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## Executive summary

As people face a life-limiting illness, people want to focus on relationships and finalising key priority issues. Any care that is provided must support people at the end of life in these key areas. The care that is provided at this time of life has consequences not only for the person who is dying, but also for their families and friends at the time and after the person's death.

Australia provides excellent palliative care that is, by international standards, well integrated into health service provision. There is a trained workforce that has been built up over the last quarter of a century, to complement the role that every health professional has in providing care for people at the end of life, but especially to work alongside primary care.

There is a need to continuously improve the quality of the care that is offered. This can best be done by measuring patient-centred outcomes at every clinical encounter. Benchmarking between services can help all service providers to systematically improve their care. In research and teaching, Australia is amongst the world leaders.

Systematic improvements that can be made include:

Ensuring people with diagnoses other than cancer have adequate access to specialist palliative care services, given their similar needs at the end of life.

Adopting a needs-based approach to assess people referred to specialist services to ensure those with the most complex needs are given priority.

More effective engagement of primary care, especially general practitioners. The funded mechanism for this is already available through the Medical Benefits Schedule through case conferencing, which has been shown to improve significantly the provision of care.

Measuring the health and wellbeing of caregivers in the years after having relinquished the role. Long term carer outcomes need to be a specific focus of outcomes.

This submission is based on a submission to the Senate inquiry into Palliative Care, March 2012.

### **What people want as they live with a life-limiting illness**

It is easy to assume that we would all know what we want and how we would each prioritise our time if we were faced with a life-limiting illness. It is necessary to ask the right people at the right time of life 'What is important?' To do this, one must ask people facing the end of life, not simply people who are well. The answers differ from the expectations that many people who are well would have.

Steinhauser and her team asked a random sample of people with advanced cancer what was important to them as they faced the likelihood of death within months. [Steinhauser 2000] At the same time doctors, other health professionals and caregivers who had provided care for someone at the end of life were also asked. Areas where there was agreement between all four groups included pain and symptom control as the number one priority. The next four priorities were not physical: preparation for death (knowing what to expect, financial and family issues being settled, being prepared), achieving a sense of completion (saying goodbye, legacy issues), being involved in decision making preferences and being treated as a whole person (suggesting that people had felt they were not being treated as a whole person at times). Areas where people facing death put emphasis not seen in the other three groups included maintaining a sense of humour, not being a burden to family and friends, being mentally alert (even at the cost of poorer symptom control) and *not* being concerned about the actual place of death. (It needs to be noted that some people actively choose not to die at home for a number of relevant reasons. For some people, dying in a hospital or hospice is an active choice, not a failure of the health system to provide adequate care.) Individual preferences will differ, but this gives an overview of key areas that should underpin a systems-wide approach to providing and improving care.

Ultimately, good palliative care is about the active management of anything that reduces comfort or function in key areas of personhood in the face of a life-limiting illness: physical, social, emotional, sexual, or existential domains. It is the ability to function as well and as independently for as long as possible. These are therefore the goals that underpin the planning and delivery of good palliative care.

### **Do specialist palliative care services make a difference? [Currow 2011]**

It is critical to rigorously document the beneficial outcomes resulting from actively incorporating palliative care into the health system. Without these data, one could reasonably ask why there should be an investment of public money in specialist palliative care.

For the individual **patient**, studies have demonstrated:

- improved symptom control;
- higher levels of satisfaction with services;
- better comfort in the last two weeks of life;

- improved quality of dying; and
- better meeting the needs of people at the end of life

if a specialist palliative care service is involved in care. [Carrow 2011, Miller 2003, Higgins 2003]

For **caregivers**, there are significant associations between palliative care service involvement and:

- better met caregiver needs;
- greater satisfaction with the care provided;
- less anxiety while in the caregiver role; and having relinquished the role:
- **better spousal survival having relinquished the role**; and
- improved ability to move on with one's life. [Aoun 2005, Teno 2004, Christakis 2003, Abernethy 2008]

At a **health service** level *without compromise to survival*, the data support:

- reduced number of inpatient bed days
- reduced number of hospital admissions; and
- reduced costs with the use of specialist palliative care. [Brumley 2003, Abernethy 2008, Constantini 2003, Connor 2007]

## **International comparisons**

### *Service delivery*

By international standards, the care that is offered in Australia is excellent. The Economist review of palliative care globally in 2010 ranked Australia equal first in the integration of services with other health care providers and with the care that was actually provided. It also reflects that many other countries around the world have very poor infrastructure for palliative care. For example the presence of palliative care within the United States is far less systematically distributed than it is in Australia.

## **Community Care**

### **Caregivers**

#### *Reliance on caregivers*

Family and friends as caregivers are the resource around which care is built in the community. There are unmet needs for those carers and often very limited support. Direct focus on caregiver education and support is very limited, and yet the health and social systems assume that this care will be in place and will continue to be delivered. Caregiving is an enormous challenge and for most, it is one of life's major events.

There is a very high likelihood that each of us will provide care for someone at the end of life in our community. From population data, one in every three Australians will have had someone close to them die from an expected death in the last five years with one in ten people providing care in these circumstances. Most notably, one in thirty people across the community provided day-to-day hands-on care for someone at the end of life in the last five years.

At a policy level, every time the statement is made that the rates of home deaths should increase, there is the challenge of how caregivers are going to be able to deliver that care with little real help or support. Although there is a great deal of discussion about cost shifting in health care, the ultimate cost shifting is to move the financial burden of end of life care to families and friends. The costs borne by families and friends need to be factored into discussions about place of care including place of care at the time of death. Often, with little training or support, they provide extraordinary care. With increasing complexity of care delivered in the community, it is simply expected that the additional care will be taken on by this huge and largely unrecognised workforce.

#### *Let's not romanticise the role*

Although providing care for someone at the end of life may be a huge opportunity for personal growth and development, it can also be the most challenging and daunting thing ever asked of any of us. In a review commissioned by the Department of Health and Ageing, former caregivers spoke frankly about how challenging the role was for many of them. [Aoun 2005] In population data, one in four caregivers is undecided or would definitely not provide care again after having actually provided care for someone at the end of life. [Currow 2011]

There is an assumption that the person with the life-limiting illness and their caregivers will always agree about the place of care. Although few studies have addressed this, Australian data suggests that these views will be discrepant at times, and choices may change over time. [Agar 2008] These differences will either impact on place of care, the wellbeing of caregivers, or both.

#### *Initiatives to support caregivers more effectively*

One Australian study looked at assessing the needs of caregivers specifically, separately to the other patient-centred assessments. [Greene 2011] The process included a focus on the previous experiences of the caregiver, their network of support and whether there were other supports that could be mobilised or organised in a more meaningful way. The correlate was that many friends and family want to help and are often not sure what will be most useful. By having a broker or facilitator to help with these conversations, key opportunities can be identified that better support caregivers and mobilise the energy, love and commitment of a far wider circle of people.

## **Definitions (including needs-based care)**

### *Definition*

Palliative care is the active care of people with life limiting illnesses, focusing on optimising comfort and function from the time it is recognised that the person has a progressive disease that will lead to their death. Function and comfort span physical, emotional, existential, sexual, social and financial domains. It happens in parallel with other care including disease modifying treatments as appropriate. It is not a matter of choosing either disease modifying treatment or palliative care.

### *Definitional issues – palliative approach versus specialised palliative care*

Palliative Care Australia in policy documents make a distinction between a *palliative approach* (a set of competencies that every single clinician - doctor, nurse, allied health practitioner-should have and be able to adequately use when necessary from the time of completing training) and *specialised palliative care* that is the process of providing care for people with more complex needs as well as delivering high quality research and educational resources required to improve care across the community.

### *Population prevalence of needs*

At a community level, the need for palliative care is going to grow not simply because of the increasing number of people in the community but because the way we experience death continues to change. We are now dying predominantly of chronic progressive disease as opposed to a century ago when we were dying of acute infections, obstetric and neonatal deaths and through trauma and malnutrition. The majority of us will have warning of our death whether from cancer, end-stage organ failure or progressive neurodegenerative diseases. For many people, there will be a period after disease modifying treatments have stopped working. This has huge implications for health service delivery over the next half century.

### *Prevalence of palliative care needs in the acute care sector*

Within the public hospital system a recent Australian audit noted that one in three inpatients (excluding intensive care unit, psychiatry, paediatrics and obstetrics) had a palliative intent as the goal of care. [To THM 2011] **This means that it is impossible that every person can or should be seen by specialised palliative care services.** The onus is on palliative care services to find ways to help referrers identify the people with the most complex needs and offer the additional expertise and support that specialist services can offer.

### *Accessing services*

Access to specialist palliative care services is likely to be achieved by people who are well versed in navigating the health system. There is a need for an active process for seeking the people with the most complex needs, not those who can find their way through the system. This should not be a pre-requisite to accessing specialist services, and **the responsibility lies with specialist palliative care services to ensure that the people with the most complex needs are the ones who take absolute priority.**

#### *Who is seen and who is not seen*

Most services are able to describe in detail the people with life-limiting illnesses who are referred to them, but have little or no idea about the people who are *not* referred to them. In Australia, this means that services cannot describe the one in two people who will never be referred to them.

#### *Access to services – diagnosis of cancer when compared with other diagnoses*

Systematically, people with diagnoses other than cancer are missing out on access to specialised palliative care services. [Currow 2008] For more than a decade it has been acknowledged that the needs for people in such circumstances are very similar to people with cancer. Yet, consistently across the country, people with end-stage organ failure including heart failure, respiratory failure (mostly emphysema), hepatic failure, renal failure and neuro-degenerative diseases systematically miss out on services.

#### *Access to specialised palliative care services by geographic region*

Services tend to be geographically located in more established communities. Services are not well distributed particularly in the peri-urban areas of large cities. In geocoding services nationally, there are manifest problems in the availability of services particularly in the community.

#### *Access to specialised palliative care services – services responsibilities*

Services have to take a responsibility to move beyond passive case finding. There is an urgent need to take responsibility for the whole of the population within a geographic area for each service. This means that any fragmentation between inpatient services, consultative services, outpatient services and community services has to be engineered out of the system. Whole of geographic region processes mean that on a needs basis, such services should provide care in the community linked with inpatient services in both the public and private sector. Inpatient and community services cannot operate in isolation of each other and ideally are under the same organisation structure.

### **Primary Care**

The interface with primary care is crucial for good palliative care to be delivered across the nation. Some services have systematically disenfranchised primary care, and this will come



at a cost to patients (in terms of continuity) and sustainability of services (many general practitioners provide unparalleled care for people with life-limiting illnesses).

A Commonwealth funded study has highlighted the pivotal nature of good primary care at the end of life. [25] The Palliative Care Trial (PCT) explored the use of a single Medicare-funded case conference at the time a person was referred to specialist palliative care services. Case conferences usually involved the patient and caregiver, the community nurse, the general practitioner, the palliative care nurse specialist/consultant, and the palliative care doctor. Case conferences were generally timed to coincide with the period of time when global physical deterioration started. This was compared to usual specialist palliative care. The group who had a case conference had **25% fewer admissions to hospital**. Such engagement needs be part of every specialist palliative care service's model of care.

### **Specialist services**

#### *Key roles for specialised palliative care services*

One could argue that the primary role of specialised palliative care services is to provide **clinical care** for people with the most complex needs and support colleagues in their care of people wherever they are in the health system. A key partnering role is that of furthering the evidence base to improve the quality of care that is offered. That **research** agenda has to come before there can be wider education. Given that approximately one in two people who are palliative will never see a specialist palliative care service, the research has to inform the clinical care provided by a large number of practitioners across the community in order to improve the quality of care that is offered universally to people. **Education** and support for colleagues – nursing, medical and allied health – becomes a key role in care as the evidence base is expanded. The process of continuing education is crucial if the best possible care is to be provided in an area with a rapidly expanding evidence base.

All three components (clinical care, research and education) should have time and resources set aside by each specialist service, **even within the current funding platforms**. Given that specialist palliative care services are, and always will be, referral-based services, specialist services that are only providing clinical care are not fulfilling the role in a way that builds capacity for other clinicians.

### **National initiatives**

#### *Palliative Care Australia's systems approach to needs-based care*

The national body has an approach over the last decade which says that there are a number of people whose needs are already being met, a number of people whose needs will best be met by time-limited involvement to deal with a particular problem and a very small group of people who will need consistent long-term input from a specialised palliative care service from the time of referral until death.



### *Commonwealth funded needs-based tool*

The Commonwealth has funded the development of an Australian needs-based tool.

[Waller 2012, Waller 2010] This has two major audiences:

- General Practitioners and other referrers in order to establish whether this person at the end of life has unmet needs and, if so, by whom these needs should best be met. This most likely is referral for other aspects of care within the network of that particular clinician but may lead to referral to a specialist palliative care service. It also allows complex needs to be outlined quickly and efficiently in making a referral.
- For specialist palliative care services having done a thorough multi-disciplinary assessment of this particular patient, are the needs of this person in the context of their family and support network going to be better met by access to specialist palliative care or are those needs already being met? For people whose care is shared with specialist palliative care services and their general practitioner, it also allows review as time goes by.

### *Systems performance and benchmarking of palliative care in Australia*

Palliative care in Australia also leads the world in point-of-care data collection for quality of care. [Eagar 2010] With the exception of the emergency departments, intensive care units and some surgical sub-specialities, the level of clinical accountability in palliative care in the community and inpatient units is second to none in Australia. The Palliative Care Outcomes Collaborative (PCOC) allows true benchmarking built around patients at comparable points in their disease trajectory. This is world-leading with no other country in the world having this level of clinical accountability. This has led to demonstrable improvements in clinical care across the system including patient care and caregiver supports. This federally funded program has been running since 2006 and now collects quality of care data at point-of-contact on more than 80% of all people referred to specialist services in the country. This is crucial for the improvement of quality of care that needs to be offered. Unfortunately, not all services participate in data collection for outcomes evaluation (whether that is PCOC or some other program) and therefore are not benchmarking.

### *Undergraduate education in palliative care*

Australia has invested in developing curricula and resources to support these curricula in palliative care in a nationally coordinated way. [Hegarty 2011] Although this still depends directly on uptake at the level of each university faculty or school (or even each course), the resources are high quality. The resources create an expectation that a palliative approach is an integral part of training clinicians across the spectrum of disciplines represented in health sciences.

## **Current challenges**

### *Population health planning principles*

Death rates, causes of death and unmet needs are all well described, and yet population-based planning principles are poorly used in planning or reviewing specialist palliative care services, service structures or resourcing. For example, if there is sufficient workload to justify another medical oncologist, then there will be a direct proportional increase in the work for the palliative care team. This should not require separate funding proposals, but should be built into the business case by the referring service, be it in oncology or any other specialty that should be referring to palliative care.

For specialist palliative care services, the responsibility to triage by complexity of needs is paramount. With this in place, there is the opportunity to ensure a more transparent and equitable distribution of access to services.

### *Isolated practitioners*

States and territories all have some sort of service level role delineation / service capability framework across the spectrum of clinical care including palliative care. For larger services this works well. For smaller services, the concept is that there will be formal networks with larger services to provide higher level care for people with more complex needs. These networks vary across Australia from strong formal ties to places where there is no support for some services that comprise a fractional appointment of a nurse who has been thrust into the role. Every clinician should be able to identify a network of every discipline required in the comprehensive care for someone at the end of life, regardless of the administrative boundaries, even in the smallest service. These networks are crucial to help to further improve the quality of care, and should not rely on informal person-to-person contacts.

### *Varying models of service delivery and widely varying criteria for service involvement*

There needs to be a rapid move towards standard criteria for referral to specialist palliative care services nationally with standard criteria also, where appropriate, when a person's care no longer needs to involve the specialist team. This will help referrers understand when to initiate referral and also help specialist services manage workload with more equity for the whole population that they serve.

**With similar levels of resourcing, there are widely varying models of care and access to services.** Such anomalies need to be explored in order to minimise such needless variation and optimise outcomes for people at the end of life.

For example, every tertiary hospital should have, as a requisite for ongoing accreditation, a functioning acute symptom control / assessment unit with around-the-clock senior clinicians

on call to accept care (including accepting referrals directly from Emergency Departments in the same way that any other clinical sub-specialty does). [Ward 2009] Such a model should also include outpatient or rooms-based care. Without this, there is the assumption that specialist palliative care is only for people so sick that they need to be in hospital or so unwell they cannot leave their house.

## **Recommendations**

### *1. Caregivers*

There needs to be far greater emphasis in supporting caregivers during the role and having completed the role. This includes long term studies to evaluate the impact of caring in this setting and minimising long term health consequences. A key measure of success of good palliative care should be the health and wellbeing of caregivers in the years after having completed their caring.

### *2. Genuine and sustained engagement with primary care by specialist services*

Primary care is the backbone of the non-hospital sector (and much of the non-metropolitan hospital sector) and specialist palliative care services need to actively engage with primary care. Without doing so, quality of care is compromised and continuity of care is lost. Engagement through Medical Benefits Schedule case conferencing should be a standard of care for every person referred to specialist services. [Abernethy 2012, Shelby-James 2007]

### *3. Access through needs-based care*

Ultimately, there is an urgent need to adopt universally a needs-based approach that is nationally consistent to ensure the people with the most complex needs are systematically identified in primary and tertiary care and offered the opportunity for a comprehensive assessment by a specialist palliative care service. This includes the need for nursing, social work / psychosocial assessment as well as medical assessment. This is especially the case for people whose life-limiting illness is not cancer. [Waller 2012, Waller 2010]

Such a process requires population-based planning from data that are readily available.

### *4. An ability to improve clinical outcomes- universal benchmarking*

There are wide variations in the core outcomes such as symptom control across Australia. Such variations are *not* simply due to variations in resources available. Every specialist palliative care service should be actively engaged in service improvement by participating in the Commonwealth-funded Palliative Care Outcomes Collaborative (PCOC) and should be setting explicit goals to improve the care that is delivered.

### *5. Nationally consistent referral thresholds / admission and discharge criteria from specialist services*

Wide variations also exist regarding who is seen or not seen by specialist palliative care services. This is confusing to referrers and does not foster equity of access. Nationally consistent approaches are needed for service admission and discharge criteria.

#### *6. New and emerging roles*

Training positions in nursing, medicine and allied health must be a priority for any new funding. Substantive positions in allied health with speciality skills in palliative care are urgently needed in occupational therapy, physiotherapy, social work and pharmacy. Nurse practitioner training positions need to be rapidly expanded.

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