

## Advice

# Living as well as possible, until the end

## Introduction

Throughout 2017 there was increased community and health sector attention on Victoria's end of life care services. This focus occurred in the context of the now introduced *Voluntary Assisted Dying Act 2017*.

At the Victorian Clinical Council meeting held 7 December 2017, the council seized the opportunity created by these discussions to provide topical and timely advice on this important area of health care.

The Department of Health and Human Services and Safer Care Victoria's Palliative Care Clinical Network have undertaken significant work to support access to and improve the quality of end of life and palliative care services for Victorians.

In 2016, the department released Victoria's end of life and palliative care framework. The framework acknowledges that changing community expectations about care and Victoria's rapidly growing population means that it is no longer possible to leave end of life care to specialist palliative care providers. It states, amongst other things, that end of life care should be everybody's responsibility and that end of life and palliative care models must support the realisation of people's choices about the care they receive as they approach the end of their lives. The department continues its program of work to implement this framework.

The Palliative Care Clinical Network provides clinical leadership, expertise and advice to Safer Care Victoria and works to identify, implement and deliver best practice palliative care to Victorians with a life-limiting illness.

Priority projects for the network include:

- standardising the approach to prioritising access to palliative care
- improving the recognition and care of the actively dying person
- supporting clinical recognition of people with a life limiting illness and their referral to palliative care services.

## Recommendations

### Recommendation 1: Develop an end of life and palliative care capability framework

The council endorses the development of a capability framework and recommends that the framework is tied to a toolkit of established resources<sup>1</sup>. The capability framework should cover, as a minimum:

- triggers for end of life care conversations, such as advance care planning, with a person and their significant other/s. Whilst triggers are outlined in Victoria's end of life and palliative care framework, it would be useful to specify the following for primary care: the 45-49 year old check-up, over 50 year old health assessment for Aboriginal and Torres Strait Islander people, the 75 year old health assessment, as well as admission to aged care.
- expectations for the degree of palliative care service provided by generalist, non-palliative care clinicians in the community, primary care and acute settings. Consideration should be made for the particular needs of people in rural areas to access the care they need.
- guidance on assessment and referral requirements to specialist palliative care services. This may include clear stipulation of triage guidelines.
- how the system will flexibly adapt to changing care preferences of a person who is actively dying.
- workforce implications, including: actions to address the end of life care health literacy gap for generalists; and training and resource requirements for generalists to embed end of life and palliative care skills into everyday practice.

### Recommendation 2: Address critical workforce knowledge and skill gaps

The council recommends targeted efforts be undertaken to improve:

- clinician ability to conduct early, quality end of life care discussions. In particular:
  - supporting access to materials for clinicians across primary, community and acute services to conduct end of life care conversations with the dying person and significant others and with the community more broadly. Training and support materials should also support culturally appropriate engagements with the Aboriginal and Torres Strait Islander community and culturally and linguistically diverse groups
  - ongoing support for the Compassionate Communities approach to improving health literacy and the appropriateness of end of life care in the community
- clinician access to a person's end of life or advance care plan and goals of care through My Health Record

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<sup>1</sup> Resources including those found at: CareSearch - Palliative care knowledge network; Program of Experience in the Palliative Care Approach (PEPA); and other tools such as the Supportive and Palliative Care Indicator Tool (SPICT) and Care plan for the dying person.

- understanding and use of common end of life and palliative care terminology. Despite clear definitions in Victoria's end of life care and palliative care framework for example, there is great variability in how the terms end of life care, palliative care and specialist palliative care are used and understood
- appropriate concurrent provision of curative and end of life care by building awareness and skill in identifying a person who is at risk of dying or who is actively dying
- undergraduate and post-graduate exposure to generalist and specialist palliative care services. The council acknowledges that until end of life and palliative care becomes everyone's business, there will not be sufficient placement opportunities to support undergraduate and post-graduate skill development in this area.

### **Recommendation 3 – Embed a culture that strives for better end of life care**

The council acknowledges the challenge faced by the department and the sector more broadly to make end of life care everyone's business. The council recommends:

- the department capitalise on all opportunities within its end of life care program to embed system-wide ownership of a person's end of life care needs. Workforce, organisational and system culture change requirements will need consideration
- that person and family experience underpins the work of the department in designing the system to support end of life care for all Victorians.

### **Recommendation 4 – Develop metrics that ultimately support people to live well until the end**

#### **Metric purpose**

The council supports the use of metrics that:

- promote end of life care being everyone's business and inform a shift of care to the community and primary care settings.
- provide insight into the quality of care and of outcomes for people and their family or carer/s, including measures around care provision according to a person's preferences or values.
- aid decision making for services and clinicians that will drive on-going improvements locally and across the system
- provide insight into the end of life and palliative care services delivered by non-specialist services and clinicians
- broaden the current focus of patient experience beyond that of pain management to include measures that cover a range of typical symptoms such as anxiety and breathlessness.

## **Metric recommendations**

The following metrics represent a minimum set recommended by the council, with other measures to be informed by the Palliative Care Clinical Network's Insight group and other stakeholders:

- percentage of people dying in place of choice. The council acknowledges the issues regarding this metric, in particular, the potential for changing care needs and preferences when someone is actively dying; however, other jurisdictions have made significant progress against this type of metric. The aim for Victoria should be for specific year on year improvement.
- proportion of last six months of life spent at home or in a community setting. This metric will more accurately reflect the ability of the system to support the person to remain in their place of choice during their final months.
- a family or carer type of reported outcome measure. This measure would seek to understand whether the family or carer believed that the care delivered improved quality of life, function, symptom management and other factors important to the dying person.
- clinical indicators for pain. This metric is currently measured against specialist palliative care services. The council recommends that symptom management related measures be applied more broadly into the non-specialist, generalist space.
- percentage of actively dying people with a care plan for the dying person in place. This measure reflects the National consensus statement: essential elements for safe and high-quality end-of-life care, which is considered best practice.

## **Recommendation 5 – Implementation of council recommendations and the broader end of life and palliative care program**

Successful implementation of these recommendations and the broader end of life and palliative care program requires partnership and shared responsibility for outcomes across the department, Safer Care Victoria and the Victorian Agency for Health Information.

Our consultations with these agencies highlighted clear synergies between the different work programs. The commitment to this work was notable for each member of the different teams engaged and these qualities should be harnessed to strengthen the overall approach for Victoria.