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Access

Quality

EOL

Towards quality care at the end of life

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Towards quality care at the end of life

EoL – Towards quality care at the end of life

The policy forum of Palliative Care Australia (PCA)

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A MESSAGE FROM THE GOVERNOR-GENERAL

I am very proud to be Patron of Palliative Care Australia. I admire so much your truly personal engagement with people who depend on you; your generosity of spirit and competence in offering quality care; the honesty and sensitivity that echoes through your friendship, compassion and humility, and the professionalism and dedication that shines in your work.

I see palliative care as an assurance to our society, at the deepest level, that we are honouring our value for the worth and the dignity of every human being.

You help to meet the physical, social, emotional, spiritual and cultural needs of all people, their families, carers and communities. You provide empowering choices for our loved ones at the

end of life. You affirm families through times of apprehension and doubt, offering guidance, and elevating knowledge.

You also lead community dialogue around the issues central to your organisation. You are advocates and guides in shaping our response in these testing and complex areas of our collective life.

This publication creates an important space for informed debate and careful conversation.

I praise your impressive and vital work and thank you warmly for your rich contribution to our nation.



QUENTIN BRYCE AC
*Governor-General
Commonwealth of Australia*

FROM THE PRESIDENT

In 2007, 137,900 deaths were registered in Australia. This number is expected to increase. Close to 100,000 deaths each year are expected deaths, meaning a person has a terminal condition and their death in the foreseeable future would not be a surprise.

As the Australian population ages and life expectancy rises, people are living with and dying from conditions characterised by multiple co-morbidities, thus requiring increasingly comprehensive care. Furthermore, more people are dying from chronic conditions with longer periods between diagnosis and death.

Growing service demand means care at the end of life will increasingly be delivered by health professionals across the health sector, and across care settings: hospitals, hospices, aged care homes and community care. End-of-life care will become everyone's responsibility.

Whilst great advances have been made in the delivery of quality specialist palliative care, in general, health and other care services do not always perform well for people who are dying. Our existing models of care do not necessarily match the needs of many living with a terminal condition, creating unnecessary stress and pain at this crucial time.

We need to get it right to ensure people are not suffering from preventable pain. We need to get it right to ensure people receive the care they need when they need it.

There are many barriers, but with open discussion and policy debate, we can work together to get it right.



PROFESSOR MARGARET O'CONNOR AM
*President
Palliative Care Australia*

THE ISSUE – PREVENTABLE PAIN

Why do some people experience pain that can be prevented?

As a society, we aspire to quality care at the end of life. Quality care meets the needs of patients, their families and carers: needs that are physical, emotional, spiritual, cultural, and social.

Whilst great advances have been made in the delivery of quality care at the end of life, the health care system cannot, in good faith, promise that all people at the end of their lives will always have access to care that is customised to their preferences and reliably delivers symptom control. Quality care is care that prevents and treats the various facets of pain: physical and emotional.

Why is the health care system unable to meet the needs of all people at the end of life, why do some people experience pain that can be prevented?

EoL: Towards quality care at the end of life explores this issue, identifying barriers to care and proposing policy solutions.

In Australia, it remains a reality that between 30 and 50 percent of people will experience physical pain that is under-treated at the end of life.¹ This means the chance of experiencing pain – that could be prevented – is very high.

As a consequence, patients and their families experience a significant reduction in quality of life. The price of untreated pain is very high and is borne by the individual, their families and communities, together with the health system.

This edition of *EoL* examines the causes for untreated pain under three themes.

Systemic arrangements

The structure of the health system itself, can be responsible for the delivery of sub-optimal care. Access to medicines necessary for pain and symptom control is not universal. Furthermore, the interplay between public and private provision of end-of-life care leads to inequities.

Workforce capacity and resourcing

Health professionals across the health system are often involved in delivering end-of-life care, including the aged care, acute and sub-acute, and primary care sectors. A lack of knowledge and resourcing to address the needs of people at the end of life, and importantly clear referral pathways to access specialist care when required, lead to sub-optimal care.

Consumer health literacy

Consumers having the knowledge and ability to access care that meets their needs and actively participate in decision making is crucial to the delivery of quality care.

Contributions from leaders across the health sector identify some of the reasons people experience preventable pain at the end of life, and propose strategies to guide the policy debate to deliver on the promise of quality care at the end of life for all.

Palliative Care Australia encourages wide participation in its policy development and advocacy processes. To become involved on these or any other issue, contact the National Policy Director.

¹ In Australia, there is no systematic research into the under-treatment of pain in people at the end of life. International studies have concluded nearly one of two patients with cancer pain is under treated. S Deandrea, M Montanari, L Moja, G Apolone, 'Prevalence of undertreatment in cancer pain: A review of published literature', *Annals of Oncology*, vol. 19, no. 12, 2008.

UNMET NEED – PHYSICAL AND EMOTIONAL PAIN

- widespread consumer and medical professional misconceptions about opioids
- knowledge and training for the general practice workforce

Since I started in palliative care in 1992, the investment in research has strengthened the science of palliative care and the evidence base for pain management has improved significantly. There are now new medicines, new therapeutic combinations, and better use of existing medicines as part of the armoury against pain.

However, despite the existence of very good pain medicines, patients still continue to suffer from preventable pain – pain that quite simply and unforgivably is under-treated and generates a significant reduction in the person's quality of life.

Academics and clinicians have studied the cultural, medical, legal, policy, ethical as well as health system reasons behind under-treatment of pain.¹

Unlike many countries that have significant access issues relating to opioid medicines, Australian clinicians do have good access to effective medicines, notwithstanding some challenges in terms of affordability and access across care settings.

There are two key, yet easily addressed, barriers to patients receiving good pain prevention and treatment: consumer misconceptions about pain medicines, and professional education and training.

The word morphine, the primary opioid medicine, conjures up all sorts of difficulties for patients and families. They're scared and this affects our ability to control pain and give the patient the best quality of life possible. Academics know this phenomenon as *opiophobia* which is compounded by *opiognorance*.

The community needs to be educated about pain medicines. When you explain 1mg of morphine is actually equivalent to one panadeine tablet, a big weight is lifted off patients and families because they understand one panadeine is not going to make you addicted, one panadeine is not going to make you 'ga-ga', one panadeine doesn't mean you are going to die yet.

This difficulty is compounded by a general perception in the medical sphere that morphine is a very dangerous drug. This is reinforced by the necessary and unavoidable administration and approval systems for accessing opioids as a strictly controlled medicine.

Undergraduate and postgraduate education teach that if you give too much morphine to anyone, they will die of respiratory failure. In reality, when used

Despite the existence of very good pain medicines, patients still continue to suffer from preventable pain.



appropriately, morphine and other opioids are not dangerous and patients don't die even from high dosages.

To overcome these misconceptions, young doctors need to work in palliative care, so they see opioids are actually very safe, very effective, and essential in the range of medicines available for pain control.

Overcoming a fear of opioids is one aspect, the other is health professional education in pain management. The needs-based model for palliative and end-of-life care in Australia is one that relies on the general practitioner to provide the majority of care with either direct support or referral to specialist palliative care services in complex cases.

General practitioners generally do a very good job, but in some instances the system of specialist referral disconnects the general practitioner from their patient. When disconnection happens, general practitioners are deskilled.

It is very often only when a patient sees a palliative care service that the general practitioner is reconnected with the patient. But because the general practitioner has had no involvement in treatment, they are not knowledgeable in caring for the increasingly complex conditions and treatment the patient has.

This deskilling though can be something supported by the nature of practice models. Many general practitioners may only see one or two palliative care patients a year. With this small case load, it is very difficult for a general practitioner to gain expertise in pain treatment, or to rank this subject as a continuing professional education priority.

Because the continuing professional education regime is not curriculum-based, general practitioners understandably focus on expanding their skills in areas they see most, like managing diabetes or hypertension.

If the continuing medical education regime were to become curriculum-based, and palliative care ranked as mandatory, general practitioners could become more skilled in palliative care, as well as other areas not encountered in high frequency – yet areas that present high risks in terms of quality of life and care to the patient.

When general practitioners have to care for a palliative care patient and control their pain, they can get into trouble because there are no triggers built into the system, for this specific population group, to tell the general practitioner when specialist assistance is required.

I recently received a call from a rural-based general practitioner. He was concerned that his treatment regimen involving 4,000mg of morphine was not controlling the patient's pain. In cases such as this, it is necessary to add another drug to make the patient more responsive to the morphine. However, ideally this would be introduced when the patient was on 800mg of morphine. As a consequence, the patient was needlessly experiencing high levels of pain as well as side effects of the high and ineffective doses.

Another key issue is that palliative care patients are not easy to treat. When patients become frail, it is increasingly difficult for them to attend a general practitioner's office. Fewer general practitioners have the time to visit patients at home. When they do, home visits are very time consuming and general practitioners are not well remunerated. The general practice business model functions on an office-based practice – patients come to see the doctor. Better pain prevention and treatment will require recognition of home-based care by the primary care team.

Of course, in addition to physical pain, there is emotional pain – grief and bereavement. General practitioners are similarly largely unpractised in this area. There is a lack of understanding of what is normal grief and what kind of grief should trigger a referral to specialist care. Often people will also try to hide their grief for fear they have a mental illness.

I look forward to a health system that works consistently and reliably to prevent and treat pain that people experience at the end of life.

ASSOCIATE PROFESSOR RICHARD CHYE
*Director of Palliative Care
Sacred Heart Palliative Care Services*



SYSTEMIC INTEGRATION – END-OF-LIFE CARE

- development of a comprehensive and integrated primary care platform
- broaden the scope of speciality palliative care services
- increase options for individuals to identify the setting in which they choose to die

The importance of the Australian health care system ensuring, as far as practical, that each person experiences a 'good death' was a recurring issue at many of the public consultations conducted by the National Health and Hospitals Reform Commission.

A similar theme was expressed in the many hundreds of written submissions the Commission received. These views were often accompanied by fears or concerns that when that time comes, the system would fail them and their family: resulting in unnecessary burdensome treatment that doesn't respect their wishes and does not include family when requested.

Of the approximately 137,900 deaths that occur in Australia each year, Palliative Care Australia estimates that 100,000 could be expected or anticipated.

These figures put into perspective the importance of our health care system having a significant focus on end-of-life care.

Australia has much to be proud of in the way the system provides good end-of-life care. We have many excellent examples of superb and appropriate responses from the health care system allowing

individuals to die in a familiar setting, comfortable and surrounded by loved ones.

However, a number of barriers were identified to the Commission that limit this reach including: workforce shortages, lack of access to appropriate clinicians, carer fatigue, and the reluctance of some private health insurers to fund non-hospital-based palliative care.

We heard many examples of people being transferred to hospital to die, sometimes against their wishes. It was the absence of appropriate palliative care, or the lack of knowledge and confidence possessed by the generalist provider supporting the people in their preferred setting at a critical time, that led to this.

A constant issue also raised was poor or lack of communication about realistic options concerning both treatment and support through the terminal stages of an individual's life.

For those involved or interested in palliative care these are troubling issues as their resolution is fundamental to good end-of-life care.

Given the scale of the population requiring good end-of-life care, the Commission shares the view expressed by the Australian and New Zealand



The importance of all health care professionals recognising they have a role to play in end-of-life care is critical.

Society of Palliative Medicine that it is neither feasible nor desirable that all dying patients should be managed by specialist palliative care services.

For a sub-group, these services will, of course, continue to play a vital role. They will also be an important resource for general and other specialist health care professionals and providers.

However, the importance of all health care professionals recognising they have a role to play in end-of-life care is critical. It may be to engage appropriately with their patients in discussion about realistic options and the patient's views, concerns or desires about future action. It may be as part of team supporting someone through the terminal stages of their illness.

The Commission has recommended in its Interim Report that we build on the solid base we already have.

Specifically, we recommended that we broaden the scope of specialist palliative care services to meet changes in disease patterns, such as the increasing incidence of dementia and the growth in chronic disease, so that these services are available to those who need them and the expertise is available to generalist and other specialist clinicians treating these groups of patients.

We recommended the development of a comprehensive and integrated primary care platform for the health care system, supported by the specialist palliative care services for the provision of good end-of-life care.

This approach does not necessarily mean positioning in one service or location. It may be a virtual integration, but it does mean that funding and program structures need to facilitate such an approach.

Such an increased capacity in primary care across the country should also increase the options for individuals to identify the setting in which they

choose to die. This is not to suggest that it is appropriate that all people should choose to die at home. For some there are cultural, social and practical reasons that make it unrealistic.

One of the large gaps in our current health system is the appalling health outcomes for Aboriginal and Torres Strait Islander people. While the Commission addressed the issue broadly, it is important to recognise the cultural dimension in service delivery to this group of citizens at their end of life.

The Commission also highlighted the importance of focusing on end-of-life care for people living in residential aged care facilities and recommended the national implementation of an advance care planning program.

This approach is based on the common law right of individuals to make decisions about their medical treatment including the right for a competent person to refuse treatment.

A number of states have legislated to highlight this right and in doing so, have perhaps unintentionally confused some clinicians regarding the law and their responsibilities. The Commission has welcomed the decision of Attorneys-General across Australia to undertake work on harmonising relevant aspects of existing state legislation.

The broader and perhaps more systemic approach to end-of-life care, if taken up by governments across Australia, will also have significant ramifications for our health workforce who will need to be trained and supported.

THE HON ROB KNOWLES AO
Commissioner

National Health and Hospitals Reform Commission



EQUITABLE ACCESS – MEDICATIONS IN COMMUNITY CARE

- inequitable access to non-PBS drugs
- palliative care formulary for hospitals
- resourced workforce linked to specialist expertise

The Pharmaceutical Benefits Scheme (PBS) provides cost effective access to the majority of medications used by patients at the end of life. However, in spite of these efforts, there are still barriers to accessing medications in the community. These barriers impact on people being able to choose their care setting at the end of life.

Some medications used in palliative care are currently not on the PBS, and are therefore more difficult to access in the community.

A small number of these medications are under study at the moment by the Palliative Care Clinical Studies Collaborative. The aim is to see if improved evidence can be obtained so, together with pharmaceutical company support, applications can be made for these medications to be firstly approved by the Therapeutic Goods Administration (TGA) for the palliative care indication, then considered as cost effective and listed on the PBS.

However, for most of these medications, evidence of their cost-effective benefit to the level required by the PBS is unlikely to be obtained even though these medications are standard in palliative medicine throughout the world.

These medications include: midazolam (terminal restlessness), octreotide (vomiting), levomepromazine (delirium/nausea/vomiting), gabapentin (neuropathic pain), lorazepam (anxiety/insomnia), cyclizine (nausea/vomiting), hyoscine hydrobromide (excess oropharyngeal secretions), ketamine (severe pain), and parenteral fentanyl/sufentanil (severe pain).

Whilst many of these medications are used regularly by specialist palliative care services, they are often unfamiliar medications for clinicians outside palliative care.

What happens now?

Although they are not on the PBS, many patients are able to access these medications in public hospitals as inpatients. In the community, however, there is an inconsistent approach. Patients either have to pay for these medications, or have to rely on a public hospital providing them at no or PBS co-payment cost. Access is inconsistent and unreliable, dependent on local service-level decisions.

In some parts of Australia there is good access to non-PBS medications in the community. In these

Access is inconsistent and unreliable, dependent on local service-level decisions.



cases, the patient is generally involved with a specialist palliative care service that is part of, or has developed a good relationship with, a public hospital. These services and more importantly the public hospital are sensitive and empathetic to the importance of these medications. This scenario is not limited to patients of large tertiary referral hospitals in metropolitan areas.

One patient group that has particular difficulty accessing non-PBS medicines are those in low care facilities, such as hostels, particularly where there is not an associated high care facility.

Palliative care patients in these facilities do not have the same access to Schedule 8 medications (such as morphine and other opioids) as patients living in a high care facility or their own home. As such, accessing medications for general pain control and for breakthrough pain is problematic.

This is because there is generally no twenty-four hour registered nurse cover for these hostels. Hostels largely rely on assistants in nursing and resident care assistants to administer medications. These personnel are not able to administer Schedule 8 medications.

This issue is compounded by a lack of workforce skills in palliative care, difficulty in accessing medical and specialist palliative care support and a lack of culture for assessing pain. This scenario is also often seen in the nursing home environment.

Options for the future

Any new medications that have a palliative care indication need to go through the same TGA and PBS processes as other medications.

In the meantime, however, it may be time to draw a line in the sand and come up with a 'palliative care formulary' that each public hospital must have available to be provided to patients via the palliative care or community nursing service that is managing their care.

The medications in question are not expensive and have long expiry dates. Having these medications accessed through palliative care services would provide an opportunity for these services to be involved in the education of the quality use of these medications in patients at the end of life. Alternatively, the medications could be administered under prescribed guidelines to ensure their safe use.

This approach requires a satisfactory workforce of specialist palliative care practitioners across metropolitan, rural and remote health services. The Australian and New Zealand Society of Palliative Medicine recently estimated there is a shortfall of 97 full time equivalent (FTE) palliative medicine specialists in Australia (currently there are 114 FTE).

Delivering medications to the patient's home would also require a functional, seamless relationship between the public hospital and the palliative care, primary care or community nursing service. This highlights the need for collaborative and innovative approaches engaging public hospitals, specialist palliative care services, community nursing services and finally general practitioners to ensure equity of access for all patients regardless of where they are.

What are the benefits of improving access?

Building and maintaining a system that allows people in the community to receive medication to ease pain and suffering will go a long way to giving patients the ability to die in their place of choice. Furthermore, patients would need fewer unnecessary visits to hospitals or hospices which can be a major undertaking when they are so ill.

DR PHILLIP GOOD
Senior Staff Specialist
Department of Palliative Care
Calvary Mater Newcastle



CONSUMER CHOICE – CARE SETTING

- **consumer choice**
- **investment in primary care to prevent unnecessary hospitalisation**
- **introduction of electronic medication management**

The Australian Healthcare and Hospitals Association (AHHA) believes people living with a terminal condition should, as far as possible, have the choice of receiving care in their homes and communities.

Unfortunately, our current health and community care system does not always provide this choice with the result that many people end up in hospital unnecessarily. This can have a serious impact on quality of life and prevent families and friends from participating in their care at this important time.

There are three key barriers to providing people with end-of-life care in the community setting. The first is insufficient preventive and primary care services.

Australia's primary health care system is not currently meeting the needs of either consumers or providers. Many people have problems accessing a primary health care provider of their choice and growing workforce shortages in many areas mean consumers with chronic conditions do not receive well planned and coordinated care.

The result of this failure in primary care is that many people end up in hospital with conditions that could have been treated in the community setting. This adds a considerable strain to our overburdened hospital system. In fact, the Australian

Institute of Health and Welfare has estimated that over 500,000 Australians are hospitalised every year for conditions which could have been prevented or managed in the community.

More than many other health care consumers, people living with terminal conditions are impacted upon by this lack of focus on primary care as they typically require planned on-going care, usually from multiple providers. To improve care provided to people living with a terminal condition and chronic conditions, AHHA supports a greater investment in primary and preventive care and increased efforts to shift care from the hospital setting to the community, where this is supported by evidence as a safe and cost-effective option.

The second barrier is poor health information management infrastructure. The ability of Australia's health system to effectively meet the needs of people living with terminal conditions is severely hampered by our inadequate health information technology infrastructure.

When different areas of the health system and different health care providers are not able to communicate easily, patients experience gaps and duplication in their care and restrictions in their options to receive care in their place of choice.



Many people end up in hospital unnecessarily.

Improving health information management would equip the health system to provide high quality and comprehensive care, both in the hospital and community setting.

The introduction of electronic medication management across the health system is imperative. This would dramatically reduce the rate of medication errors and thus have a significant impact on the safety and quality of health care. For people with terminal conditions who move from hospital to other forms of care, electronic medication management is extremely important to improve the coordination of care and reduce the risk of medication error.

With the appropriate technology in place, many forms of care traditionally provided in hospitals can be provided in a community setting. This would increase the options for people who wish to remain in their homes or communities and improve the overall safety, quality and efficiency of health care in Australia.

The third barrier is health workforce shortages. Workforce issues are a major challenge facing the future of our health system and a key barrier to improving the care for people with terminal conditions. Without an adequate health workforce, no other reforms or changes to the ways in which we fund and deliver palliative care will be effective.

Currently, our Australian-trained health workforce is unable to cope with the growing demand for health care and worldwide workforce shortages mean that we will not be able to continue to rely on recruiting health care professionals from overseas. This situation needs to be addressed as a matter of urgency.

Workforce problems affect most sectors of the health system, in particular primary care, public hospitals, rural and remote health services and aged care. These sectors are all crucial for the delivery of high quality care to people at the end of life.

Addressing the complex care needs of this important group must be a focus of all health workforce planning at both Federal and state/territory level. To help achieve this aim, we support the development of a national health workforce strategic framework to ensure a nationwide approach to workforce planning and management. It must focus on training enough health care workers to meet our community's need for health care and to encompass an integrated and long-term approach to health workforce planning.

The establishment of an advisory agency, reporting to health ministers, would systematically facilitate and evaluate health workforce innovations. This evaluation should include extensive consumer involvement, including from people with terminal conditions, their families and carers, to ensure that workforce changes reflect consumer priorities and concerns.

An increased focus on care for people at the end of life is important. This should involve general reforms of the health system to improve the way in which health care is delivered, as well as specific measures to address the needs of consumers with terminal conditions.

In implementing these reforms, it is vital that consumers with terminal conditions, their families and carers, are consulted to ensure that the changes being made address their needs.

Stakeholders must work together to improve the choices and the quality of care available to people with terminal conditions.



END-OF-LIFE CARE – WHO PAYS?

- mismatch in demand and supply
- need to reduce unwanted and unnecessary admissions to hospitals
- private health insurance must recognise the full needs of palliative care patients

An evaluation of the call for improvement in the delivery of quality care at the end of life must be accompanied by an understanding of the funding – who pays and how this investment delivers, or can be better shaped to deliver, choice and quality care.

Defining the end of life population group is relatively simple if one looks back from death rather than forward from diagnosis. This population is 72 percent of all deaths – those that are expected, where our best clinical evidence confirms that death will not be ‘a surprise’ and that we have time to shift the focus of care from cure to quality of life.

But where is this care accessed and who pays? According to recent reports into cancer care, although up to 90 percent of patients spend the majority of their final year at home, only about one third of patients receiving palliative care actually die at home.¹ This is in spite of evidence that the majority of terminally ill patients would prefer to die at home.²

While there is a considerable lack of reliable data that supports resource planning and importantly

performance measurement, one should question the current mismatch in demand and supply that is caused by the disparate, misaligned funding drivers across care settings.

The complexity of end-of-life care resourcing matches that of the whole of health. Funding is allocated within each of the traditional domains: public hospitals, primary care, pharmaceuticals, private hospitals, residential aged care, community health, and allied health services. Investments are characterised by the inherent cost shifting incentives between the various sectors that work against seamless care.

In addition to state and territory funding, the current Federal funding for end-of-life care under the Australian Health Care Agreements for service provision is very roughly in the order of \$40 million per annum. Another \$20 million per annum has been allocated for national development programs. This is in addition to the costs of aged care, community care, Medicare, the PBS, and consumer contributions. It is not a large investment per person for this population, even in the absence of a

¹ B Tabor, EA Tracey, P Glare, D Roder, *Place of death of people with cancer in NSW, 2007*, Cancer Institute NSW.

² B McNamara, L Rosenwax, C D’Arcy Holman, E Nightingale, *Who receives specialist palliative care in Western Australia and who misses out*, 2004, University of Western Australia.

The complexity of end-of-life care resourcing matches that of the whole of health.



palliative care identifier. Patients, families and carers can carry a large proportion of these palliative care costs.

The approach of the acute care sector in caring for people at the end of life is somewhat confused. The general policy is to keep people out of hospital and in the home. However, a recent review of hospital bed blockages identified an increase in demand for services provided to older patients, services generally not in the best interests of patients and their families, including:

- inappropriately aggressive treatment of patients who are clearly dying
- management of palliative care patients in acute care settings because of poor end-of-life planning
- lack of planning for treatment failure in frail medical patients with complex conditions.³

The current reform activities hold great promise for the future. The challenge lies in ensuring that all the changes eventually align and build an effective and efficient system. Work on changing the focus of acute care settings and growing the sub-acute sector for end of life under the National Partnership Agreements is an opportunity for stronger integration through better resourcing.

The overall scorecard rests in the ambition to reduce unwanted and unnecessary admissions to hospitals. This matches the primary wish of the population group. However, this does not in any way match the current capacity and capabilities of the other care settings.

Quality home-based care can only be a real choice if resourcing is available to better support general practitioners in delivering end-of-life care and stronger referral pathways to specialist direct or consultative care are established. In addition, access to community nursing, home based allied health supports, family carers support and readily

available respite, and access to affordable medicines must also be available.

Today home care options are not reliably and consistently ready to catch this demand.

While we put aside the whole of health financing challenges, I highlight one improvement that is within reach today.

Unless you live in a select two or three places in Australia, your private health insurance will not cover your home-based palliative care needs. Should you elect to exercise your choice and use your private health insurance – you in fact have no choice but to spend your end of life in the private hospital setting.

The *Private Health Insurance Act 2007* introduced a number of changes, including an expansion of services that can be covered under private health insurance. However, palliative care is multidisciplinary and private health insurers have yet to fully develop products that match the needs of palliative care patients. There is little incentive to offer multidisciplinary care.

Furthermore, Australia's current competitive health insurance funding model works against any single fund offering a product ahead of its competitors. This is exacerbated by a fear of cost-shifting from the public sector into the private sector. Some private hospitals are not funded or elect not to offer some services their patients require.

Palliative Care Australia is pleased to join Catholic Health Australia in calling for a minimum definition of 'palliative care' for the private health insurance industry that includes multidisciplinary coverage provided in the patient's setting of choice.

Over the next 12 months, key decisions are being made that will shape the delivery of quality care at the end of life. There is a lot to gain, and lose, if we do not get it right.

³ PA Cameron, AP Joseph, SM McCarthy, 'Access block can be managed', *Medical Journal of Australia*, 6 April 2009, vol. 190, no. 7.

DONNA DANIELL
Chief Executive Officer
Palliative Care Australia



PALLIATIVE CARE – A PRIMARY HEALTH CARE PERSPECTIVE

- nationally recognised competencies
- flexible and customised palliative care packages
- effective collaboration and referral pathways

The primary health care sector is the corner stone of the Australian health care system. This sector is largely responsible for the delivery of palliative and end-of-life care services.

However, there are issues in primary health care that need to be addressed to support health promotion at the end of life and improve the quality and accessibility of palliative and end-of-life care.

The first goal of the Australian Government National Palliative Care Strategy (the Strategy)¹ is 'awareness and understanding'. Palliative care is broadening its focus and becoming more inclusive of disease states outside of cancer, health promotion strategies, and the palliative approach in broader areas of health service delivery such as aged care. As this happens, the roles of education and nationally recognised competencies in palliative care become more crucial.

Standardised skill development and maintenance for all health providers will increase community capacity and care coordination, and sustain a general acceptance of the importance of quality of life at the end of life.

The second goal in the Strategy is 'quality and effectiveness'. Systems must be established to support quality improvement measures for primary care that encourage, strengthen and sustain the delivery of effective quality care at the end of life.

Furthermore, health policy should support flexible and customised 'palliative care packages' for palliative care services to be delivered in the home. These 'packages' could fulfil the complex care requirements of each individual palliative patient and their carer/s according to need. This could involve equipment provision, flexible after-hours home visiting arrangements by a variety of health professionals (for example, medical officers, nurses, occupational therapists, pastoral care workers, nutritionists) and bereavement counselling.

Building capacity within the health system to provide comprehensive palliative care service packages to support needs-based and home-based care will strengthen health service provision, and in turn support quality care and effectiveness.

Research to support evidence-based practice is paramount to quality assurance and effectiveness.

A strengthened health system is dependent on the interface and dynamics between the structural tiers in the health care system.



As it stands, there are several recognised barriers to research in palliative care outlined by CareSearch, including: historical and social barriers to researching dying and death; a lack of established research, infrastructure and training programs; methodological and ethical issues in undertaking palliative research; lack of focus on health promotion at the end of life; and funding difficulties. Nevertheless, when research in palliative care highlights gaps in quality service provision they must be closed.

The third goal in the Strategy is 'partnerships in care'. An issue for primary health care in palliative care is ensuring the development and maintenance of relationships and collaboration to achieve coordinated care and capacity building across the tiers (primary, secondary, tertiary) of Australia's health care system. This means, in part, ensuring effective relationships exist between primary care and specialist palliative care.

A strengthened health system is dependent on the interface and dynamics between the structural tiers in the health care system, working collaboratively to deliver coordinated care. *EHealth* is one way of implementing this dialogue. Palliative care patients and carers need the integration and partnership of health care delivery, for the purpose of holistic, collaborative and multidisciplinary care.

Communication between providers is a key issue to ensure a positive patient experience. Care and referral pathways are relationship dependent and their dynamics need to be acknowledged and managed accordingly. The importance of relationships, both informal and formal, and stakeholder engagement are fast being recognised as essential in any form of communications and referral pathways and strategies.

The primary health care issues pertinent to palliative care may be summarised as primary health needing to integrate into a team based service delivery model, eradicating the 'silo effect' between the tiers of the health system and working towards a new vision of health - quality of life for all.

Nationally endorsed compulsory competencies in palliative care, research, strategies such as flexible packages and strategic and systematised communication, care and referral pathways need to be supported.

A paradigm shift in health service delivery is slowly developing, via the influence of more holistic approaches to medicine such as the palliative approach and palliative care, away from the culture of curative medicine towards health promotion and quality of life fulfilment. This shift is focussing on holistic care and collaboration between health care providers, not just health as defined by a unilateral diagnostic disease state.

This paradigm shift engages with coordinated, collaborative multidisciplinary care and is sustained by a health system that recognises the complexities of holistic care and health promotion at the end of life. This care needs to be evidence-based. This care is founded in partnerships, and this care brings quality of life at the end of life for all.

DAVID BUTT
Chief Executive Officer
Australian General Practice Network



DR MICHAEL TAYLOR
Chair, RCP Management Advisory Group
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AGED CARE - QUALITY CARE AT THE END OF LIFE

- **recognition of pay inequities**
- **improved regulation, accountability and transparency**
- **licensing and accreditation of personal carers**

The aged care workforce is one that is under increasing pressure. Trends are placing undue stress on nurses and carers and ultimately the quality of care in nursing homes will be compromised – indeed already is in some instances.

The acuity of care required by nursing home residents has intensified. Over seventy percent of all residents are now 'high care' yet the number of qualified nurses has decreased significantly. Carers make up the majority of the workforce in aged care. They are a dedicated and hard working workforce. But are we asking too much of a carer who has little or no formal education for the work they do?

Sixty-five percent of carers have a Certificate III qualification in aged care, the remainder have no qualifications. However, more and more we are relying on them to manage complex health problems as registered nurses (RNs) and enrolled nurses (ENs) do less clinical care.

The industry is at last recognising that nursing home residents require high level nursing care, but argue they cannot recruit RNs or ENs. Australian Nursing Federation research found a number of barriers to recruitment, including poor remuneration. Aged care workers earn on average \$300 per week less than nurses in other sectors making it impossible

to compete for nurses. There is also a feeling among workers of being undervalued, although the community does value aged care workers; an ever increasing workload that leaves no time for quality care, just the bare minimum; and a frustration that funding from the government is not accounted for properly by the providers.

The aged care sector must have the resources necessary to deliver the best care possible. In addition to addressing the wage gap, there must be improved regulation, accountability and transparency in aged care to ensure taxpayer funds go to caring for residents. Also, mechanisms to ensure safe, minimum levels of staff and skills across the industry are required.

Equally important is regulation of the workforce. Given that the role of the personal carer has developed quickly and without real planning, it is timely to examine their impact on the sector, care delivery and outcomes and ask how we can build their input into a health care framework.

Gone is the argument that aged care is a lifestyle choice, where residents need a little helping hand. We know that seventy percent of residents are high care and government data indicates the average length of stay for males going into care is six



...job entry knowledge, skills, experience, health and character to provide safe and competent care, including palliative care and pain management.

months. This shows an intensity of end-of-life care and consequently, demands on carers have rapidly increased.

Generally, unlicensed health care workers provide care to people of all ages who are ill, frail or injured; who have multiple and complicated co-morbidities with decreased independence caused by physical, psychological or neurological origin.

Add to that the vulnerability of the people who are cared for in the health and aged care systems and the inherent potential for harm in delivering care, it is alarming that we have a major part of our health workforce that is not subject to a professional legal framework to manage such large risks.

Licensing can manage risk through regulation and we need to start considering the need to license our personal carers. Licensing has long been used for many professions, including health care workers. The role of this type of regulation is multi-faceted and includes:

- establishing of registers of licensed workers that can be searched by employers, community members and other persons seeking to establish the credibility of a person claiming to be qualified
- setting of standards of education and practice to ensure that health care providers have the necessary job entry knowledge, skills, experience, health and character to provide safe and competent care, including palliative care and pain management
- providing a more robust method for routine review of a person's ongoing capacity to provide safe and competent care

- a reporting and disciplinary system so action can be taken when a health worker's practice has the potential to place people under their care at risk, whether the cause is related to their inadequate ongoing professional development, health or conduct.

There is no doubt that personal care workers work in the same system as licensed workers and logically for the same reasons deserve the protection, professional recognition and career framework that licensing will bring.

We know, through our research in preparation for our national campaign, 'because we care – quality care for older Australians', that unlicensed workers are proud of the work that they do, they do it because they enjoy it and they feel they are part of the nursing workforce. They respect and take pleasure in being with the people they look after. They feel strongly that they want to bring the best quality nursing care to the people for whom they are responsible. They identify as nursing staff and want to receive professional support and recognition. Licensing guarantees professional recognition and educational and competency standards.

Economic considerations are important to the sustainability of Australia's health, disability and aged care sectors, but when considering efficiency we must also consider the impact on standards and quality of care and our obligations to consumers and their families.

GED KEARNEY
Federal Secretary
Australian Nursing Federation



HEALTH LITERACY – ADVANCE DIRECTIVES

- patients and health professionals need health literacy
- decisions about care must be clearly communicated
- authority and significance of advance care directives must be established

Kevin Manderson and his wife Shirley (not their real names) came to see me about what Kevin should do now he had decided that next time he went to hospital with a flare-up of his emphysema, he did not want active, intervening treatment.

Kevin is in his late 70s and for a decade his breathlessness has been getting progressively worse. “Mate,” he said, “I’ve seen all the family. We’ve shed a few tears. We’ve said good-bye. Next time, no tubes or ventilators, right?”

Would that it were as simple as that!

What Kevin was saying (with the sad agreement of his wife) was that when his next downturn came, he wanted to be allowed to die. “How will I die?” he asked, “I hear it’s a pretty awful death”.

I explained that this need not be so, that with care, appropriate to his wishes, his would be a peaceful departure – no drama, no feeling of suffocation, no people jumping on his chest.

My clinical interest is directed to patients such as Kevin with chronic respiratory problems who require care from a wide range of allied health professionals and medical practitioners for quality living.

People with these problems have limited life expectancy and often face death stoically aware of its imminence. In the later stages of their illness they face challenges about what therapy they consider best suits their needs, and how to make their preferences known by those charged with their care.

Advance directives, prepared by a person who does not wish to receive active treatment if their condition is irretrievable, are in fact harder to prepare and more difficult to have enacted than one might expect. Patients need education – the gift of health literacy and not simply the language of medical technology – to communicate their wishes. At times a lack of true health literacy among health attendants creates problems.

A young doctor receiving a seriously ill patient from an ambulance late at night will be loathe to remove the oxygen mask that is ‘killing the patient with kindness’, delivering high quantities of oxygen that the patient’s body has long managed without. The effect is that without clear permission to do so, the doctor is in the position of withdrawing treatment to fulfil the patient’s directive. Distressed family and a patient too exhausted and breathless to speak are not good advocates.

Health literacy means a lot more than simply knowing the right words to describe an illness, or the terminology of treatment.



Fearful for his or her professional reputation, a doctor treating a seriously ill patient whom they have not seen before, whose medical record may not be available, may not have the confidence to be guided by written advance directives provided by a relative.

The doctor may feel obliged instead to treat the patient actively, and leave decisions about what to do next until the morning when senior staff are on hand. By then the patient may be in the intensive care ward, rather too late for their 'hands off' treatment wishes to be respected.

This response is fully understandable: the saving of life is a primary function of medicine. To see the world through the eyes of a person who has 'had enough' and wishes only to be treated for comfort in their final hours is very difficult.

Health literacy – a complete understanding of all that is happening to the patient, his or her family, the general rules of clinical care and more – cuts both ways: for patients and their family and professional carers.

Nor is every family fully agreed upon therapy according to advance directives. I have treated patients where the directives, carefully negotiated before the event, unravel when frightened family arrive to see their loved relative in hospital. Faced with a potentially terminal episode, and often unaware of how the patient is feeling, they beseech staff to do everything to keep the patient alive. Even one family member who cannot face the decision is a fearful opponent for a doctor who may otherwise be prepared not to institute resuscitation efforts.

Educating people – patients, carers and health service providers – as to the significance and authority of advance directives is a BIG task, requiring more than what often passes for 'communication'.

The term 'health literacy' has multiple meanings, but in the context of treating people with terminal conditions, it means a lot more than simply knowing the right words to describe an illness, or the terminology of treatment.

It encompasses an understanding of the health system, how to access and use it, how to manage it, and how to manage oneself, to best advantage in the face of illness and disability. This includes the discussion, phrasing, medium of communication and politics of advance directives – how to develop them, promote their authority with the treating doctors and staff, educate relatives and carers in their use and the practical logistics of ensuring that they are available, read and understood when needed.

In our research into the needs of patients with chronic illnesses in western Sydney, we have found bewilderment to be a universal experience – bewilderment with the illness, treatment and prognosis, the language used, the complex network of services, and with the medications.

The possibility of each patient with a chronic problem having their own electronic record is an exciting one. This record would be immediately available to all involved in the care of a person with such an ailment. If advance directives were loaded into such records, they could bridge the gap that so painfully traps many people at present who want one thing, but get another.

Let's hope that the day of the electronic record dawns soon! Kevin Manderson and thousands like him will be grateful.

PROFESSOR STEPHEN LEEDER
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A WAY FORWARD – ADVANCE CARE PLANNING

Investing in advance care planning is the biggest and most important thing we can do as a society to get it right in terms of providing quality care at the end of life that accords with the individual's needs and preferences.

Providing the individual with meaningful choice over the circumstances in which they receive care at the end of life and the type of care they receive is critical.

Advance care planning is also a mechanism through which the health system can plan and coordinate access to resources and services to match anticipated care needs.

What is advance care planning?

Advance care planning is a process to help people discuss, formulate and communicate their preferences regarding the care they would like to receive in the future. It involves communicating preferences with family and friends who may become future substitute decision-makers, and with care providers.

The process might include an advance care directive which has a legal status and is intended to uphold a person's previously articulated preferences during future incapacity.

Importantly, advance care planning allows for resource management to deliver care according to consumer preferences. If a consumer articulates through an advance care plan, a wish to die at home, the health system has the evidence to know what is required and the ability to plan for the equipment and support necessary to make this a reality.

A single model?

A single model for advance care planning could not meet the complexity of need of all involved in the process – people, families, health professionals – across all care settings.

Instead, a way forward to a workable system would be agreement on a national framework, recognised and capable of implementation across all jurisdictions and care settings.

What would it look like?

A framework for advance care planning must take into consideration the following:

design

must be consumer driven and controlled to provide the consumer with a reliable mechanism to anticipate and express care choices

access and integration

process and responsibility must be fully integrated in the health system and aligned with appropriate performance measures allowing for the management of resources to deliver care in accordance with individual choice

provide access and be universally applicable and mutually recognised across care settings and geographical locations

education

to raise the level of awareness and health literacy in the community of the individual's role in their own health interventions

health professionals must know their role in assisting patients to have the skills to do this.

Where to from here?

A process for establishing national agreement and recognition of a framework of principles from which tailored, universally valid, advance care planning models can be developed is required.

QUALITY CARE AT THE END OF LIFE – A VISION AND A PROMISE

In 2007, 137,900 deaths were registered in Australia.¹ For approximately 100,000 of these people, death might have been expected or anticipated.

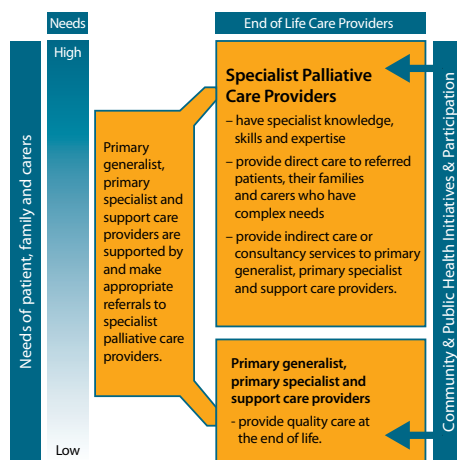
It is this cohort of the population that is the focus of Palliative Care Australia's mission to influence, foster and promote the delivery of quality care at the end of life for all Australians.

All health professionals and the community have a responsibility to care, when required, for people at the end of life and thus require a level of knowledge and skill in the philosophy and practice of palliative care.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, and appropriately skilled and resourced primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people: needs that are physical, emotional, social, cultural and spiritual.

Quality care at the end of life maximises quality of life through appropriate needs-based care. Needs change over time and the network of services must be responsive and flexible to ensure no patient or family falls between the gaps.

Quality care at the end of life is provided by health professionals along a continuum of care – from primary or generalist care providers to specialist palliative care providers – based on the patient, carer and family needs and choices, as illustrated below.



The Palliative Care Australia framework for provider networks to deliver quality care at the end of life.

Quality standards

The national standards for palliative care, the *Standards for providing quality palliative care for all Australians*, define the expected components of quality for care provided at the end of life.²

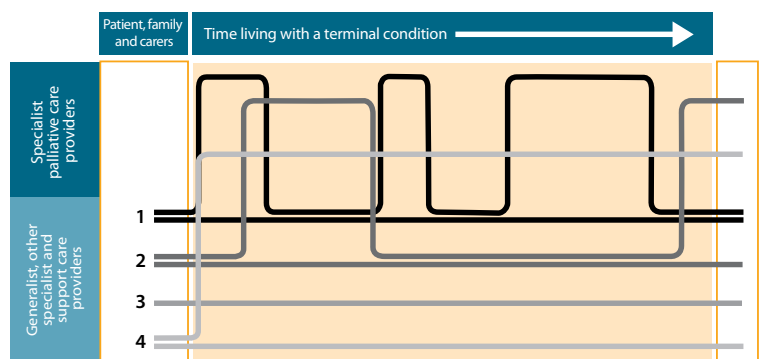
These thirteen standards express the reasonable expectations for care at the end of life and provide a benchmark for quality.

The future

Ensuring the promise of equitable, needs-based quality care at the end of life becomes a reality will require leadership and collaboration across all sectors of the health care system.

The work is focussed on:

- enshrining the right to quality care at the end of life for all Australians in health and social policy
- implementing effective networks of care providers
- ensuring appropriate funding and resourcing
- building the skills of all health care workers to deliver quality care
- developing community capacity to foster caring, supportive communities.



The responsive models of interaction between specialist palliative care providers, primary generalist, primary specialist and support care providers, illustrate the involvement of, and linkages between, all providers of care to meet the changing needs of patients, their families and carers.

1 Australian Bureau of Statistics, *Deaths, Australia 2007*, 2008, Canberra.

2 Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, 4th edition, 2005, Canberra.



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