



30 July 2015

Ms Lilian Topic  
 Secretary  
 Legal and Social Issues Committee  
 Legislative Council - Parliament House  
 Spring Street  
 MELBOURNE VIC 3002

Dear Ms Topic

**Re: Inquiry into End of Life Choices**

The Office of the Health Services Commissioner (OHSC) accepts and resolves complaints from consumers of health care about health services in Victoria. The OHSC achieves resolution predominantly through alternative dispute resolution approaches which assist parties to a complaint generating solutions to their grievance. Formal investigation is conducted in matters that raise serious or systemic issues and that are not amenable to resolution via conciliation.

The issues outlined in this submission will be offered through the lens of complaints resolution. As such, it is not commentary on the entire system but those aspects of the system to which the OHSC becomes aware. Nevertheless, while the number of complaints raising explicit end of life issues is relatively few, the complaints provide insight into a system which may be struggling to meet the growing need for specialist inpatient and community based end of life care.

1. *Assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;*

The OHSC managed relatively few end of life/palliative care complaints over the past 12 months. The following examples are offered as being indicative of the issues experienced by consumers and their families.

The themes that emerge from an examination of the complaints are:

- Poor communication;
- Transfer to alternative care;
- Entry criteria for inpatient palliative care; and
- Availability of community based palliative care.

*Poor communication*

With most of the complaints received in the OHSC, poor or miscommunication lies at the core of the grievance. In end of life care, communication problems can be very distressing for the consumer and their family.

For example, one family did not understand their relative was being transferred into palliative care and did not understand how rapidly their relative was deteriorating. Part of the complaint to the OHSC centred on the level of shock they experienced when their relative died.

Another complainant states she was holding her father's hand when her father's condition deteriorated and a medical officer came into the cubicle, stood at the end of the bed and said "he will not live past midnight". This upset the complainant greatly who asked the medical practitioner to speak to her outside the cubical where her father was. This incident, whether an accurate reflection of the facts or not, has had a lasting negative effect on this complainant, including long term depression and an inability to work.

Another family gave explicit instructions that their relative was not be informed that he was dying because doing so would cause him to 'drop his bundle' and lead to deterioration in his condition. A consultant medical practitioner disclosed the terminal diagnosis to the consumer and he deteriorated. A decision was made to transfer the consumer into a nursing home on the basis the consumer was stable. The family did not agree with that assessment but felt powerless to stop the transfer. The time of transfer was not disclosed to the family prior to the transfer taking place and when the family arrived at the nursing home, their relative was dead. The transferring service had a palliative care ward on campus so the family did not understand why their relative was not transferred into that unit. A disagreement occurred between the two services about which service would complete the death certificate.

A family was not called following a fall in the bathroom of the facility by their relative. An assessment was undertaken and no injury was sustained. Three hours later, a code blue was called. The relative died that night and the family then learnt of a significant heart condition that had been diagnosed. It was not until the last two days of the relative's admission that the heart disease was treated.

The OHSC also receives complaints where family members either do not understand the consequences of not for resuscitation or limitation of treatment orders or the wrong family members are consulted about them.

All of these examples had a significant effect on both the consumer of the health service and their family. End of life care can be very stressful and emotional for the families of loved ones who are dying. People's perception of what is said can be affected by those stressors so it can sometimes be easy to miscommunicate in such situations. Nevertheless, because this is a well known phenomenon in end of life care, great care should be taken in all communication.

One solution to this need would be to provide more training at an undergraduate, postgraduate and continuing professional development level for clinicians in good communications about end of life issues and wishes. This could be achieved both in person and online.

#### *Transfer to alternative care*

As the demand for inpatient palliative care services is high and the available services limited, a practice exists within the sector of transferring people out of the inpatient service into alternative services if, in the clinician's opinion, the person is stable. At least four matters dealt with by the OHSC complained about his aspect of the care.

Transfers are usually to aged care facilities. Relatives can be tasked with finding an aged care facility for the transfer which adds stress to an already stressful situation. While palliative care has been one of the standards required to be met by aged care facilities, the level of care offered varies significantly. Aged care facilities are staffed, in large part, by either personal care attendants or assistants in nursing with Registered Nurses fulfilling a supervisory role for a large number of residents. This means the care provided by unregistered carers is unlikely to be adequate for the needs of the personal requiring palliative care.

Additionally, the demands of other residents and the minimal staffing numbers may result in inadequate time being provided to a palliative care resident whose care needs are often complex and extensive.

Finally, transfer of younger people to an aged care facility is problematic because the environment is geared towards the care of older people and may lead to feelings of isolation.

#### *Entry criteria for inpatient palliative care*

As demand for inpatient palliative care is high, the criteria for entry into inpatient care can be restrictive. For example, families are being told that their relative needs to be within two weeks of dying for entry into some facilities. As a person draws closer to their death, their care needs often increase substantially. This can create an enormous burden on relatives as the primary carers. This could be alleviated by community based palliative care but such care is also limited. Some consideration could also be given to standardising the entry criteria across the sector to make clear what entry criteria exist regardless of geographical location.

#### *Availability of community based palliative care*

The demand for inpatient palliative care could be mitigated by the availability of community based palliative care. There will always be a need for specialist inpatient palliative care services but, with people increasingly wishing to die at home, specialist community based palliative care is also important and complementary. Transfers to aged care facilities are likely to decrease with appropriate home based care. At present, some community based palliative care and domiciliary nursing services undertake this role, particularly after hours but the coverage is patchy. The needs of palliative care patients often increase as they move closer to death and have specialist care needs. This requires specialist skills and knowledge. There is great variability in the way domiciliary nursing services engage and work with local palliative care services in Victoria. The model can be quite different depending on where you live and die. This is a source of frustration and confusion for carers and families. This raises questions of equity of care because it should not matter where you live in accessing and receiving quality community based palliative care.

#### *2. Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions*

The Australian Capital Territory Health Services Commissioner, Ms Mary Durkin, responded to a request for further information to my interstate counterparts. There are three ways to record end of life wishes in the ACT:

1. Complete an Enduring Power of Attorney (EPA);
2. Complete an Advanced Care Plan (ACP);
3. Complete a Health Direction under the *Medical Treatment (Health Directions) Act 2006*.

The EPA and the Health Direction are legal documents. The ACP provides an indication of a person's wishes but is not legally enforceable. Similar approaches exist in New South Wales. Queensland has a document called an Advance Health Directive which is a legal document completed by an individual about their future wishes. A similar scheme exists in South Australia, the Northern Territory, Tasmania and Western Australia.

In the United Kingdom, the Parliamentary and Health Service Ombudsman published a report in 2015 into the key themes they identified in the complaints they received about end of life care. They found a number of key themes which were:

**Not recognising that people are dying, and not responding to their needs**

They comment that if the needs of those who are close to death are not recognised, their care cannot be planned or coordinated appropriately. This can lead to more crises and distress for the person and their family and carers.

**Poor symptom control**

They state that people have watched their loved ones dying in pain or in an agitated state because their symptoms have been ineffectively or poorly managed.

**Poor communication**

Like complaints to the OHSC, poor communication is an important element in their complaints on end of life care. They state it is clear that healthcare professionals do not always have the open and honest conversations with family members and carers that are necessary for them to understand the severity of the situation and the subsequent choices they will have to make.

**Inadequate out-of-hours services**

Like the examples from the OHSC, the Parliamentary and Health Service Ombudsman says people who are dying and their carers suffer because of the difficulties in getting palliative care outside normal working hours.

**Poor care planning**

The Parliamentary and Health Service Ombudsman found a failure to plan adequately often leads to a lack of coordinated care, for example, GPs and hospitals can fail to liaise.

**Delays in diagnosis and referrals for treatment**

The Parliamentary and Health Service Ombudsman says this can mean that people are denied the chance to plan for the end of their life and for their final wishes to be met.

The report can be found here: <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity>.

*3. Consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.*

Advanced Care Plans should be given effect as legal documents so that an individual's wishes can be considered where capacity is lacking. A person's autonomy should not be violated by virtue of a lack of capacity or the lack of a legal instrument indicating their enduring wishes.

Consideration should also be given to clarifying a medical practitioner's legal position under the 'doctrine of double effect'. This doctrine relates to the provision of sufficient pain relief for the relief of pain which may have a secondary result of hastening a person's death. Some reluctance to giving adequate pain relief may be related to a medical practitioner's perceived legal vulnerability in providing it.

Thank you for the opportunity to comment on this important Inquiry. Should you have any queries or wish to discuss this submission, please do not hesitate to contact me on [REDACTED].

Yours sincerely

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Dr Grant Davies  
**Health Services Commissioner**