

SUBMISSION PREPARED ON BEHALF OF ROD CHRISTIAN JOHN THOMPSON IN ACCORDANCE WITH PART (C) OF THE TERMS OF REFERENCE OF SENATE INQUIRY INTO AGED CARE.

PART (C)

THE APPROPRIATENESS OF YOUNG PEOPLE WITH DISABILITIES BEING ACCOMMODATED IN RESIDENTIAL AGED CARE FACILITIES AND THE EXTENT TO WHICH RESIDENTS WITH SPECIAL NEEDS, SUCH AS DEMENTIA, MENTAL ILLNESS OF SPECIFIC CONDITIONS ARE MET UNDER CURRENT FUNDING ARRANGEMENTS.

DETAILS OF YOUNG PERSON CURRENTLY IN AGED CARE FACILITY

NAME	ROD CHRISTIAN JOHN THOMPSON
BORN	26 FEBRUARY 1977
AGE	27
	ADMITTED TO NURSING HOME AT AGE 19.

SUBMISSION PREPARED BY PARENTS

**JOHN HILTON THOMPSON
KAREN LOIS DRINKWATER.**

We the parents of ROD CHRISTIAN JOHN THOMPSON make a submission on behalf of our son for the information of the Senate Inquiry into Aged Care. We are prepared to attend and give verbal evidence to the Senate Inquiry. The relevant part of the Inquiry we wish to address is Part (c). Rod has a severe acquired brain injury and is currently a resident of he QUEEN BEATRIX NURSING HOME, PINE STREET, ALBION PARK, N.S.W. He has been a Nursing Home resident since the age of nineteen. We believe that an Age Care Facility is inappropriate accommodation for our son. Aged Care Facilities fail to meet his special needs and requirements.

The circumstances which led to him being a patient of an Aged Care Nursing Home are: -

Rod was born on 26 February 1977; he was a normal and healthy person. He excelled at sport, was popular with family and friends and was doing well at school. His life proceeded normally until at the age of seventeen, he was involved in a horrific and tragic accident. On 4 November 1994, he fell ten metres down a stair well, landing on his head. The fall caused severe brain damage. He was admitted to St Vincents Hospital, Darlinghurst, N.S.W. After a short time he was transferred to the Brain Injury Unit, Liverpool, where he underwent a long period of rehabilitation. The damage caused by the accident was so severe that rehabilitation was almost negligible. Rod was admitted to a Nursing Home in 1996.

Injuries include, quadriplegia, with marked spasticity. He is unable to speak; unable to eat and is P.E.G. Tube fed. He has short-term memory loss. He is incontinent, with no bowel or urine control. He has a severe scoliosis of the spine, his legs are straight and rigid, his feet are hooked and rigid, his hip has been removed and he has only limited use of his right arm. His physical condition makes it very difficult to make him comfortable both in bed and in a sitting position. He needs to be continually readjusted and made comfortable. He needs to be turned on a regular basis to avoid pressure sores. He is totally dependent for all his needs, now and in the future.

Rod's condition has improved to the stage that he now has a high level of awareness. His short-term memory is improving albeit very slowly. Rod is able to communicate by spelling on an alphabet board using a laser pen. The one thing he repeats over and over again is that he does not want to be in a Nursing Home and that he be allowed to live at home.

HE ALWAYS WANTS TO GO HOME.

Living at home is not an option, as he requires such a high level of qualified nursing care and his compensation falls way short of funding such an option. His life is a constant misery punctuated with some occasional quality of life from carers and family.

Rod did receive compensation as a result of his injury, but the level of compensation was reduced by 90% due to his contributing negligence. The money is in trust and is used to employ carers / companions over and above nursing home staff and that of which his family provides. The carers take him on outings and keep him company in the nursing home for a few hours each day. As mentioned previously the compensation is not enough to take him home and set up a long term nursing care situation.

The Department of Aged Care has calculated a percentage of the compensation that should be paid, for his Nursing Home care. As parents we do not believe that part of the compensation payment should be paid to Aged Care. We believe that compensation should be used for the employment of Carers over and above that of Nursing Home Staff. By paying part of his compensation payment to Aged Care it means we have to reduce the money that the trust can spend on employing Carers. It also eliminates any chance we ever had of building up sufficient capital to the stage where he could be taken out of the Nursing Home and cared for at suitable home.

Rod is going to be in the system for some time and will become a burden on the government very shortly if various government departments continue to clawback his funds. The thinking here on government policy defies logic.

A NURSING HOME IS NOT THE RIGHT PLACE FOR ROD OR ANY OTHER YOUNG PERSON.

Nursing Homes do not readily accept Young People as they find them too difficult to manage and handle. To get Rod into a Nursing Home in itself was a difficult process and to transfer him to a more conveniently located Nursing Home that is of a satisfactory standard is almost impossible. To get him into this current nursing home we had to convince them by offering to take him out on day trips, bathe him And generally be around to take the pressure off them.

We as parents live some distance away which makes it difficult and expensive to visit regularly, which of course we do! John has a 170km return trip and Karen 110km return trip, and Karen actually lives next door to Coledale Hospital which specializes in nursing and rehabilitation care but cannot take Rod as he is already placed. The catch 22 of the nursing home world.

Nursing Homes do not want young people as much as young people do not want to be in a nursing home.

The Staff at the Nursing Home are not trained to care for young brain injured patients with specific needs and requirements. They are only trained to deal with Aged Care patients.

Nursing staff are over worked and underpaid with a high turnover and sick leave. There is always a chronic lack of staff and they do not have enough time to pay the necessary attention to him.

As a result of his brain injury, Rod exhibits antisocial and abnormal behavior. Nursing Home Staff are usually intimidated by his behavior and either spend minimal time with him or avoid him all together. Staff have complained to Management about his behavior. (what more evidence could one need of a complete lack of training for such patients) They do not know how to deal with him so they choose to ignore him as much as possible. There is little or no empathy.

Rod's personal hygiene is poor. He never seems to be properly clean. Whether it is the fact that he resists nursing home staff tending to his personal hygiene needs or whether they do not care or whether it is because they are intimidated by him or they are just too busy, is not clear. He sometimes lies for hours unattended with his head against the bars saturated in either his own urine or the food from his leaking

food tube. The fact remains that he is totally dependant upon Nursing Home Staff for personal hygiene needs and these needs are not being adequately met.

NURSING HOMES ARE NOT EQUIPPED OR FUNDED TO HANDLE YOUNG PEOPLE WITH DISABILITIES AND BRAIN INJURY AND STAFF ARE NOT QUALIFIED, TRAINED OR COMMITTED TO LOOKING AFTER THEM.

Rod requires continual mental stimulation. He attempts to communicate with the Nursing Home staff. In the main they have no time or desire to talk to him. If Rod did not receive monetary compensation he would be left to lie in bed with little or no attention other than that of his parents.

Rod is the only patient of his age and condition at the QUEEN BEATRIX NURSING HOME. He has no interaction with other patients. He is not involved in any of the outings or in house entertainment organised by the Nursing Home. If it was left up to the Nursing Home Staff he would remain isolated in his room with no outside stimulus. Everything is aimed at entertaining and caring for aged patients. Examples of entertainment and stimulus are sing a longs of songs from the early 1900's. Bingo etc. There is nothing aimed at stimulating or entertaining a person of Rod's age or condition which is what he constantly craves. Nursing Home Staff have never taken him on an outing.

I find it difficult to understand why there were almost unlimited funds available to spend on Rod's Hospital care, immediately after his accident right up to him being placed into a Nursing Home. Treatment and care at hospital was excellent. However once he was admitted to a Nursing Home the difference was obvious. The standard of care compared to a State Hospital is completely opposite and almost non-existent. It is as if the mind set is :-

“ ENOUGH HAS BEEN DONE. NOTHING MORE CAN BE DONE, SO THE PATIENT IS PUT INTO A NURSING HOME. PATIENTS ARE HELD IN BASIC CONDITIONS UNTIL THEY DIE. THERE IS NO EMPHASIS PLACED ON REHABILITATION AS AGED CARE PATIENTS DO NOT NEED REHABILITATION AS THEY ARE GOING TO DIE SOONER RATHER THEN LATER. WHY YOUNG PEOPLE ARE PLACED INTO THIS ENVIRONMENT DEFIES BELIEF AND LOGIC. TO PLACE A YOUNG PERSON INTO A NURSING HOME IS A DENIAL OF THEIR BASIC RIGHTS.

To place a young person with quadriplegia and severe brain injury requiring 24 hour medical and nursing care into an aged care environment is an indictment on government planning and funding.

This is by no means a new issue! Some years ago another government enquiry came up with this result – not enough funding available at this time. (read votes)

A 2 day conference in Melbourne in 2003 titled Young People In Nursing Homes (YPINH) showed up Federal and State governments for their “pass the buck” attitude.

Then Federal Minister, Amanda Vanstone, failed to attend to attend to open the conference and instead sent along a video tape revealing to the several hundred attendees an appalling lack of understanding and compassion for the issue and passing the blame onto State governments.

She displayed a complete lack of leadership and failed to facilitate a national approach to the issue drawing together all the parties to tackle the issue head on.

The fact remains that society is keeping Rod alive – he is on life support and has no options or choices available to him due to his condition, other than what we as parents can strive for to make his existence at least bearable.

If there were no family to look after Rod’s interests the governments response would be to place him into a nursing home with the minimum of care, staring at 4 walls without stimulus or interaction until he died.

Disgusting to say the least!

SUGGESTED ACTIONS

SHORT TERM

- 1. Recognition and support of the Young People in Nursing Homes (YPINH) organization as a valuable network involving parents able to assist government.**
- 2. Provision of dedicated staffing in nursing homes for young disabled people with such staff trained and qualified to provide appropriate care and paid accordingly in recognition of their expertise.**
- 3. Access to State based disability funds to assist with providing these services.**
- 4. Compulsory regular meetings (and recorded minutes) with nursing home management and staff, parents and carers with standing agenda items relating to quality care and lifestyle outcomes for people in these inappropriate environments.**

LONG TERM

- 1. Federal leadership in tackling the issue of YPINH through coordination of a joint approach to planning and funding.**
- 2. Provision of appropriately funded group homes/facilities for young people currently in the aged care system. This will have the added advantage of freeing up thousands of beds for the aged.**
- 3. Examine of other systems as in New Zealand for compensation and support of injured people so that all needs are met equally and not left up to the courts to give compensation awards on an inconsistent and unfair basis.**

John Thompson

Karen Drinkwater