

July 6 2015

## Re: Inquiry into End of Life Choices

Legal and Social Issues Committee

Parliament of Victoria

Email [lsic@parliament.vic.gov.au](mailto:lsic@parliament.vic.gov.au)

We welcome the opportunity to submit to this important Inquiry. Our submission is based on our recent experience – witnessing the prolonged and painful death of a close friend of 40 years standing.

We make the following general comments.



**The definition of ‘terminal illness’, as it applies to the provision of palliative care to someone who is dying needs review.** It excludes those who make a rational decision to end their life. Thus great and prolonged suffering can occur.

**We state that palliative care is the right of all people when they are dying.** Palliative care is generally applied when a person is suffering from a life-threatening illness. **The case we describe in this submission illustrates the extreme suffering that occurs when someone makes a rational decision to die by refusing food and hydration – but does not have a specific, life-threatening illness and is refused palliative care.**



**Aged-care homes, hospitals and rehabilitation centres do not, of themselves, have the staffing levels or skill levels required to provide holistic compassionate end-of-life care. Dying residents/patients should not be left unattended for hours without adequate pain relief.**

At the end of this submission we provide one example of correspondence between ourselves and the family of our friend. We submit this personal email to illustrate both the deficiencies of the care she received and the extreme distress we, her friends, felt at the time.

Linda Sparrow  
Judy Taylor

# Submission

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## Background

A long-term friend died on May 12 this year. She was 85 years old and had made a decision to end her life following a fall resulting in a hip fracture. It took six weeks for her to die after refusing food.

She was a strong, resourceful woman who had been prominent in many aspects of public life in Victoria.

She had championed people whose voices were not easily heard. She stated to us that she feared loss of control over her own life more than death.

**We believe that she made a rational decision to end her life.** She had multiple, debilitating health conditions. She had recently experienced a fall and undergone hip surgery. She was dependent on others for almost all of her daily living tasks. She stated that she had lost all quality of life.

She was fearful that she would no longer be able to remain in her independent living unit in a retirement village and that a decision would soon be made that she must move in to residential care.

She had a close knowledge and understanding of the current system of aged care and found it wanting. This was not a life she wished for herself.

## The Issues

1. She was moved from a public hospital to a long-term rehabilitation centre some days after she made a decision to end her life by refusing food.
2. Medical staff, both nurses and clinicians, at the rehabilitation centre, admitted that they had little experience in treating someone in this situation.
3. The treating health professionals believed that she did not meet the current definition of having a 'terminal illness' and therefore she was ineligible for palliative care.
4. Because of the concern about assisting suicide, she had little pain relief during the six weeks leading to her death. In the later stages she was given just 1 ml of morphine every 4 hours. This did not alleviate her extreme pain and suffering as witnessed during our frequent visits.
5. The treating clinicians had no other 'tool kit' with which to treat her.
6. There was no effort made to seek any in-depth understanding of her situation as to why she had chosen this course. It was perhaps because of this that the compassion normally provided to someone at the end of life was not forthcoming.
7. The nursing care was often deficient as illustrated by the email below. We have no explanation as to why this was so.
8. There was scant regard for this woman's personal dignity during the period leading to her death. This was exemplified in many ways – as evidenced in the email appendix to this submission.

## Conclusion

We are shocked that this prolonged, painful death was allowed to occur without adequate pain relief and appropriate, attentive nursing care.

We cannot understand why a rigid interpretation of what is classified as a 'terminal' illness could be allowed to determine the treatment of our friend.

It was clear in the very early stages of this situation that she had decided to die and would not be deterred, yet no appropriate treatment plan was put in place.

To allow an 85year old woman to die in this way is extremely cruel.

# Appendix

## Email report of visit

Hi family & Linda

Choked back tears when I arrived this morning at 10.30. Stunned to see \*Barb naked to the waist exposing her skeletal wet chest, and all bedding pushed down - soaking wet. Her bed was at floor level as usual – so distressing to see her on the floor. I could scarcely believe the state of her and only imagine how abandoned and cold she must feel.

I pulled up the dry end of the bedding to cover her before I rushed to nearby reception. To the question as to who was in charge, a staff member said she was 'in charge of the whole ward'. She did not express any concern or regret about what I had found. I asked that something be done immediately. Then followed a search for another nurse to help. I asked the person in charge how long it had been since someone had checked on my friend.

Shortly afterwards two staff changed the bed while I was at reception checking on when Barb had been given her last injection. Was told the night staff would have done it before handover (but my question didn't warrant a check of the file). Next question from me – what time was handover – answer 7.00 am. I was still really angry so said I presumed another injection was due no later than 11.00 am.

Back with Barb, my patience had evaporated by 11.10 am, so out I went again. My question 'how long now?' was answered by 'someone is just fixing it'. She got it shortly afterwards but again I wondered just how long would it have been if I hadn't been there?

Barb continues asking for frequent mouth swabbing - she either now can't swallow or is holding back swallowing. I thought that if she could have a sipper cup she may be able to manage moistening her mouth when alone.

A social worker came in and I asked for the sipper and her assistance to alleviate pain in Barb's feet. This had been previously alleviated by staff by wedging a pillow between the bed end and her feet. I couldn't believe this hadn't been done when the two nurses changed the bed.

As I dragged bedding away from Barb's feet, I was shocked to find the blankets sopping wet. I put the soggy bundle into the hands of the social worker who was extremely unhappy by the situation. She said she would be raising the matter at the next staff meeting.

Leaving her was so difficult. Hope I haven't told you too much detail, but I needed to let you know all of it. Ring me if you need to.

Judy

*\*not real name*