From:

To: LSIC

Subject: Submission to The Victorian Parliamentary Enquiry into End of Life Choices

Date: Sunday, 26 July 2015 12:31:22 PM
Attachments: Hugh"s story about Lesley.docx

## Dear Sir.

In the last twelve months I have had the awful experience of watching my wife being slowly and cruelly killed by metastatic breast cancer. My brief submission follows and I attached a more detailed description of Lesley's ordeal.

In 2002, Lesley had a mastectomy for Breast Cancer. Sadly, the cancer returned in the form of inoperable tumours in 2011. The tumours encircled her neck and painfully emerged in her shoulder muscles. The tumours slowly but surely constricted her wind pipe and blood supply to her brain and made it difficult for her to eat. Severe Lymphedema caused one arm and both legs to swell so much that the fluid seeped out of her skin causing lesions and requiring frequent dressing changes.

First drugs and later chemotherapy failed to halt the disease. For 12 months, Lesley had to endure pain, discomfort and loss of dignity. Pain killing drugs were not fully effective and had nasty side-effects. By April, it was patently obvious to her specialist, Lesley and I that all there was no hope of any cure or halting the disease and she was terminally ill. Lesley then clearly said that she would have preferred to have had an "Exit Party" and taken drugs that would have mercifully ended her life and her suffering. Myself, all our family and Lesley's doctors all felt that she should have had that option. Sadly, that was not allowed and she had to suffer until July 11<sup>th</sup> when she died. Believe me, palliative care was helpful but did not completely eliminate awful pain, discomfort, and loss of dignity.

Please enact legislation that would allow terminally ill people the option of voluntary euthanasia assisted by properly trained doctors. I understand that this could lead to abuse but it would be possible to enact appropriate safeguards for example two independent doctors' opinions and a submission to a magistrate who would need to be satisfied that the patient was freely volunteering to end their life.

I find it intolerable that the majority of Australians want voluntary euthanasia legalised but this is held up by a few religious zealots who wish to impose their opinions on everyone else. If an animal were suffering intolerable terminal pain we consider it merciful to end its life and cruel to prolong it. How come, we don't take the same view with humans?

Yours faithfully



## Lesley's Story

My wife, Lesley Sykes, died of metastatic breast cancer on Saturday 11 July 2015. She was 69 years old. Lesley's Mother is still alive at 91, so cancer probably took about twenty years off her life.

During her working life Lesley had been a geography teacher and later retrained as a design and technology teacher. She was always held in high regard by both colleagues and pupils, who achieved excellent HSC results. She was also mother of two children and grandmother to four wonderful grandchildren. In retirement Lesley loved being a grandmother. She was also a highly skilled wood craftswoman, and built beautiful rocking horses, dolls houses and miniatures. Since her retirement we happily ticked off our bucket list, including travel to France, Spain, Switzerland, Italy and Egypt during 2008-2009 while living in England for eight months.

Lesley's battle with breast cancer commenced in 2002. Following her diagnosis, she had a mastectomy, which at the time we believed had solved the problem. She got on with her life until 2011 when a small lump appeared on her neck, which turned out to be a secondary tumour. Scans showed that there too many tumours to be removed surgically, so Lesley began treatment with Femara, an estrogen reducing drug which temporarily halted the cancer. However it started spreading again in 2014. Now her specialist prescribed two drugs that were taken together, Exemestane and Afinitor, but they caused terrible side effects – crippling headaches, abscesses and cellulitis. Lesley also tried three types of chemotherapy, but all failed. By April this year it became clear that she was going to die - there was no hope of a cure or halting the disease.

Cancer is a cruel and sadistic executioner. Tumours encircled Lesley's neck, blocking her windpipe and restricting blood supply to her brain. At one stage her mental function was severely impaired because the powerful medications were affecting her brain. The tumours also made eating very difficult, and she could no longer eat solid food.

In the last six months Lesley battled pain, weakness, immobility, lymphedema in one arm and both legs. Lymphatic fluid accumulated and seeped through the skin causing sore skin lesions and frequent change of dressings. Tumours growing in her shoulder muscles were very painful. Drugs reduced but did not eliminate her pain and discomfort.

In the hospital most nurses were kind and capable, however some were not. We realised the importance of having a family member present to advocate on her behalf, to make sure that she would always be well looked after.

In the last two months of her life Lesley needed someone to shower her, take her to the toilet and help her manage personal bodily functions. For a normally active and independent person, this was humiliating and distressing.

Lesley was completely helpless in the last week of her life. She did not want a slow, miserable death, but she did not have a choice. She had earlier described her ideal death in an article published in "Mama Mia", written by journalist Shelly Horton: "What I long for is to have a happy farewell party with friends and family here in my hospital room, and after they have gone, to be able to take the appropriate pills or injection to put me quietly into the final peaceful sleep."

My family and I, as well as Lesley's medical and nursing staff believe that she should have had that option. Now I am left feeling very sad that Lesley had to endure the pain, discomfort and indignity of the last three months of her life. I would not wish it on my worst enemy and certainly not on the wife I loved.

**Hugh Sykes**