

**Admin, LACO**

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**Subject:** FW: Submission: End of Life choices

**From:** Elima Sykes  
**Sent:** Monday, 23 October 2017 10:28 PM  
**To:** Joint Select Committee on End of Life Choices <[eolcc@parliament.wa.gov.au](mailto:eolcc@parliament.wa.gov.au)>  
**Subject:** Submission: End of Life choices

**Dear Members of the Joint Select Committee on End of Life Choices,**

I apologise for the lateness of my submission. I was late hearing about the Inquiry and later of the end date for submissions. I hope some overtime is allowed as this is a matter of deep personal concern as well as vital importance for the whole Western Australian community. Others will have explained better than I can how any changes to the law that would permit euthanasia or assisted suicide could disastrously affect relationships between patients and medical professionals, relationships within families, and attitudes in society at large to the principle of the sanctity of human life. I would like to concentrate on the effects changes to the law are likely to have on the provision of care to the incurably sick, the suffering and the dying.

I have been shocked that so little mention has been made on the role of palliative care to address the concerns of people faced with the prospect of dying from incurable and painful diseases. I believe we should be campaigning for world's best practice palliative care in this state. Until this is made available to **all** West Australians it is surely inappropriate to be considering the easy quick-fix legislative option of simply making it easier for our suffering citizens to kill themselves or have someone else kill them. Surely it is illogical to campaign to encourage drug users and the suicidally depressed to seek help rather than kill themselves while recognising the need to provide greater resources to this end but when it comes to the physically suffering we do the opposite? There is much that can be done to improve the provision of palliative care in this state and I beseech

the Committee to urgently consider submitting to Parliament the need for an Inquiry into this matter.

Firstly, we need many more and better trained palliative care doctors, nurses and carers. Palliative care and Geriatric medicine seem to be an afterthought in the provision of health care when they should be in the forefront and supported to become Primary specialisms. Palliative care should be seen to include not just provision of pain relieving medication but many supporting services including expert nursing, nutritional support, emotional and psychological support and the guidance and support of carers, including family members, in caring for patients. Palliative care should be available to all patients when needed not just the terminally ill and cancer sufferers and not only when all treatment measures have ended. This would have the added benefit of taking away the extraordinary stigma which attaches to the term for some people and leads them to refuse palliative care as they associate it with 'giving up'.

If I might cite my own personal experience, I had wonderful support from the Silver Chain palliative care service in Perth when looking after my mother once she was diagnosed with multiple myeloma although much of the benefit was simply in help with caring with her needs in relation to her old age and Alzheimers rather than specific symptoms of cancer which in her case manifested largely as increasing weakness and fatigue. Having a wonderful nurse, a doctor on call who knew her case, and sympathetic respite carers gave me confidence and peace of mind in looking after my parents until they died, at home, within 6 weeks of each other. It would have been the greatest possible cruelty to put her in hospital or a nursing home and unbearably distressing for my father. It was a pity we could not access the same service for my father until the diagnosis of the return of his previously treated bowel cancer not long before he died.

Failing the provision of a full palliative care team I suggest that a service such as that which in England used to be provided by district nurses should be considered. Area based nurses could visit the elderly, the disabled, the chronically sick and new

mothers to provide advice, support and basic nursing services such as wound dressing, injections and taking blood and liaise with patients own doctors without infringing their jurisdiction. This would save a lot of the anxiety which leads people to give up living in their own homes prematurely often causing unhappiness, social disruption and greater expense to the state in provision of nursing home beds. It should also bring benefits in the care of diabetics which is an increasing problem and health cost. A visiting nurse might also be able to provide advice and training to family and other volunteer carers failing a specialist service for this. Considering how much voluntary carers save the state by supporting the sick, the elderly and the disabled at home so that they need not go into hospitals or nursing homes a little invested in training, advice and where needed, financial support would reap an enormous return. I believe many more people would like to care for their loved ones if they knew they would be given help and support. Of course, I do not mean that a visiting nurse should supply for a trained Palliative Care team where required for terminal illnesses and conditions involving difficult to treat pain.

Palliative care needs to be provided equally for **all** Western Australians including those living in the country. I have a friend who took on the care of someone with terminal cancer until he died but found Silver Chain would not visit when she needed because she lived too far out of Albany although within the city limits. While I was living in Perth and caring for my parents up to 2010 Silver Chain had an excellent model of care for in home patients and I suggest it be extended across the state. Distance from a centre may mean it may take longer for help to come but it should not mean no help is available at all.

Finally, I would urge the establishment and promotion of Hospices. My brother Hugh died in Shenton Park Hospice in 2000. He spent the last six months of his life in Sir Charles Gairdener Hospital and the Hospice. The position of his lymphoma and his cerebral palsy complicated his nursing. He could not straighten his back and he could not change his position in bed on his own. The hospital treated his cancer with

chemotherapy and treated his infections and the palliative specialist adjusted his pain medications but the nurses varied and too often he was left alone too long when he needed help. Nurses are too often over stretched. I believe extra staff should be allocated when there are disabled or otherwise incapacitated patients. In the Hospice he was not only made comfortable, he was made welcome by the excellent specialist palliative care nurses and was able to enjoy simple pleasures like being wheeled out into the garden in his bed and welcoming visitors in a pleasant environment. It was also a pleasant environment for my parents with a comfortable lounge and kitchen so they could stay as long as they liked and an apartment where they could stay the last couple of nights before he died. I had a similar excellent experience of the Hospice in Canterbury in England where my aunt died. I was appalled when Shenton Park Hospice was closed and greatly relieved that my parents didn't require the close monitoring and adjustment of pain medication that hospices provide. I was told that palliative care beds had been provided at certain hospitals instead but on the two occasions when my mother used those beds for a couple of nights I found them no different to the regular hospital service and not at all like the Hospice. Fortunately I was able to stay with her so she was not alone in, to her, a frightening environment. I would urge the government to provide or support at least two (north and south of the river) genuine hospices in Perth separate from the hospitals and one in each regional centre. Hospices have an additional social benefit by providing a focus for community support of the sick through fundraising and volunteering in the hospice and enabling people easily to visit their terminally ill friends and relatives thus familiarising and normalising the experience and removing some of the inordinate fear of illness and death.

I apologise for the length of this submission but to summarise I would ask the Joint Committee please to consider the need for greatly improved palliative care services with more and better trained p c doctors, nurses and carers; provision of p c services throughout the state; support for voluntary

**carers; better provision for disabled and  
incapacitated; provision of hospices.**

**Thank you.**

**Elima Sykes**