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New legal framework needed for assisted dying

By Dr Rodney Syme

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The Victorian Upper House Committee of Inquiry into End of Life Choices produced an excellent report last year, which stated that "the current legal framework is not serving Victoria well", and recommended that the government legislate for assisted dying with appropriate safeguards (which it broadly described). In response, the government announced it would introduce legislation in 2017, and wisely determined to move cautiously, appointing an expert ministerial advisory panel, chaired by a former president of the Australian Medical Association, Brian Owler.

The only disappointing aspect of the parliamentary report was the recommendation assistance in dying only be available to people who were within "weeks or months" of dying. The other determinant was that the person was suffering from "a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable".



A fundamental difficulty for the panel is that these two conditions are in conflict in two fundamental ways. The first is that "serious and incurable conditions" are not confined to those with only weeks or months to live – essentially people who are terminally ill, or to be more specific, actually dying (in the terminal phase of a terminal illness). The second is that "enduring and unbearable suffering" is not confined to those with "weeks or months" to live.

The evidence of the Victorian coroner, upon which the inquiry placed great weight, reveals that at least half of the three to four Victorians a week who because of a serious medical condition commit violent suicide do not have only weeks or months to live. They had what I describe as an "advanced incurable illness" – note the similarity to "a serious and incurable illness" cited by the inquiry.

They are people with chronic organ failure in the broadest sense. It is not difficult to comprehend that people with chronic heart or respiratory failure, perhaps reliant on continuous oxygen, suffering from fatigue, diminished mobility, pain, and, most

importantly, severe breathlessness, have a serious and incurable illness, but their trajectory to death is unpredictable. Similarly, people with neurological failure, such as multiple sclerosis, motor neurone disease and Parkinson's disease, who have progressive diseases, and those with profound stroke or high quadriplegia who have a static condition, may have an ill-defined trajectory to death, and while suffering unbearably, may be discriminated against by narrow legislation. There are other uncommon examples of chronic organ failure of the urinary and gastro-intestinal systems (particularly in relation to continence) and musculo-skeletal systems (predominantly chronic poly-arthritis) which also deserve consideration.

The critical point is this: confining assistance to those with "weeks or months to live" is discriminatory, and will leave many people to suffer intolerably, and perhaps continue to take their own lives in a violent manner. And it will not resolve this issue from a medical perspective; these people will still attempt to engage with their doctors for assistance, and those doctors with empathy and compassion will still find it either impossible to help ease their deaths, or will continue to act outside a law that is not effective.

The essential problem is that terminal illness is a vague and difficult to define concept, and intolerable suffering can occur outside this frame. Finding a form of words that is neither too narrow and discriminatory nor too broad is the difficult task for the panel and the government. Mental illness and those without competence (for example, dementia) are already excluded.

It is important for legislators to understand that this is a matter that goes beyond physical pain to other forms of physical suffering, and, equally importantly, to associated psychological and existential suffering. Many politicians in 2008, when this issue was last debated in the Victorian Parliament were perplexed by the term "existential" in relation to suffering. It relates to our existence as human beings and to those fundamental things that give us quality of life – independence, pleasure, purpose, and a sense of control over our life.

The panel and the government should take note of the two most important safeguards against abuse – both incapable of being defined in legislation, but of fundamental importance in argument and practice. First, people do not want to die; they will fight and hang on to life as long as they can. A request for assistance to die only comes from, and is acted upon, in situations of extreme suffering – give suffering people the control and they will not use it unless there is no alternative. Second, the medical profession is the guardian of people's lives, and will not act to assist without extreme caution, and in clearly defined circumstances.

Dr Rodney Syme's new book is *Time to Die* (MUP). In recent days he was recognised as Australian Humanist of the Year for 2017 by the Council of Australian Humanist Societies.

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