

Submission– For the Victorian Parliamentary Committee’s Inquiry into End of Life Choices.

An account of Margot Curtis’s excruciating dilemmas and final death.

**Note –**

This is the account of another dying human who thirsted for legal assisted suicide more than water. The news of this parliamentary inquiry is fantastic. However, it is too surgical for a daughter to summarize this 5 page submission in bullet points. I am writing about a human being I loved. All I can say is the account below is the lead up to, and consequences concerning my mother’s death. Yet I do believe that 20 years of reflection shortened in 5 pages should be helpful to your objective of understanding.

My mother, **Margot Curtis** was a gorgeous woman, widely loved and admired for her great intellect, wit, adorable sense of humour and incredible inner strength. Unfortunately she was diagnosed with **multiple sclerosis** at the age of 40, in 1970. It took 22 years of deterioration before she died. If the highly evolved voluntary euthanasia law now being campaigned for in Australia 2015, had been available for Margot, she would have **willingly** and gracefully **died 5 years sooner**. Margot was confident of that conclusion. Below is an account of her lead up to it, that was tragically **denied her**.

Just nine years into the disease, Margot had already suffered years of ‘**excruciating pain**’, in her own words. She was already struggling even to walk from one end of the house to another. Sometimes her **legs** would just **collapse**. Whenever I found her this way after school, she’d been struggling **on the floor** to get up for hours. One time I was lucky to get a few kind men who were doing roadwork up the street to help me lift Margot up.

It was around this time, 1979, my mother first told me **she wished she could suicide**. However, at that stage, although Margot wanted to die, she wouldn’t have chosen that option even if voluntary euthanasia had been allowed. She was incredibly brave and **wished to hang** on for two reasons.

1. While she knew my father would be strong enough to cope, both her kids were still in high school. They were too young to abandon, let alone by suicide.
- 2 There was still some faint hope of new surgery that could reduce the pain.

Unfortunately, those **operations** not only **failed** but left her in an even **worse state**. So, by the time I had matriculated, in 1983, Margot was unable to drive, nor walk unaided beyond from bed to the bathroom. She had already endured dozens of **ineffective** experimental **treatments** and several failed **operations**, with only the rewards of **accelerating her decline** and no longer being in a position to kill herself.

From 1983, sometimes when she was overwhelmed with suffering, she couldn’t help confide to me again that she wished she could die. Each time she would then express how guilty she felt and apologise. I would always assuage her guilt. She had enough to suffer by herself, even if all I could do was offer my arms and cry too.

Margot always did **feel better emotionally** for just being able to admit the depths of her feelings. However, in retrospect, it would have been better if there had been a psychologist who had specialisation in the area of voluntary euthanasia, (V.E.), issues. While it was **obvious that Margot was not ready to die**, it would have been the right time to get **Advanced Care Directive** and observe the level of seriousness in Margot's desire to die.

The family **priority** at this stage was just to **keep her at home**. My father and I both agreed on this course, but it was more firm for me since one of my first jobs had been a casual assistant nurse for many nursing homes around Sydney. I had seen enough to know it would have been a double nightmare for Margot rather than the simpler one we were able to sustain with the help of a district nurse.

Nevertheless, it was already too bad by 1987. A trained psychologist would have also seen that the humane line had been crossed by that year. Neither my mother, father, nor myself could comprehend how her demise could get worse, but we knew it would.

For these reasons Margot's death wish conversations with me, had become far more frequent. There is a difference in someone expressing a fantasy of release to truly being ready for it. I don't believe that Margot was at that point until 1987. She was now confined to bed in constant pain even on 8 endone a day, feeling too diminished, helpless and crying uncontrollably at some point, most days.

As her daughter and main carer I knew how heroic her sacrifice had already been, since the first time she told me. So I told her that I would help, if that's what she really wanted. I knew I would be arrested, but I wanted to give her the same level of courage and sacrifice for love she had shown me and the rest of her family. But now her reasons she didn't want to die in such a way were not personal, but legal -

1. She couldn't die knowing that I would go to jail.
2. Because it wasn't state sanctioned, any assisted suicide would be without proper medical means or knowledge, so there wasn't a way that wouldn't leave her family and friends utterly traumatized.

Margot despised this unjust law that placed her in a bitterly unsolvable dilemma.

It would have been better if she hadn't had this added psychological torment of having no control over her death.

Margot's disease was rotten enough. It robbed so much control over her body and life. Then at the time the theft was almost complete, the law robbed control over her death. While the disease was a natural disaster medicine was unable to avoid, her disastrous death was entirely man-made.

If Margot had been allowed to die when her desire was beyond doubt, she would have still had her mind, her home, her meaning, her loved ones around at the last.

I'll spare you a blow by blow account of around 1821 days of her painful descent from 1987 to her death 1992, but it was those last five years that shouldn't have happened.

So briefly, try to imagine the last time you had a headache or bad pain and the relief you felt after it left within hours. Then try to imagine 43,704 hours waiting for relief. That's 43,698 hours more than Christ had to go through during his crucifixion!

Also imagine Margot's last stage of hell. The one we had tried to avoid, but absolutely had no choice after she had her last stroke – a nursing home. Dad and I found the best possible placement after I researched 30 and visited about a dozen with my Dad. I am going to briefly paint her perspective in this "best of possible worlds".

After all she had already gone through, this is what she got, but let's imagine it's you-

Your body is heavy, cumbersome, sensitive, always in pain, unwieldly, impossible even to the trained. So while pushed by wheel chair into your morning shower, you are regularly bumped into walls, sometimes even dropped in the shower.

You've had too many strokes. You can't speak properly, so you're treated like a baby, dragged daily into a hoist, verbally abused for being difficult, regularly, because you're crying in pain. You have lost all your humanity and rights to the point that you are screaming out because –

- You are in pain and no-one is listening. They aren't listening because they just think you aren't all there.
- You are desperate to die but can't because you are administered drugs, force fed with a 24 hour milk shake up your nose, or worse, nursing home food.
- No-one will let you die because it **could** be the wrong thing to do. So everyone goes home secure in the knowledge that they have done the 'right' thing. As they are sleeping peacefully in the middle of the night, you have woken up to an impenetrable wall of agony and alienation.
- You scream out for more drugs. The Sister comes in and short temperedly says, "It's not time for your next dose." You try to say that for some reason your body is not responding to her theory, but you can't because half your face is paralyzed and she's already left the room anyway.
- That the horror is far more than just the pain. It's also the brutality, cruelty, humiliation, anguish, physical torture, fully immersed, fear, powerlessness and stupidity of your situation. Yet the outside world is blind to it and everyone inside accepts it or chooses ignorance because 'they can't go there'.
- That is, everyone except the people who dearly love you, who are just as helpless to stop the madness.
- So maybe you're not completely alone, but on top of everything else, you have the anguish of knowing what this is doing to the people you love the most.
- That looking back, you've had a beautiful, dignified and loving life, but like everyone else, didn't know a thing about this underworld of the diseased young or frail old.

- That this legal blind spot and brutal mistake in our society could trap you and close you off from everything you have earned, learnt, loved, and believed you were entitled to, particularly at the end.
- At that moment and every night until you die, you will have woken up to the nightmare that this society is mad, with the tragic irony that it is too late for you to do anything about it.
- You also know that it will continue happening to others because the people who understand this pit of hell on Earth are those experiencing it, or witnessing it with selfless love. That to see it courageously in all its terrifying truth must leave such survivors so traumatized, they may be too disabled themselves to effectively challenge the law.

No doubt you will think this is full on, but it's nothing to the reality of all the ubiquitous and outrageous "end of life" scenarios lived out daily. Don't imagine that this only happens to a minority -After Margot did die, I worked and witnessed the reality in many more nursing homes in Sydney - It happens to the majority in old age.

The common refrain I would hear, "If I'd only known how bad it was going to be, Linda. If I'd only known." That was, for the ones who still had a mind. My mother was merely in the minority, having got there twenty years sooner through early chronic disease.

My only consolation being that the last words I said to her when she was alive was, 'I love you.' Not enough. Not enough!

So, I'm sorry if this hurts you, but perhaps I have to be this blunt to get you to take voluntary euthanasia seriously. As Harry S Truman once said, 'I never give them hell. I just give them the truth and they think it's hell.'

Except Truman was responsible for the nuclear bomb, whereas I desire this text to trigger a love bomb – empathetic education and action to explode an archaic, horrendous law. We need to close off this labyrinth of stupidity and madness in our society and find a new way.

We need well established and drafted voluntary euthanasia, (V.E.) laws in Australia now.

We also need Baby Boomer tours of nursing homes so they have a chance to see how their future misery, frailty and aging is 'managed', 'pre-ordained', and economically irrationalized, by our outdated systems. For it's the Baby Boomer generation who are the first to be enlightened and confident enough to say, 'Hell, No!'

We need to be aware that the religious right that are against V.E. also happen to run nursing homes and gain tens of millions of dollars in revenue streams. That therefore religious orders in the industry have a huge conflict of interest in the V.E. debate. More V.E. = less nursing homes = less revenue. Each should be forced to declare their financial interests before being allowed to challenge humane change.

What happened to Margot happens to millions of people in the West. It is likely to happen to you or me, if we don't address these problems. When so many innocent people are

imprisoned in their body, by a regime of irrational thought, law and action, what else can this be called other than a silent holocaust? One that only a gray revolution can stop.

I'm not living out my last days in a private hell and silent war. Nor should anyone, who doesn't want to. Nor do I intend to watch another member of my family live beyond the time they are desperate to die. It is so mediaeval and so wrong; and no being of such brilliance and beauty such as Margot Mary Curtis can die so insanely without precipitating – permanent change.

I hope all the letters that dare to show the raw reality add up to your committee confidently concluding the same.

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