

mal Submission No. 061

(Dementia)

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2407/12

Standing Committee on Health and Ageing
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Dr Clegg

Re: Inquiry into Dementia: Early Diagnosis and Intervention

In response to your invitation to provide a submission to the *Inquiry into Dementia: Early Diagnosis and Intervention*, I am pleased to provide the attached submission.

RCNA is the peak professional organisation for nurses in Australia. RCNA represents nurses across all areas of practice throughout Australia. RCNA has members in all states and territories of Australia, and internationally. A not-for-profit organisation, RCNA provides a voice for nursing by advocating on health issues that affect nurses and the community. With representation on government committees and health advisory bodies, RCNA is recognised as a key centre of influence in the health policy arena in Australia. When health policy decisions are made, RCNA presents a professional nursing perspective, independent of political allegiance.

RCNA looks forward to the outcomes of the inquiry and we wish you well in the project.

Yours sincerely

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Inquiry into Dementia: Early Diagnosis and Intervention House of Representatives Standing Committee on Health and Ageing

RCNA is pleased to provide a submission on the *Inquiry into Dementia: Early diagnosis and intervention* for the House of Representatives Standing Committee on Health and Ageing.

RCNA supports the view that dementia early diagnosis and intervention can significantly improve health and lifestyle outcomes for people with dementia causing illnesses. However, the following comments are made recognising that dementia is not a single disease. Dementia is a set of symptoms that can result from a wide range of illnesses, some of which are reversible and some of which are able to be moderated if a diagnosis of the underlying cause is made. Furthermore, it is recognised that early diagnosis can be difficult due to a range of other conditions presenting similar symptoms to that of dementia. It is the experience within nursing that conditions of delirium, depression, dehydration, pain, bereavement and grief, and malnutrition may be misdiagnosed as dementia. As a result of misdiagnosis dementia symptoms may persist unnecessarily, if appropriate and effective treatment is not given.

This submission provides a general response to the inquiry and outlines the potential of the nurse workforce to contribute to the coordination and delivery of care to people with a range of conditions causing dementia.

General Response to Terms of Reference

Early stage inter-professional collaboration

Early diagnosis is an important step in enabling people with dementia causing illnesses to remain independent in the community for as long as possible. Early diagnosis that leads to early discussion and collaboration within health care teams is key to developing effective inter-professional care pathways focused on improving and maintaining an individual's optimal physical and emotional wellbeing.

Early diagnosis provides opportunities for accurate diagnosis of the condition and allows for early interventions that can result in the reversal of some symptoms and moderation of other more persistent types of illness. The end result includes a reduced level of dependence on the health system while providing greater opportunity for positive health and social outcomes for people with dementia symptoms and their families. However, to have this impact, it is essential that early interventions are collaboratively planned in close consultation with the person and their family and carers, and coordinated throughout the continuum of care. A key element in achieving an accurate diagnosis of the cause of dementia symptoms is the collaboration between nurses and medical professionals involved with families in pursuit of a focused care and treatment strategy that produces dementia symptom relief.

Role of nurses as coordinators

To meet the goal of supporting people with dementia symptoms to remain independent for as long as possible, health service and care pathways should be developed that seamlessly link people through appropriate investigations and a confirmed diagnosis so that interdisciplinary primary health care teams can provide effective services. These teams should have the capacity to understand the full range of dementia-causing conditions, possess the skills to deliver contemporary treatment and care, provide information and advice, as well as be able to coordinate care. Community and specialist nurses skilled in this field of care are uniquely placed to provide a coordination role linking people diagnosed with dementing illnesses with other health professionals and social services as required. Such services include dental care, social workers, occupation therapists, transport services and legal/financial support services.

The skill repertoire and roles of registered nurses equip them to undertake comprehensive health assessments; to provide treatment and care interventions; as well as to develop care plans that address physical and psychosocial health needs. As part of a highly flexible workforce, nurses are well placed to collaboratively plan and coordinate individualised care that includes meeting both the individual and the wide range of health and social needs of people who have conditions which result in intractable mental confusion.

Nurses are present in all health settings, often reaching communities that are not well serviced by other professional groups; thus issues of limited access to skilled nursing advice and assistance are less likely to arise when nurses undertake the role of care pathway coordinator. National health policy should develop strategies and direct investment to maximise the roles of general nurses in all contexts to be able to deliver dementia care based on the underlying pathology which is causing the symptoms.

Accessible services and support groups

Early diagnosis and early interventions which are planned and provided by an interdisciplinary team must be easily accessible within the community context and connect people with local support groups where they are available on diagnosis. There are local support services and groups within the community designed specifically for people in the early stages of dementia, for example, the *Living with Memory Loss* support program provided by Alzheimer's Australia. Such services, in combination with specialised health and medical advice, can provide opportunity for people in early stages of dementia, along with their families and carers, to overview issues and options and to provide regular contact and connection with others experiencing the early stages of dementia.

Education and information provided to the patient and their family is an important aspect in maintaining quality of life. Education about the disease which may be causing the dementia symptoms including the prognosis, progression of the illness, as well as what to expect, management of daily activities of living, and planning for the future, in the context of small, supportive, or individual group sessions with dementia support staff, are all important therapeutic treatment steps. Early discussion about topics such as goals of care, respite, in-home respite and residential aged care assists people with dementia and their carers to understand the issues and considerations they will face as the disease progresses.

The important roles of support groups in influencing people's ability to maintain optimal independence must not be underestimated. Support groups are indispensable services that if appropriately funded can not only provide important information but also promote social inclusion by providing activities that reflect the social interests of group members. These groups provide physical, emotional, psychological care and support and must be adequately funded to form part of a framework of early diagnosis intervention strategies. Community-provided transport is also a central need in the promotion of independence in early stage dementia.

Nurse Workforce: Care Coordinators

Expanding the role of nurse

RCNA believes nurses are generally underutilised in the delivery of health care services in Australia. While there are positive trends towards enhancing and expanding the roles of nurses, particularly in the promotion of private sector aged care and primary health care services, there are currently many areas within health care that would benefit from greater investment in the nurse workforce. In dementia care, the roles and potential contribution of nurses to treatment and care should be examined in the development of national strategies towards improved early and accurate diagnosis and appropriate intervention practices.

Nurses, due to their prominence across health settings as well as through the nature of their service engagement, are able to support people with dementia symptoms from all dementia etiologies in their efforts to maintain good health and wellbeing. With targeted skills enhancement, registered nurses could more routinely provide dementia care and assist in setting self-management and family/carer management goals and actions in collaboration with other health professionals.

It is the experience of nurses working in dementia units that early diagnosis of and intervention for the underlying cause of dementia symptoms can be useful for providing more time for people and their carers to adjust to challenges and changes that such diagnosis can present. Changes that occur in a

person's cognitive and functional capabilities, lifestyle, living arrangements, social involvement, financial situation all become part of the comprehensive health management needs with a dementia causing illness. It is invariably a registered nurse who takes the lead in providing the coordinated care required to support people challenged by the issues that arise in the management of dementia and its underlying pathology.

Nurses should be supported to establish clinics, consultation rooms and mobile services to people with dementia in the community and elsewhere, due to their systems knowledge and clinical skills. Nurses have the capability to lead inter-professional and cross-sector teams. To ensure effectiveness and efficiency in the design and delivery of dementia care and services, strategic investment in nursing roles to support accurate early diagnosis and intervention should become a policy priority.

Recommendation: Funding be made available to establish nursing services to manage and coordinate the health care pathways of dementia patient populations.

The skilled generalist nurse

The health support needs of individuals with dementing illnesses, particularly in early diagnosis, lie in areas such as health promotion, early detection and remedy of health and social problems as well as advocacy in dealing with other aspects of the health system. Nurses in these roles provide health knowledge, information, skills and experience and are agents of connectivity within our health care system. Nurses are unique in providing essential linkages between the system's many users, health professionals and service arrangements while placing the patient and their supporters at the center of care pathways.

The skill set of the generalist nurse includes broad clinical and health care skills, an understanding of a wide range of practice environments, an ability to coordinate multi-disciplinary teams and liaise with other service agencies. The generalist nurse also advocates for people in their care. Just as general medical practitioners are able to work proficiently in the general medical environment, so too are nurses able to function effectively in general nursing contexts and have significant value to add to the care pathway of individuals with conditions that render them mentally confused.

Specialist nursing roles

Specialised advanced practice nurses and nurse practitioners are able to provide a comprehensive approach to the care and support of people with challenges to their health or safety. Specialist and consultant nurses with postgraduate specialty qualifications can greatly increase the range of services available in all care contexts and with appropriate strategic investments can be key providers in accurate early diagnosis and intervention for dementias. RCNA recommends the development of specific incentives for approved providers in aged care to engage in practice development for nursing roles. The aged care sector needs to provide more specialist nursing services to meet the rising prevalence of people with dementia causing conditions. Incentives and innovative models of care that would allow the sector to achieve this would assist in meeting the growing demand for services resulting from the ageing population.

Nurse practitioner services

Nurse Practitioners (NPs) are highly skilled and legally endorsed to perform various functions similar to medical practitioners, and have been available in Australia for several decades but as yet, Australia has not fully utilised this workforce resource nor incorporated NPs centrally in any area of the health and aged care systems^[1].

Acknowledging the emergence of national policy aimed at growing the role of NP in aged care and in primary health care, RCNA believes a great opportunity exists to further develop NP roles. RCNA also notes that there are practical issues requiring attention, including Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) options and barriers to navigating the legislative requirements for collaborative arrangements with medical practitioners. There are also service delivery and professional considerations that will need to be resolved in order to ensure an enabling environment for the greater utilisation of NPs in speciality areas. In the face of demographic change and an ageing population in Australia, NPs present a practical solution to improving access to high quality care and to reducing the high cost associated with dependence on hospital-based medical services.

The potential of the nurse practitioner

The health and wellbeing of people with dementia symptoms will continue to depend on accurate and early diagnosis and access to skilled and knowledgeable health professionals who can provide effective clinical interventions. Regardless of where this access occurs, the expectation is that these professionals will have advanced abilities in assessment, diagnosis and treatment options as well as advice on healthy and productive lifestyles and strategies in adaptation where necessary. A higher proportion of care could take place in the community setting if a cohesive framework for skilled nursing care could be established within communities. The political will to move from the dominant medical paradigm to a more inclusive and professional integrated one is required to activate this highly skilled and effective workforce to provide a greater contribution in the area of dementia care.

Recommendation: Funding incentives be provided to establish an increased number of specialised advanced practice nurse and nurse practitioner positions across aged care environments that deliver care to those with dementia causing illnesses.

References

[1] Gardner, A. Glenn E., Middleton S., Della., P. R. (2009). The status of Australian nurse practitioners: the first national census. *Australian Health Review*, 33, (4) 679-689.

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