australian nursing federation

Submission to Senate Community Affairs Committee in response to the Inquiry into Palliative Care in Australia

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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.

Members of the ANF are involved in care across the life spectrum, and are integrally involved in the care of the person with a chronic and/or terminal illness. Increasingly, and over the past couple of decades in particular, the nursing profession is taking a vital role in the delivery of palliative care – to people of all ages. As front-line health professionals in palliative care services, our members are well placed to observe the advantages of well-resourced services and the effects on individuals and communities where these services are lacking. The ANF therefore welcomes the Senate Community Affairs Committee providing an opportunity to inquire into the current state of play with palliative care in Australia.

The ANF holds to the position that the needs and circumstances of the person undergoing palliative care must be the centrepiece of the treatment and care, not the interests of the 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 for the individual and their family/carers. This will require innovation, creativity and flexibility in designing services to meet individual needs.

2. General Comments

2.1 International Council of Nurses views

The International Council of Nurses (ICN) position statement titled: *Nurses' role in providing care to dying patients and their families* views the nurse's role as

> *…fundamental to a palliative approach that aims to reduce suffering and improve the quality of life for dying patients and their families through early assessment, identification and management of pain and physical, social, psychological, spiritual and cultural needs.*[1]

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[1] International Council of Nurses. 2006. Position statement: Nurses' role in providing care to dying patients and their families. Available at: http://www.icn.ch/images/stories/documents/publications/position_statements/A12_Nurses_Role_Care_Dying_Patients.pdf

2.2 ANF position

Extracts from the ANF policy on n*ursing care of the person with a terminal illness* highlight some basic and important principles underpinning nursing practice in palliative care:

> *People with a terminal illness have the right to a choice, both in the care and treatment which is provided to them and in the way in which that care and treatment is provided. Timely and adequate information must be provided to allow such choices to be made.*
>
> *The care and treatment of the person with a terminal illness must be consistent with the person's beliefs and cultural expectations.*
>
> *People with a terminal illness have the right to access specialist palliative care services. These include controlling pain, relieving other symptoms of disease and providing emotional and psychosocial support in preparation for death. Early referral to palliative care services should be available to all persons with a terminal illness.*[2]

The above points will be revisited under relevant items contained in the *Specific comments* section.

Essentially, the ANF believes that palliative care requires particular knowledge, skills and attitudes. This means that, whether nurses are engaged in specific palliative care roles or in areas where palliative care forms a regular/intermittent part of their professional nursing practice, formal education and continuing professional development opportunities should be provided or facilitated by employers.

3. Specific comments

The following commentary is based on the issues posed in the terms of reference for the Senate Community Affairs Committee in its deliberations on palliative care in Australia.

Term of reference a): Factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

Term of reference a) i) People living in rural and regional areas

Inclusion of remote areas: The ANF wishes to correct a major oversight in the terms of reference, and that is, to include people living in 'remote' areas in the list of issues to be discussed and addressed through this Inquiry. Issues faced by people in remote sites, in relation to access to health care services, are often unique when compared to rural or regional locations. On behalf of our nursing and midwifery members the ANF, along with our colleague organisation CRANA*plus* (the association for remote area health professionals), frequently call on bureaucrats to acknowledge that situations are different in remote areas due to diminished or total lack of resources which are normally enjoyed by other sectors of the Australian community.

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[2] Australian Nursing Federation. 2011. Policy: Nursing care of the person with a terminal illness.
Available at: http://www.anf.org.au/html/publications_policies.html

Access and equity: In the continuum of care from metropolitan, to regional, to rural, and then remote, the further one goes from the urban areas the greater the:

- limitation in access to palliative care services,
- encumbrance of travel time and cost, as well as accommodation in most instances,
- impost on carer to travel with the person requiring palliative care services,
- limits to multidisciplinary team players on the ground,
- dislocation from family/usual carers required in order to access services,
- limits to choice about treatment options including access to hospice care and support in rural and remote localities, and
- anxiety engendered relating to being able to make a choice about the place to die.

When Medicare, Australia's universal health care insurance scheme, was introduced by the Federal Government in 1984, the aim was to ensure all Australians had access to medical and hospital care when they needed it. Medicare is based on principles which include:

> *Universality: All people have the same rights and entitlements to good quality health care, and*
>
> *Access: Access to care based on health needs rather than an individual's ability to pay.*[3]

Almost 30 years on from the introduction of Medicare, there still appears to be a lack of recognition by policy developers and fund holders of the equity issues involved for people from remote and many rural areas, in terms of travel time and costs (often including accommodation) who are required to travel for treatments on a frequent basis.

Access and availability of competent palliative care nurses: there are fewer registered nurses in rural and remote areas and it is extremely difficult for those nurses who are there to take leave from work to attend education on palliative care. There are adequate courses on palliative care but there are inadequate numbers of registered nurses to replace those who might otherwise access these education programs. This is compounded by the cost of such programs. Where financial assistance - for travel, accommodation, living expenses and course costs - is unavailable, many nurses are excluded from further education. Consequently, attendance at education in many geographical areas is erratic and sporadic. Knowledge is therefore more difficult to gain and is dependent on the tenacity of each registered nurse rather than on a concerted effort or plan for education and development by the health care provider.

Limited access to medical professionals: many rural communities do not have timely access to a General Practitioner. General Practitioners are not evenly distributed across geographical areas and therefore patients must travel unreasonable distances to access General Practice services. Also, General Practitioners with an interest and specialty in palliative care are rare in rural and remote areas. There is sometimes a disinclination for General Practitioners to participate in the process of teamwork in delivery of quality palliative care, in particular due to lack of understanding of current principles of palliative care; and a focus only on pain management. It is fair to say that General Practitioners in rural areas have issues similar to nurses in accessing education and professional development. Further, General Practitioners are often unavailable on weekends and after hours, leading to unnecessary hospitalisation of patients requiring care which would be deemed by a palliative care team nurse to be uncomplicated palliative care.

[3] Doctors Reform Society of Australia. Medicare Fact Sheet 1: What is Medicare. *New Doctor.* Issue No. 75 Winter 2001. Available at: http://www.drs.org.au/new_doctor/75/fact_sheet_1.html

Other major considerations for nurses and midwives working in the rural and remote regions of Australia include concerns such as:

- access to acute hospital beds;
- perceptions of the general public of their expectation of palliative care services and their understanding of what such services offer;
- the tyranny of distance in relation to:
    - proximity to quality palliative care services within a locality,
    - need for 24 hour support in rural and remote localities,
    - access and equity in relation to ambulance services,
    - access to area health services and district or visiting nursing services including palliative care,
    - access to counselling and social work services,
    - the need to establish or improve access to specialist pain services and specialist nursing (such as Palliative Care Nurse Practitioner) or medical staff skilled in managing acute pain services associated with palliation;
- fiscal considerations for patients and families in relation to:
    - Centrelink support where there is a need for carers to maintain an income to support the person in palliation,
    - access to funds where a carer is required to be absent from paid work to care for a person being palliated,
    - the current criteria in relation to access level of physical or financial support – criteria for funding may not always be parallel to level of support required;
- access and equity in relation to eligibility for services based on a person's age, especially in relation to accessing Home And Community Care (HACC) funded services for palliative care patients. Currently people are not eligible if aged under 65 years. Age limits must be removed as age should not be a barrier to the level of support needed for people in a palliative care service;
- limitations to service choice due to locality (may only have one service provider in rural and remote locality);
- the need for designated specialist palliative care beds (that are not specified 'acute') within rural and remote health services for people who can no longer manage their condition in their homes;
- limitations in the introduction of the Nursing and Allied Health Rural Locum Scheme. While the Scheme has gone some way towards enabling nurses and midwives to be released for continuing professional development, this funding does not go far enough in supporting them to meet the costs of undertaking the education (in this instance palliative care education).

Telehealth facilities: A recent development for change as part of the Australian Government's reform agenda has been the introduction of the telehealth facility. The ANF considers there is huge potential for the use of telehealth to improve access to specialist and/or support services for people in remote, rural and regional areas requiring palliative 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).

Term of reference a) ii): Indigenous people

General comment: There are considerable barriers to accessing the full range of integrated care and treatment modalities for Aboriginal and Torres Strait Islander peoples living in remote or rural parts of the country. Some of these include the travel time and accommodation costs previously mentioned, but also lack of transportation; and, most importantly, linguistic, cultural and spiritual issues, when the option is to be dislocated from family and country in order to obtain necessary treatments and care. Research confirms that as the terminal phase of the end of life journey approaches, getting home to country is the highest priority for many Aboriginal Australians[4,5,6].

The ANF notes that while the *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013: Australian Government Implementation Plan 2007-2013*[7] mentions cancer services for communities it does not include palliative care within the strategic framework. This is a major oversight given that, for example, chronic conditions such as renal disease (disproportionately high amongst Indigenous Australians) are now falling within the palliative care domain for remote area nurses. The argument for inclusion of palliative care in the national plan relates not to specific clinical presentation (such as renal disease), however, but rather to the fact that it is the overall clinical picture which determines palliation.

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 palliative 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, and palliative care is no exception. 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 palliative 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. Palliative care is not only about pain management and symptom control.

[4] Nadimi, F and Currow, D, C. 2011. As death approaches: a retrospective survey of the care of adults dying in Alice Springs Hospital. *Australian Journal of Rural Health*. 19(1) pp. 4-8.

[5] Mitchell, G,K. 2011. Palliative Care in Australia, *Ochsner Journal.* 11(4) pp. 334-337.

[6] South Australian Government Department of Health. 2005. *Providing culturally respectful palliative care to Aboriginal people in South Australia.* Adelaide. Retrieved from: http://www.pallcare.asn.au/pdf/companion_guide.pdf

[7] Commonwealth 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

Health care professionals from all disciplines involved in palliative and end of life care must learn to be respectful, mindful and dedicated to providing care within the cultural and spiritual beliefs of the individuals they care for. Such health professionals do not need to know the culture and spiritual beliefs and knowledge – they need to respectfully follow the guidance of those community members who are experts.

Aboriginal and Torres Strait Islander peoples access health services across the spectrum and across the country. There is a false view in mainstream health that Aboriginal and Torres Strait Islander peoples only access Aboriginal and Torres Strait Islander health services – that is, that they do not use mainstream health services. This is not the case. There is also a view, promulgated by the media that Aboriginal and Torres Strait Islander peoples all live in rural and remote parts of this country. This is not true, as most Aboriginal and Torres Strait Islander peoples are in urban and inner rural areas on the Australian eastern seaboard. The effect of such misunderstandings is that a view is formed by health professionals, collectively if not individually, that they never need to understand the particular cultural and spiritual implications for care in their communities because they do not work solely in Aboriginal and Torres Strait Islander health. This is a short-sighted and exclusive view, resulting in appalling ignorance and with equally appalling and insensitive care delivery.

Aboriginal Health Workers are asked to do more and more, to drive, develop and implement care within remote Aboriginal and Torres Strait Islander communities, with inadequate accessible support and assistance from all the professionals generally involved in a multidisciplinary team approach to palliative care - doctors, nurses, psychologists, social workers, physiotherapists and clergy.

Term of reference a) iii): People from culturally and linguistically diverse backgrounds

There is a need for culturally sensitive, acceptable and specific models of palliative care and treatment to be developed and implemented. Community involvement models should 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 palliation and end-of-life care must be supported to accommodate the care preferences of people from culturally and linguistically diverse backgrounds. Initiatives are required to be adopted that build cultural awareness and cultural competence of the health care workforce. Palliative care resources need to include models that support cultural liaison. This includes a commitment to building community capacity in relation to palliative care and end-of-life care through the provision of health information in a range of community languages. These should include information that specifically addresses concerns communities have about particular health issues, such as privacy and confidentiality[8,9,10].

This cohort of people also require access to interpreter services where English may not be a person's first language.

[8] Lickiss, J. 2003. Approaching death in multicultural Australia. *Medical Journal of Australia.* Vol 170 (6) pp. S14-16.

[9] 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.

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

Term of reference a) iv): People with disabilities

People with a disability have a long-term physical, mental, intellectual or sensory impairment. Australian research shows that 1:5 people have a disability ranging from mild to severe. An increase in the life expectancy for people with an intellectual disability has resulted in many living into an old age with diseases such as cancer and dementia. Many people with an intellectual disability live at home with their elderly parents who may have a serious illness.

The support of people with disabilities is important throughout their life. End of life care for people with disabilities needs to encapsulate all the principles of good palliative care. Special focus on physical comfort, symptom control, pain assessment, cultural, psychological, social, spiritual needs and appropriate care management, are essential to quality care. Grief and bereavement support to family, friends and carers should reflect their level of commitment throughout the disabled person’s life.

For people with an intellectual disability, palliative care professionals[11,12] identified the following five priority issues in providing care to people with an intellectual disability:

- patient not able to fully understand their illness
- communication with the patient
- difficulties in assessment of pain
- difficulties in assessing other symptoms
- length of time it took to gain the patient’s trust.

For carers who work with people with disabilities, studies such as that by Ng & Li (2003)[13] showed there was a lack of knowledge, particularly in psychosocial aspects (for example, effective communication with the dying person and bereavement support) and skills in palliative care principles and management.

The ANF considers that people with a disability are under-serviced in relation to palliative care and this shortfall needs to be addressed. The person with a disability and terminal illness needs resourced, seamless, person-centred care. They must have a choice about where to receive their care. If the person with a disability chooses to be in their own home environment then they may be cared for by their carer/s (family/friends), palliative care nurses and other members of the multidisciplinary team of experts.

Communication programs are required to inform the person with a disability and their carer/s of availability of palliative care community packages. These could be targeted to the final days, stabilisation, caregiver respite, complex community care, or, a specific package to meet the needs of a disabled Aboriginal or Torres Strait Islander person. If the person with a disability is in a residential or group home, they should ideally be able to remain in their “home” maintaining their lifestyle and contact with familiar people in their life, whilst receiving quality palliative care.

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[11] Tuffrey-Wijne, I. 2003. The palliative care needs of people with intellectual disabilities: a literature review. *Palliative medicine.* 17. pp. 55-62.

[12] Tuffrey-Wijne, I et al. 2008. Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine.* 22. pp. 281-290.

[13] Ng, J and Li, S. 2003. A survey exploring the educational needs of care practitioners in learning disability settings in relation to death, dying and people with learning disabilities. European Journal of Cancer Care. 12. pp.12-19.

In essence, services are required which are sensitive to the specialist needs of people with disabilities. The level of need may vary depending on the individual's unique disability and maintaining functionality within their abilities alongside the need for palliation. Acceptable and specific models of care and treatment must be developed and implemented that meet the requirements of the person's disability.

Terms of reference a) v): Children and adolescents

In relation to children and adolescents the ANF policy on *nursing care of the person with a terminal illness* states that:

> *Children and young people with a terminal illness should be informed and consulted and their wishes considered in any decisions made regarding their care and treatment. These decisions should be regularly reviewed together with the child or young person with the terminal illness and their selected family members.*[14]

The availability of a parent or significant other to support the provision of care and to support the child or adolescent requiring palliative care services is paramount. Parents and families should be supported to keep children and adolescents at home for palliative and end of life care wherever possible. Being in their own environment with their family, friends and pets nearby, reduces the stresses associated with palliation and facilitates dying with dignity. Links between nursing and medical services must be optimised, to foster trust, support and respect for the person, family and the health professionals involved in the provision of such care[15,16,17,18].

It is the view of the ANF that paediatric and adolescent palliative care services should strengthen their links with regional, rural and remote communities to support children/adolescents to remain in their local community. Where it is not possible for children and younger adolescents to remain at home, a dedicated paediatric hospice should be available in all states and territories. We consider that it is not appropriate for children/adolescents to be cared for in an adult hospice environment.

Term of reference b): Funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

The following comments relate to the funding arrangements for palliative care provision in residential aged care:

Dementia is a terminal illness with a death rate of 100%. All dementia care is palliative care and is delivered from within the constraints of general funding under the Aged Care Funding Instrument (ACFI). It is only at the end of life, in those final few days when death is imminent, and when stated in writing by a visiting general practitioner, that palliative care can be claimed for and funded under ACFI arrangements.

Specialist equipment for palliative care is not generally funded in residential aged care facilities (RACFs). Occasionally, individual facilities are able to access limited grants for equipment.

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[14] Australian Nursing Federation. Policy statement: *Nursing care of the person with a terminal illness.* Available at: http://www.anf.org.au/html/publications_policies.html

[15] South Australian Government Department of Health. 2009. *Palliative Care Services Plan 2009-2016, SA Health and Ageing.* May 2009. pp. 9-17.

[16] Association of Children's Palliative Care. 2007. *Children's and adult's palliative care: Similarities and differences.* Bristol. Retrieved from: http:// www.act.org.uk/content/view/78/127/

[17] Kumar, S.P. 2011. Reporting of paediatric palliative care: a systematic review and quantitative analysis of research publications in palliative care journals. *Indian Journal of Palliative Care*. Sep;17(3). pp.202-9.

[18] Nayak, M and Salins, N. 2011. Providing palliative care for a dying teen at home: perspectives and challenges. *Indian Journal of Palliative Care.* Sep;17(3). pp.248-50.

While access to state-funded community based palliative care services is available to RACFs, due to restraints on funding of those services, access by these facilities is generally for end of life only. At end of life, registered nurses in RACFs are quite capable of delivering quality care but may require external palliative cares services purely to access appropriate equipment. Where jurisdictional-funded palliative care services are involved, an ACFI claim may be made – however, if the RACFs registered nursing staff manage the palliative care of the residents, such that the jurisdictional-funded service is not required, ACFI funding is not accessible.

In short, those RACFs providing quality palliative care using the expertise, competence, skills, knowledge and talent available within their own nursing staff, then have no access to ACFI funding for palliative care.

Nurses working in aged care, particularly residential aged care, generally have sound, practical, current knowledge. Reduction in numbers of registered nurses over past years means that they are now a scarce clinical resource in an increasing number of RACFs. Consequently, planning and implementing quality palliative care (that accommodates the needs and wishes of the dying person and their family/friends) becomes increasingly very difficult. Moreover, this is compounded by time constraints on those remaining registered nurses – further restricting their ability to provide quality palliative care at the end of life.

Term of reference c): Efficient use of palliative, health and aged care resources

The ANF strongly argues that palliative care remains unfunded by all levels of government. This issue emerges as outstandingly evident within RACFs due to the lack of provision for palliative care as a specific line item under the ACFI funding arrangement. The consequence of poor funding of palliative care services in RACFs under ACFI, (as outlined in (b) above), means that many residents of these facilities require hospitalisation for management of acute episodes in their palliation. Care and support of dying residents, their families and friends, and, of the living residents who witness death on a regular basis, forms a large proportion of the work of registered nurses in RACFs. Adequate funding for palliative care nurses, equipment, and ongoing education opportunities for nursing staff, in RACFs, is therefore imperative to make the most efficient use of palliative, health and aged care resources.

Term of reference d): Effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

As an overarching statement the ANF considers that the effectiveness of palliative care services relies heavily on early referral for optimal outcomes.

As mentioned already, palliative care must be adequately resourced and supported. This will require exploration of service demand now and in the future, and how and where this demand can be best met. This should occur in discussion and collaboration with consumers, their families and health care professionals.

It is the view of the ANF that currently service gaps exist and that there is a need to address the demands of the future.

This will require, for example, ensuring there is a move to models of care that provide palliative care in existing services (that is, acute and aged care settings). In addition, there must be acknowledgement that specialist palliative care services are better resourced (funding and personnel) and available to enable in-reach response where such models are not possible and/or comprehensive (that is, an integrated model).

The community is entitled to be assured of dignity when accessing palliative care services when required, and in such services being available in the best location that meets their needs. This means moving to ensure care can be provided in acute settings, in the community - both in the home and in RACFs, and by specialist services - both in-patient and in-reach supports to those services referred to above.

These are areas where there are current service and funding gaps, particularly in relation to the availability of after-hours nursing services and capacity to cater for changes in care needs on-site, that must be urgently addressed.

Term of reference e): Composition of the palliative care workforce

Nurses role in palliative care

Both registered and enrolled nurses play a vital role as care providers to people requiring palliative care, in the acute care setting of hospitals, in hospices, in aged care facilities, and in peoples' own homes. In particular, registered nurses take on the care co-ordination and liaison role for people undergoing complex treatment and care across multiple services and specialities.

Many nurses have acquired formal qualifications in palliative care nursing to inform and enhance their practice in this area, whether this is the entire focus of their clinical role or forms a part of a broader role, such as a nurse in a residential aged care facility.

As stated previously nurses play a crucial role in the care provision for people requiring palliative care - in a range of health and community settings: in acute care hospitals, in hospices, in aged care facilities, and in peoples' own homes. Hence, nurses are the primary health care professionals across all geographic locations and socio-economic situations. Nurses are intimately acquainted with the difficulties faced by people due to distance from nearest available health care services; and, those living in poverty, the homeless, or otherwise marginalised from mainstream health care services.

Palliative Care Nurse Practitioners

The Palliative Care Nurse Practitioner role is a key element in the provision of expert palliative care across metropolitan, rural and remote settings. Palliative Care Nurse Practitioners work autonomously, provide professional leadership, use their expert clinical knowledge, extensive experience and advanced clinical skills to ensure that care is coordinated and responsive to the individual requiring the care, their family/friends, and the community. In common with all other Nurse Practitioners in Australia, Palliative Care Nurse Practitioners must achieve a Masters level education (in this case Master of Nursing (Nurse Practitioner) in Palliative Care), as well as many years of advanced practice in their specific area of practice in order to be eligible for endorsement by the Nursing and Midwifery Board of Australia, and are considered to be the highest clinical level in the nursing profession.

Growing the Nurse Practitioner workforce with facilitated coordinated education and clinical supervision opportunities is key to meeting the projected demand arising from: the substantially increased proportion of complex care at end of life provided in the community setting; nurse-led care options in the hospice; transitional care facilities and community shared housing arrangements; comprehensive after hours 'on call'; and, increasingly complex care in rural health care facilities and urban services.

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

Multidisciplinary care team

Palliative care is enhanced through a multidisciplinary approach. The ANF is of the view that multidisciplinary care entails a team approach to the provision of care: that is, nursing, medical, and allied health care professionals across primary care and clinical specialties, and including psychological and social support and care. Open communication between all health care professionals and integration of care approaches provide greater clarity and consistency for the individual and his/her family/carers. This is attested to by research in the area which indicates improved quality of life for the individual, when care is delivered by a multidisciplinary team[19].

Limitations to multidisciplinary care in palliative care are due to the reality that implementation will vary according to the size or location and type of service. For example, the further remote one goes, the likelihood is that a remote area nurse will be the sole health professional physically present while other members of the team are consulted by phone or electronic means of communication.

The ANF supports the principles of multidisciplinary care as developed by the National Breast and Ovarian Cancer Centre[20]. These are:

- a team approach, involving core disciplines integral to the provision of good care, with input from other specialists as required
- communication among team members regarding treatment planning
- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution
- provision of care in accord with nationally agreed standards
- involvement of patients in decisions about their care.

Identifying and promoting successful models of multidisciplinary care, and funding such approaches, would be a useful addition to the resources available to consumers and health professionals alike.

New and Emerging Roles within Palliative Care Teams

There are models that are being considered which will see the expansion of palliative care teams[21.22.23] such as:

- Palliative psychological medicine specialist and the palliative care psychologist who will be able to better assess and meet the needs of people with emergent or continuing mental health needs at end of life, those whose mental health is at risk, and to caregivers and families experiencing anxiety, psychological dysfunction or mental health crisis.

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[19] Zorbas, H, Barraclough, B, Rainbird, K, Luxford, K and Redman, S. 2003. Multidisciplinary care for women with early breast cancer in the Australian context: what does it mean? *Medical Journal of Australia*. 2003. 179 (10). pp. 528-531.

[20] National Breast and Ovarian Cancer Centre. 2008. *Multidisciplinary care principles for advanced disease: a guide for cancer health professionals.* National Breast and Ovarian Cancer Centre. Surry Hills, NSW.

[21] South Australian Government Department of Health. 2009. *Palliative Care Services Plan 2009-2016, SA Health and Ageing.* May 2009. pp. 45-51.

[22] Crawford, G and Price, C. 2003. Team working: Palliative care as a model of interdisciplinary practice. *Medical Journal of Australia.* 179. pp. S32-34.

[23] Australian Government Department of Health and Ageing. 2007. *Overview of National Palliative Care Program initiatives.* Canberra. Retrieved from: http:// www.Health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-overview-cnt.htm

- General Practitioners with a special interest in palliative care who could support the provision of palliative medical services, particularly in community settings.
- Caregiver network facilitators who utilise a health visiting approach to engage with caregivers to assist them to identify and mobilise their own local network of friends, relatives, neighbours, work colleagues and acquaintances to assist with caregiver support.
- Advanced practice roles – palliative care consultant in physiotherapy, occupational therapy, pharmacy, palliative care nurse practitioner and social worker.

These new, emerging and advanced practice roles within the multidisciplinary palliative care team should be supported to enhance the delivery of palliation services.

Term of reference e) i): Ability to meet the needs of the ageing population

Research shows that to meet the complex needs of the ageing population requires partnerships between health providers in different settings, especially the geriatric (aged care) and palliative care disciplines. The evidence suggests that there are common issues around under-assessment and under-treatment of older people who require palliative care, such as under-assessment of pain, lack of information involving decision making, lack of home care, lack of access to specialist services and lack of palliative care within RACFs.

As a partner in the National Aged Care Alliance (NACA) *Australians Deserve to Age Well: Blueprint for Reform*[24], the ANF joins in advocating that one of the key areas of reform in aged care is the notion of dying well: palliative care and dying with dignity must be ranked as major issues for older Australians. The Alliance is calling for palliative care to be a funding priority; for linkages between residential and community aged care providers and local specialist palliative care services to be improved; for the removal of barriers preventing people accessing community aged care and specialist palliative care services simultaneously; and, for mechanisms to ensure the Gateway supports access to advance care planning and palliative care services[25].

Palliative Care services within the community are not funded adequately to assist with palliative care. Limited funding restricts access to these services to end of life care – that is, the last few days/weeks of life. An example from one State is that on weekends the palliative care services are closed and Royal District Nursing Services (RDNS) nurses provide “cover”. This creates an added extra workload for the RDNS and means that strangers provide care to dying people, as continuity of care from their regular provider is interrupted. In addition to this, models of care which include 24 hour cover are limited in availability across the country.

Term of reference e) ii): Adequacy of workforce education and training arrangements

Adequate evidence-based education and training of the workforce is essential to the provision of quality, safe, contemporary palliative care.

There is a range of undergraduate, postgraduate and clinical teaching across settings providing opportunities for health care workers in palliative care and the needs of people with a terminal illness. This may be provided by health services, vocational education and training (VET) sector, or higher education (university sector).

[24] National Aged Care Alliance. 2012. Australians deserve to aged well campaign.
Website: http://www.naca.asn.au/Age_Well/Blueprint.pdf

[25] National Aged Care Alliance. 2012. Australians deserve to age well campaign. Publication: Palliative Care.
Available at: http://www.naca.asn.au/Age_Well/Palliative%20care.pdf

Palliative care services provide clinical placement opportunities for undergraduate students and have established agreements that support the development of shared teaching and learning relationships and activities with faculty partners. For postgraduate there are a range of topics and awards that are available to provide for entry-in-speciality and advanced practice needs of this specialised workforce. To support generalist health care professionals there are a number of national and state programs and networks available.

For nurses, midwives and assistants in nursing working in the aged care sector, there is a particular need for ongoing education programs to support the complex care and palliative care required to meet physical, psychological, spiritual and psychosocial needs.

Due to the increasing role played by assistants in nursing within the aged care sector, the ANF is supportive of the reintroduction 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. This unit serves as a foundation to the complexities of palliative care in aged care.

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

The ANF therefore proposes that funding be made available for on-line palliative care education to increase the reach of such programs. The ANF also urges that funding be made available for the creation of many more positions for Nurse Practitioners in palliative care.

Improved education for nurses, midwives and assistants in nursing means enhanced quality of palliative care services, and the possibility for people to remain in their own environment during the course of palliation.

Term of reference f): Adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians

The standards developed by Palliative Care Australia are designed to support and enhance quality of care for patients who are at the end of their life, their families and carers. The merit of these standards is that they are comprehensive and provide national consistency for palliative care services and providers.

The national standards have been designed for use alongside other standards for health services (for example, The Australian Council of Healthcare Standards – Evaluation and Quality Improvement Program [EQuIP], Quality Improvement Council, or the Aged Care Accreditation Standards)[26]. However, a limitation is that these national standards for service evaluation and quality improvement are adopted on a voluntary basis. While accreditation services are asked to incorporate the national standards as part of their assessment of palliative care and other services, there is no mandatory requirement to do so.

The ANF supports the Standards for Providing Quality Care to All Australians and considers that their use would be enhanced by strengthening the requirement to apply these in accreditation reviews.

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[26] Palliative Care Australia. 2005. (4th Ed.) *Standards for Providing Quality Care to All Australians.* Available at: http://www.palliativecare.org.au/Default.aspx?tabid=2051

Term of reference g): Advance care planning

Advance care planning serves a highly useful purpose in that it facilitates reflection by a person on their health status and preferences for future care needs; and, often helps initiate a conversation between family members/significant friends about sensitive and often not talked about end of life care.

While popular in many jurisdictions, there can be cause for discord however where advance care planning is given more weight than, or conflicts with, powers of attorney and/or guardianship.

Currently, advance care planning is ad hoc, not standardised and has no legal standing - it merely records a person's stated preference. It is fraught with difficulty in the aged care setting, particularly where the resident is not competent and a family member makes the advance care plan. Such plans can only reflect the wishes of the relative, and may or may not reflect the wishes of dying person.

The various powers of attorney and guardianship have all the powers required to ensure palliative care professionals, such as nurses and in particular those in RACFs, are acting in accordance with the wishes of the dying person. Due to community ignorance and often lack of knowledge and understanding among health professionals, formal powers of attorney and/or guardianship are not promoted, granted or sought at a point in our lives when each of us is competent to make decisions about our care in the future.

The issue of end of life/advance care planning is also important if the resident is transferred to an acute facility for treatment which can become end of life care. The ability to have a standardised end of life/advance care plan that can be transferred with the resident and thus made known to health care professionals in the new facility is clearly advantageous. The resident/relatives and health care providers do not then need to repeat the process. It is obviously preferable for those end of life plans to be developed in a timely fashion with family/friends in the decision making processes rather than attempting to decide at times of high stress.

In order to provide clarity and a safe legal environment for nurses and midwives, the ANF considers there is a need for funding investment in a national awareness campaign on the different functions and legal standing of advance care plans, powers of attorney and/or guardianship - for the benefit of the community and for health professionals.

Term of reference g) i): Avenues for individuals and carers to communicate with health care professionals about end-of-life care

Much of the discussion and focus in aged care, particularly residential care, is on end of life rather than the broader provision of palliative care.

The ANF takes the position that such discussions should be part of conditional entry to RACFs. The importance of the conversation at this stage would be reiterated in a policy of "no discussion, no documented decisions on palliative and end of life care and wishes, no admission".

Term of reference g) ii): National consistency in law and policy supporting advance care plans

The ANF favours national consistency in relation to laws and policies which support advance care plans. Where individuals receiving palliative care move from their home state/territory (often to be closer to supporting families/carers) it can be an added source of distress to find that carefully prepared advance care plans have no validity within the jurisdiction of their new place of residence. In addition, as noted above, this would provide clarity for nurses, midwives and other health professionals as to the standing of advance care plans for people in their care.

The development of nationally consistent law and policy supporting advance care plans would require a broad consultative process, followed by the educative campaign previously called for, for the community and for health professionals.

Term of reference g) iii): Scope for including advance care plans in personal electronic health records

The ANF supports the inclusion of a field within the Personally Controlled Electronic Healthcare Record (PCEHR) for noting whether or not the individual has an advance care plan, and has in place powers of attorney and/or enduring guardianship (the latter being important as these carry legal weight, as previously mentioned).

Term of reference h): Availability and funding of research, information and data about palliative care needs in Australia.

End of life care providers continue to benefit from an expanding body of high quality, evidence-based resources, guidelines and clinical pathways to inform and support their clinical practice and decision-making[27]. The ANF supports research on interventions related to palliative care service models that will enable specific measurements relating to care organisation and processes to be examined.

The ANF calls for ongoing national, state/territory and foundation funding of research into clinical, philosophical, technical and service model issues related to end of life care and the needs of palliative care recipients. Establishment of connected data from a range of systems and sources is required to ensure a comprehensive picture of palliative care needs and the outcomes of care at end of life for whole of population.

It is the view of the ANF that funding is required for palliative care research, and data collection to inform the needs, innovation, monitoring and evaluation of palliative care in Australia.

In relation to aged care, ANF members nationally have expressed frustration that all too often quality research is shelved as a thesis and pertinent findings and recommendations are not applied to practice. This is usually due to funding constraints. While more funding is needed for research into palliative care in residential aged care, it will prove to be a pointless exercise if the findings are not respected, and/or full funding is not applied so that the recommendations based on scientifically researched findings can be implemented.

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[27] Green, J. 2007. Health literacy: Terminology and trends in making and communicating health related information. Health Issues Centre. Vol 92. pp. 11-14. Retrieved from: www.healthissuescentre.org.au/documents/items/2008/04204909-upload-00001.pdf

4. Other comments

Palliative care is taking on an increasing focus within aged care as registered nurses working in the sector endeavour to enable RACF residents and older people in the community, to stay in these settings while they receive palliation and end of life care.

Contrary to the traditional view that registered nurses working in aged care have poor skills and knowledge, the collective knowledge of today's RACF registered nurses providing palliative care has, in general, improved immensely in the last 10 years. This has been facilitated particularly through accessing programs such as Partners in Positive Ageing (PiPA)[28]

Registered nurses employed within RACFs work in the most difficult of circumstances. There may be as few as one registered nurse for 100-150 residents, particularly during the night. There are enormous funding constraints for purchase of equipment, education and access to quality continuing professional development. There is limited access to specialist support services and access to GP support can be erratic and untimely, with GPs sometimes having limited knowledge of palliative care modalities. What limited funding that is available, is based on the authorisation of the GP, and may be granted or withdrawn by this same authorisation.

Registered nurses working in RACFs, and indeed in any setting, are frequently and commonly caught between family members of a person receiving palliative and end of life care, who are in conflict over the course of an individual's care, squabbles about property and pre-existing family power struggles.

5. Conclusion

With the nursing and midwifery professions constituting over fifty percent of the health and aged care workforce, they are delivering the greater proportion of palliative care in this country. As the union representing the professional and industrial interests of nurses, midwives and assistants in nursing the ANF has a very real concern with palliative care policies, service delivery models, access and equity issues, research, innovation, education, continuing professional development, and outcomes of models of care for recipients of palliation.

The ANF welcomes the opportunity to provide the foregoing information to the Senate Community Affairs Committee in its inquiry into Palliative Care in Australia. Palliative care models and services have improved in quality and increased in number over past years, and palliative care specialist nurses have been at the forefront of these advances. There is still much work to be done, however, and the ANF calls on the Senate Committee to act on advice received through this inquiry to make recommendations for funding investment to enable further enhancements to research endeavours, care delivery, and, education for health professionals.

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[28] Boylan, J. Partners in Positive Ageing. ACH Group. Retrieved on 16 March 2012 from: http://www.changechampions.com.au/resource/Jo_Boylan_-_Partners_in_Positive_Ageing_-_Model_of_wellbeing_for_older_people.pdf