



26 March 2012

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Committee Secretary

RE: Palliative Care in Australia Inquiry

Please find attached a submission for the Community Affairs Committee *Palliative Care in Australia Inquiry* from Catholic Health Australia (CHA). CHA welcomes the opportunity to provide this submission and would like to continue to be kept informed of any outcomes from this process.

CHA endorses the submissions of the Australian Catholic Bishops Commission, Aged & Community Services Australia, Cunningham Centre for Palliative Care Sacred Heart Centre, Little Company of Mary Health Care and Mercy Health.

This submission has been the result of consultations with CHA membership, and the following people were involved in the writing of this submission.

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- *Dr Margherita Nicoletti*, Director of Palliative Care, St John of God Healthcare
- *Eleanor Roderick*, Group Coordinator of Palliative Care and Pastoral Services, St John of God Healthcare
- *Associate Professor Mark Boughey*, Director of Palliative Medicine, St. Vincent's Health Australia, Melbourne
- *Associate Professor Jennifer Philip*, Co-Deputy Director, Centre for Palliative Care & Deputy Director of Palliative Medicine, St Vincent's Health Australia, Melbourne
- *Associate Professor Richard Chye*, Northern Network Director, Palliative Care South East Sydney LHN & St Vincent's & Mater LHN and Sacred Heart Darlinghurst
- *Dr Julia Wootton*, Clinical Director of Palliative Care St Vincent's Health Australia, Brisbane
- *Helen Walker*, General Manager/Director of Nursing. Cabrini Palliative Care Service
- *Fran Gore*, Deputy Director of Nursing/Manager, Mercy Palliative Care Services, Mercy Health

I would be happy to attend a hearing if you would like further information, and propose to invite Associate Professor Mark Boughey and/or Associate Professor Richard Chye to attend with me.

Yours Sincerely

Martin Laverty
Chief Executive Officer
Catholic Health Australia

Catholic Health Australia

**Community Affairs Committee –
Palliative Care in Australia Inquiry**

March 2012

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About Catholic Health Australia

21 public hospitals, 54 private hospitals, and 550 aged care facilities are operated by different bodies of the Catholic Church within Australia. These health and aged care services are operated in fulfilment of the mission of the Church to provide care and healing to all those who seek it. Catholic Health Australia is the peak member organisation of these health and aged care services. Further detail on Catholic Health Australia can be obtained at www.cha.org.au.

Executive Summary

Australia urgently needs an equitable, high quality, supportive system of palliative care. In response to this need CHA has developed an actionable palliative care roadmap.

The provision of palliative care should be guided by a minimum health care standard, to be developed by the Australian Commission on Safety and Quality in Health Care, the purpose being to provide a nationally consistent statement of the level of care consumers should be able to expect from health services.

Palliative care service provision is funded by states and territories with the exception of when palliative care occurs within the residential aged care (RAC) setting. The Commonwealth operational funding for RAC is insufficient as it does not relate to the actual cost of service provision, and this has been the subject of an extensive Productivity Commission inquiry.

States and territories are not bound to deliver palliative care services uniformly and indeed are responsible for determining the priority given to palliative care services and how and where they will be delivered. This results in fragmentation of service delivery across the country, between states and territories and within regions.

The funding streams, in addition to the allocation from states and territories, are diverse, and include funding under the Home and Community Care program, fee for service under the MBS, private health insurer fee provisions, the Aged Care Funding Instrument (ACFI) and those people who self fund their own care.

The challenges being faced in Australia are no different to those being faced internationally. There is a scarcity of revenue and an increasing demand for service. If major trends of demand and supply were to be examined over the next forty years it would be likely that major implications for the future structure of palliative care would emerge. Issues of workforce and the capacity for the health and aged care sectors to respond to the need for increased productivity to meet this demand would be highlighted.

CHA argue that because there is no minimum standard in health for the delivery of palliative care that this then leads to perverse service model outcomes, such as the lack of cohesive client centred service models, resulting in inequitable service delivery.

If a minimum standard were introduced (and the ensuing burden of compliance were minimised) then the ability of the sector to measure improvements in outcomes would increase. This would also drive the sector into building capacity within the community, primary care, general practice and aged care sectors to deliver high quality, equitable, supportive palliative care.

Section 1 -Introduction

Like the aged care industry in the past, palliative care today can be likened to a “cottage industry” – we see inequitable and unviable service models, lack of uniform national funding levels, on the heels of a rapid increase in the population over 70.

Palliative care began in the hospice movement and is now widely used outside of traditional hospice care. The modern hospice is a recent concept that originated and gained momentum in the United Kingdom after the founding of St. Christopher's Hospice in 1967. As this movement grew in the United Kingdom it also grew in Australia. By the late 1990s Australian governments - both federal and state- increased the availability of palliative care through attempting to make palliative care available for everyone. But it soon became evident that there were issues in expecting all practitioners to provide palliative care within their own health care setting. There were also fragmented funding pools and differing priorities given to palliative care across the states and territories. In addition many palliative patients have complex symptom which require specialist management or supportive care that cannot be provided easily.

The rise of specialisation in palliative care is a relatively new one. Palliative Care Australia, was formed in 1990, largely in response to state palliative care associations needs to meet to coordinate educational events. Around the same time the Royal Australasian College of Physicians (RACP), developed a pathway for sub-specialty training in palliative medicine with the first trainees starting supervised training in 1991. The Australasian Chapter of Palliative Medicine (AChPM) was approved by the RACP and came into existence in May 1999. It was only in 2004 when consideration was given to improving the experience of dying in residential aged care, through the National Palliative Care Program. And care of the dying in residential aged care units has largely been overlooked in the context of specialist involvement.

We are at a point in the evolution of palliative care in Australia where it is timely to consider within what frameworks palliative care sits, what priority governments should afford it and how to efficiently coordinate the use of palliative care and end of life resources, including specialist palliative care services.

Catholic health and aged care services are one of the most predominant deliverers of palliative care services in Australia –across hospitals (public and not for profit), hospices, residential aged care facilities and of course across the community. Compared with jurisdictions, Catholic providers’ spread of service delivery is far greater than any single jurisdiction. CHA believe the views of its membership can contribute significantly to this inquiry. With this in mind CHA have developed a roadmap for the future of palliative care.

Who is Catholic Health Australia?

CHA represents the largest non-government grouping of not-for-profit health and aged care services in Australia. CHA is a national peak membership organisation representing Catholic health and aged care providers.

Within the CHA membership there are service providers who manage:

- 9,500 beds across 75 hospitals;
- 550 aged care services comprising 19,000 residential aged care beds,
- 6,000 retirement units, and 14,000 aged care or community care packages.

These services represent more than 10 per cent of health and aged care services in Australia, and are operated by different bodies of the Catholic Church.

In Australia the care for people with a life limiting illness and their significant others has changed and improved dramatically over the past twenty years. People are able to live longer and in some instances

palliative approaches can assist in curative treatments. Symptom control and improving quality of life has meant that many people with life limiting illnesses that cannot be cured can live comfortably for much longer periods of time. Palliative care is crucial in achieving quality of life, not only through symptom control, but also through providing the necessary spiritual and psychosocial care from diagnosis through to death and bereavement.

Understanding the important role that palliative care plays in improving quality of life is crucial in ensuring that this type of care can be provided to all who need it, no matter where they live or what their medical circumstances are.

Section 2- Challenges

Each state and territory offer differing access to palliative care. Access to quality, coordinated palliative care depends on whether a person is lucky enough to live in a state or territory that has access to high quality innovative services. Service provision is not uniform in nature and service provision is not guided by clear directives at the federal level. The result is that there are a number of perverse outcomes that the system experiences. The challenges facing the future are many, and include the following.

Lack of standardisation

The lack of a nationally consistent statement of the level of care consumers should be able to expect from health services means that it is difficult to be certain of the level of quality of service, equity of access and identification of expenditure relating to palliative care. The absence of a standard that explores care planning, assessment and access to specialist palliative care is the single most important deficit in palliative service delivery in Australia today.

The silo nature of service delivery

Palliative care can sit across a number of distinct service frameworks. There is the distinct health model, the welfare model -which includes housing, and relates to RAC. There is the disability sector, which is strongly influenced by self-determination models, the justice system and arguably in addition to health, the mental health system.

Palliative care tries to provide services across and within these domains, which is difficult because there are differing rationales for staffing and models of dependency. This then makes it difficult to accurately and adequately plan for the future. Because of this rigid fragmentation there has been little rational exploration of new policy directions.

Diversity

Health and aged care policy assumes the palliative care population generally is a homogenous one - but it is in fact as diverse as any other part of the population. Policies and programs that use palliative care as a criterion may not always deliver the most appropriate health care response. Services that offer supportive care in addition to specialist care may in fact be preferable for some consumers, over a distinct palliative care service.

Differences are important to understand in order to respond effectively to all the diverse needs.

Confusion over what palliative care is

End of life care, palliative care, specialist palliative care, supportive care – are all terms that can be used in the space that is ‘palliative care’. They are terms used differently by different services. This confusion over terminology does not help the person who requires a service response for their care needs. Consistency in use of terms / phrases is important in building capacity of all health and aged care service providers, and is important in ensuring access to equitable, high quality, supportive palliative care.

Research

Greater use of consumer based research to drive service delivery would assist in meeting consumer need. There is currently a paucity of research funds available in this area.

Section 3- How do these challenges manifest themselves in every day service delivery?

Standards

The absence of a standard that explores care planning, assessment and access to specialist palliative care is the single most important deficit in palliative service delivery in Australia today.

The National Palliative Care Strategy, endorsed in 2010, is a document to be used to guide palliative care policy development and service delivery. The goal areas of the Strategy are:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability

This document, whilst aiming to produce a quality national palliative care system, fails to articulate the service system. The Strategy aims to support the development of innovative models and integrated and coordinated models of service without articulating what the service model should line up against. **CHA supports the development of integrated care pathways but again these must align to something.** It is recommended this be a health care standard for people approaching or reaching the end of their life, and that the current National Standards Assessment Program be the tool to assist with compliance with of the standard.

Milestones that could be achieved with the introduction of such a standard include: decreased use of emergency departments; recognition of when people are within the timeframe of end of life phases; care planning; intervention to prevent inappropriate treatment; and better family support.

In addition to the development of a national health standard for people approaching or reaching the end of their life a **national service framework that embeds palliative care and supportive care** could also assist in ensuring an equitable, high quality supportive palliative care system.

National Service Frameworks - UK

"In the UK the government set up a national service framework for each medical specialty e.g. renal disease, neurodegenerative diseases, cancer etc. The aim was to improve the quality, effectiveness and equity of access to care. A requirement of the framework was that all specialties had to address the issue of palliative and end of life care. As a result Palliative Medicine Specialists became involved with this planning and the profile of palliative care was raised enormously. This is the power of legislation. The specialists had to address issues such as prognosis and end of life. The result has been that there are now earlier referrals being made to palliative care. For many patients with a life limiting condition there is now a slower transition to palliative care, and this has proven less traumatic for patients and significant others".

Dr Julia Wootton, Director of Palliative Care, St Vincent's Brisbane

Roadmap for standards

- Development of a single Australian Health Standard for people approaching or reaching the end of life. This standard could cover issues of:
 - Care planning
 - Assessment
 - Access to specialist palliative care
- Development of a national service framework that embeds palliative care and supportive care across all care.

Service models

There was strong consensus from the CHA membership that a systematic approach to service delivery does not exist. **There is no patient pathway –just a service pathway with services provided around the funding, not the patient.** The need for ongoing service integration requires more effort. Models for the delivery of palliative care services must respond to consumer need and must strive for excellence.

The service structure for people with life limiting non-malignant disease needs to be re-examined. These group of people rarely access palliative care. This is evidenced by the fact that 96% of people who have been seen by a specialist palliative care service have had a diagnosis of cancer.

There are 144,000 people who die annually in Australia. The vast majority of people wish to either die at home or to be cared for by familiar staff, such as in a RAC. The service models we have in place to respond to people at the end of their life means that very few achieve this (16% die at home and 10% in RAC). The majority die in hospitals (54%) and the rest in hospices (20%)¹.

There are not enough community based palliative care services and there are confusing and variable policies as to who is eligible to access these services. States and territories are not bound to deliver palliative care services uniformly and indeed are responsible for determining the priority given to palliative care services and how and where they will be delivered. This results in fragmentation of service delivery across the country, between states and territories and within regions.

The lack of uniformity in the provision of equipment adds to overall service fragmentation. There are considerable structural issues in relation to who provides equipment. Some hospitals can provide equipment on discharge for one month only. Others provide no equipment. Some private hospitals do provide equipment and this is paid for out of foundational funding. The role of knowledge plays an important part in being able to access equipment. Issues of access to equipment are amplified in rural areas where availability can be an issue.

Funding models for palliative care services drive service delivery. For example funding models exist for oncology supportive care with the model of care being an integrated oncology service. Supportive care for cancer services works well, and is well funded.

The model of supportive care in place with diseases other than cancer raises issues of access, equity and efficiency. For example chronic obstructive pulmonary disease (COPD) has high rates of morbidity, but often palliative care teams do not get involved in the care or management of these patients. Anecdotally these types of chronic patients consume large amounts of resource in health services. It can often be the experience for this type of patient that they become disempowered. The current service model leads to these types of patients being admitted to hospital, and being managed in a hospital setting, and then dying in a hospital. The preferred model of care should be more flexible. People with a long lasting but life limiting chronic condition should be able to enter palliative care for supportive care management and then exit, then re-enter as required. Often the nature of these chronic diseases means that these patients may be looked after by a specialist for 15-20 years but that physician may never talk to the patient about palliative care.

The role of specialist palliative care is also crucial to ensuring an integrated service system. Not everyone with a life limiting illness will require specialist palliative care- but many people will. Specialist palliative care provides a service model that is interdisciplinary in nature and can be delivered in any setting. Specialist services also play a crucial role in educating other service providers in the provision of palliative care. They can advocate strongly for best practice in palliative care, independent of service provider or care setting.

¹ National Palliative Care Strategy <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-npcs-2010-toc>,

The factors that are important to patients and families as they move toward the last few days of life, include:

- Pain and symptom management
- Preparation for the end of life
- Relationships between patients, family members and healthcare providers
- Achieving a sense of completion.

The service system must be able to adequately address these needs. Through the implementation of support to the primary care sector, identification of service gaps, upskilling of the workforce and the introduction of a national health standard, this can be achieved.

Roadmap for service models

- Additional investment in specialist palliative care services be directed to:
 - services for people at home in the community; and
 - outpatients and ambulatory visits within their other chronic disease clinics.
- Implement greater integration of palliative care into ambulatory chronic disease clinics and cancer clinics. For example the implementation of primary care specific ambulatory clinics that offer shared care, between specialists and supportive palliative care, for chronic conditions that are life limiting.
- Identify and resource specialist palliative care services to provide education, support and advice to generalist service providers, to ensure best practice in palliative care, independent of service provider or care facility.
- Identification of appropriate triggers that can identify service gaps and which would provide greater capacity to drive system level responses.
- Ensure that palliative care services are an integral part of cancer services and are considered in the planning phases of capital projects and importantly embed them in the implementation of Regional Cancer Centres.
- Adequate generalist out of hours nursing and medical cover for palliative care patients (those in the last 6-12 months of life) at home.
- Link all generalist providers to a 24 hour Specialist helpline.
- Produce a nationwide plan to educate generalist staff (nurses and GP's) in the palliative approach. Specialist Palliative Care staff would have a significant role in this.
- Ensure that all doctors have some palliative care education initially at undergraduate level but also at specialist level eg. Oncology trainees would benefit from a term in Palliative Medicine just as Palliative Medicine Trainees currently benefit from a term in Oncology.

Data and information

Understanding the terms ‘palliative care’ and ‘end of life care’ is crucial. There is a perception that both terms are the same. There is also a need to have clear definitions of the role of specialist versus supportive and generalist palliative care. CHA calls for a mechanism to develop consensus about definitions.

In terms of data collection it is apparent that existing data collections are still not capturing the true volume of palliative care patients. For example there is no comprehensive national data collection on community based palliative care. Data collections such as PCOC and NSAP remain voluntary. With the diversity of palliative care models across the country it is essential that a data system be developed that can adapt to service needs. For example it is difficult to identify palliative care patients if they are part of shared care or have been involved in a one off consult.

Road map for data and information

- That a mechanism to promote consensus around definitions of terms is adopted.
- Initiate compulsory data collections with clear definitions about types and levels of care. This should include the capacity for consultation teams to be included in hospital coding when picking up primary units secondary referral consultations.

Private Health sector

It is well established that palliative care, for reasons of quality, is an interdisciplinary discipline. Private health insurers have yet to fully develop services that match the needs of palliative care patients. This then raises issues of equity of access and fairness. For example, while most private hospitals provide physiotherapy as part of inpatient care, there is little incentive to provide other services, particularly assessment services for the home. Private health insurers need to come to the understanding that palliative care is inclusive of malignant and non-malignant groups.

There is inadequate cover of the suite of palliative care services, such as:

- Allied health – social work, occupational therapy, dieticians
- Bereavement care
- Home based care
- Equipment to enable home based care
- Nutritional support
- Pastoral and spiritual care
- Complementary therapies

The *Private Health Insurance Act 2007* introduced a number of changes (introducing Broader Health Cover), including the meaning of hospital treatment and those services that can be covered under private health insurance. The legislation gives insurers, hospitals, and service providers the opportunity to introduce innovative delivery of treatment and services - traditionally delivered in hospital - to holders of private health insurance outside the hospital setting. In addition to cost savings, the Act gives the privately insured a wider choice in where such services can be provided.

Broader Health Cover includes cover for chronic disease management – chronic and complex care (under which palliative care would fit), and hospital substitution (assisted discharge alternative to hospital admission, again under which palliative care could fit).

Even with the introduction of broader Health Cover there remain challenges to the delivery of palliative care outside hospital settings in the private sector. Challenges include a fear of cost-shifting from the public sector through to the private sector; defining end stage palliative care in order for the suite of services to be initiated; the nature of the competitive health insurance funding model working against any single fund offering a product ahead of its competitors; the need to assess patient functionality and capacity of primary carer(s) in planning for care; and capturing specific case data.

After the implementation of Broader Health Cover it became apparent that health insurers were not supporting this type of cover.

Roadmap for the Private Sector

CHA advocate supporting initiatives to encourage private health insurance funds to cover their members for non-hospital based palliative and end-of-life care.

- Development of an interdisciplinary, patient centred approach to care, that is funded by private health insurers. This would lead to savings on inpatient days for palliative care patients.
- Development of public - private partnerships whereby privately insured patients who are discharged from a private hospital can access publicly funded allied health services.

Workforce

An equitable, high quality, supportive system of palliative care can only be delivered if the components of the workforce are appropriately skilled.

The specialist physician workforce

According to the Australasian Chapter of Palliative Medicine (2007) survey of the palliative medicine specialist workforce there was a national shortfall of 97 palliative medicine specialists. Health Workforce Australia is including palliative care physicians in their current studies of specialists. Specialist training is very metropolitan centric and finding and accessing advanced trainee registrars for the private sector/ not for profit sector is increasingly difficult. Providing supervision for these trainees is also difficult.

Competency of the workforce

Generally in terms of palliative care there is no minimum standard of competency for allied health and the VET sector. This is becoming increasingly problematic as palliative care is integrated into residential aged care as well as other settings. Nursing does have some required competencies in relation to palliative care but these could be broadened.

For physicians there is a set of competencies and recently the Royal Australian College of Physicians developed of an end of life policy. This policy will affect all trainees and the College intends to recommend that all Medical Colleges have explicit end of life training.

Roadmap for Workforce

- Given the integrated nature of palliative care service delivery a deliberate program of upskilling health, aged and community care workers in the provision of palliative care is recommended, particularly targeting the VET sector and allied professionals.

Advanced Care Planning

Enabling people to become involved in decision-making requires sensitivity to personal and cultural values, empathy and an ability to inform and empower people to make choices about their care.

The incorporation and use of advanced care plans needs to be more explicit for hospital based services and should be part of hospital-wide planning, not just in palliative care. Advanced Care Planning (ACP) should be incorporated into standards and quality assessment processes, and standards should recognise the importance of allowing Catholics and catholic service providers to utilise ACPs that are consistent with Catholic ethical teaching.

Currently the cost of instituting advance care planning places an even greater unfunded load on already stretched services. For example General Practitioners, under current fee-for-service arrangements, would require use of specific MBS item numbers in order to increase the use of advance care plans and surrogate decision maker selection.

There is agreement from CHA members consulted that the current Department of Health and Ageing supported *Respecting Patient Choices* (RPC) program is inappropriate for palliative care. Within palliative care the emphasis must be on care planning and determining the best care for the person at that time. Care planning is an ongoing, consistent and open discussion within palliative care.

CHA notes that experience of the proposed RPC program in residential care has been problematic. Training and maintenance of staff is a significant barrier to implementation. Other approaches in ACP have more utility and allow better ownership within aged care facilities and offer more flexibility for culturally and linguistically diverse residents and a variety of other cultural groups including Aboriginal Australians.

Roadmap for Advanced Care Planning

- That flexibility in what tool for advance care planning is maintained, (that is, that the RPC tool is not mandated for all) in order to understand individuals values in making decisions about their healthcare as well as respecting the impact of different cultures and beliefs.
- That the Department of Health and Ageing consider broadening it's funding to beyond support for RPC to other tools that are being developed or have been developed. A preference would be to develop a capability framework for Advance Care Planning (ACP) so that services could demonstrate that they have implemented key elements of ACP, rather than use a prescriptive tool.
- That support, through the use of a Medicare item, be available to enable general practice, primary care and specialist palliative care teams to assist services to implement and support the advance care planning initiative.

Aged Care Sector

There is an increasing practice of transferring patients from hospital, hospice or community to residential aged care (RAC). This is happening with more frequency because of bed shortages, or because of carer stress. This is a very traumatic time for people. Levels of stress are then increased by having to complete the RAC paperwork which is often described as onerous.

Support provided to RAC from either specialist and community based palliative care services is often unfunded and uncoordinated and relies on the goodwill of services and the personal relationships established with RAC. In order to address this issue in Victoria, the government has taken a step forward by employing within each health region a nurse who coordinates palliative care within the RAC facilities within in their region. The sustainability of palliative care within RAC requires a link with specialist palliative care services to provide support.

There are many examples of unfunded in-reach services into RAC. One CHA member hospital has set up weekly palliative care clinics within some RAC facilities. A nurse assesses all palliative care referrals and identifies the more difficult and complex cases. The purpose of the role is to anticipate problems, and run a weekly clinic to address these. Senior trainees in geriatric and palliative care then attend the clinic. This is an effective model of service delivery, but is unfunded.

There is a demonstrated need for support to be provided to RAC facilities in the delivery of palliative care, particularly complex care. It has been reported that registered nurses and care workers often feel unskilled in the delivery of palliative care within a RAC setting. Issues include lack of confidence in providing adequate symptom management or pain control, lack of support from treating GP and often a general feeling of not knowing when to instigate palliative care, and what that should entail. In addition GPs often feel unskilled in ensuring adequate pain relief.

Roadmap for Aged Care Sector

- Ensure RAC facilities apply the Palliative Care Australia Guidelines for a Palliative Approach in Residential Aged Care within their facilities. This may be achieved through the expansion of the aged care standards to include documented evidence of interdisciplinary teams meetings for residents who require end of life care.
- Provide incentives to ensure GPs undertake CME in the area of palliative care. Residents should expect to receive consistent and coordinated medical care from a GP and or specialist familiar with their needs.
- In terms of outreach recommend that Medicare Locals take responsibility to coordinate reach into RAC. Medicare Locals could also develop local residential aged care networks, to encourage practice development, capacity and sustainability. For example, one to two nurses could be appointed across sites as champions to spread and sustain the palliative approach /end of life care pathways.
- Consider whether the ACFI instrument is an adequate mechanism to deliver the funding required to deliver palliative care to RAC. An alternative is to consider block funding for palliative care in residential aged care settings. This block funding could also be used to educate staff in the palliative approach and end of life care and be made available for residential aged care facilities to access more allied health services in the delivery of palliative care – particularly for assessment purposes.
- Ensure proper levels of nursing are available to support care in residential aged care facilities, particularly in relation to out of hours practice and availability and maintenance of syringe drivers. Adequate levels of nursing should be monitored via the accreditation system.
- Establish and fund programs to ensure training in the palliative approach for all residential aged care facility staff, and establish a visible program to encourage advance care planning in residential aged care facilities. Compliance can be monitored through the accreditation program.

Disability/Mental Health/ Prisons

CHA members provided many examples of where service provision to the vulnerable or marginalised is inadequate. Examples includes in indigenous health, paediatrics, rural and remote communities and culturally and linguistically diverse populations. This submission however will focus on three distinct areas – disability, mental health and prisons.

Access and choice of appropriate palliative care for people living with a disability or mental health issue is increasingly difficult. People working in the disability sector report how as people with disabilities develop life limiting conditions it is extremely hard to access palliative care services because they are seen as falling in the ‘disability’ stream and therefore have their own funding for support. It is also feared that the design of the proposed National Disability Insurance Scheme (NDIS) does not allow for interaction with health services. The siloed nature of disability, health, mental health and aged care means **the care pathway for the client is wrapped around service funding, not client or patient need.**

In addition some mental health conditions, such as anorexia nervosa are not traditionally viewed as conditions that can be life limiting and requiring palliative care services. Some mental health clients’ palliative care needs can be difficult to manage. For example there can be safety issues. There are other occasions where conditions can be difficult to manage due to behavioural issues. For example some with neurological disorders can often become very aggressive. Psychiatric services are not equipped with skills to manage their care and often carers become highly stressed.

There is a social justice issue in relation to palliative care service provision in prisons. The prison population, like the rest of the population, is an ageing one. A number of CHA member service providers deliver palliative care services to the justice system. What CHA have been told is that there is no capacity to provide ongoing palliative care within the prison system. Review of care or attendance at outpatient clinics does not occur. Within the prison itself there is no capacity to deliver p.r.n medication (i.e., pro re nata ‘when necessary’ medication). There are many barriers in place that mean a sufficient palliative care service cannot be provided.

Roadmap for Disability/Mental Health/ Prisons

- Health planning for ageing population and palliative care needs to be intersectorial.
- For patients who are in institutions (prisons, forensic psychiatric centres, mental health facilities) there needs to be developed approaches to care pathways to allow for access to specialist palliative care, because of the often complex nature of support required.
- Work toward upskilling and building capacity so that wherever people access palliative care it will be of high quality.
- Identify groups within the community that are vulnerable to not receiving adequate palliative care.

Section 4: Roadmap for the future

Catholic Health Australia calls for:

Standards

1. Development of a single Australian Health Standard for people approaching or reaching the end of life. This standard could cover issues of:
 - Care planning
 - Assessment
 - Access to specialist palliative care
2. Development of a national service framework that embeds palliative care and supportive care across all care.

Service models

3. Additional investment in specialist palliative care services be directed to:
 - a. services for people at home in the community; and
 - b. outpatients and ambulatory visits within their other chronic disease clinics.
4. Implement greater integration of palliative care into ambulatory chronic disease clinics and cancer clinics. For example the implementation of primary care specific ambulatory clinics that offer shared care, between specialists and supportive palliative care, for chronic conditions that are life limiting.
5. Identify and resource specialist palliative care services to provide education, support and advice to generalist service providers, to ensure best practice in palliative care, independent of service provider or care facility.
6. Identification of appropriate triggers that can identify service gaps and which would provide greater capacity to drive system level responses.
7. Ensure that palliative care services are an integral part of cancer services and are considered in the planning phases of capital projects and importantly embed them in the implementation of Regional Cancer Centres.
8. Adequate generalist out of hours nursing and medical cover for palliative care patients (those in the last 6-12 months of life) at home.
9. Link all generalist providers to a 24 hour Specialist helpline.
10. Produce a nationwide plan to educate generalist staff (nurses and GP's) in the palliative approach. Specialist Palliative Care staff would have a significant role in this.
11. Ensure that all doctors have some palliative care education initially at undergraduate level but also at specialist level eg. Oncology trainees would benefit from a term in Palliative Medicine just as Palliative Medicine Trainees currently benefit from a term in Oncology.

Data and information

12. That a mechanism to promote consensus around definitions of terms is adopted.
13. Initiate compulsory data collections with clear definitions about types and levels of care. This should include the capacity for consultation teams to be included in hospital coding when picking up primary units secondary referral consultations.

Private Health sector

14. Development of an interdisciplinary, patient centred approach to care, which is funded by private health insurers. For insurers this would lead to savings on inpatient days for palliative care patients, and for patients would ensure appropriate care in an appropriate setting, based on need.
15. Development of public - private partnerships whereby privately insured patients who are discharged from a private hospital can access publicly funded allied health services.

Workforce

16. Given the integrated nature of palliative care service delivery a deliberate program of upskilling health, aged and community care workers in the provision of palliative care is recommended, particularly targeting the VET sector and allied professionals.

Advanced Care Planning

17. That flexibility in what tool for advance care planning is maintained, (that is, that the RPC tool is not mandated for all) in order to understand individuals values in making decisions about their healthcare as well as respecting the impact of different cultures and beliefs.
18. That the Department of Health and Ageing consider broadening it's funding to beyond support for RPC to other tools that are being developed or have been developed. A preference would be to develop a capability framework for Advance Care Planning (ACP) so that services could demonstrate that they have implemented key elements of ACP, rather than use a prescriptive tool.
19. That support, through the use of a Medicare item, be available to enable general practice, primary care and specialist palliative care teams to assist services to implement and support the advance care planning initiative.

Aged Care Services

20. Ensure RAC facilities apply the Palliative Care Australia Guidelines for a Palliative Approach in Residential Aged Care within their facilities. This may be achieved through the expansion of the aged care standards to include documented evidence of interdisciplinary teams meetings for residents who require end of life care.
21. Provide incentives to ensure GPs undertake CME in the area of palliative care. Residents should expect to receive consistent and coordinated medical care from a GP and or specialist familiar with their needs.

22. In terms of outreach recommend that Medicare Locals take responsibility to coordinate reach into RAC. Medicare Locals could also develop local residential aged care networks, to encourage practice development, capacity and sustainability. For example, one to two nurses could be appointed across sites as champions to spread and sustain the palliative approach /end of life care pathways.
23. Consider whether the ACFI instrument is an adequate mechanism to deliver the funding required to deliver palliative care to RAC. An alternative is to consider block funding for palliative care in residential aged care settings. This block funding could also be used to educate staff in the palliative approach and end of life care and be made available for residential aged care facilities to access more allied health services in the delivery of palliative care – particularly for assessment purposes.
24. Ensure proper levels of nursing are available to support care in residential aged care facilities, particularly in relation to out of hours practice and availability and maintenance of syringe drivers. Levels of nursing should be monitored via the accreditation system.
25. Establish and fund programs to ensure training in the palliative approach for all residential aged care facility staff, and establish a visible program to encourage advance care planning in residential aged care facilities. Compliance can be monitored through the accreditation program.

Disability / Mental Health / Prisons

26. Health planning for ageing population and palliative care needs to be intersectorial.
27. For patients who are in institutions (prisons, forensic psychiatric centres, mental health facilities) there needs to be developed approaches to care pathways to allow for access to specialist palliative care, because of the often complex nature of support required.
28. Work toward upskilling and building capacity so that wherever people access palliative care it will be of high quality.
29. Identify groups within the community that are vulnerable to not receiving adequate palliative care.