



**Response to questions
on notice from Senate
Palliative Care Inquiry
Public Hearing**

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RESPONSE TO QUESTIONS ON NOTICE FROM SENATE PALLIATIVE CARE INQUIRY PUBLIC HEARING

Introduction

This response is provided to the Senate Standing Committees on Community Affairs Inquiry into Palliative Care in Australia following Ms Deborah Parker and Ms Marie Robinson attendance before the public hearings in Sydney on July 2 2012. Further clarification was sought by the committee members regarding Blue Care's submission.

Question 1

Senator Moore asked for clarification on what Blue Care is providing in North Burnett and Fraser to understand what is working well in both those regions.

Reference point 3.1.2 page 15 of Blue Care Submission

Further to the information provided in our submission Blue Care's North Burnett manager has reported that the Palliative Access program has recently experienced operational changes and is under new management.

The Palliative Care program has informed Blue Care that they will no longer be referring clients to Blue Care unless clients live outside the Bundaberg area.

Previously our service had one or two palliative clients on the books at any one time throughout the year across the four towns in the North Burnett and sometimes as many as five or six per year. Blue Care has supported these clients under regular funding for example DVA or HACC services, seeking palliative care eligibility should they fall outside this funding, or if their needs exceed what they would normally receive through these programs.

A recent example of the change in the service delivery is a referral to Blue Care via the Bundaberg Hospital for a 50 year old man for assistance with change of his subcut line. There was a note on the end of the referral that said "no funding attached with this client", where as previously palliative care funding would be provided.

This experience clearly demonstrates the need for palliative care funding to be provided direct to service providers such as Blue Care where the service will be provided rather than to the hospital where funding distribution is at the discretion of local management of the hospital.

Question 2

Senator Moore has asked for more information on the use of General Practitioners for palliative care in aged care facilities.

This work was a reference to the Department of Health and Aged Care funded project – A comprehensive evidence based palliative approach in residential aged care (cebparac). A final copy of the report is attached and is also available from the following weblink - <http://www.uq.edu.au/bluecare/comprehensive-evidence-based-strategy-to-address-the-palliative-care-needs-of-people-residing-in-residential-aged-care-facilities-racfs-cebparac>

RESPONSE TO QUESTIONS ON NOTICE FROM SENATE PALLIATIVE CARE INQUIRY PUBLIC HEARING

Question 3

Senator Fierravanti-Wells asked about how an entitlement system would work in relation to palliative care and whether something like a Medicare schedule to access services is a possible solution and further to that if an entitlement system was available how much more palliative care could be absorbed by residential aged care.

Palliative care funding is scheduled to come under Activity Based Funding (ABF) this year. Residential aged care is already funded by a form of ABF as providers are paid more for caring for residents who are ill or frailer and less for caring for residents who are more independent. In residential care, the activity is counted per day.

In contrast hospital models and palliative care will be counted by 'episode of care'. This provides opportunity to look at the range of services required based on need not only of the person who requires care but also the family. In palliative care, the unit of care is the family not only the person with the life limiting illness. In residential care for an entitlement system to work effectively identification of those who qualify would either be based on a person's estimated prognosis or based on need.

While needs based assessment is advocated by Palliative Care Australia, identification and assessment of need requires comprehensive assessment and planning by a multidisciplinary team. In residential aged care while this is desirable, the reality is that a prognosis based model of funding is more likely to be acceptable given the limited availability of a multidisciplinary team as well as the cost containment approach to funding.

The model trialled as part of the cebparac project used prognosis as the basis of triggers for key processes of care. It acknowledged the importance of advance care planning for all residents and their families at admission and at six monthly intervals or greater if a change occurs.

For residents with a prognosis of less than six months, this would be the key trigger for convening a palliative care case conference and discussing goals of care including the clinical trajectory and resident and family spiritual, social and psychosocial needs. A prognosis of less than one week would trigger the use of an end of life care pathway. At the six month estimated prognosis an entitlement system of care of palliative care could be invoked.

That care would be approved by the resident's general practitioner or specialist palliative care professional and include support from a specialist palliative care service either on a consultancy basis (specialist care doctor/nurse practitioner/clinical nurse/allied health). This service should not be restricted to the resident but should include the family (as defined by the resident) as the unit of care. Support in the bereavement phase for families is also important and currently not available. Where required based on need additional payment for physical care and complex care needs would be available.

RESPONSE TO QUESTIONS ON NOTICE FROM SENATE PALLIATIVE CARE INQUIRY PUBLIC HEARING

USA example

In the United States¹, a Medicare hospice benefit is available for residents with a prognosis of less than six months, although the accuracy of the criteria for prediction for non-cancer diagnosis has been questioned. Access to the Medicare benefit entitles the resident and family to the following:

- *Hospice nursing visits as needed including on call, the support is available to the resident as well as the family.*
- *Medical social services provided by a social worker.*
- *Consultation and oversight provided by the hospice medical director*
- *Counselling services, including dietary recommendations and bereavement counseling, with respect to the terminally ill patient, as well as adjustment-to-death support for the patient's family and friends. Bereavement services are provided for a year after the patient's death.*
- *Friendly visits, compassionate listening and companionship provided to the patient and family by trained hospice volunteers*
- *Other services provided as needed, including physical, occupational and speech therapy, as well as home health aide and homemaker services. For the provision of these services, there may be a special arrangement between the hospice and the nursing home.*
- *Drugs and medical supplies provided by the hospice as needed for palliation and management of the terminal illness and related conditions. The patient is responsible for a 5 percent drug copayment, not to exceed \$5 per drug.*
- *Pastoral care assessment. Clergy offer spiritual support as desired, and establish or maintain communication between the terminally ill patient and his or her regular congregation of worship.*

In Australia few of these services are routinely available in residential care. In some areas specialist palliative care services will provide support on a consultancy basis for residents, educate staff and assist with counselling and supporting family. This is paid for by the specialist palliative care service not funded under ACFI.

Currently the General Practitioner can claim under Medicare a range of payments which can assist in providing palliative care in residential aged care facilities. These include items for case conferences, medication review and management plans. Despite this, the uptake rate of the items is low for General Practitioners consulting in residential aged care. In addition a nurse practitioner can also attend residents, although they are limited as to what they are eligible to claim and currently there are only small number of nurse practitioners working in aged care and even fewer who are specialising in palliative care in this sector. Allied health input for palliative care is currently limited in this sector. Social work or counselling expertise should be available, but is not.

RESPONSE TO QUESTIONS ON NOTICE FROM SENATE PALLIATIVE CARE INQUIRY PUBLIC HEARING

A limitation of introducing an entitlement funding system based on prognosis in Australia is that no large scale studies have been funded to ascertain how to predict prognosis and what trajectories of care exist within this setting. International work in this area shows promise and it may be possible as has been conceived by Porock et al ² to use some current data collected using the Australian data set (ACFI) as part of the information required estimating prognosis. However it should be recognised that use of a prognostic tool can assist the clinician but should not be a replacement of clinical judgement.

Currently, most people who are in permanent residential care will die in the facility without transfer to an acute hospital. The extent to which the number of residents is inappropriately transferred to hospital at the end of life and their fate should this occur is not currently quantified in Australian statistics. There is potential for an entitlement system that provided palliative care for the resident and the family to alleviate the anxiety and distress for those where inappropriate transfers in the last few days or week of life does occur. The package needs to provide support for multidisciplinary care.

Consideration should also be given to the supports required in the form of a palliative care package for people who choose to live and receive end of life care at home. Currently palliative care funding is not available to sufficiently support the needs of many of these people in a multidisciplinary family focussed model of care.

Other models including changed roles for general practitioners could also be considered. A large number of older Australians currently die within residential care and for this group and their family the experience can be enhanced. In the oral submission to the commission the concept of the Netherlands nursing home doctor was raised. A study in 2010 by Houttekier et al ³ found that for people aged 65 and over with a diagnosis of dementia that in the Netherlands 90.7% died in a nursing home (4.75% at home, 3.0% in a hospital) but in England (probably similar to Australia) this was 55.4% with 39.1% dying in a hospital and 4.9% dying at home. It appears from this data that in countries where greater medical support is available in the residential sector the proportion of people who are able to die within residential care is increased.

Question 4

Senator Fierravanti-Wells asked for information on how the Productivity Recommendations on palliative care and the practical translations of these recommendations.

In the plan – Living Longer, Living Better the Government has indicated they will be providing direct access to specialist palliative care and advance care planning expertise through palliative care advisory services. The Government will also improve palliative care support skills of the aged care workforce through expansion of the Program of Experience in the Palliative Approach to include staff of residential and community aged care services. These reforms are expected to cost of \$21.7million over five years (including \$5.3million in 2016-17).

No other details regarding how these initiatives will be implemented are available. In practical terms allocation of money based on a population based approach would be

RESPONSE TO QUESTIONS ON NOTICE FROM SENATE PALLIATIVE CARE INQUIRY PUBLIC HEARING

most sensible. Specialist palliative care services or non-government providers of residential and community aged care (such as Blue Care) with the service capacity to support specialist palliative care positions should be provided with adequate funding for consultancy and capacity building. The money identified (\$21.7m) is not adequate to provide coverage for all dying residents in every residential aged care facility and community in Australia. In Victoria, a recent state government initiative has resulted in a palliative care position in each of the eight palliative care consortiums. Some of these positions cover over 100 residential aged care facilities and therefore impact will be limited primarily to capacity building rather than direct service delivery.

Example

In June 2009 there were 2,783 residential aged care facilities with 175,225 operational places in Australia. Number of deaths from 1st July 2008 to 30th June 2009 was 48,874. In practical terms support from a specialist palliative care service can be estimated based either on number of beds or number of resident deaths. Estimating on resident deaths – if we assume that 10% of the deaths that occur in a year require a consultation with a specialised palliative care service (nursing consultation) then this would equate to 4,887 referrals per year. If we approximate that one FTE position could manage 200 new referrals per year allowing some time for capacity building and family support then this would require 24 FTE positions nationally. In Queensland a Nurse Grade 7 is \$91,153 - \$97,676 without on-costs. Realistically with on-costs and travel it is estimated that per FTE \$150,000 per annum would be required and nationally this would equate to \$3.6 million per annum. This is within the scope of the reforms but will only provide the minimum estimated level of support (10% of estimated deaths) required and for areas where there is limited current services and distance concerns this support may be a gross underestimation.

The link (or not) between the initiatives of direct specialist palliative care services and advance care planning expertise through existing palliative care advisory services or community nursing services with palliative care expertise is unclear. We advocate that caution should be exercised in setting up services whose purpose is to only provide advanced care planning and are not linked to specialist palliative care or aged and community care providers.

References

1. Huskamp H, Stevenson D, Chernew M, Newhouse J. A New Medicare End-Of-Life Benefit For Nursing Home Residents Health Affairs January 2010 29:1130-135 doi:10.1377/hlthaff.2009.0523
2. Porock D, Parker-Oliver D, Petroski G, Rantz M. The MDS Mortality Risk Index: The evolution of a method for predicting 6-month mortality in nursing home residents BMC Research Notes 2010, 3:200 doi:10.1186/1756-0500-3-200
3. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Phillipsen B, Deliens L. Place of death of older persons with dementia. A study in five European Countries. J Am Geriatric Soc. 58:751-756 2010.

**RESPONSE TO QUESTIONS ON NOTICE FROM SENATE
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