

## Submission to Senate Inquiry

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**“Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia”**



Name: Leona Jones

I am happy for my submission to be published

Signature:

I am the mother of two young people (Craig and Nicole) who were diagnosed in their early twenties with an extremely rare form of Batten's Disease called Kufs Disease. It is a debilitating, progressive neurological disease characterised by slow degeneration of the nervous system. There is no cure. Craig and Nicole's mother died from Kufs Disease at forty-two years of age, following many years living in a nursing home. The disease was undiagnosed until after her death. It was not thought to have been passed on to her children.

In their early teens both Craig and Nicole developed severe epilepsy. Subsequent behavioural problems noticed in Craig and Nicole were thought to be related to the early death of their mother. They were both subsequently diagnosed with Kufs Disease, Craig at twenty-four and Nicole at twenty-one. Because the disease was so rare, there was no support available. Supporting both of them to live in the community wasn't sustainable, we did this for four years but as their conditions progressed, their support needs increased and we had no options but to consider aged care.

### **Term of Reference (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities**

How it felt, having our children in a nursing home

Their father Ray, made Craig and Nicole a promise that they would never have to go into a nursing home. In the end, he felt he'd betrayed them. People didn't understand the reasons why the kids couldn't be at home. We were full of guilt, we were clothed in guilt. We reacted to even the slightest criticism. When I look back on this period I realise how disconnected we felt in relation to the care of our children. We thought the horror would end once they were in the nursing home, somewhere safe. Really, the move into the nursing home was just the beginning of the horror story.

The thing I dreaded most when I went to visit them was walking out again. I felt I'd betrayed their trust by leaving them there. I overcame this fear by going less frequently, then even less frequently.

I know we were judged for this. The staff often made hurtful comments. Comments like "oh, you're the parents are you". I remember on one occasion Ray forgot the pin code to exit the nursing home, the staff member who punched the code in said to him "if you came more often, you'd remember the code." It was as if as parents we'd abandoned our children by placing them in a nursing home.

#### How living in a nursing home was for our children

To visit our children, we walked past room after room of elderly people, lying in their beds at the end stages of their life. For our children to be there and have to see that was dreadful.

Our son was frustrated and angry, he was a young man living among the elderly with dementia. We actually bought him a punching bag at one stage as a way for him to channel his frustration.

Craig and Nicole needed socialisation, they needed to get out and about. We felt that was the only way they could survive in that environment, but in reality they were just locked in and left.

They wanted to play their music, they were active and mobile at this stage but there was no therapy, no physio, and no speech therapy. Craig and Nicole were so often just sitting in front of the television, watching daytime programs that held no interest to them. I remember Nicole wanting to watch the Bathurst races, which she always loved, they made her turn it off. They were so alienated in the nursing home, their rooms became their worlds.

I think they became depressed. They were certainly disoriented and displaced. It was an uncomfortable environment for them. Craig never adjusted. He would hang

around the door, waiting for an opportunity to get out, even if it was to accompany the handyman outside.

Nicole responded differently, she made an effort. She joined the choir and used to pass herself off as a staff member, she didn't know how else to relate to the elderly residents. When residents asked her for help or direction, she was delighted.

It was not a healthy environment for them. How do you equate someone with the history and loving family of the elderly residents with someone whose life has really just started? It can't possibly work. Craig and Nicole were surrounded by people taking stock of their lives, they were only just beginning to live their lives.

### **Term of Reference (i) what have you achieved by virtue of YPIRAC funding and what are you afraid of losing?**

#### How Craig and Nicole benefitted from YPIRAC

'Karrong,' The Shared Supported Home Craig and Nicole moved into was funded by YPIRAC. It is called 'Karrong' after the Aboriginal name for home Nicole saw the move as coming home to her own place, she was totally committed and eager to get out of the nursing home, she had been there for six years.

Nicole was really proud to be considered a pioneer in this new shared supported accommodation. She wants to be remembered as one of the first people to move into this sort of care. She is very proud of this.

Craig had been in a nursing home for five years. Despite how desperate Craig had been to move out, he'd become institutionalised. Staff had convinced him that he was better off in the nursing home. He was frightened of moving out, he'd resigned himself to the fact that the nursing home was where he was going to end his days.

In the end we supported Craig to reconsider his decision. After a few months he decided to join Nicole at Karroong. Unfortunately Craig only had thirteen months living out of the nursing home before his death three years ago. In the end what



got Craig over the line was the knowledge he could bring his beloved dog Dusty with him to Karroong. Dusty is still in residence there today.

## **Term of Reference (e) the alternatives to residential aged care for young people with disability OPTIONAL**

### **Craig and Nicole's experience of Shared Supported Accommodation (Karroong)**

The difference between the nursing home and Karroong was choice. Choice about what they watched, what they ate, what music they listened to and how their room was furnished. They had access to regular physiotherapy and medical care. The quality of personal hygiene and care was significantly higher than what they'd been receiving. This was because they had a higher ratio of support.

They were surrounded by people their own age, people with shared interests. They were thought of and treated as individuals. The service was tailored to their needs, rather than them fitting the service. Their individuality was recognised. Nicole's 'attitude' was embraced and encouraged, in the nursing home there was no place for her attitude...it didn't fit. Their personal preferences were listened to and respected.

Nicole was ecstatic, she wanted everyone to know about where she was living and how it was going for her. She was proud of her room and loved decorating it.

Craig was very ill when he moved, but he enjoyed communicating with the staff. They both appreciated having staff who would listen to them and take time with them. Both and Craig and Nicole were able to discuss advanced care planning, they both had a strong preference to die in their home and not be hospitalised. It was a relief to Ray and myself that Craig's wishes were respected. We know Craig was terrified to die in hospital. At Karroong, Craig was able to die with dignity, in his own home.

### Our experience of Shared Supported Accommodation (Karroong)

Craig and Nicole moving to Karroong was huge to Ray and I. We could walk in anytime of the day or night and we were welcomed, we were made to feel part of the adventure. We got to know the staff, we've been listened to and we are supported.

At the nursing home we became disenfranchised and immobilised by our guilt. We felt dreadful having to walk away and leave Craig and Nicole in that environment.

At Karroong our opinions are valued we are deeply involved. We became part of our children's future once again. We've really embraced that opportunity and become more and more involved in many aspects of Karroong such as staff selection and membership of the advisory Board. We could never have conceived having that involvement in the nursing home.

Being able to speak freely about our children to staff has relieved us a lot of the terrible burden of guilt. Being able to speak to other parents has been very satisfying, giving us the opportunity to share our mutual journeys.

Even now, when I get in the car to go and visit Nicole, I am apprehensive, but that is to do with her deterioration, not her living situation. Once I get there I am fine though, Ray and I visit together and this way we support one another.

Every Christmas day we go to Karroong. We get so much out of the day. The Christmas just gone, we all celebrated together. We came away knowing what we'd just shared was something special, special for us, for Nicole and the other residents. This Christmas, a fellow resident who we've never heard speak, joined in and we heard him speak for the first time in six years. It was a golden moment.

I am appalled that after twelve years of having Children in care there are still young people living in nursing homes. I would walk over hot coals if I could prevent this. There is no place for young people in nursing homes.

It's so satisfying to be one of the fortunate families at the end of such a long journey. Our children have received such tremendous quality of care, in what they see as their home. I want this for other families

### **Evidence and Supporting Information**

I invite you to view a digital version of our story, told from the perspective of my husband Ray Jones.

<https://www.youtube.com/watch?v=NAmyWBtYm4o>