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CATHOLIC HEALTH
Australia

PURSUING EXCELLENCE IN PALLIATIVE CARE

PALLIATIVE CARE POLICY BLUEPRINT

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FORWARD

Martin Laverty, CEO Catholic Health Australia

We are fortunate that 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 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.

The neglect of palliative care in the broader health policy agenda presents as an urgent health challenge for governments. Palliative care is not an optional extra – it must be viewed as an integral core component of health care delivery and take place in any setting. Governments must invest in providing palliative care services as a core part of health care and not as an “add-on extra”.

The future for palliative care lies in the introduction of palliative care into mainstream healthcare. There must also be a funded program of health professional education as well as a social marketing education program for the public – the results of which will hopefully provide greater choice to individuals and families.

Each state and territory offers different access to palliative care. Access to quality, coordinated palliative care shouldn't depend on whether a person is lucky enough to live in a state or territory that has access to high quality innovative services. Service provision must be uniform in nature and guided by clear directives at the federal level. This publication, “Pursuing excellence in palliative care,” aims to contribute to the revision of the National Palliative Care Strategy and calls for an adherence to fifteen principles that should be responded to by governments and service providers in order to deliver excellence in palliative care.



Palliative care was defined by the World Health Organization in 2002 (1), as:

... an approach that improves the quality of life of patients and their families facing the problem 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. (p.14)

EXECUTIVE SUMMARY

The neglect of palliative care in the broader health policy agenda presents as an urgent health challenge for governments. Palliative care is not an added on extra – it must be viewed as an integral core component of health care delivery and take place in any setting. Governments must invest in providing palliative care services as a core part of health care and not as an “add-on extra.”

Catholic Health Australia (CHA) proposes a set of **principles** against which government policy in palliative care should be measured. These principles are:

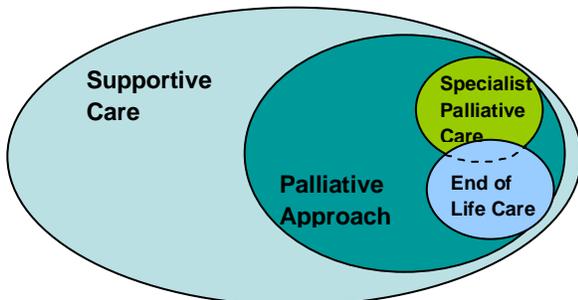
1. Consumers as participants in the process of care
2. Choice and flexibility
3. An enabling service system
4. Dying in place of choosing
5. Streamlined quality care standards
6. Integration of psychological and spiritual aspects of care
7. Maintaining best quality of life
8. Contemporary management practices
9. Embedded education
10. Real support for carers
11. Integrated care
12. Expanding supportive care
13. End of life conversations
14. Need, not diagnosis, to drive service
15. Publicly talk about the issue that won't go away – death & dying

CHA advocates for: adoption of an integrated policy approach to palliative care program planning and implementation; ensuring that consumers or their representatives are participants in palliative care and as such are in control of their care planning and delivery; access to palliative care services that are equitable; that evidence-based processes are at the centre of policy development; palliative care policies that build capacity in skill and knowledge across all settings; and palliative care service delivery philosophy that is broadly integrated and embedded across all health services.

Australia's **palliative care challenges** include:

- An ageing population
- Workforce issues
- Ensuring excellence in palliative care
- Funding of specialist palliative care services, including:
 - Private hospital funding
 - MBS item numbers
- Advance care planning

A service model and strategies that address these challenges are proposed.



Model of proposed palliative care service system¹

¹ Adapted from Associate Professor Richard Chye, Sacred Heart, Sydney

Strategies for achieving excellence in palliative care are proposed in the areas of:

- Service models
- Residential Aged Care Facilities
- Specialist Palliative care
- Quality and research
- Carers
- Communications

Specific strategies include:

Service Models
Trial the development of a rapid response service to access and help manage patients with their pain and other symptom control, including psychological issues.
Practice nurses to be funded to increase the uptake of end of life pathways and advance care planning.
Urgent commencement of negotiations with private health insurers and government to ensure equitable access to palliative care services in the not for profit and private sectors.
Specialist palliative care services to be identified and resourced to provide education, support and advice to generalist service providers, to ensure best practice in palliative care, independent of service provider or care facility
Residential Aged Care Facilities
As a matter of urgency the federal government must increase funding available for palliative care delivered in residential aged care facilities
Ensure and fund proper levels of nursing are available to support care to residential aged care facilities, particularly in relation to out of hours practice and availability and maintenance of syringe drivers.
Greater investment should be provided in researching the management of end of life care for dementia sufferers.
Development of local residential aged care networks, with purpose being 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.
Specialist Palliative Care
Greater support be provided to Specialist Palliative Care services in order to maintain quality, standards and continuity of care for patients and families/carers in need of palliative care services.
Create a funded service system whereby specialist palliative care services can offer support to generalists, for example, through discussions of managed care plans.
Quality & Research
Provide significant expansion of research in end of life care, including care in different locations and in conditions other than cancer.
Carers
Recognise the work of families and caregivers and support them to help care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities.
A full review of bereavement services including input from not recently bereaved relatives in order to measure quality care and bereavement services.
Communications
A funded communication initiative that informs the public of the benefits of palliative care. A public discussion about the issue of dying, and dying well.

CATHOLIC HEALTH AUSTRALIA

Catholic Health Australia is a Leadership Group established by the leaders and owners of Catholic health and aged care providers in Australia.

Vision

Catholic Health Australia seeks an active, effective and growing ministry which is inspired by and reflects the healing mission of Jesus.

Mission

Catholic Health Australia through the Stewardship Board has the responsibility to develop and enhance effective relationships within the sector to grow and enrich the ministry, aspiring to achieve a more visible Catholic health and aged care system. Catholic Health Australia works to promote justice and compassion in health care, influence public policy and strengthen the presence and influence of Catholic health and aged care within the Australasian health care systems.

Taking Responsibility

Catholic Health Australia's Stewardship Board will exercise its responsibility through:

- Sector leadership
- Planning assistance
- Policy formulation
- Leadership development and formation
- Advocacy and representation

Targets

- Growth in Ministry
- Advancing a Fair and Just Society
- Development of Sector Orientated Activities

CHA Strategic Plan

Strategic Priorities for 2009-2012

Social Justice: Driving better access and provision of health services in the community and improvement in the health of the poor and underserved, Indigenous Australians and our Australasian neighbours.

Strategic alliances within CHA: Developing more partnerships, alliances and special interest groups across CHA.

Health of the Catholic Sector: Identifying what is required for the long term effectiveness of the Catholic health and aged care sector.

Health & Aged Care Reform: Supporting the ministry of Catholic health and aged care through systemic reform.

The planning principles for 2009-2012 include:

Member Interests:

"The interests of the membership base will be central to development of CHA operational plans –membership is the reason CHA exists. CHA will prioritise specific interests of its expanded membership to improve the opportunity for health and aged care ministries to develop in the service of the community".

Relevance to the community:

"CHA will focus public advocacy on those prioritised issues that most impact the future viability of health and aged care ministries, that is, what is most relevant to the community and people these ministries serve. This principle relates directly to Member Interest".

In communion:

"In planning for the future CHA will work towards creating an environment in which health and aged care ministries are able to act in communion as part of one Catholic Church, sharing the rich tradition and compassionate presence of Catholic health and aged care. It is as a united entity that our collective strength can be realised by those we serve".

The poor and under-served:

"Breathe new life into the gospel imperative of preferential option for the poor through promotion of services and advocacy specifically targeting the needs of the poor and marginalised. In addition when instituting public policy CHA must always keep the "preferential option for the poor" at the forefront - public policy decisions must be viewed in terms of how they affect the poor. This is a central component of Catholic social teaching".

Ethical Challenges:

"The foundational principle of all Catholic social teachings is the sanctity of human life and CHA will aim to provide leadership in promoting the ethical nature of Catholic health and aged care beliefs".

CHA has had specific feedback from its membership requesting that broad policy be developed in the area of palliative care, and advocated for within the wider community. Equitable access to palliative care as a fundamental human right is supported by the membership.

PRINCIPLES FOR PURSUING EXCELLENCE IN PALLIATIVE CARE

Catholic Health Australia puts forward 15 principles that should be responded to by governments and service providers, in order to deliver excellence in palliative care.

1 *Participants in the process of care*

Palliative care recipients, carers and family must be participants in the process of care, rather than dependent service users. Adherence to this principle should lead to user led innovation and the creation of service solutions. In addition, health service providers must inform and empower participants in palliative care to make choices about their care.

2 *Choice and flexibility*

Development of palliative care policy must respond to each participant's choices and be flexible so that service provision can be reconfigured easily to meet changing needs.

3 *An enabling service system*

The health system must be an enabling service system, that is, a health system better able to meet the diverse needs of all who use it and which maintains high quality standards in palliative care across all healthcare settings, and along the continuum of care. It must also be a system that allows access to palliative care across the geographical spectrum of the nation.

4 *Dying in place of choosing*

Where possible the health and aged care system should support and enable people to die in the place of their choice.

5 *Streamlined quality care standards*

Minimum quality care standards in palliative care must be streamlined so that they are maintained across all settings – primary and specialist services – and promote continuity of care across these settings. This will allow specialist services to respond to the more complex range of standards as well as support primary care providers.

6 *Integration of psychological and spiritual aspects of care*

Psychological and spiritual aspects of care must integrate as integral components with palliative care service delivery in a consistent way, independent of mode or provider of service.

7 *Maintaining best quality of life*

All participants along the projector of the palliative process of care must be supported to maintain the best quality of life possible until death and into bereavement.

8 *Contemporary management practices*

Advances in management for palliative care recipients, including advances in medication, must be made fully available to all Australians.

9 *Embedded education*

Curriculum based, continuing education should be delivered to all health professionals involved in the care and management of people who have life limiting illness, with an aim to change attitudes towards palliative care.

10 *Real support for carers*

Assistance is provided to families and caregivers who are caring for loved ones, inclusive of practical supports such as respite, to a level similar to those with maternity and paternity responsibilities; and access to expert care in loss and grief through illness and into bereavement.

11 *Integrated care*

Palliative care is offered as an integral part of health care and can take place in any setting. However education and training is necessary to achieve including access to specialist support is through collaboration with primary health providers to sustain it.

12 *Expanding supportive care*

Supportive care – traditionally a service which may be required by those affected by cancer (services to address physical, psychological, social, information and spiritual needs) are expanded to support all in need of palliative care, and is provided by generalist and specialist health services as well as community services. Supportive care should be available throughout the illness trajectory, not just the terminal phase.

13 *End of life conversations*

Palliative care and discussions about end of life issues and advanced care planning need to be an integral part of care planning for people with chronic long term conditions.

14 *Need, not diagnosis, to drive service*

Services should be available on the basis of need in terms of symptoms and problems, and their effectiveness in meeting that need, rather than on the basis of diagnosis.

15 *Address the issue that won't go away*

Effort must be put towards changing the way society views and discusses death and dying. Palliative care discussion should be promoted across the community encouraging people to discuss their wishes for healthcare openly, in parallel with increasing the development and implementation of advance care planning.

In summary, CHA advocates for:

1. Adoption of an integrated policy approach to palliative care program planning and implementation.
2. Ensuring that consumers or their representatives are participants in palliative care and as such are in control of their care planning and delivery.
3. Access to palliative care services that are equitable.
4. Evidence based processes are at the centre of policy development.
5. Palliative care policies that build capacity in skill and knowledge across all settings.
6. Palliative care service delivery philosophy that is broadly integrated and embedded across all health services.

CONTEXT

Within Catholic health and aged care services palliative care is provided in acute settings, hospice settings, residential aged care settings and in the community - in people's homes.

It is difficult to define when end of life care, palliative care and supportive care happens. This is partly because it is difficult to define exactly when these care types commence. Key areas in which they occur include:

- Hospital admissions,
- Specialist palliative care services,
- Hospices,
- Community nursing services,
- Residential aged and disability care facilities.

CHA members provide many palliative care related services, located within acute settings, hospices, aged care facilities and in people's homes, and is delivered by both specialist and non-specialist providers.

CHA believe that Catholic providers provide up to 50per cent of all palliative care services across Australia. This is difficult to confirm because of the lack of comprehensive measurement of activity. Specific consideration should be given, as a matter of urgency, to the management of palliative care information, specifically definitions and data sets.

The revised definitions contained in the Commonwealth's *National Partnerships Agreement* will develop better data descriptions and definitions to ensure that palliative care can be reported against and counted uniformly across all states and territories. This work will include non-admitted settings, such as community based palliative care programs. There is not a patient level sub acute data set currently, but CHA understands that work on this is underway within the Department of Health and Ageing. Provision of accurate definitions and reporting of data, including from residential aged care, will provide governments with a greater understanding of activity. This move is welcomed.

Australia has been in the midst of one of the most difficult times it has faced in most people's living memories - the global financial crisis, climate change, including increasing water scarcity, a rapidly ageing population and increasing social disadvantage. Within this context health and aged care sectors must take account of their specific challenges into the future, including how to:

- Meet the needs of an ageing population,
- Address the increasing burden of chronic disease,
- Address the issue of an ageing workforce,
- Ensure coordination of care that is client centred and, where possible and practical, user controlled and directed,
- Support early intervention and prevention,
- Ensure access to services.

The World Health Organisation in its palliative care publication 'The Solid Facts'² explores the 10 most pressing issues to address in palliative care. These are worth considering when thinking about what issues Australia will be facing in the future in the area of palliative care service delivery.

1. **Changing Populations:** Population ageing and the implications these present for care towards the end of life are major public health issues for the 21st century.
2. **Emerging needs towards the end of life:** People living with different serious chronic illnesses often have similar concerns and needs.
3. **Palliative Care:** Policies for palliative care need to be developed as part of an innovative global public health policy.
4. **Rights and options:** Good quality care towards the end of life must be recognised as a basic human right.
5. **Effective palliative care:** Simple measures including pain relief, sensitive communication and well coordinated care,

² World Health Organisation The Solid Facts: 2004; <http://www.euro.who.int/document/E82931.pdf>

are effective in relieving symptoms and suffering.

6. **Vulnerable groups:** Some vulnerable groups within society have unmet needs and equal access to good quality palliative care must be ensured.
7. **Improving services:** Many innovative ways of improving the quality of care towards the end of life are being developed and must be shared across teams, organisations and countries.
8. **Educating professionals:** Health professionals need to be trained well in palliative care, to have opportunities to extend their knowledge, and to work within organisations that promote attitudes and behaviours to sustain these skills.
9. **Educating the public:** "The dissatisfied dead cannot noise abroad the negligence they have experienced." (Hinton, 1967)
10. **Research & Development:** Research and training in palliative care should be considered a priority, and funded in line with that for potentially curative interventions.

How palliative care is defined

Australia has not recorded its activity in relation to palliative care all that well over the past 20 years. Governments are beginning to realise this is an issue and are undertaking effort to rectify the situation. Because of this lack of data it is difficult to identify how much money is spent on palliative care nationally or indeed how palliative care is defined. We know that the United Kingdom spends only 0.18per cent of total government and charitable funding for cancer research on end-of-life and palliative care. The United States spends only 0.9per cent of its cancer research budget on palliative care.³ In Australia we do not know how much we spend on palliative care research, but it is unlikely to be very high.

Approaches to palliative care

Many OECD countries have recently reviewed their approaches to palliative care. In Canada the

Canadian Palliative Care and End of Life Strategy was written in 2002 and had a five year life. Main components of the strategy aimed to improve the standardisation of care delivery, education for health professionals, research around best practice and the development of public awareness campaigns. New Zealand developed a palliative care strategy in 2001 and established a network for palliative care service delivery, while the United States have focused mainly on the development of clinical guidelines. In the United Kingdom the *End of Life Care Strategy* was released in 2008 and looks at the wholistic delivery of palliative care with the development of care pathways for the delivery of integrated care. This strategy builds upon the National Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care tools. In Scotland the release of the *Living and Dying Well* document (2008) supports a person centred approach to delivery of consistent palliative and end of life care. The key principles of assessment, planning and delivery, communication and coordination, education and implementation provides a comprehensive framework for service providers. The new Service Delivery Framework in Victoria is also a useful reference for future development. It aims to provide a common/consistent basis for the provision of palliative care across the state. This methodology could be usefully adopted across the nation, and would ensure consistency in service delivery⁴.

Palliative care in practice

Patients and their families often need particularly responsive kinds of help when their loved ones receive palliative care, and health care must be tailored in a way that allows a rapid response as people's needs increase. Families who are often the main carers within the community require access to interdisciplinary and multidisciplinary teams in order to enable patients to live as fully as possible to the end of their lives. And people often need palliative care after initial diagnosis and continue to benefit from treatments that alter the progress of disease until the end of life.

³ World Health Organisation The Solid Facts: 2004; <http://www.euro.who.int/document/E82931.pdf> p.28

⁴ Service Delivery Framework and Funding Model Review, Victorian Government, accessed 7/4/2010 <http://www.health.vic.gov.au/palliativecare/sdffmr.htm>

Palliative care has moved beyond the realm of being a service provided to people with terminal cancer. Palliative care techniques to manage pain are often applied against complicated pain suffered by people with other life limiting conditions and non malignant conditions. Palliative care into the future needs to respond to the unique needs of the patient and carer, with a focus on the practical as well as the physical and psychological, for example more flexible use of respite, equipment and transport for home-based care and links with specialist providers.

AUSTRALIA'S PALLIATIVE CARE CHALLENGES

There are a number of challenges within the policy environment for palliative care. These include an ageing population, scarce workforce, increasing burden of disease, cost of care delivery, the availability of less carers and the need to separate the treatment decisions at end of life from debates about euthanasia.

Ageing Population

The *2010 Intergenerational Report* has recently been released. It shows that Australia's population is ageing and the percentage of our population aged over 65 years is projected to grow dramatically over the next 40 years. This means that a smaller proportion of people in the workforce will need to support a larger group of retirees. A big slice of that support will take the form of health and aged care services.

Health spending is projected to grow from 4.0 per cent of GDP in 2009-10 to 7.1 per cent of GDP in 2049-50. This population ageing will contribute to spending growth. In addition, based on past spending patterns, growth is projected to stem from increasing demand for health services and the funding of new technologies. Over the medium term, the combined effect is manifested in growth in all major categories of health spending: hospitals, medical benefits, pharmaceuticals and private health insurance⁵.

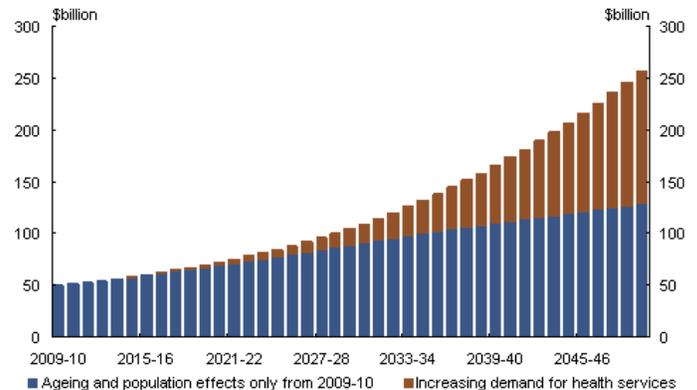
As the population ages, more people will fall into the older age groups that are the most frequent users of the public health system. Combined with population growth, this will play an important role in increasing future health costs.

From 2009-10 to 2049-50, real health spending on those aged over 65 years is expected to increase around seven-fold. Over the same period, real health spending on those over 85 years is expected to increase around twelve-fold.

⁵ Intergenerational Report 2010: http://www.treasury.gov.au/igr/igr2010/report/html/05_Chapter_4_Ageing_pressures_and_spending.asp

In addition to demographic pressures, demand for higher standards of care will place pressure on the Government to increase expenditure, as will rapid technological innovation.⁶

Figure 1: Total Australian government health expenditure with and without non-demographic growth (in 2009-10 dollars)⁷



Source: Treasury projections.

With the ageing of the population the pattern of diseases that people will die from is also changing and more people will die as a result of serious chronic disease. Older people are already more likely to suffer from multi-organ failure towards the end of life.

CHA believes there must be greater emphasis on the care of people of all ages who are living with and dying from a range of serious chronic diseases. For example people with heart failure or chronic obstructive respiratory disease may live longer but with more disability and then die suddenly. For people with dementia access to palliative care is important, particularly as conditions deteriorate. The emphasis on palliative care that is flexible in order to meet individual needs is particularly important for those suffering from dementia.

Issues such as advance care planning and medical decision making require discussion within the broader community. In some instances the futility of treatment provided to people at the end of their life

⁶ Op cit

⁷ Op cit

is not discussed with patients and their families. Anecdotally this occurs more often with people who suffer from non malignant illness. We know that approximately 70 per cent of Australians die in acute care hospitals. A quote from Professor Ken Hillman from the ABC Four Corners program "A Good Death", aired 8 February 2010, is instructive⁸:

Approximately 70 per cent of Australians die in acute hospitals. Getting sick at home, put in an ambulance, coming into the hospital, coming into the general wards, going into intensive care. It's that process which has happened subtly. And it's happened without any discussion with our society. It's just what we do.

And we do it for what we consider are the best interests of patients. We want to look after them. We want to cure them. And in doing so we've set up a situation where it's very difficult to die peacefully.

The patients that we get up to Intensive Care, we're often surprised to find that death and dying hasn't been mentioned to the friends and relatives, nor to the patient. This is often the case. Words such as "things aren't going so well. The treatment that we hoped would work doesn't appear to be working as well." It's more these sort of words that are dancing around the topic of dying.

....I had six intensive care beds 20 years ago, and they're now building me 60 intensive care beds.

REPORTER: Because of the demand?

KEN HILLMAN: *Yes because of the demand. But one could actually question whether that's real demand and whether the money or some of the money would be better spent in palliative care units, in community support.*

An intensive care bed costs around \$3,000-\$4,000 per patient per day. Palliative care services cost a lot less, and provide, as alluded to above, a peaceful way to die.

CHA also notes that palliative care options for people receiving aged care services are sometimes not at

best practice levels. Elderly Australians deserve quality care at the end of their lives, regardless of where they live. There is widespread underassessment and treatment of people who require palliative care in residential aged care facilities. Better ways of identifying residents' needs for palliative care earlier in the trajectory of the disease should be established.

Workforce

The relative neglect of palliative care in health policy presents urgent health challenges for health policy- and decision-makers, not least in the area of workforce. There must be matching of the right skills and expertise to best meet the needs of the person at the end of their life.

Types of workforce

The palliative care workforce consists of individuals working exclusively in palliative care roles, individuals whose roles combine palliative care with other health care activities, and individuals who are self-employed or working for multiple agencies.

A palliative care workforce study conducted by Victoria in 2006 revealed that over 50 per cent of people employed in palliative care service delivery were Grade 1 Registered Nurses, and over 88 per cent of the workforce was female.⁹ In this study volunteers made up more than 60 per cent of the combined labour force head count.

The Victorian workforce study identified their state funded palliative care service delivery modes as being:

- consultancy services within public hospitals, providing clinical expertise in palliative care to other terminal care providers and health practitioners within a region,
- inpatient services providing palliative care to patients through hospice units or designated palliative care beds in a hospital setting,
- community services providing in-home palliative care services,

⁸ Four Corners "A Good Death" Program Transcript: <http://www.abc.net.au/4corners/content/2010/s2813530.htm>, accessed 7/4/2010

⁹ Victorian Government: Palliative care workforce: A supply and demand study, <http://www.health.vic.gov.au/palliativecare/workforce.pdf>, p.1

- statewide services providing client care and support within the service's statewide scope, or
- target group, or consultancy to other palliative care services and health care providers¹⁰.

There are of course other closely related services that are delivered within the health care sector and outside of the specific palliative care funded services. Overlaps between the palliative care sector workforce and the workforces of other health services are therefore likely.

The Victorian report has shown overall increases in workforce requirements (driven by demand and replacement of retirements). It can be assumed that similar results to these could be applied across the nation. One of the risks identified in the report was that potentially the available workforce pool for the palliative care sector would be diminished if overall supply to the health workforce pool was insufficient – which we know to currently be the case.

Whilst there is a strong and compelling need for specialist palliative care services, there is also a need for the greater development of an informed health workforce those generalists who can competently deliver care to those in need of palliative care and end of life care. This generalist model, supported by access to specialist advice and support, would enable best practice palliative care, independent of care setting or provider.

The community based health workforce must be supported in enhancing the health literacy of the community in relation to end of life care and palliative care. The workforce must be competent at introducing ideas such as advance care planning and advance directives.

Palliative Medicine

In terms of industry benchmarks for the palliative medical workforce, Palliative Care Australia¹¹ recommends 1.5 fulltime equivalent (FTE) Palliative Medicine Specialists per 100,000 population. The

¹⁰ Victorian Government: Palliative care workforce: A supply and demand study, <http://www.health.vic.gov.au/palliativecare/workforce.pdf>, p.43

¹¹ Palliative Care Australia (2003) Palliative Care Service Provision in Australia: A Planning Guide. Canberra: PCA.

Royal College of Physicians (UK)¹² suggests a minimum of 2.0 FTE Palliative Medicine Specialists per 250,000 population. Queensland Health¹³ has used a ratio of 1.0 FTE Palliative Medicine Specialists per 100,000 population in their state-wide cancer plan.

This modelling has been based on the traditional referral patterns to specialist palliative care services. If the pattern of referrals was to change, (for example, the addition of patients with organ failure, degenerative neurological diseases, frailty and dementia) many more Specialist Palliative Medicine Specialists would be needed to meet demand in a timely manner.

The general medical workforce, including junior doctors who need training in advance care planning and the relevant state training bodies, need to have this on their agenda for targeted populations of patients with advanced chronic disease or dementia.¹⁴

Ensuring excellence in Palliative Care

Palliative Care Australia has done an excellent job in pulling together the various aspects of quality in relation to palliative care with the National Standards Assessment Program, the involvement in the Palliative Care Outcomes Collaboration and the Palliative Care Knowledge Network. In addition to these quality initiatives there are also the Palliative Nurses Association which in the process of developing indicators, and the Australia and New Zealand Specialist Palliative Medicine Clinical Indicators Working Group. However streamlining of these quality processes is possibly warranted. The development of a guidance document by Palliative Care Australia may go some way to streamlining processes. It will provide specific guidance on the

¹² Royal College of Physicians, (2008), Consultant Physicians Working for Patients. 4th edition.

¹³ Queensland Health (2008) Queensland Statewide Cancer Treatment Services Plan 2008-2017. Available at: http://www.health.qld.gov.au/publications/qh_plans/QS_cancer_plan_final.pdf

¹⁴ Gold Standards Framework (2006) Prognostic Indicator Guidance. Available at: http://www.goldstandardsframework.nhs.uk/content/gp_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%202025.pdf

necessary steps to achieve quality care for all Australians who require palliative care.

Funding of Specialist Palliative Care Services

It makes sense that seeing patients and their families/carers in their home or residential aged care facility in the community is both beneficial and helpful for patients. One of the challenges facing the palliative care service sector is that there is not appropriate incentive and reward for specialist palliative care services.

Private hospital funding

In not for profit and for profit private hospitals there is little incentive and limited capacity for the same organisational impetus as the public sector to provide palliative care services. CHA recommends commencement of negotiations with private health insurers and governments, to ensure the not for profit sector and the private sector can further develop services in palliative care that are **at least** equal to those found in the public sector. This is a matter of equity and justice.

The Private Health Insurance Act 2007 was supposed to have given insurers, hospitals and service providers the opportunity to introduce innovative service delivery of treatment and services – traditionally delivered in hospital – to holders of private health insurance outside the hospital setting. In practice this has not occurred uniformly, although one large not for profit Catholic provider does provide a home based palliative care service- and this is unique. The Broader Health Cover policy, in practice, does not reflect contemporary clinical practice.

There is a need for private health insurance to provide coverage for **home based palliative care**. This approach would:

- Maximise choice for consumers, increasing demand for home based services, and;
- Decrease pressure on hospitals and hospices and may offer Palliative Medicine Specialists and allied health professionals increased opportunities for private practice, providing an incentive to these professionals to practice this specialty and improve workforce shortages.

Not all people who receive palliative care at home actually die at home. Whilst there is a paucity of published data on the subject, a NSW report¹⁵ reports that although 90% of terminally ill patients spend the majority of their final year at home, only a third of these people actually die at home. More data is needed to identify the reasons why.

Application of the Private Health Insurance Act 2007 and some changes to Medicare should also allow for hospital and non-hospital organisations to offer Specialist Palliative Care services in the home. Provision of access to Specialist Palliative Care services occurs in some settings and jurisdictions and has many benefits such as maximising consumer choice, meeting demand for services, avoiding use of acute care and supporting the continuum of care.

CHA believes there should be greater integration of hospital, hospice and community palliative care services to promote coordination and integration of care. It is particularly important that residential aged care facilities have increased access to Specialist Palliative Care services. Specialist Palliative Care services that are based in hospitals have proven that they can provide integrated care across all settings. Most funding models do not recognise the role of Specialist Palliative Care services in supporting primary care services.

Paediatric Palliative Care

Paediatric palliative care is a highly specialised area. Children who receive palliative care need to adjust physically to their needs, and health professionals need to be cognisant of physical and cognitive developmental needs.

The potential length of illness trajectory for chronic disease in children can be long and the burdens experienced by carers during this time is significant.

CHA supports the development of national paediatric palliative care steering group that can consolidate resources and research for this small population group.

MBS item numbers

The concept of palliative care as an intervention must be developed and used to meet the needs of

¹⁵ NSW Government: *Place of death of people with cancer in NSW*

all the population. The Medical Benefits Schedule should be reviewed to allow this to happen more readily.

For example there are inequities in access to different MBS item numbers that should be addressed. General Practitioners (GP) have access to Enhanced Primary Care (EPC) items that allow a patient who has seen a GP to access five services in a year from an allied health practitioner, who is then able to bulk bill the patient for these services. Palliative Care is an multidisciplinary specialty, but this approach is not supported by the MBS. Palliative Medical Specialists do not have access to EPC items and therefore when they see a patient who requires services such as counselling, hand rails or physiotherapy, they do not have access to allied health practitioners who will bulk bill, because of a lack of access to the Medicare Plus Program. 62 per cent of all palliative care services are delivered in the community¹⁶ and palliative care recipients who happen to see a Palliative Medical Specialist deserve the same access to allied health services as they would if they saw a GP. This is again a matter of equity and justice.

Advance Care Planning

Advance care plans are tools that can be followed by health professionals and relatives if the person with a life limiting illness becomes unable to make treatment decisions for themselves. There is reluctance to discuss issues of death, dying and bereavement. Good care planning and advance care planning rely on dialogue and partnership. Emerging needs of people living with serious chronic illnesses, together with new evidence of the effectiveness of palliative care, mean advance care planning tools must now be offered more widely and integrated more broadly across the health care services¹⁷.

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 should be incorporated into standards and quality assessment processes.

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.

It should also be recognised that advance care planning presents particular challenges for people with dementia, especially since comparatively few receive a diagnosis early in the condition.

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.¹⁸

¹⁶ Australian Institute of Health and Welfare 2008. National palliative care performance indicators: results of the 2007 performance indicator data collection. Cat. no. HWI 99. Canberra: AIHW. P.30

¹⁷ World Health Organisation The Solid Facts: 2004; <http://www.euro.who.int/document/E82931.pdf>, p.9

¹⁸ The Solid Facts: Palliative care: edited by Elizabeth Davies and Irene J Higginson. World Health Organization, Europe, 2004, p.16

PROPOSED STRATEGIES TO CONSIDER FOR THE FUTURE

Service Models

Models for the delivery of palliative care services must respond to consumer need and must strive for excellence. They should adhere, where possible, to the set of principles outlined earlier.

The proposed health reforms, and the proposed implementation of Local Hospital Networks, sit well with a model of palliative care service delivery that is locally responsive. This type of service model should also allow palliative care services to sit within, and be part of, Integrated Cancer Care centres.

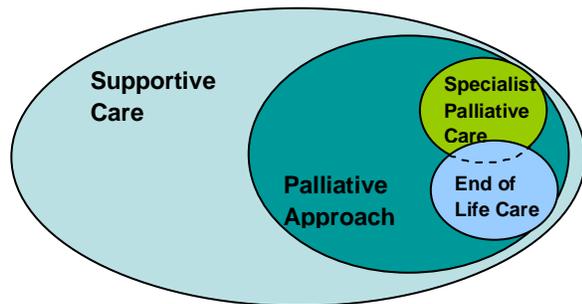


Figure 2: Model of palliative care service system¹⁹

A service system is recommended in which the definition of supportive care is broadened to encompass service provided by generalist and specialist health services as well as community services. Support from family, friends, support groups, volunteers and other community-based organisations makes an important contribution to supportive care, as does the multidisciplinary team. As Figure 2 illustrates, supportive care can occur at any stage through a person's illness. There comes a time, though, when a palliative approach to care should be commenced. This palliative approach is commonly seen in residential aged care, but the principles can also be applied more broadly across community and hospital settings. Service providers,

¹⁹ Adapted from work undertaken by Associate Professor Richard Chye, Sacred Heart, Sydney

volunteers and carers can offer care that takes into consideration an individual's specific needs. A palliative approach improves quality of life by providing pain and symptom relief, spiritual and psychosocial support, and provides space for conversations about end of life issues, (if they have not already occurred) such as advance care planning. 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 multidisciplinary 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.

End of life care, as illustrated in Figure 2, refers to the last days of someone's life. Pathways can be implemented and specific support provided to consumers, carers, family members and significant others. Ideally this support continues after the loved one has passed away. End of life care may require the input of specialist palliative care teams or it may not. Each individual's needs are different, regardless of their diagnosis. It should also be noted that many non-malignant diseases have a natural history of progression and exacerbation which makes the identification of the beginning of the end of life phase difficult to identify. If the consumer is placed at the centre of care then it can be expected that every patient dying a predictable death can experience the benefits of good end of life care²⁰. The factors that are important to patients and families at the end 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 completion²¹.

The service system must be able to adequately address these needs.

²⁰ Rutledge DN, Donaldson NE, Pravikoff DS. End-of-life care series. Part II. End-of-life care for hospitalized adults in America: learnings from the SUPPORT and HELP studies. *Online Journal of Clinical Innovation*. 2001;4(6):1-60

²¹ Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *Journal of Pain and Symptom Management*. 2001 Sep;22(3):727-37

Strategies for achieving excellence in palliative care

Service Models

1. Create a new national palliative care intake assessment model which would provide:
 - a new single point of access and referral – including the development of a web portal – in which all referrals for service are forwarded onto the responsible Local Hospital Network or equivalent.
 - a number that would be available 24/7 with details taken and passed to the appropriate professional immediately.

The model could be similar in design to the proposed Pregnancy & Perinatal Helpline that is being funded and implemented under the *Improving Maternity Services Budget Package*.

2. A national palliative care intake assessment model should take into account the complexity of need, particularly in rural areas and in relation to access to certain medications. Therefore it is recommended that such a model be trialled on a state by state basis, commencing with Western Australia, which already has a similar system in place under the Medical Specialist Outreach Program (MSOP).
3. Improve integration of hospital, hospice, residential aged care facilities and community palliative care services to promote coordination and integration of care.
4. Invest in education in advanced care planning through developing specific MBS item numbers for general practitioners, to increase the use of advance care plans and surrogate medical decision makers.
5. Trial the development of a rapid response service to access and help manage patients with their pain and other symptom control, including psychological issues.
6. Implement and fund a national approach to the roll out of uniform end of life care clinical pathways (Liverpool Care Pathway and the National Gold Standards Framework). This will require significant education to avoid inappropriate use of pathways and validation of the effectiveness of the tools. Proper guidance measures must be developed as there is currently a risk that people are being put on

these pathways too soon, and perhaps are dying earlier than need be.

7. Evaluate existing models of integrated care and disseminate findings – turning results into real service change.
8. With the allocation of the Health and Hospitals fund of \$1.3 billion towards building a world class cancer system and the implementation of Regional Cancer Centres, ensure that palliative care services are an integral part of cancer services and are considered in the planning phases of these capital projects.
9. Fund practice nurses to increase the uptake of end of life pathways and advance care planning.
10. 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.
11. Urgently commence negotiations with private health insurers and government to ensure equitable access to palliative care services in the not for profit and private sectors.
12. Populations with poor access to palliative care (i.e. specific specialist requirements such as paediatrics and adolescents or intellectual/mental health disability and those where barriers are related to language and culture including ATSI, deaf, CALD populations) should be specifically targeted when considering development of new service delivery and funding models.

Residential Aged Care Facilities

1. 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.
2. Urgently increase federal government must funding for palliative care in residential aged care facilities. The ACFI instrument may not be an adequate mechanism to deliver the increases required. Consider block funding for palliative care in residential aged care settings. This block funding could be used to educate staff in the palliative approach and end of life care. It could

also be made available for residential aged care facilities to access more allied health services in the delivery of palliative care – particularly for assessment purposes.

3. Implement end of life tools (such as Liverpool Care Pathways or the Gold Standard Framework). This would improve practice and assist in identifying when external support is needed. Implementation of end of life tools could be made part of accreditation criteria.
4. Develop and fund a residential aged care leadership program in palliative care, including identifying best practice approaches.
5. 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.
6. Residents should expect to receive consistent and coordinated medical care from a GP and or specialist familiar with their needs.
7. Invest more in researching the management of end of life care for dementia sufferers.
8. 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. This can be monitored through the accreditation program.
9. Consider adopting mandatory “residential aged care bag” – like a doctor’s bag that contains palliative care medications for after hours /weekend / emergency availability.

Specialist Palliative Care

1. In recognition that more palliative care will be available in the community, provide greater support to Specialist Palliative Care services in order to maintain quality, standards and continuity of care for patients and families/carers in need of palliative care services. Seeing patients and their families/carers in their home or nursing home in the community is beneficial – and appropriate incentives should be provided for this practice.

2. Make the Medicare Plus Program available to doctors who hold a FACHPM.
3. Create a funded service system whereby specialist palliative care services can offer support to generalists, for example, through discussions of managed care plans.
4. Development of national paediatric palliative care steering group that can consolidate resources and research for this small population group.

Quality & Research

1. Address the gaps in research and deficiencies in the current end of life care evidence base.
2. Significantly expand research in end of life care, including care in different locations and in conditions other than cancer.
3. By 2012 all health and community based providers will demonstrate best practice in end of life care against recognised quality standards, for example through the use of the Palliative Care Australia Guidance document.

Carers

1. Policies must recognise the work of families and caregivers and support them to help care for the patient and to cope with the sense of loss that the illness brings. This might include assistance similar to that often granted to those with maternity and paternity responsibilities.
2. CHA advocates for a full review of bereavement services including input from not recently bereaved relatives in order to measure quality care and bereavement services.
3. Carers should have access to integrated and personalised services needed to ensure a balance between caring and non-caring.
4. Fund coordinated training for carers to support them in their caring role, accessed through the proposed single point of access and referral.
5. Develop a self assessment tool that identifies which carers need most support services.

Communications

1. Fund a communication initiative that informs the public of the benefits of palliative care. A public discussion about the issue of dying, and dying well.

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