

## **Submission to Senate Inquiry into Aged Care:**

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Damian O'Sullivan

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My only exposure to a Young Person in a Nursing Home is Chris Nolan. Chris has very severe hypoxic BI. He went to work in Vietnam in 1996 as a solicitor in Freehill's Hanoi office and suffered a catastrophic ABI.

In coma for 6 months, Chris 'woke up' laughing at a joke his cousin had made in his hospital room! (I took this news with a healthy dose of scepticism) After hospital, because he had no compensation, the only option was an aged care nursing home. His parents, who have a farm 2 hours west of Melbourne, made a decision to keep Chris in Melbourne close to his friendship and social group and to allied health and medical expertise in severe brain injury. Chris had and has a great capacity for people and friendship.

I lived with Chris in 2 shared households for a couple of years prior to Chris leaving for Vietnam. He was an amazingly charismatic person and our group of friends had him destined for greatness – most likely Prime Minister of Australia – and I'm not joking. He had the looks, the poise, the brains, the words, the common touch, the whole package.

The reason I am making a submission is to give you a personal insight from a friend who knew and lived with the very able Chris Nolan and who now sees him 'trapped' in a profoundly disabled body and communication system – unable to move, speak or see much.

Mary, Chris's mother, has been telling anyone that would listen that Chris hears and understands and communicates expressively and receptively with facial expressions and a long blink for Yes. I went along with this and dismissed it as a mother who had fantasised a reality into existence – for her!

I stopped visiting Chris. My rationale was that he didn't know who I was anyway and that it made no difference. This rationale hid a more unpalatable truth that I didn't get anything out of it and it was horrible to be with a profoundly disabled person as it confronted my sense of self that did not want to be that way and therefore was quick to reject any intrinsic value to this way of being.

People who are non-speaking are often treated as if they do not understand and are 'not there', that is not cognitive. They are regarded by many as the most marginalised group in society.

In May of this year (2004) I visited Chris for his 36<sup>th</sup> birthday. This was the first time in the 7 ½ years of Chris's new world that we had been together alone. I was apprehensive at first and then I started to talk to him about all sorts of things. When I touched on humour – especially in relation to 2 shared friends that have always cracked us up – his face lit up and he laughed! I couldn't believe it and part of me didn't want to believe it. So, of course, I tested him out to see if this was just a serendipitous happening. I spoke of the serious and mundane and then I mentioned Trevor and Craig again and again his face lit up and he started laughing.

Still not convinced that he REALLY knew what I was talking about. I spoke to him about some of my (very funny) brother's exploits – who Chris lived with as well – and he cracked up laughing again.

I was incredibly touched, moved and inspired by this. My thoughts went straight to what it must be like for him. I had never gone there before. But when I connected with this human being on a deep and fundamental level, I got his experience and I was profoundly moved.

I witnessed the courage, the determination, the gallant hero that we had destined for greatness many years ago and here he was. I had just failed to recognise him through the filter of my fears.

Chris is aware and can understand, he is just trapped inside a body that can't utilise the standard modes of communication. His communication however is profound. To connect at the level of being really encompasses the gamut of human endeavour.

Chris and others in his situation require resources to live and fulfil their potentials. It is a measure of a society that not only cares for its vulnerable, disenfranchised citizens but elevates their status to be recognised and valued members of the community. Chris has contributed to many people's lives and I know that but for a twist of fate he would be reading this very submission and making a powerful stand for Young People In Nursing Homes with an Acquired Brain Injury and making a positive difference and contribution to their lives.

Chris is the youngest resident in his nursing home and one of those who has lived there longest. 13 men died in Chris's 4 bed room in the first 4 years he was in the nursing home. He wept for the ones who had become close friends and attended two funerals.

People entering nursing homes are usually appropriately letting go of life. A young person with ABI who has 'woken up' from coma after weeks or months is trying over the following years to re-engage with life and people. The two attitudes (and 'cultures') are in opposition... It is distressing for young people to have older people dying around you.

It is not bad enough that Chris is in an aged care facility, his nursing home, Harold McCracken House in North Fitzroy is closing and re-locating to Eltham. Chris needs a home, close to family and friends and with the care and environment to live and thrive and interact with others – as he did with me. If there is no intervention, Chris will go to Eltham, this will cut off friendships and mean prohibitive transportation costs to appointments and gatherings.

As Chris's mother said to me:

"Given the chance people like Chris can fulfil an important role in society, not in powerless dependency, not as we or they might have chosen, but giving and receiving and perhaps teaching some of us who are more able bodied, aspects of what life and love and being is about."

I urge you to consider – with urgency - this amazing group of people and deliver the services and resources that they require to fulfill their potential as valued members of our community.