

17 April 2019



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Health, Communities, Disability Services and
Domestic and Family Violence Prevention Committee
via email: careinquiry@parliament.qld.gov.au

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Thank you for providing AMA Queensland with the opportunity to provide a submission to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee's (HCDSDFVPC) inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

AMA Queensland is the state's peak medical advocacy group, representing over 6000 medical practitioners across Queensland and throughout all levels of the health system. We are strong advocates for increased funding and access to palliative care, and the greater uptake of end of life care planning.

Palliative Care

Our health care system must give people the opportunity to die with dignity and with minimal suffering. Access to medical practitioners is a fundamental factor influencing access to and choice of appropriate palliative care. The demand for quality palliative care in all health care settings is increasing as our population ages.

Sadly, evidence provided to a Queensland Parliamentary committee in 2013 indicated there was significant unmet need for palliative care in Queensland and that this need was continuing to grow. Access to palliative care services was deemed to be largely based on three factors, namely the patients age, location, diagnosis and cultural background and the level of education of their health care professional.¹ Specialist services are "understaffed, under-resourced, mostly have insufficient beds, and do not have the capacity to provide adequate community care and after-hours cover."²

Reliable data on the use and uptake of palliative care is difficult to come by given a lack of data on funding an expenditure on palliative care at a state level³. Interestingly, the 2013 Parliamentary inquiry also noted this difficulty and recommended that Queensland Health undertake a state-wide assessment of palliative care needs. Despite AMA Queensland's best efforts, we have not been able to ascertain whether this recommendation, which was accepted by the Government of the day, was ever undertaken. If this assessment was never undertaken, we urge the HCDSDFVPC to make a recommendation that a review be undertaken, and that this data be released publicly within 12 months.

What is clear is that there is a significant unmet need for palliative care services in Queensland today. Both the Queensland and Federal Governments should share equal responsibility for remedying this by ensuring the provision of comprehensive palliative care services to all Queenslanders, within a coordinated, strategic framework. Emphasis should be placed upon the need for the provision of adequate long-term and recurrent funding to enable the implementation of a sustainable, equitable palliative care policy for Queensland. We call upon the Queensland Government to establish as a priority the infrastructure necessary to enable health care providers to address with efficiency and compassion the growing need for palliative care services in Queensland.

¹ Health and Community Services Committee, *Palliative and Community Care in Queensland: towards person-centred care*, Queensland Parliament, May 2013

² *ibid*

³ Australian Senate Committee Inquiry, *Palliative care in Australia*, 50–53

AMA Queensland advocates for the provision of a variety of palliative care services to allow maximum flexibility with regard to care options, and maintains that continuity of care is pivotal to the effective management of palliative care patients. We would also like to see an understanding of the palliative care needs of patients with particular disease entities, and we uphold the need for a culturally sensitive approach to the provision of palliative care to Aboriginal and Torres Strait Islander communities and people from non-English speaking backgrounds.

AMA Queensland believes the coordination and resourcing of palliative care services in Queensland should and would be best performed by designated multi-disciplinary palliative care service units. Importantly, these units should be led by a medical practitioner as they play an instrumental role in all aspects of palliative care. Specialist doctors, including palliative care physicians, oncologists, geriatricians and general practitioners provide palliative care directly to patients. They work with nurses, allied health professionals, carers and families to plan, deliver and support patient care.

Each palliative care unit should be responsible for a specific geographic region and should coordinate and resource palliative care services within that region, based on evident need, ideally determined by means of targeted research.

These units should facilitate the implementation of community-based palliative care models, providing a training, consultation and respite resource for community and other-hospital based palliative carers within designated geographic regions, as well as each providing a domiciliary visiting team to support General Practitioners and domiciliary nurses within their designated community.

Community care should be provided by integrated teams of community-based carers, led by a well-trained, palliative care general practitioner and consisting of appropriately trained and experienced nursing, allied health and volunteer staff.

Care should be provided in the location of choice wherever possible. Within that environment, there is a place for inpatient hospice units which could be freestanding or attached to other hospital and/or community services. These units would have a supra-regional role.

Each major training hospital should be resourced to set up a highly skilled palliative care team within a specialised dedicated Palliative Care Unit. Although hospital-based, these teams should support and work within the framework of the community-based palliative care model.

AMA Queensland recognises the need for and strongly promotes specialised palliative care training and education. Access to this training and education should exist for all providers of palliative care within the medical, nursing and allied health professions, as well as within the community generally. The special training needs of volunteer palliative carers should also be taken into account.

We also support the training of a number of general practitioners to take a leading and informed role in facilitating a greater palliative care participation and commitment of their GP colleagues. These practitioners would provide an interface between other General Practitioners, domiciliary nursing and specialised palliative care services, as well as hospitals, nursing homes and other groups involved in professional care. Further, we believe as many GPs as possible should receive sufficient basic palliative care training to enable them to provide high-quality and effective care to palliative patients.

Palliative Care and its interface with Aged Care

Today many patients receiving palliative care, who are too ill to live in their own homes, reside in residential aged care facilities (RACFs). Feedback from AMA Queensland's General Practitioner members indicates the medical care offered to patients who move into RACFs is fractured and difficult to access.

When a patient moves into an RACF they lose a large part of their independence, including the opportunity to visit their own GP.

GPs report that they find it extremely difficult to treat their patients in RACFs due to limited organisational support at some RACFs and poor financial incentives. Many GPs are forced to relinquish

giving care to these patients. Other GPs provide extra, unpaid, work to patients and their families by writing prescriptions out of hours and providing bereavement support.

This is not a sustainable model of care. GPs need to be supported to provide care to patients in RACFs. The Queensland Government should lobby the Commonwealth Government for increased Medicare payments for GPs and other allied health groups to provide palliative treatment to patients in RACFs. Increased medical treatment in RACFs is an efficient way of treating patients and will relieve pressure on acute treatment beds in hospitals.

End of Life Care

Advance care planning is a vital tool in ensuring that Queenslanders receive the care that they want at the time of their choosing. Despite the importance of this planning and the concept having existed since the early 1970s, there is an extremely low uptake rate in Queensland. This is likely due to a variety of barriers such as;

- **Avoidance of acknowledging death and dying:** The predominant barrier to effective advance care planning is the societal, and cultural, stigma attached to discussions around death. Despite being a universal health outcome many of us refuse to think of our own mortality, or serious illness, until it is too late. Most individuals, including clinicians, prefer to avoid thinking and talking about death.⁴ There can also be cultural factors, where clinicians are unsure of how to raise the topic for fear of touching on cultural taboos. Advance care plans are most effective where they are made when the principal is healthy and has capacity.⁵
- **Uncertainty about when to initiate ACP discussions:** Clinicians can be unsure of when to start discussing advance care planning with patients. If the discussion is held too early it can undermine the patient's coping strategies or deter them from participating in self-management activities.⁶ Compounding this, intuitive prognostications can be inaccurate and struggle to provide clear timelines within which advance care planning can occur.⁷ These factors can delay clinicians discussing advance care planning with patients until it's too late.
- **Uncertainty about who should initiate ACP discussions:** There also remains the issue of who should initiate the advance care planning discussion. Where there are complex co-morbidities there may be several members of the treatment team that are each waiting on the other to initiate the conversation. The general practitioner, who in many cases has known the principal for the longest period, could be waiting for the specialist to raise the issue. The specialist, who is managing the condition that requires advance care plans, may feel that it is inappropriate to raise it given their comparatively limited engagement with the patient. Both clinicians may be waiting for the principal, and their family, to raise the issue. The end result is that the treating team doesn't have the vital discussion of advancing care planning before it's too late because they all believe it's more appropriate if someone else raises it.⁸
- **Final copy of an advance care plan:** Even where a principal has made a legally valid advance care plan there are difficulties over providing the treating clinicians with a copy. While a will can be kept at a safety deposit box, to be retrieved by the executor of the estate as necessary, it is counterproductive to store an advance care plan in the same manner. Treating clinicians either have no advance care plan, where one exists, or an old or outdated care plan. These inconsistencies erode confidence in their usage as clinicians instead revert to standard clinical guidance, even if it is contrary to the wishes espoused in the inaccessible advance care plan.

⁴ Scott, I, Mitchell, G, Reymond, E, Daly, M, *Difficult but necessary conversations – the case for advance care planning*, Med J Aust, 2013

⁵ Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012, p1030

⁶ Ibid 1031

⁷ Scott, I, Mitchell, G, Reymond, E, Daly, M, *Difficult but necessary conversations – the case for advance care planning*, Med J Aust, 2013

⁸ Ibid.

Cultural considerations also present another possible barrier to full implementation of advance care planning. As a society with a plurality of cultures, a “one size fits all” approach is impossible to achieve. For instance, in Navajo culture, an important concept is “*Hozho*”, which involves harmony, goodness, positive attitude and universal beauty. Negative thoughts of death and illness raised in discussions about advance care planning can potentially conflict with this philosophy.⁹ As another example, in East Asian cultures it is widely regarded as inappropriate and wrong to talk about diagnoses of end-stage illnesses, such as cancer. And in a small descriptive study of Aboriginal people living in the Northern Territory, researchers found if information was not communicated in the “right way” through the “right story” to the “right people,” the sick person could be left frightened and anxious.¹⁰

Research has also shown patients of minority cultural and language backgrounds are fearful that if they complete advance care plans and advance directives in a mainstream health care context, they may be left to die in instances where further medical intervention could improve their health outcomes. Thus, they hold fears that not only might they not benefit from policies on advance care planning and advance directives but that these might actually work to their detriment.¹¹

The lack of appropriate resourcing, confusion and inconsistency that surrounds such an important concept in end-of-life planning is leading to poor outcomes for Queenslanders and their families. While studies have shown most Australians would prefer to die at home, the reality is that most will die in acute care hospitals.^{12 13} Doctors report that too many people are entering hospitals at the end of their lives without having planned the type of care they would like to receive or discussed their preferences for quality of life with their families. Indeed, almost one quarter of intensive care beds are occupied by patients receiving potentially inappropriate care, while up to a quarter of total health budgets are spent on inpatient care during the last 18 months of life without extending overall survival or impacting on quality of life.

AMA Queensland recognises and acknowledges the hard work of other stakeholders in the space, including the Queensland Clinical Senate, in identifying the barriers to an effective end of life care sector. We believe the following measures, in broad consultation with other relevant stakeholders, are necessary to position Queensland as the national leader in end of life care planning.

Improved Education: To address the cultural and societal stigma with regards to death and dying the Queensland Government must invest in a public education campaign to improve health consumer literacy and knowledge about the issue. This program should endeavour to normalise discussions about advance care planning among a variety of cultural and societal groups. This should include, but not be limited to:

- An education campaign targeted directly at residents of aged and retirement homes
- An education campaign, delivered in partnership with peak representative bodies, targeted at distinct cultural groups such as the Aboriginal and Torres Strait Islander populations; and
- An education campaign to help reduce the stigma of the discussion in regional and rural centres.

To help equip clinicians with the skills and training to have these discussions the Queensland Government, in consultation with AMA Queensland, should invest in the design, piloting and roll-out of an integrated multi-disciplinary education program for clinicians, designed by clinicians, on advance care planning. This program will help ensure they are conversation ready.

⁹ *Culture, Ethics and Advance Care Planning*, A.H Swota, <http://goo.gl/PXc2TE>

¹⁰ *Journal of Transcultural Nursing, Ethics and Advance Care Planning in a Culturally Diverse Society*, Megan-Jane Johnstone and Olga Kanitsaki, 13 July 2009, <http://goo.gl/6CGWDK>

¹¹ *Journal of Transcultural Nursing, Ethics and Advance Care Planning in a Culturally Diverse Society*, Megan-Jane Johnstone and Olga Kanitsaki, 13 July 2009, <http://goo.gl/6CGWDK>

¹² Media Release: We need to talk about dying – survey. Palliative Care Australia May 2011.

<<http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf>> Accessed 20 March 2014.

¹³ Lorna K Rosenwax, Beverley A McNamara, Kevin Murray, Rebecca J McCabe, Samar M Aoun and David C Currow. Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care. *Med J Aust* 2011; 194 (11): 570- 573

Improved Multidisciplinary Guidelines: The Queensland Government should task Queensland Health and the Queensland Clinical Senate, to develop a comprehensive set of guidelines as to when clinicians should discuss advance care planning with their patients. The objective should be to allow clinicians to refer to a well-established set of guidelines when they initiate these discussions and to comfort their patient that these constitute professional best practice. These guidelines could focus on indicators such as number of hospitalisations within the preceding 12 months, or other certain diagnoses. This should help alleviate some of the anxiety over the appropriate time to have the conversations.

The Queensland Government should also commit to discussing, with the Federal Government, the establishment of dedicated MBS rebates to properly remunerate clinicians for taking the time to step through advance care planning with their patients. While AMA Queensland does not believe that clinicians are currently neglecting this planning for financial reasons it is important that they are appropriately compensated for having difficult conversations that can reduce the burden on the health system.

Improved Accessibility and Reliability: If clinicians are to use advance care plans they must have confidence that the document in front of them is the true and final record of the patient's wishes. The form must also be straight-forward enough so as to allow any principal to accurately complete an advance health directive that is simultaneously robust enough so as to provide instructions on the elements of their care that is important to them and their family. The Advance Care Directive, as utilised by Tasmania, provides a clear example of how a form can be designed that fulfils both these requirements.¹⁴ Queensland's forms are, by comparison, much more complicated.¹⁵ AMA Queensland strongly recommends the Queensland Government adopt a similar format to make it simpler and easier for principals to complete these forms and, ultimately, improve completion rates of Advance Care Directives.

While there is protection for clinicians from liability in those circumstances where they can't access the latest copy of the principal's advance care plan, the treatment team must be confident that they can access the final copy of the document where necessary. The Queensland Government should commit to establishing a central registry for advance care plans in Queensland: Queensland must follow the lead of Tasmania and establish a central registry for advance care plans that clinicians can quickly and easily access. This registry should be housed within the Department of Justice and Attorney-General and be accessible by hospital and health services, aged care facilities, and the broader palliative care sector. To ensure that the records within this registry are contemporaneous the Queensland Government should consider amending the *Powers of Attorney Act 1998 (Qld)* to only allow advance health directives to be legally binding once they are validly filed in the registry. This should be matched with funding to ensure the service is appropriately resourced to deal with demand effectively and efficiently.

Voluntary Assisted Dying

AMA Queensland will be deciding our position on voluntary assisted dying (VAD) when the Council of AMA Queensland meets to decide the position on 17 May 2019. In particular, Council will consider whether to uphold the position reached in the AMA Federal's position statement on this issue, which states, "that doctors should not be involved in interventions that have as their primary intention the ending of a person's life. This is separate and distinct from administering treatments or other actions intended to relieve symptoms which may have a secondary consequence of hastening death."

AMA Queensland understands that we have been given an extension to submitting our formal response on VAD to the Inquiry until Monday, 20 May 2019.

¹⁴ Advance Care Directive for Care at End of Life (Tasmania), <http://bit.ly/1Po2gcl>, Accessed August, 2015

¹⁵ Advance Health Directive, <http://bit.ly/1N6opOn>, Department of Justice and Attorney-General, Queensland Government, August 2015

AMA Queensland thanks you for providing us with the opportunity to provide you with a submission on this consultation paper. If you require further information or assistance in this matter, please contact Mr Jeff Allen on (07) 3872 2262.

Yours sincerely

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