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Ms Lilian Topic
 Secretary
 Legal and Social Issues Committee
 Parliament House,
 Spring Street,
 Melbourne Vic. 3002

**Eastern Palliative Care Association Incorporated's submission
 Standing Committee on Legal and Social Issues
 Inquiry into End of Life Choices**

Thank you for this opportunity to provide this submission on End of Life Choices. Eastern Palliative Care Association Incorporated (EPC) is proud of its accomplishment in providing support to clients who have a terminal illness who are living at home in the Eastern Region of Melbourne. We are very experienced in supporting clients and carers connecting the client, their GP, acute services and aged care services. We provide a unified approach using the specialist skills and expertise of Nurses, Psychologists, Social Workers, Massage Therapists, Pastoral Care Workers, Music Therapists, Physicians and Volunteers, to enhance and support the quality of life and improve the sense of wellbeing for people with specialist palliative needs.

Where we work

EPC considers home to be a person's own home, a family members home, nursing home, hostel, supported home, caravan park, mobile home or boarding house.

Specialist palliative needs

We work with people who have been diagnosed with a terminal condition, with little or no prospect of cure, and for whom the primary treatment goal is quality of life. We also work with carers who may be a family member, friend, neighbour or significant support person.

The people we work with may benefit from specialist, home based palliative care in one or more of the following ways:

- Assessment and treatment of symptoms such as pain, anxiety, nausea or depression
- Spiritual, social or psychological support to affirm life and regard dying as a normal process
- The provision of information and support to manage end of life care

Our interdisciplinary approach assists the client and caregivers to cope during the stress of a life limiting illness, to live as actively as possible until death and in bereavement.



Dying in your place of choice

In the 2014/15 financial year we admitted 1333 new clients and achieved 59% deaths in the person's place of choice. In total we had 1107 deaths. Twenty five percent did not die in their place of choice. For the remaining 16% the choice was not known.

Death does not always occur at home and this can be due to a number of reasons including:

- The clients wish to die in a place other than home
- The disease process
- Lack of an able/available carer
- Living alone
- Unexpected death while undergoing treatment in hospital
- A social situation where it may not be safe in the home

Example:

Jane is dying and her illness may result in a catastrophic haemorrhage which will cause death. Jane has young children and does not want her husband and children to experience this distressing event. Jane has chosen to die in a hospice.

Jane's wish may not be fulfilled as a catastrophic haemorrhage may happen suddenly and not be anticipated. Jane is currently stable and reasonably well. Her husband has been prepared by our staff should a catastrophic haemorrhage occur. This involves giving an injection of morphine as prepared by staff and calling EPC for assistance. Hopefully Jane will get her wish to go to hospice when she reaches the terminal phase of her illness.

Example:

Doris is elderly and lives with her son and daughter in law. Doris' grandson who also lives in the home has an illegal drug dependency. Doris requires regular doses of morphine and other medications for pain. All medications are kept locked up but the grandson still manages to steal the medications leaving Doris short of supply. As Doris's disease progresses, in consultation with her Oncologist, Doris makes the decision to go into hospice so that her medications can be managed without interference from her grandson.

Example:

Bruce lives in a share house where he currently cares for himself. He has a terminal condition and has been referred to community palliative care for support and advice on medication management. The house where he lives is known as a drug house and security is an issue for staff both during the day and after hours.

Bruce agrees to meet EPC staff at a friend's house for assessment and ongoing care. It is understood by Bruce that we will not provide an afterhours visit to the share house however if he can get to his friend's house we can provide services out of hours there. These arrangements are agreed and care is being provided appropriately. Bruce understands the risks to his medications while he lives in the share house and the limitations his accommodation places on his care provision.

The Family Support Worker at EPC works with Bruce regarding his future plans for place of care and place of death. Currently this is the friend's house and the friend is agreeable to this.

Support for Carers

In order to provide clients with a choice in regards to where they wish to die and how they want to be cared for, we need to fully support the carers who will ultimately be providing the "hands on" daily care for the client. Carers are coming to terms with the news that the person they care for is going to die and at the same time they need to be practical and resourceful in order to be able to provide care 24 hours per day, 7 days per week. Care for carers is critical. Practical hands on assistance is needed to support carers. Often carers are reluctant to leave the person who is dying. More support services in the home for carers are required to ensure carers do not "burn out" prior to and during the terminal phase of the illness.

Shane is a 45 year old man who has lived alone for over 25 years. He lives in a converted garage in the bush. He has metastatic lung cancer with multiple secondary's. When Shane was in hospital he was unhappy in that environment which made the provision of care difficult for all concerned. He discharged himself home and his mother moved in to assist him. He initially refused admission to EPC but eventually agreed to see our Nurse Practitioner. Medications for pain management were reviewed and altered and the Nurse Practitioner worked with Shane regarding his preferences for care and his wishes which were to remain at home and to be left to manage as much of his own care as he could.

EPC provided a hospital bed (he had been sleeping on a mattress on the floor), and medication advice and support to the GP who was not overly involved in care. EPC also provided support and education to Shane's mother regarding the care that her son needed. Our goal was to provide Shane with his choice of place of care and place of death.

Ensuring understanding at all levels of Government as to what 'caring' means is essential. Certain supports need to be planned and put in place ahead of time but some assistance and resources are needed quickly almost as an emergency either when the stress of caring becomes too much or the person's condition changes. This is where EPC experiences limitations in the services we can offer. We do not have the resources to put a registered nurse into the home to provide care and support at night when the carer needs to rest. In home support and assistance particularly overnight respite, may allow the carer to take a short break (even just a night or 2 of sleep) so they can continue to care.

The role of palliative care volunteer in providing informal support to carers needs to be recognised and enhanced. EPC is privileged to have the great support of over 135 fully trained volunteers who work across many areas including the provision of home based respite and socialisation. EPC volunteers do not undertake 'hands on' care but provide in home respite, transport to appointment, respite for the carers to attend medical appointments, shopping or to attend a social group or Church. Our Biography Volunteers assist clients to write their life story, allowing people to take time to reflect on their lives and write down for family and friend important times of their lives. Many of our biographies are used when the client dies in funerals or family remembrances. We have now completed over 700 Biographies.

The emotional and physical struggle of caring can place undue stress on families particularly as more than 66% of our clients are over the age of 70. Often this means that the carers are also around the same age.

The image of a caring family with many helpers rostered so that there is always a member of the family present is not always a reality. In the eastern region of Melbourne 19.5% of clients live alone and 3% of clients have no carer.

The number of clients and/or family members with mental health issues has also increased significantly over the past 5 years. This adds to the complexity of care required and increases our workload and the need for support from other agencies. It can also limit the choices for the client and the ability of a carer or family to manage the care of the client in the terminal phase of life.

Example: The client has an intervention order against his daughter. On a number of occasions as the man continues to deteriorate his daughter tries to return home and is very disruptive to the client and to the neighbours. The police are called a number of times. On the death of the client the daughter moves back into the family home placing the elderly carer in danger. Involvement of many agencies is required to support the now alone elderly bereaved carer. Extensive time and resources are required to keep this carer safe.

Complexity of Care

Recent figures regarding the survival rates of people with cancer in our society indicate five-year cancer survival has increased from 47% to a record high of 64% in the period from 1985 to 2009 (Cancer Council Victoria, 2011). Aspects of these improved survival rates could be attributed to improved treatments and access to cancer services. As a result clients who would have benefitted from these improved treatments often experience a higher degree of complexity at end of life.

Many of our clients come on to our program with multiple issues and need regular hospitalisation to:

1. Support and relieve the carer/s
2. Investigate unexpected symptoms
3. Control medication regimes or initiate medications that need to be provided as an inpatient
4. Provide palliative radiation or chemotherapy

The collaboration between hospitals and specialist community palliative care services is essential and needs to go above and beyond the good will of individuals to be a requirement of the system in order for client choice to be acted on. Returning clients home after hospitalisation also needs to be an expectation, not an option. Many clients are reluctant to go to hospitals because they feel they will not get an opportunity to be home again, when in fact a short hospital stay may improve their quality of life. EPC constantly keeps in touch with hospitals when clients are admitted to ensure that they know we are involved and the services we can provide. Many hospitals believe that complex care can only be provided in hospital ignoring the choices of the client and their families.

An understanding of our interdisciplinary approach to care provided in the community and the need to be client focused is essential. It is not only about medical care but about what the person sees as important in their life. Palliative care talks about the quality of life of clients but without being client centred this cannot happen. Public hospitals are often limited in providing interdisciplinary client centered care due to tight resources and limited ability to access the appropriate professional resources.

Access to community based palliative care

EPC has averaged a 4% growth each year in new clients over the past 6 years. EPC benchmarks its data nationally through the Palliative Care Outcomes Collaborative (at Wollongong University) and in our latest report it shows that **76.7%** of our clients who are ready for care are seen within **48 hrs**. Only those with a lesser priority or are not ready for care are seen outside this timeline.

Not all clients who have a terminal illness are admitted to our program. Our admission criteria states:

“ The client has been diagnosed with a terminal or eventually fatal condition, with little or no prospect of cure. The primary treatment goal for the client is quality of life and the client has an identified need for specialist palliative care services.”

Clients who have a chronic condition but no specialist needs should be supported by the Primary Health Care Practitioners such as their GP, RDNS, Hospital at Risk Program (HARP) or mental health program. A specialist palliative care program cannot be expected to support all clients who are dying with a chronic condition in the community.

Over the past few years we are increasingly being approached by health practitioners to admit clients to our program because the client will eventually die from their disease. A misconception appears to be building in some areas of the community that once you go onto a palliative care program that your death will be managed and maybe brought forward. People cannot come onto a specialist palliative care program just because they seek death. This is not our role nor is it a role we seek.

EPC does not support euthanasia. We have a statement on our website clearly defining our policy on this issue. The media portray palliative care as an option to euthanasia however this is not the case. Specialist palliative care is offered to those clients who have uncontrolled symptoms. Through good symptom management, both physical and psychological, people can be supported to maintain quality of life until death.

Over the past 3 years EPC has undertaken activities to ensure referrers understand our services and understand how we can assist clients who are dying. Our Intake Team have visited public and private hospitals, consultants, GP's surgeries etc. to inform, provide brochures and support referrers ringing for advice.

We have worked very closely with the Aboriginal Health Services at Healesville and Mullum Mullum to ensure our services are culturally appropriate to the local community. This work is built on relationship and we have had some very successful outcomes for clients through this work.

In 2010 Eastern Palliative Care commenced a new service called our Priority Assessment Team (PAT). Our data showed that a number of clients each month were dying before we could get to visit them. This new service, which ran as a pilot for 12 months, 3 days per week, allowed us to prioritise clients who were at risk of dying within 7 days to be fast tracked and seen within 4 hours of referral. The pilot was very successful with 41 clients in the year strictly fitting the admission criteria and 41% of these clients not having cancer as a primary diagnosis. The majority of clients admitted by PAT die at home.

People with chronic non-malignant conditions are more likely to have a sudden exacerbation of their symptoms and enter the terminal phase of life rapidly and often unexpectedly.

With the introduction of PAT, deaths occurring prior to a first assessment dropped from 10 per month to less than 4 per month over the pilot period and now stand at 2 per month. The figure will never be 0 as some clients never make it out of hospital because of an acute event.

We have worked with the Migrant Information Centre to ensure our brochures and information, including our Consent Forms, are available in the 10 major languages in the region. We have attended Community Expos and community days to ensure we get the message across that we are there to support the community and that there is an alternative to dying in a hospital.

We are currently running a Chinese Cultural project to ensure the local Chinese Community understand the services we offer. This project has come about due to the generous support of a philanthropic benefactor.

Staff have worked with the Royal Children's Hospital to ensure our services meet the needs of children. At any one time we will have 1% of our clients below the age of 24. We also have a significant number of clients with young children and they also need to be supported when a parent is dying. As with all our bereavement programs these children are then supported for up to 13 months following the death of the parent if that is the wish of the remaining parent/guardian.

Funding

Palliative Care is funded by the Department of Health and Human Services (DHSS) and each month we receive grant funding to operate. Over the past couple of years our funding has been indexed by approximately 1.7% (1.5% in 2015/16). This is well below the requirement with 80% of our incurred costs being attributed to staffing. Currently staffing costs increase by 3% per year. This is an unsustainable position for our organisation particularly where client numbers continue to grow. Although we have received a small increase in funding this year (4%) the issue remains that we are not receiving growth funding on a regular basis and in the

next 12 months we will need to cut services as the lack of ongoing regular growth funding is placing undue financial pressure on our organisation. The ramification of this change is that people in the community who want to die at home may have their choices further limited. In effect this will mean a commencement of a waiting list and further prioritisation of clients who are referred.

Meeting the preferred site of death in Aged Care facilities

There is a lot of pressure on aged care facilities to provide quality end of life care without the appropriate staffing levels. Turnover of staff is also high, aggravating the issues. Owners of aged care facilities need to value highly their workforce and develop strategies for retention of appropriate staffing. EPC has developed the Palliative Support Nurse position to work with the 135 aged care facilities in our region to embed the Palliative Approach and to promote appropriate referrals to our service to support good symptom identification and management.

Without Division 1 Registered nurses in facilities we find it hard to provide the required level of care. Some facilities will have a nurse on call when a situation arises out of hours, for example when a client is terminal and this is most effective, but the nurse needs to understand the client and have a level of skill in relation to the management of symptoms and the appropriate use of medications utilised in palliative care – the nurse cannot be an agency nurse.

Advance Care Planning

Eastern Palliative Care has developed a kit and education package for staff on Advance Care Planning. Specific education has been provided to ensure all staff understand the principles of this activity. The need for an advanced care plan is obvious but people in the community have little interest in this activity unless they are faced with a crisis in their health. Advance care plans allow clients to express their wishes and desires based on their values for their end of life. This needs to be communicated with all health care providers to ensure it can be carried out.

An Advance Care Plan may be limited to the choice of place of care and place of death or it may be very detailed with how and under what indications specific care is to be provided.

The Law and Palliative Care

With the current media coverage, more and more clients are engaging in conversations with staff about euthanasia. Our organisation does not support the practice of euthanasia and all staff are educated during orientation about our Code of Ethics and are provided with support and mentoring when conversations about euthanasia arise.

Clients are told that we do not support euthanasia but that we will work with clients to control their symptoms and explore any psychosocial or spiritual issues that may be causing distress.

The law and community expectation provide some grey areas in palliative care. Palliative sedation is an area that often causes confusion for people because they have limited understanding of palliative care. The use of Morphine remains an issue with many community

members think this is a drug that is given to hasten or bring on death. The misinformation regarding morphine is one of the impediments to good symptom management.

Palliative Care Deaths in Disability Homes

EPC supports clients in disability homes to remain in their home as long as possible and to die in that home if that is their wish and staffing is appropriate. The problem is that if a client dies in the home the staff are required to inform the coroner and a coronial investigation is undertaken.

This hinders staff in the home offering the level of care to allow the client to die in their home. Where the death is predictable, someone has a life limited illness, there should not be requirement to notify the Coroner. Disability homes are also limited in their staffing and this can impact on a person's wish to die at home.

Conclusion

People need to know what options are available to them when they are ill. Whether they have a chronic conditions or a malignancy, all people need to have access to information and services which offers them information leading to choices of care. Generally, people do not think about this until they are faced with an inevitability

Thank you for the opportunity to make this submission. We look forward to your report and would be happy to present to the Committee if we can add value.

Yours sincerely,

A large black rectangular box redacting the signature of Jeanette Moody.

Jeanette Moody
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Eastern Palliative Care Association Inc.