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nursing federation

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Submission No. 079

(Dementia)

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Submission to the inquiry by the House of Representatives
Standing Committee on Health and Ageing into dementia
early diagnosis and intervention

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1. Introduction

Established in 1924, the Australian Nursing Federation (ANF) is the largest professional and industrial organisation in Australia for nurses, midwives, and assistants in nursing. The core business for the ANF is the professional and industrial representation of our members and the professions of nursing and midwifery. This representation is undertaken through Branches in each State and Territory of Australia, and the Federal Office.

The ANF has a membership of over 214,000 nurses, midwives and assistants in nursing. Our members are employed in a wide range of settings in urban, regional, rural and remote locations, in both the public and private health and aged care sectors.

The ANF participates in the development of policy relating to: nursing and midwifery practice, professionalism, regulation, education, training, workforce, and socio-economic welfare, health and aged care, including reform agendas, community services, veterans' affairs, occupational health and safety, industrial relations, social justice, human rights, immigration and migration, foreign affairs and law reform.

2. Summary of recommendations

Recommendation 1:

That Nurse Practitioners be included within the funding mechanism for health professional support measures, under the Australian Government Aged Care Reform Package.

Recommendation 2:

That the role of Nurse Practitioners and other registered nurses in dementia early intervention assessment and care be recognised and facilitated, with funding provided to support education at undergraduate and postgraduate levels, and continuing professional development.

Recommendation 3:

That the role of care co-ordinator for dementia care be undertaken by registered nurses, in residential aged care and community settings.

Recommendation 4:

That the telehealth facility be extended beyond use of videoconferencing techniques, to enable:

- Medicare reimbursement to health professionals for utilising telephone link-up;
- use between general practice and residential aged care facilities; and,
- use in case conferencing, mentoring and education.

Recommendation 5:

That this inquiry recommend amendment to the *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013: Australian Government Implementation Plan 2007-2013* to specifically include dementia early diagnosis and intervention.

Recommendation 6:

That the inquiry recommend education for the health and aged care workforce include culturally sensitive, acceptable and specific approaches to the diagnosis and early intervention of dementia for culturally and linguistically diverse communities, and those with diverse gender preferences.

Recommendation 7:

That the Australian Government make provision for on-going funding to support:

- Scholarships for education and professional development specifically in dementia care for all nursing staff in aged care;
- Scholarships for education and professional development specifically in dementia early identification and intervention measures for Nurse Practitioners and other registered nurses;
- Inclusion of a compulsory unit of competence in nationally accredited training packages for all certificate III and IV workers in aged care and Aboriginal Health Workers, on dementia care;
- On-line dementia care education to increase the reach of dementia specific programs;
- Reinstatement of more positions for registered nurses in residential aged care settings; and,
- Creation of more positions for Aged care Nurse Practitioners working across residential facilities and community aged care settings.

Recommendation 8:

That dementia early diagnosis and intervention include advance care planning, while the individual concerned is still able to participate in the discussions, is competent to make decisions, and able to articulate their preferences for future care needs.

Recommendation 9:

That the Australian Government fund research targeted to:

- early identification of dementia,
- commencement of appropriate evidence-based dementia care interventions from the findings,
- on-going refinement of models of dementia care which can be adapted to differing communities, and
- quality use of medicines in dementia care.

3. General comments

3.1 Nurses in aged care and in dementia care

Members of the ANF are involved in care across the life spectrum. In particular, registered and enrolled nurses and assistants in nursing form the largest cohort of care workers for older people in this country – both in community based services, in peoples' own homes, and in residential aged care facilities. In this capacity, our members are intimately acquainted with the impact of dementia in our society: for those who have been diagnosed, those who exhibit signs of dementia but are yet to be diagnosed, and for family, friends and the broader community. Our members observe on a daily basis the effects on individuals and their family/friends of the increased incidence of dementia in the Australian community. In fact, nurses may well be the first health professional to notice changes consistent with early onset of dementia. Further, as nurses are interacting with people at all stages of the life cycle, they are often the health professional to first notice signs and symptoms of early onset dementia in younger people.

Many nurses have acquired formal qualifications in dementia care nursing to inform and enhance their practice in this area, whether this is a focus of their clinical role, such as in a residential aged care facility, or forms a part of a broader role, such as in community care (for example, mental health nurses).

As front-line health professionals in aged care services across geographic locations and socio-economic situations, our members are well placed to observe the advantages of well-resourced services and the effects on individuals and communities where these services are diminished or lacking. Nurses are intimately acquainted with the difficulties faced by people due to distance from nearest available aged care services; and, those living in poverty, the homeless, or otherwise marginalised from mainstream health and aged care services.

Increasingly, and over the past couple of decades in particular, the nursing profession is taking a vital role in research activities aimed at improving the delivery of care to people who have acquired dementia.

Of concern to ANF members is the reduction in numbers of registered nurses over past years in aged care. They are now a scarce clinical resource in an increasing number of residential aged care facilities. This may have the consequence of delaying identification of dementia signs and symptoms and thereby timely intervention.

Likewise ANF members have given feedback at state Branch level that dementia related positions (as well as positions for an advance care planning role) are often on a contract basis and left unfilled for long periods. This is detrimental for the people with dementia and their families and support networks, as it undermines the importance of continuity of care (with consistent and familiar personnel) for people with dementia.

It is the position of the ANF that the needs and circumstances of the person diagnosed with dementia must be the centrepiece of treatment and care, not the interests of service providers. This means that extra effort, in terms of financial and material resources, must be instituted to provide services at the point of care which will be most convenient and appropriate for the individual and their family/friend carers. This will require innovation, creativity and flexibility in designing services to meet individual needs, and a commitment to sustainability of funding for continuity of care.

3.2 Aged Care Nurse Practitioners

The Aged care Nurse Practitioner role is an exciting development over recent years and is emerging as a key element in the provision of expert dementia care across metropolitan, rural and remote settings. Aged Care Nurse Practitioners work autonomously, provide professional leadership, use their expert clinical knowledge, extensive experience and advanced clinical skills, to ensure that comprehensive assessment is made of care needs, that this care is evidence-based, and, that it is responsive to the individual older person requiring the care, their family/friends, and the community.

In common with all other Nurse Practitioners in Australia, Aged Care Nurse Practitioners must achieve a Masters level education (in this case Master of Nursing (Nurse Practitioner) in Aged Care), as well as many years of advanced practice in their specific context of care, in order to be eligible for endorsement by the Nursing and Midwifery Board of Australia. They are considered to be the highest clinical level in the nursing profession, co-ordinating care and providing support, advice, guidance and leadership to other nursing staff in aged care settings.

Growing the Nurse Practitioner workforce with investment in education, ongoing professional development opportunities, and enabling innovation in models of care, is key to meeting the projected demand arising from: the substantially increased proportion of complex care for older people required and provided in the residential aged care and community settings; nurse-led care options; transitional care facilities and community housing arrangements; and, increasingly complex care in rural health care services.

The ANF argues that the role and scope of registered nurses and Aged Care Nurse Practitioners should be supported in all areas to meet the needs of Australia's diverse population and communities. This is especially important for aged care in regional, rural and more remote locations.

4. Blueprint for Aged Care Reform

The ANF has been vigorously campaigning for reforms in the aged care sector through significant national campaigns:

Because We Care – a national ANF-led campaign over the past two years to improve aged care through workforce sustainability measures including education, career incentives, and licensing of currently unregulated aged care workers;

and,

Australians deserve to age well – a recent national blueprint for aged care reform led by a consortium under the National Aged Care Alliance banner. This campaign, building on the ANF identified workforce reforms, broadened the scope of issues critical to preparing for future aged care needs in this country. With specific reference to the current inquiry into dementia, the *Australians deserve to age well* campaign called for the Australian Government to “ramp up the fight against dementia, arguably the most unrecognised scourge of our time” by “investing in dementia-risk reduction and research to reduce future numbers of people with dementia.

5. Inquiry into dementia early diagnosis and intervention

With a significant number of members working in the aged care sector, and the ANF's heavy involvement in campaigns for aged care reform, we welcomed the announcement in March 2012 of the inquiry by the House of Representatives Standing Committee on Health and Ageing into dementia early diagnosis and intervention. The ANF noted the Committee's terms of reference and recognised the importance of the identified areas for the focus of the inquiry on dementia early diagnosis and intervention practices in Australia.

The ANF highlights the need for there to be a more equitable distribution of Australian Government funds away from subsidy of relatively ineffective medicines (that too often become the focus of early diagnosis and intervention) towards care of the person diagnosed with dementia (whatever the age of onset), education and support for the person, the health professional workforce, and for families and carers.

6. Aged Care Reform Package

On 20 April 2012 the Australian Government announced its Aged Care Reform Package: *Living Longer. Living Better*. The ANF applauds the inclusion in these reforms of funding for measures directed to addressing issues related to dementia diagnosis and care. While further detail will be necessary, initial information on the funding targeted to dementia care indicates that work can commence with this package of money, on early diagnosis and intervention. The ANF will outline below issues which either have not been dealt with in the reform package in an inclusive manner for health professionals, or have not been included at all, and thus need to be highlighted to this inquiry for appropriate recommendation and action.

7. Issues for the Inquiry

The ANF raises the following issues to the Committee, which we contend need to be considered within this inquiry for appropriate recommendation and action, in order to deliver comprehensive and timely dementia care.

7.1 Expansion of Aged Care Reform Package

One of the areas targeted for funding under the reform package component 'tackling dementia' is

Supporting GPs to make a more timely diagnosis of dementia allowing opportunities for earlier medical and social interventions, reduced risk of premature admission to aged care services and reduced hospital admissions.

As outlined above under section 2.2, the Nurse Practitioner role is growing within the aged care sector. The expertise of these clinicians enables them to identify and diagnose early stage dementia, and to prescribe the appropriate treatment modalities. This also applies to Nurse Practitioners in the mental health field. The ANF therefore requests that the inquiry recommend the inclusion of Nurse Practitioners within the funding mechanism for health professional support measures, under the reform package.

Recommendation 1:

That Nurse Practitioners be included within the funding mechanism for health professional support measures, under the Australian Government Aged Care Reform Package.

7.2 Early nursing care intervention

Early intervention assessment and care by Nurse Practitioners and other registered nurses can make a significant difference in the level of independence for the individual with a dementia diagnosis. Areas of particular concern include management of:

- Continence
- Mobility
- Falls

Where interventions in these areas are instituted early in the progression of the condition there is a greater chance for positive health and social outcomes for the individual. As the health care professionals who spend the greatest degree of time with older people, nurses are best placed to manage these interventions. This role should be recognised and facilitated, with funding provided to support education at undergraduate and postgraduate levels, and continuing professional development.

Recommendation 2:

That the role of Nurse Practitioners and other registered nurses in dementia early intervention assessment and care be recognised and facilitated, with funding provided to support education at undergraduate and postgraduate levels, and continuing professional development.

7.3 Care co-ordination

Nurses in residential aged care facilities frequently see people who have come into their care too late in the progression of their dementia to be able to institute successful health care interventions. This either means their health status has been compromised due to lack of timely interventions when the person was cognitively capable (for example, implementation of continence management strategies), or social interaction or behavioural patterns have developed which are detrimental to others in their environment. Our members advise us of the critical role nurses can and do play in care co-ordination of individuals diagnosed with dementia, to implement timely interventions for optimal health and social outcomes.

Due to the expertise required for this care co-ordination (especially assessment skills), the ANF contends that this role be undertaken by a registered nurse, with delegation of aspects of care according to competence, to enrolled nurses and assistants in nursing.

Recommendation 3:

That the role of care co-ordinator for dementia care be undertaken by registered nurses, in residential aged care and community settings.

7.4 Telehealth facilities

A recent development for change as part of the Australian Government's reform agenda is the introduction of the telehealth facility. The ANF considers there is huge potential for the use of telehealth to improve access to specialist gerontology and/or support services for people in remote, rural and regional areas requiring cognitive assessment and dementia care. However, we believe this facility should be extended beyond use of videoconferencing techniques, to enable Medicare reimbursement to health professionals for utilising telephone link-up, where this is the only communication facility available in remote sites (or the only reliable service available). In addition to this, we consider that the telehealth capabilities should be expanded for use between general practice and residential aged care facilities; and, for use in case conferencing, mentoring and education.

Recommendation 4:

That the telehealth facility be extended beyond use of videoconferencing techniques, to enable:

- Medicare reimbursement to health professionals for utilising telephone link-up;
- use between general practice and residential aged care facilities; and,
- use in case conferencing, mentoring and education.

7.5 Aboriginal and Torres Strait Islander Peoples

The ANF notes one mention of dementia in the *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013: Australian Government Implementation Plan 2007-2013*¹ (the Framework) as follows:

Support dementia training, awareness raising and increased knowledge about dementia in Aboriginal and Torres Strait Islander communities.

The ANF requests that this inquiry recommend the Framework be amended to specifically include dementia early diagnosis and intervention. The particular needs of Aboriginal and Torres Strait Islander peoples may require innovative models of treatment and care or recognisable adaptations of more generic or universal models used in dementia care.

Specific comment: Aboriginal and Torres Strait Islander peoples do not have their cultural, spiritual or community needs respected and met at any point within mainstream health care. Given that Aboriginal and Torres Strait Islander peoples are not a homogenous culture, that great differences exist within and between groups, it is imperative that dementia care is controlled by each community and within each community.

Our colleague organisation, the Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN) advises that when engaging with Aboriginal and Torres Strait Islander peoples the best advice is to ask – to acknowledge the expertise of the elders of each community and involve them as teachers, guides and experts.

Recommendation 5:

That this inquiry recommend amendment to the National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013: Australian Government Implementation Plan 2007-2013 to specifically include dementia early diagnosis and intervention.

¹Commonwealth of Australia. 2007. *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013: Australian Government Implementation Plan 2007-2013*. Available at: [http://www.health.gov.au/internet/main/publishing.nsf/Content/6CA5DC4BF04D8F6ACA25735300807403/\\$File/nsfatsihimp2.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/6CA5DC4BF04D8F6ACA25735300807403/$File/nsfatsihimp2.pdf) pp.35.

7.6 Diverse communities

There may be a need for culturally sensitive, acceptable and specific approaches to the diagnosis and early intervention of dementia in culturally and linguistically diverse communities. Community involvement care models could be explored based on examples seen with people from ethnic backgrounds where whole of family and community involvement in illness is more demonstrable than usually seen in mainstream western society.

Flexibility in models of dementia care must be supported to accommodate preferences for intervention for people from culturally and linguistically diverse backgrounds. Initiatives are required to be adopted that build cultural awareness and cultural competence of the health and aged care workforce.

Dementia care resources need to include models that support cultural liaison. This includes a commitment to building community capacity in relation to dementia care through the provision of health information in a range of community languages, including information that specifically addresses concerns communities have about particular health issues, such as privacy and confidentiality^{2,3}.

Consideration also needs to be given to the fact that access to interpreter services may be required where English may not be a person's first language.

Sensitivity education programs for the health and aged care workforce around cultural diversity need to include recognition of people with diverse gender preferences as a special needs group.

Recommendation 6:

That the inquiry recommend education for the health and aged care workforce include culturally sensitive, acceptable and specific approaches to the diagnosis and early intervention of dementia for culturally and linguistically diverse communities, and those with diverse gender preferences.

7.7 Workforce education and training

Adequate evidence-based education and training of the health and aged care workforce is essential to the early identification of dementia and then subsequent intervention to provide competent, safe, contemporary care.

Due to the increasing role played by assistants in nursing within the aged care sector, the ANF is supportive of a compulsory unit of competence being incorporated into nationally accredited training packages for all certificate III and IV workers in aged care and Aboriginal Health Workers, on dementia care. This unit would serve as a foundation to the complexities of dementia care in aged care.

² Federation of Ethnic Communities' Council of Australia. 2007. Improving health and well-being outcomes for Australians from culturally and linguistically diverse backgrounds. *Health policy statement: FECCA*. Canberra.

³ National Health and Medical Research Council. 2005. *Cultural competency in health: a guide for policy, partnership and participation*. Australian Government. Canberra.

Many people in the very early stages of dementia present to community health or GP clinics or mental health facilities suffering from depression and/or anxiety. The recognition of these early symptoms would be enhanced by providing appropriate dementia education and training to general practice nurses and mental health nurses. Early recognition and timely intervention in the early stages of dementia can be critical to future care and quality of life. A primary health care and mental health workforce that is better equipped to see beyond the primary diagnosis and recognise the early signs of dementia will have a positive outcome both for the individual and the community.

While the ANF acknowledges that there is currently a range of workforce education and training arrangements in place this is not always accessible to nursing staff due to geographical, financial or workplace barriers. Particular cohorts of nurses experiencing difficulties accessing education opportunities are those in: rural and remote areas, aged care facilities, or more marginalised practice settings such as general practice or community clinics.

The ANF therefore proposes that funding be made available for on-line dementia care education to increase the reach of such programs. This education should include early diagnosis and intervention care measures for dementia onset at any age.

The ANF acknowledges current Australian Government funding for Aged Care Nurse Practitioner positions and urges that this funding be sustained and improved to enable the creation of many more positions for Nurse Practitioners for the aged care sector.

Improved education for nurses and assistants in nursing means enhanced quality of dementia care services, and the possibility for people to remain in their own, familiar environment (particularly younger people) for a longer period of time.

Recommendation 7:

That the Australian Government make provision for on-going funding to support:

- Scholarships for education and professional development specifically in dementia care for all nursing staff in aged care, primary health care nurses (including general practice nurses) and mental health nurses;
- Scholarships for education and professional development specifically in dementia early identification and intervention measures for Nurse Practitioners and other registered nurses;
- Inclusion of a compulsory unit of competence in nationally accredited training packages for all certificate III and IV workers in aged care and Aboriginal Health Workers, on dementia care;
- On-line dementia care education to increase the reach of dementia specific programs;
- Reinstatement of more positions for registered nurses in residential aged care settings; and,
- Creation of more positions for Aged care Nurse Practitioners working across residential facilities and community aged care settings.

7.8 Advance care planning

Advance care planning serves a useful purpose in that it facilitates reflection by a person on their health status and preferences for future care needs; and, may help initiate a conversation between family members/significant friends about sensitive and often not talked about end of life care. The ANF proposes that advance care planning should be undertaken in the early stages of dementia while the individual concerned is still able to participate in the discussions, is competent to make decisions, and able to articulate their preferences for future care needs.

Currently, differing positions exist across jurisdictions as to the legal standing between advance care directives and powers of attorney and/or guardianship. In raising the issue of advance care planning with a person recently diagnosed with early stage dementia, they and their family will need to be provided with information about what is appropriate for the state/territory in which they reside (or may possibly reside if moving to be closer to family/friends).

Registered and enrolled nurses are critical to the provision of education and support for the person and their family/friends in discussing and documenting advanced care plans/directives.

Recommendation 8:

That dementia early diagnosis and intervention include advance care planning, while the individual concerned is still able to participate in the discussions, is competent to make decisions, and able to articulate their preferences for future care needs.

7.9 Research

As stated earlier, the nursing profession is taking an increasingly prominent role in research activities aimed at improving the delivery of care to people who have acquired dementia. Due to the reach of nurses into community and aged care settings, across all geographical regions, nurses are ideally placed to be engaging in research targeted to early identification and, commencement of appropriate evidence-based interventions from the findings. On-going research is required on refining models of care which can be adapted to differing communities and which will deliver optimal outcomes for individuals and their families/friends.

Currently, large amounts of money are spent by drug companies on producing and promoting medicines for individuals who have acquired dementia. To date there is little evidence that these medicines are significantly altering the course of dementia progression in individuals. There are even instances where the use of these medicines has led to profound adverse reactions. More research is clearly required to improve the quality use of medicines in dementia care.

Recommendation 9:

That the Australian Government fund research targeted to:

- early identification of dementia,
- commencement of appropriate evidence-based dementia care interventions from the findings,
- on-going refinement of models of dementia care which can be adapted to differing communities, and
- quality use of medicines in dementia care.

8. Conclusion

With the prevalence of dementia on the increase it is imperative that measures be instituted now, to make early diagnosis and interventions, for better outcomes for the individual and the Australian community.

The ANF provides the foregoing information to assist the House of Representatives Health and Ageing Committee in its inquiry into dementia early diagnosis and intervention. The recently announced Australian Government Aged Care Reform Package has gone some way towards addressing issues relating to dementia care.

There remain outstanding matters, as outlined in this paper.

The ANF therefore urges the Committee to make recommendations for funding investment to enable further enhancements to early identification, care delivery, education and workforce practice for health professionals, and research endeavours.