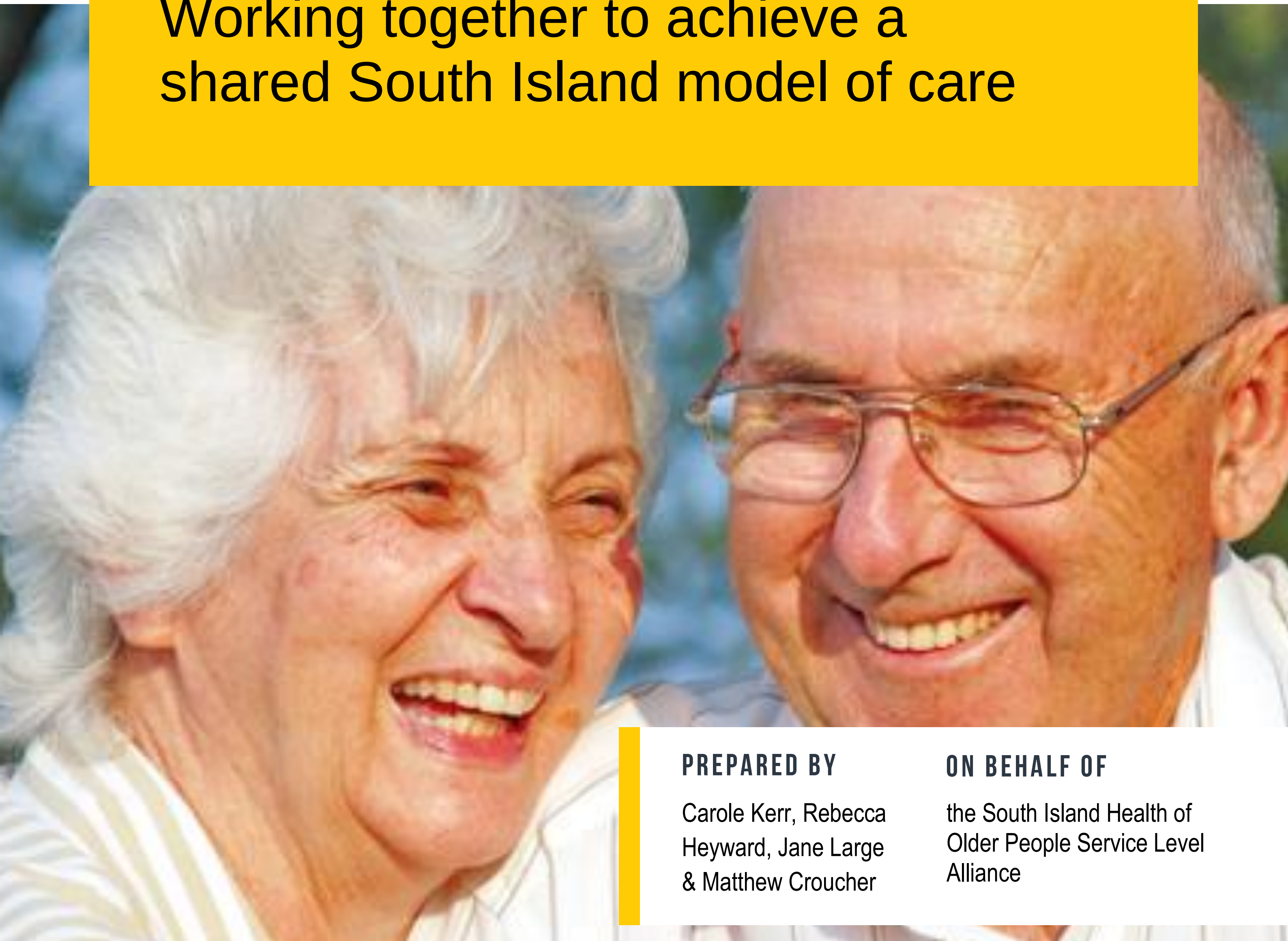
# DEMENTIA IS EVERYBODY'S BUSINESS

## Working together to achieve a shared South Island model of care



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## SOUTH ISLAND HEALTH OF OLDER PEOPLE SERVICE LEVEL ALLIANCE
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*The cultural equity section is adapted with permission from principles developed by Harold Wereta for the “Walking in Another Shoes” dementia education programme.  The authors are grateful to the South Island Alliance’s Māori advisors for their participation in writing this section.*

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## DEMENTIA IS EVERYBODY'S BUSINESS
## WORKING TOGETHER TO ACHIEVE A SHARED SOUTH ISLAND MODEL OF CARE

CHAPTER

# 1

# INTRODUCTION AND AIMS

# INTRODUCTION AND AIMS

## WHY A SOUTH ISLAND MODEL OF CARE?

***"Dementia" is the umbrella term for a family of chronic progressive neurodegenerative brain diseases that lead to significant impairments in functioning and challenging symptoms for people living with one of these conditions.***

We want people living with dementia to be supported to maintain their well-being. We want people with dementia and those that support them to receive high quality, compassionate support, with timely diagnosis, access to good information and advice, and to participate in community life without stigma. We want all people, including those from diverse communities, to receive person-centred support where people living with dementia and their care partners can express their own needs and priorities (NHS, 2013).

### WHAT ARE OUR AIMS?

This paper outlines a vision and provides a template for collaboration amongst all the South Island's dementia health services to progress towards:

- more **consistency** of access across parts of the South Island and for all groups of people;
- more **integration** amongst different service providers in each local health area;
- more **comprehensive** coverage of the whole dementia journey for people living with dementia and their care partners;
- more **person-centred** services; and
- services that continuously improve in respect of **best practice**.

### WHY IS THIS IMPORTANT?

This is essential because

- the number of people with dementia in our region is rapidly increasing
- the human and economic costs relating to dementia are very considerable at every level of the system, and
- there are pre-existing significant unmet needs in this sector.

Our system would require significant improvement even if the number of people living with dementia was not increasing more rapidly than services will be able to cope with. We cannot afford to leave our current models of care unmodified.

# WHAT IS THE CONTEXT?

***This paper will assist the South Island Health of Older People Service Level Alliance (HOPSLA), our District Health Board (DHB) Planning and Funding divisions, and private and public dementia service providers to make progress to meet the challenges outlined and the goals set by the New Zealand Framework for Dementia Care. This publication is intended to address the needs of South Island people living with dementia and the needs of their care partners at all levels of the system: from people living in their own homes supported informally by unpaid family, whānau or friends right through to people living in formal care settings with professional care staff.***

## HOW DOES THIS DOCUMENT FIT WITH NATIONAL APPROACHES?

The vision outlined in this document fits with evolving regional, national and international healthcare approaches to chronic disease in general and to dementia specifically. This document sits naturally alongside the New Zealand Healthy Ageing Strategy (2016). It also complements the New Zealand Framework for Dementia Care (2013, referred to as “the New Zealand Framework” in this document) and its companion document “Improving the lives of people with dementia” (2014). South Island health services can use the principles in these documents to help reach the government’s overarching goal of a health sector that provides the right care in the right place at the right time for all people affected by dementia.

## WHAT ABOUT THE RESOURCES?

There are significant constraints on the system’s capacity to respond at present, due to our ageing workforce and its uneven spread across the region, and to financial limits that must be recognised. The main opportunities to respond to these issues are

- to better utilise our existing human and other service resources,
- to ensure that working with people with dementia is seen to some extent as everybody’s business,
- to encourage the understanding that working in this specialist field is well-supported and satisfying, and
- to make resource and financial savings by enhancing care.

The savings that may arise from enhanced care include

- delaying entry into aged residential care,
- reducing the number and length of episodes of secondary care, and
- minimising inappropriate medical interventions for people with dementia.

It may require investment at the outset to create the change needed to realise these savings.

# A SHARED VISION

The South Island needs its health governance bodies to mandate an increasingly consistent, integrated, comprehensive, person-centred, and best-practice model for dementia services in the region. We need our DHB planners and funders and our DHB managers to facilitate and then support good service development in this clinical space. We need our service providers to identify and adopt whatever changes are appropriate for their services to further these aims. Our Regional Services Plan and DHB Annual Plans must outline the steps intended to achieve local progress as well as how they will be monitored.

This document builds a shared South Island model of care for dementia services by considering these core aims throughout the dementia journey, in light of the challenges and opportunities that South Island stakeholders have communicated to HOPSLA during our consultation process.

## SERVICES THAT ARE

### CONSISTENT

With equal access for all parts of the South Island and for all groups of people

### INTEGRATED

amongst service providers in each local health area

### COMPREHENSIVE

covering the whole dementia journey for people living with dementia and their care partners

### PERSON-CENTRED

### BEST PRACTICE

with continuous improvement

CHAPTER
2

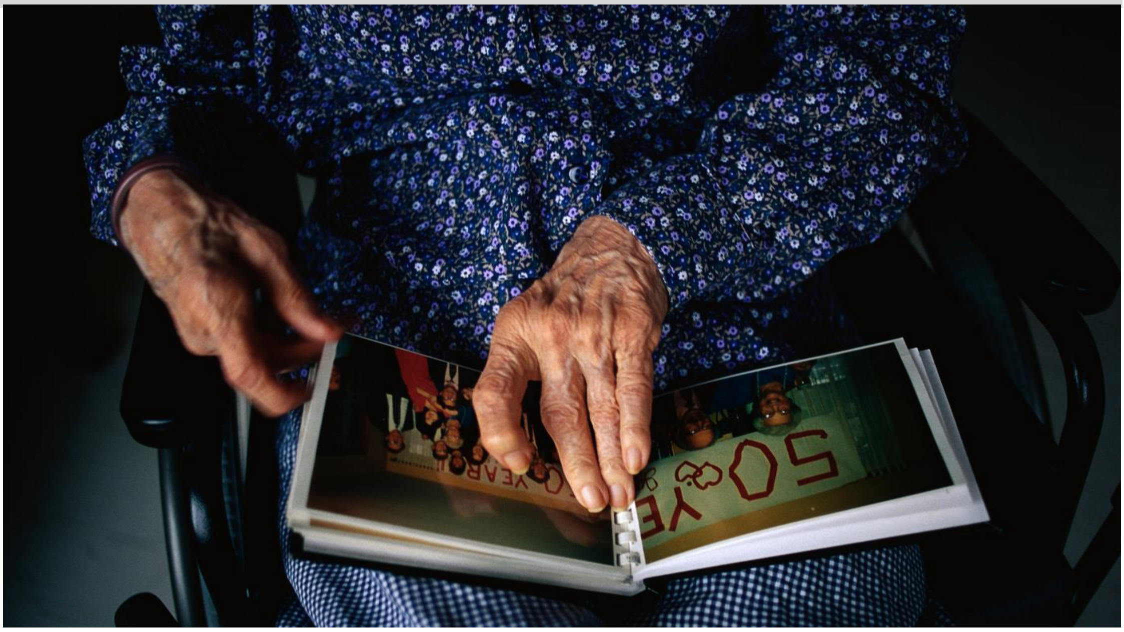
# PRINCIPLE GOALS FOR A REGIONAL MODEL OF CARE

# PRINCIPLE GOALS FOR A REGIONAL MODEL OF CARE

The purpose of this regional model of care for dementia is not to constrain or inhibit service development within the five South Island DHBs or by the many service providers in our region. Rather, the purpose is to spur on collaborative and innovative service development that aligns with the Ministry of Health's New Zealand Framework and other key guidelines, that enhances service quality, and that works towards more equitable accessibility of services for people living with dementia and their care partners across our Island. There is agreement that the current models of dementia care in our region are not yet adequate to support the highest possible standards of services for people living with dementia and their care partners.

## CONSISTENT SERVICES.

It has been noted that there is inconsistent access to primary care, disability support (including aged-residential care but also all community / home-based care and respite services), NGO, and secondary care services across the South Island between our five DHB areas, especially when comparing our rural with our urban citizens. Challenges relating to the island's geography and its uneven population distribution contribute to inconsistencies in the accessibility of dementia services. A key driver for an integrated model of care is to consider ways that our clinical and support services for people affected by dementia can respond to this challenge. There is also significant inconsistency in respect of services provided between our DHBs based on historical care and funding models, on availability of personnel and, in some cases, of equipment. For example, the threshold for and availability of timely entry into residential care is not wholly consistent around the region. Growing variability in the uptake of technologies (usually privately funded) that are emerging to assist people with dementia to live well at home may also become a significant threat to equitable care.



Another important category of inconsistency is in respect of particular groups of South Island citizens, such as between people of differing cultures living with dementia, among people affected by dementia across the whole of the socio-economic spectrum, between people with younger and older ages of dementia onset, and among people with dementia associated with differing comorbid conditions such as people with lifelong intellectual disabilities or people living with various chronic neurological conditions. Many services are good ‘fits’ for the average or typical person with dementia but ‘fit’ less well for people in one or more of these special groups.

A further important aspect of consistency is that a person with dementia, whether or not they have a diagnosis yet, should expect to receive broadly similar assessments, treatments, and information irrespective of what part of the health system they have engaged with.  Strategies to implement a dementia model of care in a consistent manner across the South Island therefore need to be agreed and implemented together to avoid widening existing disparities.

## INTEGRATED SERVICES

Integration of services and effective communication between NGO, aged-residential care, GP-based primary care, secondary care and occasionally tertiary care dementia service providers is limited.  There are also important gaps in respect of integration with social agencies outside the health sector.  A key to the successful development of a South Island dementia services model of care will be ensuring that the primary, community and specialist health and social care systems are resourced and confident to operate in an integrated way to diagnose and support people with dementia.

## COMPREHENSIVE SERVICES

As is the case in every health system, there is plenty of room in our region for improved coverage of the needs of the community and for individuals affected by dementia throughout the whole journey, from dementia prevention through diagnosis and management to dying with dementia, rather than solely emphasising timely diagnosis or the management of behavioural and psychological symptoms.  It is not only important to work towards better coverage of needs from the start to the finish but to ensure that people with dementia and their care partners receive better continuity of care from their initial presentation through to the end of life.  That continuity will usually be provided by their primary health care team supported by NGO and specialist services.  The whole health care workforce therefore needs to understand the syndrome and have skills in person-centred care planning to be able to meet the needs of people with dementia and their family / whānau / carers.

## PERSON-CENTRED CARE

There are increasing calls for a more person-centred approach from services operating in the dementia clinical space.  Reflecting this local and international trend, which is also becoming more evident in the clinical literature, the New Zealand Framework encourages services to follow a person-centred approach at all stages of the dementia journey in addition to the provision of best-practice medical care and disability-support services.

Person-centred care views people living with dementia first and foremost as persons: valued and unique individuals whose experiences must be understood and for whom considering unmet psychosocial needs is usually the most effective way of offering care (after Dawn Brooker's "VIPS" model (for example, Brooker 2007)).  This view conceptualises people in terms of their individual strengths and human needs rather than in terms of their illness-related symptoms and disability support needs. An important aspect of person-centred care is culturally safe care that enhances well-being within and because of the cultural context, not in spite of it.

Access to and engagement with the various educational and workplace systems that provide training in and support for person-centred cultures of care is not consistent around the South Island nor across the whole dementia care sector.

Another important aspect is caring for the care partners in addition to the person living with dementia.  Carer stress is thought to be the single most predictive factor for whether a person living with dementia needs to move to a higher level of care, no matter what their living situation is – from living in one's own home to living in a dementia specialist (psychogeriatric) private hospital.  Some of our services may be so weighted toward care of the person with dementia that care partners are relatively neglected.  Other services may be weighted in the reverse direction.  Our shared model of care across the island should support all services to attend to both sides of the care relationship, at least in so far as unmet needs are identified and appropriate health navigation provided.

## BEST PRACTICE SERVICES

Access to and uptake of high-quality training in and clinical and managerial support for excellent best-practice dementia care is not consistent around the South Island for informal carers (family / whanau / community), for care staff without professional qualifications, or for health professionals.  Moreover, the current traditional models of care and education are less focussed on enabling people with dementia to live well than they are on imparting information about dementia illnesses and focussing on detecting and managing dementia-related symptoms and disabilities.  In other words, education often focuses more on knowledge than on skills or attitudes, and on minimising the negative rather than on accentuating and enhancing the positive. A better balance is needed.

When services for people with dementia and their care partners are audited they are typically measured in terms of client throughput or against readily quantifiable task-oriented or medical standards such as medication audits and avoidance of harms.  On a day to day operational level, what is most frequently the focus for our dementia workforce: whether a person living with dementia may have been agitated or whether they had their shower by breakfast time, or rather what activities they enjoyed the most that morning and how they were facilitated to exercise choice over their daily schedule? Our current quality measures are important but they may not capture what matters most to South Island people affected by dementia.  Our future models of care must engage with broader definitions of best practice and novel methods to achieve and measure our progress towards them.

# A FRAMEWORK FOR DEMENTIA CARE

CHAPTER

3

# A FRAMEWORK FOR DEMENTIA CARE

The national framework lays out the stages of the dementia journey as well as the core aims within each stage that health services must work towards. It discusses key issues relating to each stage of the dementia process. Here these have been supplemented by our consultation with South Island stakeholders.

**(Adapted from the Framework)**

## AWARENESS AND RISK REDUCTION

### KEY ISSUE 1

### BUILDING KNOWLEDGE

While many of us know someone with dementia, the general public's understanding of this clinical syndrome is low. Dementia is often incorrectly understood as being a normal part of growing older rather than being due to an organic brain disease process that is not experienced by the majority of people at any age. There is a lack of awareness of the range of symptoms other than memory problems associated with dementia. What many people understand to mean 'dementia' corresponds to the later stages of the disease. The helplessness frequently associated with common concepts of advanced dementia brings with it fear and stigma which make the experience of people living with dementia even worse.

### KEY ISSUE 2

### REDUCING STIGMA.

Stigma and misunderstanding can have a devastating impact on all stages of a person's journey through dementia (World Health Organisation, 2012). Dementia care can be extremely challenging, particularly for family caregivers, so the knowledge that people with dementia can live well in the community will encourage those experiencing early signs and symptoms to come forward for diagnosis and support. It will also reduce reluctance among health practitioners to make and communicate a diagnosis. Better awareness will facilitate enhanced involvement with and support from the wider community. Giving care partners an understanding and appreciation of the situation faced by the person living with dementia will reduce fear for all involved.

Building knowledge and understanding of dementia so as to reduce stigma is therefore a key component of the creation of dementia-friendly communities and environments, especially within the health sector. Availability of good quality and culturally appropriate information covering all aspects of the dementia journey can greatly assist those with dementia and their care partners. Building knowledge and reducing stigma are essential precursors to enhancing access to the diagnostic process and for improving all other stages of the dementia journey.

## KEY ISSUE

## 3

## DEMENTIA PREVENTION

Enhancing the community's and the health system's engagement with dementia prevention is also an important goal, something that has only become clear in the last ten years and a treatment focus with which our health sector has not yet engaged. Fortunately, the key messages in respect of lifestyle factors under the control of individuals that have the most impact on dementia incidence at a population level are very similar to the key messages already being promoted in respect of diabetes, obesity, heart disease, cancer, and indeed healthy ageing. What is missing is widespread and routine promotion of these messages by every part of the health sector, a specific endorsement of their relevance to dementia, and knowledge about the dementia-specific details that are emerging.

# DIAGNOSIS AND MANAGEMENT

KEY ISSUE

1

## TIMELY DIAGNOSIS

A timely diagnosis is one that is made and communicated at a time and in a way that best matches the physical, emotional, medical, and other needs of the person with dementia and their care partners.  Timely diagnosis facilitates a better understanding of the condition and opens the door to the person-centred provision of information, supports and best-practice medical interventions that make up a comprehensive, proactive plan of care.  Once they have received a diagnosis, the person with dementia can plan for the future, fulfil short-term goals and access support services, which can delay the need for residential care (Banerjee & Wittenberg, 2009; Alzheimer's Society, 2007).  A relative weakness of the current system is that if diagnosis occurs at all, it is often late in the journey, and comprehensive management has often not been made available.

KEY ISSUE

2

## EARLY MANAGEMENT PLAN

A strong primary health care system is central to improving the timely diagnosis and care of people with dementia and support for their care partners.  Current funding models do not support GP-based primary care to easily engage with the challenges of timely diagnosis and management of dementia.  An on-going relationship with a general practice team is beneficial but this may not be optimal when it is based on opportunistic appointments initiated by patients on a self-identified and fee-for-service basis.  Not all GP clinics have sufficient clinical confidence to engage with these challenges.  Although all South Island DHBs have similar Cognitive Impairment Pathways on the Health Pathways platform, these are not identical, for example in respect of accessibility to appropriately reported neuroimaging.  These pathways are also more weighted towards supporting diagnosis than they are to facilitating a comprehensive management plan.

KEY ISSUE

3

## HEALTH NAVIGATION

All people living with dementia and their care partners also need to have a health navigator who understands local pathways of care to guide them to the right providers at the right time because the sector is complex and the journey can be long.  This is a key recommendation of the New Zealand Framework so it is discussed in a separate chapter from page 30.

# LIVING WELL WITH DEMENTIA

## KEY ISSUE 1

## MAXIMISING THE POSITIVE

It is certainly essential for people living with dementia and their care partners to be able to access best-practice, evidence-based, patient-centred medical care and to benefit from disability support services. By themselves, however, these are not enough. Such care is primarily focussed on minimising the impact of negative factors associated with dementia. The New Zealand Framework gives equal emphasis to "living well" as it does to "challenges to well-being". Health services need to maintain a hopeful and expectant focus on living well and maximising the positive, including maintaining and developing valued abilities, roles, and social connections for people with dementia and their care partners. The South Island's work to provide home-based support services with a recovery focus is important for people living with dementia but operationalising this remains challenging.

## KEY ISSUE 2

## NGO LEADERSHIP AND EFFECTIVE ADVOCACY

A strong community and voluntary sector working in partnership with properly resourced lead NGOs is central to providing access to support and social activities that allow people with dementia to live well in the community. This sector is also a key means by which people with dementia and their care partners can advocate for themselves.

# CHALLENGES TO WELLBEING

## PERSON-CENTRED CARE

Challenges to well being arise within specific contexts and often reflect unmet need. The capacity of medical or specific disability-support technologies to alleviate these challenges is imperfect. It is therefore vital that a person-centred ethos underpins analysis of and support for the individual, the environment, and care partners.

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KEY ISSUE

1

## PREVENTION AND TIMELY AMANAGEMENT

We must ensure that care partners receive appropriate information and support, that health and support workers have the knowledge and confidence to provide person-centred care, and that the care and community environments are dementia-friendly. Health services need to be confident to prevent where possible or to speedily detect and offer effective treatments for dementia-related problems that lower quality of life for people with dementia and their care partners. These needs can develop rapidly and threaten the capacity of care partners to continue providing care, which in turn can necessitate the person with dementia moving to a higher level of care. Expert responses must be available in a timely manner to prevent unnecessary personal and economic costs.

KEY ISSUE

3

## BROAD MANAGEMENT

Narrowly medicalised services or purely disability support responses are not sufficient by themselves but they are clearly important components of a harm-minimisation focus for people affected by dementia. People must be able to access skilled, often secondary care management wherever and whenever it is needed to reduce the effects of these challenges, for example by identifying and managing behavioural and psychological symptoms of dementia or by assessing dementia-related health needs and coordinating the services to mitigate them

# END OF LIFE

**KEY ISSUE**

**1**

## PLANNING AHEAD

Dementia can erode the capacity of people to clearly express their wishes in respect of care at the end of their lives. Advanced Care Planning is more challenging for people living with dementia but is arguably more important. Other aspects of planning ahead can also become very important, particularly proxy decision-making through use of Enduring Powers of Attorney or other orders covered by the Protection of Personal and Property Rights Act, and the setting up a Will. People affected by dementia need to be informed of all three of these processes and the benefits they can offer.

**KEY ISSUE**

**2**

## PALLIATIVE CARE AND AVOIDING UNNECESSARY TREATMENTS

Health services for people dying with dementia and for their care partners need to be knowledgeable and effective so that people can be well supported during this final journey. This does not just encompass formal Palliative Care services but all parts of the health sector. The number of people dying *from dementia* is noted to be increasing internationally but everyone with a dementia illness will die *with dementia* and this needs just as much knowledgeable and careful support from services. One important aspect of service development is to prevent unnecessary or burdensome medical investigations and treatments being utilised at a time when the focus should be on dying well.

## CHAPTER 4

# DEMENTIA IN THE SOUTH ISLAND

# DEMENTIA IN THE SOUTH ISLAND

There are no prevalence studies from New Zealand that enable direct estimation of the number of people living with dementia in this country. Clinical coding, InterRAI, dementia NGO registration or similar sources of information are also not reliable enough for this purpose. Therefore, dementia prevalence estimates are made by considering the characteristics of overseas study populations and carefully applying them to census data from New Zealand.

**62,287 kiwis**

**2016**

## CURRENT NUMBERS

The only readily available report estimated that there were 62,287 people living with dementia across New Zealand in 2016, a significant increase of 29 percent compared with the 2011 estimate by the same authors (Alzheimers New Zealand, 2017).

**154,000 kiwis**

**2050**

## FUTURE ESTIMATES

International projections indicate that the number of people living worldwide with dementia is set to increase rapidly to 131.5 million people by 2050 (ADI, 2015). New Zealand's projections are in line with this: 154 000 New Zealanders are predicted to be living with dementia by 2050 (Alzheimers NZ, 2017).

## AN AGEING POPULATION

The main drivers for these changes are increasing longevity and the baby-boom demographic. Although dementia is not considered to be part of normal ageing, the strongest single factor associated an increased risk of the diagnosis of dementia is increasing age.

## AN OLDER REGION

In 2013 just under 15 percent of the New Zealand population was aged 65 years and older. In the South Island however, the average was just over 15 percent of the population and in the Marlborough district over 20 percent of that population was aged over 65 (Statistics New Zealand, 2015). Therefore, the South Island is likely to have a higher prevalence and a higher rate of increase (or increased incidence) of dementia than some other parts of New Zealand.

**THE TOTAL COST** of dementia to the New Zealand health system in 2016 was estimated to be around $1.7 billion of which government funded services accounted for around $1.1 billion with productivity losses and indirect costs making up the remainder (Alzheimers New Zealand, 2016). This New Zealand cost estimate for 2016 was 75% higher than the 2011 figure, dollar for dollar, and the rate of increase in these costs per annum is also thought to be accelerating, but at a higher rate than prevalence figure. The large majority of the government costs relate to provision of subsidised residential care so it is important to note that most people living in these environments across all levels of care are thought to have a dementia, diagnosed or not (for example, Ministry of Health, 2002). Considered together, these are arresting statistics.

**DIFFERENT ETHNIC GROUPS** are experiencing different rates of population ageing. The number of people who identify as Māori aged 65 or older is predicted to increase three-fold from 2006 to 2026, whereas the growth in people who identify as European is predicted to be less than double (Statistics New Zealand, 2013). This is thought to be mainly driven by improving life expectancy of tangata whenua, hopefully redressing some aspects of the health inequalities that are a special focus for New Zealand health and social services. Asian and Pasifika elders will also increase in number following significantly different trends compared with the European majorities in each South Island DHB area. It must be noted that the prevalence of dementia among Māori and other ethnic groups is not known and may not be the same as the rate for the general population.

**OTHER SPECIAL POPULATION GROUPS** include people with younger-onset dementia, people with intellectual disabilities and dementia, refugees and migrants with dementia, and people with chronic major mental illness and/or various neurological conditions who may develop dementia. The prevalence of dementia in these source populations is largely unknown but is not expected to be the same as the prevalence in the general population, rather, it is usually higher and sometimes substantially so.

***It is important for a South Island Model of Care for Dementia to address and cater to the needs of the whole population and not simply for the majority of current 'typical' services users***.

# VOICES

CHAPTER

5

# VOICES

## THE GAP

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Some comments from South Island people illuminate how far we may have to go:

### JANE, A PERSON WITH DEMENTIA

*"Four people came to see me today from the hospital … I didn't know who they were but they kept on coming … and they all brought different things and told me different information … I still don't remember their names even."*

### DENISE, WIFE OF A PERSON WITH DEMENTIA

*"My husband was only 52 when he was diagnosed with dementia. We have a young family and I was working full time. Because I was working full time, I was ineligible for carer support … he needed someone with him during the day but he felt too young to attend the available day programmes."*

### DANIEL, SON OF A PERSON WITH DEMENTIA

*"My mum was admitted to hospital three times, and on the third time, her discharge summary said she had 'Dementia - probable Alzheimers type' … no one had told me this and no one told me what this meant … we saw this happening, but wish it had been explained in more depth and also wish it was picked up on one of the first two admissions, because the third could have been avoided."*

### HEATHER, WIFE OF A PERSON WITH DEMENTIA

*"It took us five years to get a diagnosis of dementia for my husband and the whole time it felt like we were pushing and pushing."*

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### LYNDA, SISTER OF A PERSON WITH DEMENTIA

*"Why can't you organise for him to live in a Rest Home in his [rural] home town? He'd be much happier and the staff would have far fewer problems if he could live where he knows everyone, where he feels like he belongs."*

### JUDY, CLINICAL ASSESSOR

*"I have had a couple of cases lately where the client and family have been severely disadvantaged by the GP diagnosing dementia but not doing anything further. These clients are presenting with moderate to severe levels of dementia without having good knowledge about dementia or the supports of the local dementia organisation made available to them, no knowledge of EPOA and it is too late by the time we see them, no information about dementia and driving, and no referral for early needs assessment or knowledge about what home supports are available. By the time we see them, the family are ready to pull the plug, the person goes straight into care…*

# THE POSITIVE

In contrast, these quotes from South Island sources illustrate how well things can work:

### PAUL, A PERSON LIVING WITH DEMENTIA

*“Since my diagnosis there has been lots of support and help from the local Alzheimer’s organisation. When my GP started the process I didn’t know what having Alzheimer’s was. The process was clear and supportive. The Alzheimer’s organisation has made me feel secure. It is great to be with others on the same journey and my wife feels the same. When there is tension at home we can ring up and talk to someone.”*

### JIM, A PERSON LIVING WITH DEMENTIA

*“I think the earlier [a diagnosis of dementia] can happen the better … it means the more information we have and that we can prepare better for the future. If I had one piece of advice I could give to my doctor … timely diagnosis would be it. Because it certainly helped me.”*

### JULIA, HOUSE SURGEON IN DISCHARGE LETTER

*“Known diagnosis of dementia prior to admission. .. During admission noted to have problems with executive functioning including - word finding difficulties, poor memory recall (both short and long term memory), poor orientation to person, place and time, poor problem solving techniques, and [problems with] task initiation, information repetition and psycho-motor agitation. These signs are all consistent with progression of her dementia.”*

CHAPTER

6

# CULTURAL EQUITY: MĀORI AND OTHER CULTURES

# CULTURAL EQUITY: MĀORI AND OTHER CULTURES

Health services are already making progress in partnership with tangata whenua to recognise their responsibilities under Te Tiriti o Waitangi. This means offering collaborative services in a manner that protects and promotes the health-related strengths of Māori whilst recognising and providing appropriate services to enable Māori to meet their illness and disability-related needs. Likewise, the health and social support sectors need to work in partnership with Māori to develop health and social supports that can meet the needs of Māori living with dementia and their whānau in a culturally appropriate way.

Dementia may not be considered by whānau but may be normalised as a normal part of ageing or seen as an inevitable consequence of other aspects of poor health. There are certainly strengths to a cultural approach that seeks to maintain personhood and avoid the stigmatisation and negative features of medicalisation. On the other hand, timely but culturally appropriate diagnosis is considered best practice because it opens the door to the individual and their whānau to consider alternative ways of understanding what is happening, to make unhurried and considered plans for the future, and to secure supports predicated on a diagnosis of dementia when needed, including accessing dementia NGO services, dementia-specialty aged residential or secondary care, and dementia-specific medical treatments.

## THE FOLLOWING PRINCIPLES SHOULD BE CONSIDERED WHEN PLANNING SERVICES WITH AND FOR MĀORI:

### WHANAUNGATANGA

Services must take time to build a relationship with whānau. By having this, you then have a connection which will make service delivery easier.

### MŌHIOTANGA

Research shows that good communication is essential. This means being able to explain a condition and the types of services available, including their limits, so that whānau are well informed.

### AROHA

Relating to dementia services development and delivery, this concept is about planning and being seen to put the needs of others first.

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### KOTAHITANGA

A joint vision of care with whānau will improve the planning and delivery of services. It also means each person and their whānau are seen as unique and are being valued as such.

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### KAITIAKITANGA

This is about service leadership and mutual respect. Professional health services are respected for their expertise within their tikanga. It is expected that they will know best how to support and manage what is happening from their perspective, however this will be done in partnership with the person with dementia and their whānau.

### KOTAHITANGA

This means ensuring care plans and wider service performance are reviewed so that there is ongoing improvement and that the focus of meeting the needs of Māori living with dementia and their whānau is continuously maintained.

## RANGATIRATANGA

Whānau need to feel they have an appropriate level of control of the situation and the service therefore needs to demonstrate that it can work respectfully with whānau to get the best outcomes in a culturally safe way. All important decisions, whether clinical or non-clinical should ideally be made with whānau. This reduces any tensions or stresses that may arise.

## MANAAKITANGA

Responsive care and support is key. This also means being realistic - we can only confidently deliver what we specialise in. If there are limits then work with whānau to engage other services (for example accessing expertise to communicate in Te Reo Māori, to interpret possible cultural manifestations of illness, or to navigate protocol for hui and other aspects of Te Ao Māori). This demonstrates that the provider is seeking to do its best for the person with dementia and their whanau.

Naturally, there is a need to have an understanding of the diversity within and across all other ethnic populations who live in the South Island and who may have invested their own sense of nationhood in New Zealand. We are an increasingly ethnically diverse community with multi-cultural aspirations in addition to the special bicultural Treaty obligations we acknowledge. Therefore, there is a parallel need to develop reciprocal and respectful relationships across and within other ethnic populations: everyone is affected by dementia. This should include a focus on Pasifika and Asian populations as the two other largest ethnic groupings in the South Island, recognising that these cultural headings encompass significant diversity in themselves, as well as focussing on other ethnicities based in our health areas. The very special needs of refugees and migrants living with dementia also need to be considered, especially those who have recently moved to New Zealand and those who have left their home countries under threatening circumstances.

CHAPTER

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# HEALTH NAVIGATION FOR PEOPLE AFFECTED BY DEMENTIA

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***By definition, a navigator assists a traveller on their journey by helping them to know where they are and to plan a route to enable them to get to where they want to be. Health navigation has been defined in various ways, typically combining features of case management such as individualised care, a personal relationship, accessibility and clinical expertise with knowledge of the wider health system and a trusted ability to advocate for the client within it.***

**THE ROLE** of Health Navigator within the New Zealand Framework is understood to be held by someone within the person with dementia's care team who has an overview of all dementia-related health and social support services available to the person and their care partners. The navigator is envisaged to be responsible for providing advice, assisting with self-management, explaining local care pathways and options, and also for coordinating referrals, enhancing access, and facilitating transitions between services. They provide an important point of continuity and both the person with dementia and their significant others know who they are and how to contact them. The navigator role can shift during the course of the dementia journey but there must always be an identified navigator.

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**IN THE DEMENTIA SPACE**, health navigation functions are currently carried out to varying degrees by General Practices, by Dementia NGOs, by DHB secondary care teams, and by care coordinators of various kinds. It is agreed that rather than create a specific dementia health navigator role as has been attempted in some other jurisdictions, in the South Island our approach will be to clearly identify a health navigator for each person living with dementia at every stage of their journey, and to ensure that each person and their key care partners are aware who their navigator is and how to contact them. It is recognised that this navigator must be the individual and/or service best equipped to fulfil this role at each particular phase of the person with dementia's journey.

## FILLING THE NAVIGATOR ROLE

For people actively being case-managed by a secondary care specialist team in respect of their dementia, the dementia health navigation role is likely to be best fulfilled by the case manager.  For the small number of people actively managed by a complex case clinician of some kind, for example by a primary care-funded clinical nurse specialist, the dementia health navigation role is likely to be best managed by them.  For all other people, it is likely that the General Practitioner or a clinician within the local dementia-specific NGO is likely to be the best person. In all these cases, there are likely to be knowledge gaps that need to be addressed for dementia health navigation to operate more effectively in the South Island.

There is a balance to be struck between longitudinal and comprehensive knowledge of the person with dementia and their supports (often held by the general practice) and detailed knowledge of the services available to people affected by dementia (often held by the dementia-specific NGO).  The national framework suggests collaborative health navigation is a possible solution.

## MOVING FORWARD

This model of care document does not prescribe a universal approach to this need but it does firmly endorse the New Zealand Framework's definition of dementia health navigation, the requirement for all people affected by dementia to know who their navigator is at all stages of the journey, and the need for navigators to improve their skills and knowledge.  Rising to this challenge should form part of each DHB's next responses to the New Zealand Framework.

# KEY ELEMENTS OF A SHARED SOUTH ISLAND MODEL OF CARE FOR DEMENTIA

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# KEY ELEMENTS OF A SHARED SOUTH ISLAND MODEL OF CARE FOR DEMENTIA

Planning the future direction for each DHB's model of care for people affected by dementia, each service provider's model of care, and indeed for the South Island's shared model of care must pick up speed and energy now. Given the current level of unmet need in relation to dementia and the predicted growth of that need on a population level, if service provision as a whole in ten years' time is being provided and organised in a manner that is substantially similar to current models then we will have failed.

The most important ideas for each DHB and each service to work towards in the first instance have been enunciated by stakeholders during the preparation of this document. The status of these ideas is not absolute. They are not directives. However, they do allow stakeholders' voices to be heard as to the most highly prioritised methods that the region, DHBs and individual services should consider when reviewing their response to this document.

1. All people affected by dementia should have effective access to a health navigator in respect of their dementia journey.

2. All services for people living with dementia should work towards improved cultural responsiveness, especially for Māori.

3. All services should attend to the challenge of providing not only best practice medicalised and disability support care, but more person-centred care for people living with dementia and for their care partners

4. Specific service improvements and new initiatives within our improving models of care should incorporate the goals of increasing social connectedness and social capital for people living with dementia and for their care partners.

5. Specialist services need to ensure special patient groups receive the best possible access to the most appropriate services irrespective of where they live and where they present for assistance.

6. People living with dementia have an increased risk of delirium and should be targeted for efforts to improve prevention, timely detection, and effective management of this syndrome.

**7**

Strategic work to develop the existing South Island dementia workforce's capacity, knowledge, skills, and attitudes is an important and increasingly pressing need. This will require liaison with national and regional bodies such as the New Zealand Qualifications Authority, Careerforce, Te Pou, the South Island Workforce Development Hub, education providers including professional colleges, and employers.

**8**

Health professionals working in the dementia space should be enabled to operate to the fullest potential within their scopes of practice and in new ways that enhance dementia services. There is particular scope to consider how nurse specialist and nurse practitioner roles might enhance the operationalisation of enhanced models of care.

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A strong emphasis on dementia prevention by altering health behaviours should become a consistent and routine message within all health services, and partnerships should be made with agencies already promoting healthy lifestyles.

**10**

Future treatment options need to be carefully monitored as they become available internationally, and the South Island needs to carefully invest in local 'proofs of concept' and trials of new care options that have the potential to improve service provision in the face of increasing need but limited resources.  A commitment to shared investment may be more successful than investment in siloes.

**11**

A commitment to a shared approach to monitoring engagement with new models of care and with the outcomes of both old and new service initiatives needs to be embraced.  Particular measures of importance should include delayed entry into aged residential care at each level, reduced carer stress and reduced use of inappropriate treatments.

**12**

NGOs and community organisations, particularly the dementia-specific NGOs, should be integrated into the diagnostic and initial management planning process at the earliest stage as a matter of course, in primary and secondary care. Taking the role of these partner organisations more seriously will also mean that their funding support by DHBs must be realistic.

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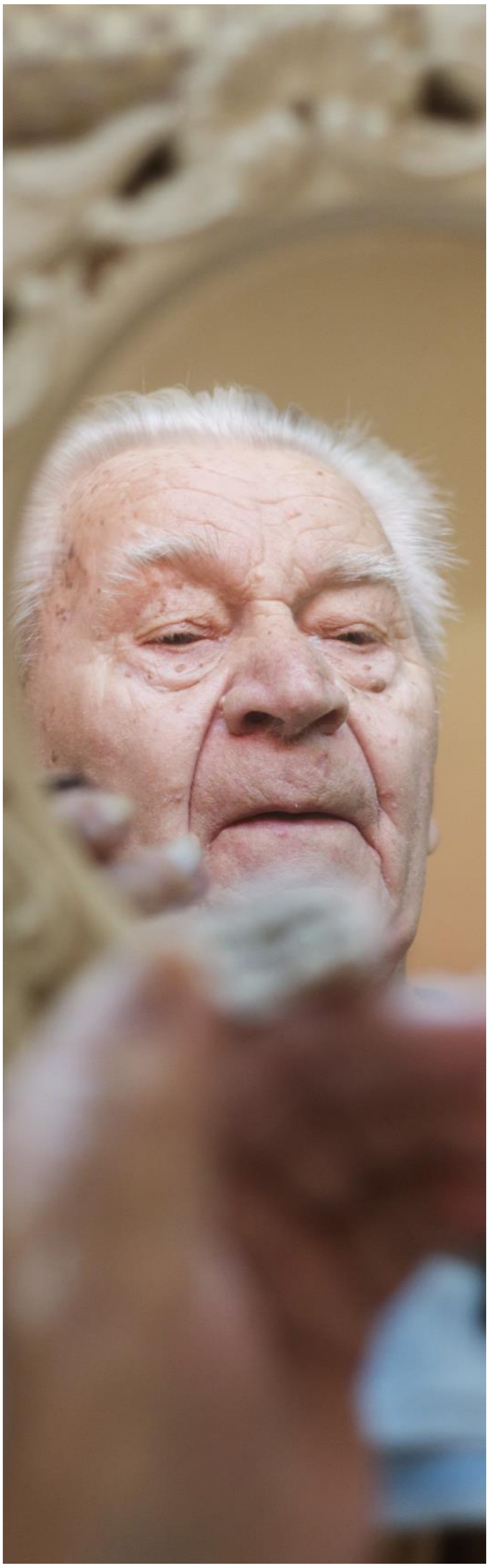

**13**

Discharge planning and discharge communication from all secondary care services should always specifically note and account for dementia when it has been diagnosed and advise appropriate steps to diagnose it when it is deemed likely to be present.

**14**

Primary care teams need to be meaningfully supported to carry out what is clearly an increased role in the dementia care system. A lack of knowledge, resources, and confidence have been identified as barriers to general practice engagement with dementia care. There are challenges that need to be addressed by primary care itself, by funding models and by the support available to primary care from NGOs, secondary care, and other relevant organisations.

**15**

Each DHB and all relevant services should attend to the end of life phase when considering enhancements of their care pathways, especially in relation to the Advanced Care Plan initiative in the South Island and to the role of Palliative Care services assisting the health system to care better for people dying with and dying from dementia.

**16**

Consistency in respect of the dementia / cognitive impairment health pathways used across the South Island needs on-going attention to reduce existing and possible future gaps between DHBs.

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# DEMENTIA IS EVERYBODY’S BUSINESS

# DEMENTIA IS EVERBODY'S BUSINESS

## WORKING TOGETHER TO ACHIEVE A SHARED SOUTH ISLAND MODEL OF CARE

The national framework sets out the key areas of focus within the dementia journey. This shared model of care enunciates our key goals in those areas of focus and enunciates the main current challenges and opportunities that have already been identified, and the priority areas for early consideration as articulated by stakeholders.

## FACILITATION

The South Island has an existing structure for the facilitation of regional and local dementia service development under the banner of the South Island Dementia Initiative. Since the creation of the South Island Alliance and the publication of the New Zealand Framework, this is now under the governance of the Health of Older People Service Level Alliance on behalf of the sector. This South Island structure provides the initial means by which we can move towards the shared model of care described in this document.

The Health of Older People Service Level Alliance will continue to guide the sector's attention to a few specific goals each year within the dementia space and inform the Regional Services Plan – which in turn helps to inform our DHB annual plans. The main current foci are primary care dementia education and person-centred dementia care education. Current HOPSLA goals with important overlap with dementia relate to advanced care planning and delirium. Promoting DHB attention to a health navigation function for people affected by dementia integrated with wider health navigation needs has been identified as a key new focus in our region.

The South Island Dementia Initiative will continue to host regular regional meetings between the five DHB stakeholder groups to share successful initiatives from our region and to encourage further service development. These meetings will also serve as one method that HOPSLA can use to assess progress and thus inform future Regional Service Planning. In addition, it is here that progress from each DHB will be reported twice each year.

The South Island Dementia Initiative will monitor developments outside our region to ensure they quickly reach our stakeholders for consideration, and it will provide an advisory bridge between clinical and academic leadership in this area and HOPSLA. The South Island Dementia Initiative will also serve as a resource to assist DHBs and, if practical, individual services when questions arise about best practice, outcomes measurement, and new knowledge.

# A SHARED VISION

## AIMS

The overarching framework for the HOPSLA’s monitoring will be to ensure that across the region we are steadily improving in respect of our core aims:

- more **consistency** of access across parts of the South Island and for all groups of people;
- more **integration** between different service providers in each local health area;
- more **comprehensive** coverage of the whole dementia journey for people living with dementia and their care partners;
- more **person-centred** services; and
- services that continuously improve in respect of **best practice**.

## SCOPE

These aims need to be applied at every stage of the dementia journey:

- awareness and risk reduction;
- assessment, diagnosis, early intervention and on-going support;
- living well with dementia;
- addressing challenges to maximise well-being; and
- the end of life.

## NEXT STEPS FOR DHBS

Each DHB is expected to maintain its own dementia stakeholder group whose purpose is to provide a local platform for all dementia service providers and funders to meet together to work on continuously improving dementia services in the DHB’s area. Service users must be increasingly represented in this process in the most appropriate and effective way. These groups must now consider this model of care document, determine what the next steps will be in their own area, including timelines and proposed monitoring, and report these to HOPSLA.

Once detailed local DHB plans are submitted, HOPSLA will provide guidance about ongoing monitoring strategies so that shared communication is possible between DHBs.

# PLANNING TOOL FOR SOUTH ISLAND DEMENTIA MODEL OF CARE: MATRIX OF AREAS TO CONSIDER

| NEW ZEALAND FRAMEWORK KEY AREAS | WHOLE COMMUNITY | GP BASED PRIMARY CARE | OLDER PERSONS HEALTH SECTOR INCLUDING ARC, HBSS AND NGOS | SPECIALIST OLDER PERSONS HEALTH SERVICES |
|---|---|---|---|---|
| **Awareness and risk reduction** | | | | |
| **Diagnosis and management planning** | | | | |
| **Living well with dementia** | | | | |
| **Challenges to wellbeing** | | | | |
| **End of life** | | | | |

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