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Submission to Standing Committee on Health and Ageing

Inquiry into Dementia: Early Diagnosis and Intervention

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About RDNS

RDNS Limited (Royal District Nursing Service) is the oldest and largest home nursing service in Australia. Each year RDNS provides care to over 35,000 clients. Although RDNS provides a service to people across the lifespan, the majority are frail older Australians with approximately 70% aged over 65 years.

The staff of RDNS are experienced in the care and support of people with dementia and have seen firsthand the impact that dementia has on the individual and the family and friends. We are aware that dementia is under diagnosed or not diagnosed in a timely manner. It has been our experience that of people receiving in home nursing care, only 7.8% of RDNS clients have a documented medical diagnosis of dementia. Yet, our staff report 32.6% of older clients had problems with memory loss, 29.4% exhibited signs of confusion, and 22.3% had a confirmed medical diagnosis of dementia. Further:

- 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 did not have a carer

Our recent suite of dementia care projects show that much more can be done to improve care through the timely and early identification of dementia to prevent or forestall ongoing problems associated with the condition. RDNS has committed to greater emphasis on early intervention to prevent the client's condition deteriorating significantly, and preventing the potential breakdown of the family situation where possible.

We therefore thank the Committee for the opportunity to provide a response based on our experience as a leading home care provider to this particular population in Australia.

We recommend that the committee reconsider use of the term early diagnosis as the paradigm for this inquiry and rather adopt the perspective of timely diagnosis. RDNS acknowledges that much of the literature has indicated the potential benefits of early diagnosis, in particular the ability to implement early intervention strategies to diminish the onset of further symptoms. The recent report from Alzheimer's Australia *Timely Diagnosis of Dementia: Can We Do Better?* (Phillips, Pond & Goode, 2011) highlights longstanding concerns that there remain significant delays in diagnosing dementia and subsequent management of the condition. It is noted that in Australia symptoms of dementia were noticed by families an average of 1.9 years prior to the first health professional consultation and there was an average of 3.1 years before a firm diagnosis was made. Many reasons for this delay have been identified and have been articulated in Alzheimer's Australia's report. These have been found to reflect three different areas of particular challenge:

- Patient and carer factors,
- GP barriers, and
- Systemic factors.

However in our view for interventions to be successful, the dementia sufferer, their family and friends and the broader community have to be ready to seek information, diagnosis, treatment or other interventions. This readiness will come at different times for different people but when it does expeditious and timely assessment is then critical.

Recommendation 1
RDNS supports the concept of timely, rather than early, diagnosis and intervention.

Response to the specific elements listed in the Committee's Terms of Reference.

Improve quality of life and assist people with dementia to remain independent for as long as possible

How might barriers to early intervention be overcome to enable independence for as long as possible?

RDNS has identified a number of ways in which barriers to early intervention can be overcome to enable independence for as long as possible.

1. *Up skilling nurses to undertake early identification of dementia in the person's home.*

In 2006 the RDNS Helen Macpherson Smith Institute of Community Health completed a project to develop a model of mental health care (Nunn & Allen, 2006). The study showed that nurses and other health professionals providing care in the home can play an important role in early identification of dementia, rather than this role being restricted to GPs; however funding for such activity is restricted to GPs through the MBS, or through specialist services. Programs funding in-home care must recognise the capacity of health professionals with existing trusted relationships to assist clients and carers to deal with the challenge of accepting a diagnosis of dementia. The support required is best handled in the home environment but funding is not currently available for this in most cases.

We are not alone in identifying the important role nurses can play, studies internationally (Manthorpe, Illife & Eden, 2003), have also shown that with appropriate training and support nurses can play a greater role in diagnosis and support. In addition there are potential benefits of screening in the home environment including greater acceptance by the person being assessed rather than in a clinic, and this is where services such as RDNS can make a significant contribution to both timely diagnosis and ideally early diagnosis. It is however important to note that appropriate clinical governance structures, ongoing education and training must be in place. Monitoring of outcomes via organisation clinical quality and risk committees and auditing of the practice of nurses in undertaking this work is important to ensure neither under diagnosis, nor over diagnosis. It is not appropriate in RDNS's view that nurses undertake dementia screening without the necessary governance structures in place.

Recommendation 2
Skill nurses to undertake dementia screening.

Recommendation 3
Ensure that services providing nurse screening have the requisite clinical governance structures in place

Recommendation 4
Fund programs to enable health professionals with existing trusted relationships to assist clients and carers to deal with the challenge of accepting a diagnosis of dementia

2. *Use a model of care that includes the use of appropriate cognition assessment tools*

RDNS has demonstrated that a large number of the identified barriers can be overcome through the implementation of a model of care developed for dementia. In particular, the use of a Cognition Assessment (the RUDAS and MMSE tools were used) was shown to be effective in identifying client issues and problems which had not been previously identified. But importantly the Model was seen to provide 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.

Interestingly our nurses' experience of this new Model of Care varied and was sometimes contradictory. This was seen to reflect the highly individual impact of cognitive impairment on people, and the variable experience and skill of nurses. A highly flexible Model of Care is required to respond to these variables, including comprehensive education for nurses and access to specialist staff with well developed skills and experience to support the nurses to provide responsive and flexible care. On further examination we found that the care of people with cognitive impairment requires a high level of skill, and therefore the need to provide dementia care for a high proportion of RDNS clients creates a very real resource challenge.

RDNS advocates for continued investment in education of health professionals in regard to identifying the early signs of cognitive impairment and dementia, and what steps should be taken to further investigate and manage these symptoms. Training on how to manage conversations with clients and carers on this topic is also required. It has been our experience that staff are reluctant to undertake this challenging conversation unless they are skilled and experienced in this role. In addition to education support through the use of tools such as dementia services pathways that outline key areas to discuss can also facilitate the effective identification and discussion of dementia.

The following case study illustrates the complexity that our staff encounter in caring for clients with dementia and how services such as RDNS support people with dementia to live independently at home for as long as possible.

> *Case Study 1:*
> *Mrs A, 50, Type 2 diabetes, divorced mother of two young adult children—18 and 22, was diagnosed with early onset dementia. At the time of diagnosis, the family were offered pamphlets and other written information, including information about services available to assist eg , Alzheimer's Australia, Carer's Australia. The family did not accept services, however RDNS received a referral from the GP who was concerned Mrs A was no longer managing her diabetes and concerned that she was not taking her medicines. Nurses began visiting for medication management including oral diabetes medicines.*
> *Mrs A was usually home alone when nurses visited, one child was studying, the other in full time work. Mrs A was unable to give a coherent history and appeared to be quite thin and frail; there was concern regarding recent weight loss. Nurses spoke to the 22 year old daughter who seemed to have little understanding of her mother's condition.*
> *The nurse referred Mrs A to a RDNS Social Worker (SW) who met Mrs A and made contact with both her son and daughter. Both had little understanding of their*

mother's condition despite all the written information that had been given at the time of diagnosis. Concerning the issue of their mother not eating, they said she had always been a picky eater so they just bought whatever they thought she would like and felt that she would prepare food and eat when she got hungry. The children interpreted a lot of their mother's behaviours as intentional or attention seeking, "She's just doing this because she doesn't like us going out".

Several sessions were held with one or both of the children to discuss—using the materials previously provided—the process of dementia, changing behaviours etc. It was very difficult for Mrs A's young adult children to accept the changing roles with them becoming decision makers for their mother rather than the other way round. With assistance they discovered that their mother's sister held Enduring Power of Attorney, and she began to take on more of a role in Mrs A's care. Previously the sister had assumed that Mrs A had been managing well as she had received no requests for assistance.

This then allowed the introduction of community services—home meal preparation, personal care and respite that made it possible for Mrs A to remain safely at home for some time and for her children to continue their work/study. The RDNS Social Worker was also able to advise on Centrelink entitlements they had not been receiving and additional community supports. The Social Worker also supported the family through the difficult decision making around planning for Mrs A's eventual placement into residential respite followed later by permanent care.

Recommendation 5

Invest in education and training of nurses and other health professionals in dementia assessment and care planning managing the difficult conversations about dementia diagnosis and treatment

3. *Expand the opportunities for people to gain information at the rate that suits them.*

In our experience, there are a number of factors that impact on people's ability to come to terms with and understand the aetiology and the impact dementia will have on the lives of the newly diagnosed and the carers involved. Written information or information provided by a professional in a clinic setting alone is not the best way to provide early intervention for people with dementia and their carers. In our experience most people require timely information provided in a range of different ways. People often require time to process what they have read and sometimes, time before they are willing to even read the information. It can sometimes take face to face contact with someone who can provide some support to the individual, family and carers in reaching this stage, as demonstrated in the above case study.

There are also instances where the use of the term 'dementia' can in fact be a barrier in itself due to the fear and stigma still attached to this term. In such cases it has can be beneficial to focus attention on understanding and treating the particular signs and symptoms, rather than emphasising the diagnosis of dementia.

The role relationship between the person with dementia and their carer can also add difficulties especially where the carer was in a previously subordinate relationship such as a child caring for a parent or in situations where the relationship prior to the diagnosis of dementia was poor. Often in these situations the carer interprets difficult behaviours as purposeful—"They just act that way because they know it upsets me". These role difficulties are often best addressed in the context of ongoing, trusting relationships that health professionals such as RDNS nurses and social workers often have with their clients.

Recommendation 6
Provide support to people with dementia in their preferred setting, and where possible involve any carers and family members the person may have. Gaining understanding and acceptance of a diagnosis of dementia will take time for many clients and their carers. Regular contact and support from appropriate health professionals is required throughout this time

Recommendation 7
Consider the use of language carefully when developing written material advertising campaigns as the use of some words can be a barrier to the message providing information in common languages or use of interpreter in client & carer interactions and discussions.

Increase opportunities for continued social engagement and community participation for people with dementia

What have we learnt on this issue?

During 2010 RDNS sought a greater understanding of the impact of living alone on older clients with cognitive impairment or early stage dementia, and to identify ways in which we could contribute to improvement in quality of life and appropriate care for this population.

Our study found that while staff consistently used the term 'social isolation' to describe those who we knew to be living alone and assumed to be socially isolated, and/or lonely, the participating clients did not necessarily describe themselves as lonely or socially isolated. They believed they had the ability to maintain a connection with others despite losses and change. The self-identified needs of older people do not always mirror those perceived by the people caring for them, and t therefore health professionals and other service providers need to engage more with older person in order to provide care collaboratively.

We also found that the study participants did not share the same concerns about risk factors (eg leaving the house unlocked and going out), thereby highlighting that risk management must involve a collaborative, rather than prescriptive approach.

The general consensus for both staff and clients participating in this study was the desire for an individual approach to management of issues relating to social isolation. However it was found that assessment and management of issues that relate to social isolation was limited because it was not perceived by the health professional to be a part of the funded program of care available; indeed many participants indicated that social support was not a priority for service providers as most had not been offered such support.

RDNS has adopted the Active Service Model or 'reablement' as its general approach to care and recommends that assisting the older population to achieve their health goals and social needs is part of holistic care as the two issues are interdependent.

Recommendation 8
Social engagement and community participation must be planned collaboratively with the client, and be congruent with their interests.

Recommendation 9
Greater emphasis must be placed on the value of social engagement in avoiding isolation and potential depression.

Recommendation 10
Funding programs must recognise the benefit of holistic care. It is argued that currently many are seen as ‘task focussed’.

Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements

What have we learnt on this issue?

Our experience shows that there is a need for enhanced community knowledge of legal and financial implications of dementia and self-decision-making. 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 earliest 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.

The ‘Out of the Shadows’ project (Nunn et al, 2009) identified 48% of clients benefitted from developing forward planning advice. This was achieved through a process that prompts the clinician to consider the client’s long-term decision making ability in the context of their presenting problems. Evidence gathered prior to the commencement of the project 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 are those clients whose dementia has progressed to such a level that it has the potential to compromise their capacity for self determination. It is these clients that health practitioners need to recognise and seek an advocate who can either support the client’s right to autonomy or seek an assessment of cognitive capacity.

RDNS recommends the following improvements for enhanced community knowledge on the need for future planning:

- Community education that focuses on informing the general public will assist in increasing a perception of an accessible and transparent process and will encourage family or interested parties to be involved in the process of substituted decision making where necessary.
- A focus on education of GPs is required as the local GP is often in a position to provide important information and support for an individual/family. They may also assist with assessing capacity, although it is our experience that many GPs are reluctant to become involved in this process.

- Other health professionals already providing care for other conditions are also well placed to identify issues and provide information and support.
- Training in the principles of advanced care planning for relevant professionals (eg nurses, doctors, social/welfare workers, housing workers) could be provided through articles in professional journals and information sessions.
- Specific education for CALD communities is important as many clients from CALD backgrounds have limited experience of guardianship/substituted decision making. Education will need to cater for vastly differing levels of literacy and English as a second language.
- Expanding the resources of the Office of the Public Advocate (or equivalent) to provide information to the general public and interested parties, on the processes, criteria and prerequisites of the system would be very beneficial. In addition providing more explicit step by step information would be conducive to community understanding.
- Additional community education on Powers of Attorney/Guardianship should also occur. If people are to be encouraged to make their own choices for their future then the need for authorities to appoint substitute decision makers should decrease.

The following case study illustrates the importance of future planning to prevent potential crises, and the way in which it can alleviate anxiety through empowering individuals to take greater control of their future decision-making in an informed way.

> *Case Study 2:*
> *Mr and Mrs M, both in their late 70s, live together in their own home. They have one child from whom they are estranged and no other relatives in Australia. RDNS nurses have been visiting Mr M for wound care. Over the course of RDNS' involvement, Mrs M tells the nurses she is concerned about what might happen to the two of them if they are unable to care for themselves and very concerned that their estranged son, who she says has substance abuse issues, will take over their affairs. She is also concerned that her husband's memory is declining.*
> *The nurse referredthe couple to a RDNS Social Worker to discuss Enduring Power of Attorney (EPOA) and future planning. The Social Worker provided general information and strongly advised that they both see their GP to discuss/assess capacity before making EPOA to safeguard against future challenge. The GP assisted Mrs M by witnessing her EPOA. The GP also referred Mr M to a geriatrician for capacity assessment and Mr M was also able to complete an EPOA. Mr M was also referred to a Memory Clinic and diagnosed with mild cognitive impairment.*
> *The RDNS Social Worker continued working with Mr and Mrs M, providing information about community services. As Mr M's cognition declined and he was diagnosed with dementia, Mrs. M accessed additional community services and support and was able to care for her husband at home until his death.*

How can information be shared more effectively?

There are many different responses people may have in relation to a loved one being diagnosed with Dementia. Whilst education and information is essential, a document designed to provide information to a broad range of people will not always reach those that it most needs to reach. RDNS nurses and social workers are often involved in situations where carers have been spoken to and given information about dementia (usually in a hospital or clinic setting), but still demonstrate a very limited understanding of what is happening. In many cases, for example, the information provided was not provided in a language spoken by the family and the information provided assumed some level of understanding of health that entailed a cultural bias. In these cases it is often found that the carer assumes that forgetfulness or other behavioural changes are due to the person being difficult. Sometimes the carer and other family have not realised what is occurring, missed the significance of subtle early changes and begun to compensate for those changes. In our experience it is often helpful to be present in the environment (the home setting) to talk about issues over time, reiterate, reinforce and assist with the interpretation of behaviours. To help support people to make that transition of understanding is often best done over time with both information and a trusted professional.

Recommendation 11
Broader community education on the process and benefit of future planning for financial and legal affairs is needed.

Recommendation 12
Care pathways and models of care must highlight the need for health professionals to introduce discussion of future planning early in their intervention.

Recommendation 13
Financial and legal planning information and processes must be cognisant of diversity issues, particularly English as a second language, and different perspectives on advanced care directives and substitute decision making in other cultures.

Recommendation 14
Discussions on these delicate issues are often best managed in the home environment and developed over a period of time.

How best to deliver awareness and communications on dementia and dementia-related services into the community

General perceptions of dementia are focused on the progressive nature of the condition, and the significant impact that it will have on physical, emotional and psychological independence. It is generally seen as something from which the sufferer will not recover.

It is necessary to promote a more positive and less inevitable scenario for dementia in order to encourage individuals and their families to recognise the benefit of early/timely diagnosis, and embrace measures to better manage the condition in order to improve overall health status, prevent health crises, and agree on future decision making processes.

There are now many high profile older Australians who have made public their struggle with dementia. However in most cases the focus remains on the struggle with progressive decline, rather than positive messages about the benefit of early intervention and the potential to delay/stop progression of the condition. Greater emphasis on the ability to maintain independence is required. Such moves would hopefully reduce some of the stigma still strongly attached to a diagnosis of dementia.

Manthorpe, Iliffe and Eden (2003) state there is already international evidence that early identification of dementia:

1. Can sometimes facilitate effective treatment by maintaining functioning for some time or delaying cognitive decline;
2. May respond to individuals' or their families' searches for an explanation of their problems;
3. May enable planning for the future; and
4. May uncover other problems amenable to treatment that co-exist with or mimic dementia.

Such benefits need to be promoted to the community in order to assist clients and their families to overcome any fears associated with the potential of dealing with cognitive impairment.

Recommendation 15
Greater promotion of the significant benefits of early intervention is required.

Recommendation 16
It should be highlighted that dementia is not a normal part of the ageing process, and effective treatment can delay cognitive decline or identification and treatment of other conditions which display cognitive symptoms

In summary, in regard to early diagnosis and intervention of dementia, our experience at RDNS tells us:

1. There is considerable variation among health professionals' skill and knowledge in relation to dementia care. More education and support in this condition is required.
2. Assessment in the home environment can greatly assist the accurate and timely assessment of cognitive capacity. Nurses are well placed to undertake this role if adequately prepared.
3. The availability of specialist health professionals (in our environment this is Aged Care Clinical Nurse Consultants) can result in improvement in care provision to clients with dementia and their families.
4. Dementia-focused care should be a core competency of all district nurses involved in clinical care, including accurate use and interpretation of dementia screening tools.
5. 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.
6. Clinical pathways and frameworks must recognise the importance of clinical and emotional support in the early stages of diagnosis, as must funding programs.
7. Current blockages in the service system prevent timely referral to and from other providers which result in the client's needs not always being adequately addressed.

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