

Dian Deckys



The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

INQUIRY INTO AGED CARE

Re: TERMS OF REFERENCE

(c) the appropriateness of young with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements.

Due to a recent personal experience I have been made aware of the terrible plight facing young people who have suffered a disability and encounter the lack of appropriate accommodation post hospitalization.

Under current funding arrangements young people with a disability have little choice but be admitted to an aged care facility, when in fact they would prefer to have the right to choose where they would live.

On February 3rd 2004, my 23 year old son Grant, was involved in a car accident near the Bli Bli roundabout. Due to the serious nature of Grant's injury (closed head injury) resulting in Diffuse Axonal Injury, he was immediately stabilised at Nambour General Hospital and transported via helicopter to the Royal Brisbane Hospital. where he remained for seven weeks in a state of coma (27 days in the Intensive Care Unit and a further three weeks in the Neurosurgical Ward.). Whilst in Royal Brisbane Hospital Grant received the following services to assist in his recovery

- Physiotherapy twice daily 7 days per week to assist in maintaining his lungs and thus avoiding infection
- Showered daily in a high-backed shower chair
- Sitting out of bed twice daily to assist in avoiding pressure sores and to maintain a clear airway.

He was transferred back to Nambour General Hospital to Ward 2C, a Medical Ward, on Wednesday 24th March, still in a state of coma, on the premise that Royal Brisbane Hospital were not providing any more services for Grant than Nambour General Hospital could. However on his return to Nambour General Hospital we were informed that Physiotherapy services were available Monday - Friday and once daily only, and showering and sitting out of bed may not be possible as chairs were not available.

Recently I spoke to a Physiotherapist who specialises in cases such as Grant's and advice indicated that unconscious patients require a higher level of care and really he should have Physiotherapy three times daily. My other son and I give Grant arm and leg exercises four to five times daily as the NGH only give them every second day, once only, Monday to Friday. Also we massage Grant daily to assist in good circulation, and perform swallow triggering stimulation three times daily, as the Speech Pathologist can only manage to do it occasionally.

During Grants hospitalization we give recognition to and appreciate the wonderful care provided by the supporting medical team, allied health and nursing staff.

Nambour General Hospital is now pushing to send Grant to an Aged Care Nursing Home. I pointed out that Nambour General Hospital was the best place for Grant to be as they have a treatment plan all ready to go to assist Grant in reaching rehabilitation stage. Furthermore we expressed the fact that aged care facilities focus on caring for the aged not the young (remember Grant is just 23), and that nursing homes do not develop an Individual Service Plan, their focus is on physical care and therefore Grant's changing needs would not be met.

The needs of young people and people with disabilities are very different to older, frail Australians in terms of physiotherapy, occupational therapy and stimulating activities.

Throughout the meeting I was adamant that an Aged Care Nursing Home was inappropriate accommodation for Grant. Also I stated that this was a government problem, not mine.

It has been a very confrontational process where I am seen as an annoyance, when I believe I should be seen as a caring family member wanting to maximise opportunities for Grant to live a quality life both now and in the future.

I am not satisfied with the outcomes of meetings and therefore request that Grant remain in Nambour General Hospital for a further 3 - 6 months to see if any further progress can be made. If there is no further progress then I would like to arrange care for him at home. I believe this would ensure that he becomes a lesser burden on the health system if his care is maintained at home

I am aware of precedence set on the Sunshine Coast in the mid nineties where a similar case occurred and the young man's care(although on a ventilator) at home was funded by Queensland Health. I therefore am making a similar request.

Grant requires a high level of care at this time, however following a recent neuro-physiotherapy assessment I was told that if Grant receives the necessary therapies for slow stream rehabilitation he would be walking and talking within two years. It was recommended that Grant seek accommodation in Jacana at Bald Hills, an ABI residential care facility.

There are only two long-term accommodation facilities for young people with ABI in Queensland. One has 16 beds (Casuarina) and the other (Jacana) 50 beds only. This is the type of accommodation which would be appropriate for Grant right now, but due to the heavy demand for this service he could be waiting for up to 4 years- he needs it now.

Grant cannot speak for himself right now, but as he has always lived at home I know that would be his choice of place to live - not an Aged Care Facility.

Grant suffers from recurrent situations with his lungs, is very prone to infection and requires:

- access to acute medical intervention so as to prevent minor problems becoming major ones
- 24 hour one-on-one care by someone trained to meet his needs
- a dietician, neuro physiotherapy, occupational therapy, speech therapy
- coma arousal therapy

This young man deserves the right to access the rehabilitation interventions necessary to optimise his opportunities to live a full, meaningful life - this will not happen in an aged care facility.

The current use of aged-care facilities for housing young people with high level care needs resulting from ABI is inappropriate and inadequate to meet the specific and complex needs of this group.

Therefore I request:

- a policy of no new admissions into residential aged care facilities for younger people with disability.
- development of an action plan for moving all younger people with disability currently living in residential aged care facilities into community living, giving priority to the youngest.
- development of pathways for people with disability which exclude residential aged care facilities as an option. Preferred alternatives of care would include hostel accommodation, group homes, an individualised package based on providing funding tailored to the needs of individuals to enable people to remain living at home.
- urgent resolution of the State and Commonwealth Government dispute about who is responsible and of the cross-government issues.

It is time to act not just talk! I speak not just for my son but for all young people crying out for help to be given the human right to choose where they might live.

