RIGHTS OF THE TERMINALLY ILL BILL 2013
Second Reading – May 9, 2013

The Hon. TREVOR KHAN [11.30 a.m.]:

I will not be supporting the bill, but I do so after a considerable amount of thought. I do not approach this matter from a religious perspective at all; I approach it in circumstances where I have lived with the death of my father for about four years. In all the emails I received—I sought to read as many as possible—I was constantly confronted with the words "palliative care" and, in a sense, how that was the miracle that would save people in their final times. I will tell the House a little about my experience with my father.

My father was a general practitioner in Wollongong and had practised there for more than 50 years. He had such a large practice that even when he was eventually in the nursing home the number of nurses and nurses aides who volunteered that either they or one of their relatives had been delivered by dad was remarkable. I know that one Labor member in this place had some of her children delivered by my father. He had a significant reputation in the Wollongong area. Indeed, I think I could say he was genuinely loved by a large section of the community. He was an interesting man. He was manic, he had a huge work ethic, he was articulate—

The Hon. Dr Peter Phelps: Like his son.

The Hon. TREVOR KHAN: There was a DNA flow-on. He was a larger than life character in so many ways. Nevertheless, as with all of us, he grew old and eventually retired—I think in his 80s. When he began to develop some symptoms he went to an oncologist in due course and they identified a mass in his chest.
The oncologist's view was that this was not the primary cancer. To cut a long story short, he was sent to Wollongong Hospital—a hospital in which he had practised for years and in which there can be no question of anyone having done anything wrong in the care that he received. They took him off all his medications so that he could have a colonoscopy because they believed that may have found the primary source. He was due to have the colonoscopy on a Monday morning and was woken at 7.00 a.m.
He had suffered the most tragic of strokes. From that moment he was left incapable of walking or using one side of his body, incontinent with no control of his bowels or bladder and mentally debilitated to a significant extent. At that stage he was still able to talk: he could string a little sentence together but no more. He was not the same man in any way. We were told that he could live maybe for days or weeks. In those days they did not talk about months. At that stage he could not swallow and they were talking about inserting a tube so they could feed him. At that time we knew that if that happened he was gone. Once a person is intubated and the like it is too hard.

Nevertheless, starting from that very Monday my mother was there with him every day trying to help him. She was with him until he died more than 3½ years later. She was there every day apart from five days, four of which were because she was locked out of the nursing home because of infection. I would try to visit at least once a fortnight. Going into a nursing home is an interesting experience. When I would approach his room often the first thing I would prepare myself for was the pervasive smell of faeces. This man had held a significant position in his community: he was proud and intelligent. And there he lay, even with the help of the nursing home, unable to speak by the end. He would look straight through me. He did not really speak to me at all. I never quite knew whether it was because he had difficulty speaking, because he was angry with me or because he could not articulate what he was thinking. I did not know what he was thinking.

He lay there for more than 3½ years in his own faeces and urine. Palliative care? In fact, he was assessed by palliative care, which said he did not fit within the criteria. I was left staggered and feeling humiliated for him. The patients would continue to visit; his friends would continue to visit, but as time went by they drifted away. The only person who was there every day was my mother: feeding him, trying to humour him, trying to make his life just that little bit better. There was no dignity in that for him. In a sense there was no relief from the suffering. He was not experiencing pain. I hear people talk about palliative care and pain. Many people in our community do not suffer pain in their end stage of life; they suffer the debilitating impact of disease in so many other ways.

As with the emails, I simply wonder about people's insight into the process of death and how terribly demanding it is on the individual involved and those around them. As I said, I come here with a lot of baggage in terms of this debate. I come here believing that no-one deserves to end their life like that. No-one on this planet deserves, after dedicating their life to medicine, to be lying in a bed like that. Before my father lost the capacity for intelligent speech, before the operation, he had prepared an advance care directive. He knew that he had cancer and that his life was going to end. He had lived with death his whole life. He had seen his friends die. He cared for his friends as they died. He prepared an advance care directive that said, "If I've got cancer that is extensive in my bowel then make sure there is no blockage and put me back together." He was not looking for a miracle outcome; he knew his life would end.

In those early times in the nursing home when he could still speak I know he approached my sister and told her that he wanted to die. And he approached me and asked me whether I would kill him. And I could not.

To this day I wonder, when he looked at me, whether he felt that I let him down, whether by letting him live like that for 3½ years all I did was leave him in agony.

There are no simple ways out of this. Life is terribly cruel, I have decided. It can come and kick you in the guts, and there is no way that some people can be spared that outcome.

In those circumstances, having looked at this bill and having agonised over what I should do as a human being, I understand what the Hon. Cate Faehrmann wants to do. I understand what so many people who wrote to me want, and I understand why they want it—I really understand why—but I cannot provide an answer that cures people from the suffering of life and death. I feel that the bill goes too far. It asks for a medical practitioner, in one sense, to kill a person. I just cannot see that as being a good outcome in our community. I could not see that it would have been appropriate for dad, in his role as a doctor, to have killed one of his patients, however much their suffering was.

I have some sympathy for the right of people to make their own decisions in life and death. That is a different question. I feel that this bill, in a sense, conflates two different issues and makes it difficult. A professor down the road from where we lived when I was growing up in Wollongong took his own life because he had a brain cancer. He was a very intelligent, articulate professor, and he did it by gassing himself in his car. I cannot accept that as a way to go—alone in a car, gassing yourself through a piece of pipe. I think there has to be something better than that. But, again, this bill conflates the issues, and I cannot feel comfortable with it.

Notwithstanding my inability to support the bill, the debate we are having now is an important debate for all of us. It is important for all of us at some stage to consider the issue of death—not in the context of those final times when we are getting close to it but now, whilst we are still healthy. How do we want our end to be?

In my view it is wrong to say that there is some preordained outcome for us. There is capacity for us to influence. I have spoken of this matter with various people. It is one thing that dad did, although he did not go far enough. He only dealt with the operation in his advance care directive; he did not deal with what he expected when he lost the capacity for input himself. I have no doubt, had he gone into that area, he would have said, "Do not give me my diabetic medication, do not give me the blood thinners and do not give me the antibiotics so that when I am lying in bed in an unconscious or semi-conscious state you keep me alive for another 12 months, 18 months or two years." He would have said that was ridiculous. One of the problems for us is that we do not make advance care directives. It was too much for mum. I could not really expect my mother to say, "Take him off all of his medication", because she loved him. She loved him until the day he died, and he died with her there. It was his decision to make and, unfortunately, he did not make it.

The bill, in a sense, starts at the wrong point. It starts with a regrettable, discrete class of people diagnosed with a terminal illness. It does not deal with many of the people I saw come and go in that nursing home. The beds would be full and then they would be empty. They were filled with people with dementia who would wander the halls. I remember one lady who would wander into dad's room and ask where her daughter was. She asked each day until she died where her daughter was. She was there alone, in a demented state. There was another wing that I could not get into where violent dementia patients were. They were kept in another wing of the hospital. Dignified? Not at all, but they were there. If they had a choice earlier, no doubt they would have said something about their level of medication usage, for instance. If people were encouraged to do that I think there would be different outcomes and perhaps better outcomes.

There is no dignity in death. There are no simple answers to any of these problems. This is a debate worth having. It is worthwhile considering what we should do for people in the end stages of their lives, but regrettably this bill does not do that. Because of my experience I cannot support the bill. However, again because of my own experience, I will not vote against the bill; I will abstain. I am sorry if my personal experience has been a little too much, but thank you.