



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Submission to Select Committee on End of Life Choices in the ACT

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I am writing this submission at the Canberra Hospital, sitting next to my husband, ██████████ who is dying of metastatic cancer and a perforated bowel. He has been an inpatient for more than five weeks. The progression of his disease has been rapid and his overall condition is very poor.

██████████ has been screaming in pain for nearly a week. The pain wakes him up from sedation. He has been reduced to tears, saying he feels worthless as his pain is either not being taken seriously or not adequately relieved.

██████████ declined to be admitted to Clare Holland House, perhaps in part because he saw it as giving up hope and perhaps in part because he did not want to be treated in a religion based service or setting. This is his right. I know from experience others have had a similar response.

While the Canberra Hospital has many dedicated and caring doctors and nurses, it is woefully under resourced to deliver effective palliative and end of life care. The service operates on a consultancy basis - there are no specialist palliative care staff on duty on weekends or after hours, and for some reason the ward staff have seemed reluctant to page or consult them out of hours. Effective treatment has been further hindered by the fact that after hours and weekend medical cover is generally provided by junior doctors with little experience in palliative care, pain management or even oncology.

We have had meetings with the treating (oncology) and palliative care doctors, and agreed management plans. Most recently, these have not been charted or delivered. Further adding to his and our anguish, we have been told by some staff, doctors and nurses, that ██████████ pain is not real and we have been shut in the room, so his cries do not disturb others.

██████████ is in a pitiful state and my sons and I are physical and emotional wrecks. Our pleas and complaints have met with inadequate or short term responses. We feel let down by the system as a whole, while gratefully acknowledging the many wonderful people who work within it.

I am told the Canberra Hospital is not adequately resourced to deliver 24 hour seven day a week palliative care. This is not acceptable in a human rights focussed, modern city or a tertiary hospital in the nation's capital. The hospital needs to be able to provide this service to all in need, not just to some, some of the time.

I feel strongly that these issues would be avoided or addressed by resourcing full time palliative care teams (including treating doctors, not just consulting) and by better educating other medical staff in end of life symptoms, pain management and palliative care principles and practices.

To address the broader terms of the Inquiry, [REDACTED] has expressed no interest in assisted suicide. At all times he wished to be able to spend quality time with his family, and did not wish to hasten death. Equally he did not wish to suffer like this.

I care little that we are reducing the deficit more rapidly than predicted when essential and humane end of life care is not adequately resourced or valued. To that end, I also question why the Rapid Assessment Unit of the Canberra Region Cancer Centre only operates business hours Monday to Friday, leaving vulnerable cancer patients to the mercies of the Emergency Department. Further, waiting nearly two hours for an ambulance when [REDACTED] was in agony is also not acceptable, and a sign of serious under resourcing

Finally, please note that I have taken up my concerns with [REDACTED] care with staff and management and will continue to advocate on his behalf, despite some trepidation. Given our experiences, and my personal and professional knowledge (having worked for two palliative care organisations) of what effective end of life care can and should deliver, I also seek to draw these issues to the attention of the Committee.

Regards

[REDACTED]
[REDACTED]