



**Palliative
Care
Australia**

**Submission to the Australian Senate
Standing Committee on Community Affairs
Inquiry into Palliative Care in Australia**

on behalf of

Palliative Care Australia

Contact:

Dr Yvonne Luxford
Chief Executive Officer
Palliative Care Australia
PO Box 24
Deakin West ACT 2600
Ph: 02 6232 4433
0420 537 211

yvonne@palliativecare.org.au

April 2012

<i>Table of Contents</i>	
Executive Summary	6
Recommendations	10
Background Summary	10
List of Recommendations	13
PART A: Palliative Care and the Australian Situation	24
1. Introduction	24
2. Background	25
3. A Vision for palliative care	29
4. Context	32
4.1. Living longer	33
4.2. The changing face of disease in Australia	34
4.3. How many people die each year in Australia?	35
4.4. The cost of growing old	36
4.5. Attitudes to death and dying	36
4.6. Access to palliative care	36
4.7. Planning for a good death	38
4.8. Who provides palliative care?	38
4.9. Who receives palliative care?	39

4.9.1. Differences by hospital characteristics	40
4.9.2. Differences by Indigenous status	40
4.9.3. Differences by geographical remoteness	41
4.9.4. Differences by socioeconomic status	42
4.10. Who pays for the care?	42
4.11. Where are palliative care services provided?	43
4.12. Where do people die?	43
4.13. A palliative care approach is good public health	43
4.14. Efficient and effective palliative care makes good public policy	44
PART B: Addressing the Senate Terms of Reference	46
1. The factors influencing access to and choice of appropriate palliative care that meets the needs of the population including:	46
1.1. People living in rural and regional areas	48
1.1.1. Higher burden of disease	48
1.1.2. Challenges to health service provision	49
1.1.3. Transport and access to services - Patient Assistance Travel Scheme (PATS)	50
1.1.4. Uniqueness of rural and regional areas	51
1.1.5. Workforce incentives and retention	51
1.2. Indigenous people	55
1.2.1. Chronic disease and mortality	55
1.2.2. Culture	56
1.2.3. Communication	56
1.2.4. Geographical challenges	57
1.2.5. Workforce	57
1.2.6. Information, education and training	58
1.2.7. Local strategies	59
1.3. People from CALD backgrounds	61
1.4. People with disabilities	66
1.4.1. What is the difference between palliative care and care for children with disabilities?	66
1.4.2. Care Coordination	67
1.5. Children and adolescents	68
1.5.1. Service Provision	68
1.5.2. Leadership	69

1.5.3. Young adults	69
1.5.4. Neo and ante natal palliative care	70
1.6. Access to appropriate palliative care for older people	71
1.6.1. Aged Care Reform	71
1.6.2. Barriers to the provision of quality palliative care	72
1.6.3. Residential care barriers and disincentives	72
1.6.4. Community care barriers and disincentives	73
1.6.5. There are some barriers and disincentives which affect both the provision of palliative care in a residential or community setting	73
1.6.6. The role of aged care services in providing palliative care	74
1.6.7. Shifting the balance to home based palliative care	74
1.6.8. Case studies of quality palliative care provision to older people in aged care	75
1.6.9. Interface between Aged Care, Palliative Care and the Acute Sector	76
1.6.10. Medicare Locals	77
1.6.11. Aged Care Funding	78
1.6.12. Standards	78
2. The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent	81
2.1. Sub-Acute Bundling	81
2.2. Activity Based Funding	82
2.3. Funding Inconsistencies	84
2.4. Future Funding	85
2.4.1. Short term	85
2.4.2. Long term	86
2.5. A note on Private Health Insurance	86
3. The efficient use of palliative, health and aged care resources	90
3.1. Fast Tracking Palliative Care Patients	92
4. The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities	94
5. The composition of the palliative care workforce	98
5.1. Workforce Groups	98
5.1.1. Specialist palliative care providers	98
5.1.2. Primary health care providers	98
5.1.3. Primary generalist providers	99
5.1.4. Primary specialist providers	99

5.1.5. Primary carer	99
5.1.6. Volunteers	99
5.1.7. Development of a framework for palliative care in a primary health care setting	101
5.2. Its ability to meet the needs of the ageing population	104
5.3. The adequacy of workforce education and training arrangements	108
5.3.1. Workforce distribution, retention and attraction	109
5.3.2. Workforce roles and changing delivery models	110
5.3.3. Education and training	111
6. The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care for All Australians	114
7. Advance care planning	117
7.1. Avenues for individuals and carers to communicate with health care professionals about end of life care	120
7.2. National consistency in law and policy supporting advance care plans	122
7.3. Scope for including advance care plans in personal electronic health records	124
8. The availability and funding of research, information and data about palliative care needs in Australia.	126
Appendix One: Glossary of terms	129
Appendix Two: Additional material to inform the Senate Inquiry	132
1. The Benefits of Palliative Care	132
2. Medication Management	135
3. Supporting Carers	139
4. Supporting Volunteers	140
Appendix 3: Some State Profiles at a Glance	142
Acknowledgements	146

Submission to the Australian Senate Standing Committee on Community Affairs, Inquiry into Palliative Care in Australia

Executive Summary

Access to palliative care and appropriate treatment of pain is clearly a human right in accordance with various international declarations and protocols. Yet access to palliative care in Australia is nothing short of a lottery, predominantly determined by your location, but also affected by your diagnosis, the education of your health professional, your cultural background, and your age.

In July 2010 Australia was honoured by ranking second internationally in the Quality of Death Index – a study conducted by The Economist to ascertain how different countries rate in their provision of end of life care. Australia should be duly proud of its ranking, and the stated commitment of all governments to the provision of palliative care.

Yet, despite government commitment and the dedication of health professionals, carers and volunteers, many Australians continue to miss out on receiving appropriate end of life care. Like most issues in health the reasons are complex. There is not enough funding dedicated to palliative care, there is insufficient training of health professionals in this field, there are a lack of culturally appropriate resources and services, there is an unwillingness in society to accept and openly discuss dying, and our population is rapidly ageing.

Our world status is testament to Australia's commitment to ensuring that every Australian who needs it has access to high quality palliative care. This Senate Inquiry further attests that commitment.

But we remain a very long way from achieving our goals, and Australians will continue to die inadequately supported, and in pain, until we address some core issues.

There is no debate that the majority of Australians indicate a desire to remain at home as long as possible, and even to die at home. This final wish is currently being granted through the delivery of community based palliative care provided in people's own homes – but you have to live in the right place to access such care. The differential between states in funding directed to community based care per head of population is ten to one. The hard work of health professionals and passion of volunteers cannot overcome funding differentials of that magnitude.

Our health professionals seek to provide the best possible treatment for their patients in all circumstances. But if your education completely ignores recognition that a patient is dying and alterations to appropriate referrals and care plans resulting from this, you are unlikely to provide end of life care at an optimal level.

This situation is exacerbated in circumstances where there are a lack of highly qualified health professionals combined with increasing burdens of chronic disease, such as within the aged care sector, and in rural and remote Australia.

Cultural background also impacts profoundly upon access to healthcare, and access to palliative care is no different. The expectations of many cultures that 'family' meetings are inclusive of a broad extended family network along with relevant community members are often not well supported in the Western medical tradition, nor even in the physical planning or clinic scheduling of our hospitals and health centres. The significance of returning to country to die for many Indigenous Australians is similarly often not understood, and rarely financially and physically supported.

As a nation we need to recognise that the social determinants of health are little different from the social determinants of death, and we need to address these issues just as effectively to ensure that every Australian has the opportunity to live well until they die, with their carers and loved ones also receiving appropriate support.

It is often argued that death has become a taboo subject, detrimentally affecting the level to which death is discussed, including discussion by health professionals who are also situated within the prevailing culture. Details of gruesome traumatic deaths, and those of celebrities are splashed across the media as both news and entertainment. Yet there is apparently little discussion of death on a personal level. It has been argued that this reflects the secularisation of society, the movement of illness and death from home to hospital, a simple fear of dying, and the Aussie attitude of hiding or disguising one's true feelings. Whatever the explanation, we need to ensure greater levels of death literacy. We need to raise awareness of end of life care, and concurrently encourage Australians to complete advance care plans and appoint substitute decision makers in case they lose capacity.

This latter point can be assisted by legislation and practice. The current confusion of legal requirements surrounding advance care planning needs to be replaced with a single legal instrument and accompanying requirements across the country. This could be achieved using the same legal mechanisms as were utilised in establishing national registration and accreditation of health professionals. If both the general public and health professionals feel that legislation around advance care plans is supportive and clear they will use it. A simple practical measure to also improve use of advance care plans and concomitant good patient care is to ensure that they are an integral part of all eHealth records, whether the national Personally Controlled Electronic Health Record, or any localised version of same.

Palliative care continues to be closely associated with cancer, although the care of Australians with many other terminal illnesses could greatly benefit from appropriate palliative care. As complex chronic disease and the incidence of dementia continues to rise it is vital that mechanisms be developed to meet this growing need. Currently care can be restricted according to diagnosis due to levels of funding. Under resourced palliative care services are forced to make unpalatable

decisions, restricting care to diagnoses of cancer or motor neurone disease. Financially based restrictions such as these result in Australians dying unsupported and in pain.

Potentially the group who most lack access to palliative care are ageing Australians. Whilst the Productivity Commission declared that palliative care is core business for aged care services and should be a core educational competency for aged care workers, this remains far from the truth. Staff receive minimal education regarding end of life care, neither staff nor families are uniformly offered bereavement support, advance care planning is an often misunderstood process, funding procedures for palliative care loadings are complex, and a lack of connection with well resourced health professionals can lead to poor pain and symptom control. Given current circumstances, it is not surprising that Australians express fear about their end of life care within the aged care system.

Palliative care has been defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering.

Palliative care is a fundamental part of Australia's healthcare system and will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. To work effectively in concert with the rest of the healthcare system, it needs adequate, appropriate, equitable and sustained resourcing for training, infrastructure and research.

Palliative Care Australia (PCA) believes that palliative care must be of the highest quality, timely, resourced to enable choice, based in accordance with an individual's level of need, and evidence based in accordance with current research. Palliative care must be available regardless of location, age, income, diagnosis or prognosis, social and cultural background, to support Australians to live well at the end of life.

The Australian Senate's Inquiry into Palliative Care in Australia provides an opportunity to look at the big picture in palliative care and assess its strengths and weaknesses, identify gaps and provide a few solutions in the form of recommendations to the many issues that impact on this relatively new, emerging and vital health discipline. The Senate's terms of reference are broad and PCA has attempted to address each one keeping in mind the many contextual overlaps between individual terms of reference.

Australia needs to rapidly advance towards a position where any person, from diagnosis to the advanced non-curative stage of disease, in any setting, lives well and dies well in the place of their choosing. This means person centred, integrated and holistic service planning and delivery. It will ensure that every Australian receives high quality, coordinated, reliable care over which they retain control, choice and dignity to the end of their life.

PCA has a vision for the future – of a reformed, modernised palliative care system.

We see:

- A future in which well resourced palliative care services are developed to achieve a person centred choice, resulting in an enhanced experience for the patient and family; improved access to responsive, integrated and flexible services; a reduction in inappropriate admissions to hospital and increase in achieved preference for place of death; a response to patient need rather than diagnosis; appropriate and well coordinated comfort measures when a person is actively dying; and positive experiences from patients, families and carers during the person's last year of life.
- A future where there are sufficient numbers of appropriately skilled people in the right place with adequate systems to support safe, quality care.
- A future where death and dying are normalised through early exposure to the topic at schools and in the curricula at tertiary institutions teaching medicine, nursing and other clinical disciplines, and focus on a healthy approach to death and dying.
- We also see that these personal efforts should be supported by a system that moves away from the technocratic, medicalised approach to dying, recognising that dying is a community responsibility and that people want to die in familiar places, in the company of people who care for them and without pain.
- A future where advance care plans are standard for people reaching the end of life. Where discussions between family members, friends and health practitioners about the future needs and wishes of the dying person becomes the norm.
- We also see advance care plans incorporated into the personally controlled electronic health record of Australians, so all those sharing that information are aware of the needs and wishes of that individual.

In whatever way we perceive palliative care to be, the bottom line is that it is about life - about the proper care of someone who is alive, someone who still has days, months or years remaining to their life. It is about maintaining and improving on a quality of life that you and I would deem reasonable for ourselves and others that ensures comfort, dignity and freedom from preventable pain. This is not an impossible ask. In fact it is imperative that we, as a civilised nation, ensure our end days are filled with good experiences and memories of meaningful and worthwhile relationships.

We see a future where these experiences are commonplace.

Recommendations

Background Summary:

People living in rural and regional areas

Rural and remote populations have a greater prevalence and burden of disease compared to metropolitan areas, which is compounded by the limited availability of, and access to, health services. There is an under supply of health facilities and health professionals which results in people from rural and remote areas experiencing poorer palliative and end of life care. Governments must plan to ensure that palliative and end of life care services are available to all Australians, regardless of where they live, and models of care developed for rural and remote communities need to be flexible and responsive to local needs, taking into account their uniqueness and diversity.

Australian Indigenous peoples

The health profile of Indigenous Australians is very different from that of other Australians. Palliative care can, and should, improve end of life outcomes for Indigenous people. Strategies to train more Indigenous workers in palliative care, and compulsory cultural awareness training for all health practitioners is needed. Cultural safety must underpin all improvements in palliative care for Indigenous Australians, as must community engagement and ownership of locally developed strategies to improve end of life care in Indigenous communities.

People from culturally and linguistically diverse backgrounds

The cultural diversity of the Australian community is increasing and with this, the potential of providing inappropriate palliative and end of life care. Respecting the different beliefs, values and practices of people from culturally and linguistically diverse backgrounds is integral to providing good quality palliative care and avoiding unnecessary suffering.

All health practitioners should have a level of cultural competence and proactively engage in cultural issues.

People with disabilities

Overall, access to quality care for this population is inconsistent. Ongoing education of disability care professionals, supportive organisational structures and cultures, and intelligent financing solutions, are essential if end of life care for people with disabilities is to improve.

Children and adolescents

There is a need to recognise that palliative care for children and adolescents is different from palliative care provided to adults. The provision of paediatric palliative care varies widely across Australia, with some states and territories not having dedicated paediatric services. There is a need to ensure that families know what services are available, care is well coordinated, high quality and supported by the best available research and evidence.

Access to appropriate palliative care for older people

Palliative care should be core business for aged care, but the current system is not meeting the end of life care needs of older Australians. Aged care is not funded in a way that provides high quality palliative care services to older Australians; does not have an adequate workforce training to manage end of life care needs; and is not resourced to meet the demands of Australia's ageing population. Aged care services should ideally be able to play one of two roles in the provision of high quality palliative care; services should be able to offer a general palliative approach and facilitate high quality palliative care to support people to die with dignity and in comfort at home or in a residential facility if they so choose, or deliver specialist palliative care services themselves, where appropriate and possible.

Funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

There are opportunities available for palliative care with the introduction of activity based funding, but only if the unique nature of the delivery of palliative care is fully understood and incorporated in the funding structure. The guiding principle of funding for palliative and end of life care should be equitable support for all Australians and a flexible system based on individual needs, across all care settings.

The efficient use of palliative, health and aged care resources

A lack of efficiency in palliative care service provision is underpinned by a lack of planning and strategy in the delivery of services leading to duplication in some cases. Improvements in palliative care service provision not only results in better care of the dying, but can improve the efficiency of the health care system as a whole.

The prevention of hospital admissions, emergency admissions, a reduction in the use of acute services, and the minimisation of futile treatments and procedures will result in the co-benefits of financial savings for the health system and freeing up of acute hospital beds for those who need them.

The composition of the palliative care workforce

A key feature of palliative care is that it is provided by a multidisciplinary team, resulting in truly holistic care which aims to maintain the patient's quality of life. Many different individuals contribute to the multidisciplinary team. The role of carers and volunteers cannot be underestimated and there is a need to strengthen the role of volunteers in the system, which could not maintain the relatively high quality of care currently experienced in Australia without them.

Its ability to meet the needs of the ageing population

Residential aged care is, and will continue to be, the place of death for people with terminal conditions. In addition, people will increasingly present with a range of more complex chronic diseases. Palliative care must be a core competency for aged care workers and core business for aged care facilities if we are to meet the needs of older Australians in residential aged care. The aged care workforce needs to be increased, in both number and skills in end of life care.

The adequacy of workforce education and training arrangements

All health practitioners need to be appropriately prepared for providing end of life care, to ensure they can deliver care consistent with the *Standards*. The nature and scope of preparation will vary between primary and specialist settings and between disciplines, but must enable health practitioners to meet a level of competence necessary for their scope of practice. This workforce should be accessible and well distributed to allow equitable access for all Australians. There is a need for a comprehensive workforce strategy in this regard, which embeds palliative care as a core part of the curriculum across all undergraduate, postgraduate and continuing education courses.

The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Palliative Care to All Australians (the Standards)

Standards should underpin the provision of palliative care in Australia. It is important that they are relevant, reflecting the day to day practice of the way palliative care is provided to patients, their families and carers, and relevant to the whole Australian population. There is a need to ensure that the *Standards* can be implemented across all levels of service provision in Australia, not just limited to specialist palliative care services.

Advance care planning

Quality end of life care is realised when it works to address a patients needs and acknowledges their care preferences. Giving patients the opportunity to consider and identify care preferences through advance care planning is one mechanism toward achieving quality end of life care, and should be regarded as part of the role of the end of life care team.

National consistency in law and policy supporting advance care plans

There is no single piece of legislation regarding advance care planning in Australia. States and territories have different provisions, meaning that it is difficult for one jurisdiction to recognise the advanced care directive from another. This is further compounded by the use of different terminology. Legislative differences also make it difficult for healthcare professionals to know their rights and responsibilities in this area. There is a need to achieve national consistency for advanced care planning.

Scope for including advance care plans in personal electronic health records

PCA sees advance care plans incorporated into the personally controlled electronic health record of Australians, so that all those sharing the information are aware of the needs and wishes of the individual.

The availability and funding of research, information and data about palliative care needs in Australia

Australia is a world leader in palliative care research and there should be an investment to ensure that we remain so. The development of a research framework

and the establishment of a national centre of excellence will ensure that palliative care research is relevant, useful and translatable for everyday practice.

List of Recommendations

People living in rural and regional areas

1. That funding be quarantined for rural and remote health care that incorporates palliative and end of life care in all appropriate initiatives.
2. That the profile of the Patients Assistance Travel Scheme (PATS) be raised through increased marketing and promotion of the scheme in all jurisdictions to boost awareness to patients and all health care practitioners including GPs.
3. That access to and experience of the Patients Assistance Travel Scheme (PATS) be improved for Indigenous patients including expansion of the definition of 'escorts' and inclusion of them in the schemes.
4. That telehealth services be supported and funded to link remote communities to specialist palliative care services.
5. That national streamlining of the administration of the Patients Assistance Travel Scheme (PATS) be achieved through the adoption by all jurisdictions of a prepayment system (vouchers, tickets or advance bookings) and a reduction in the paperwork required to one page form covering all episodes of care.
6. That travel and accommodation assistance is made available for all appropriate treatments listed on the MBS (Enhanced Primary Care items).
7. That the Person Controlled Electronic Health Record links the Patients Assistance Travel Scheme (PATS) with treatment provided by GPs and other health care practitioners with access to the patient's PCEHR.
8. That national research on issues that impact on the provision of palliative care in rural areas and remote communities be funded and promoted.

Australian Indigenous peoples

9. That all policies, procedures and processes of health care must respect and reflect different cultural and ethnic values, beliefs and practices that surround death, dying and end of life care.
10. That clear policies, procedures and mechanisms are established to support 'return to country' for Indigenous Australians who are approaching the end of their life.

11. That commitment is made to education and training that builds the cultural competence and cultural awareness of Australia's healthcare workforce through undergraduate, postgraduate, vocational and continuing professional education, including:
 - a. significant investment by government to increase the number, qualification levels and professional registration of Indigenous peoples in the health workforce;
 - b. appropriate training and education about cultural perspectives relating to palliative and end of life care issues, in core curricula for all health workers and health practitioners providing services to Indigenous people;
 - c. inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV
 - d. continuation of PEPA to build on or develop cultural appropriate education for Indigenous health workers.

12. That there is a commitment by service providers to work with Indigenous organisations to develop models of palliative and end of life care services appropriate to meet the needs of Indigenous people. This will require:
 - a. fostering the practice of advance care planning and family case conferencing to involve the patients and broader family in decisions about culturally appropriate care;
 - b. review of organisational policies that may hinder access to culturally appropriate palliative and end of life care;
 - c. the development of organisational and service planning models which incorporate strategies and initiatives to address the identified equity and access issues which inhibit or prevent Indigenous people from benefiting from end of life services;
 - d. all services to provide ongoing workforce training on the issues affecting the delivery of appropriate services to Indigenous people;
 - e. the development and delivery of information in a culturally appropriate way to Indigenous people.

13. That there is support and funding of an increase in the availability and accreditation level of interpreters to communicate with the estimated 55,000 speakers of Indigenous languages, many of who may have English as a second, third or even fourth language.

14. That there is support and funding for culturally specific research on the nature of grief and bereavement in Indigenous communities and the implications for this in the development of appropriate support services.
15. That strong linkages between community controlled health services and specialist palliative care services be developed and fostered.

People from culturally and linguistically diverse backgrounds

16. That there is flexibility in delivery of palliative care to accommodate the care preferences of people from CALD backgrounds.
17. That cultural liaison officers with the necessary skills, experience and knowledge about end of life care be trained and resourced.
18. That support, development and provision of culturally appropriate health information and resources in a range of community languages be increased.
19. That availability of, and support for, qualified and trained translators and medical interpreters who can ensure effective, efficient and reliable communication between health practitioners and patients, their families and carers, particularly at the end of life be increased.
20. That protocols be developed for health practitioners to guide the use of interpreting and translation services, including addressing the issue of people not feeling able to honestly relay information due to their own cultural beliefs.
21. That research in the Australian context of the cultural implications for quality care at the end of life, to reliably inform policy and funding decisions be supported and funded.

People with disabilities

22. That comprehensive case management services are available to all families who require them.

Children and adolescents

23. That funding is provided to ensure that children with life threatening conditions and their families have equitable access to quality information and responsive and appropriate palliative care services.
24. That the Australasian Paediatric Palliative Care Reference Group be funded to develop and implement a National Paediatric Palliative Care Strategy.
25. That a data collection system for paediatric palliative care, including establishment of quality indicators, be designed.

26. That a research project to explore the palliative care needs of young adults and the appropriate service responses be funded.

Access to appropriate palliative care for older people

27. That the Australian Government implements the aged care reforms as proposed by the Productivity Commission and supported by the National Aged care Alliance as a matter of urgency.
28. That all Residential Aged Care Facilities (RACFs) be required to have an effective relationship with a specialist palliative care service in their region and this should be reflected in the aged care accreditation standards.
29. That community and residential aged care recipients with complex palliative care needs should be eligible to receive specialist palliative care consultancy support across the country and this should be reflected in funding agreements.
30. That funding to cover the provision of palliative care should be included in aged care subsidies.
31. That the National Palliative Care Standards can be reflected in all aged care provision.
32. That eligibility be confirmed for community aged care clients with complex palliative care needs currently receiving HACC or packaged care to receive specialist palliative care consultancy support across the country and this should be reflected in funding agreements.
33. That there be a national rollout of the evidence based Palliative Approach Toolkit www.uq.edu.au/bluecare to support RACFs in providing a palliative approach.
34. That the Australian Government make palliative care for older people and aged care service support a palliative care funding priority in 2012-2013. The need for this priority to be created can be tied to its ability to decrease unnecessary, undesirable and costly hospital admissions and usage.
35. That the Aged Care Funding Instrument be amended to facilitate provision of palliative care.
36. That the aged care 'Gateway' should provide information and support to access on advance care planning and palliative care services. Assessment for referral to palliative care should be an integral aspect and skill of Gateway assessors.
37. That the VET review should include specific reference to quality palliative care training, including whether palliative care should be an elective or mandatory subject.

Funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

38. That sub-acute funding provided to states and territories should have specific amounts dedicated to palliative care service provision.
39. That the pricing model developed for activity based funding includes:
 - a. An expanded notion of the 'patient' as including family, carers and others in the delivery of palliative care.
 - b. Flexible systems to allow for differing diagnoses and resulting complexity of care.
 - c. An expanded to definition of 'clinician' to include the full multidisciplinary care team.
 - d. An expanded notion of 'service event' to reflect the background work which underpins palliative care service delivery.
 - e. Funding based upon phase of care.
 - f. Improved data collection.
40. That funding through the Australian Government's National Palliative Care Fund be reinstated and increased.
41. That palliative and end of life care is recognised in the Guidelines for the Department of Health and Ageing's flexible funding streams, specifically the Aboriginal and Torres Strait Islander Chronic Disease Fund, the Aged Care Workforce Fund, the Communicable Disease Prevention and Service Improvement Grants Fund, the Health System Capacity Fund and the Health Surveillance Fund.
42. That flexible funding arrangements be adopted to enable rural and remote communities to access palliative care resources and services to meet their needs.
43. That resourcing formulas be developed that incorporate assessment of local population palliative care needs, cost of service delivery and that support the achievement of desired outcomes.
44. That both public and private funding is directly linked to care of people who are approaching the end of their life, irrespective of the care setting.
45. That affordable access to aids, equipment and medications necessary to provide quality care at the end of life in the community is ensured.
46. That RACFs are accurately and adequately resourced to reflect the cost of delivery of palliative care to residents, and support for families and carers.

47. That Specialist Palliative Care funding models are reviewed to reflect the changing demand pattern for palliative care services and changing service role, i.e. to reflect demand for palliative care service for people suffering from non-malignant life threatening illness, and to better reflect the growing need for specialist consultancy advice for generalist palliative care providers.
48. That funding be organised as packages for the delivery of education to RACFs, or an activity based funding model be set up to allow clinical staff to be released for planning and presenting educational programs.

The efficient use of palliative, health and aged care resources

49. That all state and territories be required to have strategic and business plans in place with appropriate evaluation systems reporting on service outcomes.

The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

50. That residential and community care providers receive appropriate payments for delivering palliative care, including accessing specialist palliative care services where required as recommended by the Productivity Commission.
51. That flexible funding models and support structures be adopted for regional and remote access to specialist palliative care services e.g. fly in/fly out programs, or teleconferencing.
52. That the current system of discrete care packages across community and RACFs be replaced with a single integrated and flexible system of entitlements, including palliative care services, as recommended by the Productivity Commission.
53. That every specialist palliative care service which is classified as Level 3 by the *Standards* be funded to employ a Community Nurse Practitioner, Palliative Care, to provide palliative care in RACFs, the training of palliative care practice to staff of RACFs and for liaising with GPs, Geriatricians and other medical specialists.
54. That all major hospitals have an adequately staffed palliative care consultation service.

The composition of the palliative care workforce

55. That a *National Palliative Care Volunteer Workforce Strategy* be developed and implemented.
56. That Palliative Care Australia and the National Medicare Local Network be supported to move from a development to an implementation phase of the Australian Primary Palliative Care Framework to support GPs to provide appropriate and much needed end of life care to Australians.

Its ability to meet the needs of the ageing population

57. That end of life care should be acknowledged as a basic competency for aged care workers, regardless of the setting in which they work, and included in the core curricula of aged care worker education and as an element of ongoing training.
58. That nationally standardised referral criteria for patients with palliative care needs that promote needs based service provision be developed and implemented, with the support of a national education campaign.
59. The systems for coordinating the management of pain and symptom relief for residents in RACFs be introduced that address limitations in who can prescribe and administer medication so as to ensure residents' care needs are appropriately met.
60. That a feasibility study should be conducted to determine how integration of the *National Palliative Care Standards* with the *Aged Care Accreditation Standards* could best be achieved.
61. That workforce shortages in aged care must be addressed as this is negatively impacting on the capacity of services to provide quality end of life care.
62. That the role of specialist palliative care in supporting primary health care provision of needs based end of life care be better recognised and supported through appropriate funding and program development.
63. That the number of palliative medicine specialists be increased from the current level of 0.5 FTE per 100,000 people to 1.5 FTE per 100,000 people as recommended in the *Palliative care service provision in Australia: A planning guide*.

The adequacy of workforce education and training arrangements

64. That a Palliative Care Workforce Strategy should be funded, developed and implemented which identifies workforce resources required across all services (general, specialist and community) and aims to ensure that end of life care is a basic competency for aged care workers.
65. That all health professionals should be appropriately qualified and competent for the level of service offered. This means:
 - a. all undergraduate and entry to practice courses in the health professions should meet the benchmarks established by the *Palliative Care Curriculum for Undergraduates* (PCC4U) project, to enable all health practitioners to develop core capabilities in end of life care;
 - b. continuing professional education programs should be underpinned by a nationally consistent set of core competencies in end of life care,

and be able to be delivered flexibly to meet differing needs and changing circumstances;

- c. all health practitioners working in specialist palliative care services should have access to training programs to enable them to demonstrate specialised knowledge, skills and competence as defined by relevant professional and disciplinary standards.
66. That a systematic analysis of the palliative care workforce be supported and funded to identify gaps between population need and workforce availability (both for staff type and geographical distribution), and the implementation of appropriate strategies to ensure sufficient numbers of training positions are available to meet current and future needs of the specialist palliative care workforce.
 67. That a national approach be ensured to implementation of the competency standards for specialist palliative care nursing practice.
 68. That national, state and local workforce development plans are developed that are aligned with a population based model of service delivery that reflect advances in practice.
 69. That a role delineation framework based on Palliative Care Australia's *Standards* be implemented and appropriately resourced in each of the states and territories of to ensure that health practitioners are working within a supportive, high quality service structure, and that clinical and academic education and training programs are adequately resourced to ensure achievement of the *Standards*.
 70. That evidence based guidelines for staffing of inpatient/hospice and community services be developed with the collaboration of all jurisdictional governments.
 71. That all jurisdictional governments commit to education and training that builds the cultural competence of Australia's health workforce through undergraduate, postgraduate, vocational, and continuing professional education.

The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Palliative Care to All Australians (the *Standards*)

72. That the National Standards Assessment Program be supported to work with appropriate Australian universities to inform research into quality standards for palliative care.
73. That no service be entitled to call itself a palliative care service unless implementing The *Standards*.

74. That National Standards Assessment Program be funded to expand its focus beyond specialist palliative care services to include implementation of the *Standards* in primary health care and aged care.
75. That a review of *The Standards* be funded, to include mapping with the *National Safety and Quality Health Service Standards* to minimise the impact for services implementing both sets of standards to ensure that their patients get the best care from the perspective of safety, quality, and palliative care.
76. That all jurisdictional governments ensure that the requirement to meet national health care and palliative care standards is incorporated into all funding agreements for services providing care to people at the end of life, with regular reviews to ensure that these standards are met.

Advance care planning

77. That ongoing national campaigns be funded, developed and implemented to increase community awareness of end of life planning options and community capacity to discuss and plan for death and dying.
78. That a national training program on how to engage in end of life discussions and advance care planning be supported, and that it is incorporated into end of life care education for primary and specialist health care providers.
79. That a single common legislative requirement regarding advance care planning be adopted across Australia.
80. That national guidelines be funded and implemented to promote good practice in advance care planning by specifying the key elements to be addressed in working through this process with patients and their carers. These national guidelines and their promotion should be of relevance regardless of the particular method employed for noting and recording advance care plans.
81. That advance care planning is included in the role of aged care workers in RACFs and that appropriate training and remuneration is provided to aged care staff undertaking this role.
82. That in the lead up to national legislation, the Australian Government ensures greater national consistency and harmonisation between the States and Territories in legislation governing the scope and implementation of advance care directives and advance care plans, and the appointment and status of substitute decision makers to ensure they are valid across jurisdictions.
83. That, following evaluation, the Cradle Coast Electronic Health Information Exchange (eHIE) project be implemented nationally.

84. That advance care plans be made an integral part of all eHealth records, whether the national Personally Controlled Electronic Health Record, or any localised version of same.
85. That a person's substitute decision maker be recorded on all eHealth records, whether the national Personally Controlled Electronic Health Record, or any localised version of same.

The availability and funding of research, information and data about palliative care needs in Australia

86. That the development and implementation of a *National Palliative Care Strategic Research Framework* be funded that:
 - a. identifies evidence based research priorities and focuses on translating research into practice
 - b. guides decision makers and funders in selection of nationally significant and useful areas of human research.
87. That national research in the nature and frequency of treatment of non-malignant terminal conditions across care settings, including RACFs, be undertaken.
88. That human research ethics committees and other decision making and funding groups develop a better, broader understanding of the aims of palliative care research to allow for collaborative, national palliative care research into areas that non-palliative care clinicians may find challenging. For example, research into the dying process and research in non-hospital settings (e.g. at home or in residential aged care).
89. That there be regular independent reviews undertaken of the NHMRC palliative care grants to assess evidence of translation into practice and to avoid duplication across subsequent funding rounds.
90. That the Australian Government provides support and funding for the establishment of a Centre of Excellence in Palliative Care Research.

Medication Management

91. That the *Assist Clients with Medication* learning unit becomes a mandatory core component of the Certificate III and IV in aged care and home and community care, and a competency gained by all aged care workers.
92. That all RACFs should have a functioning Medications Advisory Committee, and this requirement is reflected in the aged care accreditation standards.
93. That the Lead Clinician Group work in collaboration with Aged Care, Pharmacy and other peak bodies and professional advisory councils, to

systematically review relevant practice guidelines to improve the interface between all professionals who work to support and care for older people across community and residential care and health settings.

94. That COAG, working through the Australian Health Ministers Advisory Council, establish a working party to consider adopting uniform national model legislation in relation to drugs, poisons and controlled substances across Australia's states and territories.

PART A: Palliative Care and the Australian Situation

1. Introduction

Palliative Care Australia (PCA) is the peak national organisation representing all state and territory palliative care organisations, the Australian and New Zealand Society of Palliative Medicine, and the interests and aspirations of all who share the ideal of quality care at the end of life.

Our vision is to achieve quality care at the end of life for all. PCA's mission is to influence, foster and promote the delivery of quality care at the end of life for all. PCA advocates for equitable, needs based delivery of quality care at the end of life through promotion of the principles of palliative care; development of evidence and needs based service provision models; workforce capacity building; awareness and community capacity building; appropriate funding and resourcing.

Palliative care has been defined by the World Health Organization (WHO)¹ as:

An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

¹ World Health Organisation, *WHO definition of Palliative Care*, 2008.
<http://www.who.int/cancer/palliative/definition/en/>

Palliative care will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. When an illness cannot be cured, the focus of care changes to supporting and assisting patients to have the best quality of life possible while managing their symptoms. Palliative care maintains quality of life by addressing physical symptoms, such as pain or nausea, as well as helping with emotional, spiritual and social needs. A person receiving palliative care will have an active, progressive and far advanced disease, with little or no prospect of cure. The aim of palliative care is to achieve the best possible quality of life for the individual patient, their carers and families.

It is important to distinguish between palliative care, as defined above and which may be provided over the course of a life threatening illness (including chronic or degenerative conditions), and end of life care which refers to the care provided in the last weeks or days of life. End of life care is only one stage of quality palliative care provision and is often when people are at most risk of being cared for inappropriately.²

2. Background

Palliative care is a fundamental part of Australia's healthcare system but to work effectively in concert with the rest of the healthcare system, it needs adequate, appropriate, equitable and sustained resourcing for training, infrastructure and research.

PCA has three key reference documents to assist in the planning and development of efficient, effective and appropriate high quality palliative care services. These include:

- ***The Standards for providing quality palliative care for all Australians*³ (The Standards)**

The *Standards* represent a nationally endorsed whole of sector approach to ensuring high quality, needs based care. The *Standards* are key governing statements that influence both primary and specialist palliative care service providers in the way they plan and deliver palliative care.

The *Standards* set out the relationship between primary health care providers and specialist palliative care services. They also articulate the level of expectations for all services involved in the provision of palliative care to people with a life threatening illness.

They are the cornerstone of the National Standards Assessment Program (NSAP).

² Palliative Care Australia, *Palliative and end-of-life care glossary of terms*, Palliative Care Australia, Canberra, 2008.

³ Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, Palliative Care Australia, Canberra, 2005.

➤ **The Palliative care service provision in Australia: A planning guide⁴**

The Guide aims to improve patient and carer outcomes through guidance on palliative care service delivery.

PCA is concerned that all Australians should have equitable access to quality palliative care regardless of where they live, their age or social or cultural background. The Guide outlines the minimum professional staffing required to ensure palliative care is provided to all who need it.

➤ **The Guide to Palliative Care Service Development: A population-based approach⁵**

This key reference document provides the context within which the *Standards* and the Guide can be interpreted and applied. The document articulates a needs based approach to palliative care and implications for service development.

In 2011, PCA developed the *National Palliative Care Consensus Statement⁶* (NCS). It was developed following a Stakeholder Forum convened by PCA in May 2011 at Parliament House, Canberra, and represents the Forum's collective analysis, evaluation, and opinion.

The NCS was developed out of a need for clarity on four key issues identified as recurring themes in palliative care internationally and nationally:

- where people prefer to die
- the need for advance care planning
- access and equity in provision of palliative care services
- awareness about palliative care in the general community and in groups of healthcare professionals.

The NCS identifies priorities needing urgent action and goals to achieve what Australians want – a system that supports us all to live well at the end of life. It is worth reiterating what the priorities identified in the NCS say:

- All Australians must have reasonable access to resources to support them to die in the location of their choice.
- A single common legislative requirement regarding advance care planning must be adopted throughout Australia.
- All Australians have a right to equitable access to quality palliative care when and where needed.

⁴ Palliative Care Australia, *Palliative Care Service Provision in Australia: A Planning Guide*, Palliative Care Australia, Canberra, 2003.

⁵ Palliative Care Australia, *A Guide to Palliative Care Service Development: A population-based approach*, Palliative Care Australia, Canberra, 2005.

⁶ http://www.palliativecare.org.au/Portals/46/Palliative_Care_Consensus_Statement_final.pdf

- All Australians must have access to education about dying and death.
- Adequate and appropriate education in quality end of life care must be a standard provision for all health practitioners.
- The Standards for Providing Quality Palliative Care for all Australians must be embedded in all appropriate care settings.
- Appropriate funding must be made available by all levels of government to palliative care services on an equitable population needs basis.
- Research in palliative care must be appropriately funded and targeted.

The NCS accords with the Australian Government's *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*⁷ in recognising a need for the Commonwealth, States and Territories to work cooperatively and collaboratively in achieving common and agreed goals. Endorsed by the Australian Health Ministers' Conference in November 2010, the Strategy is the policy document that the Australian Government and State and Territory Governments use to guide palliative care policy development and service delivery across Australia.

The Strategy forms part of the Australian Government's *National Palliative Care Program*⁸. The Program has three sources of funding to:

- improve palliative care in the community
- support the national program
- strengthen palliative care services through local palliative care grants.

In addition, the Australian Government provides funding to states and territories for the enhancement of sub-acute care services (including palliative care) under the Council of Australian Government's (COAG) *National Partnership Agreement on Hospital and Health Workforce Reform*⁹. The Program offers support in four areas:

- For patients, families and carers in the community - grants to local groups, health and aged care providers and charitable organisations to support patients and their families receiving palliative care.
- Increased access to palliative care medicines in the community - the *Palliative Care Clinical Studies Collaborative*¹⁰ (PACCSC) manages multi-site clinical drug trials in order to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and possible listings on the Pharmaceutical Benefits Scheme (PBS).

⁷ Commonwealth Department of Health and Ageing, *National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*. Australian Government.

⁸ National Palliative Care Program, Department of Health and Ageing, Australian Government.

⁹ Council of Australian Governments. *National Partnership Agreement on Hospital and Health Workforce Reform*. Australian Government. 2011.

¹⁰ Palliative Care Clinical Studies Collaborative. <http://www.flinders.edu.au/clinical-change/research/palliative-care-clinical-studies-collaborative-paccsc.cfm>

- Education, training and support for the workforce - the *Program of Experience in the Palliative Approach*¹¹ (PEPA) is a work placement training program for health practitioners in a specialist palliative care service of their choice.
- Research and quality improvement for palliative care services - there are four primary areas of activity which include:
 - The *Australian Palliative Care Outcomes Collaboration* (PCOC). A consortium of four universities, PCOC supports services to compare and measure the quality of their outcomes to ensure continued quality improvement¹².
 - The *Palliative Care Research Program*, managed by the National Health and Medical Research Council, aims to improve the quality of palliative care, inform policy development, improve clinical practice and develop researcher capacity by funding priority driven research grants, training awards and research development grants¹³.
 - The *Palliative Care Knowledge Network* (CareSearch) is a web-based source of information and practical resources for clinicians and other healthcare professionals providing palliative care, researchers, patients and carers¹⁴.
 - The *National Standards Assessment Program* (NSAP). The National Standards Assessment Program (NSAP) is a quality improvement program available for all specialist palliative care services across Australia. It is a resource that enables services to engage in continuous quality improvement through self assessment against the *Standards*, action plan development and implementation as well as peer mentorship. The key objective of NSAP is to improve the quality of palliative care experiences and outcomes for patients, carers and families. The *Standards* influence both primary and specialist palliative care service providers in the way they plan and deliver palliative care and articulate the level of expectations for all services involved in the provision of palliative care to people with a life threatening illness.

Both the PCA's NCS and the Australian Government *National Palliative Care Program* and *National Palliative Care Strategy 2010*, accord with developing and implementing quality palliative care and together form a sound foundation to progress contemporary approaches to both palliative and end of life care in Australia. Both PCA and the Australian Government continue to strive to:

- Significantly improve public awareness and an appreciation of dying and death as a normal part of our lives.
- Enhance community and health professional awareness of the scope of, and benefits from, timely and appropriate access to palliative care services.

¹¹ The Program of Experience in the Palliative Approach (PEPA) is an initiative of the Australian Government Department of Health and Ageing.

¹² Australian Palliative Care Outcomes Collaboration (PCOC).

<http://www.ncbi.nlm.nih.gov/pubmed/20497731>

¹³ Palliative Care Research Program, NHMRC, Australian Government.

¹⁴ Palliative Care Knowledge Network (CareSearch). of Australian Government.

- Make sure that appropriate and effective palliative care is available to all Australians, based on need.
- Build and enhance the capacity of all relevant sectors of society to provide quality palliative care.
- Provide informed choice, through advance care planning, of a preferred place to die and the type of care wished for.

PCA believes that palliative care must be of the highest quality, timely, resourced to enable choice, based in accordance with an individual's level of need, and evidence based in accordance with current research. Palliative care must be available regardless of location, age, income, diagnosis or prognosis, social and cultural background, to support Australians to live well at the end of life.

PCA is encouraged to see the Australian Government Senate Inquiry into this vital area of the health care system. The following is a compilation of knowledge, facts, experiences, views and concerns of the palliative care community in Australia.

3. A Vision for palliative care

PCA's vision for the future is for a reformed and modernised palliative care system.

Australia needs to move towards a position where any person, from diagnosis to the advanced non curative stage of disease, in any setting, lives well and dies well, in the place of their choosing. This means person centred, integrated and holistic service planning and delivery. It will ensure that every Australian receives high quality, coordinated, reliable care over which they retain control, choice and dignity to the end of their life.

The way we die in Australia has improved significantly in the last century assisted by better pain management and understanding about the process of dying. However, the institutionalised way we deal with dying is out of touch with how most people wish to live at the end of life. This situation is not isolated to Australia. Research demonstrates key issues that continue to act as challenges for palliative care.

The need for reform and modernisation of palliative care in Australia reflects the growing acceptance nationally and internationally, amongst the public and health practitioners, that palliative care is not disease specific and not purely a specialist activity.

In addition, it has become clear that existing models of care, which were largely developed to support the needs of patients with malignant cancer, no longer meet the needs of our population, which is living longer and often with non-malignant chronic disease. Neither do the models truly reflect the holistic goals of palliative care.

This widespread recognition of the need for change in Australia and elsewhere has led to plans for the reform of palliative care services. This need for change has been

articulated by experts in the field and in a number of countries where rhetoric has been transformed into national policy.^{15,16,17,18,19,20}

Common themes in the call for change are the need to increase the availability and quality of palliative care through better coordination of services; identification of patients with palliative care needs; increased provision of out of hours care; community and health professional awareness of dying as a natural part of life; access to quality care and equity in its availability; a patient's choice about where to die; and planning for the end of life.

In Australia, most of these themes have been adopted and, where supported by evidence, have been transformed into PCA's NCS. The NCS picks up on four key issues in palliative and end of life care, and along with the *National Palliative Care Strategy 2010* guide the achievement of our vision for the future.

Issue 1 - A patient's choice about where to die:

In the lead up to the development of the NCS, a national poll revealed that nearly 75% of Australians who had thought about it would prefer to die at home or in the place of their choice, yet we know most will die in hospital.²¹ We need to make choice a right, not a privilege, and create a health and social system with the capacity to achieve it.

We see a future in which well resourced palliative care services are developed to achieve a person centred choice, resulting in an enhanced experience for the patient and family; improved access to responsive, integrated and flexible services; a reduction in inappropriate admissions to hospital and increase in achieved preference for place of death; a response to patient need rather than diagnosis; appropriate and well coordinated comfort measures when a person is actively dying; and positive experiences from patients, families and carers during the person's last year of life.

¹⁵ End of Life Care Programme - www.endoflifecareforadults.nhs.uk

¹⁶ National Council for Palliative Care - www.ncpc.org.uk

¹⁷ Scottish Partnership for Palliative Care - www.palliativecarescotland.org.uk

¹⁸ Living and Dying Well: a national action plan for palliative and end of life care in Scotland
<http://www.scotland.gov.uk/Publications/2008/10/01091608/4>

¹⁹ Department of Health, Social Services and Public Safety (2009) Palliative and End of Life Care Strategy for Northern Ireland consultation document -
http://www.dhsspsni.gov.uk/palliative_and_end_of_life_care_strategy_-_consult.pdf

²⁰ Written Statement by the Welsh Assembly Government (2009) Palliative and End of Life Care - Allocation of central funding 2010-11, via
<http://wales.gov.uk/docs/cabinetstatements/2010/100427palliativeen.doc>

²¹ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

Issue 2 - Access to quality care and equity in its availability:

Despite some remarkable gains we have observed over the years, there is still much more to be done to ensure that every Australian has access to quality palliative care regardless of where they live. Access and equity in palliative care is about ensuring the right approach, in the most suitable setting, at the right time. It requires good systems and processes to support access to information and services. This is critical in providing high quality palliative care.

Quality palliative care is about providing evidence based interventions supported by a strong research base and services that have good systems of quality control and cultures of quality improvement.

We see a future where there are sufficient numbers of appropriately skilled people in the right place with adequate systems to support safe, quality care.

Issue 3 - Community and health professional awareness of dying as a natural part of life:

We think nothing about planning for and talking about the birth of a child and accept it as a natural part of life. So too should we accept death and dying as a natural part of life, talk openly about it and plan for it. However, many people find it difficult to talk about death and are reluctant to have those discussions. The reasons for this reluctance are many and varied, ranging from fear of the unknown to religious and cultural taboos.

Efforts to increase both community and health professional awareness centre on increasing health literacy and promoting death and dying as a natural part of life. Australians need to talk more openly about death and dying so that we become an accepting 'death literate' society. Nevertheless, building awareness and understanding about death and dying must be undertaken in a culturally respectful way. For some cultures, there are explicit norms around how these issues are approached. This is particularly important for Indigenous people. Given that about 25% of Australians come from a Culturally and Linguistically Diverse (CALD) background, awareness campaigns and services themselves must be culturally safe and appropriate²².

We see a future where death and dying are normalised through early exposure to the topic at schools and in the curricula at tertiary institutions teaching medicine, nursing and other clinical disciplines, and focus on a healthy approach to death and dying.

We also see that these personal efforts should be supported by a system that moves away from the technocratic, medicalised approach to dying, recognising that dying is a community responsibility and that people want to die in familiar places, in the company of people who care for them and without pain.

²² Australian Bureau of Statistics. 2012. Australian Government.

Issue 4 - Planning for the end of life:

Most of us do not think about dying and in most cases the prospect of our death is too far away to contemplate. However, those with life threatening illness or older people nearing the end of their lives, need to plan for their care in advance. This is a safeguard in case they find themselves in a position where they can no longer make rational decisions or are physically incapacitated and can no longer make themselves understood to their family, friends and carers.

Advance care planning is an investment in future quality care tailored to the dying person's needs and wishes. Creating such a plan encourages people to have difficult but vital conversations about how they want to die before they are caught up in the crises that mark the last weeks of life. If people have these conversations ahead of time they are more likely to be able to shape what happens to them, including where they wish to die, when they are in the midst of crisis.

We see a future where advance care plans are standard for people reaching the end of life. Where discussions between family members, friends and health practitioners about the future needs and wishes of the dying person becomes the norm.

We also see advance care plans incorporated into the electronic health record of every Australian, so all those sharing that information are aware of the needs and wishes of that individual.

A new beginning

In whatever way we perceive palliative care to be, the bottom line is that it is about life - about the proper care of someone who is alive, someone who still has days, months or years remaining in their life. It is about maintaining and improving on a quality of life that you and I would deem reasonable for ourselves and others that ensures comfort, dignity and freedom from preventable pain. This is not an impossible ask. In fact it is imperative that we as a nation, ensure our end days are filled with good experiences and memories of meaningful and worthwhile relationships.

We see a future where these experiences are commonplace.

4. Context

*'We all die eventually. People who are dying are among the most vulnerable in society. The quality of care they receive must be one mark of society's humanity as a whole. Good quality care towards the end of life must be recognised as a basic human right.'*²³

²³ World Health Organization . *Palliative care: the solid facts 2004* WHO/Europe | Palliative care. The solid facts.

*'As everyone on this earth must die, for many this means suffering, including physical, existential and spiritual pain. With chronic diseases, millions have slow painful deaths. A public health approach offers the best opportunity to use our knowledge and skills in cost-effective interventions that can reach everyone.'*²⁴

Australia's health care system must be able to meet the needs of people with life threatening diseases by supporting them to live well and maintain a decent quality of life for as long as possible with minimal suffering and pain.

The Australian health system has changed radically over the past half century. Advances in medical care mean that we can now do more to treat illnesses and conditions that were once immediately fatal. Consequently, we live longer and die differently from those who lived 50 or 60 years ago.

The current misalignment between the orientation of the health system and the needs of people approaching the end of life creates challenges in ensuring that patients, and their families and carers, have the best possible experience. These challenges exist at all levels from the individual patient to communities, health practitioners and care systems. In part they emerge as a consequence of our difficulty in facing the reality of death, talking about death and dying and communicating with those who are approaching the end of their life.

These challenges also arise from whole-of-health system structural barriers that are associated with health system fragmentation and a complexity of funding responsibilities and performance accountabilities between governments. They are further compounded by little common understanding or agreement between states and territories, or for that matter, within the health sector, as to the most effective ways to provide palliative and end of life care services.

4.1. Living longer

Australians are living longer than they did a century ago. Overall life expectancy is increasing in Australia and other developed countries. Improvements in public health and advances in medicine have increased life expectancy so that a child born in Australia in 2006 can, on average, expect to live to 81 years (for males it is 79 years, for females, 84 years).²⁵

Australia has the joint third highest life expectancy for females and joint fourth highest life expectancy in the world for males. In Australia, as in most countries, female life expectancy is higher than in males.²⁶ There is a gap of approximately 16 years in life expectancy between Indigenous and non-Indigenous Australians.²⁷

²⁴ Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks. The Irish Hospice Foundation 2008.

²⁵ AIHW, Australia's Health 2010, Australian Government. 2010.

²⁶ Ibid

²⁷ Ibid

Population ageing and the implications it presents for care towards the end of life are major public health issues for the 21st century. Some of the implications of living longer include increased demand for, and use of, health services and particularly aged care services. The ageing population is expected to contribute to significantly increased spending on health care over the next 40 years.²⁸

The significance of our ageing population to aged care, and the demand on aged care services for palliative care, is substantial and will intensify with the expected increases in the proportion of the population aged over 65 years. Over the next 40 years, the proportion of the population over 65 years will almost double to around 25%. The number of Australians aged 65 and over is expected to increase rapidly, from around 2.5 million in 2002 to 6.2 million in 2042. For Australians aged 85 and over, the growth is even more rapid, from around 300,000 in 2002 to 1.1 million in 2042.²⁹

It is not yet entirely clear whether increased longevity is inevitably accompanied by longer periods of disability towards the end of life. Some recent findings and predictions suggest an optimistic picture, with disability declining in successive cohorts of people as they age. However, if more people live to older ages, and if chronic diseases become more common with age, then the numbers of people in a population living with their effects will increase. This means that there will be more people needing some form of help towards the end of life. Australia must begin to plan now to meet the needs of ageing populations for care towards the end of life.

4.2. The changing face of disease in Australia

A century ago most people died from infectious disease and injuries. The capacity of modern medicine to cure many communicable diseases has changed our attitude towards disease and illness. Today, we are now more likely to die from a range of chronic or non-communicable diseases like heart disease, diabetes, dementia, chronic obstructive pulmonary disease (COPD), stroke, cancer or others.³⁰

In line with the ageing of the population, the pattern of diseases that people suffer and die from is also changing. Increasingly, more people die as a result of serious chronic disease, and older people in particular are more likely to suffer from multi-organ failure towards the end of life.

In Australia, deaths from dementia related illness have increased 138% since 1999. The proportion of people with dementia is projected to increase from about 230,000 in 2008, to 465,000 in 2030, and to over 730,000 in 2050. This chronic disease alone will put extraordinary demands on palliative care services.^{31,32}

²⁸ AIHW, *Australia's Health 2010*, Australian Government. 2010.

²⁹ Australian Bureau of Statistics. Australian Government.

³⁰ AIHW, *Australia's Health 2010*, Australian Government. 2010.

³¹ AIHW, *Australia's Health 2010*, Australian Government. 2010.

³² *Alzheimer's Australia, Fact sheet*, 2011.

Health care systems must place much greater emphasis on the care of people of all ages who are living with, and dying from, a range of serious, complex chronic diseases.

4.3. How many Australians die each year and where?

During 2010, there were 143,500 deaths (73,500 males and 70,000 females) registered in Australia. From 1990, the number of deaths registered has increased by about 0.6% per year on average for males and 1.2% per year for females, with year-to-year fluctuations. The steady increase in the number of deaths over time reflects the increasing size of the population and, in particular, the increasing number of older people. With the continued ageing of the population, the number of deaths is projected to continue to increase throughout the middle of the century. It is projected that by 2056, the death rates will more than double to over 320,000 registered deaths per annum.^{33,34,35}

People aged over 65 years account for 79% of all deaths, and those aged over 80 for just over half of all deaths (51%). The median age at death was 77.9 years for males and 83.9 years for females. While the majority of deaths occurred in older people, younger people also experience life threatening illnesses.³⁶

Most people will say that they want to die at home, in whatever way they consider 'home' to be. However, the reality is that most people will eventually die in an institutional setting. Many factors influence the actual place of death for an individual and for some, their desire to remain at home will change as their illness progresses. A number of studies about place of death have reached similar conclusions.^{37,38,39}

As the Australian population ages, we can expect that more people will require residential aged care and many will die there. The population of residential aged care facilities (RACFs) is expected to increase by 70% in the next 30 years. Currently, almost one quarter (24.6%) of permanent residents of RACFs die within six months of admission, and 45.5% will die within one year. Currently about 35% of all deaths occur in RACFs.⁴⁰

³³ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

³⁴ Australian Bureau of Statistics, Deaths Australia 2010, Cat No. 3302.0.

³⁵ AIHW, *National Mortality Database*. Australian Government.

³⁶ Ibid.

³⁷ Tabor, B et al., *Place of death of people with cancer in NSW*. Sydney. Cancer Institute NSW, 2007.

³⁸ Steinhauser, KE et al. 2000, 'Factors considered important at the end of life by patients, family, physicians, and other care providers'. *Journal of the American Medical Association*, vol. 284.

³⁹ Smith, RA, 2000, 'A good death'. *British Medical Journal*, vol. 320.

⁴⁰ Parker et al 2010. Implementing and evaluating a comprehensive model of palliative care in residential aged care facilities. Report to Department of Health and Ageing.

4.4. The cost of growing old

Australian government spending on aged care is also projected to rise between 2009 and 2050 from 0.8% to 1.8% of GDP. Growth in spending on residential aged care (e.g. nursing homes and hostels) is the main contributor to the increase, reflecting the expectation that the number of Australians aged 85 years or older will more than quadruple over the next 40 years.⁴¹

Spending on community aged care (i.e. care provided to people in their own homes) is also projected to rise significantly. Population ageing is the primary driver of increased aged care spending to 2050, accounting for two thirds of the projected increase in real spending on aged care per person.⁴²

Australian government spending on health is projected to rise from 4.0% of GDP in 2010 to 7.1% in 2050. Not all of this projected increase in health spending is attributable to population ageing. Expected technological advancements in health, and demand for higher quality health services by people of all ages, are also expected to contribute to greater spending on health.⁴³

4.5. Attitudes to death and dying

Our attitudes to death and dying are shaped by a range of historical and cultural perspectives to disease and illness, spiritual beliefs of family and community, and by individual and collective experience of grief and loss through war, accident, displacement and disaster. These influences have shaped the way we think about death and dying and how we organise care at the end of life.^{44,45}

A century ago most people were cared for while sick at home and some died from their illness. Today most seriously ill people are treated in hospital. As a result, fewer people in the community have direct experience of caring for those who are ill or dying.

4.6. Access to palliative care

Australia is a geographically large and diverse country. Where we live can influence how we live; the number, type, access to and quality of services and other resources.

Employment patterns and social mobility have changed our community structures. Social isolation is more common today compared to a century ago as people may no longer live near their family or have less time to develop social networks and to build and sustain social capital.

⁴¹ Australian Bureau of Statistics, 2012, Australian Government.

⁴² Ibid

⁴³ AIHW, Australia's Health 2010, Australian Government. 2010.

⁴⁴ Rhee, JJO et al. 2008, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners'. *Journal of Palliative Medicine*, vol. 11.

⁴⁵ Knauff, E et al. 2005, 'Barriers and facilitators to end-of-life care communication for patients with COPD'. *CHEST*, vol. 127.

At the same time, there is a growing sense within our society of the individual as a health consumer, with the patient and family being active contributors to health decisions and practices from pre-birth to death and post death bereavement. Much of what makes an individual a discerning health consumer is dependent on the individual's level of health literacy. This is particularly so in understanding a specialised area of health care like palliative care. Affordable access to medicines can be an important part of palliative care. Medicines used in palliative care are available under the Pharmaceutical Benefits Scheme (PBS).^{46,47}

People living with a life threatening illness may require different types of care and approaches to care and support, depending on their disease, where they live, or other characteristics such as age or culture.

When groups with particular needs are identified, special care processes may be developed. Some of the groups that have specific palliative care needs include older Australians, those with dementia and other non-malignant illnesses, children, people living in rural and remote Australia, people from a low socioeconomic background, homeless people, those with a physical or intellectual disability, Indigenous Australians and those from other cultural backgrounds. There is evidence to suggest that a range of groups have unmet palliative care needs.^{48,49,50,51,52,53,54}

Access to quality palliative care and by inference a 'good death' is also dependent on how many health practitioners and other carers are trained in or have the right skill base to provide quality care at the end of life. Training and development of a skill base in palliative care is dependent on tertiary education institutions providing appropriate palliative care courses. Where those institutions are located, what they teach and the level at which the subject is taught, has a significant influence on the numbers and availability of a trained palliative care workforce.

⁴⁶ Department of Health and Ageing, Australian Government, www.pbs.gov.au

⁴⁷ National Prescribing Service and Palliative Care Australia, *Achieving quality use of medicines in the community for palliative and end of life care*, Canberra, 2009.

⁴⁸ Sullivan, K et al., *National Indigenous palliative care needs study: final report*, prepared for the Australian Government Department of Health and Ageing, Canberra, 2003.

⁴⁹ Sheenan, D and Schirm, V 2003, 'End-of-life care of older adults'. *American Journal of Nursing*, vol. 103.

⁵⁰ Rhee, JJO et al. 2008, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners'. *Journal of Palliative Medicine*, vol. 11.

⁵¹ Murray, S and Sheikh, A 2008, 'Care for all at the end of life'. *BMJ*, vol. 336.

⁵² Skilbeck, J and Payne, S 2005, 'End of life care: a discursive analysis of specialist palliative care nursing'. *Journal of Advanced Nursing*, vol. 51.

⁵³ Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia: Report to Support Australia's First National Primary Health Care Strategy*.

⁵⁴ Palliative Care Australia, *A Guide to palliative care service development: A population based approach*, Canberra, 2005.

4.7. Planning for a good death

Providing comprehensive care requires an understanding of the specific needs and circumstances of the individual patient. Advance care planning is one mechanism that can support discussion and decision making regarding care options.

Of the 143,500 or so people who die each year in Australia, half are expected deaths. All Australians should be supported to consider, and provided the opportunity to specify, the type of care they would like to receive at the end of life. Continual reassessment of current circumstances and likely future scenarios are part of this consideration. Advance care planning offers everyone, and especially people living with a terminal condition, their families and significant others, the opportunity to take control of decisions which affect their care and provide an opportunity for a dignified death.

4.8. Who provides palliative care?

Palliative care within Australia is provided by many different health practitioners in a variety of health settings and in the community. Palliative care in Australia has often developed in response to local needs using different service models.

A key feature of palliative care is that care is provided by a multidisciplinary team. The team's focus is to optimise the patient's comfort and maintain a quality of life. Many different disciplines and professional groups contribute to palliative care individually and as part of multidisciplinary care teams. Those involved in palliative care may include:

- Specialist providers: Medical, nursing and allied health staff who have undertaken further study in palliative care or have significant experience in the area.
- Generalist providers: Those clinicians (medical, nursing and allied health) working in other areas of the health system who have a professional involvement with people requiring palliative care.
- Support services: Including those who assist with the processes of daily living, enhancing quality of life, and/or providing emotional and spiritual support.

Because palliative care sees an increasingly wide range of conditions in patients at various stages of their illness, it follows that palliative care teams offer a wide range of care. This may range from managing the physical symptoms in patients receiving treatment for cancer, to treating depression in patients with advanced disease, to the care of patients in their last days and hours. Much of the work involves helping patients with complex or severe physical, psychological, social, and spiritual problems. Most hospice organisations offer grief counseling to the patient's partner or family.

Specialist palliative care services provide care to those patients with life threatening illness whose needs exceed the capacity and resources of primary health care

providers. However, specialist palliative care services act not only as a direct provider of care, but also as a resource and support for primary health care providers.

Most people living with a life threatening illness will have intermittent involvement with a specialist palliative care service. These services provide assistance as needed in association with primary health care providers. For a smaller number of patients with symptoms needing careful management, there may be the continuing involvement of a specialist team.

Palliative care services offer inpatient care, home care, day care, and outpatient services, and work in close partnership with mainstream services. Hospices often house a full range of services and professionals for both paediatric and adult patients.

Palliative care is a complex healthcare area, requiring an understanding of many different clinical and social fields and academic disciplines, which can add to the complexity of professional practice.

The palliative care workforce like other areas of the health workforce and the population in general is ageing.

Carers, both family and volunteers, are crucial to the palliative care system. Carers and patients often form lasting friendships over the course of care. As a consequence, carers may find themselves under severe emotional and physical stress. Opportunities for carer respite are some of the services hospices provide to promote carer wellbeing.

4.9. Who receives palliative care?

Palliative care is provided to people of all ages who are dying, and to their family, carers and loved ones. Some of the common medical conditions of people receiving palliative care include cancer, HIV/AIDS, motor neurone disease, muscular dystrophy, multiple sclerosis and end stage dementia.

Cancer is the most common principal diagnosis related to palliative care accounting for 31,450 of the 52,347 palliative care cases, or approximately 60%, of those reported in 2008-2009. Cardiovascular disease as the principal diagnosis accounted for 4,273 cases and respiratory related disease accounted for 4,192 cases. For diseases other than cancer, the two most frequently reported principal diagnoses were heart failure and COPD, each accounting for 2% of inpatient palliative care separations.⁵⁵

Although palliative care is closely associated with cancer patients, other diseases are considered to be amenable to palliative care with nine such diseases classified by the Australian Institute of Health and Welfare (AIHW) including heart failure, COPD,

⁵⁵ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW

renal failure, motor neurone disease, liver failure, dementia and Alzheimer's disease, Parkinson's disease, Huntington's disease and HIV/AIDS.^{56,57}

It is expected that within the next decade or two the numbers of people developing chronic diseases other than malignant cancer will more than double as a result of Australia's increasing ageing population and the impact of health behaviours and lifestyle choices. This will impact significantly on the numbers of people requiring palliative care. There is room for research in this area before any definitive position can be taken on resource allocation to palliative care in the expected tide of deaths over the next few decades associated with a range of chronic diseases.⁵⁸

Opening up palliative care to the wider range of life threatening chronic diseases has implications for the way palliative care is perceived and provided 'upstream' to integrate into the care of people at the earlier phases of a life threatening disease - in keeping with the WHO definition of palliative care. This would help address the apparent confusion around 'what' constitutes a palliative care patient.

Families and carers also receive support from palliative care services. Families provide much of the care for people who are dying, and practical and emotional support for them in this role is critical.

4.9.1. Differences by hospital characteristics

Information from the AIHW indicates that for people diagnosed with cancer as the principal diagnosis, a higher proportion of them were admitted to public hospitals rather than private hospitals in the lead up to their death (74% and 57% respectively).

This was particularly the case in the ACT, Northern Territory and Victoria (88%, 83% and 82% respectively). This contrasts with Western Australia, where data shows that palliative care patients with a principal diagnosis of cancer made up 80% of those who died in private hospitals. This contrasts with less than half of those with cancer as a principal diagnosis who died while in admitted patient care in a private hospital in New South Wales or Victoria (44% and 48%, respectively).⁵⁹

4.9.2. Differences by Indigenous status

Indigenous Australians are less likely to be diagnosed with cancer than non-Indigenous Australians. However, it is often suggested that when Indigenous people are diagnosed, the cancer is likely to be at a more advanced stage and this may increase the need for palliative care services.⁶⁰

⁵⁶ Ibid

⁵⁷ Murray, SA et al. 2005, 'Illness trajectories and palliative care'. *BMJ*, vol, 330.

⁵⁸ McNamara, B et al. 2004, *Who receives specialist palliative care in Western Australia—and who misses out*, University of Western Australia.

⁵⁹ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

⁶⁰ Ibid.

Studies suggest that existing services are not culturally appropriate and that this adversely impacts usage by Indigenous people. However, while there is limited research on this topic, studies suggest that these cultural differences are not reflected in the practice of palliative care among Indigenous Australians and non-Indigenous Australians in the period leading up to death.⁶¹

There is room for more research in this area before any definitive position can be taken on the appropriateness, quality and effectiveness of palliative care in Indigenous communities.^{62,63,64,65}

4.9.3. Differences by geographical remoteness

Evidence suggests that cancer patients who live in more regional and remote areas are less likely than their urban counterparts to have accessed palliative care services. Studies suggest that people's access to palliative care is influenced by distance from health services.^{66,67,68,69,70}

These studies are supported by data that shows a higher proportion of cancer patients who live in a major city were palliative care patients before they died compared to patients who live in remote areas (73% and 52% respectively).^{71,72,73}

⁶¹ Prior, D 2009, 'Bridging the gap of inequities—Indigenous Australians'. *EoL*, vol. 1(2).

⁶² National Rural Health Alliance 2006, *The health of Aboriginal and Torres Strait Islander Australians*, Canberra.

⁶³ Maddocks and R Rayner, 'Issues in palliative care for indigenous patients', *Medical Journal of Australia*, vol. 179, no. 6 supplement, 2003.

⁶⁴ Sullivan, K et al. 2003, *National Indigenous palliative care needs study: final report*, prepared for the Australian Government Department of Health and Ageing, Canberra.

⁶⁵ National Aboriginal Community Controlled Health Organisation 2008, *Our guiding principles*, Canberra.

⁶⁶ Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*.

⁶⁷ B Pink and P Allbon, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*. Australian Institute of Health and Welfare, Canberra, 2008. National Rural Health Alliance.

⁶⁸ Maddocks and R Rayner, 'Issues in palliative care for indigenous patients', *Medical Journal of Australia*, vol. 179, no. 6 supplement, 2003, pp. S17-S19.

⁶⁹ P McGrath and H Holewa, 'Seven principles for Indigenous palliative care service delivery: research findings from Australia', *Austral-Asian Journal of Cancer*, vol. 5, no. 3, 2006, pp. 179-186. 7 Resource Kit, 2004

⁷⁰ *The health of Aboriginal and Torres Strait Islander Australians*, National Rural Health Alliance, Canberra, 2006.

⁷¹ White, K et al. 2004, 'Out of sight out of mind: reframing remoteness in providing palliative care in remote Australia'. *Collegian*, vol. 11(3).

⁷² AIHW 2001, *It's different in the bush—a comparison of general practice activity in metropolitan and rural areas of Australia, 1998–2000*, Canberra.

⁷³ Phillips, J et al. 2006, 'Enhancing palliative care delivery in a regional community in Australia'. *Aust Health Rev*, vol. 30.

4.9.4. Differences by socioeconomic status

People living in areas classified as having the lowest socioeconomic status account for a relatively higher proportion of palliative care compared to those classified as living in higher socioeconomic conditions. Males account for more than 50% of the care across the socioeconomic spectrum except in the highest socioeconomic status area where males and females accounted for similar numbers.⁷⁴

Information from AIHW indicates that for people whose principal diagnosis was cancer, living in areas in the highest socioeconomic status group were, more likely (75%) than those living in other areas to have been a palliative care patient during their final hospital stay. Conversely, those patients with a principal diagnosis of cancer who lived in areas in the lowest group (67%) were less likely to have been a palliative care patient during the hospitalisation that ended with their death.⁷⁵

4.10. Who pays for the care?

The *National Hospital Morbidity Database* (NHMD) provides information about the main funding sources for health care (admitted patients separations). In 2008-2009, 77% of palliative care was for public patients; 16% of these cases were funded by private health insurance and 7% by the Department of Veterans' Affairs.⁷⁶

There are marked differences in funding sources for palliative care in public hospitals across jurisdictions ranging from 68% public funding in New South Wales to 96% public funding in the Northern Territory. The proportion funded by private health insurance ranges from less than 1% in the Northern Territory to 23% in New South Wales.⁷⁷

The main funding source for palliative care in private hospitals is significantly different from that in public hospitals. Private health insurance pays for 54% of palliative care in private hospitals of which 31% is for public patients, and the Department of Veterans' Affairs funds 12%.⁷⁸

There are also clear differences in the main funding source by jurisdiction in private hospitals. For example, the proportion of palliative care which is designated for public patients and provided in private hospitals ranges from less than 1% in Victoria to 61% in Western Australia.⁷⁹

In the work undertaken by the AIHW in estimating funding for palliative care, there is an obvious gap, acknowledged by the AIHW, in our understanding about unmet

⁷⁴ Palliative Care Australia 2005, *A Guide to palliative care service development: A population based approach*

⁷⁵ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

⁷⁶ National Hospital Morbidity Database. Australian Government.

⁷⁷ Ibid.

⁷⁸ Ibid.

⁷⁹ Ibid.

demand for palliative care services. For example it would be useful in terms of service planning to compare those who were palliative care patients with those who could have benefited from being such a patient at the end of their life.^{80,81}

4.11. Where are palliative care services provided?

Palliative care services can be provided in various settings: the home, in community based settings like nursing homes, RACFs, palliative care units, hospices and in hospitals. People who are dying need to be able to move freely between these places in response to their medical care and support needs.

The pattern of care will be different for every person and may depend on factors like geography, availability of services in an area, and the needs and desires of the person, family and carers.

The AIHW estimates that in 2008-2009, 68% of palliative care provided in an admitted setting was for people whose usual place of residence was in a major city; 21% lived in an inner regional area, 10% an outer regional area, and 2% in a remote or very remote area.⁸²

4.12. Where do people die?

There is no single national collection that provides information on where people die in Australia. However, data from the NHMD can be used to examine what proportion of all deaths occurred within admitted patient settings.

Of the 143,500 or so deaths in Australia, the NHMD estimates that 52% of these died as an admitted patient in an Australian hospital. This proportion includes deaths that occurred in hospices that were affiliated with hospitals. However, data is not available in the NHMD on the number of deaths that occurred in a hospice rather than elsewhere in the hospital system.^{83,84}

4.13. A palliative care approach is good public health

The key feature of a palliative care approach is the incorporation and action of multidisciplinary teams providing individualised, needs based, evidence based, holistic care to a person with a life threatening disease. It is concerned with the suffering, the dignity, the care needs and quality of life for people, along with the care and support of their families and friends. This type of holistic care, which incorporates the patient in the context of their everyday life, not just their disease

⁸⁰ AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

⁸¹ Australian Government National Health and Hospitals Reform Commission 2009

⁸² AIHW 2011. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

⁸³ Tabor, B et al. 2007, *Place of death of people with cancer in NSW*. Sydney. Cancer Institute NSW.

⁸⁴ Hunt, RW et al. 2001, 'Where patients with cancer die in South Australia 1990–1999: a population based review'. *Medical Journal of Australia*, vol. 175.

state, places palliative care firmly within a public health framework and delineates palliative care as a key factor in providing good public health.

Health care systems need to be flexible in their response and perceptions about care towards the end of life. Traditionally, palliative care in Australia has been offered most often to people suffering from malignant cancer, partly because the course of the disease has been more predictable making it easier to recognise and plan for the needs of patients and their families.

However, the emerging needs of people living with serious chronic disease, together with new evidence for the effectiveness of palliative care, means that it should now be offered more widely and integrated more broadly across the health care sector. Palliative care needs to be core business for the health care sector, in keeping with its role as a key factor in public health.

Placing palliative care within a public health framework enables it to identify and act on the social, environmental and behavioural determinants of health and health service delivery in Australia. These approaches identify groups that may have differential access to resources and services, or who may have specific needs in ensuring equitable care.

4.14. Efficient and effective palliative care makes good public policy

The relative neglect of palliative care in health policy in Australia presents urgent public health challenges. Not being able to meet these challenges will have serious consequences for palliative care; the health care system; and for the person with a life threatening illness, their family and carers. So, what would it mean if we don't meet the challenge?

- Australia's ageing population is placing a greater burden on palliative care services and the health care budget which means Australia will have to urgently address the aged care agenda as set out in the Productivity Commission report *Caring for Older Australians*.
- An ageing, under skilled and underrepresented health workforce in palliative care means many people will die without dignity and in pain.
- An under resourced palliative care workforce with less than optimum training in palliative care means poor quality palliative care.
- Low levels of awareness and general discussion in the community about death and dying means our wishes to die in a place of our own choosing and with the desired type of care, will not be fulfilled.
- People's wishes to die at home not being met means inappropriate referral to acute care settings to die in emergency rooms adding to the cost of care.

- A lack of awareness in the health sector about death and dying means inappropriate and less than optimal care.
- An under-funded and under-resourced palliative care sector means fewer options available for a 'good death' – dignified and pain free.
- Under-resourced and poorly targeted palliative care research means less social and translational research to inform effective, efficient and appropriate care.
- Inequitable resource distribution and access problems in palliative care means a significant proportion of the Australian population misses out on quality palliative care.
- Low levels of palliative care services provided to Indigenous communities means exacerbated health care issues.
- Low levels of palliative care services provided in many CALD populations means exacerbated health care issues.

PART B: Addressing the Senate Terms of Reference

1. The factors influencing access to and choice of appropriate palliative care that meets the needs of the population.

General Comments on Access

There are a number of factors that contribute to less than optimal access to quality palliative care in Australia and present a range of contemporary issues and challenges for health practitioners, health service program managers and planners, policy makers and researchers. They include:

- Australia's geographic diversity – the sheer size of the country influences how we live, the number, the type, access to and quality of services and other resources. The more rural and remote areas of the country compound the issue of access to quality palliative care.
- An individual's awareness and level of health literacy in relation to death and dying contributes to the level of access as does socioeconomic status, ethnicity and cultural background. Breaking the taboo of talking about death and dying is essential to making care at the end of life everyone's business. It enables the person to appreciate the value of communication and conversations with family and carers about what they need for a good death and planning for it well in advance.⁸⁵
- The number of health practitioners and other carers trained in or having the right skill set to provide the right type of care, in the right place, at the right time, are contributing factors to quality care, as is where these numbers of individuals are located.⁸⁶
- The inability or unwillingness of health practitioners to recognise those who are dying and treat them appropriately. Part of the problem is that health practitioners have the ability and the strongly held desire to treat and cure. Our systems of care and training limit our capacity to recognise that a person is dying, a journey that may have begun decades earlier with the emergence of chronic health problems. Another part of the problem is the lack of understanding of the indistinct boundary between chronic and complex health care problems, ageing and dying.
- A common meaning of and understanding about palliative care and how it is able to support, provide comfort to and enhance the quality of life for the dying person would assist greatly in its practice; as would a single definition to replace the many current definitions of palliative care.

⁸⁵ Australian Commission on Safety and Quality in Health Care 2009.

⁸⁶ Australian Health Workforce Advisory Committee 2005, *A Models of Care Approach to Health Workforce Planning*, Health Workforce Information Paper 1.

- The number of educational institutions providing courses in palliative care, their quality and the number of students taking up courses is another factor, as is the availability of training to upskill existing health professional in palliative care.
- A key determinant of the ability to access services is the influence of culture and ethnicity on end of life care, both from the perspective of consumer and carer choices, and the cultural competencies of health care providers.^{87,88,89}
- Many of the problems associated with the effective provision of end of life care, and indeed the management of complex and chronic cases in general, relate to barriers that occur at the interfaces between settings, between services and between health care professionals. There is an urgent need to get the interfaces right and address service fragmentation.^{90,91}
- Without relevant, timely information and data it is not possible to undertake informed decision making about service delivery, assess current practice or indeed enable assessment of the impact of improvement efforts. High quality information is a key lever for change.
- The challenges in meeting the future development needs of the specialist palliative care and wider health care workforce to provide high quality care to people approaching the end of life can be considered to be a subset of the broader challenges of developing a sustainable, skilled and adaptable workforce to meet the health needs of the Australian community. Nevertheless, this challenge is amongst the most crucial if we are to meet our obligations in providing optimal quality care and dignity to the needs of the dying person.^{92,93,94,95}
- The provision of high quality care at the end of life is not possible without adequate, appropriate, and equitable resourcing. Inadequate resourcing also fundamentally affects workforce distribution and this in turn affects the ability of patients and carers to gain access to a service, often resulting in suboptimal

⁸⁷ Lickiss, JN 2003, 'Approaching death in multicultural Australia'. *Medical Journal of Australia*; vol. 179.

⁸⁸ National Health and Medical Research Council 2005, *Cultural Competency in Health: A guide for policy, partnerships and participation*.

⁸⁹ Krouskos, D 2009, 'Equity—A view from the multicultural frontline'. *EoL*; vol. 1(2).

⁹⁰ Health System Reform and Care at the End of Life: A Guidance Document. 2010. National EOL framework Forum. PCA.

⁹¹ Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks. The Irish Hospice Foundation 2008.

⁹² Crawford, GB and Price, SD 2003, 'Team working: palliative care as a model of interdisciplinary practice'. *Medical Journal of Australia*; vol. 179.

⁹³ Segal, L 2009, 'Issues facing the future health care workforce: the importance of demand modelling'. *Australia and New Zealand Health Policy*, vol. 6.

⁹⁴ National Palliative Care Program 2005, *Principles for including palliative care in undergraduate curricula*.

⁹⁵ Australian Government Department of Health and Ageing 2009, *Primary Health Care Reform in Australia*.

outcomes. Funding and other resources need to support flexible models of care, rather than create barriers to them.⁹⁶

- A conservative culture within the palliative care sector, that sees the discipline as relevant to people with malignant cancer and the management of their pain, resulting in people with life threatening chronic diseases other than malignant cancer, sometimes unable to access palliative care.^{97,98}

All of the above factors and more lead to a 'poverty of access' to quality palliative care in Australia. Many of these factors are reflected in the experiences of PCA's member organisations.

1.1. People living in rural and regional areas

Urban and rural health disparities in Australia, including health status, life expectancy and prevalence of disease, are widely documented.⁹⁹

It is clear that those living in regional and remote areas, compared with major cities, generally have poorer health outcomes when compared on specific health status measures, such as life expectancy and the prevalence of chronic disease. The key health challenges impacting on the supply of health services for regional, rural and remote communities are dominated by:

- issues of poorer health outcomes compared to urban populations
- the burden of disease and injury is higher in rural areas
- inequitable access to health care in rural and remote areas
- resourcing for services is poorer in rural and remote areas
- cost pressures associated with distance and rural isolation
- inequitable distribution of health funding.

While it is clear that there are many economic, social and environmental factors that influence health outcomes in rural communities, primary health care has a central role to play in improving the quality of health services to rural and regional communities.

1.1.1. Higher burden of disease

National health status and disease burden research data shows life expectancy is one to two years lower in regional areas and up to seven years lower in remote areas compared with major cities. The prevalence of chronic disease data shows the

⁹⁶ Health System Reform and Care at the End of Life: A Guidance Document. 2010. National EOL framework Forum. PCA.

⁹⁷ Yohannes, A 2007, 'Palliative care provision for patients with chronic obstructive pulmonary disease'. *Health and Quality of Life Outcomes*, vol. 5.

⁹⁸ Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks. The Irish Hospice Foundation 2008.

⁹⁹ AIHW, Australia's Health 2010. Australian Government.

incidence of cancer is about 4% higher than that in major cities with significantly higher incidence rates for preventable cancers. Lifestyle risk factors or health behaviours are attributed to the burden of disease in these communities, with people in remote areas found to be engaging in more behaviours that carry health risks.¹⁰⁰

Cancer and heart disease are among the two leading causes of the burden of disease nationally, with an expected likely rise in the number of people with diabetes, mainly due to higher obesity levels and the ageing of the population. In terms of differentials, national data shows regional areas account for 33% of the burden and remote areas 2.5%, with males experiencing more of the burden than females. Of the ten leading specific causes, type 2 diabetes is the leading cause of burden in remote areas with Indigenous populations experiencing over 3 times the prevalence compared to non-Indigenous populations. The total burden per head of population increases with remoteness, with remote populations having a 26.5% greater burden than populations in major cities.

For regional, rural and remote areas the prevalence and burden of chronic disease is compounded by the availability of and access to health services. Geographical location impacts on transport, with access to appropriate transport services a major impediment to accessing health services in these areas. Generally, there is an under-supply of facilities and health care practitioners also impacting on service waiting times.

1.1.2. Challenges to health service provision

Many of the challenges facing metropolitan or urban communities are also shared by rural and remote communities but often are present to a greater degree through reasons of geography, cost and service availability. Many of these issues e.g. lack of specialists, nurses and allied health workforce are generic to the health system and require system-wide funding changes and integrated multi-stakeholder strategies to change the disincentives that currently limit access to services.

There is a lack of research literature on the issues that impact on the provision of end of life care in rural areas and remote communities. However, there is some evidence that rural and remote Australians receive poorer palliative care than those in urban areas. Population based admission rates to palliative care services are 30–50% lower in regional and remote locations than in metropolitan areas; GPs are more time pressured and dealing with specialist services and primary care providers can be problematic.

There are particular problems in accessing services after hours and on weekends with the associated issues of difficulties in assessing the patient's condition and uncertainties around symptom management. Poor choices for home care are impacted by families having limited knowledge about service availability and

¹⁰⁰ AIHW, Australia's Health 2010, Australian Government.

economic and physical barriers associated with distance. Access to allied health services, such as bereavement counselling and occupational therapists, are also challenging. Rural palliative care nurses also have difficulties in providing 24-hour care over vast distances. Access to appropriate palliative care is further exacerbated in communities with significant numbers of Indigenous people.

Equity is about equal access to services for equal need, equal use of services for equal need, and equal quality of care for all. Central to this is the recognition that not everyone has the same level of health or capacity to deal with their health problems, and it is important to deal with people differently in order to work towards equal outcomes. If a service is evidence based, cost effective, and available to the population, the government must plan to ensure it is accessible to all, irrespective of where people live. Unfortunately, many services are not available in rural and remote areas so patients have to travel to access the services. Transport is a social determinant of health and is intricately linked to access to health services and therefore health outcomes.

1.1.3. Transport and access to services - Patient Assistance Travel Scheme (PATS)

The Australian healthcare system is based on the principle that all Australians are able to have the same equity of access to the same level of health care regardless of where they live. Ensuring access for all Australians to high quality needs based palliative care is also a key aim of the Australian Government *National Palliative Care Strategy 2010*. Appropriate care is critically important in supporting and maintaining quality of life for people who are dying. It is also crucial in enabling families to come to terms with the death and to continue functioning as part of community and society.

Every state and territory health department in Australia has a scheme in place to enable patients to access treatment not available at local level. The Patient Assisted Schemes (PATS) are designed to assist patients through a form of a subsidy towards the cost of travel to a specialist, and accommodation costs associated with that journey. Many rural and regional patients have to travel to the city or regional centres for medical treatment because the type of treatment is not available locally.

The need to be away from home due to illness can result in financial and other burdens for many families. Cancer patients, in particular, often face enormous difficulty arising from the need for radiotherapy, which is only available in large metropolitan centres, and must be delivered to patients daily for several consecutive weeks.

Although PATS serves a basic purpose, there are a number of issues that make it less than equitable and less effective than it should be in rural remote communities. This includes the need for PATS to be better marketed to health service practitioners, including GPs; better access for Indigenous patients and provision for the definition of escorts to include family members; transport and accommodation assistance for all treatments listed on the Medicare Benefits Schedule; development of a system

that incorporates both eHealth and PATS; streamlined administration of the schemes through the adoption by all jurisdictions of a pre-payment system (vouchers, tickets or advance bookings) and a reduction in the amount of paperwork required to be filled out (such as one form covering all episodes of care).

1.1.4. Uniqueness of rural and regional areas

While the defining characteristic of rural health remains its geography (and related issues of access to health care services) rural and remote Australia is also sociologically, culturally, economically and spiritually different from metropolitan areas, as well as internally diverse.^{101,102}

There is significant agreement across the literature that rural and remote communities are not homogenous; each community is unique and there are different social constructs relating to rural and remote communities, such as self-reliance and independence that needs to be factored into how palliative and end of life care services are planned for and provided. Models of care need to be flexible and responsive to local circumstances and community capacity with the ability to leverage the well coordinated relationships often found between rural and remote primary health care providers.

The evidence suggests that a population based approach to palliative care service development based on local need and capacity is the most appropriate framework for the delivery of effective and efficient palliative care in rural and regional areas .

Rural health care needs better targeted interventions to address the barriers and issues identified above which are specific to regional, rural and remote areas. To assist it to do so, there should be quarantined funding for rural and remote health care in all initiatives based on local needs assessment which must include end of life and palliative care services.

1.1.5. Workforce incentives and retention

There continue to be attempts by governments to attract and retain health practitioners to the workforce and in particular to the rural and remote areas of the country. Some examples include the Australian Government's *Rural Health Workforce Strategy*, which provides investment and incentives for GPs to locate and remain in rural and remote areas of the country, as does the *Rural Retention Program*. For nursing and allied health, the Nursing and Allied Health Scholarship and Support Scheme offer incentives for a range of health professionals. However, in spite of these and other mainly financial incentives, retention of health practitioners in rural and remote areas remains problematic.

¹⁰¹ AIHW 2001, *It's different in the bush—a comparison of general practice activity in metropolitan and rural areas of Australia, 1998–2000*, Canberra

¹⁰² AIHW. Australia's Health 2010. Australian Government.

The shortage of health practitioners is not just confined to Australia. It is a global problem particularly in rural and remote areas with negative consequences for health service accessibility and health outcomes in the affected population.^{103,104} In Australia, the rural health workforce shortage results from many factors, including inadequate workforce policies, changing patterns of employment, rationalisation of rural health services and changes in the nature of rural medical practice.^{105,106}

Since the early 1990s, Australian governments have responded to the rural workforce crisis with recruitment strategies and retention incentives designed to attract and keep health practitioners and in particular GPs in rural and remote regions. Unfortunately, there is little evidence that these incentives have made any significant difference to the workforce supply in underserved areas¹⁰⁷.

While considerable research has concentrated on health workforce recruitment strategies in Australia, much less attention has focused on the effectiveness of retention strategies¹⁰⁸. Good workforce retention contributes to ensuring the provision of high quality health care because it is usually associated with increased experience and skills among staff and greater continuity of care for patients.¹⁰⁹ In contrast, avoidable loss of employees can result in significant costs to the organisation, including loss of expertise and recruitment expenses.^{110,111}

Many factors influence the decision of a rural or remote area health practitioner to stay in or leave a job including financial and economic, professional and organisational issues of support and infrastructure, social factors such as housing, education and transport and support for families as well as the characteristics of the local community itself.¹¹²

What we know about workforce incentives and retention can be summarised as:

¹⁰³ Australian Government Department of Health and Ageing. *Report on the Audit of the Health Workforce in Rural and Regional Australia*. Canberra: Commonwealth of Australia, 2008.

¹⁰⁴ Productivity Commission. *Australia's Health Workforce, Research Report*. Canberra: Productivity Commission, 2005.

¹⁰⁵ Australian Government Department of Health and Ageing. *General Practice in Australia: 2004*. Canberra: Department of Health and Ageing, 2005.

¹⁰⁶ Kamien M. Staying in or leaving rural practice: 1996 outcomes of rural doctors 1986 intentions. *The Medical Journal of Australia* 1998; 169.

¹⁰⁷ Australian Government Department of Health and Ageing. *Report on the Audit of the Health Workforce in Rural and Regional Australia*. Op.cit.

¹⁰⁸ Ibid

¹⁰⁹ Garnett S, Coe K, Golebiowska K et al. *Attracting and Keeping Nursing Professionals in An Environment of Chronic Labour Shortage: A Study of Mobility Among Nurses and Midwives in the Northern Territory of Australia*. Darwin: Charles Darwin University Press, 2008.

¹¹⁰ Humphreys J, Wakerman J, Wells R et al. *Improving Primary Health Care Workforce Retention in Small Rural and Remote Communities – How Important Is Ongoing Education and Training*. Canberra: Australian Primary Health Care Research Institute, 2007.

¹¹¹ North N, Rasmussen E, Hughes F et al. Turnover amongst nurses in New Zealand's District Health Boards: a national survey of nursing turnover and turnover costs. *New Zealand Journal of Employment Relations* 2005; 30.

¹¹² Dussault G, Franceschini M. Not enough there, too many here: understanding geographical imbalances in the distribution of the health workforce. *Human Resources for Health* 2006; .

- Retaining health workers in rural and remote areas is a global problem.
- The costs associated with poor workforce retention are high.
- Although many rural health workforce incentive and retention strategies have been implemented, few have been rigorously evaluated.

A review of incentives and retention in the rural health workforce by Buykx et al¹¹³ found that the above financial, social and professional factors compound the decision of a health practitioner to remain in the rural workforce and that addressing them collectively rather than singularly and in a piecemeal fashion is more effective.

Summary

Rural and remote populations have a greater prevalence and burden of disease compared to metropolitan areas, which is compounded by the limited availability of, and access to, health services. There is an under supply of health facilities and health professionals which results in people from rural and remote areas experiencing poorer palliative and end of life care.

Governments must plan to ensure that palliative and end of life care services are available to all Australians, regardless of where they live, and models of care developed for rural and remote communities need to be flexible and responsive to local needs, taking into account their uniqueness and diversity.

Recommendations:

- 1. That funding be quarantined for rural and remote health care that incorporates palliative and end of life care in all appropriate initiatives.**
- 2. That the profile of the Patients Assistance Travel Scheme (PATS) be raised through increased marketing and promotion of the scheme in all jurisdictions to boost awareness to patients and all health care practitioners including GPs.**
- 3. That access to and experience of the Patients Assistance Travel Scheme (PATS) be improved for Indigenous patients including expansion of the definition of 'escorts' and inclusion of them in the schemes.**
- 4. That telehealth services be supported and funded to link remote communities to specialist palliative care services.**
- 5. That national streamlining of the administration of the Patients Assistance Travel Scheme (PATS) be achieved through the adoption by all jurisdictions of a**

¹¹³ Buykx P, Humphreys JS, Wakerman J & Pashen D (2010). A systematic review of effective retention incentives for health workers in rural and remote areas: Towards evidence-based policy, *Australian Journal of Rural Health*, 18.

prepayment system (vouchers, tickets or advance bookings) and a reduction in the paperwork required to one page form covering all episodes of care.

6. That travel and accommodation assistance is made available for all appropriate treatments listed on the MBS (Enhanced Primary Care items).

7. That the Person Controlled Electronic Health Record links the Patients Assistance Travel Scheme (PATs) with treatment provided by GPs and other health care practitioners with access to the patient's PCEHR.

8. That national research on issues that impact on the provision of palliative care in rural areas and remote communities be funded and promoted.

1.2. Indigenous people

Indigenous communities in all parts of Australia have a close association with death and dying. In part, this is because death rates for Indigenous Australians are among the highest in the world. This is particularly so in the 25–45-year age range, where death rates are 5–8 times those of non-Indigenous Australians, leading to a life expectancy up to 19 years less than non-Indigenous Australians.¹¹⁴

An intimate awareness of death and dying is also facilitated by the close involvement of extended family in supporting a patient during terminal illness, and in the ceremonies that follow a death. Gatherings of family and the community may extend over several weeks.

Cultural considerations that need to be respected include Indigenous understandings of causes of disease, attributions of blame for sickness, the performance of ceremonies after death and the importance of dying on traditional lands.

Indigenous people use healthcare services reluctantly, and palliative care services rarely. However, it has been shown that the involvement of Indigenous health workers in clinical care increases confidence in the healthcare system as a whole.^{115,116}

1.2.1. Chronic disease and mortality

The health profile of Indigenous people is very different from that of other Australians. Indigenous Australians have poorer life expectancy, higher infant mortality - three times that of the general population - and adult mortality that is most marked in early adulthood to middle age. In contrast, the overall Australian population has one of the highest life expectancies in the world, relatively low infant mortality, and death rates for persons aged 35-44 and 45-54 years that are five times less than those recorded for Indigenous people.¹¹⁷

In 1999-2003, the three leading causes of death for Indigenous people resident in Queensland, South Australia, Western Australia and the Northern Territory were diseases of the circulatory system, external causes of morbidity and neoplasms. Appropriate palliative and end of life care can improve the end of life outcomes in the first and third of these diseases. Different disease challenges lead to different palliative care requirements and different models of care, for example the palliative care service in Alice Springs delivers much care patients suffering from end stage

¹¹⁴ AIHW. Australia's Health 2010. Australian Government.

¹¹⁵ A Cass, A Lowell, M Christie, P Snelling, M Flack, B Marrnganyin and Isaac Brown, 'Sharing the true stories: improving communication between Aboriginal patients and health care workers', *Medical Journal of Australia*, vol. 176, no. 20, 2002.

¹¹⁶ P McGrath, *The development of an innovative model for Indigenous palliative care service delivery*. National Rural Health Alliance.

¹¹⁷ AIHW. Australia's Health 2010. Australian Government

renal disease, who have significantly a different illness trajectory and care requirements than those with cancer.

Among the factors identified as significant contributors to the high levels of morbidity and the early age of death of Indigenous people are poor antenatal care, poor child health, chronic disease, poor housing, poor access to good food, poor education and lack of employment. There is also evidence to suggest that there is also a need to understand racism as a cause of ill health in Indigenous people.^{118,119,120}

1.2.2. Culture

Indigenous culture is dynamic and diverse across the Australian continent, both between different cultural traditions, and between urban and non-urban locations. The concept of cultural safety needs to underpin improvements in Indigenous palliative and end of life care. Fundamental to cultural safety is acknowledgment of cultural assumptions, lived experiences, Indigenous holistic concepts of health, and the historic context of illness, dispossession and racism. Health practitioners must be aware of these factors, prejudices and the historical power disparities it reproduces in health service delivery. Furthermore, the core essence of cultural safety is that the health professional understands their own cultural identity, and is aware of the impact their culture can have on another.

Different cultural expectations can lead to poor health outcomes if not fully recognised and addressed. A family meeting with health professionals to discuss a dying family member may involve a large group of relatives and associated community members. Lack of understanding of such a cultural requirement, and lack of prepared space to accommodate such a meeting, can lead to confusion, distrust, disempowerment, and ultimately to poorer quality end of life care.

1.2.3. Communication

A failure to understand or appreciate the cultural practices of Indigenous peoples leads to inappropriate and inadequate health care. Collaboration is a fundamental prerequisite in communication and building relationships which in turn underpin better Indigenous palliative and end of life care. Collaboration between staff and patients, staff from different disciplines and with different expertise, patients and their families, health workers and interpreters, is crucial in planning and implementing strategies for change to produce optimum outcomes.

¹¹⁸ AIHW. Australia's Health 2010. Australian Government.

¹¹⁹ Y Paradies, R Harris and I Anderson, *The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda*, Discussion Paper Series: No.4, Cooperative Research Centre for Aboriginal Health, 2008

¹²⁰ Australian Bureau of Statistics. Australian Government.

Studies have demonstrated that in discussions regarding management of kidney disease there was a significant lack of shared understanding, despite the cultural respect of the doctor. Given that death and dying are areas of even greater cultural diversity and taboos, it is vital that true understanding is achieved, preferably through the use of an interpreter where needed.¹²¹

Given the historical background of lack of trust by Indigenous Australians in mainstream health services, particular attention is needed to foster and sustain respectful, honest, trusting and productive relationships between consumers and providers. Service delivery models may need adjustment in order to ensure all involved have the time and space to create these relationships.

1.2.4. Geographical challenges

Around 2% of Australia's population is Indigenous. However, in the Northern Territory nearly 24% of the population is represented by Indigenous peoples with lower percentages in the more populated states of Western Australia, South Australia and Queensland. While the majority of this population lives on or near accessible highways, a minority live in remote areas that can be difficult to access. The provision of health care and palliative and end of life care in these areas can be challenging.

Indigenous people living in more rural and remote areas may have to travel to major centres for appointments and treatments. This may be their first time away from country. For many Indigenous people the principle of 'dying in place of choice' has a particular meaning: this is the concept of 'going home to country'. While logistically it may be enormously challenging for the patient, family and community to achieve, it has the potential to realise the greatest gain for patients, their families and communities at the end of life.

Living in some rural and remote communities poses special issues in the delivery of palliative and end of life care. These include issues related to the storage of medications and compliance, and the need for care providers to be aware that multiple health problems are more common among Indigenous people.

1.2.5. Workforce

Indigenous people are underrepresented both in the health workforce and among those with higher education health qualifications. In 2004, it was estimated that to achieve proportional representation in the health workforce would require a further 2,000 trained Indigenous health workers. Indigenous doctors, nurses, psychologists and social workers play an important role in palliative and end of life care. Indigenous Home and Community Care (HACC) workers and Indigenous health workers play a key role in providing appropriate community based care and in

¹²¹ Kate Anderson, Jeannie Devitt, Joan Cunningham, Cilla Preece and Alan Cass, "All they said was my kidneys were dead": Indigenous Australian patients' understanding of their chronic kidney disease *Med J Aust* 2008; 189 (9): 499-503.

liaising with other health care professionals involved in planning and delivering end of life services. There is great need for more Indigenous people working in these settings.^{122,123,124,125}

Much Indigenous healthcare is delivered by the community controlled sector. These services deliver holistic health care and therefore have a definite congruence with the delivery of palliative care, however are rarely closely linked with specialist palliative care services for consultation or education.

1.2.6. Information, education and training

There is an urgent need for the development and provision of palliative and end of life care education and training for Indigenous health workers and for staff based in Indigenous health care settings. Education in cultural awareness and Indigenous issues in palliative and end of life care, including bereavement care, should be provided to GPs, nurses and allied health staff as a specific module in undergraduate training and as ongoing professional development. The provision of information sessions about palliative and end of life care in Indigenous community settings is clearly important to assist in overcoming the misunderstandings which inhibit access to available services.

The Australian Government funded Professional Experience in a Palliative Approach (PEPA) program aims to improve the quality, availability and access to palliative care for people who are dying, and their families, by improving the skills and expertise of health practitioners, and enhancing the collaboration between service providers. The program is flexible and customised to local needs within each state and territory.

PEPA offers a tailored workshop for Indigenous health workers, designed for Indigenous communities, to help increase awareness in caring for people who are dying. It targets Indigenous health workers, community workers, liaison officers and elders with other members of the community able to attend workshops if requested. The program is underpinned by the principle of Cultural Respect. Ongoing evaluation of PEPA shows that the program is having a positive and sustainable impact on the confidence and skills of health professionals in the delivery of a palliative approach to care. It is therefore imperative that PEPA continue to be developed and resourced by the Australian Government to provide appropriate education for Indigenous health workers in palliative care.

¹²² P McGrath and H Holewa, 'Seven principles for Indigenous palliative care service delivery: research findings from Australia', *Austral-Asian Journal of Cancer*, vol. 5, no. 3, 2006.

¹²³ The Program of Experience in the Palliative Approach (PEPA) is an initiative of the Australian Government Department of Health and Ageing, funded through the National Palliative Care Program.

¹²⁴ Kimberley Interpreting Service, *Discussion paper: Indigenous language interpreting services*, Kununurra, 2004.

¹²⁵ K Sullivan, L Johnston, C Colyer, J Beale, J Willis, J Harrison and K Welsh, *National Indigenous palliative care needs study: final report*, Prepared for the Australian Government Department of Health and Ageing, Canberra, 2003.

1.2.7. Local strategies

Indigenous peoples have different cultures and histories and in many instances different needs. Nevertheless, all groups are affected by the problems that face them as unique Australians. The differences must be acknowledged and may need to be addressed by locally developed strategies. Local solutions must come from within the local community, with local consultation and local engagement. Without ownership by the community, engagement and sustainable improvements in the quality of end of life care are not possible.

Summary

The health profile of Indigenous Australians is very different from that of other Australians. Palliative care can, and should, improve end of life outcomes for Indigenous people.

Strategies to train more Indigenous workers in palliative care, and compulsory cultural awareness training for all health practitioners is needed. Cultural safety must underpin all improvements in palliative care for Indigenous Australians, as must community engagement and ownership of locally developed strategies to improve end of life care in Indigenous communities.

Recommendations:

- 9. That all policies, procedures and processes of health care must respect and reflect different cultural and ethnic values, beliefs and practices that surround death, dying and end of life care.**
- 10. That clear policies, procedures and mechanisms are established to support 'return to country' for Indigenous Australians who are approaching the end of their life.**
- 11. That commitment is made to education and training that builds the cultural competence and cultural awareness of Australia's healthcare workforce through undergraduate, postgraduate, vocational and continuing professional education, including:**
 - a. significant investment by government to increase the number, qualification levels and professional registration of Indigenous peoples in the health workforce;**
 - b. appropriate training and education about cultural perspectives relating to palliative and end of life care issues, in core curricula for all health workers and health practitioners providing services to Indigenous people;**

- c. inclusion of palliative and end of life related topics in the core curricula for Aboriginal health worker Certificate III and IV
- d. continuation of PEPA to build on or develop cultural appropriate education for Indigenous health workers.

12. That there is a commitment by service providers to work with Indigenous organisations to develop models of palliative and end of life care services appropriate to meet the needs of Indigenous people. This will require:

- a. fostering the practice of advance care planning and family case conferencing to involve the patients and broader family in decisions about culturally appropriate care;
- b. review of organisational policies that may hinder access to culturally appropriate palliative and end of life care;
- c. the development of organisational and service planning models which incorporate strategies and initiatives to address the identified equity and access issues which inhibit or prevent Indigenous people from benefiting from end of life services;
- d. all services to provide ongoing workforce training on the issues affecting the delivery of appropriate services to Indigenous people;
- e. the development and delivery of information in a culturally appropriate way to Indigenous people.

13. That there is support and funding of an increase in the availability and accreditation level of interpreters to communicate with the estimated 55,000 speakers of Indigenous languages, many of who may have English as a second, third or even fourth language.

14. That there is support and funding for culturally specific research on the nature of grief and bereavement in Indigenous communities and the implications for this in the development of appropriate support services.

15. That strong linkages between community controlled health services and specialist palliative care services be developed and fostered.

1.3. People from CALD backgrounds

Quality care at the end of life is realised when it meets the person's needs and upholds their preferences which are based on many factors including individual cultural beliefs. It is also realised when strong networks exist between specialist palliative care providers, primary and support care providers and the community working together to meet the needs of people.

The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for the patient, family, carers and community. As Australia's cultural diversity increases, cultural misunderstandings resulting in the provision of inappropriate end of life care to people from CALD backgrounds has the potential to grow. There can be issues with translators and medical interpreters where they do not feel able to honestly relay information due to their own cultural beliefs.

Respecting and being sensitive to people from CALD backgrounds and their community ties is integral to the delivery of quality care at the end of life. Cultural practices are not the sole determinants of patient preferences and there may be significant individual differences within communities.

The needs of older people from CALD communities, and new and emerging communities, raise broad equity and access issues. The cultural implications of patient autonomy in regard to decision making, acceptance and use of advance care directives, and truth telling must be understood and respected on a case by case basis.

All health practitioners must have a proactive engagement in CALD issues, and need a level of cultural competence when caring for people from different cultural backgrounds and the knowledge about when and how to consult further cultural expertise when needed.

The experience of care and the nature of death have as significant an influence on the subsequent grieving process of people from CALD communities as they do for people in the mainstream Australian community.

Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life. Culture, even for people who do not usually follow traditional practices, is particularly important in shaping attitudes about dying, death, and preference for end of life care. Clinicians also hold strong culturally determined beliefs about dying and death and these inform their practices in caring for people who are dying. Health care providers should recognise the basic values, principles, and assumptions of western medicine and bioethics are

themselves culturally determined and may be alien concepts to patients from different cultural backgrounds.^{126,127,128}

The concept of 'good', of what is beneficial and right for the patient, is influenced by the cultural framework from which the health professional comes and from their personal and professional experiences. These culturally informed actions can be in conflict with the desires of the patient. However, it is important to realise there can be a vast diversity within specific ethnic groups manifest through wide variation of beliefs and behaviours. Cultures are not static, but evolve over time.

As a result of profound worldwide demographic change, doctors and other health practitioners will increasingly care for patients from cultural and faith backgrounds other than their own. Australia is one of the most culturally diverse countries in the world and will remain that way for generations to come. In Australia, over 300 languages are spoken, more than 100 religions and beliefs are practised and many of the world's ethnic groups are represented, from over 230 different countries. Furthermore, Australia's ageing CALD population is experiencing more rapid growth than the general population. Today, it is estimated that over 1 million Australians over 65 are from CALD backgrounds.¹²⁹

Whilst there may be cultural specifics broadly applicable to people from similar cultural backgrounds, and these may guide the delivery of care:

'Patients should never be approached as empty vessels, as the bearer of particular cultures'.¹³⁰

Rather, patient care should be individualised, taking into consideration a range of factors.

*'Care is, in the end, given to a particular individual, here and now, in his or her time and place and particular circumstances.'*¹³¹

The concept of patient autonomy and patient directed care is a key principle in the Australian health context. This approach is not equally applicable across cultural groups and can thus cause ethical dilemmas for health practitioners who associate autonomy with the right to know. In some cases, physician and family based decision making may be preferred over patient autonomy: family duties and

¹²⁶ Keri Chater. Chun-Ting Tsai. Palliative care in a multicultural society: a challenge for western ethics *Australian Journal of Advanced Nursing*. 2009. Volume 26 Number 2.

¹²⁷ Diver, F. Molassiotis, A., and Weeks, L. 2003. The palliative care needs of ethnic minority patients: Staff perspectives. *International Journal of Palliative Nursing*, 9(8).

¹²⁸ Duffy, S. Jackson, F. Schim, S. Ronis, D. Fowler, K. Cultural concepts at the end of life. *Nurs Older People* 2006. 18:10–4

¹²⁹ Palliative Care Outcomes Collaborative 2009, *National Report on Palliative Care in Australia*.

¹³⁰ L Crawley, P Marshall, B Lo and B Koenig, 'Strategies for culturally effective end-of-life care', *Annals of Internal Medicine*, vol. 136, no. 97, May, 2002.

¹³¹ J Lickiss, 'Approaching death in multicultural Australia', *Medical Journal of Australia*, vol. 179, no. 6 supplement, 2000.

obligations take precedence. Diagnosis may be first conveyed to the family and indirect nuances preferred over truth telling in relation to prognosis. The patient may exercise the right not to know. Furthermore, tools and treatments considered integral to the provision of quality care at the end of life are not universally accepted. Advance care directives may be seen as prolonging autonomy when autonomy is not sought. There are also large variations in attitudes towards pain relief.¹³²

Other cultural considerations include the care setting – there may be strong resistance to institutionalised care; language and communication - English language skills are not universal and may be a second, third or more level of communication as the spoken language at home; the role of the family in caring may or may not be an integral feature in the family culture; diet and food may be an integral part of the dying process; personal care rituals may form part of specific cultural beliefs and religious practices.

Health practitioners need to understand each patient's view of their situation and their expectations of the mode of decision making and type of care that should follow. Cultural competence has been identified as constituting more than an awareness of a range of customs. Cultural competence includes communication issues, disclosure and consent; modes of decision making – how or when is the patient or family involved; the role of advance care planning; concepts of disease; the meaning of pain and other symptoms; ways of conceptualising death and dying in relation to the rest of life; customs surrounding death, burial or cremation, and bereavement; attitudes to medication especially opioid drugs and sedatives and to nutrition and hydration; privacy issues; spiritual matters, as well as religious issues, including rituals.¹³³

It is not realistic for health practitioners to understand the breadth of cultural beliefs in relation to illness. However, it is reasonable that they understand this in relation to populations they care for and have the skill to identify when they need further assistance and the pathways to access this assistance.

CALD communities may not have the same approach to health issues as the western medical system. These differences include individualism versus collectivism; definition of family; common views on gender roles and care of older adults; communication patterns including direct and indirect and nonverbal; views of physicians, suffering and afterlife.

From the community perspective, the capacity of CALD communities to interact positively with the health care system can be seriously hampered by a number of factors including lack of knowledge about available health and social services; fears

¹³² K Chater and C Tsai, 'Palliative care in a multicultural society: a challenge for western ethics', *Australian Journal of Advanced Nursing*, vol.26, no. 2, December 2008/February 2009

¹³³ J Lickiss, 'Approaching death in multicultural Australia', *Medical Journal of Australia*, vol. 179, no. 6 supplement, 2000.

the health care system will not understand and respect their health care needs; belief systems, and patterns of health service use; and low levels of literacy in English and first language.¹³⁴

In partnership with efforts to improve the cultural competence and responsiveness of the health system, much can be done to improve the capacity of CALD communities to interact positively with the health system through the provision of educational materials in community languages and the empowering of communities to provide information to the health system on culturally appropriate approaches to care.

Summary

The cultural diversity of the Australian community is increasing and with this, the potential of providing inappropriate palliative end of life care. Respecting the different beliefs, values and practices of people from culturally and linguistically diverse backgrounds is integral to providing good quality palliative care and avoiding unnecessary suffering.

All health professionals should have a level of cultural competence and proactively engage in cultural issues.

Recommendations:

- 16. That there is flexibility in delivery of palliative care to accommodate the care preferences of people from CALD backgrounds.**
- 17. That cultural liaison officers with the necessary skills, experience and knowledge about end of life care be trained and resourced.**
- 18. That support, development and provision of culturally appropriate health information and resources in a range of community languages be increased.**
- 19. That availability of, and support for, qualified and trained translators and medical interpreters who can ensure effective, efficient and reliable communication between health practitioners and patients, their families and carers, particularly at the end of life be increased.**
- 20. That protocols be developed for health practitioners to guide the use of interpreting and translation services, including addressing the issue**

¹³⁴ Federation of Ethnic Communities' Councils of Australia, *Improving health and well-being outcomes for Australians from culturally and linguistically diverse backgrounds*, Health policy statement, FECCA, Canberra, 2007.

of people not feeling able to honestly relay information due to their own cultural beliefs.

21. That research in the Australian context of the cultural implications for quality care at the end of life, to reliably inform policy and funding decisions be supported and funded.

1.4. People with disabilities

In 2003 the ABS estimated that 20% of the Australian population had some degree of disability of whom 6% had a severe disability. Many people with disabilities suffer from diseases that will eventually cause their death, the majority of whom are considered palliative care patients. There are issues for Australians with a disability accessing palliative care services which include:

- the inability to provide 'dying in place'
- family and carer burnout
- difficulty locating and accessing specialist palliative care services when required.
- very few services in rural and remote settings
- palliation is often a medically complex and lengthy process
- inability to access palliative care funding, due to the blurring of the line between disability and palliation
- inability to access funding for specialised palliative care equipment.

People with disabilities are often referred to a palliative care service prematurely and have complex needs that do not fall within the current scope of palliative care. Inappropriate referral to a palliative service often arises from the health system that has limited funding streams for disabled patients so these patients may end up in alternative funded streams even though the stream may be inappropriate.^{135,136}

1.4.1. What is the difference between palliative care and care for children with disabilities?

There is often confusion or a lack of understanding about the roles played by specialist palliative care services and disability services. Palliative care for children is different to the care for children with disabilities in a number of ways. Many children and young people with palliative care needs, also have multiple disabilities. However, the risk or certainty of death in childhood or young adulthood and their changing needs, adds a degree of complexity and urgency to their care and the support that is needed for the family.

Many families will receive a package of care through Disability Services which may meet some of their needs at a particular time but generally disability services are not able to provide:

- Short and longer term in and out of home respite for children with complex medical needs as they do not have the staff with the requisite skills.
- The link between the acute sector, appropriate medical specialists, and the family and other providers.

¹³⁵ Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia*, cat. no. 4430.0, ABS Ausstats, 2003.

¹³⁶ AIHW Australia's Health 2010. Australian Government.

- Specialist management of symptoms and specialist equipment.
- Psychosocial and bereavement support for all of the family.

If the social and emotional needs of children with life threatening illness and their families are to be fully met, then they must be recognised as a discrete group and be supported to be fully integrated into their local communities. They should have access to appropriate generalist and specialist palliative care services.

1.4.2. Care Coordination

The reality for many families is that they will have ongoing relationships with a number of providers from a range of sectors including specialist palliative care; specialist paediatric palliative care; GPs; general paediatric; case management; disability; early childhood; education; HACC; religious groups; support groups e.g. disease specific or cultural groups; bereavement counselling and support.

Coordination of this extensive range of services is daunting and often falls on the shoulders of the parents. Effective case management is critical to ensuring that care meets the continuously changing needs of the child and family. This is not uniformly available across the country.

The challenge of coordination and information provision is further exacerbated when families come from rural and remote areas or a special needs group.

Summary

Overall, access to quality care for this population is inconsistent. Ongoing education of disability care professionals, supportive organisational structures and cultures, and intelligent financing solutions, are essential if end of life care for people with disabilities is to improve.

Recommendation:

22. That comprehensive case management services for people with disabilities are available to all families who require them.

1.5. Children and adolescents

Palliative care for children is different from adult palliative care in several ways:

- The number of children dying is small, compared with the number of adults.
- Many of the individual conditions are extremely rare with diagnoses specific to childhood, although the child may survive into early adulthood.
- The time scale of children's illnesses is generally different and disease trajectory unpredictable.
- Some illnesses are familial. There may be more than one affected child in the family compounding the burden of care and bereavement.
- Care embraces the whole family and impacts on each family member. Parents bear a heavy responsibility for personal and nursing care.
- A characteristic of childhood is continuing physical, emotional and cognitive development. Carers need to be aware of each child's changing levels of communication and ability to understand their illness, treatments and prognosis.
- Play and education are an essential mix, that introduces an additional dimension adding to the complexity of care.
- Grief associated with a child's death is acknowledged as particularly intense with a high risk of complicated bereavement.

The vision for paediatric palliative care is very similar to that of adult services. *Together for short lives*¹³⁷, a United Kingdom program, has identified four key areas as critical to families having the best quality of life and standard of care:

- That families know about services that are available to support them and know how to make the system work best for them.
- That the care that families receive is as coordinated as possible – with health, community care and education services working together in a seamless way.
- That families are secure in the knowledge that the care their children are receiving is of the highest quality.
- The families have confidence in the future availability and sustainability of services.

These key areas also relevant to the Australian setting but are not addressed uniformly in Australia.

1.5.1. Service Provision

The provision of paediatric palliative care varies across the country. The larger states are more likely to have dedicated paediatric services. For example, in Western

¹³⁷ <http://www.togetherforshortlives.org.uk/>

Australia the Child and Adolescent Health Service is responsible for palliative care for children across the state in conjunction with primary and specialist health providers. In Tasmania, the rare paediatric case is generally managed by the hospital, while in the Northern Territory paediatric cases are cared for by staff in specialist palliative care and they have little or no education in how to manage a child effectively to the end of life. The Victorian State Government palliative care policy identifies paediatric palliative care in some of the priority areas and has allocated additional funding for service provision and training.

1.5.2. Leadership

Palliative care is a small but critical area of the health sector and paediatric palliative care is smaller again in a resource intensive field. One of the key findings of the Commonwealth's *Paediatric Palliative Care Service Model Review 2003*¹³⁸ was a proposal to establish a *Paediatric Palliative Care Reference Group* to develop evidence based palliative care models including developing information, education and research strategies aimed at improving delivery.

The Australian Government *National Palliative Care Strategy 2010* has recognised the importance of collaborative, proactive, effective governance of national care strategies and resources. Nevertheless, the Reference Group is still without formal recognition or financial support. The Reference Group has a track record and is well placed to take on this leadership role if resourced to do so. It has the expertise to provide leadership in some important areas that currently face paediatric palliative care, plus the broader role outlined in the 2004 report, such as:

- the development of a research agenda
- provide advice regarding data collection
- identify workforce needs and gaps.

Many paediatric palliative care services believe there is a dearth of data in Australia needed for effective service planning. We do not know the real numbers of children requiring or using palliative care services. We also do not know the age ranges, illnesses or disabilities of these service users. Services have argued that the PCOC data collection does not suit the nature of service provision in the paediatric setting, given their greater emphasis on respite and psychosocial support than in the adult services and the difference in diseases and illness trajectories.

1.5.3. Young adults

Services are increasingly reporting on a group of clients that do not fit neatly into the current service system – young adults between 18 and 30. Technology has increased the lifespan of some children who historically would have died in their childhood such as those with cystic fibrosis, non-malignant conditions and those with multiple

¹³⁸ Australian Government Department of Health and Ageing 2003, *Paediatric Palliative Care Service Model Review Final Report*, Rural Health and Palliative Care Branch.

disabilities. They are discharged from the children's services at 18 and find it difficult to access the range of services they require in the adult system, particularly appropriate respite.

1.5.4. Neo and ante natal palliative care

Generally the care and coordination of services for neonates with life threatening conditions happens in maternity hospitals, so access to quality palliative care can be ad hoc. Similarly, for women who decide to proceed with a pregnancy when the child will be born with a life threatening condition, their support is primarily provided by obstetricians. Specialist palliative care or familiarity with a palliative approach can improve the outcomes for these families.

Summary

There is a need to recognise that palliative care for children and adolescents is different from palliative care provided to adults.

The provision of paediatric palliative care varies widely across Australia, with some states and territories not having dedicated paediatric services. There is a need to ensure that families know what services are available, care is well coordinated, high quality and supported by the best available research and evidence.

Recommendations:

- 23. That funding is provided to ensure that children with life threatening conditions and their families have equitable access to quality information and responsive and appropriate palliative care services.**
- 24. That the Australasian Paediatric Palliative Care Reference Group be funded to develop and implement a National Paediatric Palliative Care Strategy.**
- 25. That a data collection system for paediatric palliative care, including establishment of quality indicators, be designed.**
- 26. That a research project to explore the palliative care needs of young adults and the appropriate service responses be funded.**

1.6. Access to appropriate palliative care for older people

The WHO has called for 'Better Palliative Care for Older People'¹³⁹ to address the challenges posed for older adults by a combination of physical comorbidities, cognitive changes, and reduced social support.

Currently 13% of all deaths in Australia occur in residential aged care facilities. If Australia follows a similar trend as is occurring in the United States, then this could increase to 50% by 2020. Most aged care facilities are unable to offer appropriate palliative care but a recent Australian study has demonstrated that with proper support and appropriate training, good palliative care can be provided in this setting.¹⁴⁰

The demand for residential aged care in Australia is anticipated to increase more than threefold by 2045. Currently, almost one quarter of people who are admitted to a residential aged care facility die within six months of admission and 35% will die within one year. Many of these people would benefit from palliative care.

1.6.1. Aged Care Reform

The recent Productivity Commission (PC) Inquiry *Caring for Older Australians* has recognised that there are large systemic problems with the financing and operation of aged care and that the current models are not sustainable to meet future demand. In relation to palliative care they concluded that:

'there is a strong case for residential and community care providers to deliver excellent palliative and end of life care'.

However, the current system is not meeting the end of life care needs of older Australians due to a number of factors:

- The number of available nursing hours falls well short of those required for intensive terminal care.
- There are often not enough appropriate staff to provide medication and adequate symptom assessment.
- There is often a lack of GP support to RACFs due to relatively poor remuneration and lack of support systems in RACFs for them.
- The knowledge and skills of nurses, carers and GPs of palliative care is suboptimal.
- The availability of allied health services is limited.
- Medical specialists and many specialist palliative care services do not go into RACFs.

¹³⁹ Better Palliative Care for Older People. WHO 2004.

¹⁴⁰ Parker et al 2010. Implementing and evaluating a comprehensive model of palliative care in residential aged care facilities. Report to Department of Health and Ageing.

The National Aged Care Alliance (NACA) is made up of 28 leading stakeholders in aged care and they support the direction of the PC reforms and have also echoed many of the concerns raised by the Commission.

1.6.2. Barriers to the provision of quality palliative care

Although aged care services are provided towards the end of life, the provision of quality palliative care in RACFs and community care settings is the exception rather than the rule.

Conversations about dying are generally ad hoc, and remain largely taboo. Symptoms such as pain and dysphasia are often managed poorly; and end of life processes such as respiratory failure, dehydration and anorexia are too often treated as medical emergencies that prompt hospitalisation, rather than as a normal process in dying that can generally be managed appropriately by palliative care teams or by staff with education and clinical confidence in providing end of life care.

Any discussion of barriers and disincentives to the provision of quality palliative care must acknowledge the various financial arrangements around Australia for these services. The different approaches to funding and delivery of palliative care create quite different outcomes for individuals depending on where they live. In WA, for example, the state government provides significant funding for home palliative care through Silver Chain and this service is often quoted as best practice, with 60% of admitted clients dying at home. WA also has a lower rate of people dying in hospital. There are different barriers and disincentives for the provision of quality palliative care in residential and community care which are outlined below.

1.6.3. Residential care barriers and disincentives:

- Inability to meet Aged Care Funding Instrument (ACFI) palliative care funding requirements for care to be under the directive of a Clinical Nurse Consultant (CNC)/Clinical Nurse Specialist (CNS) in pain or palliative care (with 5 years experience) or a medical practitioner and include a pain assessment. Lack of access to these professionals, and the absences of pain for people with non-malignant diseases (such as end stage respiratory disease) make claiming for palliative care difficult.
- No funding for the provision of bereavement services, including psychological services for families of residents pre/post death.
- Lack of systems and processes to assist care staff and case managers to make appropriate decisions at a time of medical crisis (particularly agency nurses, or care staff who do not know the resident and their particular situation).
- Limited/no access to the latest equipment because of funding levels and restricted grant opportunities available to RACFs.
- Lack of appropriate funding for the delivery of palliative care, including appropriate aids and equipment. Current funding under the ACFI for palliative care is only about one third of the amount that specialist palliative care services receive per individual and is only provided for terminal care.

- Inadequate access to specialist palliative care consultancy services to augment care provision for people with complex needs.

1.6.4. Community care barriers and disincentives:

- Community aged care funding does not include any explicit provision for palliative care and there is an implicit assumption that this is provided through the health system.
- Ambiguity of HACC policy guidelines around provision of, and access to, specialist palliative care services. There is tension between the programs with people needing palliative care sometimes being denied access to HACC services.
- In some regions people who are receiving palliative care are denied access to packaged care and the reverse can also occur with people who are receiving packaged care being denied access to palliative care services.

1.6.5. There are some barriers and disincentives which affect both the provision of palliative care in a residential or community setting including:

- Limited access to GPs (themselves sometimes not trained in palliative care), to palliative care specialists (under agreed and consistent referral and access criteria), to nurses (who can administer opioids) and other health practitioners (such as allied health practitioners) to ensure multidisciplinary care is provided.
- Limited access to PBS subsidised palliative medicines. The bigger issue can be access to non-PBS listed drugs that are available in hospital because the state governments fund them. This provides a significant disincentive to returning to the community.
- Lack of education and training of both new and existing (upskilling) staff including clinical care requirements and in case management/coordination processes (e.g. case conferencing, use of advance care directives).
- Limited adoption of advance care planning – often not developed in a timely way and in some cases, not stored or recorded in ways that will allow them to be effective when needed. They may, for example, be stored in resident/client files that are not transferred to hospital if an ambulance is called.
- Limited knowledge of, and no universal access to, available specialist and community palliative care services and resources.

These barriers are exacerbated for people with dementia, where pervasive stigma and misunderstanding of the condition on the part of both aged care providers and family carers, poor recognition of symptoms, and communication barriers often result in missed opportunities for quality palliative care, and as a result there are many acute and unnecessary hospitalisations.

Not all of the issues facing the provision of good quality palliative care for older people lie in specific aged care services. More broadly the specialist palliative care services are often time limited (in Queensland there is a three month limit). This

criterion is difficult to meet for older clients with non-malignant disease where prognosis is much less certain than for clients with a defined malignancy.

One other aspect to consider here is why aged care services do not generally seek to become specialist palliative care providers either in the community, if meeting the appropriate palliative care standards, (as Silver Chain has done in WA) or in residential care given their infrastructure suitability for the provision of hospice care.

Access to state government funding can be limited and the entry of new players creates further competition for limited resources. However, as the nature of residential care service provision changes to more short term interventions with people who are frailer and have higher needs, eligibility for state funding and federal responsibility for older people will need to be actively considered to ensure that quality palliative care is available for this target group.

1.6.6. The role of aged care services in providing palliative care

Palliative care is core business for RACFs and this will increasingly be the case for community care as people remain living at home for longer.

Most older people express a preference to live and die at home. This can be difficult to access and coordinate across aged care and specialist palliative care services. Program boundaries can also limit the support well known services can give existing clients who require palliative care.

Cancer, while core business for specialist palliative care services, is not the leading cause of death for older people. For people aged 65 and over in Australia leading causes of death are ischemic heart disease, cerebrovascular disease, lung cancer, COPD, other heart disease and dementia. Dementia, while currently the third leading cause of death behind ischaemic heart disease and stroke, is increasing in prevalence. From 1998 to 2007 there was an increase by 126% of deaths from dementia related illness.¹⁴¹ It is likely that this trend will continue.

The *PCA Standards for the Provision of Quality Palliative Care* should be considered as a quality framework for residential or community aged care services. In cases where the aged care provider has become a specialist palliative care service these standards should be applied.

1.6.7. Shifting the balance to home based palliative care

Generally people express a preference to die at home. There is a need to increase the provision of palliative care delivered in the home and create a shift away from unnecessary and undesirable admission to acute care.

As stated earlier, WA is very successful in the provision of home based palliative care services. Silver Chain is the sole specialist community palliative care provider for the entire Perth metropolitan area – greater than 5,000 square kilometres with a

¹⁴¹ Australian Bureau of Statistics. 2007 Deaths Australia Cat No.3303.0, 2008

population of 1.6 million people. The service admits approximately 3,000 people annually, with more than 660 people admitted on any given day, and an average length of stay of 84 days. Sixty per cent of admitted people are supported to die at home (compared to national average of 25-30%). A 2007 study '*Factors affecting place of death in Western Australia*'¹⁴² demonstrated that those who accessed community palliative care were seven times more likely to die in their own home. Recent analysis of Silver Chain data demonstrates that 60% of those who died at home had no hospital admissions during their episode of care with the service, and 28% had only one.

Funding for the service is provided by the WA Department of Health, Department of Veterans' Affairs, donations and bequests. There is no charge for the service, and it includes the provision of equipment and medical devices from Silver Chain's supply chain management service, CarePlus. The program uses a 'whole of metropolitan service', employs GPs, provides 24/7 service at home and provides personal care respite.

1.6.8. Case studies of quality palliative care provision to older people in aged care

NACA reviewed the following case studies to try and understand why and where palliative care works well and how people's preference to die at home can be supported:

- Palliative Aged Care Link Nurse Positions, Victoria (residential care focus)
- Metro South Palliative Care Services RACF PC Service, Queensland (residential care focus)
- Comprehensive Evidence Based Palliative Care in residential aged care (cebparac), Queensland (residential care focus)
- Multidisciplinary Palliative Care Case Conferencing for residents with end-stage dementia, Queensland (residential/dementia focus)
- Hunter Collaborative Palliative Dementia Care Framework, New South Wales (community, residential and dementia focus)
- Silver Chain Community Palliative Care, WA (community focus)

They found that there is a clear connection between the quality of the palliative care provided, the outcomes for individuals and families, and the existence of good linkages between specialist palliative care services and aged care providers.

NACA also identified that one of the key linked issues for the provision of quality palliative and end of life care at home or in residential care is the ability of staff and informal carers to administer necessary pain medications including syringe driver medications. There have been projects to provide training to informal carers and to aged care staff in using syringe driver medications and these have been successful in supporting people to die in place.

¹⁴² 126 McNamara B and Rosenwax L (2007) Factors affecting place of death in Western Australia. *Health Sociology Review*.

A recurring theme for quality palliative care provision is access to ongoing training. NACA acknowledged that the Australian Government, and a number of other bodies, have put considerable effort into training development through programs such as PEPA and PCC4U. While these are good initiatives the reach is limited (particularly in allied health and medicine) and the high turnover of aged care staff means that it needs to be continually available. These initiatives need to be built on and address the variable quality issues of VET training and barriers to aged care staff take up of the available training and education.

1.6.9. Interface between Aged Care, Palliative Care and the Acute Sector

It is a common complaint in the health and community sectors that services are provided in silos without adequate consideration of coordination of, or the transition between, services. While much work has occurred in the states and territories to improve discharge planning from hospitals, there is still a regular stream of disquiet with older people being discharged to RACFs for end of life care without adequate medical handover and without access to specialist palliative support. Unfortunately the result is often that residents are returned to hospital - a poor outcome on all levels.

Growth of aged care services for older people with chronic and complex conditions will need to be complemented by an expansion of the capacity and competence of primary health care services to provide generalist palliative care for people living in the community and in aged care homes, supported by increased collaboration and networking with expanded specialist palliative care services.

The consultancy and education services provided by specialist palliative care services to aged care varies considerably across Australia. Some admit residents of RACFs as patients, others don't but provide advice to the facility staff, and some others just provide education on request. A community palliative care team may consider a referral from a RACF as a low priority because they are in 'a bed.' It has also been reported that older people being supported in the community by an Extended Aged Care at Home package have been considered ineligible for palliative care support.

Clinical leadership and linking models need to be further developed and resourced. These also have the potential to provide improved structural solutions to workforce challenges. Examples include:

- Aged Care Nurse Practitioners – they play a valuable role in educating, encouraging and supporting staff, as well as liaising with GPs, allied health practitioners, pharmacists and specialist palliative care practitioners. Evidence indicates the introduction of such roles increases service users satisfaction, improves outcomes (timely access, assessment and client interventions), reduces the prescription of pharmaceuticals, decreases readmission to acute care and reduces costs.
- Link nurse models - whereby an appropriately educated and resourced aged care nurse leads the palliative care delivery in that service. This person links with their closest specialist palliative care service for consultation, education and

support. The PEPA program could assist with the education of these nurses. However, link nurses and palliative care services generally have no right to work within aged care facilities – it is up to the management of the facility to agree to access. This is an important issue of equity of access to services where residents may well gain from specialist palliative care support.

“Our service relies on referrals from the aged care sector. We notice that while some workers have an excellent understanding of the palliative care approach, there are others that don’t. This means that patients that we know of don’t receive the optimum levels of care, and we feel powerless to intervene. Mandatory palliative care education of aged care workers could help address issues like this for us.”
(Palliative Care Nurse from a Specialist Palliative Care Service)

1.6.10. Medicare Locals

Medicare Locals could play a vital leadership role in developing more integrated health services, including developing and implementing the necessary referral criteria and the enhanced workforce education that will be necessary, if a truly integrated, multidisciplinary model for palliative care is to be developed. Exactly how this could happen is still problematic. The Department of Health and Ageing discussion paper on governance and functions of Medicare Locals¹⁴³ does not attempt to tackle how GP, specialist and allied health professional service referrals and multidisciplinary team work will be managed, financed, and coordinated to achieve better integration of care services for people with terminal conditions, or indeed needing aged care.

The final report of the National Health and Hospitals Reform Commission (NHHRC) in 2009 recognised the importance of palliative care and made a number of recommendations to improve palliative care services in a range of settings¹⁴⁴. They stated that Medicare Locals will work to improve coordination and integration between primary health care and other local health services. Medicare Locals will play a key role in linking people to care in remote and rural areas, including:

- Ensuring local primary health care services are better integrated and more responsive to local needs.
- Planning, administering and purchasing after hours services for the local area.
- Working with Local Hospital Networks to bring together primary and acute care practitioners and services, to ensure seamless transition by patients between

¹⁴³Department of Health and Ageing Oct 2010. *Medicare Locals – Discussion Paper on Governance and Functions*,

<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/MedicareLocalsDiscussionPaper>

¹⁴⁴ Commonwealth of Australia, *A Healthier Future For all Australians: Final Report of the National Health and Hospital Reform Commission* – June 2009, Australian Government, Canberra, 2009, available online at

[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/publications?OpenDocument&ct=National Health and Hospitals Reform Commission](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/publications?OpenDocument&ct=National+Health+and+Hospitals+Reform+Commission).

services.

Although the definitive role and function of Medicare Locals is yet to be determined it has been suggested that they could, if funded, provide specialist palliative care advice and information to residential and community aged care services using specialist nurse practitioners or nurse consultants, in collaboration with GPs (trained in palliative care). Medicare Locals could also have the option to purchase services from the State and Territory health systems.

The Australian General Practice Network has identified opportunities to improve the situation for residents within RACFs which include resourcing Medicare Locals to support timely access to GPs and primary health care professionals through locally relevant initiatives that address practical and financial barriers to the provision of primary health care services; providing more appropriate funding for provision of palliative care following a review of current funding arrangements; national roll-out of a systematic approach to advance care planning for residents in aged care facilities; and access to afterhours care, preferably 24/7 services.

1.6.11. Aged Care Funding

If appropriate palliative care is to be provided in RACFs then the funding instrument (ACFI) must provide funds for it. Allied health care services such as physiotherapy, speech therapy, social work and occupational therapy are not funded appropriately and therefore psychosocial, spiritual, loss and bereavement needs are often not met.

As part of the reform process the PC recommended a 'cost of care' study to set subsidies that reflect the real cost of care. The implementation of a palliative approach and appropriate care must be part of this study and the resultant subsidies.

1.6.12. Standards

Palliative Care and Aged Care have separate standards that they must meet. There is an urgent need to harmonise these standards so as to ensure efficient, effective and appropriate care is delivered in the right place at the right time.

The current revision of the Aged Care Accreditation Standards could assist this through support for advance care planning, and through the provision of true palliative care, not terminal care as it is often currently misunderstood to mean.

Summary

Palliative care should be core business for aged care, but the current system is not meeting the end of life care needs of older Australians. Aged care is not funded in a way that provides high quality palliative care services to older Australians; does not have an adequate workforce training to manage end of life care needs; and is not resourced to meet the demands of Australia's ageing population.

Aged care services should ideally be able to play one of two roles in the provision of high quality palliative care; services should be able to offer a general palliative approach and facilitate high quality palliative care to support people to die with dignity and in comfort at home or in a residential facility if they so choose, or deliver specialist palliative care services themselves, where appropriate and possible.

Recommendations:

- 27. That the Australian Government implements the aged care reforms as proposed by the Productivity Commission and supported by the National Aged care Alliance as a matter of urgency.**
- 28. That all Residential Aged Care Facilities (RACFs) be required to have an effective relationship with a specialist palliative care service in their region and this should be reflected in the aged care accreditation standards.**
- 29. That community and residential aged care recipients with complex palliative care needs should be eligible to receive specialist palliative care consultancy support across the country and this should be reflected in funding agreements.**
- 30. That funding to cover the provision of palliative care should be included in aged care subsidies.**
- 31. That the National Palliative Care Standards can be reflected in all aged care provision.**
- 32. That eligibility be confirmed for community aged care clients with complex palliative care needs currently receiving HACC or packaged care to receive specialist palliative care consultancy support across the country and this should be reflected in funding agreements.**
- 33. That there be a national rollout of the evidence based Palliative Approach Toolkit www.uq.edu.au/bluecare to support RACFs in providing a palliative approach.**
- 34. That the Australian Government make palliative care for older people and aged care service support a palliative care funding priority in 2012 2013. The need for this priority to be created can be tied to its ability to decrease unnecessary, undesirable and costly hospital admissions and usage.**
- 35. That the Aged Care Funding Instrument be amended to facilitate provision of palliative care.**
- 36. That the aged care 'Gateway' should provide information and support to access on advance care planning and palliative care services. Assessment for**

referral to palliative care should be an integral aspect and skill of Gateway assessors.

37. That the VET review should include specific reference to quality palliative care training, including whether palliative care should be an elective or mandatory subject.

2. The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent

2.1. Sub-Acute Bundling

The mechanism for palliative care funding distribution has altered over time, and there is definite jurisdictional inconsistency. The National Partnership Agreement on Hospital Health Workforce Reform¹⁴⁵ in December 2008 allocated funding on the basis of the category of sub-acute services, meaning that palliative care sat alongside rehabilitation, geriatric evaluation management, and psychogeriatric services. \$500 million was committed by the Commonwealth in 2008-09 for the State and Territories to expand service provision levels by 5 per cent annually over the period 2009-10 to 2012-13, and to better address regional availability. Unlike all other aspects of this agreement, no financial commitment was required from the states and territories to increase this sub-acute funding.

Each state and territory could allocate the funding across the sub-acute sector as they determined appropriate to local needs. Whilst a standard template has not been used to report on Implementation Plans, and not all have delineated spending between specialties, the sharp contrasts between jurisdictions are evident. Of its \$39,973 sub-acute funding South Australia committed \$11,970 to palliative care. On the other hand, Queensland allocated none of the sub-acute funding to palliative care, but committed to undertake a review of the current palliative care service system in 2009-2010 from within existing state funding, and develop a strategic direction for palliative care. This service provision review has been undertaken, but not publicly released.

Subsequently the 2010 Budget allocated \$1.62 billion to deliver 1,316 subacute care beds, also to be allocated between specialties by the different jurisdictions. (The Secretary of the Department of Health and Ageing confirmed at a public forum that this allocation could be utilised for bed equivalents such as community care packages, rather than just for beds.) There has yet to be public reporting of the allocation of these funds, but feedback from the sector does not indicate that there has been flow through to palliative care service provision.

We know that many more Australians would benefit from access to palliative care, yet it is clear that bundling funding allocations within the sub-acute category is not leading to improved service provision and access across the country.

If such bundled allocations continue, whether or not in conjunction with Activity Based Funding, a significant level of funding must be specifically allocated to palliative care (as a minimum) to ensure greater access to quality end of life care for Australians in need.

¹⁴⁵ Council of Australian Governments, National Partnership Agreement on Hospital Health Workforce Reform, December 2008.

2.2. Activity Based Funding

It has been agreed that all subacute services will transition to Activity Based Funding (ABF) on 1 July, 2013. Whilst the aims of ABF in achieving funding transparency, consistency and equity are respected and supported by PCA, we are extremely concerned that the development of the pricing model will not appropriately recognise the nature of palliative care, and that under-resourcing may result.

The concept of the patient in palliative care is unique within the health system. In addition to the person with a terminal illness, palliative care treats and supports the family, carers, loved ones, and others. This care delivery to all related individuals, and inherent expansion of meaning of the concept of the term patient is integral to the philosophy of palliative care. It is essential that this expanded notion of a patient is recognised within the funding models.

Given that the plans for ABF indicate a service event is between one patient and one health professional, it is essential that an expanded concept of patient be applied to palliative care. PCA understands that it is already the intention of the Independent Hospital Pricing Authority (IHPA) to treat bereavement services delivered to the carer/s and loved one/s of a deceased patient as a service event, this conceptual expansion may offer a mechanism to expand the overall concept of patient in palliative care delivery.

It is also understood that palliative care delivered in an inpatient setting will be funded on the basis of the phase of care. Whilst this will potentially increase the data burden on services, PCA supports the concept as it can better account for the complexity of care needed in patient care.

A potential fault with this model is its lack of delineation between diagnoses. Some disease trajectories may require greater complexity of care at every phase, others at specific phases. There is no current data to enable clear baselines to be established, so the impact of different diagnoses may be an important factor in costing. Even if not included initially, the system must be flexible to allow for changes to ensure adequate levels of resourcing.

A further issue with ABF is the definition of a service event as being delivered by a clinician – defined as a medical, nursing or allied health practitioner. Palliative care is delivered by a multidisciplinary team that extends beyond this definition of clinician. Whether a pastoral carer providing spiritual support, a care worker assisting with showering, or a volunteer carer who still needs funding for training and coordination, the inclusion of these non-clinicians must be recognised within the costing model. All are integral to providing dignified end of life care.

ABF intends to recognise all of the background work that contributes to the delivery of a service event, but PCA is concerned that the breadth and the time required for such background work in palliative care may not be fully acknowledged and resourced. We already know that many GPs are reticent to provide comprehensive

end of life care to residents in RACFs because there is no payment in their fee for service model which compensates for the extensive time and effort in coordination of care whether through phone calls or otherwise. Similarly ABF need to include compensation for the extent of the background work performed that underpins the delivery of the palliative care service event, especially within the community setting. The time and complexity of communications to coordinate care, multidisciplinary team meetings, and other components such as volunteer management contribute to the unique nature of palliative care. This essential foundation work must be recognised as a component of each service event.

Palliative care delivered by a consultancy service will not be initially included in ABF. It is difficult to envisage how such service delivery will be appropriately costed, given the definition of a service event, and the fact that a consultancy palliative care service is delivered whilst a patient is already under the care of another clinician. It is essential that the development of funding mechanisms for consultancy services do not restrict service delivery, and even incentivise clinicians to refer to palliative care consultancy services.

PCA recognises that the collection of cost data across the country has been very poor, and hopes that the requirements of ABF will lead to an improvement in the quality of data collected.

Until the 2011 Budget, funding for many projects and programs (including the major quality improvement projects of NSAP, PCOC and Caresearch) was delivered through the Australian Government's National Palliative Care Program, administered by the Department of Health and Ageing. This has been amalgamated (along with 158 other programs) into 18 flexible funding streams.

Similar to Alzheimer's Australia's concerns with the dismantling of funding dedicated directly to dementia, PCA is very concerned that there is no funding dedicated to palliative care. PCA welcomed the opportunity to contribute to the consultation on the Guidelines for the Chronic Disease Prevention and Service Improvement Fund, and is heartened to see the inclusion of end of life care in the Fund's priorities of early detection and appropriate treatment; integration and continuity of prevention and care; and self management.

Several other flexible funds would also be suitable sources of funding for the work of PCA. These include the Aboriginal and Torres Strait Islander Chronic Disease Fund, the Aged Care Service Improvement and Healthy Ageing Grants Fund, the Aged Care Workforce Fund, the Communicable Disease Prevention and Service Improvement Grants Fund, the Health System Capacity Development Fund, and the Health Surveillance Fund.

Whilst there may be benefits in the ability to seek funding for projects outside of the main funding stream, it is of great concern to PCA that none of the Guidelines regarding these funds refers to palliative or end of life care. The lack of recognition of palliative care, especially within core areas such as aged care and communicable

disease, is likely to have the unintended consequence of restricting access to funding, rather than expanding it.

This broad diversity of funding sources and associated range of application dates, priorities and reporting requirements will not only impose a significant administrative burden on small organisations such as PCA, it is likely to also lead to missed opportunities to ensure that all Australians have access to the best possible quality of end of life care.

2.3. Funding Inconsistencies

Historically, palliative care service funding has been linked to funding for cancer services. Modern cancer treatments have seen an increase in the symptom burden during the palliative phase. More people are now dying from end stage organ failure and dementia, and management of these disease trajectories are significantly more complex. It necessitates more coordination of multidisciplinary care and a rethink about funding and the way in which sub-acute funding is provided and used. However, the historical cancer based funding model has not been reviewed and changed to meet these increased demands. For instance, cancer patients still comprise around 90% of the palliative care service caseload in New South Wales. This has resulted in inequitable service provision for patients suffering from non-cancer related terminal conditions such as dementia, renal failure, heart failure, end stage respiratory disease and many others.

There are a number of related anomalies or inconsistencies in funding models that impact on the efficient and effective delivery of palliative care:

- Inconsistency in funding models and the provision of specialist palliative care consultation teams to improve the quality of end of life care

“In rural and regional areas a significant number of services operate without formal agreements for specialist medical support. This is most often provided on a good will basis by fly in/fly out palliative care medical specialists from metropolitan services. This is not a sustainable model and needs to be reviewed”. (New South Wales)

- The funding and delivery mechanisms for acute and sub-acute inpatient care and community based services vary markedly throughout Australia. In areas where inpatient and community based services are delivered through different agencies or services, funding anomalies can significantly impede effective care. For instance, sub-acute inpatient funding may only cover the basic costs of the bed, and not any other services or treatments that may be required for the patient.
- Aged care funding is structured on the assumption of ‘stable’ care requirements. If a resident becomes ‘unstable’ there is no provision for funding to provide necessary services, even where they could be most effectively delivered at the RACF. As a result, RACFs often have to transfer a resident to hospital to access necessary treatment.

- There is a pervading ‘fear’ in many states and territories that by grouping palliative care under the collective banner of sub-acute funding:

“it is likely to result in non targeted funding that fails to recognise the specific needs of palliative care service provision, threatens to fragment the holistic nature of palliative care into pockets eg. Physical, emotional, social and spiritual and then bereavement tacked on at the end. Reductionism is harmful to holistic service delivery, and fails to ensure comprehensive health outcomes”. (South Australia)

- In Victoria in 2005, the Palliative Care Resource Allocation Model (PCRAM) was introduced as a more equitable way of allocating new funding to community palliative care services. The PCRAM allocates funding based on the needs of the population within defined geographical catchment areas. The PCRAM takes into account population growth, ageing, rurality and low socioeconomic status, and provides funding to support services to manage the impact these population characteristics have on service demand.
- The implementation of Activity Based Funding (ABF) in hospital auspiced palliative care will begin across the Australian health system from 1 July 2013. Theoretically, ABF will enable funding models to better reflect the costs and resources involved in delivering palliative care and to place resources where they will deliver the best outcome for clients.
- In comparison to ABF, the primary aim of Flexible Funding is to ensure that money can be assigned where and when it is needed in circumstances outside of prescribed boundaries defined by the ABF. These circumstances often arise in palliative care where for instance, if a person wishes to die at home their palliative care requirements and quality of care are not compromised simply because their care needs fall outside of case-mix codes.

2.4. Future Funding

The guiding principle underpinning funding is that there should be quality and equitable palliative care and support available to all Australians no matter where in the country they might live and no matter what form of accommodation or facility they are in. It is useful to view funding arrangements in terms of short term and long term measures:

2.4.1. Short term:

Establish a population based model that will set targets for states to aim at in terms of service provision of specialist palliative care services such as that proposed in PCA’s *A Guide to palliative care service development: A population based approach*¹⁴⁶. Undertake the necessary work as outlined in the *National Palliative*

¹⁴⁶ Palliative Care Australia 2005, *A Guide to palliative care service development: A population based approach*

Care Strategy 2010 to prepare for a more long term and rigorous funding system including:

Identify and recommend improved funding models that explicitly promote flexibility to meet the needs of the patient and their family. This may include:

- Funding based on assessed need.
- Funded care packages, including rapid access/rapid response options.
- Fund holding by appropriate providers, including aged care services, to source and coordinate (case manage) appropriate care regardless of location, outside the aged care assessment process.
- Explore new and enhanced roles for aged care providers in palliative care.
- Undertake further research and ongoing monitoring of the relative cost of care and cost effectiveness of care models in the last year of life, particularly savings to be gained through appropriate hospital avoidance for clients approaching the end of their life.
- Undertake further work to identify, classify and cost, specialist palliative care clients and their care.
- As part of the aged care reform process consider how aged care can be funded for palliative care by incorporating it into the subsidy and fee structure or loading the ACFI.
- Fund specific programs to improve the links between specialists palliative care services and aged care and the acute system.

2.4.2. Long term:

- Create a system that is based on a person's need rather than their disease or age. The program should follow that patient across all settings: hospital, residential and community care, hospice and home. Some exploration should take place regarding different types of funding models given that in both aged care and health there is an increasing movement towards user pays systems and sometimes with the person being able to reduce the financial risk through insurance.

2.5. A note on Private Health Insurance

With appropriate arrangements in place the private sector could play a useful role in providing more choice and access, as well as diversifying the funding sources.

In 1999 the Commonwealth piloted the Hospital in the Home (HITH) program. One of the six trials was conducted by Cabrini Health and it focused on providing cost effective community based palliative care to patients who were covered by one of the participating private health insurance funds. The pilot was successful and the program still operates today. The details of the funding model currently used by Cabrini are not public but patients are able to use their health insurance for in-patient and home care with those at home being able to receive one nursing visit per day.

Australian Health Management has looked at the benefits of private health insurance becoming involved with palliative care. They have identified challenges particularly relating to support outside the hospital setting:

- Funds have a fear of cost shifting where the public purse may have funded these services.
- Defining end stage palliative care.
- Assessing patient functionality and the capacity of carers.
- Allocating a budget.
- Managing the private-public mix of services and subsequent funding.
- Locating the required services.

There is no legislative barrier to the private sector providing palliative care and the patients claiming for these services through their health insurance. However, insurance funds do not see why they should place it on their schedules. It is seen as a 'bottomless pit' rather than a prudent investment where they could save on in-patient and drug costs.

Some private palliative care services have a successful track record in gaining funding from private health insurers as a result of in-depth work they have done to demonstrate a business case. Understandably, they wish to safeguard their intellectual property. However, the general lack of willingness of private health insurers to fund more cost-effective palliative care reduces the overall efficiency of the health system and inhibits equity of access. This is an area where national leadership by the Australian Government in relation to demonstrating the business case and negotiating greater participation by private health funds in the funding of palliative care, could be very helpful and productive.

Summary

There is a need to move away from the traditional funding arrangements for palliative care which are based on cancer services, to reflect the fact that Australians are dying now from an increasing range of complex chronic diseases.

The guiding principle of funding for palliative and end of life care should be equitable support for all Australians and a flexible system based on individual needs, across all care settings.

Recommendations:

38. That sub-acute funding provided to states and territories should have specific amounts dedicated to palliative care service provision.

39. That the pricing model developed for activity based funding includes:

- a. An expanded notion of the 'patient' as including family, carers and others in the delivery of palliative care.
 - b. Flexible systems to allow for differing diagnoses and resulting complexity of care.
 - c. An expanded to definition of 'clinician' to include the full multidisciplinary care team.
 - d. An expanded notion of 'service event' to reflect the background work which underpins palliative care service delivery.
 - e. Funding based upon phase of care.
 - f. Improved data collection.
40. That funding through the Australian Government's National Palliative Care Fund be reinstated and increased.
41. That palliative and end of life care is recognised in the Guidelines for the Department of Health and Ageing's flexible funding streams, specifically the Aboriginal and Torres Strait Islander Chronic Disease Fund, the Aged Care Workforce Fund, the Communicable Disease Prevention and Service Improvement Grants Fund, the Health System Capacity Fund and the Health Surveillance Fund.
42. That flexible funding arrangements be adopted to enable rural and remote communities to access palliative care resources and services to meet their needs.
43. That resourcing formulas be developed that incorporate assessment of local population palliative care needs, cost of service delivery and that support the achievement of desired outcomes.
44. That both public and private funding is directly linked to care of people who are approaching the end of their life, irrespective of the care setting.
45. That affordable access to aids, equipment and medications necessary to provide quality care at the end of life in the community is ensured.
46. That RACFs are accurately and adequately resourced to reflect the cost of delivery of palliative care to residents, and support for families and carers.
47. That Specialist Palliative Care funding models are reviewed to reflect the changing demand pattern for palliative care services and changing service role, i.e. to reflect demand for palliative care service for people suffering from non-malignant life threatening illness, and to better reflect the growing need for specialist consultancy advice for generalist palliative care providers.

48. That funding be organised as packages for the delivery of education to RACFs, or an activity based funding model be set up to allow clinical staff to be released for planning and presenting educational programs.

3. The efficient use of palliative, health and aged care resources

It is increasingly clear that new knowledge about effective care rarely leads to widespread improvement without a deliberate effort being made to change practice. Many countries including Australia are attempting to develop more systematic ways of using knowledge to improve their health services. These methods include developing clinical guidelines and audit; developing care pathways; involving users of service in designing change and seeking their feedback more regularly; and devising methods that encourage teams of professionals to work together to improve the quality of the services provide.

However, changing organisational practice and behaviour is not easy or simple. In the cancer field, for example, developing evidence based clinical guidelines for health practitioners has met with mixed success. Reviews of these initiatives suggest that guidelines need to be locally developed and championed, and supported by education, feedback, multiprofessional collaboration and effective project management.

Through ensuring palliative care provision receives a valid share of Commonwealth sub-acute monies together with an improved share of state funds, pressure on the acute care system can be supported in three ways:

- Provision of sub-acute beds for palliative care enables transfer of appropriate patients away from acute beds.
- Improved resources for community palliative care increases community (non-hospital) stays.
- Acute inpatient palliative care hospital consultation teams facilitate discharge or transfer out of the acute care system where possible, as well as reducing the use of clinically futile and frequently expensive treatments and investigations.

Improved access to palliative care services has the potential to improve both the effectiveness and the efficiency of healthcare services for the dying, and the healthcare system as a whole:

Efficiency – by avoiding inappropriate and preventable admissions to emergency and acute services, thus, a more cost-effective use of health resources. Further, by minimising or avoiding investigations, treatments and procedures that offer no improvement in quality of life.

Effectiveness – by providing better outcomes for patients and their families.

A conservative analysis of available data indicates that the cost of palliative care services can be between half and three times less expensive than care in an acute bed or intensive care bed. The estimated costs of this can be broken down as follows:

- An Intensive Care Unit Bed (ICU) costs around \$4000 per patient, per day, or \$1.5M per bed per year, according to Professor Ken Hillman, who says:

“at least half of my ICU patients shouldn’t be there...Dying in ICU is a very cruel, awful way to die.”

Senior Intensive Care Specialist Dr Peter Saul says:

“in terms of health costs, our final year of life is our most expensive. Almost all of this expense is in the last few weeks. Dying in an ICU, costs more than most of us have ever paid in contributions to the Medicare levy. Nor is it a particularly pleasant experience. Evidence suggests that as many as half the people admitted to an ICU at the end of life would have chosen otherwise had they been given the choice.”

- An Acute Hospital Bed costs more than \$1100 per day on average
- Ambulance callouts cost between \$300 and \$5000
- The cost of palliative care varies depending on where it is provided and the particular needs of the patient, but it has been broadly estimated at between \$200 per day (for a patient in a RACF) and \$600 per day (for an Inpatient Palliative Care Facility).

Palliative Care can play a pivotal role in achieving efficiency in the health system by:

- Making prevention every ones business – palliative care can help prevent the types of distressing, often lengthy, costly and unnecessary acute hospital admissions at the end of a patient’s life.
- Creating better experiences for people using health services – One of the principal aims of palliative care is to enhance quality of life, and create better experiences for patients and their families. Studies have shown that families of patients who have undergone palliative care and have received bereavement counselling have much better experiences during the terminal phase of their loved one’s illness, have an acceptance of death and lower rates of depression six months after the death.^{147,148}
- Investing more in palliative care services has the double benefit of achieving significant financial savings, and freeing up acute hospital beds.

“If palliative care was recommended appropriately and readily available, not just as a last resort, overall efficiency could be improved”. (Tasmania)

“Health resources are inefficiently utilised when dying people are provided with futile, ineffective, burdensome, unwanted or otherwise inappropriate treatments. This is a particular risk in the broader population of dying Australians because of a

¹⁴⁷ Dinef O, (1999) Orthodox Perspectives on Death, Dying and Bereavement, Woodville, South Australia, Western Palliative Care Service.

¹⁴⁸ Dying Matters - Raising awareness of dying, death and bereavement - www.dyingmatters.org

reluctance amongst health care providers to diagnose dying and negotiate new goals of care with their patients which entails the phasing out or cessation of curative treatments and the introduction of palliative care measures". (Western Australia)

Palliative care providers throughout Australia report increasing growth in demand for their services while resources to meet the increased workload have not grown at the same rate. The implication of this is that palliative care services are doing more work with the same amount of resources which raises the question that either efficiency/productivity is improving or quality of care is sacrificed. Evidence from NSAP and PCOC suggests that quality of care is not, on the whole, being compromised by services.

What is being compromised is the population served. With increased demand and reduced or static funding some palliative care services are required to restrict their delivery to patients with specific diagnoses, such as cancer or motor neurone disease. This means that access to high quality end of life care is denied to many who need it.

The lack of a needs based service delivery model across the country results in inefficient distribution of services with overlap or duplication in some locations, contrasting with a lack of access elsewhere.

"Some health service districts have only one contracted provider of primary services and others have up to six. In the Brisbane area, three specialist palliative care consultancy services service the same health service district". (Queensland)

It can be both difficult to determine where the overlaps occur, and difficult to implement strategies to reduce wasteful duplication. However:

"... developing and implementing a population based state wide plan for palliative care service delivery in Queensland would lead to more centralised control of funding and improve the state's capacity to maximise the efficient use of resources". (Queensland)

3.1. Fast Tracking Palliative Care Patients

Fast tracking palliative care patients from Emergency Departments (ED) and Intensive Care Units at any hour of the day or night seven days a week into the palliative care stream provides a more efficient system, prevents delays in appropriate care and frees up beds for those who need them most.

Eastern Health in Victoria has successfully developed a protocol for fast tracking patients from EDs. Not only have they improved the quality of patient care and the flow through the hospital, but this initiative has saved an estimated 172 bed days and more than \$100,000 at no additional cost to the system. An evaluation of the protocol shows that 87% of the transfers have been appropriate: i.e. they have not had to transfer back to acute care.

“Mrs F was a 64 year old smoker with a known pancreatic cancer, struggling to care for herself at home. She was brought in to the ED by her family as they were concerned that she was no longer able to look after herself and was not eating. Mrs F hated being admitted to the oncology unit as it was impossible for her to smoke in the ward and smoking was one pleasure in her life. After a fast track transfer to palliative care, Mrs F was able to be cared for in a room overlooking a garden and to smoke safely outside. In addition, Mrs F’s quality of life was improved by visits from volunteers, borrowing books from the library and even a massage. Mrs F died with her family present two weeks later. Had she been admitted to the acute system, she may have had three or four bed moves in that time”. (Victoria)

A significant gap in efficiency is the absence of strategic planning in palliative care at state and territory level. The majority of states and territories do not have current palliative care strategic plans. This makes planning for service provision including funding and evaluation of service outcomes extremely problematic.

Efficiency of service delivery could also be enhanced by encouragement of increased use of advance care plans (supported by appropriate nationally consistent legislation). Such plans should be attached to all eHealth records, along with inclusion of a person’s substitute decision maker to enable efficient and appropriate service delivery should the person lose decision making capacity.

Summary

A lack of efficiency in palliative care service provision is underpinned by a lack of planning and strategy in the delivery of services leading to duplication in some cases. Improvements in palliative care service provision not only results in better care of the dying, but can improve the efficiency of the health care system as a whole.

The prevention of hospital admissions, emergency admissions, a reduction in the use of acute services, and the minimisation of futile treatments and procedures will result in the co-benefits of financial savings for the health system and freeing up of acute hospital beds for those who need them.

Recommendations:

49. That all state and territories be required to have strategic and business plans in place with appropriate evaluation systems reporting on service outcomes.

4. The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

While palliative and end of life care should be core business for aged care services many end of life care needs of older Australians are not being well met under the current arrangements for community and RACFs. The evidence is clear that the preference of older people to die in familiar surrounding including their own homes or in the facility they are living in, so they can be cared for by people they know rather than having to move to unfamiliar surroundings such as a casualty or hospital ward. However, there are limited options for this when it comes to receiving specialist palliative care. In the Productivity Commission report *Caring for Older Australians*, it was acknowledged that some aged care facilities provide excellent palliative and end of life care, but in general it was poorly provided and inconsistent in many RACFs.

Some aged care facilities have relatively good access to both primary care physicians skilled in palliative care and to specialist palliative care physicians. Some facilities, particularly high care facilities, have systems in place to limit hospitalisations by providing care in place.

In their submission to the Productivity Commission, Eastern Palliative Care Association stated that while palliative care was 'core business' for aged care facilities, often staff were not equipped with the appropriate skills:

"... we find that the quality of direct care staff in aged care facilities fluctuates, some facilities have excellent proactive well trained and competent care staff, other facilities employ care staff that have absolutely no understanding of the palliative approach and the specialist nursing care required for good palliative care for these residents. It is our view that a sound understanding of the palliative approach would be 'core business' and imperative in the aged care sector".

Too often, older Australians are transferred to acute care hospitals for pain management and to die, due to insufficient expertise being available in the residential care or home environment. A key area of concern is the lack of knowledge and skill among the aged care workforce in the area of palliative and end of life care. An expansion of aged care services for older people with chronic conditions will need to be complemented by an expansion of the capacity and competence of primary health care services to provide generalist palliative care for people living in the community and in aged care homes, supported by increased collaboration and networking with expanded specialist palliative care services.

The Productivity Commission considers that there is a strong case for a greater role for residential and community care providers to deliver palliative and end of life care. Not only is this likely to be less expensive than equivalent services delivered in a hospital, but more appropriate care can be provided in a home environment that best meets the needs and wishes of the dying. In terms of cost of care, the

Productivity Commission quoted the United Kingdom's Care Quality Commission (CQC):

'Where money may be shifted from one part of the system to another, the transformation of services may sometimes be cost neutral, rather than reducing costs. However, if such service transformation results in improved outcomes for those using the services and a greater sense of empowerment and quality of life, then this certainly represents far greater value for money for all involved'.

Older Australians should have access to specialist palliative care irrespective of their care setting. It can lead to a more efficient use of services (including reducing the strain on public hospitals) and result in better care outcomes. Payments for palliative and end of life care services should be aligned with those provided in other health care settings to ensure that those people receiving palliative care in RACFs do not receive a lower standard of palliative care than someone in an alternative setting.

However, high quality, effective palliative and end of life care can only be provided in residential and community aged care settings if staff are adequately trained and resourced. As a 'core' aged care business, it should be a basic competency of aged care worker training. Specialist palliative care services could also complement the care provided by residential care staff and GPs (as is done in hospitals). The Australian Healthcare and Hospitals Association supports:

'... the need for better access to specialist palliative care services and would like to see more emphasis placed on up-skilling a range of health professionals at all levels in palliative and end of life care'.

At a minimum, best practice guidelines for palliative care should be used by providers of aged care to improve routine care. In the Productivity Commission's report they recommended that PCA be funded to educate and provide advice to providers about applying best practice guidelines. The Productivity Commission also recommended a formal link between the standards for providing quality palliative care and the *Residential Aged Care Accreditation Standards*.

Hospitals are often not equipped to provide appropriate palliative care and more needs to be done to increase their capacity to provide quality care along with improved care pathways enabling patients to move to appropriate settings when required. The proposed activity based funding model may help to better define where a patient is best placed for palliative care i.e. either in a RACF or sub-acute facility, but the need for flexibility both in terms of individual patient needs (who may need to move across different settings at different times) and funding (which should follow the patient rather than the patient fitting the funding model), will always be a matter of importance in providing the most effective outcomes for palliative care patients. A better coordinated and seamless system would provide a more effective outcome for palliative care patients but there needs to be more resourcing for care coordination and management.

The *National Palliative Care Strategy 2010* identifies consumer involvement in the planning of palliative care services as one of the key ways to improve quality and effectiveness. It also implies ownership and acceptability of the process. Representations or case studies of both patients and family members' experiences provide a feedback loop to improve the system and should be incorporated in research and evaluation into palliative care service design and planning in all settings where palliative care is provided. Effectiveness in palliative care arrangements arises when health service consumers have access to a flexible system with services closer to home providing a range of choices. There needs to be more investment and appropriate funding mechanisms (including flexible funding) in place to support this so that the right care is provided in the right place, at the right time. Continuity of care depends on the integration and coordination of service and organisations involved in patient care.

The National Health and Hospitals Reform Commission (NHHRC) recommendation for a needs based approach to palliative care delivery acknowledges that patients have different needs that may change over time and ensures people can access the right care in the right setting. *PCA's A guide to palliative care service development: A population based approach* provides an overview of the actions required to ensure access to palliative care based on identified need. The Australian Government has a key role in promoting a population based approach to palliative care service delivery across the continuum of care and ensuring greater adherence to the principles of this approach to care by primary, aged, acute care and specialist palliative care services. A population based palliative approach will ensure that resources are distributed equitably based on need and will make better use of acute care services.

Hospital care is often not the most appropriate option for palliative care for a number of reasons. It can be alienating, noisy and confusing for many patients particularly the frail aged; shared rooms are often not appropriate for the patient or the grieving family members; and many staff do not understand or have training in palliative and end of life care.

Community care can be effective where staff are suitably trained and can access specialist support and equipment if required. However, this is only practical where the home environment can be modified to accommodate any necessary equipment and the family/individual are desirous of home based care. In some instances it can be distressing for family members, and individuals can experience high levels of anxiety about how they will cope. In many cases, where appropriately supported, a community setting is the most effective way of meeting the individual's needs and wishes. Underpinning a good support base and effective palliative care in the community setting is the need to involve GPs and other members of a multidisciplinary team who in turn are supported by specialist palliative care physicians.

Unfortunately the availability and location of specialist palliative care physicians is limited around the country. GPs have always and will continue to provide care of the dying patient in the community. However, there needs to be adequate funding of

specialist palliative care physicians to provide both an education service for primary health care practitioners' upskilling and a consultancy service for all GPs.

A critical issue impacting on provision of effective care is the advent of the consolidation of general practices around the country and a trend away from committing to do home visits leading to a reduction in the numbers of GPs available to visit patients in their homes. It is unlikely there will be a significant increase in the numbers of specialist palliative care physicians in the foreseeable future which will impact most in rural and remote areas. However, given this reality, the next best option is to build the capacity of the existing health practitioner workforce through access to undergraduate courses in palliative care (PCC4U) and extending the coverage of palliative care courses throughout the tertiary teaching sector; GP training in palliative care (both undergraduate and post graduate training) and increased funding to the Medical Specialist Outreach Assistance Program (MSOAP) to provide more exposure in rural and remote areas.

Summary

The quality of palliative care provided through primary health care services including GPs is variable, and largely reliant on the individual knowledge and experience of the GP and the primary health care team. The strength of local networks between health practitioners and services can have a significant impact on the comprehensiveness, timeliness, and adequacy, of care received. Too commonly there are poorly established local networks and primary care providers have limited relationships with specialist services.

Recommendations:

50. That residential and community care providers receive appropriate payments for delivering palliative care, including accessing specialist palliative care services where required as recommended by the Productivity Commission.

51. That flexible funding models and support structures be adopted for regional and remote access to specialist palliative care services e.g. fly in/fly out programs, or teleconferencing.

52. That the current system of discrete care packages across community and RACFs be replaced with a single integrated and flexible system of entitlements, including palliative care services, as recommended by the Productivity Commission.

53. That every specialist palliative care service which is classified as Level 3 by the Standards be funded to employ a Community Nurse Practitioner, Palliative Care, to provide palliative care in RACFs, the training of palliative care practice to staff of RACFs and for liaising with GPs, Geriatricians and other medical specialists.

54. That all major hospitals have an adequately staffed palliative care consultation service.

5. The composition of the palliative care workforce

The palliative care workforce represents a true multidisciplinary team whose approach to providing palliative care is holistic and needs based. A palliative approach is an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life threatening condition, their family and carers.

A multidisciplinary team is a group of health care providers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs of the target population. A multidisciplinary team typically includes one or more physicians, nurses, social workers, psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may also be part of the team.

5.1. Workforce Groups

5.1.1. Specialist palliative care providers

Is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body that provides consultative or ongoing care for patients with a life threatening illness, and support for their caregivers and family. Specialist palliative care builds on the palliative approach adopted by primary health care providers, and reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers work in two key ways: first, by providing direct care to referred individuals and their families; and second, by providing a consultancy service to primary health care providers and therefore supporting their care of the patient and family.

5.1.2. Primary health care providers

Is taken to include all those health services and staff that have a primary or 'first contact' relationship with the patient with a life threatening illness. The use of the term 'primary health care provider' in this context refers to GPs, community nurses, staff of RACFs and multi-purpose centres. It also includes other specialist services and staff, for example oncologists, renal, cardiac or respiratory physicians, and staff of acute care hospitals and services. These staff, while specialist in their own areas, may undertake an ongoing role in the support of patients with life threatening illness by adopting a palliative approach to the care they provide. In this context they are seen as the primary health care service, with specialist palliative care services involved on an 'as required' basis only. In general the substantive work of the primary health care provider would not be with people who have a life threatening illness.

5.1.3. Primary generalist providers

In the context of end of life care, a primary health care provider is the first contact medical, nursing or allied health professional, who undertakes an ongoing role in the care of patients with an eventually fatal condition. In general, the substantive work of a primary generalist provider is not in the care of people who are dying. Primary health care providers in end of life care include: GPs; Community nurses; Allied Health practitioners; Pharmacists; staff of RACFs; Health practitioners in acute care hospitals; and trained volunteers.

Primary health care services provide on-going support from diagnosis through to the death of the patient, in accordance with PCA's population based service provision models. Primary health care services assess and refer patients to specialist palliative care providers when the patient's needs exceed their services capability. Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people.

5.1.4. Primary specialist providers

In the context of end of life care, other primary specialist providers include all other specialists that have first contact and include oncologists, renal, cardiac or respiratory physicians. In general, their substantive work is not in palliative care.

5.1.5. Primary carer

The primary carer is usually self-identified. The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the coordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, eg the administration of medications. They provide the primary support role for the patient at all levels of need. (see Appendix 2)

5.1.6. Volunteers

The integral role that volunteers play in palliative care is an exception, rather than the norm in health care delivery. They have shaped palliative care and are a vital core of the membership of interdisciplinary palliative care teams. Currently in Australia the essential role of the volunteer in the palliative care team is acknowledged through policies such as the *National Palliative Care Strategy 2010*, the *Standards* and the *Health System Reform and Care at the End of life: A Guidance Document*. The important role of volunteers is also recognised in the PC report into *Caring for Older Australians*.

Following extensive training volunteers increase and enhance the range of supports palliative care services can offer to their clients. Their presence makes services more

consumer responsive, and the involvement of volunteers in all aspects of service planning and delivery can be an effective means of consumer empowerment. Volunteers often liaise between health care professionals and the community by showing the former the particular needs of their community.

Palliative care volunteers increase the social, emotional and practical supports available to the patient and family. Most importantly, volunteers bring normality into the lives of the terminally ill and their carers during a time that may otherwise be dominated by medical treatments. They are often the one constant for patients and families and as a result get to know them much better than the doctors and nurses.

Appropriately trained volunteers can perform tasks that otherwise may need to be undertaken by professional staff, allowing professional staff to focus on their areas of specific expertise and reducing their stress, and possibly enabling the service to take on more clients. (see Appendix 2)

There is currently a lack of evidence of where palliative care volunteer programs should be based, how they operate and ensure best practice, what are the necessary roles of volunteers and where they work. Anecdotal evidence suggests there is significant variation in how volunteers are recruited, selected, trained, supervised and supported.

All of this can result in issues relating to quality of service (including management, supervision, training and evaluation including program evaluation), wasted time spent reinventing the wheel, restricted numbers of people willing to volunteer, impact on service provision and innovation, and issues with palliative care volunteer movement between localities.

The development of national palliative care volunteer standards and nationally consistent competency based education and training will ensure end of life care is maximised and of the best quality. Palliative care volunteers work with some of the most vulnerable people yet there is no consistent quality practice across the country. They can reduce the pressure on the hospital and aged care system through the provision of respite, emotional and practical support.

The development of the inaugural National Strategy for Volunteers, which demonstrates the contribution of the not for profit sector, and the Productivity Commission's report, Caring for Older Australians, both outline the importance of a strong best practice volunteer workforce if Australia is to meet future health needs. The role of the palliative care volunteer will become increasingly important in the future with the shrinking pool of experienced staff and increasing consumer and carer need.

5.1.7. Development of a framework for palliative care in a primary health care setting

Most of the last year of a person's life is spent at home, and most health care is provided by a person's general practitioner (GP). However, providing high quality care at the end of life is among the most complex challenges for GPs.¹⁴⁹ Patient symptoms may be severe, disease trajectories difficult to predict, family issues complex and the GP's own beliefs and fears about death and dying challenging.¹⁵⁰ There are also a number of structural and resource barriers including lack of time and remuneration, lack of training, knowledge and resources, and experience in palliative approaches.¹⁵¹

Despite these barriers there is evidence that the proactive involvement of GPs enables more terminally ill patients to die at home and that this is the preference of patients and their carers.¹⁵² There is also widespread agreement that a high value health care system needs to be built around a primary health care focus with the primary medical responsibility being borne by the GP, supplemented by specialist teams on the basis of complexity of need.¹⁵³ It is imperative therefore that GPs, and the primary health care teams that support them, are well equipped to provide care to people as they approach the end of their life.

Developing, refining and rolling out an Australian Primary Palliative Care Framework would help fulfil a number of the Australian Government's health reform objectives and is considered a high level priority for both PCA and the National Medicare Local Network (formerly AGPN).

It is proposed that the Australian Primary Palliative Care Framework be modelled on the Gold Standards Framework (GSF) developed in the United Kingdom. The focus of the GSF is on helping people live well until the end of life. It is a systematic, evidence based approach to optimising care delivered by generalist providers for all patients nearing the end of life. The GSF provides the fundamentals of quality care at the end of life through education and promotion of quality end of life care delivery; enables organisational and system changes to accommodate optimal delivery of end of life care; supports care planning in the final year of life; provides the context for discussion of advance care plans; enables care closer to home; is patient led and focused on patient need; and can be applied across all care settings including home, hospice, hospitals and others.

¹⁴⁹ Mitchell, GK et al. 2008, 'Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomized controlled trial'. *Palliative Medicine*, vol. 22.

¹⁵⁰ National EOL Framework Forum, 2010. *Health System Reform and Care at the End-of-life: A Guidance Document*. Palliative Care Australia.

¹⁵¹ Rhee, JJO et al. 2008, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners'. *Journal of Palliative Medicine*, vol. 11.

¹⁵² *Ibid.*

¹⁵³ National EOL Framework Forum.

The model will need to be adapted from the United Kingdom to the Australian health care system to suit the Australian context. However, the Australian Primary Palliative Care Framework would complement and build on existing models at state and territory level rather than duplicate them.

The establishment of Medicare Locals provides the foundation for implementing the Framework as they have already been charged with the task of developing and implementing coordinated, integrated primary health care services that meet the needs of local communities and ensures access to appropriate health care for the whole population, including older people. They are ideally placed to work with GPs and other primary health care providers in their local communities.

A project will be developed through a collaboration between the National Medicare Local Network, PCA and a panel of experts in the delivery of palliative care services in a primary health care setting.¹⁵⁴ The main components of the proposed approach will be:

- Establishment of a steering committee comprised of experts in the delivery of palliative care services in primary health care settings drawn from general practice, allied health and specialist community based palliative care services, and academics with expertise in major elements that may be required for the Framework.
- Review of the GSF and other international and national models and initiatives to ensure the proposed Framework complements and builds onto existing initiatives.
- Roll out of a pilot program and Framework refinement which will involve the trialling of the Framework in up to six Medicare Locals who can demonstrate a significant interest and capacity to undertake a pilot program.
- System-wide adoption of the Australian Primary Palliative Care Framework, involving a system-wide roll out of a final Framework among those Medicare Locals that are 'system ready' to adopt it.

A comprehensive evaluation of system (i.e. primary health care provider, specialist services etc.) outcomes and patient/family outcomes will be built into the program from the inception of the system-wide roll out.

Summary

A key feature of palliative care is that it is provided by a multidisciplinary team, resulting in truly holistic care which aims to maintain the patient's quality of life. Many different individuals contribute to the multidisciplinary team.

¹⁵⁴ Australian General Practice Network. Healthy ageing: time for action. Draft submission to the 2012-2013 Federal Budget.

The role of carers and volunteers cannot be underestimated and there is a need to strengthen the role of volunteers in the system, which could not maintain the relatively high quality of care currently experienced in Australia without them.

Recommendations:

55. That a National Palliative Care Volunteer Workforce Strategy be developed and implemented.

56. That Palliative Care Australia and the National Medicare Local Network be supported to move from a development to an implementation phase of the Australian Primary Palliative Care Framework to support GPs to provide appropriate and much needed end of life care to Australians.

5.2. Its ability to meet the needs of the ageing population

Services for people with life threatening conditions, including COPD, dementia and heart failure are underdeveloped and fragmented in Australia. There is no mention of the need for palliative care for people with life threatening chronic diseases in the few disease specific reports and documents available in Australia, yet it is chronic disease beyond malignant cancer that is a significant emerging challenge for the health system in general and for palliative care in particular. People will be dying in increasing numbers from a range of complex chronic diseases that were not as prevalent 20 or 30 years ago.

“The staffing levels have not changed a lot in the last few years though the number of clients is increasing. We are also suffering from the lack of Palliative Care consultants in Australia as we have not been able to recruit to some of the medical positions for several years. Though we currently don’t have a large ageing population in the NT we do have an Indigenous population who are suffering from preventable chronic diseases and are dying up to 17 years earlier than their non-indigenous counterparts”. (Northern Territory)

End of life care should be considered a core competency for aged care workers as recommended by the PC in their report *Caring for Older Australians*. Aged care services need to develop and implement workforce and service development plans that acknowledge their end of life care responsibilities. Furthermore, the implementation of needs based end of life care should be informed by standardised referral criteria that outline the requirements for referral pathways relevant to aged care, primary health care and specialist palliative care.

To meet these increasing demands the Australian and New Zealand Society for Palliative Medicine (ANZPM) has pointed out the shortfall in palliative medicine specialists in Australia. In terms of the specialist workforce, there is significant gap between the current and ideal workforce numbers. According to the Australasian Chapter of *Palliative Medicine Workforce Report of 2007* there are 0.5 FTE Palliative Medicine Specialists per 100,000 population in Australia. The *Palliative care service provision in Australia: A planning guide* estimates that the minimum number of specialists for a reasonable provision of service is 1.5 FTE per 100,000 population. This position has evolved over the past decade where, increasingly, palliative care services are being asked to advise on aspects of the care in patients with other life threatening chronic diseases. For many services, 30-40 % of their work will have a focus on non-malignant chronic diseases, many of which are associated with the increasing older population and lifestyle patterns of Australians. There is an expectation that this proportion will increase significantly in time as more people require palliative care for a range of non-malignant chronic diseases.

The significance of our ageing population to aged care, and the demand on aged care services for end of life care, is substantial and will increase with the expected increases in the proportion of the population aged over 65 years. For dementia

alone the 'epidemic' affecting an estimated 280,000 people today is expected to affect about one million Australians by 2050.¹⁵⁵

Dementia care as palliative care requires a different approach than palliative care for conditions such as cancer as the disease process will take place over a longer period of time. It involves early engagement in advance care planning, and requires more flexibility than palliative care approaches to other diseases. Unlike cancer, where a person at the end of their life is likely to be similar in personality and cognitive ability to the person first diagnosed, the course and prognosis of dementia means that most people with the disease will be subject to significant changes in cognition, functional abilities, and possibly behaviour, emotions and personality. This means that the palliative care process evolves over time, and involves a shift in the locus of control and decision making from a collaboration involving the person with dementia, their carers and health practitioners in the early stages, to carers and health practitioners only later on.

Declining cognition also means that a person dying with dementia is unlikely to have the capacity (legal or functional) to make decisions and communicate their preferences regarding care. This means that any such decisions must be made much earlier in the course of dementia than for other diseases, or alternatively, must be made by proxies on behalf of the dying person. Dementia is difficult to diagnose in the early stages, and while dementia inevitably leads to death, the prognosis, once diagnosed, is difficult to determine. Unlike other terminal illnesses where the course and prognosis might be given with relative certainty at the time of diagnosis, the unpredictable course of dementia (in terms of both time and rate of decline) means that the palliative care process will require greater flexibility by health practitioners to adapt to new circumstances as the condition progresses.

RACFs are increasingly the place of death for people with terminal conditions, unless residents are transferred to acute care facilities. Access to, and the quality of, palliative care is diverse and inconsistent in RACFs in Australia. Some aged care facilities enjoy ready access to primary health care physicians well skilled in palliative care and to specialist palliative care physicians. Some facilities, particularly high care facilities, have systems in place to limit hospitalisations by providing care in place. Supporting aged care facilities to work towards providing quality end of life care will require RACFs to be additionally resourced to provide appropriate palliative care. This will include appropriate access to GPs, to palliative care specialists under agreed and consistent referral and access criteria, and to nurses who can administer opioids. It will also include access to PBS subsidised palliative medicines for residents, and the structuring and resourcing of specialist palliative care services so that they are able to provide care and consistent support for primary health care providers in the RACF setting.

More needs to be done to make RACFs culturally sensitive to the care needs of people with terminal conditions. Cultural awareness programs for all RACF staff

¹⁵⁵ Alzheimer's Australia <http://www.fightdementia.org.au/understanding-dementia/statistics.aspx>

should become mandatory beyond the current Indigenous cultural awareness program.

The *Guidelines for a Palliative Approach in Residential Aged Care* were launched in 2004 and distributed to every aged care home in Australia to help aged care team members to apply a palliative approach in RACFs. In 2011 the *Guidelines for a Palliative Approach for Aged Care in a Community Setting*, were launched help aged care team members apply a palliative approach in older people's own homes.

PCA has been involved in projects implementing the residential Guidelines, including a Resource Kit, assisting the development of training resources for Certificate III and Certificate IV competency units in a palliative approach and working with the Australian General Practice Network (now the Australian Medicare Local Network) and Divisions of General Practice (now Medicare Locals) on the Engaging GPs' Support for the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care project.

Summary

Residential aged care is, and will continue to be, the place of death for many people with terminal conditions. In addition, people will increasingly present with a range of more complex chronic diseases.

Palliative care must be a core competency for aged care workers and core business for aged care facilities if we are to meet the needs of older Australians in residential aged care. The aged care workforce needs to be increased, in both number and skills in end of life care.

Recommendations:

57. That end of life care should be acknowledged as a basic competency for aged care workers, regardless of the setting in which they work, and included in the core curricula of aged care worker education and as an element of ongoing training.

58. That nationally standardised referral criteria for patients with palliative care needs that promote needs based service provision be developed and implemented, with the support of a national education campaign.

59. The systems for coordinating the management of pain and symptom relief for residents in RACFs be introduced that address limitations in who can prescribe and administer medication so as to ensure residents' care needs are appropriately met.

60. That a feasibility study should be conducted to determine how integration of the National Palliative Care Standards with the Aged Care Accreditation Standards could best be achieved.

61. That workforce shortages in aged care must be addressed as this is negatively impacting on the capacity of services to provide quality end of life care.

62. That the role of specialist palliative care in supporting primary health care provision of needs based end of life care be better recognised and supported through appropriate funding and program development.

63. That the number of palliative medicine specialists be increased from the current level of 0.5 FTE per 100,000 people to 1.5 FTE per 100.000 people as recommended in the Palliative care service provision in Australia: A planning guide.

5.3. The adequacy of workforce education and training arrangements

“Staff turnover and the difficulty of keeping skills maintained for all staff. Recruitment of specialised staff is difficult due to shortages nationally in Medical and nursing avenues. The Territory is not on par with other states and territories in reimbursements in relation to isolation and there is a lack of support for rural and remote clinicians”. (Northern Territory)

The profile, skills and capabilities of the Australian health workforce is being shaped by changing patterns of disease, increasing demands for quality care at end of life, system-wide shortages of health practitioners, and reforms to systems of care.

Population based approaches, together with an understanding of differing care pathways that are responsive to the needs of specific populations, should provide an organising framework for development of models of care and health service delivery plans. A workforce with skills and capabilities to support emerging models of care is needed to meet community expectations of safe and quality care for all.

Quality end of life care is required for people at all ages and across all settings of care. In practice, health practitioners will provide services for people who are dying to varying degrees, depending on their specialty and practice setting. An integrated and person centred system of care for people at end of life requires all healthcare professionals to be appropriately prepared for providing end of life care, to ensure they can deliver care consistent with *Standards*. The nature and scope of preparation will vary between primary and specialist settings and between disciplines, but must enable health professionals to meet a level of competence necessary for their scope of practice.

Health practitioners working in specialist palliative care services need to demonstrate specialised knowledge, skills and competence as defined by relevant professional and disciplinary standards.

A well distributed, accessible and appropriately trained and skilled specialist and primary health care workforce is required to meet the needs of people at end of life. Specific incentives and alternative models may be required to match the service challenges in regional, rural and remote locations.

A systematic strategy for developing capabilities in end of life care for the whole health workforce is integral to the provision of high quality and sustainable services for people who are dying. This strategy requires appropriate educational responses at all levels, including courses which prepare health practitioners for entry to practice and continuing professional development, as well as specialist training programs.

Access to sufficient numbers of specialist training positions and educational programs is needed to meet the growing demand for quality end of life care. The number of training positions should be determined on the basis of a robust

workforce planning model. Continuing professional development in palliative care requires flexible approaches to meet the needs of health practitioners in various practice contexts to promote accessibility and to enable ongoing learning. A knowledge-led culture that supports opportunities for health practitioners providing end of life care to engage in ongoing learning and continuous improvement is integral to quality end of life care.

Inter-professional learning, combined with appropriate discipline specific learning opportunities, are emerging as effective approaches for preparing health practitioners to provide quality end of life care.

Cultural competence and culturally safe practice needs to be integrated into learning at all levels. Of particular importance will be the need to effectively address the delivery of end of life care services to Indigenous and CALD communities, requiring a fundamental shift in the ability of the health workforce to meet their needs.

5.3.1. Workforce distribution, retention and attraction

A major challenge to equitable access to palliative care services is the poor distribution of health practitioners, particularly in rural and remote regions. System-wide issues such as inability to take leave, limited availability of locums, lack of inter-professional support and other lifestyle and professional considerations, all impact on workforce availability. There is strong anecdotal evidence that specialist palliative care services are not available when and where required, particularly where the only service that is provided is through a single palliative care provider. This situation has significant detrimental impacts for the quality of care and the choices that people at the end of life and their families can access.

Australia has about half the palliative medicine specialists it needs under current referral patterns, with unmet need being by far the greatest outside of metropolitan areas. Data for New South Wales shows that the number of palliative medicine specialists outside of the greater Sydney metropolitan area is about one third per 100,000 of the state average¹⁵⁶. This has significant implications for the ability to develop flexible models such as shared care or hub and spoke models in non-metropolitan areas as they rely on specialist medical care to be close within a geographical service region.

Palliative care nurses have the same aged profile issues as the rest of the workforce^{157,158}. However, there is some evidence to support the anecdotal view that sector turnover is low and that new recruits are being drawn into the available palliative care nurse workforce pool¹⁵⁹. While this may bode well in the short term, there is a larger risk that the overall growth in the available workforce may be

¹⁵⁶ Palliative Care New South Wales.

¹⁵⁷ Department of Human Services *Palliative Care Workforce A supply and demand study* (2006).

¹⁵⁸ SA Health *Palliative Care Services Plan 2009-2016*

¹⁵⁹ Department of Human Services. op.cit.

insufficient to meet needs, or that industry dynamics, such as the enormous growth in GP practice nurses over the last decade may impact on availability.

The emerging role of nurse practitioners in palliative care in providing a model of care that reflects changing needs of the health system is evident, with a small number of palliative care nurse practitioners now accredited in Australia. To date, analysis of the potential for such roles, and the training and support requirements for them to reach their potential, is limited.

The availability of GPs is a generic problem with about half the number being available to regional, rural and remote areas compared to metropolitan areas (although availability in some outer metropolitan areas is an issue as well). These shortages are further exacerbated by logistical challenges of servicing highly dispersed populations

For end of life care, the workforce situation is further exacerbated for other health practitioners that are a key part of the specialist and non-specialist interdisciplinary team. People living in outer regional centres have access to about half as many allied health practitioners as people in metropolitan centres¹⁶⁰. Addressing the shortage of health practitioners in under served communities requires a number of incentives that are both financial and non-financial and well integrated 'hub and spoke' health service networks¹⁶¹.

5.3.2. Workforce roles and changing delivery models

Models incorporating shared workforce roles and responsibilities are recognised as being conducive to palliative care, with members sharing information and working interdependently¹⁶². The benefits of these approaches are now being recognised in the broader health service delivery contexts with the greatest shift occurring in primary health care settings.

While palliative care has been at the leading edge of interdisciplinary approaches, there will need to be greater use of referral pathways between acute, sub-acute and primary health care sectors to consolidate the real benefits to be gained from person centred team approaches. Such team approaches will require significant communication as well as flexibility and responsiveness to meet complex needs. A number of factors are also increasingly leading to a re-examination of roles, responsibilities and scope of practice of health care professionals, including inherent relationship changes caused by new team based and shared care models¹⁶³; workforce shortages; and support for better use of the full resource capacity of

¹⁶⁰ Department of Health and Ageing *Primary Health Care Reform in Australia* (2009)

¹⁶¹ Scott IS Health care workforce crisis in Australia; too few or too disabled? *MJA* 2009; 190 (12): 689-692

¹⁶² Crawford GB and Price SD. Team working: palliative care as a model of interdisciplinary practice *MJA* 2003; 179 (6 Suppl): S32-S34

¹⁶³ Ibid

existing health practitioners. This will also need proactive but sensitive management of barriers to change including professional resistance¹⁶⁴.

Emerging models of care will also require targeting of workforce development in specific sectors: ensuring a high level of competency among specialist palliative care nurses to support and, in some cases, lead interdisciplinary teams in primary health care settings; integrating the extended clinical role of palliative care nurse practitioners ensuring that residential aged care staff have appropriate and accessible training and support; and supporting GPs in further developing their lead/coordination/collaborative roles in working with primary health care and specialist interdisciplinary teams, through engagement of Medicare Locals.

Ensuring an increased recognition of specific Indigenous health workforce needs and in particular the need to raise the profile and skills of Indigenous workers in supporting palliative care as part of community controlled or mainstream health care services.

5.3.3. Education and training

As death is a normal part of the life continuum, and our health system is an important part of providing services for those at the end of life, a baseline goal is that all health care professionals require as a minimum, knowledge and skills to provide competent, safe and effective care of people approaching the end of life. This means that some preparation in the knowledge, skills and competencies required to provide care to people approaching the end of life should be built into all undergraduate and postgraduate courses that prepare health practitioners for entry to practice, and for practice in the various specialties.

The *Standards* require staff to be appropriately qualified for the level of service offered. In practice, health care professionals will be involved with people who are dying to varying extents depending on which part of the health care continuum, specialty or setting they operate within. As a result, a range of post graduate and continuing professional education and training approaches are required to flexibly cater for differing circumstances.

This will need different levels of competency and knowledge with appropriate minimum competencies being applied to match the requirements at each level. There are four common core learning domains that need to be applied across all professional groups, undergraduate, postgraduate and continuing education and all settings – end of life care principles; communications skills for end of life; assessment of a person's needs and preferences; and symptom control. Common core learning domains are important to workforce development in that they assist in developing a consistent approach to intersectoral and interdisciplinary learning. Learning and teaching of palliative care should also reflect the core values that underpin the national standards.

¹⁶⁴ Tang M Multidisciplinary teams in cancer care: pros and cons *CancerForum* 33 (3) 2009

The growing complexity of care provided in the community requires education and training of students and health practitioners to be better incorporated at all levels, in appropriately resourced interdisciplinary community based settings. This involves the adequate availability of clinical training and experience in the community as well as acute and sub-acute care settings at undergraduate, postgraduate and continuing professional education. All education and training needs to be based on effective learning methodologies and will need to provide for flexible approaches that reflect the real world. These will vary between professions and settings but are likely to encompass elements of experiential learning and reflection, self directed learning, mentoring, scenario analysis and role playing and interdisciplinary learning.

The role of specialist palliative care providers is crucial in facilitating both specialist and generalist teaching and learning. However, significant concern exists about the capacity of specialist services to provide meaningful clinical placements, and this is a generic issue that has been recognised as in need of support as part of national health reform processes.

Summary

All health practitioners need to be appropriately prepared for providing end of life care, to ensure they can deliver care consistent with the *Standards*. The nature and scope of preparation will vary between primary and specialist settings and between disciplines, but must enable health practitioners to meet a level of competence necessary for their scope of practice. This workforce should be accessible and well distributed to allow equitable access for all Australians.

There is a need for a comprehensive workforce strategy in this regard, which embeds palliative care as a core part of the curriculum across all undergraduate, postgraduate and continuing education courses.

Recommendations:

64. That a Palliative Care Workforce Strategy should be funded, developed and implemented which identifies workforce resources required across all services (general, specialist and community) and aims to ensure that end of life care is a basic competency for aged care workers.

65. That all health professionals should be appropriately qualified and competent for the level of service offered. This means:

- a. all undergraduate and entry to practice courses in the health professions should meet the benchmarks established by the Palliative Care Curriculum for Undergraduates (PCC4U) project, to enable all health practitioners to develop core capabilities in end of life care;**
- b. continuing professional education programs should be underpinned by a nationally consistent set of core competencies in end of life care, and**

be able to be delivered flexibly to meet differing needs and changing circumstances;

c. all health practitioners working in specialist palliative care services should have access to training programs to enable them to demonstrate specialised knowledge, skills and competence as defined by relevant professional and disciplinary standards.

66. That a systematic analysis of the palliative care workforce be supported and funded to identify gaps between population need and workforce availability (both for staff type and geographical distribution), and the implementation of appropriate strategies to ensure sufficient numbers of training positions are available to meet current and future needs of the specialist palliative care workforce.

67. That a national approach be ensured to implementation of the competency standards for specialist palliative care nursing practice.

68. That national, state and local workforce development plans are developed that are aligned with a population based model of service delivery that reflect advances in practice.

69. That a role delineation framework based on Palliative Care Australia's Standards be implemented and appropriately resourced in each of the states and territories of to ensure that health practitioners are working within a supportive, high quality service structure, and that clinical and academic education and training programs are adequately resourced to ensure achievement of the Standards.

70. That evidence based guidelines for staffing of inpatient/hospice and community services be developed with the collaboration of all jurisdictional governments.

71. That all jurisdictional governments commit to education and training that builds the cultural competence of Australia's health workforce through undergraduate, postgraduate, vocational, and continuing professional education.

6. The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Palliative Care for all Australians

PCA leads the development of national standards that form the key governing document influencing both specialist palliative care services and primary care providers in the way they deliver care at the end of life. *Standards for Providing Quality Palliative Care for all Australians (The Standards)* provide a framework of minimal standards for systems of care at the end of life for those people receiving palliative care. *The Standards* underpin all strategic, policy and program activities undertaken by PCA and represent a commitment to the stated ideals of quality care at the end of life for all Australians.

The National Standards Assessment Program (NSAP) is a quality improvement program available for all specialist palliative care services across Australia. It is a resource that enables services to engage in continuous quality improvement through self assessment against *The Standards*, action plan development and implementation, as well as peer mentorship.

The NSAP developed a set of quality elements to assist in measuring the criteria of the *Standards*. Specialist palliative care services then self assess against these quality elements. However, some of the wording of the *Standards* and measurable components in the quality elements are not sensitive or relevant for CALD and Indigenous groups. For example, in relation to autonomy and open disclosure of information which is not always appropriate for these groups.

There is a need to make sure that the *Standards* are relevant, reflecting the day to day work of providing palliative care to patients. This has been a major focus of the NSAP in translating the *Standards* into a practical, real life tool for palliative care professionals.

NSAP is currently for specialist palliative care services only. The challenge is to have the *Standards* appropriate and implementable for all the different service levels of palliative care. This is relevant in relation to primary health care, aged care and to rural and remote services in particular. At the moment, services self-nominate their level of service so it is difficult at times to assess who is a 'specialist palliative care service' particularly the difference between primary health care and Specialist Palliative Care level 1. NSAP has provided specialist palliative care services with a tool that makes the application of the *Standards* a lot easier. Participating in NSAP is voluntary. An external evaluation of NSAP in 2010 identified an overwhelming positive response of services to NSAP, even though at that stage NSAP was in a developmental stage.

The *Standards* have been generally endorsed by PCA member organisations although as pointed out above they do not currently ensure access for all Australians.

Palliative Care WA Inc supports the continued development of the *Standards*:

“Specific quality standards for palliative care published by Palliative Care Australia should continue to be supported as a meaningful statement of the behaviours, structures and values which we, the broader palliative care community, agree constitute good palliative and end of life care”.

And added:

“It is important that future iterations of the standards articulate with the Australian Safety and Quality Framework for Healthcare and any other relevant policies and standards”.

In the Northern Territory *The Standards* provide the basis of palliative care by which the Territory Palliative Care strives towards. The Territory Palliative Care team is involved in quality measures to maintain standards of care. However, it is increasingly difficult to apply *The Standards* as there is only a 0.1 FTE Clinical Nurse Consultant allocated to palliative care quality management across the Territory.

“There is a need to have leadership and support in quality in the guidance to maintain the standards, the efficiency and best practice care and the implementation of the NSAP program in the Territory. Having approximately 0.3 FTE (Top End) and 0.2 FTE (Central) would be a start in achieving good adherence to the Standards”.

Summary

Standards should underpin the provision of palliative care in Australia. It is important that they are relevant, reflecting the day to day practice of the way palliative care is provided to patients, their families and carers, and relevant to the whole Australian population.

There is a need to ensure that the *Standards* can be implemented across all levels of service provision in Australia, not just limited to specialist palliative care services.

The *Standards* are broadly embraced by the health professional community largely because they are developed by the sector, for the sector, with the coordination and guidance of the peak body, PCA. PCA looks forward to commencing work on developing the next iteration of the *Standards* later in 2012.

Recommendations:

72. That the National Standards Assessment Program be supported to work with appropriate Australian universities to inform research into quality standards for palliative care.

73. That no service be entitled to call itself a palliative care service unless implementing The Standards.

74. That National Standards Assessment Program be funded to expand its focus beyond specialist palliative care services to include implementation of the Standards in primary health care and aged care.

75. That a review of The Standards be funded, to include mapping with the National Safety and Quality Health Service Standards to minimise the impact for services implementing both sets of standards to ensure that their patients get the best care from the perspective of safety, quality, and palliative care.

76. That all jurisdictional governments ensure that the requirement to meet national health care and palliative care standards is incorporated into all funding agreements for services providing care to people at the end of life, with regular reviews to ensure that these standards are met.

7. Advance care planning

Most people living in developed countries can expect to live longer lives than in the past due in part to advances in public health, medicine and improved socioeconomic conditions. In the past, a range of infectious diseases and or injuries usually led to a rapid death. Today most of us can expect an extended period of progressive disease burden, unpleasant symptoms and pain as the end of life approaches, along with the possibility of impaired cognitive function due to dementia.

People often indicate that they fear the process of dying more than death itself. Although expectations that modern medicine can prolong life and postpone death often exceed reality, concerns about being kept alive in an unacceptable state increases as people age.

People fear being unable to make their preferences known when crucial health decisions are required after they have lost decision making capacity. Community opinion supports self-determination and appointing a trusted person to make decisions on behalf of the person dying or in an impaired decision making state. A focus on advance decision making that recognises the need for planning and communication is consistent with contemporary community interest.

The *Clinical, Technical and Ethical Principal Committee of the Australian Health Minister's Advisory Council*¹⁶⁵ has developed *A National Framework for Advance Care Directives*¹⁶⁶ which although aspirational, describes goals for which policy and practice in developing Advance Care Directives (ACD) should aim.

The National Framework defines advance care planning as a process by which people can plan ahead to make decisions and express values, beliefs and preferences known to guide decision making at a future time when the person cannot make or communicate their decisions. It provides a way to improve the quality of end of life care for people living with a life threatening condition, their family and carers and provides the opportunity to take control of decisions that affect their care. Advance care planning is not only relevant to people nearing the end of life but should be considered as an ongoing conversation between the individual, their family and carers.

Formal advance care planning usually operates within a health, institutional or aged care setting after a life threatening condition has been diagnosed. Such discussions will often result in an advance care plan. The advance care plan can be an oral or written account and may be made by, with, or for the person. An ACD is a formal recording of an advance care plan recognised by common law or authorised by legislation. However, PCA believes that advance care planning should not be reduced to a singular focus on ACDs.

¹⁶⁵ <http://www.ahmac.gov.au/site/membership.aspx>

¹⁶⁶ http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf

Advance care planning should be applied and promoted across the health sector. Facilitating end of life discussions and supporting and engaging in advance care planning is the responsibility of the whole health care system, and should engage all members of the care team. Advance care planning is not the exclusive domain of any particular healthcare sector or setting. Healthcare workers across all levels of the health system should be skilled and educated to engage in end of life care discussions and advance care planning with patients, their families and carers. Specialist palliative care providers have expertise to support all involved in advance care planning.

A review of the current models has found evidence from clinical research studies that the quality of end of life and advance care planning discussions between patients and their care team is generally poor and that there is a substantial gap between what patients want to discuss and what is actually being discussed.¹⁶⁷ The review further concluded that lack of knowledge and competency of health workers impacts on the quantity and quality of these discussions.

A review of healthcare professionals in the United States showed that they receive little or no formal training in initiating and undertaking advance care planning discussions and that many health care professionals feel unprepared for end of life discussions and the process of advance care planning. A number of initiatives in Australia - notably the *Respecting Patient Choices* program¹⁶⁸ - provide education and support to a limited number of health practitioners around advance care planning. However, anecdotal evidence indicates that, overall, a similar situation exists in Australia to that of the United States with regard to lack of expertise in health care professionals in implementing advance care planning processes.

While interventions to improve health practitioner communication skills are a central part of multi-strategic approaches to better integrate advance care planning into everyday end of life care practices, as stand alone interventions they have had inconsistent results.¹⁶⁹ More intensive and community wide interventions that involve collaborative advance care planning mechanisms have demonstrated more positive results.

Promoting awareness of end of life options and engaging in end of life care discussions and planning is not the sole responsibility of the health care system but should also be considered a responsibility of the community and the individual. Formalised ACDs can form an integral part of the advance care planning process for those who wish to develop one, serving as a vehicle for decisions about the type and level of medical intervention people wish to have.

¹⁶⁷ A F Street and G Ottmann, *State of the Science Review of Advance Care Planning Models*, La Trobe University, Bundoora, 2006.

¹⁶⁸ Austin Health, *Respecting Patient Choices program: Report on the Evaluation of the National Implementation of the Respecting Patient Choices Program*, Austin Health, Victoria, 2006

¹⁶⁹ Wilkinson, A, N Wenger and LR Shugarman, *Literature review on advance directives*, RAND Corporation, United States, 2007.

Death and dying must be understood as more than a medical event. Death and dying are profound social occurrences with an impact beyond the individual patient, occurring within a social context. Initiatives to promote advance care planning are most effective in the context of a comprehensive community effort that includes system wide processes directed at integrating advance care planning into care practices.¹⁷⁰

PCA believes that supporting greater capacity to engage in community discussions around death and dying may offer benefits that extend to other social interests. End of life discussions that ensure that the person and their wishes take centre place in planning may also provide a process for considering how to realise preferences around organ and tissue donation that accords with the agenda of some Australian jurisdictions to better support uptake of organ donation.

There is evidence that demonstrates patient care preferences change over time and in accordance with their changing health status and personal circumstances. Over time it is reasonable to expect that a patient's health status and likely future scenarios may change. This underlines the necessity of situating advance care planning as an ongoing process – an ongoing communication process that begins as early as possible in a patient's illness trajectory; is embedded in clinical routines and professional practice; and is preceded by a screening process that assesses the capacity of people.^{171,172}

Legal differences governing advance care planning between states and territories make greater uptake of advance care planning difficult. This contributes to the inconsistencies of language and terminology used in advance care planning. An ACD is a collective term that currently has different meanings across Australia. For instance in New South Wales and Tasmania, an ACD is a common law document that records a person's future preferences for health care but does not appoint a substitute decision maker (this is a deficit which needs to be addressed and promoted throughout Australia). In South Australia, an ACD is a collective term for legislated instruments that record directions and appoint substitute decision makers for health and personal decisions. In Western Australia, an ACD is increasingly used as a collective term for Advance Health Directives, Enduring Powers of Guardianship and common law health directives. Neither Queensland nor Victoria use the term ACD but refer separately to each different instrument by name. The National Framework calls for nationally consistent terminology and defines specific terms and how they are used within its *Code of Ethical Practice for Advance Care Directives* and its *Best Practice Standards for Advance Care Directives*¹⁷³.

¹⁷⁰ Lewis, M, *Medicine and Care of the Dying*, Oxford University Press, New York, 2007.

¹⁷¹ Fried, TR, AL Byers, W Gallo, P Van Ness, VR Towle and JR O'Leary, 'Prospective study of health status preferences and changes in preferences over time in older adults', *Archives of Internal Medicine*, vol. 166, 2006.

¹⁷² Ditto, PH, JA Jacobson, WD Smucker, JH Danks, and A Fagerlin, 'Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences', *Medical Decision Making*, vol. 26, 2006.

¹⁷³ http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf

Summary

Quality end of life care is realised when it works to address a patient's needs and acknowledges their care preferences. Giving patients the opportunity to consider and identify care preferences through advance care planning is one mechanism toward achieving quality end of life care, and should be regarded as part of the role of the end of life care team.

Until there is a uniform approach to advance care planning nationally, there will continue to be uncertainty within the health care sector and the wider community about the worth of ACDs.

Recommendations:

77. That ongoing national campaigns be funded, developed and implemented to increase community awareness of end of life planning options and community capacity to discuss and plan for death and dying.

78. That a national training program on how to engage in end of life discussions and advance care planning be supported, and that it is incorporated into end of life care education for primary and specialist health care providers.

79. That a single common legislative requirement regarding advance care planning be adopted across Australia.

80. That national guidelines be funded and implemented to promote good practice in advance care planning by specifying the key elements to be addressed in working through this process with patients and their carers. These national guidelines and their promotion should be of relevance regardless of the particular method employed for noting and recording advance care plans.

7.1. Avenues for individuals and carers to communicate with health care professionals about end of life care

“The Australian Government may directly, or through Medicare Locals, consider funding trained advance care planning facilitators to do follow up visits to patients and families to assist with the time consuming paperwork and communications”.
(New South Wales)

“RPC Facilitators need to spend time with patients and families to carry out advance care planning consistently and across the board. It takes at least an hour to assist with Advance Care Plan paperwork and this may be preceded by several conversations with the patient and family. Palliative care workers may be in a situation where the time to advance care plan with the patient is not factored in to their clinical role. If advance care planning attracts Activity Based Funding through the federal scheme this may help”. (South Australia)

In Tasmania the *'Healthy Dying'* initiative of the State Government is currently providing a peer support program to disseminate information and assistance with completing an advance care plan. However, it is likely that funding for the program will cease after June 2012. The Tasmanian Association for Hospice and Palliative Care has deep concerns that all the initial work done on advance care planning will be wasted if funding is not continued after June 2012.

Take up of advance care planning is very low in Western Australia despite the proclamation in early 2010 of legislation permitting people to create Advance Health Directives and appoint Enduring Guardians. Barriers to advance care planning include: reluctance of doctors to discuss end of life and advance care planning issues with their patients; poor community understanding and uncertainty about the legal status of advance directives; low levels of training in health care providers and the absence of integrated systems to capture plans and provide clinicians with information when they need it. Integrated advance care planning programs such as the *Respecting Patient Choices Program* have evolved to overcome these barriers and the evidence they are effective is mounting. Such programs are implemented across entire healthcare organisations and have a particular focus on managing change successfully within each organisation.

In the Northern Territory, healthcare practitioners are still unsure about advance care planning and find it a difficult and lengthy discussion to have with their patients.

Carers must be recognised as both a key partner in the care team and a recipient of care in accordance with the palliative care service provision model.

Advance care plans should be incorporated into the Personally Controlled Electronic Health Record (PCEHR) of Australians. This will ensure that all those sharing the information are aware of the needs and wishes of the individual.

Summary

Enabling people's preferences to receive quality care at the end of life in the setting of their choice depends on a number of factors including ongoing physical, emotional, practical and spiritual support from individual carers and their communities as well as health practitioner support.

The key to ensuring a person's preference is open and clear communication including instructions entered into a patient's PCEHR.

Recommendations

81. That advance care planning is included in the role of aged care workers in RACFs and that appropriate training and remuneration is provided to aged care staff undertaking this role.

7.2. National consistency in law and policy supporting advance care plans

While advance care planning is used in all Australian states and territories, they have different forms and names and while recognised under common law, may be prescribed by legislation. This variability makes it difficult for one jurisdiction to legally recognise an ADP from elsewhere. A further difficulty has been the lack of case law in Australia to provide direction on legality of an ACP and how an ACP should be followed in practice.

Australia's Health Ministers recognise the need for standardised national format for ACD and have decided that the challenges posed by divergent laws and concern expressed about the use and application of ACPs are best addressed by a national policy framework. This Framework acknowledges the practical and ethical challenges inherent in this undertaking and the diversity of legislation across Australia. However, it also recognises the potential improvements ACPs may make to care and decision making during times of impaired capacity, especially towards the end of life.

The history of ADP in Australia is consistent with legal differences between jurisdictions beyond common law. In the 1980s South Australia and the Northern Territory enacted the Natural Death Acts which allowed end of life medical preferences to be recorded in a 'living will'. They were subsequently viewed as too limited and several other jurisdictions passed laws providing for Advance Care Directives (ACD) which provided a broader range of decisions including values and lifestyle preferences. In the late 1990s, almost all states and territories had guardianship legislation allowing a person to appoint a substitute decision maker (SDM) to make health and other personal decisions. Some states have legislated ACDs that specifically record health care and medical treatment preferences while others rely on common law. South Australia and Victoria each legislated four different ACDs under three different Acts that contain both internal and external inconsistencies.

The inadequacies and divergence of Australia's ACDs has been the subject of several state and national reviews. These have resulted in the ACT and Queensland each combining their ACD under one single Act to make them more accessible and easier to understand. Other states have retained their Enduring Power of Guardianship.

New South Wales relies on common law ACDs and issued guidelines in 2005. Western Australia and South Australia conducted reviews in 2008 and Queensland, Northern Territory and Victoria in 2009. The issue faced by most jurisdictions in relation to the legality of ACDs has been the lack of case law in Australia to provide direction. It was only in 2009 that a decision in the Supreme Court of New South Wales¹⁷⁴ affirmed the legality of ACDs and provided a summary of principles for practitioners to follow when provided with an ACD in an emergency situation.

¹⁷⁴ Hunter and New England Area Health service v A (2009) NSWSC 761.

Generally speaking, treating staff who provide treatment in opposition to a known directive may be criminally liable. However, legislative inconsistencies across jurisdictions extend to protection of health practitioners who do not follow directives. Advance care directives which are deemed valid are recognised under common law, but to date there have been no Australian cases that have considered when a common law directive will or will not be accepted as valid.

Most Australian jurisdictions have passed laws that empower various kinds of substitute decision makers, though these are not nationally consistent. Substitute decision makers can be appointed by the individual or, in accordance with the statutes, provision is provided for appointment by a tribunal or of someone close to the patients. Anecdotal evidence suggests that legislative inconsistencies across Australian jurisdictions are implicated in failure to uphold advance care directives and in confusion amongst treating staff about rights and responsibilities in relation to directives. For these reasons, PCA supports the La Trobe University review recommending that Australian Government agencies promote the national uniformity of legislation and policies regarding the implementation of advance care plans.

Summary

There is no single piece of legislation regarding advance care planning, in Australia. States and territories have different provisions, meaning that it is difficult for one jurisdiction to recognise the advanced care directive from another. This is further compounded by the use of different terminology.

Legislative differences also make it difficult for healthcare professionals to know their rights and responsibilities in this area. There is a need to achieve national consistency for advanced care planning.

Recommendations

82. That in the lead up to national legislation, the Australian Government ensures greater national consistency and harmonisation between the States and Territories in legislation governing the scope and implementation of advance care directives and advance care plans, and the appointment and status of substitute decision makers to ensure they are valid across jurisdictions.

7.3. Scope for including advance care plans in personal electronic health records

The Cradle Coast Electronic Health Information Exchange (eHIE) project is one of the nine new nationally coordinated and funded eHealth lead implementation sites. Total funding for the national PCEHR project is \$467 million. The Cradle Coast eHIE forms part of the national Personally Controlled Electronic Health Record (PCEHR) project.¹⁷⁵

The project is made up of a consortium of General Practice North West, North West Area Health Service, UTAS Rural Clinical School, and the Cradle Coast Authority, Tasmania.

The aim of the project is to support high quality, dignity promoting palliative and other supportive care for residents of RACFs in North West Tasmania. Outcomes of the project will provide lessons on incorporating Advance Care Plans within the PCEHR and will provide essential national policy lessons for future PCEHR based end of life care components.

The project will connect RACFs with General Practice, acute hospital services, after-hours services such as 'GP Assist', and Allied Health providers such as pharmacy, to enable coordinated care through a shared electronic health record. The project targets residents of RACFs in the first instance, with a view to being rolled out in the future to older people being cared for in the community.

The project will enable a supportive palliative care program for people in the last years of life. The project supports and tests cross boundary access of authorised users to the consumers' care planning and health record (PCEHR). Key documents provided to the PCEHR include Shared Health Summary, Enduring Guardian and Statement of Wishes.

The project will use off-the-shelf care planning software to share the Advanced Care Plans and Directives until the national PCEHR infrastructure is in place.

Summary

PCA sees advance care plans incorporated into the personally controlled electronic health record of Australians, so that all those sharing the information are aware of the needs and wishes of the individual.

Recommendations

83. That, following evaluation, the Cradle Coast Electronic Health Information Exchange (eHIE) project be implemented nationally.

¹⁷⁵ <http://www.cradle-coast-ehealth.org.au/>

84. That advance care plans be made an integral part of all eHealth records, whether the national Personally Controlled Electronic Health Record, or any localised version of same.

85. That a person's substitute decision maker be recorded on all eHealth records, whether the national Personally Controlled Electronic Health Record, or any localised version of same.

8. The availability and funding of research, information and data about palliative care needs in Australia.

Research and training in palliative care should be considered a priority, and funded in line with that for potentially curative interventions. The United Kingdom spends only 0.18% of its total government and charitable funding for cancer research on end of life and palliative care. The United States spends only 0.9% of its cancer research budget on palliative care. There appear to be no comparable figures for Australia.

Once research has established evidence of needs and of effective interventions, considerable work remains to be done in translating this work into everyday practice within the health services. There is a need for developmental funding of initiatives to educate professionals at different stages of their careers, to improve their skills in assessing needs and changing practice. Methods to coordinate palliative care between professionals working in different settings need to be tested in demonstration projects.

“Research has potential to improve the quality of care for patients with life threatening illness and should form part of the routine work of all Level 3 palliative care services. Level 1 and 2 services should conduct research according to their capacities”. (New South Wales)

In moving towards a needs based approach to palliative care and reducing disparities, funding will be needed for research in non-malignant as well as malignant conditions and across care settings, including RACFs.

Systems and strategies need to be established to support more rapid translation of research findings into clinical practice. Implementing research outcomes occurs within the context of strong evidence, an environment receptive to change and skilled facilitators to drive the change process.

There is a need for human research ethics committees and other decision making and funding groups to develop a better, broader understanding of the aims of palliative care research to allow for collaborative, national palliative care research into areas that non-palliative care clinicians may find challenging. For example, research into the dying process and research in non-hospital settings (e.g. at home or in residential aged care).

Palliative Care WA Inc points out that Australia lacks a strategic research priorities framework for publicly funded research and that the lack of strategic guidance can result in taxpayer funds being used on *“useless research.”*

“A strategic research priorities framework should be resourced - the process for developing the framework should include broad consultations with consumers, primary health care providers, palliative care providers and academic researchers. The aim of the priorities framework should be to identify gaps in knowledge which

effect the broadest number of Australians and it should serve as a guide for researchers and grant makers when proposals are created and assessed” (Western Australia).

The National Palliative Care Program has in the past funded the NHMRC to provide palliative care research grants with the primary objective to promote the development of new researchers and research teams through implementation of innovative projects focusing on palliative care. The outcome of the funding according to Palliative Care WA Inc is that: *“... in my humble opinion this NHMRC strategy has been successful and good!”*

Translating research findings into practice is important:

“Initiatives like PCOC and NSAP are part of this process: they identify gaps in practice at the national level and can work with researchers and CareSearch et al to identify best evidence for closing those gaps, then use quality improvement approaches to embed new practice. A strategic research priorities framework can help mitigate against useless, untranslatable research being funded in the first place”. (Western Australia)

In the Northern Territory, they:

“... would love to do more research in palliative care, especially with the Indigenous population but we are time and people poor”.

It is felt that a lot more work needs to be undertaken in Indigenous communities particularly around how best to engage in and implement advance care plans, medications, bereavement and the notion of the part culture plays in understanding death and dying. Knowledge about these factors and more is required to inform our understanding about Indigenous behaviour in remote areas. It was also felt that funding should be made available for better data tools.

Summary

Fundamentally, Australia has an excellent record in palliative care research. However, the excellence gained over time will be lost if we cannot consolidate and make practical use of it. Coordination of palliative care research within a national research framework should be developed through an Australian Centre of Excellence in Palliative Care Research. This Centre would provide the hub through which national research could be coordinated, supported, communicated and funded.

Recommendations

86. That the development and implementation of a National Palliative Care Strategic Research Framework be funded that:

- a. identifies evidence based research priorities and focuses on translating research into practice**
 - b. guides decision makers and funders in selection of nationally significant and useful areas of human research.**
- 87. That national research in the nature and frequency of treatment of non-malignant terminal conditions across care settings, including RACFs, be undertaken.**
- 88. That human research ethics committees and other decision making and funding groups develop a better, broader understanding of the aims of palliative care research to allow for collaborative, national palliative care research into areas that non-palliative care clinicians may find challenging. For example, research into the dying process and research in non-hospital settings (e.g. at home or in residential aged care).**
- 89. That there be regular independent reviews undertaken of the NHMRC palliative care grants to assess evidence of translation into practice and to avoid duplication across subsequent funding rounds.**
- 90. That the Australian Government provides support and funding for the establishment of a Centre of Excellence in Palliative Care Research.**

Appendix One: Glossary of terms

Level one – palliative care approach

Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel. The palliative care approach aims to promote both physical and psychosocial wellbeing. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

Level two – general palliative care

At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings.

Level three – specialist palliative care

Specialist palliative care (SPC) services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. SPC services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services. SPC services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine. SPC services are available within primary health care settings, acute general hospital settings and specialist inpatient units.

Non-specialist palliative care

The practice of palliative care principles by all health care professionals with a focus on quality of life, which includes good symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those that matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues.

The term 'non-specialist palliative care' refers to both Level 1 palliative care approach and Level 2 general palliative care as defined in the NACPC report of 2001.

Community specialist palliative care/Home care teams provide specialist support and advice to patients, families and community-based health care professionals when appropriate.

Specialist inpatient units

The specialist inpatient unit is the core essential element of the specialist palliative care service. It provides a wide range of specialist services to patients and families, addressing their medical, nursing, psychosocial and spiritual needs. It is also referred to as a hospice.

End of life care

There is no exact definition of 'end of life'. However, the evidence indicates that end of life care is relevant where there is:

- the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate
- the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of end of life.

Life-limiting disease

Any illness where there is no reasonable hope of cure and from which the person will die.

Chronic disease

Chronic diseases are long-term diseases, lasting more than six months, are non-communicable, involve some functional impairment or disability and are usually incurable.

Chronic disease management

Chronic disease management is a system of coordinated health care interventions and communications for populations with long-term conditions. Such programs are patient-centred and holistic, dealing with health and social needs, not just the physical consequences of illness and are predicated on enabling patients self-management and involvement in decision making and planning, where appropriate.

Primary health care

An approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being, which would include specialist community services.

Secondary care

Specialist care that is typically provided in a hospital setting.

Tertiary care

National and regional specialist services for complex specialist care, normally confined to a small number of locations.

Allied health practitioners

Allied health practitioners work with all age groups and within all specialties. Their particular skills and expertise can be the most significant factor in helping people to: recover movement or mobility, overcome visual problems, improve nutritional status, develop communication skills, and restore confidence in everyday living skills.

Appendix 2: Additional material to inform the Senate Inquiry

1. The Benefits of Palliative Care

The evidence that palliative care delivers quality of life benefits and better use of limited health resources provides a strong case for increased funding of palliative care as an integral part of our health and aged care services.

a. Improves quality of Life

- A study conducted in 2008 of 33 high quality systematic literature reviews and 89 intervention studies concluded that there is strong to moderate evidence that palliative care improves important aspects of end of life care, such as reduction in distressing symptoms and relief of caregiver burden¹⁷⁶.
- Studies of a range of palliative care interventions from Europe, Canada, Australia and the United States demonstrate consistent improvement in pain and other symptoms, patient and family satisfaction, and likelihood of receiving care in the place of choice¹⁷⁷.
- Hospital palliative care consultation programs have been associated with reductions in symptoms and higher family satisfaction with overall care, and greater emotional support as compared with usual care¹⁷⁸.
- A multi-method study at the Royal Melbourne Hospital involving a retrospective audit of 171 deaths during 2007 found that referral within the hospital to the palliative care service resulted in key improvements in the care of the dying patients including implementation of appropriate end of life medication orders, cessation of futile treatment and interventions, and improved communication with families. However, the majority of dying patients in the hospital were not referred to palliative care, with concerning evidence found for deficiencies in quality of care, such as: mouth care, lack of communication with GPs and the assessment of religious and spiritual needs¹⁷⁹.
- Results of a randomised trial of in-home palliative care in two United States health organisations found that patients reported greater satisfaction with care at 30 and 90 days after enrolment and were more likely to die at home, their preferred location, than those receiving usual care. They were also less

¹⁷⁶ Lorenz et al, 2008, reported in Rand Europe and the National Audit Office, 2008, The Potential Cost Savings of Greater Use of Home- and Hospice- Based End of Life Care in England, National Audit Office, 2008.

¹⁷⁷ Casarett, D; Pichard, A; Bailey, F A; Ritchie, C; Furman, C; Rosenfeld, K; Shreve, S; Chen, Z; Shea, J A; 2008 'Do Palliative Care Consultations Improve Patient Outcomes?' *Journal of the American Geriatric Society*, 2008 No 56.

¹⁷⁸ Morrison, R S; Penrod, J D; Cassel, B; Litke, Ann; Spragens, L; Meier, D E, 2008, 'Cost Savings Associated with US Hospital Palliative Care Consultation Programs', *Archives of Internal Medicine* 168, No 16 (2008).

¹⁷⁹ Le, B; Watt, J, 2010, 'Care of the Dying in Australia's Busiest Hospital: Benefits of Palliative Care Consultation and Methods to Enhance Access', *Journal of Palliative Medicine* Vol 13, No 7, 2010.

likely to visit emergency departments or to be admitted to hospital than those receiving usual care. The study provided strong clinical and cost saving evidence supporting the provision of palliative care in the home of terminally ill patients with cancer, chronic heart failure and chronic obstructive lung disease with a life expectancy of approximately one year¹⁸⁰.

b. Improves Health Resource Use

- According to a review conducted by the United Kingdom National Audit Office of 36 research studies on the costs of palliative care, there were average cost savings of around 30% for cancer patients receiving palliative care in the last year of life. Consistent savings result primarily from fewer hospitalisations and, when hospitalisation occurs, savings are from less utilisation of acute hospital care resources. The study concludes that palliative care is cost-saving – this was true for the various types of provision, including inpatient hospice and home based care. The evidence is most clear for cancer patients¹⁸¹.
- A study examining 2004-2007 data to determine the effect on hospital costs of palliative care consultations for patients enrolled in Medicaid at four New York state hospitals found that patients who received palliative care incurred \$6,900 less in hospital costs during a given admission on average than a matched group of patients who received usual care¹⁸².
- A recent inter-institutional comparative analysis found that the total mean charges per admission to the Cleveland Inpatient Palliative Care Medicine Unit (CCPIM) were \$7,800 lower than at other peer institutions despite an equivalent severity of illness, longer length of stay and higher mortality in the CCPIM unit. The lower charges were due primarily to lower laboratory and pharmaceutical charges¹⁸³.
- A study comparing the daily costs of 123 patients prior to and following admission to the St Thomas Palliative Care Unit in Virginia found a 66% reduction in overall costs (including a 74% reduction on expenditure on medications and diagnostics). Reasons cited include a change in the goals of care once people are clearly identified as dying and associated changes in care patterns. The authors found evidence of intensive and expensive interventions for patients receiving care outside the palliative care unit, even when the patient and family were

¹⁸⁰ Brumley, R; Enguidanos, S; Jamison, P; Seitz, R; Morgenstern, N; Saito, S; McIlwane, J; Hillary, K; Gonzalez, J; 'Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care', *Journal of the American Geriatric Society*, 2007, Vol 55 No 7.

¹⁸¹ Ibid

¹⁸² Morrison, R, Sean et al, 2011, *Health Affairs March 2011* vol 30 no.3.

¹⁸³ Davis, M; Walsh, D; LeGrand, S; Lagman, R; Rybicki, M; 2005, 'The Financial Benefits of Acute Inpatient Palliative Medicine', *The Journal of Supportive Oncology*, Vol 3, No 4 July/August 2005.

accepting death. They suggest that the most likely reason was that the medical care team did not know how to change care patterns¹⁸⁴.

- Hospital palliative care consultation teams are associated with significant hospital cost savings. This was the finding of a United States study involving analysis of data from 8 hospitals with established palliative care programs. Patients receiving palliative care were matched by propensity score to patients receiving usual care. The study found the average total direct cost per admission for palliative care patients discharged alive was around US\$1700 less than for matched patients who received usual care. For palliative care patients who died the net savings per admission were almost US\$5000 compared with matched patients receiving usual care who died¹⁸⁵.
- A 2009 United States study found that patients with advanced cancer who reported having end of life discussions with their doctors had on average 35% lower health costs (\$US1041) in the final week of life compared with similar advanced cancer patients who had not had those discussions. Higher costs among those advanced cancer patients who had not had end of life discussions with their doctors were associated with more physical distress in the last week of life and worse overall quality of death as reported by the caregiver. There was no survival difference associated with higher healthcare expenditures¹⁸⁶.
- A 2006 Spanish study found that the provision of palliative care services to advanced cancer patients generated savings of 61% in the cost of care during the last 6 weeks of life compared with conventional medical care provided to similar patients in a 1992 study. The cost savings from palliative care were due to reduced use of emergency rooms, a shift from conventional acute care beds to palliative care beds, reduced average lengths of hospital stay and associated use of home based care¹⁸⁷.

¹⁸⁴ Smith, T; Coyne, P; Cassel, B; Penberthy, L; Hopson, A; Hager M; 2003, 'A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Costs', *Journal of Palliative Medicine*, Vol 6, No 5, 2003.

¹⁸⁵ Morrison, R S; Penrod, J D; Cassel, B; Litke, Ann; Spragens, L; Meier, D E, 2008, 'Cost Savings Associated with US Hospital Palliative Care Consultation Programs', *Archives of Internal Medicine* 168, no 16 (2008).

¹⁸⁶ Zhang, Baohui; Wright, Alexi A; Huskamp, Haiden A; Nilson; Maciejewski, Matthew L; Earle, Craig C; Block, Susan D; Maciejewski, Paul K; Prigerson, Holly G; 2009) 'Health Care Costs in the Last Week of Life: Associations with End of Life Conversations', *Archives of Internal Medicine* (2009) March, 9.

¹⁸⁷ Gomez-Batiste, X; Corrales, E; Porta-Sales, J; Amor, M; Espinosa, J; Borrás, J de la Mata, I; Castellsague, X, 2006, 'Resource Consumption and Costs of Palliative Care Services in Spain: A Multicentre Prospective Study', *Journal of Pain and Symptom Management*, Vol 31 No 6.

2. Medication Management

An effective medication management system involves many people working together to ensure the safe administration of medicines to bring about better health outcomes. There are three main areas where there are issues with the current system in relation to medication management and appropriate pain management for those who are dying.

- GPs generally control the prescribing of medication for people in residential care and many facilities report that it is difficult to get GPs to visit because the Medicare rebate is inadequate. Also, some GPs can be reluctant about prescribing opiates, which are the main drugs used for pain management. Inconsistencies and inaccuracies in the writing up of medication charts, delays in writing up new scripts, and delays in promptly addressing pain needs of residents were also reported. Plus specialist palliative physicians are often not called in even where symptoms are difficult to manage.
- Pharmacists dispense and review medications and while there is generally satisfaction with their services residential facilities have noted problems with workload, packaging accuracy with Dose Administration Aids, accuracy of medicine labelling, poor or missing communication between acute facility, pharmacy and GP when patient is discharged from acute care to their residential facility.
- However the critical players in medication management and administration are the Registered Nurses (RN), Enrolled Nurses (EN) and care staff who are hands-on 24/7, monitor and assess residents plus manage and administer the drugs.

The percentage of nurses within residential care has decreased since 2007 as shown by the Department of Health and Ageing censuses and the percentage of care workers has increased. This is at a time when the acuity of residents has increased. The reasons for this are multifaceted but include:

- Wages for nurses in aged care are lower than in the acute sector.
- Funding for residential care is being squeezed by inadequate indexation of subsidies.
- There is a worldwide shortage of nurses.

A shortage of RNs and the consequent difficulty in attracting, recruiting and retaining them in the sector, means that the historical service models are no longer practical and will not be into the foreseeable future. New models of care are required, and already the role of the EN and community worker has become critical in assisting the RN with the delivery of medicines.

RNs have a duty of care to their patients and while S8 medications, which include the morphine and opiates generally used for pain management, can be given by other

staff under the supervision of an RN, in some states nurses are often reluctant to delegate this task. In high care facilities there is always an RN in the facility but they may be responsible for over 50 residents and pressured for time. In low care facilities an RN is not always on site and often the night shift is covered by care workers. RNs are not always confident about the skills of care workers given their limited training.

Due to these staffing arrangements issues arise with appropriate pain assessment and management. Regular pain monitoring, drugs being given strictly on time, monitoring of the effects of the drugs (positive and negative), titration of pain medications to match pain levels and access to 'breakthrough' pain relief in liquid and injectable forms are some of the concerns. Transfer to emergency departments and hospitals often results. Access to these medications is also an issue. Many low level RACFs do not have a medication imprest system to ensure timely emergency pain relief and they are not required by regulation to do so. In Victoria, some RACFSRACFSS services choose to obtain a Health Services Permit, for which an annual fee must be paid. To improve the situation some have argued for licensing or registering care workers which would require that they meet nationally approved minimum qualifications and work experience, including medication assistance.

a. Medication Advisory Committees (MAC)

The *Australian Pharmaceutical Advisory Council Guidelines* for medication management in RACFs state that facilities should establish a MAC to facilitate the quality use of medicines. It is a group of advisors who are responsible for the development, promotion, monitoring and evaluation of policies and activities to assist in the achievement of best possible health outcomes for residents by ensuring quality use of medicines in the facility. Formation of a MAC provides a forum that promotes the active partnership between the GP, pharmacist and the RACF staff in managing medication within the facility.

The MAC should include, as a minimum, a representative from the following groups: Management; GPs; Nurses; Pharmacists supplying medications in the RACF; Pharmacists conducting medication reviews; and a Resident advocate.

The MAC has an important role in the development and monitoring of quality systems to ensure the safe management of medication within the RACF. The MAC should develop systems for written policies on:

- Prescribing of medications, including guidelines for emergency medication orders.
- Administration of medication including persons responsible for administering medications within the RACF.
- Ordering, delivery, storage and disposal of medications.
- Management and administration of Schedule 8 medications.
- List of nurse initiated medications that may be used within the RACF.

- Guidelines for altering the dose formulation (e.g. by crushing) of oral medications to enable medication to be administered.
- Processes for medication reviews, including collaborative Residential Medication Management Reviews.
- Documentation of medication incidents.
- Dissemination of information relating to medication management to staff and residents.
- Training and support for staff involved in the prescribing and administration of medications.

Unfortunately many residential facilities do not have MACs and therefore do not have a systematic way to review and improve their practice.

b. National Uniformity

A problematic aspect of medication administration and management is the various jurisdiction's medicines/poisons legislation and regulations, which have differing permissions and prohibitions for staff working in aged care across the whole medication management system.

The legislative framework for medicines, drugs and poisons is state/territory based. The legislation is very broad in its content and is difficult to interpret in an aged care medication management context. There is minimal reference in the legislation to aged care specific related practices. Of particular concern is the differing, or lack of, definitions and range of functions for care workers, assistants and health workers.

The *National Registration and Accreditation Scheme*¹⁸⁸ includes as a key strategic priority to 'drive national consistency of standards, processes and decision-making' and Health Workforce Australia has shown an interest in the area. A National Lead Clinician Group (NLCG) has been established and Local Lead Clinician Groups (LLCGs) are to be established as part of the National Health Reform Agenda. The NLCG will provide clinical advice on the prioritisation of the development and implementation of national clinical standards and guidelines that will maximise health outcomes and improve patient care.

LLCGs will play an important role in the community and work with Local Hospital Networks and Medicare Locals, existing state and territory clinical advisory structures, RACFs and community aged care providers in ensuring best practice clinical governance across their entire respective regions.

¹⁸⁸ <http://www.ahpra.gov.au/About-AHPRA.aspx>

Recommendations:

- 91. That the Assist Clients with Medication learning unit becomes a mandatory core component of the Certificate III and IV in aged care and home and community care, and a competency gained by all aged care workers.**
- 92. That all RACFs should have a functioning Medications Advisory Committee, and this requirement is reflected in the aged care accreditation standards.**
- 93. That the Lead Clinician Group work in collaboration with Aged Care, Pharmacy and other peak bodies and professional advisory councils, to systematically review relevant practice guidelines to improve the interface between all professionals who work to support and care for older people across community and residential care and health settings.**
- 94. That COAG, working through the Australian Health Ministers Advisory Council, establish a working party to consider adopting uniform national model legislation in relation to drugs, poisons and controlled substances across Australia's states and territories.**

3. Supporting Carers

The WHO advocates that palliative care should not only improve the quality of life for patients but also for their carers and families. Many countries, including Australia, have established standards for palliative care that aim to support carers and families of the dying person and after death. Regardless of the place of death, it is estimated that up to 90% of people in the terminal phase of a life threatening illness spend the majority of their time at home supported by a carer.

Economic benefits are a factor in determining Government investment in services. In the case of programs to support carers, the justification is compelling. Australia's health care costs would be significantly higher without the contributions of carers. The importance of the contributions the 2.6 million carers make to the Australian economy has not been lost on the Australian Government which has invested in a *National Carers Strategy*¹⁸⁹ and two PC reports; *Disability Care and Support*¹⁹⁰ and *Caring for Older Australians*.

The NCS is an integral part of the Australian Government's broader social inclusion agenda and it sits alongside and complements the *National Disability Strategy*. In conjunction with the Carer Recognition Act 2010, it forms part of the Australian Government's *National Carer Recognition Framework*¹⁹¹. Within the *National Carers Strategy*, carers include family members, friends, relatives, siblings or neighbours, grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers. Most states and territories also have carer recognition legislation.

There is still much to be done to improve access to timely and appropriate information and support for carers by the Commonwealth and State/Territory Governments. For the most part, the strategies have been identified and articulated; the priority now is for adequate resourcing so that they can be implemented effectively. It is important that implementation is responsive to the diversity of our communities, including cultural and linguistic differences, rural and remote locations and special needs.

The Australian Government needs to ensure that the *National Carer Strategy*, the *National Palliative Care Strategy 2010* and the *National Disability Strategy*¹⁹² are resourced so that the priorities to improve information and support for carers are addressed. This will impact on the sustainability of community based, out-of-hospital models of care, which align with most people's preferences for place of death and more effective use of health resources.

¹⁸⁹ *National Carers Strategy* <http://www.health.gov.au/nationalcarerstrategy>

¹⁹⁰ *Disability Care and Support* <http://www.pc.gov.au/projects/inquiry/disability-support>

¹⁹¹ *National Carer Recognition Framework* <http://www.health.gov.au/nationalcarerstrategy>

¹⁹² *National Disability Strategy* <http://www.fahcsia.gov.au/sa/disability/proqserv/govtint/Pages/nds.aspx>

4. Supporting Volunteers

The integral role that volunteers play in palliative care is an exception, rather than the norm in health care delivery. They have shaped palliative care and have been called a 'national treasure'. They are vital core members of interdisciplinary palliative care teams. A 2005 Victorian palliative care workforce study showed that palliative care volunteers made up 60% of the combined palliative care labour workforce.

Currently in Australia the essential role of the volunteer in the palliative care team is acknowledged through such policies as the *National Palliative Care Strategy*, the *Standards* (Standards 12 and 13) and the *Health System Reform and Care at the End of Life Guidance Document*. The important role of volunteers is also recognised in the PC report *Caring for Older Australians*.

Palliative care volunteers work across all palliative care domains - physical, spiritual, social and emotional. Following extensive training they increase and enhance the range of supports palliative care services can offer to their clients. Their presence makes services more consumer responsive, and the involvement of volunteers in all aspects of service planning and delivery can be an effective means of consumer empowerment. They can liaise between health care professionals and the community by showing the former the particular needs of their community. Palliative care volunteers increase the social, emotional and practical supports available. Most importantly, volunteers bring normality into the lives of the terminally ill and their carers during a time that may otherwise be dominated by medical treatments. They are often the one constant for patients and families and as a result get to know them much better than the doctors and nurses. Appropriately trained volunteers can perform tasks that otherwise may need to be undertaken by professional staff, allowing professional staff to focus on their areas of specific expertise and reducing their stress, and possibly enabling the service to take on more clients.

Managers of Volunteers are essential to the designing of volunteer services and the recruiting, induction and training, supervision and support of volunteers. They provide a diverse human resource management role often supporting a large numbers of volunteers. Currently many of these Managers work in isolation. Some are unfunded. To do their job appropriately these positions must be filled by qualified people with human resource and education skills, salaried appropriately and their programs resourced well. Opportunities for networking with other Managers of Palliative Care Volunteers are essential to support retention and best practice.

Very little palliative care volunteer workforce development has been undertaken in Australia. The United Kingdom is currently investing heavily in research and development in this area. Canada has undertaken a national survey of palliative care volunteer services and has developed guiding principles to assist in developing

standards for palliative care volunteers. These have now been included in accreditation processes.

Over the past 4 years the state of Victoria has been very innovative in specialist palliative care volunteerism. The Department of Human Services has undertaken a palliative care volunteer survey, and, together with Volunteering Victoria, developed the *Victorian Palliative Care Volunteer Standards and Templates* (the only ones of their kind in Australia). Palliative Care Victoria (PCV) has developed and recently evaluated a state-wide *Palliative Care Volunteer Training Resource Kit* that is now also being used ad hoc in other states and territories and in some other countries. PCV works with the Managers of Palliative Care Volunteer Network on issues relevant to the sector. Some other states have, or are starting to develop, state Managers of Volunteer Networks.

Currently Australian palliative care volunteer programs are guided by a myriad of broad standards and guidelines; the overarching *National Palliative Care Standards* (Standards 12 and 13), the *Volunteering Australia Standards*¹⁹³ and the *Working with Volunteers and Managing Volunteer Programs in Health Care Settings*¹⁹⁴. Understanding their specific application for the palliative care volunteer sector can be confusing and very time consuming.

There is currently no national consistency around palliative care volunteer training and any specific training requirements or volunteer competencies. The majority of palliative care volunteer induction and on-going training programs are developed locally.

Victoria has already developed state-wide guiding standards and training competencies specifically for palliative care volunteer services and these could be used as a base line for adaption and adoption nationally.

The changing demographics of prospective volunteers and the growing need for palliative care means it is imperative that Australia has a national strategy for palliative care volunteering, if it is to retain and grow the valuable contributions of volunteers involved in palliative care and end of life care. There is also the opportunity to extend the involvement of volunteers to related areas, such as aged care, where volunteers are involved mainly in lifestyle activities and administration, rather than supportive care for residents and their families at the end of life.

¹⁹³ *Volunteering Australia Standards*

http://www.volunteeringaustralia.org/html/s09_search/default.asp?s=Volunteering%20Australia%20Standards%20&dsa=14368

¹⁹⁴ *Working with Volunteers and Managing Volunteer Programs in Health Care Settings*

<http://www.ozvpm.com/resourcebank/documents/nh48.pdf>

Appendix 3: Some State Profiles at a Glance

1. Victoria

Service Provision

- 10,638 people received community palliative care (primarily in the home) from 39 community palliative care services in 2009/10. The average length of stay on a community program was 110 days. 4 day hospices provided assessments, respite and activities.
- There are 264 designated palliative care beds located across 30 health services. In 2010/11 86,000 specialist palliative care bed days were provided.
- 16 specialist palliative care consultancy services provide expert advice and education to community, hospital and aged care providers.

- There are 6 funded state-wide services:
 - Australian Centre for Grief and Bereavement Counselling
 - HIV Aids Consultancy Service
 - Motor Neurone Disease Association of Victoria
 - Palliative Care Victoria
 - Very Special Kids
 - Victorian Paediatric Palliative Care Program.

Palliative Care Funding

Total specialist palliative care funding is approximately \$108 million per annum. This is allocated as follows:

- \$55 million to inpatient services (bed based and consultancy teams)
- \$38 million to community palliative care services (home based care, day hospices, flexible funding)
- \$5 million for consultancy services
- \$5.2 million for state wide palliative care
- \$3.5 million for research, education and training
- \$1.57 million to Regional Palliative Care Consortia

In 2011/12 a palliative care bed cost \$566 (metro) and \$571 (rural) per day. This compares with an average cost of a hospital bed of \$1,117 per day.

State government Palliative Care Policy

Strengthening palliative care: Policy and strategic directions 2011-2015

2. Australian Capital Territory

Service provision

- Clare Holland House is an interdisciplinary service including a 19 bed inpatient hospice, specialist outreach services to people's homes (Home Based Palliative Care), consultancy services to hospitals, a nurse educator, Nurse Practitioner, bereavement services, PEPA, and the Calvary Centre for Palliative Care Research, all managed by Calvary Health Care, ACT.
- The Canberra Hospital – non-designated palliative care inpatient beds managed by the Oncology Department, and palliative care consultancy services including Specialist Palliative Care physicians, a Nurse Practitioner, Counsellor and Pastoral Care, managed by the Capital Region Cancer Service.
- Palliative Care ACT is a non-government, not for profit organisation for the facilitation and promotion of excellent palliative care in the ACT, the Society professionally trains and supports palliative care volunteers.
- ACT Government, through the Health Directorate, is responsible for the provision of many health care services for palliative care patients, including allied health services and community nursing. These professionals who are considered primary care providers under the national standards. Primary care services are also provided by a range of people who are specialists in other areas, such as oncologists, renal, cardiac and respiratory physicians and staff in acute hospitals. These health care providers support large numbers of people needing palliative care and their carers in the ACT.
- GPs, Winnunga Nimmityjah Aboriginal Health Service, private medical specialists, HACC services, RACFs and private hospitals, form another essential component of ACT primary palliative care service provision.
- There is also a range of publicly funded not for profit organisations that provide services to palliative care clients and their carers. These include ACT and Australian Government funded organisations, including ACT Eden Monaro Cancer Support Group and Cancer Council ACT, which provide home assistance and carer support to palliative care clients and their families/carers.

Funding

The ACT Government, through the Health Directorate, provides funding for the inpatient, outpatient and community based specialist palliative care services in the ACT.

Territory Government Palliative Care Policy

The *ACT Palliative Care Strategy 2007–2011* sets the strategic direction for the delivery of palliative care services in the ACT. The Strategy was developed in the context of PCAs national palliative care standards, and commits the ACT to

delivering services in accordance with these standards. The Strategy aims to strengthen palliative care services by:

- Improving community education, awareness and participation.
- Further developing a comprehensive ACT palliative care service.
- Strengthening provision of primary care through the palliative approach.
- Strengthening specialist palliative care services.
- Further developing a skilled workforce.
- Improving information management and data collection.

The ACT Government Health Directorate is reviewing the current *ACT Palliative Care Strategy 2007-2011* and developing a service plan for palliative care services in the ACT

3. Queensland

Service provision

- It is estimated that 10,234 terminally ill Queenslanders receive specialist palliative care per year, however this figure only includes patients (and does not include family members, many of whom will receive counselling or bereavement support).
- The average length of stay on a community palliative care program is 45 days.
- Queensland Health funded 56,000 bed days for palliative care.
- There are 186 dedicated specialist palliative care beds in Queensland (102 public, 84 private).
- 11 Queensland Health and 5 Non-Government specialist palliative care consultancy services provided expert advice and education to community, hospital and aged care providers.
- There were seven funded non-government service providers that offered a range of both generalist and specialist services:
 - Little Haven Hospice Service.
 - Cittamani Hospice Service.
 - Karuna Hospice Service.
 - Ipswich Hospice.
 - Toowoomba Hospice.
 - Hopewell Hospice Service.
 - St Vincent's Hospital.
- There are three state wide palliative care projects funded by Queensland Health:

- Centre for Palliative Care Research and Education.
- Palliative Care Helpline.
- Palliative Care Queensland.

Funding

The total amount of funding provided to specialist palliative care services in Queensland is not known, however the following information has been published by Queensland Health:

- \$8.3 million provided by the Commonwealth to purchase community palliative care services.
- \$49.05 million in bed days to support palliative patients (54,494 beds days at \$900/day).
- \$4 million to support Govt and NGO providers of palliative care and other counselling, information, education and research organisations.
- \$12.6 million to St Vincent's Brisbane to provide a range of in-patient services that include palliative care.
- At a cost of \$900 per patient per day, an in-patient palliative care bed is far more expensive than the average daily cost of caring for a palliative care patient in the community, approximately \$63 per day or \$1875 per month.

4. Tasmania

Service Provision

- Approximately 3,924 people received palliative care from 3 community palliative care services in 2010-2011.
- More received advice but the numbers are not kept of these contacts.
- There are 19 designated palliative care beds in Tasmania.
- In 2010-2011 there were 7665 bed days available.
- 3 specialist community palliative care services provide expert clinical advice, psychosocial support and education to patients, families and health practitioners.
- Some palliative care is provided through St John's Private Hospital but the numbers are not known.

Funding

- No details available

State Government Palliative Care Policy

The Tasmanian Palliative Care Plan 2002-2005

Acknowledgements

Palliative Care Australia would like to acknowledge the input to the submission from its member organisations and from individual CEOs and members of the PCA Board and Council.

In particular PCA would like to acknowledge the work of Lesley Dredge from Palliative Care Victoria, Associate Professor Rohan Vora, Dr Mary Brooksbank, Associate Professor Deborah Parker and Professor Patsy Yates for their constructive input to the document.