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**ANMF (Victorian
Branch)
Submission to
Discussion Paper –
Greater Say for
Victorians:
Improving End of
Life Care**

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The Australian Nursing and Midwifery Federation (ANMF) was initially established in 1924. The ANMF is the largest industrial and professional organisation in Australia for nurses and midwives, with Branches in each state and territory of Australia. The ANMF (Victorian Branch) represents in excess of 75,000 nurses, midwives and personal care workers (the latter predominantly in the private residential aged care sector).

The Australian Nursing and Midwifery Federation participates in the development of policy relating to nursing and midwifery practice, professionalism, regulation, education, training, workforce, and socio-economic welfare; health and aged care, community services, veterans' affairs, occupational health and safety, industrial relations, social justice, human rights, immigration, foreign affairs and law reform.

The depth and breadth of nursing and midwifery practice reaches into: people's homes, schools, general practice, local councils and communities, industry, offshore territories, aged care, retrieval services, rural and remote communities, Aboriginal and Torres Strait Islander health services, hospitals, the armed forces, universities, mental health facilities, statutory authorities, general businesses, and professional organisations.

The core business for the Australian Nursing and Midwifery Federation is the representation of the professional and industrial interests of our members employed in the professions of nursing and midwifery. Registered and enrolled nurses and registered midwives form the largest health profession in Australia, providing care to people throughout their lifespan and across all geographical localities nationally. The Australian Nursing and Midwifery Federation (Victorian Branch) represents the interests of nurses and midwives that are employed in a range of health care enterprises that provide end of life care and therefore has an interest in any reform that may impact on the role and function of nursing and midwifery work.

We welcome the opportunity to provide the Department of Health and Human Services with comment into the *Improving End of Life Care* discussion paper. The examination of a range of issues to improve end of life care, including the review of relevant legislation and any potential changes to current processes to support and assist Victorians to formulate their own individual end of life preferences, for both current and future health conditions, that inform the development of an end of life care framework is timely.

The ANMF (Victorian Branch) supports the development of a process whereby individual health consumers are supported through informed choice about their health care options at end of life. We acknowledge the intent of the discussion paper to outline an approach to build a new framework for end of life care in Victoria by identifying some of the challenges in order to encourage and enable open and honest conversation with individuals and families about death and dying.

The ANMF (Victorian Branch) acknowledge that the Victorian health care system currently provides for end of life care in a range of designated palliative care inpatient and outpatient services as well as hospital based and regional consultative services and to a lesser extent, day hospices and respite services.

The questions proposed in the Discussion Paper have been considered, as follows:

1. What Principles should Guide the Victorian Framework for end of life care?

The overarching principle is to ensure that there are mechanisms in place to support and assist health consumers and their families to make informed decisions about what is the right path of care for them, as unique individuals. In order to get the principles right, requires policymakers to ensure health consumers know that they have genuine choices available to them about end of life (EOL) care options, especially while they have a capacity to make informed decisions. The major issue is to make sure that where a competent person makes a decision about their options, that the decision is recorded/documentated and their nominated competent person is aware of their decision at end of life as well as ensuring that individual decision making is accessible to the person's treating health service, their general practitioner or other health practitioner, as well as ambulance and firefighting personnel that may be involved in treatment/care provision of the person at end of life.

Therefore, the development of any guiding principles must cover elements such as:

- The health consumers understanding that care can/will be provided through a range of health care services at EOL, via both public and private acute and palliative care services, home care, hospice, day care, aged care and respite care;
- Education about EOL choices, including education about advanced care plans (ACP)/advanced care directive (ACD);
- Access to free public respecting patient choices (RPC) programs through participating healthservices, general practitioners, primary care partners, community groups and residential and community aged care service providers, that are designed to facilitate ease for people to make unique and genuine choices that best suit their philosophy of life and death;
- Acknowledgement of the importance of nurses and doctors being at the forefront of this cultural shift across the Victorian community and health care and the position/s they hold in order to have EOL conversations with health consumers about planning for unique wishes for EOL decision making and documentation;
- That the individual health consumer is educated to access their treating general practitioner (GP) as the initial contact point to commence ACP conversations; and that they do so in partnership with the registered nurse employed in the general practice or part of established Primary Health Networks (PHN's);
- The Australian Commission on Safety and Quality in Health Care (NSQHC) has developed a national consensus statement in relation to the essential elements for safe and high quality end of life care that clearly outline a number of guiding principles for EOL care (page 4). These principles have already been developed and should be accepted as the universal principles that are adopted across the country, including Victoria.
- Ensure the principles for EOL care are developed in accordance with the NSQHC, EOL principles to ensure consistency and to support the health consumer, their significant others and family and/or their nominated guardian or carer in EOL decision making. Furthermore, they must incorporate points like, access and equity to services and highlight practical hands on considerations relating to the type of

care, the place of care, or alternatively, expressed with for no interventional care at all, and just promotion of a comfortable death.

- Enable entry points for conversations, along the life span continuum and incorporate conversations with people as early as primary school level.

2. What are the most Important Features of the kind of End of Life Care you would want for your Loved Ones?

- Consumer directed;
- Person focused;
- Enable a process for shared informed decision making about EOL Care;
- Incorporate the various multidisciplinary health care team members where appropriate, including nurses; and embeds processes for care co-ordination that takes place in different Australian healthcare jurisdictions - incorporating any specific Victorian features that are unique;
- Incorporate safety net features in the systems design to ensure the person's choices are recognised and respected especially when they may be approaching EOL or may present at a treating health service. This concept is more about the treating health service being aware of the health consumer's treatment wishes and respecting their choices. For example, a person with motor neurone disease, who has a ACP/ACD who has an expressed wish about what their choices are at EOL, but is unable to communicate due to the disease process. Thus, any pre-prepared ACD wishes are respected by clinicians involved in care provision.
- Outline the goals of any care being contemplated;
- Retain control over self;
- Embed dignity and privacy;
- To have control over pain relief and the choice of where death occurs;
- Have access to the kind of information that is deemed necessary.

3. How does Victoria ensure that people with a Life Limiting Illness are involved in, and have Genuine Choices, about Decision regarding their Medical Treatments and Care for both Current and Future Medical Conditions?

This phase of EOL care requires intensive resources to be allocated through both primary and tertiary health services, in order to provide the required education and training of skilled clinicians to raise the subject, offer informed choices and outline the steps required to put an ADP/ACD in place. There must be inherently sound governance and organisational policies and systems set up and put in place to support and supervise EOL decision making.

Respecting Patient Choices programs or other similar EOL education programs are very useful starting points to enable EOL care conversations, nonetheless where they are available, they must be fully funded to assist health consumers in their decision making options. Furthermore, any systems that are put in place in relation to information collection, storage and data management must comply with relevant legislation and align with the NSQHS Standards.

Health consumers will also need to have an understanding of the medical treatment Act and any other associated legislation to guide their decision making, including clarification about opt in and opt out abilities that form the ACD.

The critical point is that doctors and nurses are pivotal in the process, as they are well placed within the Victorian community to be involved in conversations that explain what options there are available to people about the choices available to them at EoL. Such conversations can be targeted to the individual to inform their decision making, regarding their current or future medical interventions and subsequent treatment options/care choices for their medical conditions.

The Victorian Department of Health and Human Services has some very pertinent contemporary publications relating to health professionals having such EOL conversations with health consumers about their EOL care and advanced care planning choices. There are currently a range of materials available to assist people to have conversations about EOL care and are available for access at: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/acp-strategy>¹.

People must be empowered to direct their own care, whenever that is possible. Unless medical practitioners are directed for a specific legal reason, they are not required to initiate or continue with treatment that does not offer any health benefit or aid in the person's quality of life. For these reasons, people with a life limiting illness must know they have genuine choices, about making EOL decisions regarding their medical treatments and care.

Whilst EOL care is the responsibility to health care professionals at the person's interface, health consumers have a right to maintain their dignity, comfort and privacy and therefore their care provision must incorporate fundamental elements like compassion and respect, to proactively support the individual health consumer's EOL care plan.

4. How does Victoria ensure people have options regarding where they want to be Cared for, where they want to spend their Last Days of their Life and Where they want to Die?

This can be achieved through a variety of mechanisms, for example:

- Community education programs about what options health consumers have at EOL, and raising and promoting awareness about forward planning for EOL and making EOL decision about individual care options in advance.

It is important to recognise that not one size will fit all in this scenario and this is an individual process and must include what is in the best interest of the decision making for the person at the centre of the decision outcome.

- Consumers should be aware of their rights outlined within the relevant legislation, specifically the Guardianship and Administrative Act 1986, which incorporates the

¹ Department of Health & Human Services. 2015. Advance care planning strategy. Accessed 26.11.15
<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/acp-strategy>

options for guardians to be appointed where a person may lose their capacity to make decision in the future.

- Forming relationships with treating health services/PHN/GP/palliative care services to ensure their choices are known and processes are established to facilitate enablement of individuals EOL care preference/s.
- Applying some basic principles that ensure:
 - The consumer is informed;
 - They are seen as the whole person, requiring care at EOL, while recognising that they are the best person to make decisions about their care,
 - That their options are consistent with their values and beliefs;
 - Conversations incorporate the families and/or carers in decision making, where relevant;
 - Documented choices can change during the progression to EOL or as treatment option change;
 - All options are designed to benefit for the patient.

5. How does Victoria Improve the Experience of People with Life Limiting Illness and give them Access to the Support they need?

- Support the workforce to have EOL conversations by improving access to availability to service providers, by community awareness programs, support the paid workforce and volunteers to be identified about what they do in the EOL decision making processes.
- Improvement in the way people are attracted to work in the sector and having access to educational programs and funding streams to ensure capacity building in both existing and future workforce.
- Involve care agencies and families.
- Ensure flexibility, adaptability and individualisation is embedded in the core values of the EOL care journey.
- Embed culturally sensitivity into the structure of any reform, especially in relation to aboriginal people, as a separate need to people of cultural and linguistic diverse [CALD] backgrounds.
- Provide a 'roadmap' of services and where they are available.

6. How can the community services and Specialist Health Teams assist people and their Families or Carers to be Safe and Enjoy the Highest possible Quality of Life for as Long as Possible?

This objective may be achievable where the following principles are incorporated into processes:

- Establishment of EOL case co-ordinators through specialist health services and primary care partners.
- Enable the individualisation of care that incorporates the family and carers in partnership with the person's decision at EOL.
- At the terminal stage of the EOL process, ensure that every individual has access to a team leader/care coordinator.
- Nominate a point of contact person to assist communities and health care teams to liaise with a *point of contact* person.
- Provide assistance with practical needs at EOL, like support services and funding, case management that are all considered steps to enablement for consumers.
- Style the focus of care more community centric, rather than hospital centric care hubs.

7. Conclusion

The ANMF (Victorian Branch) supports the development of guiding principles that enable and assist Victorian health care practitioners to be able to better provide and deliver the highest quality, end of life care, to health consumers.

We support the prospect of enabling consumers a genuine choice about their unique and individualised care options at EOL.

We support the inclusion of high end supports for individuals, families and carers, that respects and responds to the diversity of needs in our communities, yet still provide the capacity for new and expanded job roles for health practitioners. It is essential to recognise the any guiding framework must incorporate mechanisms to ensure service providers are adequately staffed, recognise that treatment is not always wanted, and promote communication and EoL care conversations about care options when the health consumer is on their trajectory to EoL. By the incorporation of these fundamentals into the Victorian EOL framework, health consumers can be guided in making informed choices and care decisions for their unique EOL plan.