Palliative Care in Australia

Submission to the Senate Committee on Community Affairs

HammondCare

An independent Christian charity

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Established in the 1930s, today HammondCare is an independent Christian charity specialising in dementia care, palliative care, rehabilitation, older persons' mental health and other health and aged services. HammondCare has a particular commitment to dementia care and research as well as to people who are financially disadvantaged.

Funding arrangements for palliative care

Sub-acute funding from the NSW Government for inpatient palliative care services has not kept up with demand. Activity targets for sub-acute hospitals have remained unchanged for too long, despite an increase in the number and acuity of palliative care patients as the population ages, and there is no mechanism for adjusting ongoing funding to meet these challenges. In the past three years, HammondCare has increased the number of palliative care beds at its services in northern Sydney by 47 per cent to meet growing demand but it has not received further funding for these extra beds from the state government. Further, the funding that is available only covers operational costs, with no provisions for construction work or building depreciation. An additional source of funding in this area is crucial, given that the National Health and Hospitals Reform Commission (NHHRC) identified sub-acute services as the 'missing link' in the health system and called for a "major capital boost" for these facilities.[1]

In NSW, COAG funding intended for sub-acute services is distributed varyingly through local health districts (LHDs), limiting the scope of services that specialist affiliated health organisations (AHOs) are able to deliver to people living in their own homes or in residential aged care.

Recommendation 1: *The Introduction of a variably responsive subsidy for sub-acute services that reflects the changing acuity and activity of palliative care patients as the population ages.*

Recommendation 2: *That the Australian Government allocates funding to infrastructure development in sub-acute hospitals through its Health & Hospitals Fund (HHF).*

Recommendation 3: *That specialist AHOs receive direct auspice of COAG funding to ensure that expected outcomes are delivered.*

The effectiveness of a range of palliative care arrangements

It is widely acknowledged that acute hospitals are not an ideal setting for people with life-limiting illnesses who do not require active treatment. While there is a strong desire among many people to remain in their own homes and communities at the end stage of life, community palliative care services are often stretched, and without extensive support from family or informal caregivers, community options for people at the end of life are, in many cases, inadequate or untenable without costly, additional private support. International and Australian research suggests that inadequate palliative care resources in the community are a common cause of unnecessary acute hospital admissions at the end of life, when symptoms intensify.[2]

Despite recent efforts to improve the end-of-life experience within aged care facilities, the lack of specific funding, staff training, and specialised equipment, limits the scope and quality of palliative care provided. Due to these difficulties and constraints, residents are often transferred to hospital emergency departments at the end of life for symptom control, increasing the likelihood of distress and a bad death.

The Palliative Care Suite model

To address these issues, HammondCare launched a dedicated Palliative Care Suite (PCS) within one of its own aged care facilities in southwest Sydney in November, 2011. The PCS has a specially trained multidisciplinary team, enabling it to provide around-the-clock nursing care, pain relief and symptom control to residents who have been assessed by a specialist palliative care team. The team is supported by a 24-hour telephone advisory service, attended by specialist staff from the palliative care unit at HammondCare's Braeside Hospital, who can also consult with residents' GPs and conduct weekly case conferences. The pilot PCS has nine, modern single rooms, each equipped with a kitchenette and a fold-out bed, making it possible for family caregivers to stay with their dying relatives.

[1] National Health & Hospitals Reform Commission, p.6. (See also p.171.)

[2] Van den Block, L., Deschepper, R, et al., p.572.

Through these distinguishing features, the PCS model provides better clinical, social and emotional outcomes for older, end-of-life patients who need specialist palliative care but cannot access sufficient services in the community and do not require hospitalisation. The model also supports Goal 5(2) of the National Palliative Care Strategy[3] and Recommendation 55 of the National Health and Hospital Reform Commission's final report, which emphasised the need for better palliative care in aged care facilities.[4]

The PCS model was initiated by HammondCare with no additional funding from government and has proven to be strongly cost efficient. However, without cross-subsidisation from the existing 120-bed aged care facility and the strong links with the palliative care specialists at HammondCare's own Braeside Hospital, it would not have been possible to develop and run the suite. HammondCare hopes to extend this model to other locations where it also provides residential aged care and sub-acute palliative care services. The PCS model could be introduced by other service providers in areas with established specialist palliative care teams, creating focused pockets of expertise for complex palliative care cases. To be sustainable, the PCS model would need a dedicated source of top-up funding, in addition to regular Commonwealth aged care funding and resident fees, to cover the cost of extra registered nurse hours and medical expenses. According to HammondCare's modelling, the cost of this top-up funding is $50,000 per bed, per annum, or $137 per bed day.

Recommendation 4: *That the Australian Government examines the feasibility of funding and expanding the PCS model in residential aged care settings.*

Recommendation 5: *That palliative care be included in a revised Commonwealth aged care funding and service framework, in line with the Productivity Commission's recommendation.*[5]

The composition of the palliative care workforce

Meeting the needs of the ageing population

There is already a shortage of medical and nursing specialists in the area of palliative care, with several unfilled senior positions in this discipline throughout NSW, especially in rural areas. Adding to this problem, a significant proportion of experienced medical specialists and nurses are ageing, and are expected to leave the workforce within the next decade. Palliative care specialists frequently report that other non-specialist health and medical staff who work with patients and clients with life limiting illnesses, lack detailed knowledge and understanding of palliative care.

The adequacy of workforce education and training arrangements

In order to develop a skilled, specialist palliative care workforce, it is important to develop a significant cohort of senior teachers and academics to deliver specialist training to health and medical students, doctors, therapy staff and nurses. It is crucial to provide healthcare students with challenging experiences in palliative care settings at an early stage in their professional education, as otherwise, the discipline is not normally considered an attractive specialty among health and medical professionals

To address this need, HammondCare has established a multidisciplinary Clinical Training Centre (CTC) at its Greenwich Hospital, drawing together senior medical, nursing and allied health teaching academics who will be able to provide specialist palliative care training in a clinical setting. A similar medical academic position in palliative care is also being established at HammondCare's Braeside Hospital. While the Commonwealth Government has provided capital funding for the CTC's building upgrade, current funding arrangements for some of the academic positions are ad hoc and tenuous, particularly for non-medical academic staff.

[3] "Explore new and enhanced roles for aged care providers in palliative care."; National Palliative Care Guide, p.15.

[4] National Health & Hospitals Reform Commission, p.23.

[5] Recommendation 9.4; Productivity Commission, p.LXV.

There is also a strong need for further training in the fundamentals of palliative care for GPs and community nurses through initiatives like the Program of Experience in the Palliative Approach (PEPA). Due to time and financial restraints, it is especially difficult for doctors to leave their practices to undertake necessary training and, perhaps even more importantly, to conduct costly and emotionally intensive house calls to dying patients. GPs also require better incentives to conduct home visits to dying patients to ensure that the outcomes of this training can be applied properly.

Staff members in residential aged care facilities also require regular, ongoing training in palliative care, especially in the area of effective communication with dying relatives and their families. A recent study on the adoption of a palliative approach in low care facilities highlighted that hostel staff are often unsure about how or when to begin talking about sensitive, end-of-life issues with residents and their families.[6] On-site training in aged care facilities would also benefit visiting medical and health professionals.

Recommendation 6: *That the Commonwealth reviews the adequacy of:*
(a) back-fill pay for GPs undertaking palliative care training through programs such as PEPA; and
(b)the Medicare items that reimburse doctors for case conferences and home visits to dying patients.

Recommendation 7: *That increased funding be provided to enable senior medical and nursing staff with specialties in palliative care to provide on-site, palliative care training in residential aged care.*

Recommendation 8: *That every Commonwealth-funded aged care facility be funded to establish an on-site palliative care nurse champion with appropriate training and support, who would be able to provide advice to other staff members within the facility and consult with specialists when necessary.*

Recommendation 9: *That the Australian Government provides further funding for the development of practical communication courses and scholarships for aged care staff and other health professionals to assist them in talking to residents/patients about care strategies and options at the end of life.*[7]

Advance care planning

At the moment, the forms and documentations for advance care plans vary not only from state to state, but also among different facilities and health services within the same state. This inconsistency adds to the existing confusion among clinicians and members of the general public about advance care planning. It is also important to consider the use of electronic recording forms, such as videos, to record individuals' wishes about advance care planning. This practice, which captures body language, facial expressions and tone of voice, is being used increasingly in other countries, such as the USA.

Recommendation 10: *That the Australian Government works with the states and territories to develop a unified, national system of forms and documentation for advance care planning, along with a public education campaign.*

Recommendation 11: *That nationally consistent policy and legislation for advance care plans include provisions and guidelines for the use of electronic recording forms.*

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[6] McVey, P., p.247.

[7] HammondCare employs specialists who have conducted research on communication around palliative care and are experienced in running these courses.

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