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SUBMISSION TO: INQUIRY INTO END OF LIFE CHOICES

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I lost my wife, Marie, to Alzheimer's disease in 2009. She was diagnosed in January 2003 at the age of fifty-four and died in October 2009 aged sixty-one.

I became involved with Alzheimer's Australia Vic in 2003 and, in 2007 a book I had written, *Remember me, Mrs V? Caring for my wife, her Alzheimer's and others' stories*, was published.

From my personal experience and from anecdotal evidence gathered from people while researching and writing my book, I submit that there is an urgent need to reform legislative and regulatory matters relating to end of life.

The key issues which I believe require reform are:

1. The Advance Directive: I am aware that COAG was seeking (circa 2014) to have a uniform Advance Directive in all Australian jurisdictions. While I applaud a nationally recognised document, I would like to see:
 - The Advance Directive be given the same legal status as a will. Its current legal status is unclear and it appears that the wishes enshrined in these documents are often ignored or modified.
 - That Advance Directives be made freely available in simple, clear format (such as Enduring Powers of Attorney or Guardianship). Current pro forma documents are complex, difficult to follow and finding them online or elsewhere is a challenge.

If the Advance Directive has clear legal status and is freely available, dementia sufferers and others who are unable to articulate their views as they approach end of life will have the opportunity to make their desires clear. An Advance Directive can be prepared well before a person is judged to be *non-compos mentis*.

2. Physician assisted dying: When my wife was in a nursing home in a near vegetative and then vegetative state, there were times when she was clearly in pain and/or distress. The staff agreed that her facial and body contortions indicated her extreme discomfort and yet they were reluctant to administer additional pain medication for fear of her dying – and their loss of accreditation. Doctors who I consulted were also reluctant to increase her pain medication for fear of being embroiled in a Coronial Inquiry. Yet when my father was dying in 1992, a cardiologist saw him in extreme pain. My father's heart was failing and his lungs were filling with fluid. The cardiologist (with my agreement) administered morphine, my father's pain subsided and he died within an hour. Would he

have lived another day or two in extreme pain? Nobody can tell me the answer. I am eternally grateful to the cardiologist who was prepared to give my father morphine and thereby end his suffering.

What kind of system is so inhumane that it deters healthcare professionals from administering appropriate levels of pain relief for fear of bureaucratic and legal backlash?

3. Medical science and the ethical debate: for some years it has been clear that medical science has moved well ahead of the ethical debate. Prolonging life is just one area where the science has advanced. Just recently there has been public debate about parents being able to choose the gender of their next baby due to advances in genetic science. Organ donation and stem cell research are two other areas where science is years ahead of community ethos and understanding.

The prolonging of life had generated very little debate whereas terminating life is still debated. There is, however, now a large majority of the population that accepts physician-assisted dying and voluntary euthanasia. The attitudinal research is well publicised and needs no further comment in this submission.

It is, however, time for the policymakers and legislators to enable people at the end of life to make their own choices.

