

## End of life Inquiry

From: Bernadette Cheesman



Some questions to consider, especially when dealing with changing existing or drafting new legislation:

1. How to ensure that the person has freely made the decision to end their life?
2. Especially if the person, especially a severely disabled person, has difficulty communicating, how to determine if this person wants to end their life, if they have not previously specified such a decision?
3. End of life decisions should not be limited to doctors' advice or decisions. How many doctors may give advice that provides 'closure' to the patient's relatives and/or clears the hospital bed? Were these the possible reasons for a doctor's advice to a cousin to consent to her mother's life support to be turned off? This under the guise of 'We all know she wouldn't like to be left an invalid...'
4. At what point will the severely disabled be considered 'burdens on the community' and their lives terminated, when a patient might otherwise be revived?
5. How to counsel people, who find themselves having to make difficult decisions in critical situations, that doctors do *not* know everything and that they can often only provide somewhat educated guesses? Who else can be brought in to provide independent advice and support? Specially trained health/para-legals?
6. How to recognise that doctors/medics in stressful, busy situations are subject to the same foibles, failings and personal beliefs as anyone else and that their judgement can also be clouded?
7. How to ensure that, when doctors/medics do provide advice, they accept responsibility and are held accountable? As an example, following a car accident, I had the prescribing specialist refuse to accept responsibility for prescribing modafinil for me.

The following sums up my concerns:

### An open letter to my second oldest uncle

Dear Uncle,

I remember you: so proud of your then eight year old, oldest niece, who, playing 'I spy,' had you try to guess the 'v' word - 'v' for 'vegetation' - on the long drive home.

I remember you on crutches, still able to get around, then having to relinquish them and take to your wheelchair. We, your nieces and nephews, learned very quickly that it was polite to speak with you face to face. As we got older, we found we were expected to kneel or crouch down, not just bend over...

I remember you teaching me how to play chess and backgammon: teaching me how to use my mind, not just my body. I still have the backgammon set you gave me for Christmas.

I remember you and your blind friend, both at university, helping each other study, and relishing in each other's company the independence you both sought. He would help you into your modified car, you would drive, then he pushed you around the supermarket. You would call the directions, to-be purchases and obstacles. We were at the same university residential college for a couple of years. Your friends were very kind...

I remember you - so determined - claiming, 'I am inconvenienced, NOT disabled'.

You could appear stubborn. I remember during my own illness and recovery, being accused of being like you and 'driving away the people who want to help you.' I quite agree: there's always the frustration, because so much of the time, it's not help, it's control...You were right, again: a lot of it *is* a bit of a test....the number of times people say one thing with their mouths, while their eyes and actions do the opposite, is quite astounding...Your father's, my grandfather's, wise words still linger: 'trust a person by what they do, not what they say.' I live by them, still...I gather you did, too...if that makes us difficult to work with, or be company with, so be it...

I remember you listening to your favourite records, among them Leonard Cohen: was he leading you to the way of '...you need the cracks so the light can get in...'...?

I remember you returning from Lourdes, having gone to see if Mother Mary would make you well. You didn't blame her for the outcome, accepting that responsibility: 'I didn't believe, or not enough...'

I remember you, going to gatherings, under church auspices, and the readings you brought home and shared with me: eg; 'If I stay angry at you, I commit violence against myself.' ...

I remember you giving your car to me, when you finally came to terms with yourself and your increasing lack of capacity...the diabetes locked you into blindness and deafness, while the friedreich ataxia locked you further into your body. It was a great old car: made the year I was born and repainted by Grandpa, it had good clearance, so could go a bit off-road...

I remember my last visit to you. You were tucked away in a remote town's country hospital, because everywhere else claimed they didn't have the capacity to care for you. A doctor took my father, your older brother, aside and quietly asked: 'What the family would like done? If [your] heart failed again, should [you] be revived, or 'let go'? I mean, [you] wouldn't want to be a burden on the community, would [you]?'

My father was very upset and refused such permission: to give the doctor permission to kill his brother? No! He was even more upset that they hadn't bothered to broach the subject with you. You were completely sentient, even if difficult to communicate with, as the deafness and muscle failure, that made speech difficult, locked you further into yourself. Now...there's so much technology that could help...

I remember the news of your death. I was far away at the time and at work when I received the phone call. I am still not quite sure how I made it through those next four hours. All I could think of was: did you really give up? You, who had, and who could have, taught us so much about life and living...Did you die, knowing that the people who had taken oath to preserve life were allowing you to die and you couldn't tell them that you didn't want to go just yet?

I was grateful that your loving and so supportive parents were no longer with us - your father dead

of a broken heart and your mother back in her childhood from dementia - so didn't know of your final trials. You were very lucky: you had parents who could afford to support your dreams...

You were buried, my uncle, in the same grave as your older brother, my oldest uncle, who had died of the same disease as you. He had the early onset version, so was dead at 16, the time of life that you, with the later onset version, began to weaken.

There's also questions that I still don't even really know how to ask...I remember reading in a text book about disability that many family members were relieved at their disabled relative's death, because the disability embarrassed them. Was this textbook basically retelling the old story of putting away from the group those who are 'other'? There's also the perennial questions: 'What is 'disabled'?', 'What is 'normal'?' and 'What/who is a burden on the community?' etc. ...

The questions became personalised when things happened to me. So many of these people walking around claim to be 'normal'...??? Yet, a seven year old Downs Syndrome boy, born to a Karen refugee family on the Thai-Burma border, who could speak three languages (was learning English as a fourth) and helped out in the village vegetable gardens and with the chooks, was the reason his family were denied resettlement in Australia: with Downs Syndrome, he could be 'a burden on the community'. This family went to Canada...

I still 'see' you around the place: in the spastic young man who lives locally and can now cross the road by himself; in the McCallum residents going out for their shopping trips, in the young man on TV, interviewed about the budget cuts to carers and his longing for independence – just like you - and so many others...He was luckier than you: he'd had partner and a child – his own family...something you had always longed for...When I asked you about this after you'd made comment, you shrugged, 'Who'd want someone like me?' My eleven year old self dreamed of a fairy princess who would come and love and take care of you...

While your body and mind are now at rest, is your spirit at peace, or is it still about, determined to bring the rest of us into your light? At the first onset of the disease, doctors said you'd have a normal life expectancy: 60-65 years. You were determined to prove the doctors right. You made it to 54. *Did* you decide to go early, or was the decision made for you? How many have had and how many more will have this decision made for them, so they, too, are not a 'burden on the community'? Were you still alive now, with the technology to hand, could you explain it, or would you ask someone to?

RIP 1997  
with love...  
Please, pay some respect  
and think on these things...

end of life enquiry