

Reforms to Human Services

Submission

February 2017



HammondCare

An independent Christian charity

About HammondCare

Established in the 1930s, HammondCare is an independent Christian charity specialising in dementia care, palliative care, rehabilitation, pain services and older persons' mental health services. HammondCare also operates a Centre for Learning and Research at Greenwich Hospital, enabling academic studies in areas of interest including palliative care research and practice.

HammondCare provides end-of-life care through a range of specialist palliative and supportive care services. The palliative care services we offer include inpatient care (Greenwich, Braeside and Neringah Hospitals in Sydney); community palliative care; palliative care clinical in-reach to public and private acute hospitals; end-of-life care in residential aged care homes; the Palliative Care Home Support Program (PCHSP) in seven NSW Local Health Districts; education and training services; and an online educational resource website (www.palliativecarebridge.com.au). HammondCare either directs, or partners in, a large number of palliative and supportive care research and service development projects, with a view to improving the person's quality of life and to assist their family. Details of HammondCare's research in palliative care can be found at the following webpage: <http://www.hammond.com.au/research/ResearchReport2015.pdf>

Last financial year, HammondCare supported 2,600 people through its palliative care services. We also provide data from the services we deliver to the Palliative Care Outcomes Collaboration (PCOC).

Contacts

Mr Stewart James

Head of Health and Hospitals
HammondCare

Prof Melanie Lovell

Senior Staff Specialist, Palliative Care
Medical Director, Greenwich Palliative and Supportive Care Services

Introduction

HammondCare agrees with the Productivity Commission's assessment that there is scope to improve the effectiveness of end-of-life care and welcomes the opportunity to provide feedback to this inquiry.

This submission contains feedback from HammondCare on end-of-life care, one of the six human service areas identified by the Productivity Commission in its Inquiry on Reforms to Human Services. It considers:

- Issues related to the potential for offering greater competition and choice in the delivery of end-of-life services.
- Ideas on opportunities for improving planning for end-of-life care by building awareness and improving staff training.
- An example of a commissioning and funding arrangement for end-of-life care in New South Wales that has proven effective in both metropolitan and rural settings, along with general principles from overseas.
- Suggestions on how end-of-life care could be better integrated into aged care settings.

It is critical that high quality palliative care is available in end-of-life care services for people who require it, wherever that care is provided, including in private homes, aged care homes, acute hospitals and specialist palliative care inpatient units.

The potential for offering greater competition and choice in end-of-life care

The Issues Paper is correct in stating that increasing user choice through contestability or competition is complex. HammondCare believes that any attempt to increase competition in this area requires careful consideration to ensure that the interests of end-of-life service users and their families are well served.

The Issues Paper notes that there is significant variability in access to high quality end-of-life care across different jurisdictions. In HammondCare's experience, services are inadequate in many rural and remote areas of Australia and the provision of around-the-clock services is also limited. Rural areas also have poorer access to specialist palliative care services which results in a greater reliance on general practitioners and community nurses, especially after hours, many of whom are not appropriately trained in the provision of palliative care. As a first priority, HammondCare believes it is critical to ensure equitable access to palliative care services throughout Australia.

When considering the contestability of end-of-life care services, it is also necessary to mention the vital role played by not-for-profit organisations in providing palliative care. Non-profits lead the way in providing palliative and end-of-life care in Australia, commonly propelled by a mission to serve the disadvantaged with care and to ensure equity of access for all people, regardless of their circumstances. Any effort to increase competition in the delivery of end-of-life care must recognise the expertise and experience of these not-for-profit organisations, as well as their past contribution and ongoing commitment to supporting people to die well.

Improving end-of-life conversations through awareness raising and training for healthcare professionals

While there is wide consensus about the benefits of advance care planning, available resources go widely unused and campaigns to normalise its practice have only resulted in minimal uptake. End-of-life conversations enable a person to define their goals and expectations for their future care and have been shown to improve patient and family satisfaction, reduce the use of aggressive and ultimately non-beneficial life-sustaining treatments (ACHR, 2016, 28) and also to reduce stress, anxiety and depression in surviving relatives (CDCP, 2016, 3).

Public Awareness: increasing uptake of advance care planning

Given these significant benefits, HammondCare supports the development and implementation of a national public awareness campaign encouraging people to talk about how they would like to die. A public awareness campaign of this kind would reduce stigma about death and dying, and help initiate discussions around advance care planning and end-of-life care services (PCA, 2011). Palliative Care Australia's 'Dying to Talk' campaign, with resources including a Discussion Starter package, a website, social media campaign and an art competition, serves as a prototype for this style of campaign.

While working to a small budget, the 'Dying to Talk' campaign reached a broad and interested audience during May 2016, with 700 radio ads played on metropolitan public radio and engaging over 190,000 people on Facebook and 65,000 on Twitter (PCA, 2016, 12).

In addition to encouraging the public to talk about death and dying, HammondCare encourages the promotion of advance care planning as normal practice across the primary, acute and aged care sectors. This would also involve addressing barriers to uptake, for example through achieving legislative consistency in regulations around advance care planning in different jurisdictions.

Training healthcare professionals to initiate end-of-life discussions

Understanding a patient's medical history and prognosis, healthcare professionals such as doctors, are often in the best position to identify those in need of end-of-life care. However, with limited training in advance care planning and end-of-life care communication, many doctors find it difficult to initiate or guide these conversations (Detering et al 2014, 1). Inadequate teaching and experience around palliation in the medical profession continues to be a major barrier to the provision of palliative care in Australia (Allen & Khan 2011, 25).

Over time a better understanding of the benefits of advance care planning has led to improved online resources to assist healthcare professionals prepare for, initiate and guide end-of-life care conversations. However despite their increasing availability, uptake has remained low and as a consequence, patients wishing to access advance care planning continue to miss out on a best practice approach.

Given the sensitive nature of such discussions, HammondCare believes that programs which engage healthcare professionals through multimodal learning are more likely to improve GP confidence and widespread adoption of advance care planning than purely self-directed, theoretical learning. There is evidence that creative, multimodal approaches to teaching around end-of-life care have been helpful in assisting students and healthcare professionals to understand

that palliative care is best delivered in a person-centred approach and not according to imposed formulas (MacLeod et al 2007).

Research has also shown that patients are less likely to take part in decisions about their care unless they perceive an open and comfortable relationship with their health professional (Bloomer et al, 2010, 734). While communication skills may improve with experience, interactive workshops can assist healthcare professionals to develop these skills and to gain the confidence to initiate end-of-life conversations. Learning should take different forms, involve active participation, have a problem-centred focus and consider a range of realistic and clinically relevant scenarios (Detering et al, 2014, 2).

One such example is the 'Next Steps,' multimodal program which was developed and studied in 2014 by researchers looking at the impact advance care planning educational programs can have on general practitioners. The studied program (approximately 3 hours) involved reading materials, DVD scenarios, e-simulation patient conversations, a workshop including role play and a training manual for future reference. The results showed significant improvement in self-reported confidence to undertake advance care planning conversations, and improved simulated ability to do so (Detering et al, 2014, 7).

HammondCare encourages similar approaches which utilise a range of stimuli and active engagement in varied scenarios to improve healthcare professionals' confidence in initiating and facilitating advance care planning conversations.

Which healthcare professionals?

In line with the Australian Centre for Health Research, HammondCare believes that end-of-life care is everyone's responsibility (ACHR, 2016, 6). All people, including families and friends, should be encouraged to talk about death and to remove the stigma attached to such conversations. Doctors typically have time and resource constraints that limit their ability to participate in end-of-life care training and to carry out the multiple conversations required for ongoing advance care planning (Bloomer et al, 2010, 734). While GPs must continue to play an important role in steering end-of-life conversations, other professionals such as nurses, are well-positioned to both identify those in need of end-of-life care and to facilitate discussions about patient goals and preferences for future care.

In 2016 HammondCare began delivering the Commonwealth Government funded *Palliative Care and Advance Care Planning in General Practice* program, with the aim of supporting GP nurses to identify patients who might benefit from early referrals to specialist palliative care services and to initiate conversations about end-of-life care. Given their active involvement in patient management within general practices, GP nurses develop trust through ongoing relationships with patients and carers and are ideally placed to detect worrying symptoms, conduct early advance care planning conversations and to identify patients who are at risk of dying in the next 12 months (CareSearch, 2014). The program includes three free online learning modules coupled with the Advance Project screening and assessment tools, as well as practical workshops and training. This program, in conjunction with the Advance Project training, has been endorsed by professionals, including GPs and GP nurses, and patients and their carers alike. However ongoing funding is needed to ensure momentum is maintained and to enable it to continue and to be expanded to other health professionals including GPs, primary health nurses and allied health professionals.

More broadly, HammondCare is committed to providing end of life care education to all health and aged care staff. In NSW, the HammondCare Consortium delivers the Palliative Care Bridge, a palliative care online education program with resources and educational videos by experts in the palliative care field. Training is also provided for community care workers, through the Palliative Care Home Support Program Care Worker Training. Since October 2013, 730 care workers have been trained in 312 rural and remote country towns across seven local health districts (LHDs).

Training for health and aged care staff should build on and supplement pre-workforce education. HammondCare commends investment into the Palliative Care Curriculum for Undergraduates (PCC4U) program, which targets health undergraduates and includes modules around communicating with people who have life-limiting illnesses. Similarly, for non-university trained health professionals, including care staff in residential aged care homes, HammondCare recommends that palliative care training courses be better promoted to increase uptake. The Program of Experience in the Palliative Approach (PEPA), funded by the Australian Government Department of Health, provides free palliative care workshops and placements in palliative care services. However, more needs to be done to increase uptake of such programs including through promotion and incentives for use.

Advance care planning for people with dementia

Where a person loses the ability to make or communicate decisions, they are more reliant on families and other carers to make those decisions for them. This can result in individuals receiving care that does not align with their previously expressed wishes (CDPC, 2016, 3). Encouraging advance care planning prior to, or soon after, diagnosis is especially important where there is increased certainty of inability to make decisions.

HammondCare is a partner in the Cognitive Decline Partnership Centre with The University of Sydney and has developed seven recommendations to ensure that the care wishes of people with dementia and other forms of cognitive decline can be known and upheld (see Attachment 1). These recommendations emphasise the importance of individuals receiving a timely diagnosis of dementia and information about their prognosis. This will improve understanding of the value of advance care planning and encourage its uptake for people with dementia and other forms of cognitive decline. In such circumstances, advance care planning should cover a range of issues over an extended period of time, and conversations should focus on understanding the individuals' values and beliefs beyond specific medical considerations. While the person receiving care should be involved in decision-making as much as possible, an early appointment of a substitute decision-maker is also critical, especially in the later stages of the prognosis.

The IDEAL project (Improving Dementia End-of-life Care at Local Aged Care) has also developed guidelines to facilitate case conferencing and person-centred decision making for people with Advanced Dementia. The guidelines include information about how to use 'triggers' to identify when a person can benefit from case conferencing and how to assess current needs and realise future goals of care.

These resources can improve end-of-life outcomes for people with cognitive decline, ensuring participation in the decision making of their future care to the extent possible.

End-of-life-care at home in Australia

The Australian and various state and territory governments currently fund a range of palliative care projects which focus on education, training, quality improvement and advance care planning. It is important that these funding arrangements target different settings, considering both urban and remote areas, and reflecting changing patient preferences. Currently, the majority of Australians die in hospital (54 per cent) or residential aged care homes (32 per cent), and only a small percentage (14 per cent) die at home (Swerissen & Duckett, 2015). Indeed Australian home deaths occur at less than half the rate of similar countries including Ireland, France, USA and New Zealand (Broad et al, 2013). However studies suggest that this is not reflective of patient preferences for place of death, and the increasing preference to die in a home setting (Scott, 2015, Rothman, 2014).

This is likely the consequence of a number of reasons including unarticulated patient wishes and a lack of resources and support services that enable patients to do so (Swerissen & Duckett, 2015).

The Palliative Care Home Support Program

Recognising this mismatch between patient preferences and the quantitative reality of deaths away from home, a HammondCare-led Consortium funded by the NSW Ministry of Health began providing the Palliative Care Home Support Program (PCHSP) in 2013. The Program is designed to supplement existing community palliative care services in seven local health districts across metropolitan, regional and rural NSW, by providing specially trained community care workers (CCWs) to support patients and their families at the end of life. CCWs receive the *Fundamentals of End-of-life Care*, a two day training workshop which includes the following:

- *Module 1: Essence of Palliative Care; Ethical issues in palliative and end-of-life care*
- *Module 2: Grief and loss; Self-care*
- *Module 3: Pain and symptom management; Last days*
- *Module 4: Communication*

This training equips CCWs with the skills necessary to provide care packages of up to 48 hours of flexibly delivered palliative care home support to referred patients and their families. The PCHSP training is also supplemented by the *Palliative Care Bridge*, an online portal with over 70 educational videos and resources by palliative care experts and specialists. The Palliative Care Bridge includes paper-based resources available to CCWs, practitioners and the public.

Key Program Findings

Between October 2013 and January 2017, the HammondCare consortium achieved the following results:

- 1,764 people (including seven paediatric patients) and their families were supported across seven local health districts (LHDs) in NSW with end-of-life care in their homes.
- The Program provided full coverage across three metropolitan LHDs and 267 towns throughout four rural LHDs. The most significant growth in activity was recorded in the Murrumbidgee (>600 per cent) and Western NSW (>300 per cent) LHDs.

- Nearly three quarters (73 per cent) of patients on the Program died at home, which compares very favourably with Grattan Institute findings that 70 per cent of people want to die at home, but only 14 per cent currently do.
- 730 care workers across the seven LHDs were trained.
- The reach of the PCHSP is currently just over four per cent (of deaths) across all serviced LHDs, with significant potential to scale-up the number of packages delivered and patients provided with a service.
- The cost of the provision of the PCHSP (not including existing services provided to the patient while in receipt of PCHSP) is about a third of the cost of substitutable inpatient palliative care.
- Families found the support of community care workers very beneficial and, in some instances, crucial for enabling end-of-life care in the home.
- Palliative care workshop training, provided as part of the Program, was well received by community care workers and was readily integrated into patient and family care.
- Local Health District Community Palliative Care Teams in both metropolitan and non-metropolitan areas recognised the benefits that community care workers provided to families and patients.

A more thorough breakdown of the results, including comparisons with the Palliative Care Outcomes Collaboration (PCOC) data can be found in HammondCare's Quantitative and Qualitative Evaluation report, July 2016.¹ This report was delivered to the NSW Ministry of Health in July 2016 and it is anticipated that an academic publication on the outcomes of the program is pending.

The PCHSP is a successful example of how flexibly delivered end-of-life support in a home setting can provide positive outcomes while remaining cost effective. It provides genuine choice and has been welcomed by both patients and their families. While the PCHSP is currently meeting around 4.2 per cent of need across the seven LHDs served by the program, conservative estimates on the number of people who have a preference for and would benefit from palliative care at home, suggest there is a potential target reach for a program such as the PCHSP for 35 per cent of deaths from all causes. There is a compelling case for ongoing program funding and the possible expansion of this program in other jurisdictions throughout Australia.

International experience

More broadly, cross-country case comparisons have revealed certain 'facilitators' of best practice service provision. Factors assisting best practice service provision included population ageing alongside advance care planning, dedicated and stable funding including the availability of specific caregiver benefits, integrated models of service provision and accountability through standards of practice and guidelines for palliative and hospice care (Klinger et al, 2014, 116). These factors help to indicate effective and efficient best practice approaches, which should be tailored according to Australia's own healthcare system and integrated services. For example, in Australia, funding for many existing palliative care programs is limited to less than three years and subject to variations, creating uncertainty and instability for providers. HammondCare calls for program funding over

¹ HammondCare can make the full report available to the Productivity Commission if desired on a 'not for citation' basis.

longer periods to enable better planning and ensure greater consistency of service and outcome delivery.

While each of these factors is essential, they remain insufficient without a concerted effort to align system-level characteristics such as legislation, regulation and financing (Klinger et al, 2014, 117).

Integrating end-of-life care into aged care settings

The integration of end-of-life care into primary health and aged care can be facilitated through improved resourcing for the adoption of a palliative approach in aged care settings. In 2011, the Productivity Commission noted that palliative care is 'core business' for any aged care system. HammondCare supports this statement and has integrated a palliative approach into its residential and home care services, in addition to acquiring several sub-acute hospitals providing in-patient palliative care. This integration of services allows elderly people who require pain management and palliation, greater choice in the setting and provision of their care. It enables continuity of care in a setting that is familiar to the person and reduces distress and suffering by minimising transitions between care settings.

Residential care

While evidence shows that around 70 per cent of people who die each year would benefit from palliative care (Alzheimer's Australia, 2013, 13), the Australian Institute of Health and Welfare demonstrated that only 22 per cent of permanent aged care residents who died in 2010-2011 received palliative care services (AIHW, 2012). Residential aged care homes have thus been identified as one of the settings which require improved access to specialist palliative care services (NHHRC 2009, in AIHW, 2012, 40).

Recognising the need for greater integration of aged care and health services, HammondCare opened the Lavender Palliative Care Suite as an innovative, integrated service within an existing HammondCare residential home, Bond House. The specialist palliative care unit supports up to nine people who have been diagnosed with a life limiting disease and have an estimated prognosis of less than 12 months. The Suite enables personalised and flexible care routines, and comprehensively provides for residents' individual physical, psychological, social and spiritual needs. Families and carers are also supported through a 24/7 visitation policy, a fold-up bed within the residents room for overnight stay, emotional support to families before the death of a loved one and bereavement support provided after death.

Lavender Suite operates a fully integrated service and utilises a multi-disciplinary approach to care. Close links are established with HammondCare Braeside Hospital Palliative Care Inpatient Unit (in nearby Prairiewood), HammondCare Clinical Training Centre (Hammondville) and the South West Sydney Local Health District palliative care team, including a 24-hour palliative care telephone advisory service. The Suite has its own in-house pharmacy licence to access emergency palliative medications, and staff also have direct access to other HammondCare specialists including pain management specialists, nursing and allied health services. While residents and families partner with staff to develop care plans and Advance Care Directives for end of life care, weekly case conferences are also conducted and are attended by a Palliative Care Specialist and Registrar from Braeside, local GPs and relevant specialists.

HammondCare's Lavender Palliative Care Suite is now a tried and tested model, with an internal evaluation revealing predominantly positive responses from staff, residents and their families. This included high levels of satisfaction with quality of care, flexibility of care, flexibility for visitation and highly responsive communication of staff. The model not only demonstrates how specialised palliative care can be delivered within an existing residential aged care setting, but also demonstrates the advantages of a residential aged care setting. However, despite its successes, there are currently no mainstream funding programs to support such models. Funding should be provided to encourage the development and sustainable implementation of innovative approaches to palliative care, especially when there is evidence that demonstrates they are successfully achieving best outcomes for all involved.

References

- Allen S & Khan K, 2011. 'Exploring barriers to the provision of palliative care in Australia,' *Australian Medical Student Journal*, 2 (2); 25-28.
- Alzheimer's Australia, 2013. Report, Paper 37: 'Quality of Residential Aged Care.' Accessed at: <https://www.fightdementia.org.au/sites/default/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-37.pdf> [Accessed 4 January 2017].
- Australian Centre for Health Research (ACHR), 2016. 'Conversations: Creating Choice in End-of-life Care': <http://www.achr.org.au/wp-content/uploads/2016/02/Conversations-Choice-in-End-of-Life-Care-ACHR-20161.pdf>.
- Australian Institute of Health and Welfare (AIHW), 2012 (Cat. no. HWI 120. Canberra: AIHW). Media release: 'Palliative care services in Australia 2012': <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737423346> [Accessed 4 January 2017].
- Bloomer A, Tan H and Lee S (2010), 'End-of-life care, the importance of advance care planning,' *Australian Family Physician*, Vol 39 (10).
- Broad JB, Gott M, Kim H, et al. 2013, 'Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential care settings in 45 populations, using published and available statistics'. *International Journal of Public Health*, No, 58, pp. 257-267.
- CareSearch. 2014. *Advance: Initiating Palliative Care and Advance Care Planning: Training and Resources for General Practitioner Nurses*. [ONLINE]: <https://www.caresearch.com.au/caresearch/tabid/4079/Default.aspx> [Accessed 11 January 2017].
- Cognitive Decline Partnership Centre (CDPC), HammondCare (January 2016) 'Future Planning and Advance Care Planning': http://sydney.edu.au/medicine/cdpc/documents/resources/J000606_CDPC_reportFinal_update2016WEB.pdf [Accessed 4 January 2017].
- Detering K, et al (2014) 'Teaching general practitioners and doctors-in-training to discuss advance care planning: evaluation of a brief multimodality education programme,' *BMJ Supportive & Palliative Care*.
- Klinger C, Howel D, Zakus D, Deber R, (2014) 'Barriers and facilitators to care for the terminally ill: A cross-country case comparison study of Canada, England, Germany and the United States,' *Palliative Medicine*, Vol 28 (2).
- MacLeod, R., Spruyt, O., Hudson, P., 2007. 'Australia and New Zealand', in Bee Wee, Nic Hughes (eds.), *Education in Palliative Care*, United Kingdom: Oxford University Press, 59-68.
- Palliative Care Australia, 2011. Position Statement: 'Euthanasia and Physician Assisted Suicide: Position Statement': <http://palliativecare.org.au/wp-content/uploads/2015/08/PCA-position-statement-Euthanasia-and-Physician-Assisted-Suicide.pdf> [Accessed 4 January 2017].
- Palliative Care Australia, 2015. Media release: 'Talking about death and dying important': http://palliativecare.org.au/wp-content/uploads/2015/11/2015092015_euthanasiadebate_final.pdf [Accessed 11 January 2017].

Palliative Care Australia, 2016. Annual Report: 'Palliative Care Australia Annual Report 2015-2016': http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2016/10/Annual-Report-Final-2016.pdf [Accessed 11 January 2017].

Rothman D, 2014, 'Where we die', *New England Journal of Medicine*, No. 370:pp.2457-2460.

Scott K, 2015, 'Dying at home more peaceful than in hospital and better for loved ones, research finds', ABC, [ONLINE]: <http://www.abc.net.au/news/2015-10-11/dying-at-home-more-peaceful-than-in-hospital-study-finds/6844746> [Accessed 4 January 2017].

Swerissen H and Duckett S, 2015, 'What can we do to help Australians die the way they want to?', *Medical Journal Of Australia*: <https://www.mja.com.au/journal/2015/202/1/what-can-we-do-help-australians-die-way-they-want> [Accessed 4 January 2017].