

## Speaking from the grave

Wednesday, August 03, 2005

Moira Rayner

There is no right to life. There is no enforceable right to life, to be exact. The *Universal Declaration of Human Rights* may say there is, but Australian laws only impose the obligation not to kill people or help them kill themselves. As A.P. Herbert put it, and the law hasn't changed much in a hundred years, 'Thou shalt not kill, but needst not strive/Officiously to keep alive.'

It's the second part of that saying that matters, today, in Victoria, as murder victim Maria Korp lies dying in a hospital and Right to Life activists assert a better right than her guardian, the Public Advocate, to decide how and when that death should occur.

There are no rights at all, once you're dead. There is only one way to speak from the grave. A will, which comes into effect at the moment of death, imposes duties on an executor to dispose of our body and property according to our wishes, subject to laws of hygiene, testamentary interpretation and a special rule that a killer may not benefit from his victim's estate.

Your rights to accept or refuse medical treatment are also lost once you're incompetent. Others make the choice, in your 'best interests', a fervent wish, which includes death. Victorian law also recognizes a device that Maria Korp could have, but didn't, use. She could have created an enduring power of attorney and given binding directions on the medical treatment she would want, or refuse, once she couldn't do it for herself. These little-used mechanisms were developed twenty years ago, when it was assumed that they would be favoured by those who, in extremis, wanted to 'die with dignity' without extraordinary interventions. But I recently read a letter from an American who had made, and wore round his neck, a 'dog tag' instructing doctors to 'use every means to resuscitate,' because he knew that doctors regularly put 'Do Not Resuscitate' instructions on ward records at his hospital, without consultation. When he explained his wishes to the hospital almoner she expostulated, 'How selfish!'



Thanks to [Fiona Katauskas](#)

Is it selfish to want to live?

Over the last twenty years courts have enormously expanded the 'right to die' of terminally ill, distressed and pain-ridden patients, mostly conscious people who couldn't persuade doctors to withhold life-prolonging treatment. But in late July 2005 a British court decided that doctors could, even against the patient's wishes. Probably at the same time that Public Advocate Julian Gardner was sitting at Maria Korp's bedside, quietly explaining that he was planning to end artificial feeding and hydration and her life, a British court was saying what I wrote in the first sentence: a patient does not possess the right to life.

That case was the tragedy of a man called Leslie Burke, who has a degenerative, incurable brain condition that removes the ability to communicate. He had asked British courts to direct his doctors not to remove his artificial hydration and nutrition feeds when he lost the capacity to consent to treatment. Late last year a High Court judge stated that patients, not doctors, decide what is in their best interests while they are competent, and beyond, if they had made an 'advanced request' for treatment, as Burke had. Burke asked for, and Mr Justice Mumby gave, a ruling that parts of the General Medical Council guidelines that appeared to give that final decision to doctors were invalid. Doctors weren't pleased, and took it to the Court of Appeal. It sided with the profession.

There are three broad approaches to doctors' role when end-of-life treatment decisions have to be made. One emphasizes a patient's right to die with dignity, with medical help. Another focuses on giving comfort, and priority to the patient's wishes. A third affirms society's commitment to the preservation of life. None are really simple, because end-of-life decisions aren't either. The Court of Appeal overruled Mumby J and gave the final power to the doctors, which doesn't fit any of them.

The Court of Appeal said that a doctor who deliberately ended someone's life by discontinuing artificial hydration and nutrition contrary to that patient's explicit instructions committed murder - except in the last stages of life, when he was no longer competent. Then, the doctor's views took over.

This was a significant development in patients' rights jurisprudence. From the medical profession's perspective, it reaffirms doctors' right to decide whether particular treatments are appropriate, over the patient's wishes. It seems to leave open the basis for deciding what is 'appropriate', or effective including the cost, the hospital's resources, and their legal exposure.

There is a very limited right to choose how to die. The law is much more respectful of your decisions about your money and property. Courts traditionally ensure that executors or trustees of wills do what their maker directed, no matter how foolish. British trustees of the Rhodes Foundation, for example,

set up by Cecil to provide prestigious scholarships for the inculcation of proper imperial values in British colonials, recently decided that they must continue to implement his original instructions and preserve the 32 American scholarships, while cutting (for financial reasons) others open to 'developing' countries, such as Uganda and Pakistan. Cecil Rhodes, then, speaks from the grave, though his imperialist values have long gone: living men and women who want to choose how and when to go there, don't speak.

I was still living in London in 2001 when a British woman in the last stages of motor neurone disease, Diane Pretty, asked the House of Lords and then the European Court of Human Rights to make it possible for her husband lawfully to help her end her life immediately, rather than choking and asphyxiating. She failed. She died as she dreaded, days later.

Imagine Leslie Burke's apprehension, now he knows that when he can no longer protest, his doctors may lawfully ignore his wish not to die of starvation and thirst.

Surely, we each have the human right to decide how to die, one we avoid thinking about. But for those who do, surely that choice should prevail. Recent mainstream movies – the fictional *Million Dollar Baby* and the quasi-factual story of Spanish quadriplegic Ramon Sampedro in *The Sea Inside* – have meditated on the rights of severely disabled people to help to end lives that have become intolerable. Sampedro, who had written that 'Living is a right, not an obligation', finally suicided, leaving a damning, open letter to the religious, political and legal authorities who outshouted him. 'It is not that my conscience finds itself trapped in the deformity of my atrophied and numb body; but in the deformity, atrophy, and insensitivity of your consciences.'

I am glad I did not have to make the decision that Julian Gardner has. I am glad he is comfortable with it. But I am not comfortable with the way society manages the most important choice a living person has to make: how to die well.

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## **Australia and the World**

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## Published Comments

What's your opinion? Tell us what you think by adding a comment to offer feedback on this story.

*I agree with your sentiments. I would not like to be Julian Gardner either. Conceptualisation of the psychological weight, resulting from being responsible for the termination of another's life, would be subjective however, I cannot help but believe, because of our culture's 'respect' for human life, an unenviable could would remain forever.*

John Jones

Thursday, August 04, 2005

*I don't have a clue about what Jones J is trying to say in response to Moira Rayner's piece on the right to die as one chooses.*

*Could he possibly re-submit?*

Anne-Marie Strickland

Friday, August 05, 2005

*The mainstream movies of which you write are exactly that: mainstream movies. They're both effective dramas but neither are particularly accurate or useful commentaries on life as a person with profound disability.*

*Every day for the last twenty-one years, as I sit in my wheelchair because of c5/6 quadriplegia, I've asked myself, what makes life tolerable and/or intolerable. Believe me, it ain't the physical impairment that's intolerable. What's unacceptable (and it's why there's a politicised disability movement wherever there are people with disability) is that we could, if we had the political will, re-shape our human, social and economic relations to include people with disability and value them but we still haven't done enough.*

*The ideal Hollywood story is the tragic but brave tale of triumph over adversity. It almost guarantees an Oscar nomination! The real challenge, though, is to build a new dispensation in which people like me are understood to be no more and no less than ordinary people living ordinary lives. We just happen to be folk with varying degrees of physical, sensory, intellectual or psychiatric impairment.*

Douglas Herd

Friday, August 05, 2005

*Here here Douglas.*

*I don't think I can add anything meaningful to your comment, but my wholehearted agreement. I say this as an interestingly labelled "able-bodied" person. Everyone is "able" to do some things, and not others, for varying reasons, the trick is to best allow all to use what ability they have - be it physical, mental or otherwise (if indeed there is an otherwise...) – whilst allowing them the freedom to choose not to.*

Grant Watson

Wednesday, August 10, 2005