

Out of the Shadows

The Development of a Best Practice Model of
Care for People Living with Dementia

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1 Introduction

1.1 Background

1.1.1 Caring for People with Dementia in the Community

Twins Katherine and Adelaide shared 81 years of memories. Neither had children, but both married after the war and they lived in the same street and saw each other every day. Adelaide died 6 months ago from chronic heart failure. When Adelaide's health declined, Katherine took over heavy jobs like carrying the groceries and vacuuming. In return Adelaide started cooking the meals and doing the banking.

Now that Adelaide is gone, Katherine doesn't feel confident driving to the shops on her own, and she realises she's forgotten how to do a lot of jobs since Adelaide had started doing them. She cries often because she feels alone and helpless. Now that Adelaide's not making out the shopping list anymore, Katherine struggles with it. She has to be very careful not to get her blood pressure tablets and her sleeping tablets mixed up. Katherine's doctor referred her to RDNS to ensure she takes her medication safely.

Katherine dreads visitors now. She's suddenly realised that she can't think of the people's names or even the names of things, and that Adelaide used to 'fill the gaps' for her. Katherine realises her memory is failing and she has no-one to talk to about it.

The above story highlights some of the issues facing people living with a cognitive impairment in the community. District nurses see clients like Katherine every day. Assisting clients to take their medications safely is a very common reason for referral however the identification of a cognitive impairment and related issues can prove to be a challenge for the nurse and other health professionals. The Out of the Shadows Project aimed to address some of these challenges.

Dementia is a progressive illness associated with decline in cognitive abilities such as thinking, remembering and learning (Kitwood, 2005). In the earlier stages of the disease, people with dementia may experience difficulties in undertaking routine tasks (e.g. shopping, driving), however, as the disease progresses, difficulties in daily living activities such as self-care, bathing, and eating become evident. Other common symptoms of dementia involve psychological and behavioural changes. These may include communication difficulties, confusion, disorientation, personality and behaviour changes, depression, delusions, apathy and withdrawal (Australian Institute of Health and Welfare, 2007).

In Australia, about 7% of people over 65 years are estimated to have dementia and, after the age of 65 years, the incidence doubles with every 5 year increase in age. Over 20% of people aged 85 years and over have dementia (Access Economics Pty Ltd, 2005; Australian Institute of Health and Welfare, 2007). In 2005, the number of Australians with dementia exceeded 200,000 (about 1% of the population). Dementia results in much greater loss to 'years of healthy life' than years of life lost through premature mortality. Disability associated with dementia accounts for three quarters of the total burden of disease. The rapid growth in the number of older people in Australia is expected to be accompanied by an equally rapid growth in the number of older people with dementia. By 2030, it is estimated that 591,000

Australians will have dementia and, in 2050, this figure will exceed 1.1 million (Access Economics Pty Ltd, 2009).

A major concern associated with the increased rate of dementia is the subsequent increased demand for medical care, community care, residential care and other support services. In 2003/04, the total hospital patient expenditure for dementia in Australia was 150.5 million dollars, and out-of-hospital medical services totalled 19.5 million dollars. The costs for residential care are also quite significant, with one analysis finding that dementia is the most expensive “condition group” in Australia (Australian Institute of Health and Welfare, 2007). Risk of entry into residential care is increased in those with dementia, especially those without access to a carer (Australian Institute of Health and Welfare, 2007).

In 2006, the Federal government declared dementia to be a national health priority envisioning ‘... better quality of life for people living with dementia and their carers and families’. The objective of the policy is to achieve “accessible, seamless pathway for people with dementia, their carers and families” through the health care system (Australian Health Ministers Conference, 2006).

The Victorian Government identifies, in their Dementia Framework Implementation Plan 2006-08, that health and community services providing home support, health care and social support for frail aged people and their carers, need to provide strategies to: identify and promote the best ways to assist people with dementia, and their families to navigate the community care system as well as promoting the provision of early support to people with dementia and their carers. The Victorian Government recognised the preference of older people to remain at home as well as the projected growth in the aged population over the next twenty years (Victorian Government Department of Human Services, 2008). Within the health and community care framework, district nursing is an essential HACC service enabling many frail older adults to remain at home through the focus on restorative care and independence, both principles of the Victorian HACC Active Service Model (Victorian Government Department of Human Services, 2008). Community nursing organisations are central to this move in enabling frail older people to stay at home (Nay & Garratt, 2004).

1.1.2 The role of district nurses in dementia care

When scrutinizing the role of district nurses in the care of people with dementia in the community, it is important to appreciate the magnitude of skills and knowledge required to respond to each individual client referred for a service. District nurses are registered nurses who have the ability to provide generalist care to their clients. These interventions commonly include wound care, continence care, diabetes management, medication management, palliative care and monitoring of health and wellbeing (Annells, 2004). However, district nursing is not just about completion of a distinct task for a client. It includes comprehensive holistic assessment and care in both the clinical and social aspects of client needs. Health promotion and education are frequently undertaken to facilitate independence. The provision of complex care is organised and delivered to each client in their home on an individual basis through case management by the district nurse, who in turn must also ensure that liaison occurs across service systems from acute to primary care.

When working specifically with a client who has dementia, the district nurse will need to draw from their knowledge of medical and community service providers available in the locality (Nay & Garratt, 2004). The district nurse regularly works in partnership with a multi-disciplinary team of General Practitioners, Aged Care Assessment Services, Cognitive Dementia Assessment Memory Service, Case Managers, Home and Community Care services, carers and families. District nurses also need to be experienced with advocacy and

communication skills to support the client and their carers to ensure that they receive the care they require.

District nurses are often the first health professional to notice changes in a client's behaviours and cognitive state and the first health professional with whom clients may discuss their fears of memory loss (Manthorpe & Iliffe, 2007). As Manthorpe & Iliffe (2007) state:

“In our view community nurses offer something that is possibly unique to the person with suspected dementia: they may have a previous trusting relationship, they know the person in their home setting and they can respond to but mainly listen to the person's question and concerns. This is a position of great influence.” (p.76)

Thus, district nurses have the potential to not only focus on the nursing task at hand but provide holistic quality nursing care and assessment to determine the presence of any suspected cognitive deficits. By working with the client throughout the dementia recognition process, the district nurse can provide continuity of care which is essential to the client (Manthorpe & Iliffe, 2007).

As described earlier, the person with dementia may require high levels of care, much of which is supplied by the informal carer. District nurses have the potential to play a vital role in the support of the family carer. A report by the Australian Institute of Health and Welfare (AIHW) (Australian Institute of Health and Welfare, 2007) identified disability, ageing and carers conducted in 2003, that there were over 25,000 people living with dementia in the community receiving informal care and over 35,000 resident or non-resident carers of people with dementia.

Carers need support from the community health care system, including district nurses, to assist the person they are caring for at home. It is important for formal service providers to recognise the primary informal carer and the extent of the care that they provide to support the person with dementia at home. Through this engagement with the primary informal carer, it becomes possible to identify what support and services are required to supplement the family care, particularly when high levels of care needs have been identified (Australian Institute of Health and Welfare, 2006).

Working with carers and families requires communication skills such as listening, empathy, compassion and counselling. Challenger & Hardy (1998) identified that carers greatest need from district nurses was information about what to expect with a diagnosis of dementia and what community services were available to help them. Goodman (2000) acknowledges that an experienced district nurse has the ability to ensure that clients and carers are aware of and receive all available and appropriate community services.

1.1.3 The Out of the Shadows Project

Royal District Nursing Service (RDNS) is the oldest and largest home nursing service in Victoria, founded in 1885 to provide skilled nursing to the disadvantaged living in the city of Melbourne. Each year, RDNS provides care to approximately 30,000 clients. Although RDNS provides a service to people across their lifespan, the majority of clients are frail older people with approximately 70% aged over 65 years.

Prior to the commencement of the Out of the Shadows project, data from the RDNS client database for the year 2004/05 revealed that 7.8% of clients had a medical diagnosis of dementia. Yet, experienced aged care nurses at RDNS had perceived the real prevalence of this condition to be much higher. Early identification of dementia might prevent or forestall ongoing problems associated with the condition and, for the families, provide greater

knowledge and support. Early diagnosis enables interventions to be put in place before the client's condition degenerates significantly or the family situation breaks down.

The first submission to the J.O. and J.R. Wicking Trust¹ resulted in a generous grant in late 2005 to fund the first year (Phase 1) of a proposed three year project to develop a best practice district nursing program for people living with dementia (see Figure 1-1).

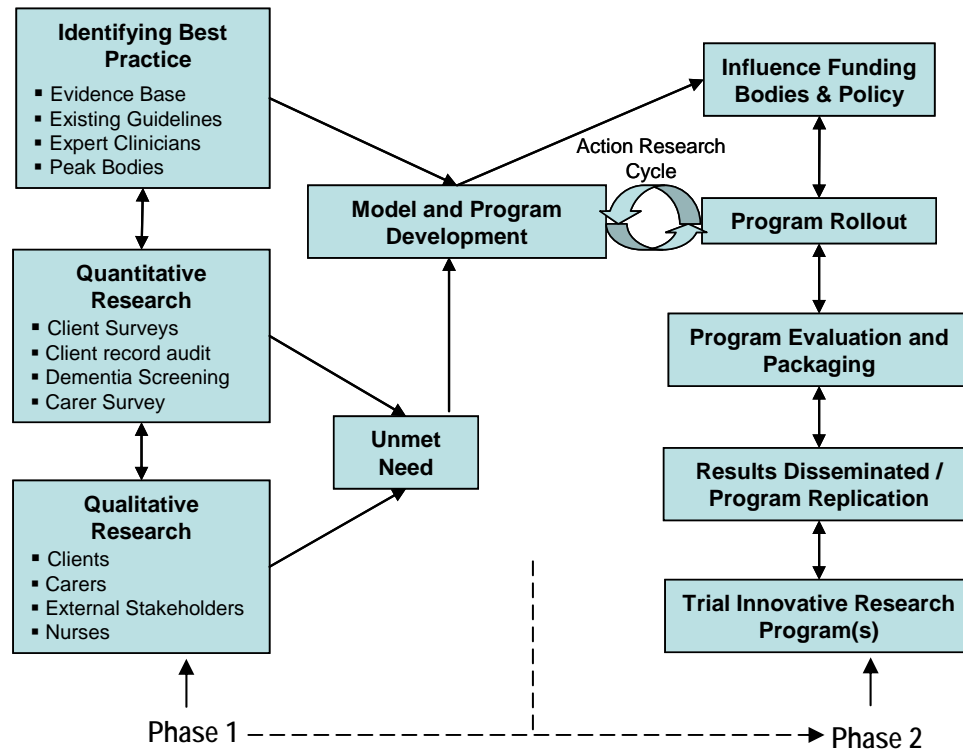


Figure 1-1 Best Practice Dementia Program Development

The aims of Phase 1 were:

1. To determine the prevalence of dementia and cognitive impairment among district nursing clients and describe the characteristics of this client group; and
2. To identify areas of unmet need in relation to the provision of district nursing care for people with dementia

In this first phase of the project, a survey identified the prevalence of cognitive impairment in older RDNS clients and quantitative and qualitative surveys described the needs of clients, their carers, nurses and external service providers (Nunn, Gliddon, While, & Sims, 2008).

The prevalence survey showed:

- Based on the report of nursing staff, 32.6% of older clients had problems with memory loss, 29.4% exhibit signs of confusion and 22.3% had a confirmed medical

¹ The J.O. & J.R. Wicking Trust is a philanthropic trust managed by ANZ Trustees that seeks to achieve systematic improvements through enduring, positive impact in the areas of care of the aged, problems associated with ageing, Alzheimer's disease, and benefits for the visually impaired.

diagnosis of dementia

- Over half of all clients with a cognitive impairment were referred to RDNS for assistance with medication management (53.4%)
- Almost one fifth (19.5%) of clients with a diagnosis of dementia had a primary language other than English
- Forty percent of clients with a diagnosis of dementia lived alone and 23.2% lived alone and do not have a carer
- Assessment and care practices of clients with dementia was often ‘task focused’, with a primary focus on the specific reason for the client’s referral

Reports from nurses showed:

- There is considerable variation among nurses’ skill and knowledge in relation to dementia care
- The availability of specialist Aged Care Clinical Nurse Consultants may result in improvements to care provision for clients with dementia
- Dementia-focused care should be a core competency of all district nurses involved in clinical care, including accurate use and interpretation of the dementia screening tools
- Early identification of cognitive impairment could benefit clients by enabling them to participate more fully in their own plan of care, obtaining relevant information supports and services, gain valuable current medical intervention and treatment and planning to avert crises
- There are difficulties referring to external services for clients with dementia and in relation to RDNS receiving referrals from other providers which results in the client’s needs not always being adequately addressed

The above suggests that district nurses are in a unique and significant position to identify, assess and support people with dementia and their families living at home. With district nurses being at the forefront of recognising the signs and symptoms of dementia, a comprehensive Model of Care that encompasses a holistic approach for the persons with dementia and their carers is invaluable to improving quality nursing care. The Out of the Shadows project aims to achieve this to improve the quality of life of people with dementia living in the community.

In 2006, RDNS received further funding from the J.O. & J.R. Wicking Trust to undertake Phase 2 of the project. The aims of Phase 2 were to:

1. Develop a best practice Model of Care designed to support the needs of district nursing clients with dementia, their families and carers incorporating screening, assessment, management and referral processes
2. Implement and conduct an evaluation of the dementia Model of Care

This report details the work undertaken in Phase 2. In Chapter 2, the process of developing the dementia Model of Care is described. Chapter 3 describes the methodology and findings of the evaluation of the Model. Finally, in Chapter 4, the results are summarised and recommendations made relating to the future implementation and sustainability of the Model.

2 Development of the Dementia Model of Care

2.1 Theoretical framework

In recent years, many frameworks have been developed to promote a better understanding of dementia care. The National Ageing Research Institute (NARI) found that the dominant premise of these frameworks was a partnership between the service provider and service user, based on a collaborative and respectful relationship (2006). Within this partnership the following principles apply:

- Both holistic and individual approaches are required to know the client as the person;
- Power and responsibility of health care decisions and information giving are shared;
- Service provider and individual staff provide an accessible and flexible service;
- Coordination and integration of care is considered from the experience of the client; and
- The service environment is easily accessible to clients and staff are supported to work in a person-centred approach.

(National Ageing Research Institute, 2006, p. 1)

Two person-centred care frameworks reflecting the above principles provided the foundations for this dementia Model of Care: the Senses Framework (Nolan, Davies, & Brown, 2006) and the Person-Centred Nursing Framework (McCormack & McCance, 2006).

The Senses Framework (Nolan, et al., 2006) provides a practical application inherent in caring for a person living with dementia. This framework harnesses the interpersonal skills district nurses utilise on a daily basis to develop and sustain interpersonal relationships in the caring environment (Queen's Nursing Institute, 2009). Through the nurses collaborative working methods, the myriad of relationships involved in the client's care can be maintained: the person with dementia remains central to care provision, without neglecting the needs of the carer.

The Person-Centred Nursing Framework (McCormack & McCance, 2006) is a discipline-specific model focusing on the nurse-client relationship. It provides a milieu in which the client is meaningfully involved in their care. Interdependence is central to the framework, supported by positive and reciprocal nurse-client relationships. The values of both the client and the nurse are made explicit, underpinning a negotiated process of mutual recognition.

Both the Senses Framework and Person-Centred Nursing Care enhance organisational and individual staff's strengths by drawing on the capacity of nurses to develop and work within reciprocal relationships with their clients, the family and carers (Queen's Nursing Institute, 2009).

There is much overlap across both frameworks, with interdependency and relationships as central factors to person-centred care. These frameworks position themselves well to meet the objectives of working in partnership with health care providers and ensuring the client receives timely and appropriate nursing care. Where the McCormack and McCance framework does not challenge the dominant biomedical view of ageing, Nolan's framework achieves this.

This theoretical framework based on the principles of person-centred care determined at the commencement of the project ensured that these principles remained central to the model development process.

2.2 Model Development Method

The person-centred theoretical framework guided the development of the dementia Model of Care. Alzheimer's Australia (Alzheimer's Australia, 2003) suggests that, in order to enhance the quality of life for the person with dementia, a triad of factors needs to exist: guiding principles, the characteristics of the care environment and best practices in care. The Model of Care developed in this project endeavoured to address these factors.

2.2.1 Search strategy

To substantiate the Model development, a scoping exercise was undertaken drawing together the evidence supplied in Phase 1 of the Out of the Shadows Dementia project (Nunn, et al., 2008) and the academic literature. The Model consists of several components, requiring separate searches which were conducted under the following headings:

1. Guiding principles;
2. Care environment; and
3. Components of the Model

A systematic search of the literature for dementia clinical guidelines was also undertaken. Key terms used for the search included: "clinical guideline*", "clinical practice guideline*", "evidence based guideline*", "best practice guideline*", "practice guideline*", "dementia", "alzheimer*".

A database search of MEDLINE, CINHALL and EBSCO host was conducted. The inclusion criteria were: English language, dated no earlier than 1997, evidence based and had undergone a process to determine the level of evidence. Other guideline sources were obtained through guideline databases (see Appendix 1), a hand search and the 'Google' search engine using the key words "dementia clinical guidelines".

For the purposes of this project, the clinical practice guideline for the care of people with dementia living in the community (Queensland University of Technology, 2008) was the primary source of evidence, along side five additional guidelines that met the inclusion criteria and post-dated the QUT guideline.

Where there was a gap in evidence arising from the clinical guidelines, a search for systematic reviews were undertaken. The databases utilised were:

1. TRIP database
2. Database of Abstracts of Reviews of Effects (DARE)
3. The Australasian Cochrane Centre

One last search was undertaken via the 'Google' internet search engine using key words "dementia" "aged" "geriatric" and "assessment". This strategy resulted in a limited number of assessments being identified, thus it was necessary to use more direct methods by contacting health care providers who were known to employ dementia or age specific

assessment practices to request copies of their tools. A total of twelve assessments or assessment guides were identified. Those assessments not developed for within the Australian context were discounted. Assessments developed more than 10 years ago were removed as dementia care has significantly changed and improved in the past decade. The remaining assessments were all considered in the context of the existing assessment data collection processes at RDNS.

2.2.2 Model development team

Where evidence was not available, Model development was informed by knowledge and experience of dementia care in the community from two different sources. First, an expert Reference Group comprising of a geriatrician, general practitioner, representatives from Alzheimer's Australia Victoria and Carers Victoria, a carer and clinical leaders in aged care from RDNS was convened on the commencement of the project and consulted throughout the project. Second, a Model Development Working Group was formed. Membership was drawn from RDNS employees and included the Cultural Liaison Co-ordinator, aged care nurse specialists, site managers and a representation from each staff grade at the initial Model development site. Their brief was to advise the project team on the refinements to the dementia Model of Care and to formulate strategies to support the implementation of the Model at clinical level. Throughout the description of the Model these two groups will be referred to either on an individual basis or as the 'model development team'.

Through an action research method, a cyclical process of change occurred. This resulted in a sequential development and implementation of the Model based on the contributions from staff as they trialled the Model in the field. The development and refinement of the Cognition Assessment in particular was facilitated by a small group of nurses called our Knox site core group. This collaboration between the project team and the clinical staff enabled multiple viewpoints to be considered. Participating nurses were asked to complete a feedback form after every completed assessment to elicit staff responses on their immediate experience of using the assessment tool.

Data were collected on:

- Time taken and number of visits required to complete the assessment
- Collection of unnecessary information
- Information that was required but not collected
- Flow and sequencing of the assessment
- Impact of the assessment on the client
- Nurses experience of the assessment

These responses assisted with the structure and flow of the assessment. Nurses were also asked to participate in focus groups to obtain their perspectives and experiences. A detailed discussion of this will appear at the end of this section. Suggestions from this working group were collated, critically evaluated and used to refine the Model. One key outcome was the transfer of the assessment from a paper based tool to an electronic format to be accessed through mobile technology at the point of care.

2.2.3 Guiding principles

Guiding principles provide a basis from which quality dementia care can develop. They define the components which underpin service provision; the roles required to achieve these components and the education required to undertake the role.

Existing principles were sourced and explored for their relevance to nursing and support for the person in their home environment. A range of documents originated from peak dementia organisations, government frameworks and evidence based guidelines (see Appendix 1). Documents were cross-referenced to determine the commonality of themes and to remove those specific to the residential and nursing home environments. Consensus on the validity of these principles was reached within the members of the Model Development Team. Eighteen principles form the basis of this Model of Care and are presented in order of the frequency in which they occurred in the literature (see Appendix 2).

2.3 Components of the Model of Care

The dementia Model of Care consists of three main components:

1. Cognition Assessment
2. Care planning and interventions plus supporting resources
3. Education

These components maximise the competency and confidence of the nurse, equipping them with the dementia care knowledge and skill set to ‘know why they are doing things; know how to do them; be able to perform appropriate activities proficiently; and then know what to do next’ (Van Loon, 2008).

2.3.1 Component 1 – Cognition Assessment

There are several elements involved in the assessment of a person with possible dementia; determining that dementia is present, uncovering the cause of the dementia, how the person’s functioning is affected, and available resources (Henderson & Jorm, 1998). The Cognition Assessment component of the Model of Care addresses a range of information necessary for informing nursing intervention. It comprises three parts:

Part A – Differential diagnosis

Part B – Biopsychosocial functioning

Part C – Carers

The evidence and rationale for the formulation of each part will be described in the following section and the full assessment appears in Appendix 3.

Assessment is the systematic collection and analysis of client health data (Barry, 1998). It is also an opportunity to enter into a shared process with the client their carer and families to identify what they require to support their independence (Cheston & Bender, 2003; Health Issues Centre, Lincoln Centre for Ageing and Community Care Research, & Council on the Ageing Victoria, 2007).

District nurses are often the first contact for the person with possible dementia. They need to be alert to early signs of memory problems, confusion or depression (Naidoo & Bullock, 2001; Queensland University of Technology, 2008). Diagnosis of dementia can only be made following a comprehensive assessment drawing on information from various sources. This should occur through a collaborative and interdisciplinary approach (Queensland University of Technology, 2008). The opportunity for observation and reporting of the clients functioning in the home environment provides better information about how they behave and

communicate in familiar surroundings and is a vital aspect of the comprehensive assessment (Naidoo & Bullock, 2001; NSW Department of Health, 2003).

A primary task at this stage of the Model development was to identify any existing dementia or age-specific assessment tools used in the community environment. The NARI Initial Needs Assessment (Appendix 4) was adapted as it provided the best interface with RDNS clinical governance system, service delivery Model and current assessment processes while incorporating the psychological, social and biological considerations required for appropriate and effective dementia care.

Nurses trialling the initial assessment tool identified that a structure was required to enable them to complete the assessment over multiple visits. The approaches taken within the evidence based guidelines to assess and manage dementia tended to fall into two designs. One was an encounter-based approach of recognition, diagnosis and ongoing support recognising the complexity of the disease (Alberta Clinical Practice Guidelines Program, 2007; Naidoo & Bullock, 2001; NICE & SCIE, 2006). Second, one that follows the changing nature of dementia defined as a staging process (Interior Health, 2006; Queensland University of Technology, 2008). Given that Phase 1 prevalence data showed the majority of clients cared for by the organisation were identified as having a possible dementia in the earlier stages of the disease (Nunn, et al., 2008), the encounter approach was chosen to formulate the assessment structure.

The Cognition Assessment was then divided into 3 parts to align with the encounter approach. This enabled nurses to carry out a differential diagnosis, identify how the cognitive impairment impacted on the persons psychological, social and biological functioning and to engage with the informal carer. Throughout the assessment process special considerations were made for the presence of visual and sensory impairment (Queensland University of Technology, 2008), education level, the potential for language impairment as a result of dementia and the needs of clients from non-English speaking backgrounds. The Model development team felt that the techniques espoused for administration of the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) were universal to any assessment process involving an older person experiencing cognitive impairment. These principles were converted into prompts and embedded into the assessment process to ensure the clinician enabled the client to take part in the assessment to their fullest capability.

It was deemed important by the Model development team that duplication of information was to be avoided. As a result, efforts were made to incorporate data from any recent nursing assessments such as the MMSE or functional assessment. Nurses were also asked to liaise with other health care agencies such as the aged care assessment teams (ACAT) to request any recent information. This approach is in line with the priority for action in the National Dementia Framework that information sharing between agencies should occur (Australian Health Ministers Conference, 2006).

2.3.1.1 Part A – Differential Diagnosis

Differential diagnosis is the first part of the Cognition Assessment. Recognition and the differential diagnosis of dementia is a key task identified in the literature. Through a structured assessment process, utilising valid and reliable assessment scales, it is possible to distinguish between dementia, depression and delirium (Alberta Clinical Practice Guidelines Program, 2007; Queensland University of Technology, 2008). The process of differential diagnosis can be seen in Figure 2-1 below. Depression and delirium are reversible conditions

and the most frequent reasons for misdiagnosis of dementia (British Columbia Ministry of Health Services Guidelines and Protocols Committee, 2008 (revised); NICE & SCIE, 2006). Identification of their presence allows for timely treatment (Naidoo & Bullock, 2001).

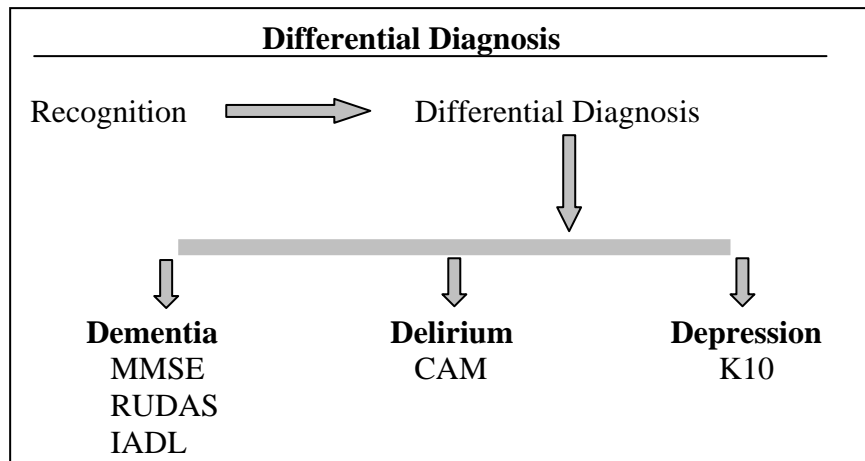


Figure 2-1 The differential diagnosis of dementia

Depression

Depression can be suspected in the person with dementia at any stage. The Cognition Assessment identifies the presence of depression through a two-phase process. First, the Physical Health Questionnaire (PHQ-2) (Kroenke, Spitzer, & Williams, 2003) provides a brief two question depression screen. It enquires about frequency of depressed mood and anhedonia (the loss of capacity to experience pleasure) over the past 2 weeks. Second, clients who screen positive to the PHQ-2 are subsequently tested using the Kessler psychological distress scale (K10) (Kessler, Andrews, Colpe, & al, 2002). The K10 is a well validated tool providing a simple measure of psychological distress based on 10 questions. It measures depression and anxiety symptoms experienced over the previous four weeks. The K10 test and information brochure have been translated into 15 different languages.

The two phase process was required because:

1. clients experiencing disruption to their short term memory would have more success in recalling their symptoms over the past two week period as required in the PHQ-2
2. the K10 is only used on clients who screened positive to the PHQ2
3. the K10 is widely used by General Practitioners (in Victoria) thus providing a consistent approach and understanding of the score interpretation within the multidisciplinary team.

However, in the second version of the assessment tool, the PHQ-2 was removed. Nurses continued to complete the K10 despite a score below cut-off for identifying the presence of depression on the PHQ-2. This suggested that nurses were not confident in the PHQ-2 as a screening tool or, on a subjective level, the nurses felt there were signs and symptoms of depression.

Delirium

The incidence of delirium is high in older people however it is difficult to recognise as it is often confused with dementia (Harding, 2006). The Confusion Assessment Method (CAM) (Inouye, et al., 1990) is a standardised instrument developed to aid the recognition of delirium quickly and accurately (Sansoni, et al., 2007). The short version of the CAM identifies the presence of the four principal features of delirium but not their severity. Delirium is an acute medical condition (Harding, 2006), and if identified as the Cognition Assessment was being conducted, the clinicians were to be advised to seek urgent medical attention (Registered Nurses Association of Ontario, 2004).

Cognition

The assessment of cognitive ability is crucial to establish the possibility of dementia (Queensland University of Technology, 2008), however a history of cognitive loss is also a significant indicator (Alberta Clinical Practice Guidelines Program, 2007; Queensland University of Technology, 2008). There was strong evidence to support the use of standardised instruments to measure cognitive loss (Naidoo & Bullock, 2001; NICE & SCIE, 2006; Queensland University of Technology, 2008), functional ability (Naidoo & Bullock, 2001; Queensland University of Technology, 2008) and depression (Naidoo & Bullock, 2001).

The MMSE (Folstein, et al., 1975) (Appendix 5) was identified to measure cognitive function (Alberta Clinical Practice Guidelines Program, 2007; Queensland University of Technology, 2008) and is already part of the organisation's existing assessment process. It is a widely recognised and utilised tool and, in Australia, is used to determine the person's eligibility for treatment with a cholinesterase inhibitor medication. However, there are some significant limitations when the MMSE is used with a client with physical or sensory disability, when administered via an interpreter, if the client has a low education level or has mild cognitive changes only. In recognition of these limitations the Rowland Universal Dementia Assessment Scale (RUDAS) (Storey, Rowland, Conforti, & Dickson, 2004) (Appendix 6) was also included as it is easily translated and culturally sensitive (Queensland University of Technology, 2008; Sansoni, et al., 2007).

An additional limitation of the MMSE is its lack of sensitivity in recognising early cognitive changes. People who experience early symptoms are commonly living in the community (Nunn, et al., 2008), therefore nurses are asked to identify the clients' instrumental activities of daily living (IADL) ability in three specific areas. Whilst there is no supporting evidence for this approach in the literature, compelling research by Cromwell (2003) supports the use of these three items to substantiate the presence of a possible dementia when the MMSE cut-off score falls within 'normal limits'. This approach was also supported by the clinical experience of the Model development team with clients who had a formal diagnosis of Alzheimer's disease, with MMSE scores of 30/30 and could not maintain independence in IADL ability.

If, at the end of the differential diagnostic process, delirium and depression have been excluded but cognitive impairment is still present, it is appropriate to suspect dementia as the underlying cause (British Columbia Ministry of Health Services Guidelines and Protocols Committee, 2008 (revised)). The outcome for the differential diagnosis was defined by the International Statistical Classification of Diseases (ICD-10) definition of dementia, which states that there must be:

1. a 6 month minimum time frame
2. progressive intellectual decline with impaired activities of daily living
3. multiple cognitive domains affected
4. and that memory involvement is not mandatory (WHO, 2007)

Part A of the Cognition Assessment enables the suspicion of cognitive impairment to be supported in evidence and this promotes a discussion with the client so that onward investigations are facilitated through their general practitioner enabling the client to take a proactive approach to self management.

2.3.1.2 Part B – Biopsychosocial functioning

Part B of the Cognition Assessment examines biopsychosocial functioning. The RDNS General Assessment Tool (GAT) is derived from Gordon's functional health patterns framework (Gordon, 2007), providing a broad based health assessment that can be applied across cultures, nursing specialities, age groups and intellectual functioning of the client. This second part of the Cognition Assessment was designed to complement the GAT by exploring dementia specific issues. Figure 2-2 below identifies the range of issues incorporated into the Cognition Assessment. Several of these domains will now be described below with a rationale for their inclusion in the context of the dementia Model of Care.

Biography

Understanding and knowing a client in the context of their life history assists the clinician to provide appropriate interventions. This approach, also known as life story work, has many functions when used with people experiencing cognitive problems. Each persons memories are unique, accumulating experiences over the life course (Gregory, 1997). A key premise is that for care to be person centred, it is essential for staff to listen to the person with dementia (Cheston & Bender, 2003; Goldsmith, 1996; Kitwood, 2005; Perrin & May, 2000) aiding the understanding and impact of past and present behaviours on care provision and also providing a profile to share with other involved clinicians (Batson, Thorne, & Peak, 2002). By enabling a new level of understanding to develop, the clinician can look beyond the dementia and see the person.

Free text fields were incorporated into the assessment, providing the opportunity for nurses to engage with their client to understand key life events, as well as document their personal, religious, spiritual and cultural beliefs.

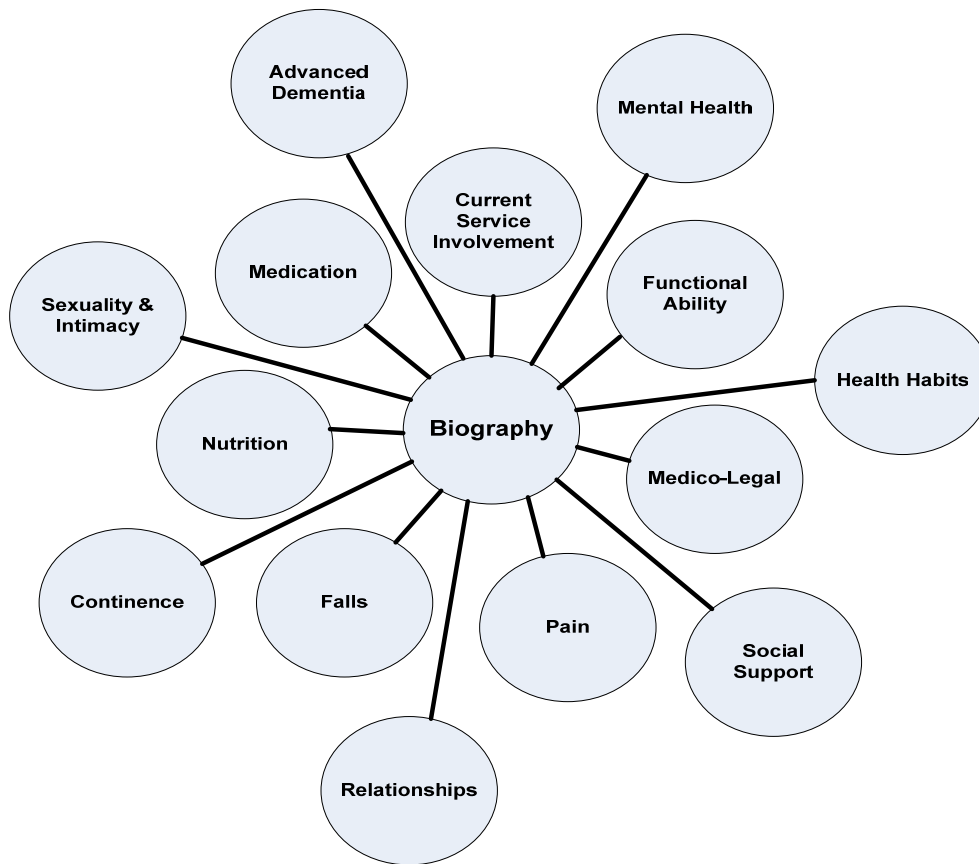


Figure 2-2 Biopsychosocial functioning

Legal issues

A community nursing organisation must receive the legal consent of its clients to provide care including entry to their home. Consent must be properly informed, freely given, specific and current. It should be assumed an individual has the capacity to consent unless proven otherwise (Darzins, Molloy, & Strang, 2000). By undertaking the differential diagnosis and identifying the presence of cognitive impairment or a possible dementia, the long-term ability to comprehend and consent to care and treatment may be affected. Whilst the assessment of competency to make a decision is a complex one, and often beyond the scope of the nurse, there is a need to ensure that the vulnerable client is protected by the presence of an authorised representative or supported to seek advice regarding advance care directives, enduring powers of attorney and guardianship in early dementia.

To this end, the inclusion of revisiting the individual’s capacity to consent (Queensland University of Technology, 2008) is an important activity within the Cognition Assessment. Nurses are asked to identify who had given the consent (an authorised representative, and informal advocate or the client) on the most current consent form. For clients who had given consent, the nurses are asked to consider the validity of that consent based on the outcome of the Cognition Assessment, either advising the client to seek forward planning advice or to contact a social worker for more immediate concerns.

Driving is another legal issue that was included within the Cognition Assessment. The presence of dementia in a driver will result in a two-fold increase in crash risk (Owsley, 2004) and given the progression of dementia is variable, predicting driving ability on the basis of diagnosis alone is not possible. A progressive dementia will at some stage impact on the ability to drive safely (Anglely, 2001).

The Model development team identified that the client with dementia, whose driving skills may have deteriorated often causes the clinician and their carer significant concern. It has been suggested that a MMSE cut off score of 18 should promote further testing of driver capacity (Fox, Bowden, Bashford, & Smith, 1997) completed by an occupational therapist (Australian Society for Geriatric Medicine, 2002). There is a need to facilitate a process to enable the nurse to identify changes to driving capacity, discuss the clients' driving needs with their GP or with their state driving authority and to seek alternative transport options available to them. In the assessment, the nurse is asked to ascertain the client's driving status, and for those still driving to determine if any concerns for safety had been raised by their carer or significant others.

Pain

The cognitive changes associated with dementia often have an impact on communication ability, confounding pain assessment practices. Health professionals assume the most accurate and reliable evidence for identifying the presence and intensity of pain is through the description by the individual who is experiencing the pain (American Geriatrics Society, 2002; Hadjistavropoulos, et al., 2007; Zwakhalen, Hamers, HuijerAbu-Saad, & Berger, 2006). While pain assessment practices within the organisation were found to be thorough, they did rely on the client's report of pain.

The Cognition Assessment sought to identify those clients whose communication ability had been impaired and then consider indicators of changed behaviour, depression and any pain related health conditions (Queensland University of Technology, 2008). By identifying these factors it was felt that this would allow the nurse to adjust the pain assessment procedure and consider the use of an observational pain scale.

Nutrition

Weight loss, weight gain, nutritional deficiencies, dehydration and muscle wasting are all potential nutritional issues secondary to a diagnosis of dementia. Adverse health outcomes from these nutritional issues include an increased susceptibility to infection, delayed wound healing, deterioration in cognitive function and pressure ulcers. Changes to the frontal lobes of the brain occur early in dementia which results in problems with executive functions such as planning, sequencing, insight and judgement, all of which are necessary for meal preparation (Dementia Guide, 2008). The presence of depression or apathy, a commonly occurring psychological symptom of dementia, will also impact on the person's ability to plan, shop and prepare a meal.

However, current guidelines focus on the changes to the eating process that generally occur in the moderate to late stage of dementia (Queensland University of Technology, 2008) where the client can forget to eat or drink or lose interest in food (Reisberg, 1988). For clients in the early stages, the Nutritional Risk Screening Tool (NRST) (Department of Human Services Home and Community Care program, 2001) provided a validated and structured assessment tool to enable the nurse to consider the impact that the early stages of dementia can have on nutritional planning and intake.

Medication

At least one prescription medication is used by 86% of adults aged 65 and over (Australian Institute of Health and Welfare, 2002) and, in this age group, over 50% of admissions into Australian hospitals are medication-related (Griffiths, Johnson, Piper, & Langdon, 2004). In the community, 400,000 adverse drug events not requiring hospitalisation are reported to the GP annually (Australian Council for Safety and Quality in Health Care, 2002).

Medication management is a significant activity for community nursing organisations. In Phase 1 of the project, it was found that 53.4% of clients with a cognitive impairment were referred for assistance with medication management (Nunn, et al., 2008).

The Cognition Assessment needed to assist district nurses to identify clients who experience deficits with orientation to time and recall ability, a reduction in attention and calculation skills as well as impairment in the ability to read and follow written instructions. These factors significantly impact on the person's ability to self-manage their medication safely. Specific items of the MMSE were used in the assessment to identify clients who were experiencing some deficits, triggering the RDNS medication management process. Also of significance was the need to utilise the Australian Home Medications Review (HMR) program more effectively. The HMR is a formalised medication review using a team approach involving the client, their GP, pharmacist and other involved health professionals. The goal of the HMR is to reduce medication misadventure and ensure optimal benefits of the medication regime to the client (Australian Pharmaceutical Advisory Council, 2006). To aid identification of the need to approach the GP with a request for a HMR, several risk factors for medication related problems (Australian Pharmaceutical Advisory Council, 2006) were included in the assessment.

Sexuality and intimacy

Sexuality and intimacy is an important part of our lives but it can be difficult to discuss for the client, carer and the nurse (NARI, 2008). There are many impediments to understanding the effect that dementia has on sexuality and relationships. The obstacles for nurses include cultural values and personal beliefs, inadequate training, ethical dilemmas, ageist approaches and embarrassment (Pappon, 2007). Barriers for clients include the failure to include sexuality issues in assessment processes, difficulties discussing sexuality and preconceived myths in relation to sexuality and ageing (Pappon, 2007). Dementia can affect the person's sexuality, including body image, sexual functioning, relationships, identity and self esteem (Pappon, 2007).

The PLISSIT Model provides a four level framework of Permission, Limited Information, Specific Suggestions and Intensive Therapy (PLISSIT) that enables the clinician to discuss sexuality issues with a client (Davies, Zeiss, Shea, & Tinklenberg, 1998). In recognition of the need to incorporate sexuality and intimacy issues into the Cognition Assessment, a simple open-ended question was drawn from the first level of the PLISSIT Model that gives the individual or couple permission to be sexual beings and the health care professional communicates acceptance of their sexuality (Davies, et al., 1998). This provided the permission for the client to discuss any concerns with their nurse.

Advanced dementia

Advanced dementia as a domain was included to assist the nurses recognise when the person with dementia is likely to require end of life care. Nurses were to consider only those clients

with a cut off score of ten and under on the MMSE or RUDAS were considered for this assessment. A score of 9 or below on the MMSE represents severe dementia (Macdonald Connolly, Pedlar, MacKnight, Lewis, & Fisher, 2000). Signs and symptoms indicating the end stage of dementia were taken from a staging tool used by the North West Melbourne Division of General Practitioners (www.nwmdgp.org.au). Through positively identifying the presence of these symptoms, further assessment of the persons palliative care needs could be facilitated and communicated to the wider primary health care team (Queensland University of Technology, 2008). The outcome of the assessment should target nursing care that promotes comfort and dignity for the client, provide information and support for the carer, and adhere to any advanced directives for the health care needs of the client (Queensland University of Technology, 2008).

Health habits

Alcohol consumption, smoking habits and prescription drug use all have an impact on clients with dementia. Heavy alcohol consumption can contribute to cognitive decline and an increased risk of falls, confusion and malnourishment that may lead to unwanted hospital admission (Tyas, 2001). Smoking increases the risk of developing Alzheimer's disease or dementia (Canadian Nursing Home, 2008). Clients with dementia are more likely to lack the ability to smoke safely or dispose of their cigarettes correctly and those who live alone are at risk of burn injuries and fire if cigarettes are not safely used and disposed of correctly. These habits impacted significantly on the safety of the person with cognitive impairment or dementia. Awareness of the extent to which the client partook in these habits also provide an opportunity for advising on the general health benefits smoking cessation and moderation in alcohol consumption could provide.

Little information and advice on smoking behaviour and misuse of medications was available in the literature to guide the nature of the assessment questions. Questions were based on clinical experience and awareness of the safety issues in the client's home. Alcohol consumption was measured through the use of a validated three question version of the Alcohol Use Disorders Identification Test (AUDIT) developed by the World Health Organisation called the AUDIT-C (Bush, Kivlahan, McDonell, Fihn, & Bradley, 1998). A score of 3 or more on the AUDIT-C indicates the need for a more in-depth assessment of drinking and related problems.

Social support

The quality of life of older people living at home is improved where there is social support in the form of neighbours, friends and community involvement (Health Issues Centre, et al., 2007). Social relationships provide support, satisfaction with life and a sense of community; they can also prevent or delay the path to residential care (Health Issues Centre, et al., 2007). Alzheimer's Australia (2006) states "An active social life is good for the brain. Research shows that people who are regularly engaged in social interaction maintain their brain vitality".

In contrast, Naughtin (Naughtin, 2008) states that people aged 80 years and above are more prone to social exclusion as are those who are living alone, have no children, are in poor mental or physical health and have no access to a car or public transport. Indeed, people who live alone have been found to experience higher levels of unmet need in areas of health, mobility, self care and toileting, social interaction, thinking and memory, behaviour and mental state and are more likely to experience poor community living environments (Health Issues Centre, et al., 2007). People with dementia living alone may experience additional

difficulties in accessing medical care and following medical instructions (Health Issues Centre, et al., 2007). Of RDNS clients, 40% with a diagnosis of dementia lived alone (Nunn, et al., 2008). These clients may be at risk of social isolation and loneliness. Identification through the assessment process would enable information on the range of services and programs available to meet their social needs to be discussed (Queensland University of Technology, 2008). Assessment questions were largely geared towards enabling the nurse to recognise the clients preferred social activity, their opportunities for accessing them and any opportunities to improve their social life.

Dependents

For the purpose of the Cognition Assessment, a dependent was defined as the person with cognitive impairment providing care or support to another, such as a grandchild, or where independent living for a couple is reliant on the person with dementia. There was a perception by the working group that these situations are often very complex and high risk. There was no evidence in the literature to support the inclusion of the dependent person in the assessment but the working group were unanimous in ensuring the inclusion of the consideration of dependents despite the recognition that it will only be applicable to a minority of situations. The assessment questions were therefore drawn from the clinical experience of the working group and focussed on the identification of the client who was a carer to another person or in a relationship which was co-dependent. Once the nurse identifies the client is providing care and support to another person, the willingness or ability to maintain this care would be discussed with the client. Additional supports can then be provided where requested or required to maintain the safety of the cared for person.

2.3.1.3 Part C - Carers

The final part of the Cognition Assessment focussed on the identification of the informal carer and the support provided. Where a carer relationship was identified, the caregiver assessment determined the effect of behavioural and psychological symptoms of dementia on the carer.

An informal carer can be defined as one who “provides unpaid care and support to family members or friends who have chronic or acute condition, mental illness, disability or who are frail aged” (Carers Australia, 2007).

Several factors have been identified as contributing to carer stress and burden; the mental and physical costs of caring (Brodaty & Green, 2002; Carers UK, 2007; Department of Human Services, 2004; NSW Health, 2007); difficulty accessing information from service providers (Department of Human Services, 2004; Elder, 2007) and accessing suitable services in a complex health care system (Elder, 2007; Koch, Marks, & Hofmeyer, 2002; Wackerbarth & Johnson, 2002). These significant factors provide strong evidence to support the need for a dedicated carers section in the Cognition Assessment in order to identify carer stress and burden before crisis point is reached (Nelis, Quinn, & Clare, 2007). Thus, nurses can provide timely and understandable information and support based on carers needs (Nelis, et al., 2007; Queensland University of Technology, 2008); inform carers of their eligibility to financial assistance and where to get that information (Queensland University of Technology, 2008); and where to access psychosocial interventions and assistance (Australian Health Ministers Conference, 2006; Nelis, et al., 2007).

Standardised instruments were used to measure carers stress (Alberta Clinical Practice Guidelines Program, 2007; Naidoo & Bullock, 2001; Queensland University of Technology,

2008) as well as the clients behavioural and psychological symptoms of dementia and their impact on the carer (Queensland University of Technology, 2008). Consultation with peak carer's agencies in Victoria, including Alzheimer's Australia Victoria and Carers Victoria, resulted in the recommendation to use a simple risk screening question. Many people do not recognise themselves as a carer or want to be labelled as such. The carer's assessment was therefore structured to ensure that the participation of the carer was based on individual choice.

Behavioural and psychological symptoms

The second activity of the carer's assessment addresses the behavioural and psychological symptoms of dementia (BPSD). These occur in a high proportion of all people with dementia and may cause significant stress and distress to those who either experience it or provide care for them. BPSD is a term that describes a range of 'non cognitive manifestations of dementia' (Brodaty, Draper, & Low, 2003; Lee, et al., 2004). Examples of behavioural symptoms are verbal and physical aggression, agitation, wandering and sexual inappropriateness or disinhibition. The psychological symptoms include depression, anxiety, delusions and hallucinations. The most common of all of these are apathy, depression and agitation (Lyketos, et al., 2002).

The assessment of BPSD was originally incorporated in the biopsychosocial aspect of the assessment. Through feedback from the core group at the development site, the project team found that nurses could not accurately identify the presence of these issues and an assessment, completed by the carer, would be more effective. The Neuropsychiatric Inventory Questionnaire (NPI-Q) (Cummings, Mega, & Gray, 1994) was incorporated into the electronic version of the assessment. It is a validated tool that assesses the 12 core symptoms associated with BPSD and their impact on the carer (Queensland University of Technology, 2008). It has been identified as applicable for use as a global measure of behavioural and psychological disorder in the community setting (Sansoni, et al., 2007).

2.3.1.4 Cognition Assessment Outcome

The completed Cognition Assessment has the potential to generate a vast range of outcomes. Differential diagnosis is completed in all cases and those clients with a suspected delirium would exit the Cognition Assessment process at this point for urgent medical attention. For some, the differential diagnosis will conclude that the client does not have a cognitive impairment. For clients with a pre existing diagnosis of dementia, the assessment findings will identify change in cognitive and functional ability, support the planning and implementation of dementia specific nursing care and improve ongoing carer support. However, clients who have the most potential to benefit from this assessment are those whose differential diagnosis reveal a potential dementia and identify dementia related impairments in the biopsychosocial aspects of their lives. These outcomes set in motion a range of interventions such as referral to the GP, referral to specialist services for support, provision of information, and adjustment of nursing care to ensure the client maintains optimal functioning. The assessment outcomes therefore provide valuable observations of the client's functional ability in their own environment, necessary for the diagnostic process.

Importantly, assessment cannot be regarded as a separate entity from care intervention (Cheston & Bender, 2003). On completion of the Cognition Assessment the nurse was encouraged to summarise the findings to the client and carer so that a process of goal identification can occur. Once voiced, these goals form the basis of the care plan.

2.3.2 Component 2 – Planning and Implementing Care

The care plan is an intrinsic component of care provision. The care plan communicates client information to the health care team by identifying interventions that will achieve the client's goals, as well as providing a vehicle by which the client's progress can be evaluated. There are two basic types of care plan, standardised and individualised. The organisation's approach to care planning is based on the standardised care plan format. This has the benefits of being evidence based, providing a benchmark for care intervention and it saves time spent on documentation.

2.3.2.1 Supporting resources

Not all district nurses have access to aged care clinical nurse consultants with dementia specialist skills and knowledge. Therefore, a series of 'intervention guides' were developed providing instructions on how to deliver dementia specific interventions, explain why a certain approach was necessary, and the supporting evidence. A total of 13 subject areas were identified;

1. Recognising cognitive impairment
2. Communication and dementia
3. Memory support strategies
4. Orientation techniques
5. Nutrition and dementia
6. Driver counselling and advice
7. Psychological and behavioural support
8. Health habits
9. Medical legal issues
10. Carers
11. Dementia and medication capacity
12. CALD and dementia
13. Social support

To enable nurses to be responsive regarding the information needs of the client, their family and carer, local care, support and advisory services (Queensland University of Technology, 2008), an electronic resource database, adapted from an existing format, was also developed. The benefit was this resource data base could be utilised through the mobile computers used by every RDNS district nurse at the point of care. Information and services identified through the assessment process as appropriate to support the client and carer could then be communicated immediately, providing timely and targeted information and support that promoted independence (Wells, Nay, Hill, & Maher, 2008).

2.3.3 Component 3 – Education

Many studies and reports have identified the need for appropriate training and education in order to understand the person with dementia. Key elements required for quality dementia care were found to be: communication skills, understanding and responding to behaviours, person centred care and knowledge of dementia (Department of Human Services, 2006; Kemeny, Boettcher, Shon, & Stevens, 2006; Kovach & Krejci, 1998; Mace, 2005). More specifically, the evidence states that health professionals need to be aware of the incidence and prevalence of dementia, have the skills to recognise the early signs of memory problems (Naidoo & Bullock, 2001), be aware of the differences in the clinical features of delirium, dementia and depression, and the knowledge of the most common presenting symptoms of the different subtypes of dementia (Queensland University of Technology, 2008). These

skills and knowledge for dementia care were mapped out against the Model of Care (Appendix 7).

Two tasks were undertaken prior to the development of the education package to support the use of the Model. The first involved a series of consultations with members of the organisations education and e-learning teams. The issues that were considered are listed in Table 2-1. The second task was to source existing dementia education packages. This had a two-fold use: to identify the range of education and training opportunities available to staff and motivate their attendance at these; and to find an educational approach and resource that could be utilised for the project.

Table 2-1 Education issues

Who would require the training?
The identification of staff who had already attended training in dementia The need to validate the currency of competency. Whether training would be mandatory
Time frame
How many courses and in what time frame? Number of sessions per course The need for updates How to capture new staff
Type of training
Set at what level, introductory, comprehensive, functional Assessment requirements if competency based
Contents
Identify core competencies Identify knowledge, attitude, skills and practice aspects Basis for inclusion
Mode of delivery
Face to face considerations include location, training venue facilities, duration of training, management of training, development of training materials, and facilitation of training sessions. On line or self directed learning package considerations include mode of delivery, management of training, and development of training materials. Mixed mode delivery considerations include which modes, coordination, implementation and monitoring issues.

Experience at RDNS has shown e-learning is an exciting medium through which training can be delivered, however a dementia package in this format could not be located. It was not possible to design one in the time frame of this study therefore face-to-face delivery of an education program was provided. Short thirty minute sessions gave an overview of dementia and person-centred dementia care for all members of nursing field staff at the RDNS sites involved in the project. A further one hour session was designed on assessment and dementia, specifically for the nurses working with the new Model of Care. A further session was planned for dementia care interventions.

The other training method utilised involved demonstrating the assessment at the point of care. This approach utilised the Clinical Project Officer's skills and knowledge in dementia practices, through a joint visit with each nurse trialling the Model of Care, to demonstrate the administration of the various assessment tools incorporated within the Cognition Assessment. This enabled the nurse to observe the completion of the MMSE and the RUDAS with the client. A subsequent joint visit occurred to encourage the nurse to take the lead on the assessment but supported by the presence of the Clinical Project Officer, facilitating a continued learning environment and feedback mechanism.

Several dementia training and education resources were located: the two day Dementia Approaches to Care course delivered by RDNS, three day workshops called the Dementia Essential for Registered Nurses and Aged Care Workers delivered by Alzheimer's Australia Victoria and a self directed online learning resource called TIME for dementia, developed by the Victorian & Tasmanian Dementia Training Study Centre. Nurses were advised of these opportunities to further their knowledge of dementia.

The TIME for Dementia education package had been designed specifically for qualified health professionals and provided the elements required in the training to support the new Model of Care being trialled in this project. Permission for use of this material was sought and granted by the team responsible for its development at the Victorian & Tasmanian Dementia Training Study Centre.

2.4 The development site

Prior to the Cognition Assessment being introduced to clinical nursing staff, the Clinical Project Officer used the assessment with three consenting cognitively intact clients who had been identified by the Operations Manager at the development site (subsequently referred to as Site 1). The purpose of this was to identify the ease of use, logical flow, gaps, impact on client and time required to undertake the assessment and if there was any correlation of score interpretation between the RUDAS and MMSE. This process substantiated the content of the Cognition Assessment and also enabled the Clinical Project Officer to make small changes and prompts in order to improve the sequencing of the Cognition Assessment before its use in the field.

The whole team at Site 1 were invited to attend a one-hour education session providing an overview of dementia and person centred care principles. Thereafter, a group of 10 staff at the site were selected by their manager to receive further training around the use of the new Model of Care, including the new assessment tool. These ten staff identified three clients known to have a cognitive impairment and suitable for assessment using the new Cognition Assessment tool. On the first client assessment for each of the ten nurses, the Clinical Project Officer conducted the Cognition Assessment as part of the training process. A second client assessment visit was planned whereby the Clinical Project Officer maintained an observational and supportive role whilst the nurse completed the assessment. Thereafter, each nurse was asked to assess another two to four clients independently (Appendix 8).

2.4.1 Focus groups with staff

Focus groups were held at Site 1 in August 2008 to capture the views of a range of nursing staff directly involved with the initial trial of the newly developed Model of dementia care. Their views about the impact of the Model on both nurses and clients and their suggestions for improvements were pivotal in further developing the Model.

2.4.1.1 Sample

Two separate focus groups were held with staff at Site 1. All but one participant was female, all had extensive experience in aged care and had been involved in the implementation of the new Model on a day-to-day basis.

The first focus group was comprised of senior staff – the client services manager, an Aged Care Clinical Nurse Consultant and a Grade 4 clinical co-ordinator, all with more than ten years experience in community nursing with RDNS in various roles.

The second focus group comprised 6 field staff who had been directly involved in implementing the Model with clients. The group included primary nurses (n=4) and care managers (n=2); all were female, and had worked in community nursing with RDNS for a median of five and a half years (range two to nine years). All had extensive experience of care of elderly clients, both in the community and residential services.

A third focus group was held with two experienced Aged Care Clinical Nurse Consultants who worked at other sites and were members of the RDNS Aged Care Clinical Leadership Group (CLG). These two nurses had worked for RDNS for 12 and 9 years respectively. These experienced Aged Care specialist nurses trialled the Cognition Assessment Tool only (with an emphasis on its suitability for CALD clients), as the assessment tool was felt to be a central component of the Model of Care and the expertise of these staff would be particularly valuable.

2.4.1.2 Data Collection

Slightly different versions of focus group guides were developed according to staff designation (Appendix 9). Participants were invited to comment freely on the new Model of Care.

There were three areas of exploration:

1. Caring for clients with possible cognitive impairment prior to the implementation of the new Model, including what were considered to be the reasons for a new Model.
2. Experiences of working with the different components of the new Model and reactions to the changes associated with the new Model.
3. Key issues for the organisation in the implementation of the new Model.

The first two focus groups were facilitated by an external consultant experienced in conducting focus groups, with a member of the project team recording field notes and completing group logistics. The same member of the project team then facilitated the last focus group with the two Aged Care Clinical Nurse Consultants.

With the participants' permission, all discussions were digitally audio-recorded. Field notes describe the demographics of those attending (primarily related to years in RDNS and experience of working in age-care), themes of the group and body language of the participants.

Separating nursing staff into two groups according to seniority facilitated free and flowing discussion. Importantly, the Clinical Project Officer involved in the training and support of the nurses in the field at the development site was not involved or present at the focus groups, to ensure this relationship did not influence the nurses' feedback.

Audio recordings were transcribed verbatim and the transcripts checked against the recording for missing words or mistakes. No individuals or institutions mentioned by name were included. Transcripts were re-read against the audio recordings to check for accuracy of word transcription, intonation and utterances.

Exploratory studies like this one require inductive identification of themes from the transcripts, therefore thematic analysis was used (Attride-Stirling, 2001). A thematic network was constructed using electronic copies of the transcripts to describe and connect categories with emerging basic, organizing, and global themes. Data analysis proceeded with extensive re-readings of hard copies of the transcripts to ensure the texts were fully explored. The initial thematic network was derived by the project team member and the external consultant, with the final thematic analysis undertaken by the external consultant.

2.4.1.3 Results

Nurses generally responded favourably toward the new Model of Care. They discussed a number of topics relating to their experiences prior to the implementation of the new Model and their experiences and expectations of this Model of Care.

The two global themes emerged relating to:

1. The need for a structured approach to caring for clients with cognitive impairment: 'Having a house with no rooms'
2. The workability of the new Model of dementia care: 'Good one day, the next day they may be saying the complete opposite'

Quotes used have been chosen to best illustrate the emerging themes. Where words have been added to quotes to enable reader understanding they are enclosed in square brackets.

1. The need for a structured approach to caring for clients with cognitive impairment: 'Having a house with no rooms':

Enthusiasm for the new Model was based on the provision for nursing staff of a tangible, concrete suite of tools and processes from which they could conduct dementia care in a similar way to other specialties such as diabetes and wound care.

'We needed something to work from, you know, a base. You need something that would collect data as well, and you needed tools. I think you needed more content. It's like having a house with no rooms. Now you've got a few rooms in there, yeah, structure.'

In addition, the new Model would provide baseline data for nurses to work with in the ongoing provision of care, whilst providing 'evidence' for referral to other agencies.

'Well you've got specific measured data to give to the GP.'

'[The new Model helps with] identifying clients with dementia before they get into crisis situations, often that might be the first time they come to our real attention.'

Proportion of nurse's time dedicated to clients with cognitive impairment

Staff identified the increasing prevalence of cognitive impairment among their clients, with many clients requiring assistance with medication management. This was thought to be due to the trend towards people with dementia staying at home using services and community care packages rather than going to residential age-care facilities.

'We had probably two hours of meds [then] now we've probably got at least five, four or five hours in the morning of meds ... so that's double and a half in probably five to ten years.'

The nurse's professional role in cognitive impairment

There was also discussion around the role and scope of the district nurse in the care of clients who have a cognitive impairment. Some nurses felt their care is highly task oriented.

'Well it's just an area we were probably lacking in... we weren't really holistically doing as well as we could I don't think.'

Interestingly, some staff reported the new Model raised questions around their professional scope.

'Once we've piled through all of our general assessment ... then figured out all that tooing and froing with the medication management and doctors orders and discharge from hospital and sorting all of that out and then they are referred to ACAS and then they'll come in, it's like where do we fit in?'

Overall, the structure of this new Model for dementia care provides guidance for nurses in the organization of appropriate care whilst raising questions for some regarding their role.

2. The workability of the new dementia Model of Care - 'Good one day, the next day they may be saying the complete opposite'

It became apparent that staff saw the Cognition Assessment as the pivotal element of the new Model of Care. Questions put to the group about the 'Model of Care' in general were often met with responses referring to the Cognition Assessment.

'It's better than what we had, we didn't really have anything, but looking at this, we definitely need a structured tool there's no doubt about it.'

The Cognition Assessment was generally well received and staff felt it would improve their overall care with this client group.

'You just need to use it [assessment tool] more. We probably need to have it as an assessment for pretty much most medication management clients and it needs to just be something that you do, maybe not at your first visit but it's a routine assessment that's done overall, like within the first couple of

weeks or whatever, just so that you've got an idea of where they [clients] sit, and to have the care plan that follows through.'

However, most staff felt the Cognition Assessment tool was long and suggested a staggered approach to the assessment over several visits. This would allow for observation over time, which reportedly enables the nurse to establish the clients' real needs through ongoing interaction and observation.

'And as we know, patients with dementia may be good one day, the next day they may be saying the completely opposite things, so that's why maybe two visits may be a good idea.'

'...they can't cope with so many questions at once.'

Moreover, staff could build rapport and trust with the client and any carer(s).

'I think it has to be done once you've got a rapport with because otherwise they [client] are threatened by it.'

This led to comments about the importance of gathering information from a range of sources, including existing RDNS information such as the initial admission assessment and from any carers or other service providers involved in the clients care.

Suggestions included breaking the assessment up into discrete parts which can be undertaken according to the clients state on any particular day; and colour-coding the assessments according to the different parts to aid in the process:

'Different colours we said for the different sections, for highlights whether we're looking at memory or emotional status or carer stress or function. '

Involving Carers

Staff reflected on the importance of involvement of carers in the assessment and planning of care, where possible. Cognitive impairment by its very nature means information gathered from the client may be inaccurate or incomplete.

'If you are interviewing dementia clients you are going on what they are telling you and in the back of your head you are thinking, is this right or...'

Involvement in the assessment helps the carer to come to terms with the client's changing cognitive state and increasing needs, whilst also identifying the impact of these changes on both client and carer.

'It's the first thing that's really addressed [with the assessment] the carers. It involves them with their own sort of assessment.'

'With the client ..., he was a bit perplexed as to why we were asking so many questions, but the benefits to the daughter who was the carer were quite marked, she was quite, felt supported.'

Staff felt it would be helpful if they had written information they could leave with carers, especially regarding the various services available to help with client's needs.

'A little resource pack that we can actually give the carer, and not necessarily in front of the client...'

However, nursing staff came to realise that involving the carer needed to be organized early on, with the carer interviewed separately from the client so to allow sensitive areas to be discussed without the client present.

'... the carers got to have a time on their own for a separate assessment without the client being there, so they can voice concerns and not be impacted by the client's behaviour in the background.'

Involving the carers in the assessment process and providing them with the results was sometimes perceived as threatening and so needs to be approached sensitively.

'And I think carers get a little anxious ... things are going along and I think sometimes don't rock the boat because everything is just fine the way it is...'

Ongoing support from Aged Care Clinical Nurse Consultants

The role of the Aged Care Clinical Nurse Consultant (CNC) is described earlier in this report. The need for access to ongoing support from an Aged Care CNC to support care of cognitively impaired clients was discussed at length. Staff felt the Aged Care CNC devoted a large proportion of time to continence consultancy, which reduced their access to information and support on aged care (including dementia) when needed.

'...definitely to have that role Model available is the key [to success]... [CNC] is just so busy. That's a big portfolio ... continence is a huge issue. You need a separate aged care specialist at each centre, each centre should have one.'

For the period of the trial, the development site was supported by the Clinical Project Officer who acted in a proxy Aged care CNC capacity.

'I've had feedback ... to say that it was great to have (Clinical Project Officer/dementia expert) there and she took (her) out to do some assessments ... it was great to have her there to ask questions, just to have a presence there, as the expert.'

Staff felt for effective dementia care and implementation of a new Model of Care, each site would benefit from access to an Aged Care CNC as an education and information resource, and to help with debriefing of staff. An aged care clinical nurse consultant at every site would aid in the referral process of clients and develop stronger working relationships with other healthcare agencies.

Working with culturally and linguistically diverse (CALD) clients

As a reflection of the demographics of the Site 1 area, no clients from a CALD background were recruited. One staff member proposed that the implementation of this Model with CALD clients would be greatly aided by the involvement of culturally specific services:

'I think you'd have to look at linguistically specific packages, and have someone to actually work with...'

The two Aged Care Clinical Nurse Consultants (from non-project sites) were asked to trial the assessment tool with CALD clients, including the introduction of the Rowland Universal Dementia Assessment Scale (RUDAS) as an alternative to the Mini-Mental State Examination (MMSE).

'...the RUDAS worked brilliantly with the CALD clients, they loved it.'

A Site 1 staff member who used the RUDAS with a non-CALD client found she preferred the RUDAS.

'I found that the RUDAS... pinpointed more areas of concern than the MMSE'

Staff education needs

Successful implementation of the new Model of Care was felt to be dependent on continuing formal education which can accommodate varying knowledge and clinical experience amongst the staff.

'The more information they're [field staff] given I think the more they understand why and why we're doing this.'

'It was a lot of information to take in I felt, it was a big, big burst, learning curve. So I think that we would probably benefit more if it was in shorter spurts.'

Perception of lack of available time to use the new Model

There was a good deal of discussion about a perceived lack of time to complete the Cognition Assessment and care plan in a time-pressured environment where staff are wary of new time-consuming initiatives. Staff, including the experienced aged care specialists from the clinical leadership group, felt strongly that the allocation of significant blocks of time, with the support of management, was necessary to conduct the Cognition Assessment and the Model effectively.

'Well it's not just the doing the assessment... education... Its everything that comes from doing the assessment or the referrals etc etc... For each step here you've got, for each section of the assessment you've got potential referrals...'

2.4.1.4 Overview of focus group findings

Overall, staff appreciated the guidance and structure the Model of Care provided for the overall role of the nurse and their day to day care for the client with dementia. They felt the Model provided them with a better understanding of their client's needs and tools to meet those needs.

The workability of the Model was discussed at length, with considerable attention to the limitations of a perceived lack of time and nursing resources, including the availability of an Aged care CNC, has on the implementation of such a Model. There were useful suggestions as to how to improve the Model and its implementation.

Staff suggestions which were felt to be appropriate and feasible for the further trial of the Model of Care were incorporated. These included:

- Conversion of the assessment into an electronic format
- Breaking up the assessment into three sections
- Emphasis on encouraging staff to gather assessment information from a range of sources such as any existing client records, carers, other service providers
- The assessment to be carried out after the clinician has developed a rapport with the client and carer, wherever possible by the primary nurse
- Use of the RUDAS screening tool with CALD clients, as well as possible benefits of using RUDAS with non-CALD clients
- Providing access to an electronic resource folder that held information on the various services available to help with clients needs
- Emphasis on involving the carer (if the client has one) in assessment and care planning

Other suggestions included:

- Availability of Aged Care CNCs. In particular, distinct separation in practice of the Aged Care CNC from the time consuming Continence CNC role.
- Addressing staff concerns about perceived lack of time to incorporate this Model when nursing resources are scarce. Useful suggestions for improving efficiency through clinical practices were noted, such as electronic format of assessment and gathering information from a range of sources other than directly from the client
- Ongoing, manageable delivery of education to staff on management of cognitive impairment, with an emphasis on assessment skills
- Providing written resources to carers

2.5 Summary

From a clinical perspective, a good assessment can promote early recognition of the signs and symptoms of dementia, thus facilitating referral pathways to specialist agencies that can provide diagnostic services and also ensures that timely nursing interventions can be initiated (Van Loon, 2008).

During the development of the Model of Care, frameworks for person centred dementia care were explored. Nolan's Senses Framework (Nolan, et al., 2006) and a nursing specific framework by McCormack and McCance (McCormack & McCance, 2006) now underpin the

Model of Care. To provide more tangible measures of person centred care, guiding principles for dementia care nursing in the community were developed.

A systematic and evidence-based approach to the development of the Model was carried out. The Model consisted of three components: the Cognition Assessment, the care plan with supporting implementation guides and an electronic resource database, and an education package for staff.

A Cognition Assessment based on evidence from existing national and international dementia guidelines was designed by the project team. The structure of the assessment was based on the NARI initial needs assessment in primary care and the evidence from the literature provided the choice of assessment scales and range of dementia specific information necessary. On completion of the assessment, nurses were guided to discuss the assessment findings with the client and carer, with a view to elicit their goals so that appropriate interventions were developed that were central to the individual's wishes. The Cognition Assessment provided the evidence base upon which the cognition care plan could be developed.

3 Evaluation of the Dementia Model of Care

3.1 Overview of Evaluation Methodology

The process of developing and piloting the Model of Care is described in Chapter 2 of this report. In this chapter, the process of implementing the Model and the quantitative and qualitative results of the evaluation will be presented.

The process of implementing and evaluating the Model of Care is displayed in Figure 3-1. The RDNS Site used to conduct the initial development work on the Model (subsequently referred to as Site 1) was involved, together with two additional RDNS Sites (Sites 2 and 3) who had no previous involvement with the project. These Sites were purposefully selected following consultation with RDNS management. The primary focus of the evaluation was Sites 2 and 3 however Site 1 continued to be involved to a lesser extent to provide information on the long-term feasibility and effectiveness of implementing the Model of Care. Staff at Site 1 also provided feedback on the utility of a nurse-to-nurse approach to training staff to implement the Model of Care.

During the development phase, staff at Site 1 provided feedback on the Model via focus groups (as described in Chapter 2) whereas data collection was restricted to assessment of clients by a core group of nursing staff and post-implementation focus groups. The procedure for implementing and evaluating the Model was identical at Sites 2 and 3. However, a significant difference between these two Sites was that Site 2 had an Aged Care Clinical Nurse Consultant (CNC) on staff whereas Site 3 did not have this resource. This factor was deliberately built into the research design to allow for an investigation of the role of the Aged Care CNC in facilitating the implementation of the Model.

At each Site, a Contact Person was identified following discussion with the Client Services Manager. The role of the Contact Person was to liaise between staff at the Site and the Project Team. The Contact Person also supported and motivated the staff to engage in the project activities. Rather than targeting all staff, a core group of six to eight nurses were identified at each Site to take responsibility for trialling the Model with clients. These core group members either volunteered or were selected based on their interest in dementia care or their availability.

All staff participated in a general training session on dementia (described in Chapter 2). For staff at Site 1, this occurred during the initial development phase, whereas for Sites 2 and 3, it occurred immediately prior to the implementation phase. Core group members at each Site then participated in two further training sessions; one on the Cognition Assessment and one on the care planning process.

Core group members then implemented the Model of Care with up to five clients over the following three months. To assist with selecting clients, staff were provided with a list extracted from the RDNS database of current clients who potentially met the project selection criteria. The selection criteria were:

- Current client; and
- Aged 65 years and older; and
- Presence of a medical diagnosis of dementia; or
- Presence of cognitive impairment (e.g. short-term memory loss) in the absence of a confirmed medical diagnosis of dementia

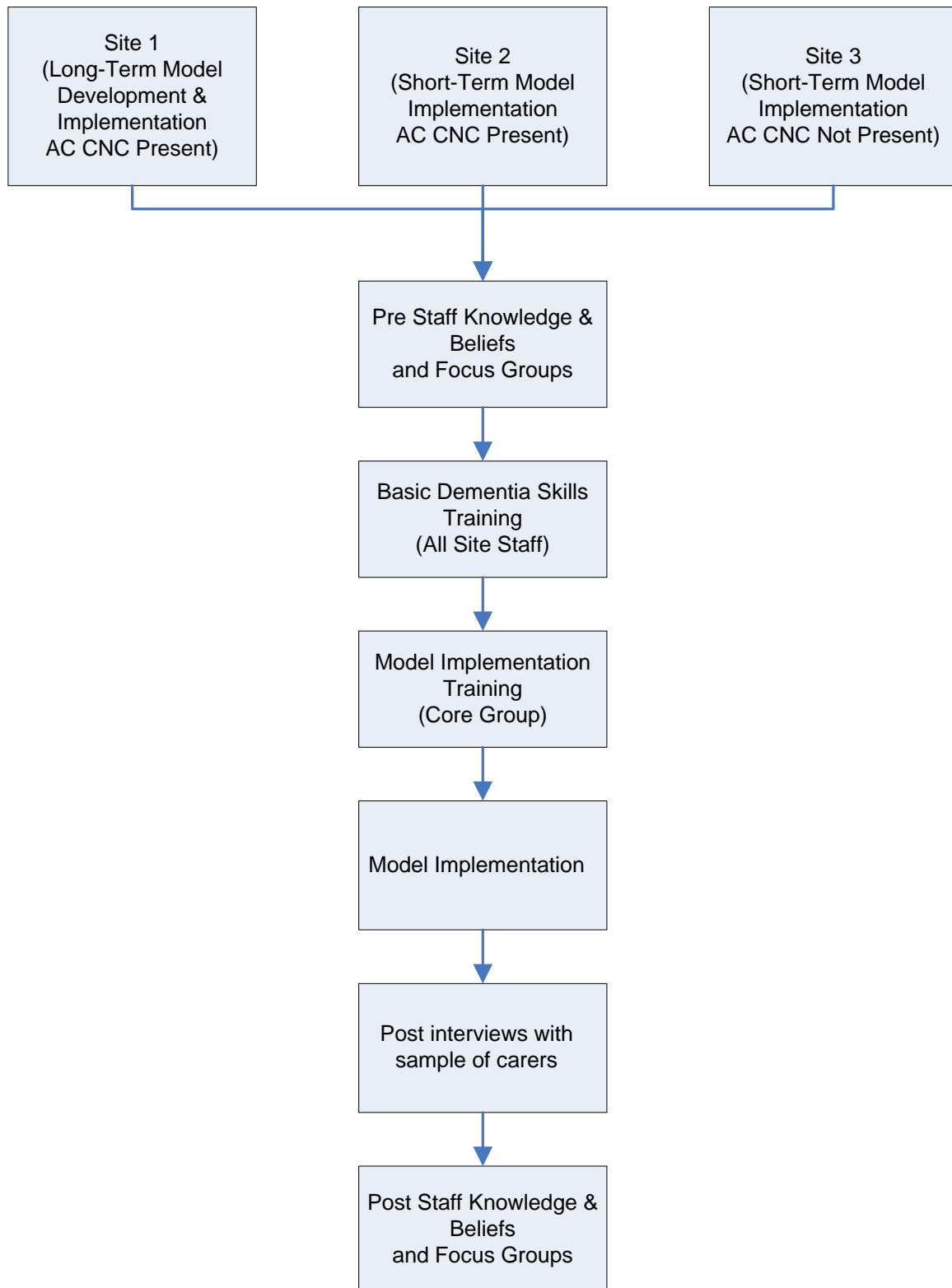


Figure 3-1 Implementation and Evaluation Design

A significant number of referrals of clients with a cognitive impairment do not have a medical diagnosis of dementia (Nunn, et al., 2008). To ensure that these clients were not excluded from the project, the list also included clients who had a record of cognitive impairment noted on their functional assessment collected at the time of admission.

Staff who decided not to implement the Model with clients on their list were asked to provide a clear rationale to the project team. The project team worked closely with staff at the project Sites throughout the implementation period to ensure that the selection criteria were adhered to and that any gatekeeping on the part of the nurse was minimised. Reasons for not implementing the Model with a client included extreme ill health or the client may have been discharged. The presence of other extenuating factors such as extreme family stress was also accepted as a valid reason for not inviting the client to participate in the project. There was also a preference for nurses to assess clients already known to them and where a degree of rapport was already established.

Core group members were asked to implement the Model with at least one or two clients from a culturally and linguistically diverse (CALD) background. Rather than using the Mini-Mental State Examination (MMSE) (Folstein, et al., 1975) with these clients, the nurse utilised the Rowland Universal Dementia Assessment Scale (RUDAS) (Storey, et al., 2004). Nursing staff could also use the RUDAS with clients who may have had difficulty completing the MMSE (e.g. those with a low literacy level). Feedback on the utility and feasibility of using the RUDAS was collected at the post-implementation focus groups with staff.

At the conclusion of the assessment visit, the nurse sought the consent of the client. If available, the carer also provided consent to the possibility of being interviewed to obtain their views on the Model of Care. Copies of client and carer Explanatory Statements and Consent Forms can be found in Appendices 10 & 11. Prior to seeking consent, the nurse used a Capacity Checklist to ascertain the client's ability to provide consent (see Appendix 12). The purpose of gaining the client's consent was to obtain permission for a member of the Project Team to visit the client at home one to two weeks following the Cognition Assessment to administer the QoL-AD, a valid and reliable quality of life questionnaire comprising 13 questions developed specifically for people with mild to moderate dementia (Logsdon et al, 2002) (see Appendix 13). The client's and carer's consent also covered the possibility of them being approached at the conclusion of the implementation phase to participate in an interview at their home.

Immediately prior to the implementation of the Model, all staff members at Sites 2 and 3 were invited to complete a questionnaire on Dementia Knowledge and Beliefs. This questionnaire (see Appendix 14) includes sections asking the nurse to describe themselves (role, experience, hours worked), self-ratings of experience, knowledge and confidence in managing people with dementia, a quiz on dementia knowledge and questions on the nurse's beliefs about people with dementia which included the Approaches to Dementia Questionnaire (ADQ) (Lintern, 1996). The questions for the dementia quiz and some of the dementia attitudes questions came from a range of sources including questions included in studies by Bryans et al (Bryans, et al., 2003), Santo-Novak et al (2001), Turner et al (2004), MacDonald and Woods (2005). The ADQ is a reliable and valid scale comprising 19 statements about people with dementia. It has two subscales, hope and personhood, derived from factor analysis which relate to the staff member's degree of optimism and the degree to which they recognise the personhood of people with dementia.

Three to four months following the commencement of the Model implementation phase, all staff at Sites 2 and 3 were asked to complete the Dementia Knowledge and Beliefs Questionnaire again.

3.1.1 Aims of the evaluation

The two primary target groups for the Model of Care are clients with dementia or a cognitive impairment living in the community and the nurses who provide care to them. For clients and their carers, the aims of the evaluation were:

- to identify issues associated with the client's cognitive impairment
- to provide a comprehensive profile of this client group; and
- to examine the feasibility of utilising a cognition screening tool specifically developed for people from Culturally and Linguistically Diverse (CALD) backgrounds

For RDNS nurses, the aims were:

- to improve the skills and knowledge of clients living in the community with a cognitive impairment; and
- To enhance confidence and approach to working with clients with dementia.

Quantitative data was supplemented by qualitative data obtained via pre and post implementation focus groups with staff and interviews with carers to probe their perceptions of the Model of Care, including change in clinical practice, and to assess any changes in client and carer outcomes.

3.2 Quantitative Findings

3.2.1 Sample

3.2.1.1 Clients

A total of 75 Cognition Assessments were completed by staff at the three project sites during the implementation period: 13 assessments were completed by staff at Site 1, 45 at Site 2 and 17 at Site 3. The mean age of clients was 83.6 years (sd=5.9, range=65-96) and 69.3% were female. A substantial majority of clients spoke English as their primary language (86.7%) and a further 9.3% spoke English as a second language. Seventeen clients (22.7%) were born in non-English speaking countries. Most of those assessed either lived alone (69.3%) or lived with other family members (26.7%). Of those clients who lived alone, thirty-three (63.5%) did not have carer.

Fourteen clients (18.7%) had a pre-existing medical diagnosis of dementia. A further 18 clients (24.0%) had short-term memory loss and 14 clients (18.7%) had mild cognitive impairment recorded as a 'diagnosis'. The remaining 29 clients (38.7%) had the presence of cognitive impairment recorded on their functional assessment. The reason for referral to RDNS for most clients (73.3%) was medication management.

3.2.1.2 Staff

At pre-implementation of the Model, 66 nurses at Sites 2 and 3 completed the Dementia Knowledge and Beliefs Questionnaire. Thirty-one questionnaires were completed by staff at Site 2 and 35 were completed at Site 3. Across both sites, the questionnaires were completed by 6 RN Grade 4 (9.1%), 9 RN Grade 3 (13.6%), 41 RN Grade 2 (62.1%) and 5 other staff

types (12.1%). Twenty-two staff (33.3%) had been employed by RDNS less than three years, 24 (36.4%) had been employed 3-10 years and 19 staff (28.8%) had been employed with RDNS over 10 years. The mean length of time since qualifying as an RN was 17.3 years (sd=10.6).

At post-implementation of the Model, 47 Dementia Knowledge and Beliefs Questionnaires were completed – 24 from Site 2 and 23 from Site 3. The respondents comprised 8 RN Grade 4 (17.0%), 6 RN Grade 3 (12.8%), 31 Grade 2 (66.0%) and 2 other staff types (4.3%). Twenty-two staff members (46.8%) had been employed by RDNS less than three years, 16 (34.0%) had been employed 3-10 years and 9 (19.1%) had been employed more than 10 years. The mean length of time since qualifying as an RN was 16.4 years (sd=10.8).

3.2.2 Data Analyses

All data were checked and analysed in SPSS (Statistical Package for the Social Sciences) Version 17. Cross-sectional data were analysed using frequencies and crosstabs. Pre and Post Dementia Knowledge and Beliefs Questionnaire data were analysed using independent samples t tests for interval level data and the Mann-Whitney U test for ordinal data.

3.2.3 Client Findings

3.2.3.1 Cognition Assessment

The Cognition Assessment is divided into three parts. Part A is concerned with differential diagnosis and includes screening tools for cognitive impairment (MMSE or RUDAS), delirium (CAM) and depression/anxiety (K10). The outcomes for Part A of the Cognition Assessment are displayed in Table 3-1. Thirty clients (40.0%) had completed a MMSE within the three months prior to the administration of the Cognition Assessment of whom eight (36.4%) scored below the clinical cut-off, suggesting the presence of a cognitive impairment. A total of 63 clients completed a cognition screening tool – forty clients (53.3%) completed the RUDAS, 23 (30.7%) completed the MMSE, two clients (2.7%) refused and, in the opinion of the assessing nurse, the administration of a cognition screening tool was not required for 10 clients (13.3%). Of the 40 clients who completed the RUDAS, 27 (67.5%) were not from a CALD background. This suggests a preference on the part of the nurses for using the RUDAS, irrespective the client's cultural background. Of those clients who completed the MMSE as part of the Cognition Assessment, 10 (43.5%) scored below the clinical cut-off (total score less than 23) and, for those who completed the RUDAS, 29 (72.5%) scored below the clinical cut-off (total score less than 22).

Of the 75 clients assessed, 14 had an existing medical diagnosis of dementia. Thirty-one clients did not have a diagnosis of dementia but were identified as having a cognitive impairment as a result of scoring below the clinical cut-off on the MMSE or RUDAS. A further 16 clients scored above the clinical cut-off on the MMSE or RUDAS and were categorised as being at high suspicion for cognitive impairment due to the presence of observed changes in cognitive function over time or the presence of Instrumental Activities of Daily Living (IADL) deficits in the areas of medications, telephone and finances. Two clients showed signs of possible delirium based on their responses to the CAM. For these clients, the nurse terminated the assessment and sought urgent medical attention. The Cognition Assessment provided no evidence of a cognitive impairment for 12 clients. The K10 identified a total of 15 clients with potential problems with depression or anxiety of whom 8 were in the severe range. Where appropriate, these clients were referred to their GP, Aged Persons Mental Health Team or RDNS Mental Health Nurse for further assessment.

Table 3-1 Cognition Assessment – Part A Outcomes (n=73)

Assessment Area	n	%
Cognition		
<i>Existing medical diagnosis of dementia</i>	14	18.7
<i>Cognitive impairment / no diagnosis</i>	31	41.3
<i>High suspicion of cognitive impairment</i>	16	21.3
Delirium		
<i>Evidence of delirium</i>	2	2.7
Depression		
<i>Severe depression/anxiety</i>	8	10.7
<i>Moderate depression/anxiety</i>	2	2.7
<i>Mild depression/anxiety</i>	5	6.7

Part B of the Cognition Assessment is concerned with biological, psychological and social factors frequently observed in conjunction with a cognitive impairment. See Chapter 2 for a description of this section of the assessment. The outcomes for Part B are displayed in Table 3-2. After removing the two clients with possible delirium, this section of the assessment was completed by 73 clients.

In the medico-legal area, almost one half (49.3%) of those assessed were determined to require advice on forward planning or advanced directives. Falls risk was identified in a substantial proportion of clients (59.9%). Although pain is an area addressed by RDNS nurses at the time of referral, the Cognition Assessment identified 10 clients with communication difficulties who may benefit from a comprehensive pain assessment. It has been noted previously that the most common reason for a referral to RDNS for clients with a cognitive impairment is medication management. The Cognition Assessment identified seven clients at particular risk for medication-related problems leading to referral to their GP for a Home Medication Review. Sexuality and intimacy are frequently overlooked in this population and nine clients reported potential issues in this area. Only four clients had advanced dementia which coincides with previous findings that most clients referred to RDNS with a cognitive impairment are in the early stages of the illness. The presence of past mental health co-morbidities was found in 12 clients with nine clients experiencing present issues. If the nurse was able to determine these mental health issues were not being managed effectively, referral to an appropriate external health professional was arranged. Substance abuse co-morbidities were observed in the area of excessive alcohol intake for ten clients, with two of those clients having severe problems. Seven clients expressed a desire to improve their social life and three clients were determined to be in a co-dependent relationship with another person and to be at increased risk as a result of this situation.

Table 3-2 Cognition Assessment – Part B Outcomes (n=73)

Assessment Area	n	%
Medico-legal <i>Advice needed on forward planning / advanced directives</i>	36	49.3
<i>Presence of driving concerns</i>	3	4.1
Pain <i>Possible pain issues</i>	10	13.7
Falls <i>Possible falls issues</i>	43	58.9
Medication <i>Request to GP for Medication Review</i>	7	9.6
Sexuality & intimacy <i>Indication of sexuality/intimacy issues</i>	9	12.3
Advanced Dementia <i>Presence of advanced dementia</i>	4	5.5
Mental Health <i>Current mental illness</i>	9	12.3
<i>Past mental illness</i>	12	16.4
Alcohol <i>Severe alcohol issues identified</i>	2	2.7
<i>Drinking above limits</i>	8	11.0
Smoking <i>Advice needed on safe smoking strategies</i>	1	1.4
Social Support <i>Wants to improve social life</i>	7	9.6
Dependents <i>Possible co-dependent issues</i>	3	4.1

Item responses to the Nutrition Risk Screening Tool (NRST) assessing nutrition risk are displayed in Table 3-3. It can be seen that nutrition-related problems are common in this client group. Problems such as the need for assistance to shop for food (82.2%) and to prepare food (41.1%) were particularly prevalent. In addition, a number of clients were found to be underweight or frail (11.0%), exhibited unintentional weight loss (8.2%) or had reduced appetite or food/fluid intake (13.7%). These findings demonstrate the importance of identifying and responding to the presence of nutritional risks in this client group. However, it should be noted that most of these nutrition-related problems had already been identified and addressed by RDNS nursing staff. Outstanding nutrition risks were identified for only five clients.

Table 3-3 NRST Item Responses (n=73)

Item	n	%
Underweight/frailty	8	11.0
Unintentional weight loss	6	8.2
Reduced appetite or food/fluid intake	10	13.7
Mouth, teeth, swallowing problems	6	8.2
On special diet	11	15.1
Needs assistance to shop for food	60	82.2
Needs assistance to prepare food	30	41.1
Needs assistance to feed self	2	2.7
Obviously overweight affecting life quality	3	4.1
Unintentional weight gain	1	1.4

Part C of the Cognition Assessment is concerned with issues affecting the client's carer. The outcome for Part C is displayed in Table 3-4. Of the three sections of the assessment, Part C was the least well completed. During training, nursing staff were actively encouraged to involve the carer in the assessment process if this was possible. However, most of the clients lived alone (69.3%) and 63.5% of those who lived alone did not have a carer. Among those who had a carer, 19 were non-resident. Despite these difficulties, 17 carers were identified as having possible issues, including the presence of stress.

Table 3-4 Cognition Assessment – Part C Outcome (n=49)

Assessment Area	n	%
Carer <i>Possible carer issues</i>	17	34.7

3.2.3.2 Quality of Life

A total of 48 clients at Sites 2 and 3 who completed the Cognition Assessment also completed the QoL-AD as a measure of their quality of life. The QoL-AD was administered by interview by a member of the project team one to two weeks following the Cognition Assessment. The mean total score for the sample was 36.6 (sd=5.1). The responses for the individual items in the QoL-AD are displayed in Table 3-5. The QoL-AD was not included in the Cognition Assessment, however, for the purpose of the current project, the data provides

a useful additional source of descriptive information and provides a baseline for possible future investigations concerned with the evaluation of the Model of Care.

The majority of respondents reported good or excellent quality of life for all items on the QoL-AD. However, the presence of low perceived quality of life for a number of clients in the areas of physical health, energy level, mood, whole self, ability to do things around the house, ability to do things for fun, financial situation and life as a whole is of concern and reinforces the importance of focussing on the entirety of the client's situation.

Table 3-5 QoL-AD Item Responses (n=48)

Item	Response			
	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Excellent</i>
Physical health	5 (10.4)	11 (22.9)	29 (60.4)	3 (6.3)
Energy level	8 (16.7)	16 (33.3)	24 (50.0)	0 (0)
Mood	1 (2.1)	12 (25.0)	35 (72.9)	0 (0)
Living situation	1 (2.1)	4 (8.3)	25 (52.1)	18 (37.5)
Memory	6 (12.5)	18 (37.5)	21 (43.8)	3 (6.3)
Family relationships	2 (4.2)	2 (4.2)	18 (37.5)	26 (54.2)
Marriage / closest relationship	3 (6.4)	2 (4.3)	17 (36.2)	25 (53.2)
Relationship with friends	1 (2.1)	4 (8.3)	35 (72.9)	8 (16.7)
Whole self	2 (4.2)	12 (25.0)	29 (60.4)	5 (10.4)
Do chores / things around house	6 (12.5)	16 (33.3)	24 (50.0)	2 (4.2)
Do things for fun	6 (12.5)	12 (25.0)	26 (54.2)	4 (8.3)
Financial situation	2 (4.2)	11 (22.9)	33 (68.8)	2 (4.2)
Life as a whole	0 (0)	10 (20.8)	29 (60.4)	9 (18.8)

* Figures in parentheses are row percentages

3.2.4 Staff

3.2.4.1 Dementia Knowledge & Beliefs

Pre and post Model implementation staff ratings of their knowledge and confidence in managing clients with dementia are displayed in Table 3-6. These items correspond to Questions 9 to 17 in the Staff Dementia Knowledge and Beliefs Questionnaire (see Appendix 14). At post-implementation, staff members reported a greater level of organisational support

in working with clients with dementia ($Z=2.83$, $p<0.01$) and RDNS was better equipped to meet the needs of clients with dementia ($Z=2.13$, $p<0.05$). There were no significant differences on any of the other items.

Table 3-6 Pre and Post Staff Self-Rating of Dementia Knowledge and Confidence

Item	Pre (n=66)		Post (n=47)		Z ^a	Sig.
	Mean [*]	sd	Mean	sd		
Knowledge about dementia	3.1	0.45	3.0	0.52	1.13	n.s.
Ability to identify presence of cognitive impairment	2.6	0.64	2.6	0.58	-0.54	n.s.
Confidence working with clients with dementia	2.5	0.62	2.6	0.58	-0.84	n.s.
Job satisfaction in working with clients with dementia	2.8	0.64	2.7	0.62	0.23	n.s.
Talking to clients about their dementia	3.0	0.56	2.8	0.68	1.51	n.s.
Giving advice regarding symptoms of dementia	3.1	0.59	3.0	0.55	0.81	n.s.
Talking to carers about the client's dementia	2.9	0.69	2.8	0.66	0.84	n.s.
Level of organisational support in working with clients with dementia	2.9	0.69	2.5	0.69	2.83	p<0.01
How well equipped is RDNS to meet needs of clients with dementia	2.8	0.77	2.5	0.62	2.13	p<0.05

* Lower mean values signify higher ratings of knowledge or confidence

^a Two group Mann-Whitney U Test

To explore further staff member's responses to the questions concerned with self ratings of dementia knowledge and confidence, the above analyses were repeated according to whether the staff member was a member of the core group or not and also whether they rated above or below the median years of experience as a Registered Nurse (median=15 years). A total of 13 core group members completed the Dementia Knowledge and Beliefs Questionnaire at the pre-implementation phase and seven completed the Questionnaire following the implementation of the Model. Analyses using the Mann-Whitney U Test revealed no significant differences on any of the items relating to self-ratings of dementia knowledge or confidence. However, staff who were not members of the core group reported higher levels of organisational support in working with clients with dementia ($Z=-2.34$, $p<0.05$) and a higher

rating of how well equipped RDNS was in terms of meeting the needs of clients with dementia ($Z=-2.19$, $p<0.05$). Analyses based on staff members years of experience since qualifying as an RN revealed a similar pattern of results with those who were less experienced reporting higher levels of organisational support ($Z=-2.24$, $p<0.05$) and a higher level of RDNS being equipped to meet the needs of those with dementia ($Z=-2.09$, $p<0.05$). Staff who were more experienced also reported a higher level of organisational support following the implementation of the Model ($Z=-2.01$, $p<0.05$). In addition, there was a trend for more experienced staff to feel greater confidence in giving advice to clients about managing the symptoms of dementia ($Z=-1.93$, $p=0.054$) and in talking to carers about the client's dementia ($Z=-1.95$, $p=0.051$).

Table 3-7 shows change in pre and post knowledge about dementia. There was a small but statistically significant increase staff member's knowledge about dementia following the implementation of the Model ($t=-1.99$, $df=109$, $p<0.05$). There was no statistically significant relationship between core group membership and years of experience as an RN and score on the dementia knowledge quiz.

Table 3-7 Pre and Post Staff Dementia Knowledge Quiz

Dementia Knowledge Score	Pre (N=65)		Post (N=46)		t	Sig.
	Mean	sd	Mean	sd		
% correct	67.4	9.3	70.9	9.1	-1.99	$p<0.05$

Pre and post-implementation findings regarding staff beliefs about dementia are displayed in Table 3-8. These items correspond to Questions 46 to 53 of the Staff Dementia Knowledge and Beliefs Questionnaire. The only significant finding relates to the statement "Families would rather be told about their relative's dementia as soon as possible" where there was slightly stronger disagreement following the implementation of the Model of Care ($Z=-1.97$, $p<0.05$). There were no significant differences on any of the other items.

To further explore the above items, supplementary analyses were conducted based on core group membership and years of experience as an RN. There were no significant differences from pre to post-implementation of the Model on any of the items concerned with staff beliefs about dementia in core group members. However, among staff who were not members of the core group, there was less agreement with the statement that district nurses have a limited role to play in the care of people with dementia ($Z=-2.22$, $p<0.05$). Nurses who were less experienced reported lower agreement with the statement that families would rather be told about their relative's dementia as soon as possible following the implementation ($Z=-2.43$, $p<0.05$) however this finding was not significant among more experienced nursing staff. Less experienced nurses also expressed lower agreement with the statement that district nurses have a limited role to play in the care of people with dementia at post-implementation ($Z=-2.81$, $p<0.01$). This finding was also non-significant in the more experienced nurses. There was a trend for less experienced nurses to believe that there is much to be done to improve the quality of life of carers of people with dementia ($Z=-1.92$, $p=0.055$).

Table 3-8 Pre and Post Staff Beliefs About Dementia

Item	Pre (N=66)		Post (N=47)		Z ^a	Sig.
	Mean [*]	sd	Mean	sd		
Much can be done to improve the quality of life of people with dementia	1.5	0.56	1.6	0.54	-0.94	n.s.
Much can be done to improve the quality of life of carers of people with dementia	1.4	0.53	1.6	0.58	-1.74	n.s.
Families would rather be told about their relative's dementia as soon as possible	1.8	0.65	2.1	0.84	-1.97	p<0.05
Providing a diagnosis of dementia is usually more helpful than harmful	2.0	1.06	2.0	0.89	-0.55	n.s.
People with dementia can be a drain on resources with little positive outcome	4.0	0.83	3.9	0.76	-0.89	n.s.
Working with people with dementia is often more frustrating than rewarding	3.6	0.88	3.5	0.72	-0.23	n.s.
There is little point in referring people with dementia to services as they do not want to use them	4.3	0.57	4.2	0.65	-0.48	n.s.
District nurses have a very limited role to play in the care of people with dementia	4.4	0.76	4.2	0.51	-1.82	n.s.

^{*} Lower mean values signify higher agreement with the statement

^a Two group Mann-Whitney U Test

Change in mean total and sub-scale scores on the Approach to Dementia Scale (Lintern, 1996) are displayed in Table 3-9. There were no significant differences from pre to post-implementation of the Model of Care in any of the Approach to Dementia Scores. For core group members, there was no significant difference from pre to post on any of the Approach to Dementia Scores. Among staff who were not members of the core group, there was a trend to score higher on the Personhood Score following the implementation of the Model ($t=1.95$, $df=89$, $p=0.055$). For less experienced nurses, there was a trend to score higher on the Total Score ($t=1.95$, $df=52$, $p=0.057$) and higher on the Personhood Score ($t=1.92$, $df=52$, $p=0.060$) following the implementation of the Model.

Table 3-9 Staff Approach to Dementia

Approach to Dementia Scale	Pre (N=65)		Post (N=47)		t	Sig.
	Mean	sd	Mean	sd		
Total Score	75.1	6.7	73.3	5.6	1.42	n.s.
Hope Score	28.1	3.7	27.7	3.3	0.57	n.s.
Personhood Score	46.9	4.5	45.5	3.8	1.80	n.s.

3.2.5 Overview of quantitative findings

During the Model implementation phase, nursing staff implemented the dementia Model of Care with 75 clients. A majority of these clients lived alone and the most common reason for referral to RDNS was for assistance with medication management. Cognition screening confirmed the presence of a cognitive impairment in the majority of clients. The importance of screening for depression/anxiety was confirmed with one-fifth of those assessed scoring above the clinical cut-off on the K10 tool. Nurses had a choice of using either the MMSE or RUDAS to screen for cognitive impairment. Most chose to use the RUDAS suggesting a preference for this tool irrespective of the client's cultural background. The Cognition Assessment successfully identified a range of additional problems and concerns in clients including falls risk, medico-legal issues, pain risk, alcohol abuse, sexuality/intimacy issues, medication risk and social isolation. The assessment also identified a number of carers with potential problems such as stress.

In relation to staff, the data suggests an increased sense of support from the organisation in managing clients with a cognitive impairment and an increased ability on the part of the organisation to meet the needs of this client group. Results from the ADQ revealed a trend for less experienced nurses to recognise the importance of adopting a more person-centred approach to working with clients with a cognitive impairment.

3.3 Qualitative findings

3.3.1 Staff

Concurrent with the quantitative data collection, focus groups were held to explore staff experiences of caring for clients with cognitive impairment both pre and post implementation of the new Model.

3.3.1.1 Sample

In total, 6 focus groups were held at Sites 2 and 3. Pre-trial, focus groups with field nurses and senior staff were held separately. The field nurses comprised the core group of staff (10 at Site 2 and 8 at Site 3) who implemented the Model with clients. These participants had varying levels of experience at RDNS, with Site 3 staff generally older and having more experience working in the organisation.

Those who participated in the Senior Staff group included Client Services Managers (Site Managers), Operations Managers and senior nurses, 5 at Site 2 and 3 at Site 3. Post-trial focus groups included both field nurses and senior staff in the same group. All participants were registered nurses - division 1.

3.3.1.2 Data Collection and Administration

See Appendix 9 – focus group guides.

Pre-trial, participants were asked to:

- Share their experiences of caring for people who may have a cognitive impairment
- Comment on positive and negative aspects of delivering services
- Comment on resources and support that are available
- Describe how services could be improved

Post-trial, participants were asked about:

- The content of the Model
- The process of implementation of the Model
- Their experiences of using the Model of Care
- How the Model could be improved

Site 1 staff were asked the same questions as the Site 2 and Site 3 staff, with the addition of questions around the nurse-to-nurse training process. Data were managed in a similar manner to the Site 1 qualitative data described in Chapter 2.

3.3.1.3 Pre-trial results

Themes identified in the pre-trial focus groups can be grouped according to two general headings: approaches to care and resources.

Approaches to care

Discussion of ‘approaches to care’ was wide ranging, included nurses describing varying confidence in providing dementia care; a sense of task-orientation and barriers to providing holistic care; importance of rapport with clients and carers and continuity of nurse; the need for guidance in care provision; perceived risks to clients; and considerations around the presence or absence of carers for clients.

Confidence managing clients with a cognitive impairment

Prior to the implementation of the Model, nurses expressed varying degrees of confidence in caring for clients with a cognitive impairment. While some said that they were confident (“we do it every day”), the nurses listed various concerns impacting on their ability to care for clients with a cognitive ability.

‘I feel that (we are) on the ball (caring for clients with dementia), but obviously there’s always room for growth and development. (senior staff, Site 3)’

However, some acknowledged that the provision of care for people with a cognitive impairment was a “high level skill” and, in a generalist environment, it was difficult for nurses to be “experts about everything”.

Holism versus task oriented care

Many participants referred to the provision of ‘holistic’ care (i.e. consideration of the whole person rather than an individual presenting health issue) as a core RDNS value. However, they expressed concern about their ability to provide holistic care, describing their care as “task oriented” (i.e. limited to administering medication or changing a wound dressing):

‘A lot of the staff felt dementia care was very task orientated in their centre. That astonished me and disappointed me a little bit because ... I find most of our staff are really tuned in to all the other issues, not the tasks.’ (senior staff, Site 3)

However, some nurses described information gathering through conversation with clients while doing nursing tasks:

‘A lot of those questions, I do while I’m doing the wound. I just ask them, ‘Do you need someone to cook for you?’’ (nurse, Site 3)

Rapport and Continuity of Nurse

Participants described the importance of continuity of nurse and consistency of care for people with cognitive impairment, and the challenges to clients without continuity:

‘You’ll occasionally get “trying to get continuity of staff for this particular client” (on the episode notes) because you do get clients that are thrown by different people coming in.’ (field nurse, Site 3)

An important outcome of continuity of nurse was felt to be building of a rapport with both clients and their carers which facilitated trust and co-operation. Nurses were concerned that time constraints may cause nurses to go in “too hard, too fast”, wanting to deal with concerns too soon, before the client is ready and receptive to deal with them:

‘It is like building a relationship – I think it’s the starting point for everything. If you identify issues and you just push into them, they won’t listen to you. But if you go the other way around, they might listen, they might accept what you suggest.’ (field nurse, Site 2)

Need for guidance

Like the nurses at Site 1, Site 3 and Site 2 nurses indicated a desire for structure and guidance.

‘You could get in there with this long visit to try and support and find yourself dancing around and scratching your head, or I would.’ (field nurse, Site 2)

A significant finding was nurses’ perception of a lack of clarity around their role in responding to clients with a cognitive impairment. They asked questions such as: Is it my job to fix this? Or does someone else do it? Or is the carer supposed to do it?

'If people perceive that you're doing too much, it's an issue. We have a responsibility to go only so far and then look at getting case managers in or getting a social worker in. But where's that boundary where we stop and get more people into aid?' (nurse, site 3)

'...where there's no case manager the staff virtually take on a case management role.' (senior staff, Site 3)

Participants described identifying a problem for a client or a carer and having insufficient knowledge or resources to guide them in their response. They specifically suggested guiding documentation for clients with cognitive impairment. One nurse said that she would like nurses to better promote a client's independence.

Perceived risk for people with a cognitive impairment

There were references to concerns about the safety of people with a cognitive impairment:

'The staff are really switched on to all of those other related issues (such as) potential abuse and financial abuse and emotional abuse and things like leaving the gas on and starting to wander.' (senior staff, Site 3)

Another area of concern were clients who do not want support services. One participant suggested that clients' unwillingness to access services may be due to depression and anxiety:

A lot of people with dementia have depression or anxiety with it (dementia), so that combination certainly keeps you(the client) from going out too often. (field nurse, Site 3)

Carers

An important finding was the variation among nurses of their definition of a carer. Moreover, they were explicitly aware of a wide variation in definition, and that affects how each nurse makes decisions and conducts their care:

'Everyone's got a different interpretation on [who is a carer]' (Field nurse, Site 2)

'If they only come once a week and they do shopping and things like that, then you assume that they are the carer then, aren't they?' (field nurse, Site 2)

Participants described being concerned about some carers' capacity to care because of their own health problems, and that carers may not understand the behaviour associated with cognitive impairment:

'... this person said "well my mother is just downright selfish". But she's not selfish, she's trying to cope with her last little bit of memory.' (field nurse, Site 3)

Furthermore, participants discussed families who do not accept services that may assist the client, are resistant to assessment and referral to Cognition, Dementia and Memory Service

(CDAMS). Some felt this reflected a lack of understanding on the part of the carer and suggested carer education would help. Notably, nurses pointed out that carers were not their clients, but wanted to provide better support for carers. Nurses felt they were in a good position to identify “carer stress” through their encounters with carers as part of their regular presence in the home:

‘There needs to be room out there for the carers and their understanding of dementia... Carers aren’t actually our client. We’re so focussed on the client. But you can’t really have the client without the carers.’ (senior staff, Site 2)

There was concern for clients without carers. Nurses emphasised these clients were more likely to have poor insight into their deficits because they don’t have ongoing feedback from family or friends about their forgetfulness or behaviour. Nurses viewed those clients living alone with dementia as often in crisis.

In summary, issues around ‘approaches to care’ included nurses varying confidence, a sense of task-focus and barriers to holistic care, importance of establishing relationships with rapport with clients and carers (particularly through continuity of nurse), the need for clinical guidance, perceived risks to clients, caring for carers and for the particularly vulnerable clients without carers.

Resources

Issues around ‘approaches to care’ as described above were felt to be related to availability of certain resources. A perception of scarcity of nurse’s time was seen as a major barrier to improving approaches to care. Education, knowledge and experience were also considered important resources for nurses, as was the availability of an Aged Care Clinical Nurse Consultant. These three resources were seen as intrinsically linked.

Time

Participants suggested that their main concern in providing care for people with a cognitive impairment was a lack of time to provide optimum care; they knew what to do but did not have time to do it:

‘In the ideal world, for my staff to be able to take a moment and put that extra hour here, or hour there, so that they can put things in place so that maybe (clients can) manage a little bit longer on their own.’ (senior staff, Site 3)

However, additional time was not a stand-alone solution for meeting client’s needs. This quote, used earlier to illustrate the nurse’s desire for guidance and structure, demonstrates that not all nurses knew how best to use additional time:

‘You could get in there with this long visit to try and support and find yourself dancing around and scratching your head, or I would.’ (field nurse, Site 2)

Education, knowledge and experience

Some staff described concerns about their lack of experience and knowledge in caring for people with a cognitive impairment.

'I just know enough to know I don't know enough.' (field nurse, Site 3)

Further to this, some described a lack of ongoing education about cognitive impairment, as well as about how to use standardised tools:

'There's very little (education), and when you consider the percentage of clients, how we deal with them, I think we should have a lot more education.' (field nurse, Site 3)

A participant from Site 3 site, which does not have an Aged care CNC as a dementia expert resource, noted the value of the Aged Care CNC in education and training:

'It's only meaningful for staff if that Grade 4 is with that other staff member for that professional development. It doesn't mean anything for that Grade 4 to go out and sort it out in the home if the staff aren't learning from that experience.' (senior staff, site 3)

Role of the Aged Care Clinical Nurse Consultant (CNC)

Participants at Site 2 site described the role of the Aged Care CNC as working well with benefits including the provision of clinical guidance and education as well as liaison with other service providers:

*'... the CNC can confirm and maybe suggest other things that may be of benefit to the client and tailor the care to the client. (post-trial, Site 2)
I am finding ACAS (Aged Care Assessment Service) have been a bit more proactive with our referrals now as a result as well (of the CNC). We're not so much on our own anymore.'* (post-trial, Site 2)

Site 2 staff said learning about how to refer clients with dementia, and who to refer to, took time. The Aged Care CNC was an important holder of this information and of working relationships with other agencies. A participant noted the role of the Aged Care CNC is particularly important for clients without case managers or other services:

'It's probably taken 9 years to get (my) head around the services out there and what's available... it takes years to know where to refer, how to refer, what they need, what to wait list them for...' (senior staff, Site 2)

Collaborations with other service providers

Some senior staff described themselves as good at accessing both services and resources. These participants worked collaboratively with other service providers:

'We find the staff are pretty good at accessing resources. They need to find out how big that problem is – family members, GP's, geriatricians, whoever might have been involved.' (senior staff, Site 3)

Participants would like to have better links with other service providers (e.g. ACAS, GPs). They felt it was important to know what services were available so they were able to provide choices for clients. A succinct list with details of other services would be “fantastic”:

‘We need something to prompt you of where to go next. Have you referred to this? Are they linked into this? Like a flowchart.’ (field nurse, Site 2)

‘I only learnt that by doing research and trying to find these clients a multicultural case manager, and talking to ACAS.’ (field nurse, Site 3 ,)

Site 3 staff described the relationship with ACAS as ‘strained’:

‘There is a strained relationship between us and ACAS because both our services are completely flat chat and there’s no room to come up to breathe.’ (senior staff, Site 3)

Whereas, at Site 2, participants attributed their good relationship with ACAS to having an aged care CNC on site:

‘When we go to these meetings, all the service providers are there... I have good relationships because I see them personally.’ (senior staff, Site 2)

Staff said that they would like to have better working relationships with GPs, including having a process for providing succinct information to GPs:

‘We’ve never had the evidence to fax to them (and say) “look I’ve done this assessment”. The Mini-Mental is not really sufficient.’ (senior staff, Site 2)

Participants were concerned that some nurses new to community nursing did not know about the services that were available.

3.3.1.4 Summary of pre trial focus groups with staff

Several pertinent ideas emerged repeatedly from the data. Nurses’ general level of confidence was high, and they acknowledged the advanced skill level required. This was felt to be difficult to achieve in an environment where they require skills in a range of specialties. The nurses recognised the breadth of care needs associated with the client with cognitive impairment beyond the ‘reason for referral’ (such as wound care or medication management). They felt impeded in addressing these broader needs by restricted resources, namely a perceived lack of time, knowledge, access to information, guiding documentation, communication with and access to other service providers. The presence of an Aged Care CNC with experience and local knowledge was seen to be of great benefit in addressing these obstacles. The nurses had questions around the boundaries of their role, both in the care of the client and carer and were concerned with safety risks and issues affecting those clients who do not have an informal carer.

3.3.1.5 Post-trial results

Themes of the post-trial focus groups revolved around elements of the Model, notably the assessment, care plan, education and the role of the Aged Care CNC. There was also comment on workability of the Model its implementation.

Nurses experiences of the content of the Model

Both Sites noted that trial of the Model of Care at their site fostered a more acute awareness and better understanding of the cognitively impaired client's care needs. They were very supportive of the Model in principle but expressed concerns about workability.

Participants from Site 2 were particularly supportive. They also said that long-term implementation would require more resources:

'Everyone in this room has had huge benefits from doing this, obviously it's fully supported.' (Site 2)

'Ongoing, long term, as a site, we would need more FTE, more resources and more staff and more hours.' (Site 2)

At the Site 3 site, one participant described the Model as "all very nice, but it's not workable in the situation we have at the moment, particularly with HACC (Home and Community Care) funding":

'To get really involved in dementia care, you need an enormous amount of time. It's just not available for the sessions we do. I don't think it's practical to actually do it. It's an idealism.' (Site 3)

Assessment

The assessment tool as provided more information than a general assessment giving nurses more "insight into the person":

'I find that this is really good. Clients we're seeing for wound care or diabetes, continence or something, who you know that they've got some deficit. This is good because we've never had anything like this to use before. To check it out.' (Site 2)

One participant referred to the assessment tool as providing "evidence" to family members who may not be accepting of a deterioration, or to other health providers such as GPs or case-managers who may not have as much regular contact with the client in their home. The nurses felt empowered by the assessment to go beyond statements such as "she's struggling" to provide measured objective data.

Some elements of the assessment were thought to present particular difficulty for CALD clients:

'With CALD clients, general questions about their significant life events and the depression scale were difficult to translate. It might be because of the dementia, but things (that) did translate also were not answered well.' (Site 2)

For some clients the assessment tool was considered to be long and tiring, while other clients were felt to be "loving the interaction", especially those who lived on their own. Nurses described clients as "engaging" with the assessment tool:

'They're after that companionship and the talking and the opening up, and somebody showing an interest in them. Sometimes when we go in there, we're quite task focused.' (Site 2)

Many described successfully administering the assessment tool over several visits. In cases where the client's cognition is less impaired, nurses were able to administer the tool in one visit.

The Rowland Universal Dementia Assessment Scale (RUDAS) was described as "fantastic, fun, user-friendly, interactive and less confronting", particularly for CALD clients:

'It's not based on education or language and that's half our clients (CALD or low literacy).' (Site 2)

'It's more like an interaction rather than a test so they're not on the spot.' (Site 2)

Some participants described RUDAS as an "ice-breaker". One participant said that using the assessment tool made her more comfortable with using interpreters:

'It was kind of an ice-breaker because it's at the start of the assessment. They have a bit of fun with youA lot of them enjoyed doing it.' (Site 2)

The need for rapport with clients

Participants described needing to have established a rapport with clients before administering the assessment tool:

'You need a rapport with them because you are asking the really personal questions and especially if they are already defensive about their dementia.' (Site 3)

Promoting relationships with clients

Participants stated that the assessment tool assisted nurses to learn more about their clients and promoted the development of a relationship. Inclusion in the assessment of questions about safety, particularly driving, were welcomed. Some nurses experienced disquiet about asking the more sensitive questions and suggested re-wording. Some participants described the more intimate questions (e.g. sexuality, depression, life history) as useful for understanding a client's social circumstances as well as their behaviours and other ways their cognitive impairment manifested. However, some participants described clients becoming "upset" at some of the questions, particularly questions about their past:

'Depression was a big one ... to actually answer those questions and realise that 'yes maybe I do have' it was very confronting for both the client and myself. You had to be careful how you approached them.' (Site 2)
'Another one said he remembered Rommell's troops coming towards them, and he ended up in tears. Sometimes we stir up things that really are unnecessary.' (Site 3)

Part of the assessment involved questions for carers. Nurses' differing views about what constitutes a 'carer' influenced whether the nurse approached those family or friends closest

to the client. Sometimes, nurses found the carer did not want to participate in the Cognition Assessment:

'It wasn't appropriate to ask the carer because they only came once a week and they didn't really do any physical caring.' (Site 2)

'The clients that I had, their carers didn't want to be involved in answering the questions ... which I thought was surprising because I thought they would have.' (Site 2)

Care Plan and GP Communication Form

For one participant, the care plan was “the best care plan I’ve ever seen”. Participants described the care plan as “very detailed” and a “good source”. They also found it helpful – it “guides you to what you may need”. One participant said finding out more about a client through the assessment enabled her to develop a care plan that included referral to the Mental Health CNC, another included a referral to the CDAMS. One participant described the care plan as positive because it entailed a formal commitment to provide follow up care:

'(Once you have) put it on a care plan, they're going to have to allow the time for it, because legally they've assessed the problem and legally they've assessed what needs to be done They're going to have to stick with the primary nurses allowing time for this care to be done.' (Site 3)

Some nurses, notably at Site 3, did not like the ‘tick box’ format of the care plan, preferring free text. Others felt this format was a useful prompt. One participant questioned whether nurses would look at the care plan:

'It's easy to tick boxes. But are people actually going to go through a Care Plan where you've just ticked boxes and look at it?' (Site 3)

Some suggested a separate smaller care plan that summarised the most important information. Another suggested a fictitious, ‘demonstration model’ care plan should be included in the resource manual as an example.

One participant suggested that it is what nurses ‘do’ with a care plan that ultimately matters. There was a suggestion that a good care plan may be written but not followed through:

'It's what they do with it, that's where the education... where do you now go with that, you just don't just manually write everything... People didn't make that connection.' (Site 3)

The GP communication form was welcomed as a good strategy across the three sites however it was not used extensively, partly because the new form was not developed and introduced until later in the project. It was noted that the communication to GPs wasn’t reciprocated. Site 2 participants commented that their colleagues had used the form:

'We'd fax off a GP Notification Form for feedback, and I never got those back so I'd ring the doctor and never got anything back from him.' (Site 1)

Education and training

Both the education and training sessions were described positively, with each complimenting the other. Participants said that the education raised awareness of their baseline knowledge about dementia, and their “obligations in reference to dementia care”. Doubling with an experienced aged care practitioner (Clinical Project Officer) ‘in the field’ helped staff to become familiar with the new Cognition Assessment Tool and provided context for the education. Participants also described the assessment tool as providing a prompt which acts as a learning aid in itself:

‘(Without the aged care expert), there would have been no guidance, no direction. You would have struggled implementing any of it – like doing the assessment. If I hadn't gone with her to do that first one, I wouldn't have got it so fast.’ (Site 2)

Participants suggested that the Model needed to be supported by educational resources. The Aged Care CNC was highly valued as an education facilitator.

‘You'd have to have an education package around it, Aged Care Consultant to deliver it, some sort of form of assessing it on the ground.’ (Site 3)

Role of the Aged Care CNC

Notably, the Site 2 staff implemented the Model with greater numbers of clients than at Site 3, which may be related to the presence of the CNC.

‘I think it's a huge benefit having an Aged Care CNC...I think she was a huge driver in coordinating this.’ (Site 2)

At Site 3 site, where they do not have an Aged Care CNC, the more senior staff did not personally feel they needed access to the clinical advice of an Aged Care CNC, but that it would be useful to support less experienced staff with clinical decision making and information about referrals and local support services. One nurse said she didn't always know who to approach and an Aged Care CNC would “hopefully provide that local knowledge”.

‘I mean there might be some people that haven't had enough experience... but I would think that the majority.... seeing as most of our group here are somewhat older... I think with younger staff who are inexperienced (having an Aged Care CNC) would be enormously helpful.’ (Site 3)

Nurses experiences of implementation of the Model of Care

Comments from some nurses about the potential difficulty of conducting the assessment during the initial admission indicted a need for more clarity around when and how to proceed with the assessment – i.e. after development of a rapport with the client.

Role of the Aged Care CNC in implementation

In addition to her clinical role within the Model of Care, the Aged Care CNC at Site 2 enabled and motivated staff throughout the staged implementation of the Model. Without the ongoing ‘driver’ the staff at Site 3 may have lost momentum. For example, although the care plan and GP form and education sessions were provided at the same time to Site 3 and Site 2

sites, there was a perception from some Site 3 staff the rollout of these was not well supported or even communicated.

Nurses decision making on the appropriateness of the Model for individual clients

Nurses involved in the Model implementation were provided with a list of clients who met the criteria for participation in the project, as described in Chapter 3 (page 36). For those clients they felt were not suitable to be approached to take part, they were asked to document the reason. They said that some of their clients on the list were inappropriate, and some would not want to participate:

'If we are going in for medication management, sometimes it's a struggle to even get them to agree to have us in there. So if we are going in there and saying "So what's the memory that you remember the most?" or "I am going to test you know how you remember things", I don't think we'd be received very well.' (Site 3)

Only a few participants at both sites had used the care plan, in part due to the development and introduction of the care plan later in the trial. Some of the difficulties were due to the length of time between doing the assessment and the care plan. Opinions about the form of the care plan differed. Perception of the tool may have influenced willingness to use it.

'It is hard to go back to reopen the assessment to get what you had to, the outcomes to follow up. We did some of our assessments last year in November, so we had to go back to reopen it to refresh and open all the sections up.' (Site 2)

Future use of Model

Participants at Site 1 and Site 2 expressed an interest in continuing to use the Model, particularly the assessment tool. A nurse from Site 3 alluded to apprehension that the Model may not be implemented across the organisation.

'It gets a bit demoralising when you put the time into these things and find they've been shelved.' (Site 3)

Site 1 (Development Site) specific issues

Nurses from Site 1 had more direct involvement in the development of the design of the Model and were exposed to the Model for a longer period of time, however many of their experiences reflected those of Site 2 and Site 3 . Site 1 alone trialled nurse-to-nurse training.

Nurse to nurse training

Nurse to nurse training at Site 1 was described as good for keeping nurses "on track", and it was considered better if the 'doubling-up' occurred more than once. Participants acknowledged the potential for inconsistency where numerous nurses are training one-another.

'Everybody gets a different slant on something....' (Site 1)

One participant highlighted the benefits of receiving peer training by a nurse with significant expertise in aged care.

'I was being taught by the best. I was fortunate in that respect (Site 1)

Interestingly, though only Site 1 formally trialled the nurse to nurse training, one nurse at Site 2 introduced a new colleague (a novice district nurse) to the assessment tool and found it a positive experience.

'I actually did a double with one of the new staff members. It was on my list and I was actually doubling with her for the day. She found it quite good, she actually did it while I sat there.' (Site 2)

3.3.1.6 Summary of post trial focus groups with staff

The post-trial focus groups demonstrated that staff at all trial sites supported in principle and welcomed the Model of Care as an important step forward in nursing care of RDNS clients with cognitive impairment. This enthusiasm was tempered by concerns around the feasibility of the Model, mainly associated with time limitations and procedural issues rather than inherent problems with the design of the Model. Comments on the content of the Model focused on four elements: the assessment tool; education, care plan and the role of the Aged Care Consultant.

There was a heavy emphasis on the Cognition Assessment Tool, which was felt to be the central component of the Model. Some staff used the terms 'model' and 'assessment' interchangeably, perhaps because of the fundamental importance of the information gathering process needed to plan care. Staff noted the value of the Cognition Assessment in relationship building and getting to know the client, although sometimes conducting the assessment felt long and repetitious. The data gathered in the assessment provided valuable tangible evidence to forward to GPs and ACAS.

Some nurses were more welcoming of the assessment and care planning tools than others. Generally, more senior, experienced staff placed less value on the tools and more emphasis on the burden of the time and resources, preferring to rely more on their experience and intuition. Although some nurses state that they were comfortable with their intuitive interpretation of client's impairments and needs, the data shows discrepancies between intuition and scores on standardised screening tools.

Suggestions

There were important suggestions for practical modifications and guidelines for the use of the Cognition Assessment tool, such as:

- conducting the assessment over several visits
- conducting the assessment only after a rapport with the client (as subjectively determined by the nurse) has been established
- allowing an average of 90 minutes overall to conduct the assessment (with much variation depending on individual client's needs).
- working towards having electronic assessments cross-populate data fields to improve efficiency and reduce repetition of information gathering
- rewording of sensitive questions around intimacy and depression

The care planning tool, staff education and the role of a dementia expert such as a CNC were also emphasised. References to the value of access to dementia experts were a feature of the discussion, some of the suggestions being that every site have an Aged Care CNC, and that the organisation develops an expert “*dementia team*”.

3.3.2 Interviews with carers

While it was the intention of the study to interview clients about the Model of Care, 2 initial interviews revealed the complexities involved in eliciting information from clients, including client’s limited ability to recall information. Further research is required to ascertain the most appropriate method.

3.3.2.1 Method

Carers of clients who participated in the trial of the Model of Care were interviewed at the conclusion of the trial to explore their perceptions of the Model of Care and describe any impact it may have had for themselves and for the client (see Appendix 9).

Five carers were interviewed. All were family members who did not reside with the client to whom they provided care. Four were women, three of them daughters and the fourth a wife. The fifth carer was a son. The carers were interviewed in their own home or in the home of the person they cared for, depending on their preference.

The carers were asked to comment on:

- The cognition of the person they care for and the impact that cognitive deficit has on their lives and relationships.
- Their understanding of the purpose and benefits of the nurse’s visits and any changes to care which may have occurred as a result of the Model.
- Their experiences relating to the implementation of the Model, particularly the assessment.
- Any negative aspects of nursing care and their ideas for improving care.

Three of the five carers said that they were not present for the assessment, while two carers could not confirm whether or not they had been present. Those who commented on the assessment questions were therefore speaking hypothetically about the possible value of the assessment questions. The findings are not generalisable due to the small client and carer sample size

3.3.2.2 Results

In the analysis of focus groups with nurses, there were definitional issues around “who is a carer?” The interviews with carers add interesting insights and provide descriptions of the role of the carer from the perspective of a carer. Although carers who were interviewed did not live with the client, all described visiting the client often:

‘I clean up and put things away around the house, pay all the bills for her. She’s had a tendency to lose some of them lately. ...I have also been trying to manage to get a few things fixed around the place.’

One carer (a daughter) described a family structure where her parents lived together and the adult children who lived elsewhere were the main carers for her mother (the client):

'She couldn't stay on her own, she couldn't be there on her own... My dad's home too. He takes a little care. I feel like he should be doing more as well.'

All carers described clients with a degree of cognitive impairment which meant that the client was unable to manage at home without support. One carer described the support by RDNS as crucial in enabling her mother to stay at home:

'If it wasn't for the nurses and council care, and probably us, she wouldn't be at home.'

Role of the nurses

The carers described the benefit to the client of having a nurse 'looking out for them', and more specifically, being more willing to listen and adhere to health advice when it was provided by a nurse. Another carer described the nursing care as helping her father to take some personal responsibility for his cognitive impairment:

'All these things that have been put in place have given him a reason to care and to help... Now he's realising "Oh hang on, I am going to have people worry about me, people care about me, I don't want to put my daughter through that". So he's taking responsibility now...It's taught him to take responsibility for his health.'

One carer described the importance of targeting services for the specific needs of the client (i.e. client-centred care) rather than a 'one-size-fits-all' approach:

'She seems to want to just stay home. She's always been that way. She's not a person to go out and talk to people. When trying to arrange that sort of thing, she's been a bit upset about it. She doesn't want to go. For other people it might be fine, but I don't think she'd actually like it. It might be a strain for her. I don't think she could cope with it.'

Participants were asked whether they had noticed any changes in care since the implementation of the Model – for example, frequency of visits or the type of care, and whether there were any referrals made or new services started. None of the participants were able to identify any changes in care as a result of the Model.

The carers described most of the care provided by the RDNS nurses as related to medication management:

'They come in the morning and give her the medication she needs... So that's a great help for me, not having to run every morning to give her the medication... They have assessed with her incontinence and they've provided some pads. That's it.'

'They administer her insulin every day, they test her sugar level and then they give her insulin. Sometimes they help her get her breakfast ready – they might warm up the milk for her cereal. At the moment she's got an ulcer on her toe again, another one, so they're attending to her wound care as well.'

Relationships with clients and carers

Most of the carers suggested that the client needed and benefited from the nurses' support and the regularity of the contact. They also describe the nurses as providing not only a benefit to clients but also providing peace of mind and relief for carers:

'The social contact is the more important part of it. The tablets are important, but the social contact is actually more important. You feel as if you've got some support. They know what they are doing. They've always been very good, we've appreciated what they have done for us.'

There was a suggestion that nurses spend more time talking with clients and carers:

'They tend to come in and go. I haven't been here that often to see what they do... I wish they could stay a little bit longer, so I could chat with them a bit more. That's probably the only downside.'

It was suggested that engaging more with the carer would benefit all parties. The nurse can benefit from the carer's role in ensuring care is 'followed up'. The carer may feel empowered by being actively involved in the care, which potentially improves outcomes for the client:

'When they are telling dad something to do – maybe if he tries this it will be better – and then to bring me in to say "I've told your father this. Can you just keep that up with him?" That helps them (the nurses) too because it's helping dad to listen to them, knowing that what they are saying is really being heard and it's being followed up with some help from somebody else, which makes their work a lot easier too. It helps everybody... whatever they are doing to bring, to kind of let the carer know.'

Education

Education for carers about cognitive impairment is traditionally accessed from support organisations like Alzheimer's Australia and Carer's Victoria. Nurses can link carers in with these organisations using the resource folder provided as part of the Model. None of the carers interviewed were offered information about education. There are no formal processes for carer education by visiting nurses, although they may impart information as part of their day to day contact with clients and carers.

Carers described the importance of education in helping them to provide appropriate care, however the practical examples given were in the management of diabetes and heart conditions:

'I learnt a lot about sugars and salt that's in different foods. That was very good for me, and helped me when I do shopping for him what to buy, to look at the back at the sugars and he's changed his diet a lot since he's had the help.'

Carer's comments demonstrated uncertainties in their understanding of dementia that could potentially be addressed by education and provide them with valuable insight to help them fulfil their roles:

'...she tends to repeat actions, I don't know what's causing that, whether that's memory or not.'

'I don't know whether that would help or not because I just think it's part of her growing old that this is happening.'

Finally, several carers described concerns about the future, and indicated that forward planning, guidance and advice about future options would be beneficial:

'They can give me advice about how to go about it, who to talk to, what places are available all that sort of stuff.'

'(When) her memory gets a bit worse and she gets a bit more frail, I am probably going to need some kind of help. I am not going to try and do it all by myself because then I will run myself ragged.'

Carers' views of the assessment

Two carers said that they could not remember whether they had been present for the assessment. A carer described 'losing track' of the numerous assessments that take place.

One carer described knowing about the assessment, though she was not present during its administration. The carer said that her mother enjoyed "the chat":

'I knew about it because my sister had told me about it, otherwise we probably wouldn't have known, unless someone called us, and I think she had an interpreter as well, she would have had an interpreter... she just said the nurse came back and had a chat, and she likes to have a little visit.'

Another carer said that she chose not to be present for the assessment because it would exacerbate tensions with her mother-in-law:

'I preferred them to do (the assessment) themselves. If I say something, my mother-in-law gets very upset and aggressive, because she doesn't believe what I am saying. She thinks I am lying.'

Carers were asked for their views about the life history questions on the assessment. One carer said that it was "definitely important". She described her mother's upbringing and cultural practices as impacting on her mother's current behaviour. She suggested that such background information was necessary for nurses to get the 'big picture'.

One carer said that it would help her to know the outcomes of the assessment. She indicated that she valued the RDNS' professional assessment:

'I am not sure how they assessed him and what they said. So maybe if one of the nurses want to give me a call, and we could discuss what went on with that, because Dad hasn't even mentioned it to me.'

3.3.2.3 Summary of thematic analysis of carer interviews

The five carers interviewed valued the support and professionalism of the nurses in their interactions with both clients and carer, however they suggested there was scope for more engagement and better communication with carers. They alluded to the benefit of being provided with information about possible services and sources of advice, and assisting carers to plan for the clients' future needs.

Carers confirmed that a client's life history impacts on a client's behaviour. They suggested that nurses knowing about a client's life history may result in more personalised care. This suggests that practices which explore and respond to clients' life histories may assist in the delivery of more appropriate and person-centred care.

4 Discussion & Conclusions

4.1 Overview of Project

The current project sought to develop and evaluate a best practice Model of Care for RDNS clients with dementia or a cognitive impairment who received home-based nursing services. To facilitate acceptability and feasibility, the Model development process involved a continuing process of consultation and review with relevant stakeholders, including experts in dementia care, nursing staff and consumers. The Model was piloted in one RDNS Site and feedback then informed further development prior to implementation and evaluation in a further two RDNS Sites. Quantitative and qualitative information collected from nursing staff, clients and carers was utilised to explore the effectiveness of the Model. The key findings of the evaluation are outlined in the following section.

4.2 Limitations

There are a number of limitations of the current project which may have an impact on the interpretation of findings.

Firstly, the Model was trialled in only one metropolitan district nursing organisation. As all community health organisations vary in the characteristics of their client populations and the environment in which they operate, the Model may not be transferable to other settings. Furthermore, the implementation period was short (three to four months) and may not have allowed sufficient time for the nursing staff to become fully acquainted with the Model of Care or for measurable changes in client and carer outcomes to occur. It will therefore be important to conduct further investigations on the impact of the Model on long-term outcomes including quality of life, referrals and the effect of care planning and interventions on identified issues. For staff, rigorous matched data on change in confidence, knowledge and approach to working with clients with dementia should be collected. Furthermore, the effect of the Model on long-term change in clinical practice should be investigated. Despite these limitations, a number of key findings have clear significance the provision of care to people with dementia living in the community.

4.3 Discussion of Key Findings

A substantial list of barriers to the provision of effective care to clients with a cognitive impairment was identified in Phase 1 of the project. Overall, the findings of Phase 2 demonstrate that a large number of these barriers have been addressed via the implementation of the Model of Care. In particular, the Cognition Assessment has been shown to be effective in identifying issues and problems in clients which have not previously been identified. Furthermore, the Model provides the foundation for the implementation of a person-centred approach to dementia care which supports relationship building and manages client risk identified through rigorous and targeted assessment.

Nurse's experiences of this new Model of Care varied and were sometimes contradictory. This reflects the highly individual impact of cognitive impairment on people, and the variable experience and skills of nurses. A highly flexible Model of Care is required to respond to these variables, including comprehensive education for nurses and access to staff (e.g.

Clinical Nurse Consultants) with well developed skills and experience to support the nurses to provide responsive and flexible care.

4.3.1 Cognition Assessment

The Cognition Assessment Tool was a major focus of the Model of Care for the nurses, with some using the terms 'Model of Care' and 'assessment' interchangeably. Prior to the implementation of the Model, many nurses intuitively identified and managed problems. Although this approach may be effective in many cases, particularly where the nurse is experienced in working with clients who have a cognitive impairment, many issues and problems may be missed and, as a result, the care planning process may be compromised. The standardised approach to assessment for clients with a cognitive impairment developed in this project provides a robust and valid alternative.

Importantly, nurses saw the Model of Care, with the Cognition Assessment Tool at its' heart, as addressing their clearly articulated desire for greater guidance and structure in caring for cognitively impaired people. Cognition is seen by some nurses as less tangible than other areas of nursing. In this project, nurses responded with enthusiasm to a Model which framed cognitive impairment in a more approachable and evidence based way. The collection of targeted assessment data was seen to form a coherent basis on which to work with clients to identify goals and plans for nursing care.

There were a total of 75 clients assessed using the Cognition Assessment Tool, 58 of whom were assessed as having a cognition impairment or high suspicion of cognitive impairment. The RUDAS cognition screening tool was more favoured over the MMSE, with the nurses choosing to use the RUDAS for the majority of assessments. Although the RUDAS was specifically designed for CALD clients and clients with lower levels of education, the nurses thought the RUDAS was more enjoyable for both client and nurse, aiding the rapport and relationship building process. The fact that nurses chose to use the RUDAS rather than the MMSE with many clients, irrespective of their cultural background, provides some basis for considering the RUDAS as the cognition screening tool of choice for community nursing organisations.

Depression and dementia can be difficult to differentiate as they share a number of common symptoms including confusion, memory loss and difficulty concentrating (NICE & SCIE, 2006). Equally, depression can co-exist with dementia (Alberta Clinical Practice Guidelines Program, 2007; Black, LoGiudice, Ames, Barber, & Smith, 2001; Naidoo & Bullock, 2001) with symptoms of depression found in as many as 40-50% of people with Alzheimer's disease usually in the earlier stages of the disease progression. Through the use of a valid and reliable depression assessment scale, we found that 15 clients screened positive for depression/anxiety, with 8 of those 15 suggestive of severe depression requiring referral for specialist mental health services support. Based on this information, subsequent referrals were made to the GP, Aged Persons Mental Health Team or RDNS Mental Health CNC. This clearly demonstrates the importance of depression screening in this high risk population. It should also be noted that depression is a reversible condition that usually responds well to treatment thereby prompt recognition may have a positive impact on the client's quality of life and possibly reduce morbidity and mortality (Registered Nurses Association of Ontario, 2004). However, some nurses expressed a level of discomfort when asking clients about sensitive issues including depression and it was noted that the K10 screening tool was not easily translatable for CALD clients. This is an area for further investigation.

Like depression, the incidence of delirium is high in older adults and is difficult to recognise as it is often confused with dementia (Harding, 2006). Delirium impacts on the cognitive functions of orientation, attention, memory, planning and organisational skills. The key to diagnosis is the fluctuating and acute onset (Black, et al., 2001). Two clients screened positive to delirium through the use of the Confusion Assessment Method (CAM) in the Cognition Assessment. Although this is a small number of clients, we must be mindful that delirium is an acute medical condition and should be treated as a medical emergency (Harding, 2006) and, for those two clients, an early response may have improved their recovery.

Part B of the Cognition Assessment covered a range of areas known to frequently occur in conjunction with and to complicate the presentation of a cognitive impairment. An analysis of the outcomes from this part of the assessment suggests it was successful in terms of identifying a range of issues which might otherwise have been missed. The presence of cognitive impairment and/or dementia may affect the client's ability to manage their legal and financial plans at a fairly early stage and, as the dementia progresses, there may be an impact on the person's health care decisions and domestic arrangements (QUT, 2008). There is a strong drive by advocacy groups such as Alzheimer's Australia to ensure that any person who is in the earlier stage of dementia is made aware of the need to consider forward planning issues such as drawing up an advanced care directive, enduring guardianship, and an enduring power of attorney. Through a process that prompts the clinician to consider the clients long-term decision making ability in the context of their presenting problems, 48% of clients benefited from forward planning advice. That only 9.3% of clients had made any provision for their future indicates that there needs to be more awareness in this area. Of equal importance however are those client's whose dementia has progressed to such a level that it has the potential to compromise their capacity for self determination. It is these clients the nurse needs to recognise and seek an advocate who can either support the client's right to autonomy or seek an assessment of cognitive capacity.

Cognitive impairment and dementia will have an impact on the client's ability to communicate pain and there is evidence to demonstrate pain recognition rates are inversely proportional to the degree of cognitive impairment (Australian Pain Society, 2005). Health professionals commonly rely on a person's self report of pain. The Cognition Assessment utilised a simple method for determining the client's communication ability and to raise awareness for the potential for pain. For the clients assessed in this project, 14.7% fell into this category.

Supporting carers was identified as a high priority by nurses, yet the assessment findings did not reflect a high level of engagement with carers. Almost a quarter of clients were identified as having 'possible carer issues', including the presence of stress, however the section of the assessment tool dedicated to carers was often not utilised. This raises many questions worthy of further exploration, such as: (1) how do nurses define the term 'carer'; (2) how and when should the nurse approach the carer; and (3) what level and type of engagement should the nurse have with the carer.

4.3.2 Appraisal of the Model of Care

Staff members at Sites 2 and 3 provided quantitative information on their confidence, knowledge and approach to managing clients with dementia. Although the research design

prevented one-to-one matching of pre and post data thus limiting any conclusions about causal linkages, some interesting findings emerged. Following the implementation period, nurses who completed the questionnaire reported an increased sense of support from the organisation in managing clients with a cognitive impairment and an increased ability on the part of the organisation to meet the needs of this client group. The fact that the organisation was conducting a project specifically designed to improve the quality of care provided to clients with a cognitive impairment may explain this finding. There was also a small but statistically significant increase in the nurse's basic knowledge about dementia which provides some evidence in support of the effectiveness of the staff training. No significant change was recorded in relation to any of the scores for the Approach to Dementia Questionnaire. This may be a consequence of the relatively small time period between pre and post assessments or it may indicate that nurses in the current project were already optimistic and person-centred in their approach to clients with dementia.

The findings from the pre and post focus groups with staff provided a rich source of information in relation to the evaluation of the Model of Care. Without a clear assessment and care plan for dementia care in place, a perceived lack of time was seen as a major barrier to achieving holistic care, to building rapport with clients, dealing with risks to the client, and supporting carers. The Model of Care was felt to provide a structure that required and justified a defined commitment of time.

Findings indicate that the care of people with cognitive impairment requires a high skill level yet dementia care is required for a high proportion of RDNS clients. One nurse summed up the pervasiveness of cognition impairment amongst people receiving district nursing care when she said "dementia care is what we do". Yet Clinical Nurse Consultant and dementia speciality skills are not always readily available in the clinical setting.

This might be interpreted in different ways. Firstly, dementia requires dedicated nursing resources, systems and tools as a nursing specialty portfolio alongside others such as continence and diabetes. Secondly, considerations for clients with dementia should be explicit within/embedded within the existing care frameworks for all clients, including the care frameworks of main portfolios of district nursing practice. The ideal may be a blend of these two approaches.

Importantly, the data showed that the Model of Care provided a framework for care which married well with the issues and problems identified by nurses in the pre-trial focus group. The assessment tool and care plan addressed the expressed need for documents to guide care. The nurse's self-perception that they have a need for more knowledge was addressed by education and training and the support of Aged Care CNCs.

Nurses reported the Model benefited both nurses and clients. For example, pre-trial, the nurses identified rapport and relationship building as important. The MMSE, which was used pre-trial, is often viewed as being too confrontational for the client. However, following the trial, nurses described the RUDAS tool as being 'a kind of an ice-breaker'.

It has already been noted that nurses expressed a wide range of views in relation to the Model of Care. For example, while some staff described the assessment as unnecessarily long, others thought it refreshingly comprehensive. Some described it as too long and tiring for their client, whereas another 'could have talked all day'. Another important example of these contradictory experiences arose from the inclusion in the assessment tool of questions around

the client's life history and significant life events – felt by some to be a valuable portal to gain insight into the person and how their illness affects them, with others feeling it was unnecessarily upsetting the clients to talk about their past.

Importantly the value of access to an Aged Care Clinical Nurse Consultant was a pervasive feature of the discussion both pre and post trial of the Model. Some nurses suggested that every site have a dedicated Aged Care CNC, and that the organisation develop an expert “dementia team”.

In addition, achieving clearer communication with other health care providers such as GPs, ACAS and CDAMS, was seen by the nurses as a high priority. They highlighted the value of the Model in achieving this aim, particularly the collection of assessment data and the provision of a template (the ‘GP communication form’) to guide information sharing. A further task is for organisations to develop and foster relationships with other health and community service organisations to ensure targeted, timely and cost-effective care is provided.

A perceived lack of time was seen as a major barrier to achieving the aims identified pre-trial, such as to provide holistic care, to build rapport with clients, deal with risks to the client, and support carers. There exists a conflict between the desire of staff to provide for the broad needs of people with cognitive impairment and their perception that they practice in a task-oriented service environment. The assessment and care planning tools were felt to provide a structure which required and justified a defined commitment of time to address these aspects of care.

Carers who participated in interviews reported on the benefit of information about possible services and sources of advice, and assisting carers to plan for the clients' future needs. This finding is supported by the suggestion that a ‘pack’ of resource information be provided to link carers with support and education opportunities.

It is not clear from the carer interviews whether the Model had any impact on the carer's perception of the nursing care of the client. This may reflect the need for developing stronger engagement and communication with carers. The nurse's highly variable working definitions of a carer influenced whether they attempted to involve those closest to the client. This variation in definition, along with the nurse's acknowledgment that some carers want less engagement, means that further exploration of when and how to engage the carer must be considered.

5. Recommendations

Based upon the findings of the current project, the following recommendations are made:

1. RDNS should consider integrating the dementia Model of Care as described in this report into existing clinical processes
2. RDNS should provide sufficient and appropriate resources, processes and policies to enable and support the implementation of the dementia Model of Care
3. Community nursing organisations should undertake investigations into the suitability of the dementia Model of Care for their environment
4. Nursing staff involved in the implementation of the Model should have ready access to a consultant nurse with expertise in the care of people with a cognitive impairment
5. All community nurses involved in the provision of care to clients with a cognitive impairment should receive basic education and training related to dementia and the principles of person-centred care
6. Care planning processes for clients with a cognitive impairment should be reviewed to ensure they comply with the principles of person-centred care
7. Issues of identifying and engaging the carer should be further explored
8. The RUDAS tool should be examined further as the potential tool of choice for screening for cognitive impairment in community nursing clients
9. Community nursing organisations should establish and foster relationships with external health professionals and agencies that provide services to clients with a cognitive impairment
10. Further research should be undertaken to explore and extend the findings of this project, including:
 - a. investigation of the impact of the Model on long-term client, carer and staff outcomes
 - b. ongoing evaluation to further develop and refine the Model of Care
 - c. replication of the findings of the project in other community settings

References

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Appendices

Appendix 1

Literature search

Guideline data bases

- TRIP data base: <http://www.tripdatabase.com/index.html>
- National guideline clearing house: <http://www.guideline.gov/>
- Canadian medical association guideline infobase:
http://www.cma.ca/index.cfm/ci_id/54296/la_id/1.htm
- The Royal College of Australian General Practitioners: <http://www.racgp.org.au/guidelines>
- New Zealand Guideline group:
http://www.nzgg.org.nz/index.cfm?fuseaction=fuseaction_10&fusesubaction=docs&documentID=22
- National Institute of clinical excellence: <http://www.nice.org.uk/Guidance/CG/Published>
- Scottish Intercollegiate Guidelines Network:
<http://www.sign.ac.uk/guidelines/published/index.html#Mental>

- Primary Care Practice Guidelines:
<http://www.medscape.com/pages/editorial/public/pguidelines/index-primarycare>

Guiding principles

- Quality Dementia Care, Position paper 2 (Alzheimer's Australia, 2003)
- Charter of Principles (Alzheimer's Disease International, 2003)
- Policy Position Dementia Care (Alzheimer's Society, 2004)
- Canadian Guiding Principles (Alzheimer Care, 2005)
- The National framework for action on dementia consultation paper (Australian Health Ministers Conference, 2006)
- Pathways to the Future, 2006 and beyond (Aged Care Branch Victorian Government Department of Human Services, 2006)
- Registered Nurses Association of Ontario (Registered Nurses Association of Ontario, 2004)
- Dementia clinical guideline 42 (NICE & SCIE, 2006)

Identification of the dementia assessment

Dementia specific assessment

- DVA Dementia/ Confusion Clinical Pathway
- The Dementia Assessment Aid for Aged Care Assessment Teams (Sach, Flicker, & Gray, 1996)
- Dementia consultancy service assessment record (trial document), Bundoora Extended Care Centre
- Tools for early identification, assessment and treatment for people with Alzheimer's disease and dementia (National chronic care consortium & Alzheimer's Association, 1998)
- CareNap-D (Meaney, Croke, & Kirby, 2005)
-

Age specific assessment

- Care planning Assessment tool (CPAT) (Flemming, 2002)
- Nursing assessment and older people: A Royal College of Nursing toolkit. (Royal College of Nursing, 2004)

- Aged care assessment service Heidelberg core assessment record, Austin Health
- Australian Community Care Needs Assessment (ACCNA)
- interRAI Home Care (VIC DHS variant) version 1.0
- Assessment process for older people (New Zealand Guidelines Group, 2003)
 - Initial needs assessment in primary care (NARI, 2001)

Appendix 2

Guiding Principles

1. Care is planned, co-ordinated and flexible to the changing needs of the person with dementia
2. Nurses are well supported and trained in dementia care.
3. The person with dementia is valued and treated with dignity and respect.
4. The person with dementia is central to and participates in decisions about their care and their future.
5. Any person with cognitive impairment will have access to early identification and interventions with access to specialised services for diagnosis and treatment.
6. Care is individualised and focused on the person's abilities not deficits.
7. Services recognise and support the role of the carer and their level of involvement in care.
8. Intellectual, social, economic and cultural background, values and beliefs should be respected in the provision of services.
9. Assessments need to be accurate, holistic, comprehensive, ongoing and specific to the needs of the person with dementia.
10. The person with dementia is vulnerable to risk, abuse and neglect. Preventative strategies need to be in place.
11. Services understand and deliver person centred quality dementia care
12. The person rights and interests are protected.
13. A whole of community approach should be adopted, supporting the person with dementia to maintain links with their community.
14. The person with dementia, their families and carers have access to support, information, education, respite and counselling services.
15. A partnership approach between the person with dementia, their carers, families and service providers is fostered in order to provide a continuum of care and smooth transitions across care environments.
16. The understanding that all behaviour is meaningful and the use of skilled interventions will minimise the behavioural and psychological symptoms of dementia.
17. Knowledge, research and best practice care is developed and accessible to all involved in the care of the person with dementia.

18. Services provide interpreters and information in the preferred language or format to ensure that people from a CALD background or who have language impairment, can access the service and understand their treatment and care.

Appendix 3

Cognition Assessment

+Assessment is indicated when cognitive impairment, short term memory loss or a formal diagnosis of dementia is identified.

Reassessment is indicated through annual review or where significant change in client condition is observed.

Is this:

initial assessment (Date) _____

re-assessment: (Date) _____

Attach client label if available
Name: _____
UR: _____

This assessment is to be used in conjunction with the client's most recent GAT

Part A: Assessment of cognitive function

Communication & Language:			
Receptive communication: Does the client have difficulty understanding simple verbal instructions? <i>(Use short, simple sentences)</i>	N <input type="checkbox"/>	Y <input type="checkbox"/>	Adjust communication strategy
Expressive communication: Does the client have difficulty making themselves understood? (eg. word finding difficulty, rambling, illogical flow of ideas, confused speech)	N <input type="checkbox"/>	Y <input type="checkbox"/>	Adjust communication strategy
Does the client have a communication difficulty that affects their ability to complete the cognitive assessment?	N <input type="checkbox"/>	Y <input type="checkbox"/> *	
* if YES to previous question, is there a family member or care giver available to interview?	N <input type="checkbox"/>	Discontinue the assessment	
	Y <input type="checkbox"/>	Ensure section C completed	
The primary language spoken at home is (Specify) _____ (this is pre populated in Camillus)			
Does the client have limited English ability?	N <input type="checkbox"/>	Y <input type="checkbox"/> *	*If 'Yes', provide client with access to a professional interpreter. Use RUDAS screening tool instead of MMSE.
At what education level did the client finish school?	Primary <input type="checkbox"/>	Secondary <input type="checkbox"/>	Tertiary <input type="checkbox"/>
	Yr 6*	Yr 8/10/12	* If client's level of education is 'primary', use RUDAS screening tool instead of MMSE.
Sensory: Does vision impairment prevent completion of this assessment?	N <input type="checkbox"/>	Check that sensory aids are accessible, clean and in working order.	Y <input type="checkbox"/>
Does hearing impairment prevent completion of this assessment?	N <input type="checkbox"/>	Prompt client to wear sensory aids during assessment	Y <input type="checkbox"/>
			Discontinue the assessment
			Consider use of Auslan interpreter OR Discontinue the assessment

Relevant dementia health history

Does client have a formal cognition related diagnosis? *Potential sources of information Client Care Record/ GP/ Family*

- No medical diagnosis* Alzheimer's disease Dementia with Lewy bodies
Skip to ACAS
 Vascular dementia Frontal lobe dementia Other _____

Formally diagnosed by whom: _____ Date diagnosed: _____

Has an Aged Care Assessment (ACAS) been conducted? Y **Date completed** _____
 N Outcome: Low care High care not known

History of cognition change *Potential Information Source: family or GP*

- Length of time of recognized changes in cognition function or behaviour: No change Days/weeks Weeks/months Months/years
- Have cognitive changes been: Sudden Fluctuating Gradual
- (Suggestive of delirium)* *(Suggestive of dementia with Lewy bodies or delirium)* *(Suggestive of dementia)*

Screening for cognitive impairment

Is there a MMSE or RUDAS on the Client Care Record that has been completed in the past 3 months?	<input type="checkbox"/> Y	ONLY REPEAT if there is an observed or reported change in the clients presentation
	<input type="checkbox"/> N	Complete MMSE or RUDAS

MMSE Past score: _____ Date: _____ No past score

RUDAS Past score: _____ Date: _____ No past score

Which screening tool will you use?

Use RUDAS if client has limited English ability regardless of education level

Use MMSE if client has primary level of education

Use MMSE for all other clients

Instrumental Activities of Daily Living

Does the GAT identify any difficulties with the following?	Managing medications	Y <input type="checkbox"/>	N <input type="checkbox"/>
	Using telephone	Y <input type="checkbox"/>	N <input type="checkbox"/>
	Managing finances	Y <input type="checkbox"/>	N <input type="checkbox"/>

Cognitive Impairment Outcomes

Screening for delirium

Does the client present with:

1. Presence of acute onset or fluctuating course of changes in mental status *and*
(Check baseline presentation with family, Are behaviours fluctuating and abnormal)
2. Inattention (inability to complete 'serial sevens' or 'spell world backwards' (see MMSE) *and either*
3. Disorganised thinking (rambling conversation, unclear flow of ideas, switching from subject to subject) *or*
4. Altered level of consciousness (hyper alert, lethargic or stuporous)

Delirium is suggested:
when question 1 & 2 and either question
3 & 4 are positive

Y

Discontinue cognition assessment.

Arrange urgent referral to GP or hospital. Advise carer/family of situation
Repeat the cognitive assessment when the delirium is resolved

N

Conduct depression screen.

Screening for depression (K10)

In the past 4 weeks	1 None of the time	2 A little of the time	3 Some of the time	4 Most of the time	5 All the time
1) About how often did you feel tired out for no good reason?					
2) About how often did you feel nervous?					
3) About how often did you feel so nervous that nothing could calm you down?					
4) About how often did you feel hopeless?					
5) About how often did you feel restless or fidgety?					
6) About how often did you feel so restless that you could not sit still?					
7) About how often did you feel depressed?					
8) About how often did you feel that everything is an effort?					
9) About how often did you feel so sad that nothing could cheer you up?					
10) About how often did you feel worthless?					

K10 score: 50

20 – 24 suggests mild depression/anxiety

Refer to Mental Health CNC and inform GP of findings
continue cognition assessment

25 – 29 suggests moderate depression/anxiety

Refer to Aged Persons Mental Health Team or GP

30 – 50 suggests severe depression/anxiety

PART B: General domains

Utilise professional knowledge of client's presentation and information from the GAT.
Follow the prompts to move through these sections.

Biography A person's life history, experiences and preferences frames their experience of any cognition changes.

Identify the client's major life events (eg. Ask about experience of war or migration, major losses or achievements, relationships parenting or employment history):

Identify the client's personal, religious, spiritual, cultural behaviours or beliefs. (eg. "What kinds of things give you comfort and peace of mind? Will these things be helpful to you now?"):

Identify the client's past/present interests, social or cultural activities, hobbies:

Does the client have any formal services

Y

N Skip to Functional – personal Care

Service provider

Local council

Veteran's Home Care

CACP

Linkages

EACH

EACH-D

Other _____

Current Services

Domestic cleaning

Shopping

Hygiene assistance

OT

Physiotherapy



In-home Respite
 Residential Respite
 Day Centre/PAG

Case Manager: _____ **Phone:** _____

Agency: _____

Functional – Personal care

Identify any personal hygiene issues related to cognitive impairment (<i>inability to maintain routine, loss of interest in personal care tasks, self neglect, apraxia – the inability to carry out learnt tasks</i>)	<input type="checkbox"/> None
	<input type="checkbox"/> Present (specify) _____ <i>If yes, consider referral to local council or Veteran's Home Care +/- ACAS, Occupational Therapist or Physiotherapist.</i>

Medico-legal Review initial RDNS consent form in conjunction with outcome of cognitive assessment			
consent was given by the client	<input type="checkbox"/>		
Is this consent still valid?	Y <input type="checkbox"/>	Offer general advice on forward planning and Advanced directives (re. life prolonging treatments)	
	N <input type="checkbox"/> 	Refer to RDNS social worker RDNS policy CP-F03, CP-B16	
Consent was given by an Authorised representative	<input type="checkbox"/>	(go to driving question)	
Consent was given by an Informal advocate	<input type="checkbox"/>	Offer general advice on forward planning and Advanced directives (re. life prolonging treatments) (go to driving question)	
Does the client drive?	N <input type="checkbox"/>		
	Y <input type="checkbox"/>	Have concerns for safety been raised?	Y <input type="checkbox"/>  Advise GP and discuss with client and family

Pain	
Are the following indicators present:	
Does the client have limited communication ability	N <input type="checkbox"/> Y <input type="checkbox"/> * If No, skip to Falls
A health condition that suggests the presence of acute or chronic pain	N <input type="checkbox"/> Y <input type="checkbox"/> * <i>If yes to any of these questions,</i>
Recent changes in Behaviour	N <input type="checkbox"/> Y <input type="checkbox"/> * <i>Complete RDNS pain assessment</i>
Depression	N <input type="checkbox"/> Y <input type="checkbox"/> *
Describe any personal or cultural health beliefs that may impact on the client's pain experience or communication of pain: _____ _____	

Falls		
Is the client very active or excessively mobile?	N <input type="checkbox"/> Y <input type="checkbox"/>	Check environmental safety and impact on nutritional needs
Has the client had any falls in the past year?	N <input type="checkbox"/> Y <input type="checkbox"/> * FB	If client unable to recall, check with relative/carer
Is the client frightened of falling?	N <input type="checkbox"/> Y <input type="checkbox"/> *	
Does the client want to do anything to prevent falling?	N <input type="checkbox"/> Y <input type="checkbox"/> *	Provide falls prevention advice
* Complete RDNS falls risk screening and action plan tool if Positive answers in these areas	Modify immediate hazards Respond to Risk assessment outcomes	

Nutritional Risk Screening Tool (NRST)		Tick if Present	Risk Addressed	If Yes: Specify how risk addressed
Obvious underweight/frailty?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	
Unintentional weight loss?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	
Reduced appetite or reduced food/fluid intake?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	
Mouth, teeth and swallowing problems?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	Referral to dentist Speech therapist referral via GP
Follows a special diet?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	Follows advised diet regimen
Needs assistance to shop for food?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	Family ,Friends/ Neighbours, Personal care worker, shopping delivery service, other (specify):
Needs assistance to prepare food?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	Family, Friends/ Neighbours, Personal care worker, Meals on wheels, Other (specify):
Needs assistance to feed self?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	
Obvious overweight affecting life quality?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	
Unintentional weight gain?		<input type="checkbox"/>	N <input type="checkbox"/> Y <input type="checkbox"/>	
Are there any outstanding risks that need addressing?	N <input type="checkbox"/>	Go to next section		
	Y <input type="checkbox"/>	Identify interventions required to meet client need and reduce risk <input type="checkbox"/> Commence monthly weight monitoring <input type="checkbox"/> GP request for: <input type="radio"/> Blood screen <input type="radio"/> Dietary supplementation <input type="radio"/> Medication review <input type="radio"/> Speech therapy referral <input type="radio"/> Dietician referral <input type="radio"/> Dental referral <input type="radio"/> Other: (specify) _____ <input type="checkbox"/> Occupational Therapy Kitchen assessment <input type="checkbox"/> Local council for shopping assistance, meal delivery or preparation <input type="checkbox"/> ACAS for packaged care <input type="checkbox"/> Other: (specify): _____		
Specify any personal, cultural or special dietary requirements or eating practices:				

Medication		
Does the client present with any of the following risk factors for medication related problems?		
Taking 5 or more regular medications	N <input type="checkbox"/> Y <input type="checkbox"/> *	* Based on knowledge of clients health, lifestyle, level of GP contact and presence of one or more risk factor Is a request to GP for Home Medication Review necessary? N <input type="checkbox"/> Y <input type="checkbox"/> Refer to GP
Taking more than 12 doses per day	N <input type="checkbox"/> Y <input type="checkbox"/> *	
Discharged from hospital in the last 4 weeks	N <input type="checkbox"/> Y <input type="checkbox"/> *	
Significant change in medication in the last 3 months	N <input type="checkbox"/> Y <input type="checkbox"/> *	
Taking medications that require therapeutic monitoring	N <input type="checkbox"/> Y <input type="checkbox"/> *	

Does the client administer their own medication? N **Go to next section**
 Y **Continue**

Have the following issues been identified?

Orientation to time	Y <input type="checkbox"/> *	N <input type="checkbox"/>	Attention and calculation	Y <input type="checkbox"/> *	N <input type="checkbox"/>
Recall	Y <input type="checkbox"/> *	N <input type="checkbox"/>	Read and follow written commands	Y <input type="checkbox"/> *	N <input type="checkbox"/>

**Deficits in these areas are suggestive of declining ability to self –manage medications*

Do you have concerns for client's medication safety? N Y **Complete medication trial**

Continenace *If any continence issues are identified, complete RDNS continence assessment or refer to Continenace CNC*

Does the GAT, client or family identify any continence issues?

Urinary	Y <input type="checkbox"/> N <input type="checkbox"/> *	* if No go to next section
Faecal	Y <input type="checkbox"/> N <input type="checkbox"/> *	

Does client have the cognitive ability to:

Locate and use toilet facilities	Y <input type="checkbox"/> N <input type="checkbox"/>	<i>Improve environmental signposting.</i>
Recognise the need to void or defecate	Y <input type="checkbox"/> N <input type="checkbox"/>	<i>Consider behavioral interventions.</i>
Manage continence products	N/A <input type="checkbox"/> Y <input type="checkbox"/> N <input type="checkbox"/>	

Sexuality And Intimacy *Use open ended question(s) to provide an opportunity for the client to raise any problems. Use clinical judgment to determine the appropriateness of further enquiry.*

Is it culturally appropriate to administer this question? Y N **Go to next section**

Does the client give any indication of intimacy or sexual issues? N **Go to next section**

(eg. "Have your health issues changed your intimate relationship with your partner?" or " you have been widowed for several years, do you miss your spouses companionship & intimacy") Y *Offer client / partner opportunity to talk further about this. Consult with Aged Care CNC . Ask permission to document any specific concerns.*

Advanced dementia		
If MMSE or RUDAS score is above 10	Go to next section	
Is client dependent on carer(s) to provide assistance with all ADL's?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Has client lost verbal ability?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Has client lost the ability to walk or stand?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Has client lost the ability to recognise food, feed self or swallow?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Is client totally incontinent?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Is there evidence of muscle atrophy and contractures?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Does the client present with extreme confusion – little or no response to surrounding environment?	N <input type="checkbox"/>	Y <input type="checkbox"/> *
Specify if the client or carer has any client personal or cultural beliefs that need to be supported at this time: _____		

* These symptoms or behaviours signify advanced dementia

Consider referral to a specialist care service.


Check for advanced care directives.

Review most appropriate place for delivery of care.


Review need for additional services.

Assess & alleviate pain and other distressing symptoms

Mental health	
Does the client have a current history of mental illness	N <input type="checkbox"/> Y <input type="checkbox"/> Specify:
Does the client have a previous history of mental illness (have you ever been treated for a nervous breakdown or similar problem?) Check medications for antidepressant or antipsychotic use.	N <input type="checkbox"/> Y <input type="checkbox"/> Specify:

Health habits		
Alcohol consumption	Answer	Points
Q1: How often did you have a drink containing alcohol in the past year?	Never Move to smoking Question Monthly or less 2 to 4 times a month 2 to 3 times a week 4 or more times a week	0 1 2 3 4
Q2: How many drinks did you have on a typical day when you were drinking in the past year?	1 or 2 3 or 4 5 or 6 7 to 9 10 or more	0 1 2 3 4
Q3: How often did you have six or more drinks on one occasion in the past year?	Never Less than monthly Monthly Weekly Daily or almost daily	0 1 2 3 4
Score interpretation		Score
Below 4 (men) = Drinking below limits Preventative advice		
Below 3 (women) = Drinking below limits Preventative advice		
4-7 (men) = Drinking above limits Check Impact on health & on prescribed medications		
3-7 (women) = Drinking above limits Check Impact on health & on prescribed medications		
Above 8 (men & women) = Cessation advice & referral for support 		

Smoking Habits	
Does	N <input type="checkbox"/> Go to next section

client smoke? Y Does client appropriately use and dispose of cigarettes? Y N *  * Advise on smoking safety strategies

Are smoke alarms fitted and operational? Y N *

Prescription drug use

Does client experience:	Sleep disorder	N <input type="checkbox"/>	Y <input type="checkbox"/>	Are Benzodiazepines prescribed?	N <input type="checkbox"/>	Y <input type="checkbox"/>	Check for alcohol consumption
	Anxiety	N <input type="checkbox"/>	Y <input type="checkbox"/>	Are Benzodiazepines prescribed?	N <input type="checkbox"/>	Y <input type="checkbox"/>	
	Chronic pain	N <input type="checkbox"/>	Y <input type="checkbox"/>	Are Opioid analgesics prescribed?	N <input type="checkbox"/>	Y <input type="checkbox"/>	Check for correct use of prescribed medications

Social support: please select the following social supports relevant to the client

the client lives alone

the client feels they have sufficient and valued contact with family and friends

the client is involved in regular social/cultural/religious activities or groups

the client is able to utilise transport to access local amenities

the client drives

Would client benefit from 1/2 price Taxi scheme N Y Advise client/ carer how to access resource

Does client want to improve their social life? N Y Discuss with the client possible options to engage with others.

Dependents

Is the **client** providing care or support to another person? Y N **If no, proceed to next section**

Is there a co-dependent relationship? Y N


Name of dependent/s _____

Relationship _____

Nature of care _____

Is the client willing/able to sustain this care? Y N

Does the client need additional assistance to maintain this care? Y N

Is the situation putting either party at risk? Y  N

If there are concerns around the client's caring role, discuss further with client/care recipient. Consider referral to local council or ACAS or Carers Victoria.

Part C: Family or care giver assessment

(PROMPT: check with informant if following information is to be kept in CCR or in a confidential file)

Carer	For this assessment, the term 'carer' is used for informal carers ie. family or friends). If a <i>paid</i> carer is considered by the client to be a main carer or friend, clearly indicate this.		
Who does the client receive informal help from?			
<input type="checkbox"/> No carer ✎ Go to Assessment outcome <input type="checkbox"/> Resident carer <input type="checkbox"/> Non-resident carer Obtain permission from the client to contact the non-resident carer by phone.			
	Name/Relationship	Contact details	Nature of support
Primary carer			
Secondary carer			
Other			
Describe any personal or cultural behaviours or beliefs of the primary carer relating to their caring role:			

Does the primary carer have multiple & competing responsibilities?			Y <input type="checkbox"/> * N <input type="checkbox"/>
If Yes: please specify: _____			
Is the primary carer willing/able to continue their current caring role?			Y <input type="checkbox"/> N <input type="checkbox"/> *
Does the primary carer require additional assistance to continue in the care giving role?			Y <input type="checkbox"/> * N <input type="checkbox"/>
Are other family/friends/carers willing/able to continue in their current caring role			Y <input type="checkbox"/> N <input type="checkbox"/> *
Would the carer like the opportunity to discuss any issues or concerns (eg. specific behaviours of concern or need for information or reluctance of the carer to accept help, or stress and burden?)			Y <input type="checkbox"/> * N <input type="checkbox"/>
Does the client / carer need advice on the following benefits or allowances:			
Carer's pension <input type="checkbox"/> Carer's Allowance <input type="checkbox"/> Half price taxi <input type="checkbox"/> Disabled Parking <input type="checkbox"/>			
Specific important carer issues to be further discussed with carer (document with permission of carer):			

all positively identified answers with an asterix require action			
<ul style="list-style-type: none"> • Offer Carer Strain Index (CSI) and RDNS carer assessment • Provide carer with information • Consider referral to local council or ACAS or Alzheimer's Australia (Victoria) or Carers Victoria 			

Behavioural and Psychological Symptoms

Please ask the following questions based upon changes and indicate “yes” if the symptom has been present in the <u>past month</u> ; otherwise, indicate “no” .	For each item marked “yes” please rate the following	Rate the SEVERITY of symptom to the client				Rate the DISTRESS you experience because of the symptom (how it affects you).						
		Mild	Moderate	Severe		No distress	Minimal (not a problem to cope with)	Mild (generally easy to cope with)	Moderate (not always easy to cope with)	Severe (difficult to cope with)	Extreme (unable to cope with)	
“Does the person have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her?” (Delusions)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the person seem to hear or see things that are not present?” (Hallucinations)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Is the client resistive to help from others at times or hard to handle?” (Agitation/ aggression)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the client seem sad or say that he/ she is depressed?” (Depression)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the person become upset when separated from you? Are there other signs such as shortness of breath, sighing, unable to relax or very tense?” (Anxiety)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the person appear to feel too good or excessively happy?” (Elation/ Euphoria)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
: “Does the person seem less interested in their usual activities or in those activities and plans of others?” (Apathy/ indifference)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the person act impulsively? Such as saying things that may hurt people’s feelings.” (Disinhibition)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“is the person impatient or cranky? Does he/she have difficulty coping with delays or waiting for planned activity?” (Irritability/ Lability)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the person carry out repetitive activities such as pacing, wrapping items, picking at buttons?” (Motor disturbance)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Does the person awaken you during the night, rise too early in the morning or take excessive naps during the day?” (Night time behaviours)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Has the person lost or gained weight, or had a change in the type of food he/ she likes?” (Appetite/ Eating)	N <input type="checkbox"/> Y <input type="checkbox"/>	1	2	3		0	1	2	3	4	5	
“Are there other behaviours present?” (Behaviours of concern)	N <input type="checkbox"/> Y <input type="checkbox"/>	<input type="checkbox"/> Hoarding belongings <input type="checkbox"/> Sundowning (late afternoon agitation) <input type="checkbox"/> Shadowing (closely following carer) <input type="checkbox"/> Leaving house unsecured <input type="checkbox"/> Other: (specify) _____						<input type="checkbox"/> Unsafe driving <input type="checkbox"/> Losing belongings <input type="checkbox"/> Repetitive speech <input type="checkbox"/> Wandering				

SEVERITY of symptom	Investigate causal factors, inform GP, seek advice and Initiate behavioural strategies	Investigate causal factors, initiate behavioural strategies and request specialist input via GP	Treat as urgent. Identify causal factors, inform GP and refer to Aged Persons Mental Health Team
Care giver DISTRESS	Offer carer support, advice and education on behavioural interventions and support services	Consult with Aged care CNC. Direct care giver to support services (eg. respite) and to address own health needs.	Treat as urgent: Refer to RDNS social worker, consult with Aged Care CNC. Involve specialist services as carer will allow.

ASSESSMENT OUTCOME:

Part A outcomes
part B outcomes
Part c outcomes

Discuss assessment findings with client and carer and determine with them their health and lifestyle goals.

Discuss with client/carer which of these are priorities for the client.

Client Goals

Care Goals

Clinical Goals

Incorporate outcomes into care planning

Referred to RDNS specialist services (specify):

Referrals to other services (specify):

Notes

Appendix 4

NARI Initial Needs Assessment

Cognition:

Functioning:

- Activity of daily living
 - Aids and adaptations
 - Communication
- Driving Ability
Mobility

Health:

- Co-morbid conditions
 - Continence
 - Feet
 - Medications
 - Nutrition
- Oral
Pain
Palliation
Sensory deficits
Sleep

Mental State:

- Mood
 - Anxiety
 - Other Mental health problems
- Psychosis
Suicide risk
Capacity

Social / environmental:

- Carer issues
 - Social support
 - Finances
 - Transport
- Abuse
Dependants
Isolation

Psycho-social:

- Challenging behaviours
 - Leisure, recreation and occupation activities
 - Perception of ability to remain at home
 - Quality of life
 - Willingness to receive help
- Cultural issues
Goals
Life History
Spirituality

Risk:

- Abuse
 - Driving
 - Poor compliance with medications
 - Poor compliance with services
 - Nutritional deficit
- Carer stress
Self neglect
Falls
Risk to others
Suicide

Lifestyle:

- Alcohol
 - Gambling
- Exercise
Substance misuse

(NARI, 2001)

Appendix 5

Royal District Nursing Service

Mini Mental State Examination (MMSE)

This assessment is read in conjunction with the client's most recent general assessment.

Attach client label if available
Name: _____
UR: _____

ORIENTATION:	Points	Score
What is the:		
Year? _____	1	_____
Season? _____	1	_____
Date? _____	1	_____
Day? _____	1	_____
Month? _____	1	_____
Where are we:		
Suburb? _____	1	_____
State? _____	1	_____
Town or city? _____	1	_____
(If client is at home substitute street name) Hospital? _____	1	_____
(If client is at home substitute house number) Floor? _____	1	_____

REGISTRATION:	Points	Score
Name three objects: taking one second to say each. Then ask the client all three after you have said them. Repeat the answers until the client learns all three. (One point for each correct answer).	3	_____

ATTENTION AND CALCULATION:	Points	Score
Serial sevens: 100, 93, 86, 79, 72, 65. Alternative: spell WORLD backwards. Stop after five answers. (One point for each correct answer).	5	_____

RECALL:	Points	Score
Ask for names of three objects learned in the REGISTRATION section. (One point for each correct answer).	3	_____

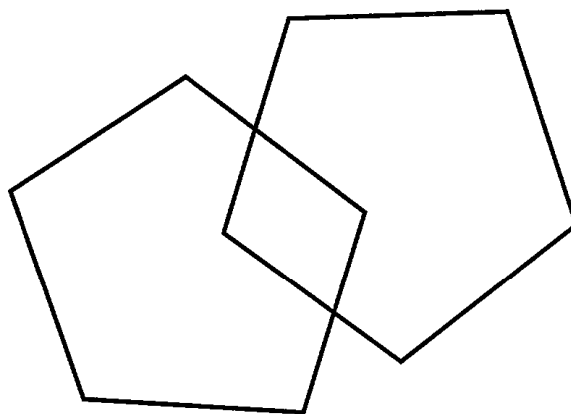
LANGUAGE:	Points	Score
Point to a pencil and a watch. Have the client name them as you point. (One point for each correct answer).	2	_____
Have the client repeat 'no ifs, ands, or buts'. (One point for a completely correct repetition).	1	_____
Have the client follow a three stage command. 'Take the paper in your right hand. Fold the paper in half. Put the paper on the floor'. (One point for each correct response).	3	_____
Have the client read and obey the following: 'CLOSE YOUR EYES' (See over)	1	_____
Have the client write a sentence of his/her own choice. (The sentence should contain a subject and a verb and should make sense; ignore spelling errors when scoring).	1	_____
Have the client copy the figure on the attached sheet. (One point if all sides and angles are preserved and the intersecting sides form a quadrangle).	1	_____
TOTAL	30	_____

Whilst the MMSE is an effective screening tool, it does not replace skilled clinical evaluation. Further assessment is needed if the score is 23 or less, even if the low scores may be due to limited education. Consult with your CNC-Aged Care, ACAS or client's doctor.

Name: _____ UR: _____

MMSE (continued)

CLOSE YOUR EYES



ADDITIONAL COMMENTS:

ASSESSED BY:
Name: _____ Signature: _____ Date: _____
Next review date: _____



This document is adapted from Folstein MF, Folstein SE & McHugh PR 'Mini-mental state: A practical method for grading the cognitive state of patients for the clinician', *Journal of Psychiatric Research* Vol 12 (3) November 1975 pp189-198.

Appendix 6

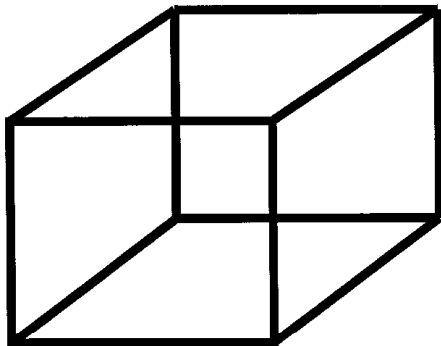
R U D A S

The Rowland Universal Dementia Assessment Scale: A Multicultural Cognitive Assessment Scale.
(Storey, Rowland, Basic, Conforti & Dickson, 2004). International Psychogeriatrics, 16 (1), 13-31

Date: ___/___/___ Patient Name: _____

Item	Max Score
<p>Memory</p> <p>1. (Instructions) I want you to imagine that we are going shopping. Here is a list of grocery items. I would like you to remember the following items which we need to get from the shop. When we get to the shop in about 5 mins. time I will ask you what it is that we have to buy. You must remember the list for me. Tea, Cooking Oil, Eggs, Soap Please repeat this list for me (ask person to repeat the list 3 times). (If person did not repeat all four words, repeat the list until the person has learned them and can repeat them, or, up to a maximum of five times.)</p>	
<p>Visuospatial Orientation</p> <p>2. I am going to ask you to identify/show me different parts of the body. (<i>Correct = 1</i>). Once the person correctly answers 5 parts of this question, do not continue as the maximum score is 5.</p> <p>(1) show me your right foot1 (2) show me your left hand1 (3) with your right hand touch your left shoulder1 (4) with your left hand touch your right ear1 (5) which is (indicate/point to) my left knee1 (6) which is (indicate/point to) my right elbow1 (7) with your right hand indicate/point to my left eye1 (8) with your left hand indicate/point to my left foot1</p> <p style="text-align: right;">..../5</p>	
<p>Praxis</p> <p>3. I am going to show you an action/exercise with my hands. I want you to watch me and copy what I do. Copy me when I do this . . . (One hand in fist, the other palm down on table - alternate simultaneously.) Now do it with me: Now I would like you to keep doing this action at this pace until I tell you to stop - approximately 10 seconds. (Demonstrate at moderate walking pace). Score as: <i>Normal</i> = 2 (<i>very few if any errors; self-corrected, progressively better; good maintenance; only very slight lack of synchrony between hands</i>) <i>Partially Adequate</i> = 1 (<i>noticeable errors with some attempt to self-correct; some attempt at maintenance; poor synchrony</i>) <i>Failed</i> = 0 (<i>cannot do the task; no maintenance; no attempt whatsoever</i>)</p> <p style="text-align: right;">..../2</p>	
<p>Visuoconstructional Drawing</p> <p>4. Please draw this picture exactly as it looks to you (Show cube on back of page). (<i>Yes = 1</i>) Score as:</p> <p>(1) Has person drawn a picture based on a square?1 (2) Do all internal lines appear in person's drawing?1</p> <div style="text-align: center;">  </div> <p>(3) Do all external lines appear in person's drawing?1</p> <div style="text-align: center;">  </div> <p style="text-align: right;">..../3</p>	
<p>Judgment</p> <p>5. You are standing on the side of a busy street. There is no pedestrian crossing and no traffic lights. Tell me what you would do to get across to the other side of the road safely. (If person gives incomplete response that does not address both parts of answer, use prompt: "Is there anything else you would do?") Record exactly what patient says and circle all parts of response which were prompted. </p> <p>Score as: Did person indicate that they would look for traffic? (<i>YES = 2; YES PROMPTED = 1; NO = 0</i>)2 Did person make any additional safety proposals? (<i>YES = 2; YES PROMPTED = 1; NO = 0</i>)2</p> <p style="text-align: right;">..../4</p>	

<p>Memory Recall</p> <p>1. (Recall) We have just arrived at the shop. Can you remember the list of groceries we need to buy? (Prompt: If person cannot recall any of the list, say "The first one was 'tea'." (Score 2 points each for any item recalled which was not prompted – use only 'tea' as a prompt.)</p> <p style="text-align: right;">Tea2 Cooking Oil2 Eggs2 Soap2</p> <p>Language</p> <p>6. I am going to time you for one minute. In that one minute, I would like you to tell me the names of as many different animals as you can. We'll see how many different animals you can name in one minute. (Repeat instructions if necessary). Maximum score for this item is 8. If person names 8 new animals in less than one minute there is no need to continue.</p> <p>1. 5. 2. 6. 3. 7. 4. 8.</p>		<p style="text-align: right;">.../8</p>
<p>TOTAL SCORE =</p>		<p style="text-align: right;">.../8 /30</p>



Appendix 7

Knowledge and Skills for Dementia Care

Knowledge	Dementia Model	Skills
Dementia frameworks Dementia disorders Signs & symptoms of dementia Progression of dementia	<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: auto;">Recognition</div>	Promoting positive attitudes Valuing the person Pattern recognition Observation
Recognising depression and delirium Holistic assessment Evidence based practice Use of assessment scales Carer issues Abuse Issues Consent Understanding BPSD Pharmacology	<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: auto;">Cognition Assessment</div>	Differential diagnosis Person centred assessment Therapeutic relationship Communication / Listening Respond to psychological distress Respond to carer issues Respond to abuse and risk Determine capacity Behaviour management
Diagnostic criteria for dementia Disclosure of findings Role of other service providers Referral pathways Education of client / carer Information giving	<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: auto;">Analysis of Need</div>	Interpretation of results Supportive counselling Multidisciplinary team work Problem solving Information giving Empowering the client
Cultural diversity Personal History Social/ family networks Activity preferences Planning and managing care Care co-ordination	<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: auto;">Care Planning</div>	Promote quality of life Collaborative care partnerships Integrating multiple perspectives Utilising resources Support cultural identity Problem solving Advocacy
Psychosocial therapies Value of biography Environmental factors Advanced care planning Palliative approach Carer support Health promotion Rehabilitation	<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: auto;">Interventions</div>	Therapeutic approaches Environmental adaptation Self care management Bereavement support Care giver support Supporting transitions Optimising health Activity and social support Pharmacological and non pharmacological interventions

Appendix 8

Development Site Project Activity

DATE	TASKS	STAFF	EVALUATION/FEEDBACK
Week 1	<ul style="list-style-type: none"> • Introduction to project 	All direct care staff	Dementia knowledge & beliefs pre-test
Week 2	<ul style="list-style-type: none"> • Preparation of dementia overview education session • Organise education sessions at development site • Working group meeting 		
Week 3	<ul style="list-style-type: none"> • Delivery of basic dementia education (3 sessions) • Begin Pre-trial of cognitive assessment • Finalise Cognition assessment documentation 	All direct care staff Clinical project officer	Training evaluation forms Journaling commenced
Week 4	<ul style="list-style-type: none"> • Preparation of dementia assessment education session • Deliver dementia assessment training to core group 	Core group	Training evaluation forms
Week 5	<ul style="list-style-type: none"> • Commence field training with individual core group staff • Continue delivery of assessment training 	Core group	
Week 6	<ul style="list-style-type: none"> • Continue field training with individual core group staff • Working group meeting 	Core group	
Week 7	<ul style="list-style-type: none"> • Continue field training with individual core group staff 	Core group	
Week 8	<ul style="list-style-type: none"> • Continue field training with individual core group staff • All core group staff now ready to commence independent assessment with 3-5 clients 	Core group Core group	
Week 9-12	<ul style="list-style-type: none"> • Clinical project officer maintain presence at development site as clinical resource • Working group meeting 	Clinical project officer	Dementia knowledge & beliefs post -test

Appendix 9

Focus Group Guides – Site 1 Development site

1. Development site Senior Staff Focus Group

Introduction:

- Welcome to the group participants and introductions (go around the group and ask for introductions and a little bit about each person (number of years experience, position etc.)
- Purpose and context of the focus group:

We are conducting a focus group with senior staff involved in the preliminary trialling of a new Model of dementia care here at (Site 1). This is part of the evaluation of project. The information collected in the discussion with you today will be used to help to review and refine the Model, which aims to improve community nursing care of clients with dementia and their carers. We wish to confirm with you all that everything discussed in the focus group will be confidential. No person(s) or institution(s) will be identified in the transcripts and pseudonyms will be used for any direct quotes in published reports or papers arising from the focus groups. Thank you for your permission to audio tape the discussion.

Questions:

I would like to start by asking you a general question about your work here with RDNS:

- a. Tell me a little bit about your experiences of working in dementia care with RDNS at (Site 1) prior to the trialing of the new Model.**

The following questions are about the new Model of Care which is being trialed here at (Site 1).

- b. What did you feel were the reasons for the development of the new dementia care Model?**

- c. Can you all tell me about your experiences working with staff participating in the trialing of the Model of Care?**

Prompt

- How well prepared are you?
- How do you find the documentation?
- What aspects of the Model are you most comfortable with? Least comfortable?
- What aspects of the Model are you most confident with? Least confident?

- d. What do you think the clients' experiences of the new Model have been?**

Prompt: Carers experiences also?

- e. What do you see as the key issues in the ability of RDNS to initiate this Model more widely?**

Prompt

- Staffing issues, organisational support
- What about CALD clients?

- f. What are the facilitators to the success of your ability to participate in this intervention?**

Prompts

- Well prepared? Well supported?
- Any barriers? – increased time?
- How important is the role of a dementia nurse consultant?

- g. In an ideal world how would you improve this Model or its implementation?**

Prompt

- What would you change?
- Anything else you would like to tell me?

To close: Thank the participants. *The data collected in the discussion today will be used to help to review and refine the Model of Care before it is then trialled in a further two RDNS locations later this year. The study will finish mid-2009. The results of the study will be available to you on request and may be presented at conferences or in academic journals*

2. Development Site Field Nurses Focus Group

Introduction:

- Welcome to the group participants and introductions (go around the group and ask for introductions and a little bit about each person (number of years experience, position etc.) **5 min**
- Purpose and context of the focus group:

We are conducting a focus group with nurses involved in the preliminary trialling of a new Model of dementia care here at (Site 1). This is part of the evaluation of the project. The information collected in the discussion with you today will be used to help to review and refine the Model, which aims to improve the community nursing care of clients with dementia and their carers.

We wish to confirm with you all that everything discussed in the focus group will be confidential. No person(s) or institution(s) will be identified in the transcripts and pseudonyms will be used for any direct quotes in published reports or papers arising from the focus groups. Thank you for your permission to audio tape the discussion.

Questions:

I would like to start by asking you a general question about your work here with RDNS:

a. Tell me a little bit about your experiences of working in dementia care with (Site 1) prior to the trialling of the new Model.

The following questions are about the new Model of Care which is being trialled here at (Site 1).

b. What did you feel were the reasons for the development of the new dementia care Model?

c. Can you all tell me about your experiences working with clients participating in the trialling of the Model of Care?

Prompt

- How well prepared are you?
- How do you find the documentation?
- What aspects of the Model are you most comfortable with? Least comfortable?
- What aspects of the Model are you most confident with? Least confident?

d. What do you think the clients' experiences of the new Model have been?

Prompt: Carers experiences also?

e. What do you see as the key issues in the ability of RDNS to initiate this Model more widely?

Prompt: What about CALD clients?

f. What are the facilitators to the success of your ability to participate in this intervention?

Prompt

- Well prepared? Well supported?
- Any barriers? – increased time?
- How important is the role of a dementia nurse consultant?

g. In an ideal world how would you improve this Model or its implementation?

Prompt

- What would you change?
- Anything else you would like to tell me?

To close: Thank the participants.

The data collected in the discussion today will be used to help to review and refine the Model of Care before it is then trialed in a further two RDNS locations later this year. The study will finish mid-2009. The results of the study will be available to you on request and may be presented at conferences or in academic journals.

3. RDNS Aged Care CLG Staff Focus Group

Introduction:

- Welcome to the group participants and introductions (go around the group and ask for introductions and a little bit about each person (number of years experience, position etc.)
- Purpose and context of the focus group:

We are conducting a focus group with Aged Care CLG staff involved in the trialling of a Cognition Assessment tool which is part of the new Model of dementia care. This is part of the evaluation of project. The information collected in the discussion with you today will be used to help review and refine the Model which aims to improve dementia care in Victoria.

We wish to confirm with you all that everything discussed in the focus group will be confidential. No person(s) or institution(s) will be identified in the transcripts and pseudonyms will be used for any direct quotes in published reports or papers arising from the focus groups. Thank you for your permission to audio tape the discussion.

Questions:

I would like to start by asking you a general question about your work here with RDNS:

a. Tell me a little bit about your experiences of working in dementia care with RDNS.

The following questions are about the new Cognition Assessment tool which is being trialled at (Site 1).

b. What did you feel were the reasons for the development of the new dementia care Model?

c. Can you all tell me about your experiences assessing clients using the new Cognition Assessment tool?

Prompts

- How well prepared are you (training needs)?
- How do you find the documentation (MMSE/RUDAS)?
- Differences CALD/non-CALD?
- What aspects of the assessment are you most comfortable with? Least comfortable?
- What aspects of the assessment are you most confident with? Least confident?

d. What do you think the clients' experiences of the assessment have been?

Prompt

- Carers experiences also?

e. What do you see as the key issues in the ability of RDNS to initiate this assessment more widely?

Prompts

- Staffing issues, organisational support, CALD.
- How important is the role of a dementia nurse consultant?

g. In an ideal world how would you improve this assessment?

Prompts

- What would you change?
- Anything else you would like to tell me?

To close:

Thank the participants. The data collected in the discussion today will be used to help to review and refine the Model of Care before it is then trialled in a further two RDNS locations later this year. The study will finish mid-2009. The results of the study will be available to you on request and may be presented at conferences or in academic journals.

Focus group questions, Carer Interview Questions

RDNS Site 3/Site 2 (PRE) SENIOR STAFF Focus Group: outline of process and questions (60 minutes) (pre - implementation of Model of Care)

Introduction:

- Welcome to the group participants and introductions (go around the group and ask for introductions and a little bit about each person (number of years experience, position etc.)
5 min

- Purpose and context of the focus group:

We are conducting a focus group with nurses involved in the trialling of a new Model of dementia care here at RDNS Site 3/Site 2. This is part of the evaluation of the project. The discussion with you today will establish baseline information about your feelings about the care that your site currently provides for people with dementia and their carers.

You will be invited to a repeat focus group to be held around March 2009, after you have implemented the new Model of dementia care at Site 3/Site 2.

Your comments will then be used to help evaluate the new Model of Care in terms of it's value to nurses, clients and carers.

In no way is individual nurse's practice being evaluated or judged. The intention is to gather your thoughts about RDNS care for clients with dementia, completely anonymously, both before and after implementing a new Model of Care.

Everything discussed in the focus group will be confidential. No person(s) or institution(s) will be identified in the transcripts and pseudonyms will be used for any direct quotes in published reports or papers arising from the focus groups. Thank you for your permission to audio tape the discussion.

Please be aware that for the purposes of this forum, the term 'dementia' encompasses the full spectrum of cognitive impairment, from suspected mild cognitive impairment to advanced dementia. This includes those clients you suspect to have a cognitive impairment who do not have a formal diagnosis.

Questions:

I would like to start by asking you a general question about your work:

- Tell me a little bit about your recent experiences of caring for people with dementia at RDNS Site 3/Site 2. **5min**
- What proportion of your clients do you think have a cognitive impairment/dementia? **5 min**
What are the characteristics of those clients – gender, CALD?

Tell me about how you see your role in providing care to clients with dementia? **5min**

Is your current role holistic or more task focused? Explain.

Describe any barriers to holistic care for clients with dementia at RDNS.

b. Tell me about your level of confidence in THE ability OF FIELD STAFF to provide comprehensive, effective nursing care to clients with dementia? **5 min**

Why do you feel your confidence is low/high?

Do you have sufficient knowledge and skills to SUPPORT NURSES TO provide care for these clients?

Is dementia care challenging, anxiety provoking?

c. How do you see THE role OF RDNS NURSES in responding to the problems experienced by **carers** of people with dementia? **5 min**

Do you ENCOURAGE STAFF TO actively seek involvement of the carer (resident or non-resident) in the care of the client with dementia?

What proportion of your clients with dementia are socially isolated? **5 min**

How do you see OUR role in their care?

Special challenges?

How could RDNS better meet their needs?

d. Tell me about the resources/tools/policies that are available to you at RDNS to support you to SUPPORT STAFF TO care for clients with dementia? Eg. people, clinical documents, policies. **5 min**

What changes or additional resources would be useful?

f.

(For Alt site with AC CNC)

Your site has an Aged Care CNC. Can you consult with her on dementia care issues? **5 min**

How valuable is the Aged Care CNC role at your site to enhancing the care of clients with dementia?

(For Frkn site with no Aged care CNC)

Whom do you consult if you need assistance with aspects of caring for a client with dementia?

Would an Aged Care CNC add value at your site in terms of enhancing the care of clients with dementia? And would this also provide you with support in dementia care than you currently do not have?.

g. Tell me about your site's working relationship with external agencies – client information sharing, client advocacy, processes for referral to and from:

ACAS, CDAMS, GP, allied health, HACC, volunteer services.

How could these relationships be improved? **10 min**

g. In an ideal world how would you improve dementia care at RDNS? **5 min**

h. What do you see as barriers or challenges to you implementing changes in your clinical practice to meet best practice standards in community nursing dementia care?

How could RDNS help you to overcome these challenges? **5min**

To close:

Thank the participants.

Total 60 minutes.

**RDNS Site 3/Site 2 Nurses Focus Group: outline of process and questions (60 minutes)
(pre - implementation of Model of Care)**

Introduction:

➤ Welcome to the group participants and introductions (go around the group and ask for introductions and a little bit about each person (number of years experience, position etc.)
5 min

➤ Purpose and context of the focus group:

We are conducting a focus group with nurses involved in the trialling of a new Model of dementia care here at RDNS Site 3/Site 2. This is part of the evaluation of the project. The discussion with you today will establish baseline information about your feelings about the care that your site currently provides for people with dementia and their carers.

You will be invited to a repeat focus group to be held around March 2009, after you have implemented the new model of dementia care at Site 3/Site 2.

Your comments will then be used to help evaluate the new Model of Care in terms of it's value to nurses, clients and carers.

In no way is individual nurse's practice being evaluated or judged. The intention is to gather your thoughts about RDNS care for clients with dementia, completely anonymously, both before and after implementing a new Model of Care.

Everything discussed in the focus group will be confidential. No person(s) or institution(s) will be identified in the transcripts and pseudonyms will be used for any direct quotes in published reports or papers arising from the focus groups. Thank you for your permission to audio tape the discussion.

Please be aware that for the purposes of this forum, the term 'dementia' encompasses the full spectrum of cognitive impairment, from suspected mild cognitive impairment to advanced dementia. This includes those clients you suspect to have a cognitive impairment who do not have a formal diagnosis.

Questions:

I would like to start by asking you a general question about your work:

a. Tell me a little bit about your recent experiences of caring for people with dementia at RDNS Site 3/Site 2. **5min**

b. What proportion of your clients do you think have a cognitive impairment/dementia? **5 min**
What are the characteristics of those clients – gender, CALD?

Tell me about how you see your role in providing care to clients with dementia? **5min**

Is your current role holistic or more task focused? Explain.
Describe any barriers to holistic care for clients with dementia at RDNS.

b. Tell me about your level of confidence in your ability to provide comprehensive, effective nursing care to clients with dementia? **5 min**

Why do you feel your confidence is low/high?

Do you have sufficient knowledge and skills to provide care for these clients?

Is dementia care challenging, anxiety provoking?

c. How do you see your role in responding to the problems experienced by **carers** of people with dementia? **5 min**

Do you actively seek involvement of the carer (resident or non-resident) in the care of the client with dementia?

What proportion of your clients with dementia are socially isolated? **5 min**

How do you see your role in their care?

Special challenges?

How could RDNS better meet their needs?

d. Tell me about the resources/tools/policies that are available to you at RDNS to support you to care for clients with dementia? Eg. people, clinical documents, policies. **5 min**

What changes or additional resources would be useful?

f.

(For Site 2 with AC CNC)

Your site has an Aged Care CNC. Can you consult with her on dementia care issues? **5 min**

How valuable is the Aged Care CNC role at your site to enhancing the care of clients with dementia?

(For site 3 with no Aged care CNC)

Whom do you consult if you need assistance with aspects of caring for a client with dementia?

Would an Aged Care CNC add value at your site in terms of enhancing the care of clients with dementia? And would this also provide you with support in dementia care than you currently do not have?.

g. Tell me about your site's working relationship with external agencies – client information sharing, client advocacy, processes for referral to and from:

ACAS, CDAMS, GP, allied health, HACC, volunteer services.

How could these relationships be improved? **10 min**

g. In an ideal world how would you improve dementia care at RDNS? **5 min**

h. What do you see as barriers or challenges to you implementing changes in your clinical practice to meet best practice standards in community nursing dementia care?

How could RDNS help you to overcome these challenges? **5min**

Post-implementation Focus Group: outline of process and questions

Introduction:

1. Purpose and context of the focus group:

The information collected in the discussion with you today will be used to help to evaluate the Model of Care which you have been trialling, with the ultimate aim being to improve the community nursing care of clients with dementia and their carers.

I wish to confirm with you all that everything discussed in the focus group will be confidential. No person(s) or institution(s) will be identified in the transcripts and pseudonyms will be used for any direct quotes in published reports or papers arising from the focus groups. Thank you for your permission to audio tape the discussion.

2. Welcome to the group participants and introductions – please state your name and your role, and how long you've been working at RDNS.

Questions:

Tell me about your experiences of providing dementia care in the past, compared with your experiences trialling of the new Model of Care. **(10min)**

“Various elements of the Model include education, the new Gemino Ax tool, care plan document and implementation guides. Also there is a resource folder at your site which guides you to referral agencies”.

First of all, tell me about your experiences of using the Gemino Cognition Assessment tool **(15 min)**

- Domains covered – feel appropriate to you?
- Length?
- **Carer section – when did you use it? When did you choose not to?**
 - Were there any incidents where carers declined contact or assessment?*
 - Can clinicians propose any different ways of engaging carers?*
 - Do clinicians feel that the current service delivery Model promotes carer support?*
- Preference to conduct over more than one visit?
- After getting to know/build rapport with client?
- *Did the cog ax enable you to spend more time with the client? did this have any benefit for you or the client*

What do you think the clients' experiences of the new assessment have been?

- What about **CALD** clients? The **RUDAS**? How does the RUDAS compare to the MMSE, particularly with CALD clients? *Do you feel comfortable using the RUDAS?*

Have you had any difficulties communicating the results of the RUDAS with external agencies? Any feedback from interpreters?

- **Carers** experiences also. Did you actively engage the carer (if present) in the assessment / care planning process?
- Did the absence of a carer for some clients pose any challenges in terms of implementing the Model? **(5 min)**

Tell me about your experiences with the new care plan?

Would implementation guides provide added support and knowledge - would they refer to them.? In what format would they want them?

Tell me about your experience using the GP feedback form? *Has there been any increase in referral to GP for diagnosis* **(5 min)**

Have you initiated any interventions as an outcome of your assessment?

Tell me about that. Has the assessment helped you link clients in with external agencies, e.g. ACAS? **(5 min)**

Did the training you received adequately prepare you for implementing the Model? Could the training have been better?

Now that you have had some experience implementing the Model, would you feel comfortable training other staff members?

What are the facilitators to your ability to provide care using this Model? **(10 min)**

- education?
- access to consult with a staff member with expert skills in RDNS dementia care?
- For Site 3 only: Would the presence of an Aged Care CNC at your Site have helped you to implement the Model more effectively?

In an ideal world how would you improve this Model or its implementation? **(10 min)**

- What would you change?
- Anything else you would like to tell me?

Thank the participants.

The data collected in the discussion today will be used to help to evaluate the Model of Care before it is then reviewed and considered by Client Services executive team for implementation across RDNS.

The study will finish mid-2009. The results of the study will be available to you on request and may be presented at conferences or in academic journals.

Wicking Out of the Shadows Project Carer Semi-structured Interview Questions

Tell me about why the nurses visit the person you care for.

How is their memory? Is it better or worse than it used to be?

Does having problems with their memory cause the person you care for any difficulties in their life?

Has it changed their relationship with their family or friends?

Are there things that the person you care for does to help themselves cope with their memory? Have the nurses made suggestions?

Some time ago a nurse came to see the person you care for and asked them lots of questions about their memory and other aspects of their life so as to thoroughly assess their memory problem.

Were you aware of or present for this discussion?

If carer was there...

What was this experience like for you?

What do you think it was like for them?

What was the best part of this talk?

If the carer was not there

Did the person you care for discuss this visit with you at all? Did they tell you what this experience was like for them?

Have there been any changes to their care lately? Any additional visits to the doctor to discuss memory issues, referrals made or new services started?

Was the person you care for able to discuss any problems that they hadn't talked about before?

(prompt – use information from assessment/primary nurse to describe problems identified)

Have the nurses helped the person you care for? In what way?

Have they helped with their physical health?

Have they helped the person you care for to feel better about their life at all?

Have the nurses been able to help you at all? In what ways?

Now can you tell me what has not been good about the nurses visiting to talk about memory?

Is there anything we could do better?



Invitation to Participate in the RDNS Memory Project – Client

(Plain Language Statement)

Names of people doing this project:

- Russell Nunn, Project Manager, RDNS Helen Macpherson Smith Institute of Community Health
- Christine While, Clinical Project Officer, RDNS Helen Macpherson Smith Institute of Community Health
- Nia Sims, Project Officer, RDNS Helen Macpherson Smith Institute of Community Health
- Terry Gliddon, Research & Development Manager, RDNS Helen Macpherson Smith Institute of Community Health

What is the project about?

Royal District Nursing Service (RDNS) is developing a new program to help clients who have problems with their memory. The purpose of the project is to gather information about how effective the program is in terms of improving your health and wellbeing.

What does your participation in the project involve?

The new RDNS program firstly involves your nurse asking you questions about your memory, health and other aspects of your life. Where appropriate, additional information may be provided by the person who helps to look after you. This information will then be used by RDNS to provide better care to you. If necessary, it may also be used to link you in with other external health and community services. Your situation will be checked at regular intervals by your nurse to monitor your progress.

If you agree to participate in the project, there is a possibility that we will be in contact with you in two or three months time to arrange an interview with you. The purpose of the interview is to ask you about your thoughts on the program and the effect it has had on your life. The interview will be done by a member of the Project Team in your home at a time that is convenient for you. If applicable, we may also ask the person who cares for you to be interviewed to get their thoughts on the program.

In addition, your nurse or the Project Team may contact services involved in your healthcare to obtain further information about you.

What happens with the information you give us?

We will use the information to improve the care we provide to our RDNS clients. Your nurse may also use the information to help decide whether further assessment is required to help you.

All information you give us will be treated as strictly confidential. Only your nurse and members of the RDNS Project Team will have access to your information.

Who decides if you take part in the project?

You decide if you take part in the project. If you would like to take part, please sign the attached consent form.

You are under no obligation to take part in the project if you don't want to. However, your participation would be greatly appreciated and the information you give us may help other RDNS clients. If you decide not to take part, this will not affect the care you receive from RDNS in any way.

If you have any questions about this project, please contact:

Russell Nunn
Project Manager
RDNS Helen Macpherson Smith Institute of Community Health
31 Alma Road, St Kilda, 3182
Tel: 9536 5356

If you have any complaints about the conduct of this project, please contact:

Lisa Donohue
Chair, RDNS Research Ethics Committee
31 Alma Rd, St Kilda, 3182
Tel: 9536 5227

Thank you for thinking about taking part in this important project.

Yours sincerely,

Russell Nunn
Project Manager
RDNS Helen Macpherson Smith Institute of Community Health



Informed Consent Form – Client

RDNS Memory Project

Your Name:(please print)
Address:
Telephone:.....

I hereby consent to participate in the above project.

- The details of this project have been explained to me verbally, and
- I have received a copy of the Plain Language Statement, and
- Any questions I have asked in regard to this project have been answered to my satisfaction.

I agree to participate in this project and understand that I may withdraw at any time without my care being affected in any way. If I withdraw from the project, any data previously collected will be destroyed. I agree that information provided by me may be used in reports or presented at conferences on the condition that neither my name nor any other identifying information is used. I understand that any information I provide will be kept private.

Your Signature: Date:

Witness' Name:(please print)

Witness' Signature: Date:.....



Invitation to Participate in the RDNS Memory Project – Carer

(Plain Language Statement)

Names of people doing this project:

- Russell Nunn, Project Manager, RDNS Helen Macpherson Smith Institute of Community Health
- Christine While, Clinical Project Officer, RDNS Helen Macpherson Smith Institute of Community Health
- Nia Sims, Project Officer, RDNS Helen Macpherson Smith Institute of Community Health
- Terry Gliddon, Research & Development Manager, RDNS Helen Macpherson Smith Institute of Community Health

What is this project about?

Royal District Nursing Service (RDNS) is developing a new program to help clients who have problems with their memory. The purpose of the project is to gather information about how effective the program is in terms of improving the client's health and wellbeing.

What does your participation in the project involve?

The new RDNS program firstly involves the nurse asking the person you care for some questions about their memory, health and other aspects of their life. This information will then be used by RDNS to provide better care to that person. If necessary, it may also be used to link the person in with other external health and community services. The person's situation will be checked at regular intervals by the nurse to monitor progress.

If you agree to participate in the project, there is a possibility that we will be in contact with you in two or three months time to arrange an interview with you. The purpose of the interview is to ask you about your thoughts on the program and the effect it has had on you and the person in your care. The interview will be done by a member of the Project Team in your home at a time that is convenient for you. If applicable, we may also ask the person who you care for to be interviewed to get their thoughts on the program.

We would also like to post you a questionnaire which asks you some questions about your life and how you are feeling. If you agree, the Project team will post you a questionnaire

shortly and again in two or three months time. The questionnaire takes approximately 10-15 minutes to complete.

What happens with the information you give us?

We will use the information provided to us by those participating in the project to improve the care we provide to our clients and those who care for them.

All information you give us will be treated as strictly confidential. Only members of the RDNS Project Team will have access to your information.

Who decides if you take part in the project?

You decide if you take part in the project. If you would like to take part, please sign the attached consent form.

You are under no obligation to take part in the project if you don't want to. However, your participation would be greatly appreciated and the information you give us may help you and others in your situation. If you decide not to take part, this will not affect the care the person you are looking after receives from RDNS in any way.

If you have any questions about this project, please contact:

Russell Nunn
Project Manager
RDNS Helen Macpherson Smith Institute of Community Health
31 Alma Road, St Kilda, 3182
Tel: 9536 5356

If you have any complaints about the conduct of this project, please contact:

Lisa Donohue
Chair, RDNS Research Ethics Committee
31 Alma Rd, St Kilda, 3182
Tel: 9536 5227

Thank you for thinking about taking part in this important project.

Yours sincerely,

Russell Nunn
Project Manager
RDNS Helen Macpherson Smith Institute of Community Health



Informed Consent Form – Carer

RDNS Memory Project

Client’s Name:.....(please print)

Your Name:

Your Address:

Your Phone Number:.....

I hereby consent to participate in the above project.

- The details of this project have been explained to me verbally, and
- I have received a copy of the Plain Language Statement, and
- Any questions I have asked in regard to this project have been answered to my satisfaction.

I agree to participate in this project and understand that I may withdraw at any time. If I withdraw from the project, any information previously collected from me will be destroyed if I request this. I agree that information provided by me may be used in reports or presented at conferences on the condition that neither my name nor that of the person in my care or any other identifying information is used. I understand that any information I provide will be kept confidential and securely stored at all times.

Your Signature: Date:

Witness’ Name:(please print)

Witness’ Signature: Date:.....

Appendix 12

RDNS Memory Project Client Cognitive Capacity Checklist

CAN THE CLIENT PROVIDE HIS/HER OWN CONSENT?

Please tick yes or no to each statement based on your knowledge of the client:

	YES	NO
The client would be able to understand what the project is about when it is explained to him/her.	<input type="checkbox"/>	<input type="checkbox"/>
The client would know that it is up to him/her only to decide to be in the project.	<input type="checkbox"/>	<input type="checkbox"/>
The client would understand what benefit s/he might have from being in the project.	<input type="checkbox"/>	<input type="checkbox"/>
The client would understand the risks and inconvenience involved in being in the project.	<input type="checkbox"/>	<input type="checkbox"/>
The client would understand that s/he can complain about the project to any one of the following people: a member of the Project Team or the Chair of the RDNS Research Ethics Committee	<input type="checkbox"/>	<input type="checkbox"/>

If you answered no to any of these or are uncertain about any of these, it is best to use the Proxy Consent Form signed by someone (a carer) who has responsibility for the daily care of the client.

Appendix 13

Quality of Life (QoL-AD)

I want to ask you some questions about your quality of life and ask you to rate different aspects of your life using one of four words: poor, fair, good, or excellent.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area. If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

First of all, how do you feel about your physical health?
Would you say it's poor, fair, good, or excellent?

Poor
Fair.....
Good
Excellent

How do you feel about your energy level? Do you think it is poor, fair, good, or excellent? *[If the person says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.]*

Poor
Fair.....
Good
Excellent

How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?

Poor
Fair.....
Good
Excellent

How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?

Poor
Fair.....
Good
Excellent

How about your memory? Would you say it is poor, fair, good, or excellent?

Poor
Fair.....
Good
Excellent

How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent? *[If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.]*

Poor
Fair.....
Good
Excellent

How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent? *[If the person is not currently married, ask how they feel about the person with whom they have the closest relationship, e.g. family, friend, caregiver. If there is no one appropriate, score as missing.]*

Poor
 Fair
 Good.....
 Excellent.....

How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent? *[If the respondent answers that they have no friends, or all their friends have died, probe further. Do you have anyone you enjoy being with besides your family? Would you call that person a friend? If the respondent still says they have no friends, ask how do you feel about having no friends — poor, fair, good, or excellent?]*

Poor
 Fair
 Good.....
 Excellent.....

How do you feel about yourself — when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?

Poor
 Fair
 Good.....
 Excellent.....

How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?

Poor
 Fair
 Good.....
 Excellent.....

How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?

Poor
 Fair
 Good.....
 Excellent.....

How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent? *[If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.]*

Poor
 Fair
 Good.....
 Excellent.....

How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?

Poor
 Fair
 Good.....
 Excellent.....



Wicking “Out of the Shadows” Dementia Project Dementia Knowledge & Beliefs Questionnaire

Please record your answer by placing a tick in the appropriate box(es) or writing your answer in the space provided.

PART A – YOUR DETAILS

1. What RDNS Site are you based at:

Site 1	<input type="checkbox"/> 1
Site 2	<input type="checkbox"/> 2
Site 3	<input type="checkbox"/> 3

2. Which of the following best describes your position within RDNS?

RN Grade 4	<input type="checkbox"/> 1
RN Grade 3	<input type="checkbox"/> 2
RN Grade 2	<input type="checkbox"/> 3
Community Care Aide	<input type="checkbox"/> 4
Other (<i>please specify</i>)	<input type="checkbox"/> 5
.....	

3. Are you involved in direct client care?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2

4. In what year were you first registered to practice as a Registered Nurse?

.....

5. How long have you been employed by RDNS?

Less than 3 years	<input type="checkbox"/> 1
3–10 years.....	<input type="checkbox"/> 2
More than 10 years	<input type="checkbox"/> 3

6. What hours do you work?

Full-time.....	<input type="checkbox"/> 1
Part-time.....	<input type="checkbox"/> 2
Casual	<input type="checkbox"/> 3

7. What time of day do you usually work?
- Day time 1
 Evening..... 2
 Other (*please specify*) 3

PART B – EXPERIENCE & CONFIDENCE IN MANAGING DEMENTIA

8. What level of education and training have you received in caring for clients with dementia?
 (*Please tick all that apply*)
- None..... 1
 Undergraduate 1
 Postgraduate..... 1
 In-Service Training..... 1
 Short course(s) 1
 Other (*please specify*)..... 1

9. How would you rate your level of knowledge about dementia?
- Very high..... 1
 High..... 2
 Acceptable 3
 Low 4
 Very low 5

10. How would you rate your ability to identify the presence of a cognitive impairment in clients?
- Very high..... 1
 High..... 2
 Acceptable 3
 Low 4
 Very low 5

11. How would you rate your level of confidence in working with clients with dementia?
- Very high..... 1
 High..... 2
 Acceptable 3
 Low 4
 Very low 5

12. How would you rate your level of job satisfaction in working with clients with dementia?
- Very high..... 1
 High..... 2
 Acceptable 3
 Low 4
 Very low 5

13. How would you rate your confidence in talking to clients about their dementia?
- Very high..... 1
 High..... 2
 Acceptable 3
 Low 4
 Very low 5

14. How would you rate your confidence in giving advice to
- Very high..... 1

- clients and carers about managing symptoms related to dementia? High..... 2
Acceptable 3
Low 4
Very low 5
15. How would you rate your confidence in talking to carers about the client's dementia? Very high..... 1
High..... 2
Acceptable 3
Low 4
Very low 5
16. How would you rate the level of organisational support you receive in working with clients with dementia? Very high..... 1
High..... 2
Acceptable 3
Low 4
Very low 5
17. In your experience, how well equipped is RDNS to meet the needs of clients with dementia? Very high..... 1
High..... 2
Acceptable 3
Low 4
Very low 5

PART C – KNOWLEDGE ABOUT DEMENTIA

18. Permanent damage to the brain occurs in most types of dementia. True..... 1
False 2
19. People with dementia usually have poor short term memory. True..... 1
False 2
20. Dementia refers to a loss of cognitive abilities (i.e. remembering, reasoning) which is severe enough to interfere with the person's daily functioning. True..... 1
False 2
21. Dementia can be caused by small strokes. True..... 1
False 2
22. Most people with dementia gradually lose their ability to communicate. True..... 1
False 2
23. The person with dementia should be encouraged to be as independent as possible. True..... 1
False 2
24. Paranoid ideas are common in early dementia. True..... 1
False 2

25. A person with dementia frequently refuses or resists personal care activities. True..... 1
False 2
26. People with dementia are unable to communicate their feelings. True..... 1
False 2
27. Alzheimer's disease usually has an abrupt onset. True..... 1
False 2
28. What percentage of older Australians (aged 65 years and above) have dementia?
4 per cent 1
7 per cent 2
10 per cent 3
13 per cent 4
29. By 2050, the number of Australians with dementia is estimated to be:
580,000 1
660,000 2
730,000 3
870,000 4
30. What is the single most significant risk factor for Alzheimer's Disease?
Gender 1
Age 2
Socioeconomic background..... 3
Tobacco use 4
31. Which of the following sometimes resembles dementia? (*Tick one only*)
Depression 1
Delirium 2
Stroke..... 3
All of the above 4
32. The effect of the most recent anti-dementia drugs is to:
(*Tick one only*)
Temporarily halt the disease in all cases..... 1
Temporarily halt the disease in some cases 2
Temporarily halt the disease in some cases but sometimes causing liver damage 3
Permanently halt the disease in some cases..... 4
33. When a person develops a sudden onset of confusion, disorientation, and inability to sustain attention, this presentation is most consistent with a diagnosis of:
Alzheimer's disease 1
Delirium 2
Major depression 3
Frontotemporal dementia..... 4
34. Which of the following symptoms are associated with Alzheimer's disease? (*Tick one only*)
Loss of cognitive abilities 1
Depression 2
Hallucinations..... 3
All of the above 4

35. Which of the following is the single most common cause of severe memory loss in people older than 65 years?
- Alzheimer's disease 1
 - Senility..... 2
 - Normal ageing..... 3
 - Hardening of the arteries 4
36. The pathology of Alzheimer's disease is characterised by:
(Tick one only)
- Amyloid plaques and neurofibrillary tangles..... 1
 - Pick bodies..... 2
 - Lewy Bodies..... 3
 - Strokes 4
37. Dementia with Lewy Bodies is hard to diagnose because of its interrelationship with:
(Tick one only)
- Multiple sclerosis..... 1
 - Huntington's disease..... 2
 - Parkinson's Disease 3
 - Diabetes 4
38. Damage to the frontal lobe of the brain causes:
(Tick one only)
- Impaired retrieval of information from memory..... 1
 - Impaired planning and problem solving..... 2
 - Impaired concentration 3
 - Impaired processing and integration of sensory input..... 4
39. Dementia with Lewy Bodies is characterised by:
(Tick one only)
- Fluctuating cognition, attention and alertness 1
 - Visual hallucinations 2
 - Falls..... 3
 - All of the above 4
40. Person-centred care involves:
(Tick one only)
- Respect and preservation of dignity . 1
 - Centering your attention on the person 2
 - Ensuring the person understands what you expect of them..... 3
 - A team approach to client care 4
41. Therapeutic communication techniques include:
(Tick one only)
- Speaking to person as you would a child..... 1
 - Speaking to them as you would a person who does not speak English . 2
 - Speaking to them as you would with someone with hearing loss 3
 - Speaking to them slowly, calmly and distinctly 4

42. Which one of the following statements is most accurate:
- People with dementia become distressed when you ask questions, so it is better to speak with their families 1
 - Health professionals often avoid seeking the views of people with dementia 2
 - Hearing aids often hinder communication for people with dementia 3
 - It is polite to pretend to take the views of people with dementia into consideration..... 4
43. Caring for people with dementia can be both rewarding and challenging for professional carers. Which one statement contains information that is untrue?
- Acquiring greater knowledge about dementia can increase work satisfaction for health professionals caring for people with dementia..... 1
 - Health professionals don't need to be supported in caring for people with dementia because of their training 2
 - Health professionals acknowledge that caring for a person with dementia can be stressful and challenging, particularly when the person with dementia exhibits behavioural symptoms 3
 - Professional care of people with dementia is easier if the health professional has the necessary knowledge to assess and manage the key aspects of dementia 4
44. When people with dementia talk about their past, it usually:
(Tick one only)
- Is enjoyed by them 1
 - Depresses them..... 2
 - Increases their confusion 3
 - Has no effect..... 4
45. Alzheimer's disease usually:
(Tick one only)
- Can be cured with psychotherapy 1
 - Can be cured with pharmacology 2
 - Goes into remission among the very old 3
 - Cannot be cured 4

PART D – BELIEFS ABOUT DEMENTIA

46. Much can be done to improve the quality of life of people with dementia.
- Strongly agree..... 1
 - Agree 2
 - Neither agree nor disagree .. 3
 - Disagree..... 4
 - Strongly disagree 5

47. Much can be done to improve the quality of life of carers of people with dementia. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
48. Families would rather be told about their relative's dementia as soon as possible. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
49. Providing a diagnosis of dementia is usually more helpful than harmful. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
50. People with dementia can be a drain on resources with little positive outcome. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
51. Working with people with dementia is often more frustrating than rewarding. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
52. There is little point in referring people with dementia to services as they do not want to use them. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
53. District nurses have a very limited role to play in the care of people with dementia. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
54. It is important to have a very strict routine when working with dementia sufferers. Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4

55. People with dementia are very much like children.
- Strongly disagree 5
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5
56. There is no hope for people with dementia.
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5
57. People with dementia are unable to make decisions for themselves.
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5
58. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5
59. Dementia sufferers are sick and need to be looked after.
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5
60. It is important for people with dementia to be given as much choice as possible in their daily lives.
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5
61. Nothing can be done for people with dementia, except for keeping them clean and comfortable.
- Strongly agree..... 1
- Agree 2
- Neither agree nor disagree .. 3
- Disagree..... 4
- Strongly disagree 5

62. People with dementia are more likely to be contented when treated with understanding and reassurance.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
63. Once dementia develops in a person, it is inevitable that they will go downhill.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
64. People with dementia need to feel respected, just like anybody else.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
65. Good dementia care involves caring for a person's psychological needs as well as their physical needs.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
66. It is important not to become too attached to clients with dementia.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
67. It doesn't matter what you say to people with dementia because they forget anyway.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
68. People with dementia often have good reasons for behaving as they do.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5

69. Spending time with people with dementia can be very enjoyable.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
70. It is important to respond to people with dementia with empathy and understanding.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
71. There are a lot of things that people with dementia can do.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5
72. People with dementia are just ordinary people who need special understanding to fulfil their needs.
- Strongly agree..... 1
 Agree 2
 Neither agree nor disagree .. 3
 Disagree..... 4
 Strongly disagree 5

Thank You

