



# **CARING FOR PEOPLE AT THE END OF LIFE**

**Submission to the National Health and Hospitals Reform  
Commission**

ANZSPM

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## INTRODUCTION

The Australia and New Zealand Society of Palliative Medicine (ANZSPM) is a specialty medical society that facilitates professional development and support for its members and promotes the practice of palliative medicine to improve the quality of care of patients with terminal illnesses and support their families. Our members are medical practitioners primarily palliative care specialists, trainees and general practitioners (GPs). However there are members from other medical specialities such as oncology.

Our Society supports the key principles as outlined in the Report released by the National Health and Hospitals Reform Commission (the Commission) in April 2008 entitled *Beyond the blame game: Accountability and performance benchmarks for the next Australian Health Care Agreements*. We are pleased to see that one of the key challenges identified by the Commission is 'Caring for and respecting the needs of people at the end of life' and welcome the Commission's stated intention to advise on a new policy framework that will overcome 'the blame game' associated with Australian Health Care Agreements.

As a member of Palliative Care Australia (PCA), we contributed to and support PCA's submission to the Commission entitled *End of life care is everyone's affair – tackling the challenge of 'end of life'*.

As the Speciality Society for Palliative Medicine, ANZSPM has additional comments to the Commission. The Australia and New Zealand Society of Palliative Medicine would be pleased to work with the Commission in the future to ensure quality care for all Australians at the end of life.

## THE CURRENT REALITY – BRIEF OVERVIEW

The changing demographic in Australia is well recognised – the population is ageing. Centenarians will soon be the fastest growing age group in Australia.<sup>1</sup> Associated with an ageing population is an increased number of people with chronic conditions such as organ failure and dementia. Also increasingly cancer survivors are requiring ongoing care for chronic conditions.

National palliative care policy describes needs based care.<sup>2</sup> This policy recognises that it is neither feasible nor in fact desirable that all dying patients should be managed by Specialist Palliative Care (SPC) Services. The majority of patients can be cared for by primary care providers with support from SPC Services and appropriate advance care planning. Others will need intermittent consultation with SPC Service. A small group of patients will need specialist care from SPC Services.

Palliative medicine specialists are the general physicians of end of life care, able to coordinate a wide array of palliative treatment options (including chemotherapy, radiotherapy, surgical options, pharmacological options) and psychosocial care, based on a knowledge of the disease, burden versus benefits of palliative therapeutics and the wishes of patient and family.

Palliative care was developed to provide end of life care for people with cancer. It is now recognised however, that many other cohorts of patients require quality end of life care, for example individuals with organ failure and neurodegenerative diseases. The trajectory of these

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<sup>1</sup> National Aged Care Alliance (2006) AHMAC and Beyond – A strategic framework for health care for older people: at home, in residential care, in hospital and in transition between settings.

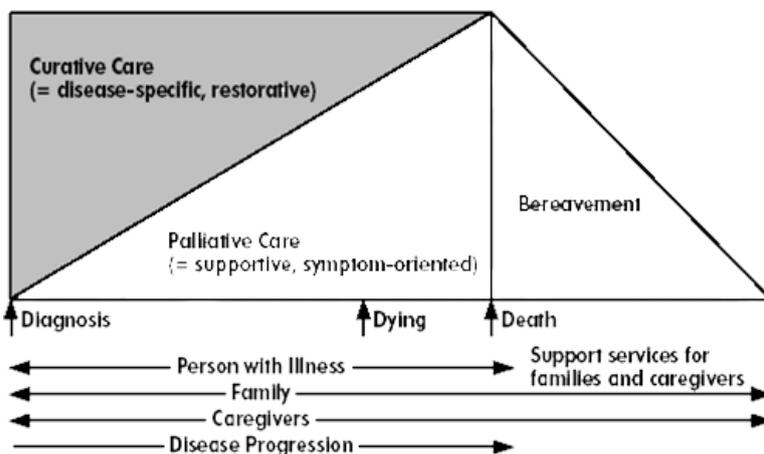
<sup>2</sup> Palliative Care Australia (2005) A Guide to Palliative Care Service Development: a population based approach. Canberra: Palliative Care Australia. Available at: [www.palliativecare.org.au](http://www.palliativecare.org.au)

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illnesses varies from the 'typical trajectory' for cancer and indicates requirement for longer term care.

The changing demographic has been associated with a change in the way palliative care is delivered. In the past palliative care was introduced when curative treatment was ceased. However, in recognition of the needs of people with chronic conditions and improved treatments for cancer, palliative care and curative treatment may be offered at the same time with the increasing role of SPC services as disease progresses. (Fig. 1) This is a more sophisticated model requiring seamless integration of palliative and curative care, excellent transfer of information, mutual understanding of goals and possibilities of care and liaison between multiple service providers working in diverse sites of care, wherever the patient is at the time.

FIGURE 1: Palliative care and curative care<sup>3</sup>



The complexity of this reality is not recognised in current funding models, performance indicators, benchmarks, targets and models of service provision for palliative care.

In Australia patients die at home, in hospices, in residential aged care facilities and in hospital although the majority die in hospital. The transition between these settings is often chaotic for patients. Hospices are changing focus to that of inpatient management of symptoms before the patient is returned home or to a residential aged care facility to die. Residential aged care facilities are becoming, or are already, the hospices for the elderly – the number of days spent in an aged care facility is decreasing and the complexity of needs of each resident is increasing. Few hospitals have comprehensive palliative care services that would allow patient and family participation in negotiating changing priorities in goals of care. This is despite the fact that many deaths in Australian hospitals are neither sudden nor unexpected, and generally occur in elderly patients with one or more life limiting illnesses. These patients have often had deteriorating health over weeks or months

In Australia the provision of specialist palliative care within the private health sector is not often a priority. The Australian Government Department of Health and Ageing is facilitating discussions with this sector but as yet the community has not seen much change.

It is known that access to specialist palliative care services is inequitable in Australia. Older Australians, females, Aboriginal and Torres Strait Islander and those with non malignant conditions have been shown to have less access.<sup>4</sup>

<sup>3</sup> WHO 1990, Cancer Pain Relief and Palliative Care, Report of a WHO Expert Committee, World Health Organization, Geneva

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The ageing of the workforce and shortages of skilled workers is impacting on the ability of the health care sector to deliver quality care at the end of life in all settings.

ANZSPM recognises the work undertaken in end of life care by the Australian Government Department of Health and Ageing through its National Palliative Care Strategy. Examples of large well funded programs include: Palliative Care Outcomes Collaborative (PCOC), Program of Experience in a Palliative Approach (PEPA) and Palliative Care Clinical Studies Collaborative (PaCCSC). Strategies to raise awareness of palliative care, support the workforce and improve quality is changing how end of life care is delivered however there are still many people in Australia who do not receive quality care at the end of life.

## DISCUSSION

### Service provision

- Key role of SPC Services
- Seamless integrated care
- The reality of hospital as the place of death

### Choice of place of death

### Complexity of end of life care

- Identifying when end of life care is appropriate
- Recognising complexity of care

### Workforce issues

- Shortages
- Reform of MBS items

## Service provision

### ***The key role of SPC Services***

A SPC Service is defined as:<sup>5</sup>

Specialist Palliative Care Service is used to denote a multi-disciplinary health care service whose substantive work is with patients who have a life limiting illness ..... Specialist palliative care professionals would be expected to have recognised qualifications or accreditation in palliative care. Specialist palliative care services provide consultative and ongoing care for patients with a life limiting illness and provide support for their primary carer and family during and after the patient's illness.

Specialist palliative care can be provided at home, in hospital, in a hospice and in aged care facilities. Services in rural and remote areas may be less developed in Australia with large level 3 services operating primarily in metropolitan areas. The Palliative Care Australia Standards<sup>6</sup> provide a quality improvement framework against which SPC Services can assess themselves. The National Standards Assessment program currently being conducted by Palliative Care Australia will promote their implementation.

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<sup>4</sup> McNamara, B., Rosenwax, L., D'Arcy Holman, C., Nightingale, E. 2004. *Who receives specialist palliative care in Western Australia – and whomisses out*, University of Western Australia, Perth.

<sup>5</sup> Palliative Care Australia (2005) Standards for providing quality palliative care for all Australians. Canberra: Palliative care Australia. Available at: [www.palliativecare.org.au](http://www.palliativecare.org.au)

<sup>6</sup> Palliative Care Australia (2005) Standards for providing quality palliative care for all Australians. Canberra: Palliative Care Australia [www.palliativecare.org.au](http://www.palliativecare.org.au)

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Specialist Palliative Care Services need to be sufficiently resourced to:

1. provide targeted care for patients with complex needs and their families
2. develop links with primary care providers and support them in the management of less complex cases in all sites of care
3. promote quality care at end of life by setting standards, conducting quality assurance and education.
4. conduct research into a wide range of areas of end of life care eg physical, spiritual, service models etc.

The needs based palliative care policy requires a system that:

- is responsive and resourced, for example, all Australians should be able to access SPC services if required.
- has partnerships that are robust, for example, through a 'hub and spoke' model for rural and remote communities linked to metropolitan services. There may need to be a requirement for all large metropolitan SPC Services to be linked to a rural/remote area and provide outreach clinics plus telephone support
- engages GPs to participate in palliative care. Latest research indicates that most GPs willingly provide palliative care and that non-participant GPs can be encouraged to participate through ongoing education and support from SPC Services (J Rhee in press).
- enables primary care providers to access expert advice from SPC Services that is useful and timely and that patients with complex needs (complex physical symptoms, no family) can be referred to SPC Services in a timely manner. This assumes:
  - appropriate referral to SPC Services. Anecdotal evidence suggests that this is not the case currently – Services report inappropriate non-complex referrals
  - timely referral. Anecdotal evidence suggests that this is not the case currently. Many patients can wait weeks for a referral to a SPC Service.
  - appropriate skills in the primary care workforce. This may not currently be the case, for example aged care homes do not have the appropriate staff mix to provide adequate pain control. Or another example, research indicates that one reason why GPs may not be involved in palliative care is because they lack confidence in their skills and knowledge.
  - formal linkages between SPC Services and primary care providers. Latest statistics from the AIHW indicate that of the services that responded across Australia the vast majority were meeting performance indicator 4 – Partnerships: the proportion of palliative care agencies that have formal working partnerships with other service providers or organisations.<sup>7</sup>

There needs to be adequate funding of SPC Services to ensure that they can manage referrals in a timely manner, educate and support GPs, develop appropriate referrals with primary care providers and develop formal linkages with primary care providers.

## ***Seamless integrated care***

Providing quality care at the end of life requires that patients with a terminal illness be able to move across health settings – hospital, home, hospice and residential aged care facility- in a way that is perceived to be seamless for the patient and their family. At present integration across settings is poor and patients often end up trying to find their way through a complex system when they do not have the physical and emotional resources to do so. This is considered by many of our members to be the single most important reform required to improve end of life care for all Australians.

Integrated care across health settings is not easy to achieve and needs to be developed locally through cooperation between services. It requires:

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<sup>7</sup> Australian Institute of Health and Welfare (2008) National palliative care performance indicators: results of the 2007 performance indicator data collection. Canberra: AIHW. Available at:

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- All health care providers to commit to the process of integration with the aim of improving care for patients at the end of their life and supporting families. This will require that all services are willing to change the way they are currently operating to meet this goal. Time and resources will need to be allocated to the task. Examples:
  - AYA care planning model at Peter MacCallum Cancer Centre (PeterMac). At PeterMac it has been recognised that the needs of adolescents with complex needs often cannot be met in the community. The service is looking at models to encourage the community to engage with the hospital and patients and to integrate palliative care into the tumour stream model of care.
  - UK nurse facilitators: this model integrates palliative care into the primary health care team. The palliative care primary team member liaises with the SPC team when needs arise beyond the scope of the primary team. This model ensures better understanding of curative care by the palliative care team and vice versa.
- Effective governance systems
- Common clinical practices through evidence-based guideline driven care
- Information technology systems that support improved patient care and outcomes at end of life through service integration. There is little integration in IT between hospital, community, aged care facilities and hospices and it is not clinically focussed. There are good examples of integrated IT in Australia that could be used as appropriate models.
- Continued reform of PBS to ensure that medications are available in the community

State and Federal Governments and other service providers need to commit the resources required to develop seamless integrated care across setting. Performance indicators, targets and benchmarks need to be developed to measure this integration. Some members of ANZSPM suggest that the only way to provide seamless care is if one organisation is providing/coordinating care in all settings. This maybe an unrealistic goal however does identify the serious barriers perceived by our members to seamless integrated care.

### ***The reality of the hospital as a place of death for some patients***

The majority of people in Australia die in hospital however:

- there are very few inpatient hospital palliative care beds in Australia and for some patients with a terminal illness, hospital is the appropriate place of care, for example, people living alone without carers, people with complex symptom control issues.
- in many hospitals, consulting teams cannot admit patients under their own bed card and directly manage the care of patients. Consequently the consultative role of palliative medicine specialists has limits in directing care and decision making. Yet the involvement of a consultative service has been shown to lead to higher community palliative care referrals<sup>8</sup> and this in turn can lead to a higher home death rate.<sup>9</sup>
- in a recent publication by the National Aged Care Alliance<sup>10</sup>, it was identified that there has been inadequate development of multidisciplinary and palliative geriatric medicine acute hospital services for frail complex older people in the 75-84 age group.
- when offered in acute hospitals, recent research indicates that the principles of palliative care are not always transported across into caring for patients dying in general hospital wards. This is supported by anecdotal evidence, recently confirmed by a number of studies including that by Hardy et al 3<sup>11</sup> which highlighted a number of areas of concern when comparing hospice care with care of the dying outside a hospice unit.

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<sup>8</sup> Spruyt O, Hamrosi M Inpatient Mortality Rates at Peter MacCallum Cancer Centre, 2002 Implications for palliative care (unpublished)

<sup>9</sup> DHS Victorian data 1994

<sup>10</sup> National Aged Care Alliance (2006) AHMAC and Beyond – A strategic framework for health care for older people: at home, in residential care, in hospital and in transition between settings.

<sup>11</sup> Hardy J, Haberecht J, Maresco-Pennisi D, and Yates P. Audit of the care of the dying in a network of hospitals and institutions in Queensland. Internal Medicine Journal 2007; 37:315-319.

All tertiary hospitals in Australia should have consultative services with capacity to admit under a bedcard with some centres having inpatient units for patients who need ongoing investigation and acute treatments more easily available in hospital than hospice settings. There should be appropriate performance indicators, targets and benchmarks for providing palliative care.

All hospitals need to develop policies and procedures that allow carers to feel a part of the care team. An example would be introducing Integrated Care Pathways for dying patients in various settings.<sup>12 13 14 15</sup> The aims of ICP for dying patients are to promote the earlier acknowledgement of the inevitability of an individual patient's death, ensure that dying patients receive a high standard of care regardless of their location, and provide guidance and support to generalist staff many of whom have little or no experience or expertise in providing end of life care.

## **Choice of place of death**

At present most patients die in hospital yet internationally, studies reveal that most patients wish to die at home. Most of these studies have been done in 'well' patients early on in their disease journey.<sup>16</sup> Further research is needed into this area. In the United Kingdom it has been shown that there has been a steady reduction in the number of home deaths. Reasons postulated are reduction in GP's consultations at home, reductions in contacts with district nurses and more people living alone.<sup>17</sup>

The emphasis on the place of death issue should be on informed choice. The concern for ANZSPM is that the belief of health authorities that dying at home is better is based on a simplistic interpretation of the research and reflects a lack of resources and the lack and expense of beds in hospitals. It also ignores the current reality of society in most developed countries where community functioning is more fragmented than in the past. While we support the principle of honoring patient choice of place of death and recognise the stated wishes of patients as revealed in the literature, we also recognise the current day realities which create barriers to achieving home death, many of which extend beyond the limits of health care and are the result of changes in society and community structures and expectations. These will require creative solutions before a real shift back to home based care and death can be realised. For example the rate of home deaths in Western Australia is higher than in other states in Australia probably reflecting the well established community service provided.

A home death should not be seen as a marker of a quality death in itself; there needs to be quality indicators developed for deaths at home.

## **Complexity of end of life care**

### ***Identifying when end of life care is appropriate***

Many patients in Australia die without receiving appropriate end of life care. In Britain the Gold Standards Framework has been introduced to ensure that patients are identified as requiring

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1994-1995 Department of Human Services Palliative Care in Victoria: The Way Forward October 1996

<sup>12</sup> Ellershaw J, Wilkinson S eds. Care of the Dying – A Pathway to Excellence. Oxford University Press; 2003.

<sup>13</sup> Ellershaw J, Foster A, Murphy D, Shea T et al. European Journal of Palliative Care 1997; 4(6): 203-207.

<sup>14</sup> Jackson K, Mooney C, Campbell D. Implementing the Principles of Palliative Care for patients dying in general medical wards: The Southern Health PICD Pilot Project. Kochipallcon XV International Conference of Indian Association of Palliative Care, Kochi India, 2008

<sup>15</sup> Evidence based End of Life Care for dying patients and their families in the acute health care setting. Australian Resource Centre for Health Care Innovations (ARCHI) website. Baxter 2006 NSW Health Awards.

[http://www.archi.net.au/e-library/health\\_administration/awards06/appropriate/end\\_of\\_life](http://www.archi.net.au/e-library/health_administration/awards06/appropriate/end_of_life)

<sup>16</sup> Hunt R, Bonnett A, Roder D (1993) Trends in the terminal care of cancer patients: South Australia, 1981-1990. A NZ J Med 23:245-51

<sup>17</sup> Gomes B, Higginson IJ (2008) Where people die (1974-2030): past trends, future projections and implications for care. Palliative medicine 22:33-41

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palliative care. While not necessarily advocating for the introduction of the complete Gold Standards Framework in Australia, ANZSPM would advocate the implementation of a simple tool for primary care providers and other specialists caring for those with a chronic disease to identify when they need to begin conversations about dying with their patients and families. Early preparation is known to improve outcomes at end of life.

In addition, at present it is not possible to identify the patients who die as a result of an anticipated death from a life limiting illness as not all are registered with a SPC Service. Identification is necessary for targeting care and also for research in palliative care, including what access this cohort had to appropriate end of life care. Ongoing research is required to improve the quality of care at end of life.

The development of a system to identify dying patients would improve end of life care. An approach to identifying this cohort could be through a code in the ICD10 (Australian version). The Commission could advocate for a code to be included in the ICD10 (Australian version). Suggestions for a code include:

- a clinical code for cachexia (irrespective of underlying diagnosis)
- code in the Z chapter of the codes - someone for whom palliative care is warranted.

Development of this code will need more thought and consultation with palliative medicine specialists.

## ***Recognising complexity***

Most systems in Australia do not recognise the complexity of care required by people at the end of life and many services do not consider palliative care to be an essential service for patients who are dying. Funding models therefore do not reflect the demands on SPC Services to deliver this quality care. For example:

- The targets by which SPC Services are funded at state level do not reflect the workload and if anything can act as disincentive to increase productivity. Examples include:
  - Targets in hospices may only allow the recording of bed-day targets but not throughput or casemix with no incentive to undertake complex care planning that will enable patients to be moved back home or to other settings. Appropriate care planning can reduce inappropriate hospitalisations and stress for families.
  - Targets in the community are focussed on number of contacts but do not address complexity. As a result it is possible for services to be good at the targets but the quality of service model may be questionable.
  - In some areas, acute bed days are occupied by people waiting to get into the palliative care unit. Many patients die before they can be admitted yet the palliative care unit can provide the care at a saving compared to other venues.
- MBS items do not reflect the time that is needed for prolonged complex clinical review consultations with patients at the end of life.

Appropriate measures need to be introduced to reflect the complexity of care of people at the end of life including the benefit of appropriate advance care planning. These include:

- MBS reform with new items reflecting complex clinical review consultations
- Alternate funding measures may include funding linked to:
  - Throughput
  - Time spent with patients
  - Pain classification score
  - Psychosocial assessment criteria -family functioning, depression, delirium, functional scores, drug and alcohol dependence, -all of which add to complexity of care

## Workforce issues

### Shortages

There is a significant shortage of palliative medicine specialists as evidenced by the number of current job vacancies around Australia. The palliative medicine specialist workforce is ageing and overworked. In a survey undertaken by the Australasian Chapter of Palliative Medicine in 2007 the average age of palliative medicine specialists was found to be 53 and the percentage of specialists over the age of 50 had increased from 38% in 2003 to 58% in 2007.<sup>18</sup> Average working hours were 49.8 hours per week for fulltime practitioners. The hours worked on call per month by the survey respondents had increased from 332 hours in 2003 to 1305 in 2007.

There is difficulty in training adequate numbers of advanced trainees or doctors wanting to change career in the midterm. Problems include:

- inadequate numbers of palliative care trainees. The Victoria Government has recognised this problem and its Department of Health Services is developing and implementing a communication strategy to attract more trainees. Incentives are required to attract trainees to palliative medicine, especially as the need for consultants increases in the future due to changing demographics.
- insufficient accredited training sites available for trainees. The COAG agreements of 2006-2007 recognised expanded settings for specialist training applications. Positions were created for community registrars but successful service applicants are having difficulty in fulfilling positions.
- lack of accredited trainers: part time workers so do not meet the Australasian Chapter of Palliative Medicine's training requirement for 1EFT of supervisor time for trainees and consultants often work across settings and therefore are not on a single site enough to meet training requirements
- private hospitals could contribute to training for specialists however often do not have a palliative medicine specialist employed and therefore cannot be accredited.
- contracts between hospitals and specialists assume that education of trainees is part of the role of specialists. Therefore the expectations of supervisors (as determined by the Royal Australasian College of Physicians) is increasing but time allowance is not made in the clinical load for this important role..

### Reform of MBS system

Reform of the MBS system could make it a more attractive speciality by ensuring adequate remuneration for services. Currently, private practice in palliative medicine is not well remunerated through MBS items. In addition, multidisciplinary practice is not well supported in the private system yet this is crucial to good palliative care. MBS recognition of lengthy consultation and care planning will provide incentives for increased palliative care specialist provision in the community and private sector.

We would encourage the commission to review the current Medicare schedule and engage with palliative care specialists in addressing the current inequities and disincentives to workforce development resulting from inadequate remuneration.

## The Commission's draft performance indicators

The Commission's 2 draft indicators for end of life care are:

- Family experience with care process: State
- Number of emergency department visits and hospital days in last 30 days of life per person: State

Australia and New Zealand Society of Palliative Medicine suggest that these indicators be revised as follows:

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<sup>18</sup> Australasian Chapter of Palliative Medicine (2007) Survey of the Palliative Medicine Specialist Workforce

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- That a formal caregiver assessment was performed (in the view of the caregiver) in contrast to caregiver satisfaction with services.
- The second indicator assumes that all visits to Emergency Departments and days in hospital are indicators of a failure of the home-based system. However some visits may be necessary and hospital beds are required for some patients. ANZSPM would like to see these performance indicators reviewed to reflect this reality.

## RECOMMENDATIONS

Australia and New Zealand Society of Palliative Medicine recommends the following:

1. SPC Services be resourced to undertake their key role as the experts and leaders in end of life care.
2. All tertiary hospitals in Australia to have consultative services with capacity to admit under a bedcard with some centres having inpatient units for patients who need ongoing investigation and acute treatments more easily available in hospital than hospice settings. All hospitals need to have policies and procedures in place to ensure that patients who die an expected death in hospital receive quality end of life care.
3. The Federal and state governments develop incentives to attract more medical practitioners to undertake specialist training in palliative medicine eg MBS item review.
4. The Federal and state governments develop increased accredited training sites.
5. A simple tool to be introduced to aid primary care providers in identifying when they should begin discussing end of life care with patients with chronic and terminal illnesses.
6. A code be inserted in the ICD10 (Australian version) to indicate a person has died an expected death.
7. Appropriate measures for funding and MBS reform be introduced to reflect the complexity of care of people at the end of life including the benefit of appropriate advance care planning.
8. The draft performance indicators produced by the Commission be reviewed and appropriate performance indicators, targets and benchmarks be develop to measure integration between end of life care in different settings.
9. A home death should not be seen as a marker of a quality death, quality indicators need to be developed for deaths at home.