



Speech by

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RESEARCH INVOLVING HUMAN EMBRYOS AND PROHIBITION OF HUMAN CLONING AMENDMENT BILL

Ms NOLAN (Ipswich—ALP) (8.00 pm): It is my pleasure to contribute to this important debate on the Research Involving Human Embryos and Prohibition of Human Cloning Amendment Bill. As I do so, I am enormously impressed by and proud of my colleagues who have spoken before me. These conscience debates are by far the best debates we see in the parliament. They draw upon members' deepest values and most careful consideration, and I believe that the respect and decency with which the debates are held do a great deal to enhance the dignity of this place. In particular, I want to acknowledge the contribution of the member for Murrumba who, in my view, after 21 years here continues to be the most gifted and wise orator among us.

We in the parliament should never be reticent to engage in conscience debates. I will vote yes today. I will do so after careful consideration. For me, embryonic stem cells are not life but they are its building blocks and I do have reservations about creating the building blocks of life for the purposes of experimentation. I resolved to vote yes primarily because I do not feel that my concern is sufficiently strong to take the enormous step of limiting the freedom of inquiry that the member for Hervey Bay so aptly spoke about as the spirit of the Enlightenment. Secondly, I do not feel that my ethical reservations are such that I should deny individuals who suffer debilitating illnesses—like motor neurone disease, cystic fibrosis or lupus—the opportunity to have their quality of life improved.

So, for me, this bill does not reach the boundary of what is ethically acceptable but it is going close. I hope then today that as we stand close to that ethical boundary we will look deeply and broadly at all of the issues at hand. My concern is that in our society our excessive medical focus causes us to neglect concern for quality of life and to treat death not as a part of life itself but too often as an aberration or a failure of the medical system.

While other cultures speak openly of death and view it as a natural spiritual extension of life, we in the West are uncomfortable talking about death or about the related concepts of living and dying well. That philosophical and sometimes spiritual failure leads us often to deal with death badly. We prolong life in people beyond the point at which quality of life is lost, and we fail to talk to the people we love about how we want to live and how we want to die. We pour money into health care beyond the point at which it is sustainable, and we contend badly with the question of at what point should treatment cease.

This failure to talk about life and death affects us at both a policy and a personal level. At a policy level, we have no intellectual framework to choose between medical research and treatments that extend life to those who are terminally ill and those that offer a better quality of life to the young. At a personal level, families struggle every day with making medical choices on behalf of family members who are no longer able to speak for themselves.

In 2004, I had the privilege of being involved in a series of workshops run by Palliative Care Queensland under the title of a World Cafe. The purpose of the World Cafe was to bring people from a range of backgrounds in groups of around 25 together to talk about death and dying. The first group I went to was run here in the city at Borders bookshop and included representatives of a number of different churches, old and young people, palliative care professionals and a couple of people whose partners had

passed away. Upon arrival, the first thing participants were asked to do was fill out a piece of paper, for your own eyes only, on which was written this question: 'What would you do if you were diagnosed with a terminal illness?' I have always kept that piece of paper on which I wrote my response.

We then went on to break into small groups to discuss specific ethical questions around the spiritual, medical and physical aspects of dying and death. It was a hard conversation but it was my experience that to talk about it was not sad; it was empowering and indeed it was uplifting. I found Palliative Care Queensland's series so moving that in conjunction with Jan Wilton, the then president of Palliative Care Queensland and at the time the director of the Ipswich Hospice, I ran a World Cafe in Ipswich. All of the people involved—and we chose people from a range of different backgrounds—reported that they had achieved real growth by talking about these difficult things.

All of us will die. Here we are constantly reminded of it by the condolence motions we have for former members on many mornings of the sitting week. All of us should think about how it is that we wish to do so. I do not suggest that talking about it will be easy or that it will lead to the avoidance of the long, slow and sad deaths that many people face, but I do suggest that as our society stands today at this ethical boundary our condition would be enriched if public debate were to contemplate not just the medical issues around life and death but the spiritual and emotional side of our own inevitable passing. I commend the bill to the House.