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14 January 2023

Mr Chris Leahy
Acting CEO
Australian Commission on Safety and Quality in Healthcare
GPO Box 5480
Sydney NSW 2001

Via email: mail@safetyandquality.gov.au

Dear Mr Leahy,

RE: National Consensus Statement: Essential elements for safe and high-quality end-of-life care.

The Royal Australian College of General Practitioners (RACGP) thanks the Australian Commission on Safety and Quality in Health Care (ACSQHC) for the opportunity to provide feedback on the consultation draft of the National Consensus Statement: Essential elements for safe and high-quality end-of-life care (draft National Consensus Statement).

Palliative and end-of-life care is a fundamental component of general practice. The number of patients seeking general practitioner (GP) care at the end of life is increasing, due to multiple interacting factors including an ageing population and a growing number of patients with progressive, chronic and life-limiting diseases.[1] Guidance on end of life care is provided by the RACGP in the RACGP *Aged care clinical guide* (Silver book), in particular Part-A - Palliative and end-of-life care.

We acknowledge and appreciate the hard work that has gone into updating the draft National Consensus Statement and provide the following comments for your consideration.

1. **Guiding Principles (page 7)**

The list of guiding principles on page 7 are appropriate and comprehensive. The ten essential elements (from page 8) refer to the importance of access to medical devices, medications and suitable living environments in order to support dignified and comfortable end-of-life care. The RACGP recommends these issues should also be included as a guiding principle because without these provisions, health practitioners struggle to provide effective palliative care.

2. **Essential Elements**

   a. **Essential element 1: Recognising end of life (page 9)**

Essential element 1 speaks of *"the referral criteria, processes, and timelines for accessing specialist palliative care services"* (page 9). It is important to also highlight that existing access gaps for specialist palliative care should be identified and addressed by governments. This should include monitoring and accountability for states and territories to address these access gaps.

Furthermore, as it is currently complex for GPs and their patients to navigate the range of services that are available, the RACGP also recommends investment in the provision of service directories and care coordinators to assist patients with the appropriate services.

b. Essential element 2: Person-centred communication and shared decision making (page 11)

As with all good medical practice, end-of-life care should be patient-centred. Compassion, dignity, respect and participation in decision-making are important to the delivery of high-quality palliative and end-of-life care.

To facilitate a patient-centred approach, there should be open and informed communication between GPs and patients, their families, carers and the people nominated to make treatment decisions where applicable. This should be an ongoing conversation, covering topics including goals of care, advance care planning, prognosis, and symptom-control measures. The RACGP recommends including a discussion about the resources available to the person receiving palliative care in **element 2.5.** This should include financial resources, level of family support and capacity to remain at home.

Element 2.6 is unclear and should be re-worded to make the responsibility for the role more explicit. It is not clear who is responsible for providing the patient with the required written information. The RACGP recommends, where possible, the patient's GP should be responsible for leading and coordinating their patient's care. If another health professional is the care coordinator, the patient's GP should always be included in discussions.

c. Essential element 3: Multidisciplinary collaboration and coordination of care (page 14)

Optimal end-of-life care is often delivered by a multidisciplinary team in a shared-care arrangement. In many cases, this will be coordinated through a general practice and may be augmented by specialist palliative care services where needed. Continuity of care is maintained across settings and between services when GPs work closely with palliative care and other service providers, including other health practitioners, Aboriginal and Torres Strait Islander health workers/health practitioners, pastoral care workers, and residential aged care facility (RACF) staff where relevant.

For example, if a patient is discharged from a hospice because they have exceeded the allowed day limit for hospice care, prompt communication with the patient's GP helps ensure appropriate follow up. This communication does not always occur. Similarly, GPs should be informed of the services that the outreach palliative care team is offering, as the patient's GP is usually the local community medical lead, and often the point of reference for both the patient and their family. It is important the GP is aware of the plans and processes taking place. Patients are up to four times more likely to die in their preferred setting when GPs are informed of their preference in the end-of-life phase.[2] Following a patient's death, their GP is usually involved in providing bereavement care to family and carers.

The RACGP recommends the definitions of 'nurse navigator' and 'Namaste Care' is included within the document glossary.

d. Essential element 4: Comprehensive care (page 16)

The RACGP recommends that essential element 4 includes active deprescribing as a component of comprehensive care. Deprescribing is a positive, patient-centred intervention, conducted under medical supervision, that reassesses the role of all medicines with a view to stopping those with no clear benefit, may cause harm, are being used for an indication that is no longer an issue and no longer fit with the current goals of care.[3] The process entails stepping down and ultimately ceasing medication.

A written tapering plan has the potential to optimise the patient's quality of life by reducing medications that are no longer appropriate in their clinical context.[4,5]

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Essential element 4 also states that 'psychosocial, spiritual, cultural and emotional support' is offered. The document should make it clear that this may not necessarily be the remit of the healthcare professional, particularly spiritual and cultural support.

e. Essential element 5: Responding to concerns (page 18)

The RACGP recommends Medicare item numbers 160-164 (Prolonged professional attendance when a patient is in imminent danger of death) are amended to make it clear that these items are available for palliative care, and not just urgent life-saving care.

f. Essential element 9: Evaluation, audit and feedback (page 24)

Whilst the revised draft of the national statement was to encompass all services where healthcare is provided to people approaching end of life, Essential element 9 appears to be written from a hospital provider perspective and does not reflect the different types of evaluation, audit and feedback that primary care services might use to reflect and review end-of-life care. For example, significant event analysis by GPs, facilitated by Primary Health Networks could identify system access barriers faced by GPs trying to assist patients in dying well. This example outlines a collaborative initiative for quality improvement with GPs involved in end-of-life care. The RACGP recommends measures of the safety and quality of end-of-life care include methods other healthcare settings may use to evaluate end-of-life care.

When evaluating care, it is important that information collected by healthcare providers is a representative sample of all potential cases. There is potential for selection bias if healthcare providers themselves choose which families/patients to talk to about their experience with palliative/end-of-life care.

Thank you again for the opportunity to provide feedback on the consensus statement. For any enquiries regarding this letter, please contact Stephan Groombridge, National Manager, Practice Management, Standards & Quality Care on 03 8699 0544 or stephan.groombridge@racgp.org.au.

Yours sincerely

Dr Nicole Higgins
President

References

1. The Royal Australian College of General Practitioners. Aged care clinical guide (Silver book), Part A Palliative and end of life care. East Melbourne, Vic: RACGP, 2019. Available at: https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a/palliative-care. [Accessed 15 December 2022]

2. The Royal Australian College of General Practitioners. Voluntary assisted dying legislation. East Melbourne, Vic: RACGP, 2019. Available at: https://www.racgp.org.au/advocacy/position-statements/view-all-position-statements/clinical-and-practice-management/voluntary-assisted-dying-legislation [Accessed 15 December 2022].

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3. The Royal Australian College of General Practitioners. Aged care clinical guide (Silver book), Part A Deprescribing. East Melbourne, Vic: RACGP, 2019. Available at https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a/deprescribing. [Accessed 15 December 2022]

4. Primary Health Tasmania. Deprescribing resources. Hobart: PHT, 2019. Available at www.primaryhealthtas.com.au/resources/deprescribing-resources. [Accessed 15 December 2022]

5. National Health Service Scotland. Polypharmacy Guidance – Medicines Review. NHS Scotland, 2019. Available at www.polypharmacy.scot.nhs.uk/polypharmacy-guidance-medicines-review/for-healthcare-professionals/hot-topics/medication-in-thefrailest-adults. [Accessed 15 December 2022]