

SUBMISSION TO LEGISLATIVE COUNCIL STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES – INQUIRY INTO END OF LIFE CHOICES

Terms of Reference

T of R (1)

I have completed Dying with Dignity's General Advance Healthcare Directive and the Advance Directive for Alzheimer's Disease (and other Dementias). I have also given my daughter authority to make decisions on my behalf under an Enduring Power of Attorney (Medical Treatment), and she is aware of my wishes.

What is missing for me though is a legislative framework that gives me confidence that my wishes will be carried out if the situation arises. As an older person I find this stressful, knowing that my end may be without dignity, and not take account of what I have taken trouble to place on the record in the clearest way I can.

Palliative care is limited. Pain cannot always be relieved. But it is not about pain that I worry most. I visit nursing homes from time to time. I regularly visited a favourite uncle. He was forced to live in a way that would have horrified him – being toileted, fed and dressed just as he was as an infant, completely unaware of his surroundings (less so than a baby), including the ministrations of those who loved him, and whom he no longer recognised. And he was surrounded by numerous others suffering from various forms of dementia, many of whom doubtless would not have wanted their lives to end in this way.

Palliative care is not able to manage the indignity that people like my father had to put up with when their physical discomforts – not pain – became intolerable. I remember this proud man crying and saying – 'I never thought my life would come to this'.

I want what my pets have always had. A comfortable ending surrounding by those who care as I am eased out of this life.

It may not of course come to this, but that it might terrifies me – as does my inability to influence the outcome even though I have – all my life – been an independent and assertive human being. Why should this change at the end of my life?

T of R (2)

I am not a lawyer, but I do know that several countries have managed to develop regimes that give people choice and dignity. Switzerland, Belgium, The Netherlands, Luxembourg and several states in the USA have managed it. The Northern Territory did too until the Federal Government overrode its legislation. There are many examples that the Inquiry could look at to access legislation that gives people the right to die with dignity in a manner that they find acceptable, without being forced to suffer – physically or mentally – beyond what they would have wished.

It is also important that any legislation that results from the Inquiry ensures that those nearing the end of their life - or their competency - are provided with information that enables them to exercise their right to die with respect.

I do of course realise that people need to be protected from those who may wish to do them harm, and safeguards must be incorporated into the legislation. Once again, I believe that overseas examples can give guidance as to how this may be done. But done it must be.

T of R (3)

As I have said, I am not a lawyer, and will leave this T of R to those who are.

Nor do I wish to appear at a public hearing.

Jan Lacey

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