

# **AGED CARE**

**THE SECRETARY  
SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE  
SUITE S1 59  
PARLIAMENT HOUSE  
CANBERRA ACT 2600**

**SUBMISSION BY:  
MS EILEEN MCCORMACK**

**INQUIRY INTO AGED CARE PART C: The Inappropriateness of Young  
People with a disability being accommodated in Nursing Homes and the  
extent to which residents with special needs, such as dementia, mental  
illness or specific conditions ( acquired brain injury) are met under current  
funding arrangements**

**28th JANUARY 2005  
MS EILEEN MCCORMACK**

**SUBMISSION TO SENATE INQUIRY INTO AGED CARE**  
**Inappropriateness for Young People with Acquired Brain Injury to Live in Nursing**  
**Homes - 28th January 2005 Written by Eileen McCormack**

This submission is to support and advocate on behalf of my friend Chris Nolan 35 yrs, James Ling (died 2004 at the age of 25yrs) and all young men and women and children who are fated to live in an aged care facility.

I write this submission with 24 years nursing experience as a RN Div 2, 14 of those years in aged care and 3 years as a Social Worker in the field of Acquired Brain Injury. I am a founding member of **Inability Possability Inc.**, a charitable organisation raising awareness and advocating on the issue of young people with an acquired brain injury living in nursing homes.

My submission is not going to present the senate inquiry with a series of statistics related to the issue, unacceptable as they are. They are frequently quoted and you can access them through other submissions on this subject and websites such as [www.ypinh.org.au](http://www.ypinh.org.au) and [www.inabilitypossability.org.au](http://www.inabilitypossability.org.au) or [www.biaq.org.au](http://www.biaq.org.au)

While I appreciate statistics are important in order to understand, plan and respond to situations and people's circumstances any number of statistics have not helped young people in nursing homes to date.

I would ask of the reader at this point to consider the following questions: Would you consider it acceptable if you or any of your siblings or children, acquired a brain injury and required high level care and had no other choice than to live in a nursing home?

Have you ever visited an elderly parent or relative in a nursing home, not an upmarket retirement village - a nursing home where most residents now are either Category 1 or 2 meaning they often have various forms of dementia or are quite physically disabled? Many nursing homes do a great job and we are grateful for the good care provided by the facility where Chris lives. The staff are caring and committed to all those in their care and the quality of care provided has meant Chris enjoys a high quality of life because of it. No matter what the standard of care provided they are grossly inappropriate for young people.

Nursing these two young men Chris and James and subsequent others, I could not be anything but moved by their determination to live life not just survive. Their spirit for life and drive to regain something of their previous life as well as striving to find new ways to engage in their lives as they are now, was and continues to be inspiring.

Chris Nolan has lived in the nursing home for 8 years, he enjoys his life but he has also indicated he does not want to remain living in an aged care facility for the rest of his life. He is estimated to have a normal life expectancy. Chris is probably like many of you reading this submission, a high achiever, captain of his school, Honours graduate in Law and Economics; involved in his local community in sport and one of the three founders of the Meredith Music Festival in 1990 and now in its 14th year.

This event came out of his vision, to give young people an opportunity to experience alternative music in a beautiful country setting. It would have to be said Chris is gregarious, passionate, loving, a thinker and did not and does not tolerate fools and was never one to allow an injustice to remain.

This was Chris before he acquired his brain injury and he has lost nothing of those qualities. He has however lost his ability to speak (although he does communicate), to see and to be able to move.

He continues to participate in life attending annually the Meredith festival, as well as concerts and bands and he continues to love going to the family farm. He didn't survive to live out his years in a aged care facility. The reality is that the majority of his time is spent at the nursing home- hearing the demented words and unusual sounds of the elderly or having to endure the sounds of the old lady who sings Home Sweet Home incessantly in the room next door. Chris is not deaf and so the sounds are acutely heard. He has enjoyed getting to know some of the men who shared his room, they often showed great kindness to him. Until he got his own room Chris experienced the deaths of 13 men in 4 years and was distressed by all of their passing.

James too lived at the nursing home where Chris lives and was making good progress. His family moved him to another aged facility in good faith to be closer to his family. It was new, lots of light and James had his own room. An intensive handover was given in relation to his care. In a short space of time he lost weight to the point of malnutrition, old pressure sores broke down with virulent infections setting in and he was often not turned for hours on end and left lying in his own excreta. His consultant GP advised the family to move James after 10 months. He was admitted to a low level care hospital where he remained. While he received better nursing care he was socially isolated with only his parents and 2 or 3 others coming to visit him. He endured great physical, psychological and emotional pain. I visited James over the period of 5 years. I cannot write about this without absolute despair that this happened and we would be fools to think this is an isolated case. James died because of complications after experiencing poor care in a system that didn't care, living in a hospital with nowhere to go as no nursing home would accept him. The health system remains wanting for those who acquire a brain injury, who have no form of compensation and require high level care. The experience of James sadly contrasts with the experience of Chris and what is possible when people are committed to providing appropriate care and providing appropriate choices of where to live.

As I indicated previously I have experience working in aged care and witnessed a deterioration in the standard of care since the introduction of the deregulation of nurses. Standards may have improved in so far as the keeping of records and documentation but at the bedside the standards didn't improve they declined with nurses and nursing assistants spending less time caring and more time writing about their intended care. Good intentions remain good intentions if they are not acted on. I would also make the comment that working with a highly dependent group of people with associated behaviours is extremely hard (but rewarding) work with poor remuneration.

I have no doubt of the good intentions of this Senate Inquiry but I implore you all to act on the findings that are determined. This inquiry into Aged Care is sincerely welcome as the aged as all citizens deserve the very best of care. It is our duty and responsibility as a civilised and caring

society. That same duty and responsibility should be accorded to young people in nursing homes by giving them opportunities and choices as to where they might live. Don't let them remain statistics which are spewed out every year but not acted upon. Don't allow politicians of all persuasions to keep offering up the same justification for inaction that 'It's a State responsibility'. Or 'its a Commonwealth responsibility'. It is our responsibility as a community, and politicians responsibility as our elected representatives.

We as Australians have show ourselves to be a compassionate people, living in a rather privileged society, Young people living in nursing homes are currently underprivileged in comparison to the privileged lives most of us enjoy.

Once again thankyou for you attention and commitment to hearing the experiences of those young and old who daily live the reality of life in aged care facilities and who entrust their well being to us. I hope we will not continue to let them down.

Yours sincerely,

Eileen McCormack