

Ms Carol Pyke  
Senior Project Officer  
Continuing care  
Health Services Programs  
GPO BOX 4057  
MELBOURNE VIC 3001

Dear Ms Pyke

**Re: Submission to Developing Victoria's End of Life Care Framework: A discussion paper**


Australian College of Nursing (ACN) welcomes the opportunity to provide a submission to the Victorian Government's *Developing Victoria's End of Life Care Framework: A discussion paper*.

As you are aware, the nursing profession plays a significant role in the delivery of high quality end of life care. The Australian College of Nursing therefore welcomes the opportunity to respond to the consultation on the development of the End of Life Care Framework for the people of Victoria.

The Australian College of Nursing consulted its Victorian members to gain their views on the discussion paper. This process elicited valuable expert opinion to inform our submission to the Victorian Government.

Please do not hesitate to contact me for further discussion about ACN's submission.

Yours sincerely



Adjunct Professor Kylie Ward FACN  
Chief Executive Officer

23 December 2015



## *Submission to Greater say for Victorians Improving end of life care A discussion paper on a framework for end of life care in Victoria*

In preparing this submission the Australian College of Nursing (ACN) consulted its Victorian members and offers feedback based upon the main topics featured throughout the paper.

### **General Comments**

The Australian College of Nursing believes that safe and high-quality palliative and end-of-life care must be provided by a well-supported interdisciplinary team and delivered from a patient, family and carer centred perspective. The effectiveness of many elements of health care is dependent on the role and presence of nurses who play a significant role in the provision of palliative and end-of-life care. Quality nursing care during end-of-life has a profound impact a person's quality of life, comfort and dignity, and have both an immediate and enduring bearing on their families and carers.

It is essential that the delivery of care is receptive and responsive to the changing and often unanticipated needs of patients and their families and carers throughout the continuum. This requires systems that support high quality care during palliation and at end of life that utilise the full capability and capacity of the nursing profession to deliver timely and integrated care. Care should be delivered in partnership by health professionals, patients and their families and be responsive to changing needs and circumstances, while maintaining a person centred focus. Patient, family and carer engagement is an essential consideration for all care planning and delivery throughout end-of-life care and is largely achieved through regular and ongoing nursing engagement. Therefore the nursing scope of practice should be developed and enhanced within innovative and flexible models of care to optimise relationships and to improve access to support during all stages of their care.

### **Feature area 1: enabling genuine choice**

#### **Focus questions**

- 1.1 How do we ensure that people with a life-limiting illness are involved in, and have genuine choices, about decisions regarding their medical treatments and care for both current and future medical conditions?*

The Australian College of Nursing believes that in order to ensure people are able to exercise genuine choice, a significant amount of effort needs to be directed toward correcting the 'information imbalance' that so often exists between the health care system and the people it cares for. To help

people to have genuine choice, it is essential that they are able to absorb and interpret vast amounts of information much of which is often not presented to them in a way they are able to understand and at times is not available at all. The Australian College of Nursing believes there is a need to generate long overdue change within the current health care culture that openly supports and encourages the role of all health care professionals, particularly nurses to ensure people are provided every opportunity to receive information relevant to their treatment and care through open and timely discussion with the healthcare professional of their choosing.

The health system currently presents a number of opportunities to improve communication regarding palliative and end of life care, however, many more need to be developed. It is essential that improving communication as part of palliative and end of life care is brought to the forefront of the reform agenda with a focus on education for communities, carers, families and importantly for health professionals across all sectors and settings. While health professionals often have a pivotal role in facilitating difficult conversations regarding illness and are often the first person that people feel confident to talk to about their treatment options, some remain uncomfortable with this role which further limits the flow of effective communication. In some settings, end of life, death and dying remain almost taboo, when what people often need is to feel these are accepted and 'normal' topics for discussion and that they are supported in beginning these conversations. Support must also include a focus on public education campaigns about palliative and end of life care and how these services are placed to interact rather than replace existing health services for those with limiting illness.

1.2 *How do we ensure people have options regarding where they want to be cared for, where they want to spend the last days of their life and where they want to die?*

It is essential that people are able to exercise choice in deciding where they wish to be cared for during the last days of their life, and indeed where they wish to die. However, truly supporting people to exercise choice in end of life care clearly suggests the need for reform to also support a person's choice of not only where but *when* to die. Current Victorian law currently recognises a person's right to refuse treatment for an existing condition, which may clearly have a life limiting effect. However the law does not currently allow a person with a life limiting illness to initiate treatment voluntarily to end their own life at a time they choose in order to end suffering and preserve their dignity. The Australian College of Nursing would encourage that this choice be supported by legislation that protects people and health professionals and also ensures all necessary safeguards are in place that address issues of competence, conscientious objection and abuse of process.

Similarly, existing Victorian legislation does not currently support people to formally record their end of life wishes. End of life decisions must be supported by an unambiguous legislative framework ensuring that choices people make regarding their end of life will be protected and not subject to the decisions and actions of others. Ideally, such a framework would be developed through a national approach increasing both consistency and transparency.

Supporting people in deciding where they wish to be cared for also requires health professionals and communities to have an improved understanding of advanced care plans (ACP) and to be proactive in discussing ACPs, and assisting people with a life limiting disease to develop them. Wider

engagement throughout communities regarding the benefit of ACPs must also focus on the need for people wanting to develop ACP to openly communicate their wishes to families and carers who may become proxy decision makers.

Australian College of Nursing strongly believes that genuine choice can also be supported by ensuring that care options people may wish to utilise, such as palliative community care, are available and adequately supported by flexible and responsive services which are able to cope with often unpredictable and changing needs of people, families and carers needs such as symptom control and medication titration. The Australian College of Nursing considers the potential role of the nurse practitioner to be underutilised within palliative and end of life care, particularly in community settings.

## Feature area 2: supporting individuals, families and carers

### 2.1 *How do we improve the experience of people with a life-limiting illness and give them access to the support they need?*

Improving the experience of people with life limiting illness requires a true person centred approach be taken in the design and delivery of care. Such an approach requires collaborative, coordinated care, delivered in accordance with people's values, desired outcomes and needs.

A person's experience of health care is improved by ensuring that clear and consistent information regarding all aspects of care is provided to everyone involved, including carers, families and other health professionals, and that it is understood and updated or clarified as needed. Fear of the unknown significantly impacts upon the experience of people with a life limiting illness and can often be alleviated or avoided by ensuring clear and consistent information and communication. Listening and responding appropriately to people's concerns, questions and fears is also crucial to improving a person's experience.

Reducing uncertainty is vital. Uncertainty for health professionals involved in palliative and end of life care may disrupt the provision of streamlined, patient centred care particularly where care plans are unclear or a person's wishes are not clearly communicated. The membership of ACN believes that there is a need for a dependable mechanism to ensure the existence of advanced care plans is communicated to health professionals across settings and sectors from general practitioners to emergency departments and ambulance services in order to avoid decisions having to be made by health professionals who are not aware of a person's wishes. Education is paramount in reducing uncertainty for individuals, their families and carers. People need genuine information provided by well-prepared health professionals so that they may make informed choices about their treatment and care and the options available to them.

The Australian College of Nursing also believes that there is scope to more fully maximise the potential of health professionals outside specialist palliative care services in order to improve the experience of people with a life limiting illness. Ensuring people have access to the services and support they need during palliative and end of life care requires a shared accountability across all groups of health professionals. The many components to quality care such as support, information sharing, communication, symptom management and coordination should not be left exclusively to 'specialist services' as this has the potential to reduce access to these services by overburdening them

as a substitute rather than an essential part of person centred primary health care. There is a need to improve education across health care professions, beginning with undergraduate preparation, to 'normalise' palliative and end of life care, increase the skills and knowledge of health professionals and in turn improve integration and accountability for palliative and end of life care across all settings.

## Feature area 3: responding to diversity

### 3.1 *How can we provide better information and support to meet the needs of all Victorians, and improve access for groups that are underrepresented in end of life care?*

The membership of the Australian College of Nursing believe that in order to understand how to engage 'under represented' groups in palliative and end of life care, there is a need to first of all understand who these groups are perceived to be, and why there is a perception that they are in fact under represented.

There is potentially a myriad of reasons why groups may not appear to utilise palliative and end of life care. These may stem from cultural or religious beliefs, a wish not to utilise formal palliative or end of life services, perceived stigma, inability to access services due to circumstance, or a lack of available or acceptable services. A greater understanding of these issues may help guide the development of services toward meeting the needs of all Victorians.

Services, and those responsible for developing them can also improve inclusiveness of Victorians by identifying communities, groups and individuals that may potentially be under represented or have potential difficulty accessing services and ensure they are considered and included in planning and implementation stages. These efforts would also need to include resources to improve the health literacy of communities and health professionals in relation to the needs of people from a diverse range of backgrounds.

### 3.2 *What should be done to provide more culturally appropriate and responsive end of life care for people from culturally and linguistically diverse backgrounds?*

A person centred approach to the design and delivery of end of life care is the most appropriate way to provide more culturally appropriate and responsive end of life care for people from culturally and linguistically diverse backgrounds. A person centered approach, rather than a 'one size fits all, this is what is available' approach will help ensure that choices appropriate to people of different backgrounds are available to them. The challenge for our health systems is to provide care to people from different cultures that is driven not by what health professionals always believe to be appropriate.

This can be complicated as some cultures prefer not to talk about dying. There is a need to consider the values and wishes of the individual and family as well as the overlay of the culture to which that they belong, for example indigenous communities. Health care professionals need to be prepared to explore what is culturally appropriate for patients, and to understand and accept this to at least develop an understanding of how best to provide ongoing care, and what values may influence a patient's decisions. This may also encourage the use of other strategies apart from language such as

analogies, storytelling, art and music which may also help patients express their needs and articulate their wishes.

The membership of the Australian College of Nursing also value the importance of cultural safety training for health care professionals and believe that there is a need for improved opportunities for undergraduate students to access to education and experience palliative and end of life care across different cultures where possible.

## Feature area 4: helping people to die well

### 4.1 *How do we ensure that palliative care services are able to provide person-centred end of life care for people with chronic disease and complex care needs?*

People living with chronic and complex health care needs often face the reality that their condition/s may be life limiting. While the trajectory of health is often unpredictable, these groups are particularly vulnerable to episodes of ill health which may precede end of life. Therefore, health care professionals caring for people with chronic and complex needs have a particular responsibility to consider this eventuality in the ongoing planning and delivery of care.

### 4.2 *What can be done to bring together health services, home care, personal support and support for carers to improve end of life services and better respond to people's preferences and individual circumstances?*

While not always a simple concept in reality, integrated service provision is vital in palliative and end of life care. This is crucial to ensure good communication and avoid gaps and or duplication in service provision and to improve responsiveness of services when a person's condition changes. Integration can be vastly improved using innovation in the development of teams and services by including multidimensional roles such as nurse practitioners working across settings and in collaboration to deliver person centred care.

Integration strategies might include block funding for the provision of short term care for people who are at end of life, who might otherwise receive their end of life care in an acute facility. The ability to provide flexible and responsive models of care would not only make the difference between staying at home and going to hospital. Intensive nursing care at home is very expensive, however, these services may vary to provide increased support for carers, including family and nursing home staff or funded accommodation within an appropriate health care facility capable of providing the level of care and support required. As mentioned in the discussion paper, the strain on carers escalates dramatically the closer the person is to end of life, and increased access to different types of support may enable a person's wishes to be granted.

## Feature area 5: supporting our workforce

For a person to be able to exercise choice, it is important that they feel empowered by a health system that provides and supports accessible, effective and flexible care options delivered by health professionals with the necessary knowledge and skills. Nursing plays a vital role in palliative and end

of life care, and Australian College of Nursing believes there is great scope to further support and develop collaborative nurse led models of care in these fields. Recognition of the integral role nurses and other health care professionals play in the provision of palliative and end of life care must also be clear in the development of supportive and transparent policy, legislative and funding frameworks. As an example, Australian College of Nursing believes there is significant capacity and capability in the autonomous role of nurse practitioner to be better utilised for its flexibility within models of care designed to improve access to high quality palliative and end of life care, particularly in the community setting.

The membership of the Australian College of Nursing believes there is a need to broaden the conversation from the delivery of palliative and end of life care palliative care services to recognise and strengthen the inherent part all health care professionals including nurses, midwives and indeed people and communities play in palliative and end of life care.

Members of the Australian College of Nursing believe that there is also a need for improved access to education for health professionals, not only for staff providing direct palliative and end of life care but as an integral part of the preparatory curriculum of all health care professionals and equally should be available for others including volunteers and spiritual carers to enable them to build confidence across diverse communities. Normalising death, dying and the end of life journey by having the open and frank discussion will continue to imbed palliative and end of life care across all aspects of care.

There is a strong belief amongst the Victorian membership of the Australian College of Nursing that Victoria should develop and or adopt a set of clear best practice principles supported by relevant educational resources, to help guide health care professionals across all sectors. These principles need to emphasise quality of life, enabling and supporting people's choices and accountability for the provision of quality person centred care. Ideally, the membership feels these principles should sit within system standards of care to support health professionals.

ACN's membership also feels there is a need to improve clarity around care planning. Care pathways and processes should be developed to provide clear and consistent maps for health care professionals to help address education needs for people, families and carers, relevant legal advice and palliation choice options across all those involved in a person's care.

The capacity and capability of health professionals to confidently offer supportive care must be strengthened, particularly health care professionals who are likely to care for a person experiencing an exacerbation or change in their condition. Supporting health care professionals to develop decision making perspectives that are not solely interventional but that also consider questions such as 'is there something reversible?', closely followed by 'should this be something we offer?' and 'let's discuss what these changes mean' would help integrate supportive, palliative and end of life care throughout all aspects of a person's journey and help avoid unwanted deviations from planned care.

To augment this approach, there is a need to improve information sharing throughout communities. A broad public health campaign to increase the understanding that there will be a time, for everyone,

when supportive care will be the best outcome and that, in fact, it is not a failure of the health system but an inevitable and normal life stage.