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

Helen Barker

To Whom It May Concern,

I'm writing this on behalf of our family, mainly on behalf of our daughter, Angela who is currently living in a nursing home at the age of 18, she has been there two years in September.

In March 2004 her ex-boyfriend bashed her and due to Victim of Crime not being compensation we were told we have no funding, VOC compensation is only a token gesture.

We were told she would probably get no better than she was in intensive care, she was virtually in a vegetive state and she should return home to Benalla (which is in country North East Victoria) to an aged nursing home. We had said, "she wasn't going to a nursing home she was coming home". Without any rehabilitation Angela would have stayed a vegetable.

We were told that she could not participate in her own rehabilitation, so none of the specialized Brain injured rehabilitation would have her. Then MECRS came and said "that they would take her even if it were just to put her in a wheelchair so we could take her home."

Do you know what it is like to be parents of a beautiful 16 year old girl and suddenly through no fault of her own, be told there is nothing that can be done and nobody even wants to try. Can you understand the horror at the thought of having to send our daughter to an aged care facility? Please put yourself in this situation, would you like your child in a nursing home living with 70-90 year olds and not getting rehabilitation? A chance to return to a normal life. That is the only option for young people who are not covered by Workcover or TAC.

We know of another young man who acquired a similar injury to Angela. He was unconscious when he was sent to a specialized rehabilitation. The only difference we can see is that he had TAC funding.

Angela went to rehabilitation at MECRS and spent five months having her arms and legs straighten using botox and serial plaster casting. This had been suggested in intensive care by the physios, but the specialists decided splints would do. Later we were told they thought she wasn't worth spending public money on. If they had done this in intensive care, it would of save her five months of pain and suffering and she would have been five months advanced in her treatment.

She continued to show small signs of improvement all the time.

After five months at rehab. she had to move on due to MECRS being a fast stream rehabilitation. And so the Slow to recover program stepped in and again it was suggested that she return home to an aged nursing facility in Benalla.

So again we fought and MECRS said she could go to Gardenview House which was a complex care nursing home, to my knowledge the only one like it in Victoria, possibly Australia?

At least she could continue to receive the specialist care she needed i.e. Physio, OT and Speech and also being able to keep in easy access of her botox specialist Barry Rawicki. Benalla does not have the facilities or the specialist to deal with someone with Angela special needs.

Angela is now two and a half years on starting to talk, stand and walk with assistance. Mentally she is fine and she is doing a writing course with the council of adult education in Melbourne. She has also delivered talks at conferences in Melbourne and Sydney. If we hadn't fought, she would have been lying in an aged nursing home in Benalla twisted and unable to respond.

The continual fight we have had to go through over this time with medical personal, financially, courts, slow to recover has taken its toll on our family, but we nearly have our daughter back. So it is all been worth it. As she says "I'm pretty good for a vegetable!"

A nursing home is not a place for young people. How can they be expected to improve around seeing so much sadness? Watching each friend you make die. One young gentleman I know of who was in the same home as his father. Unfortunately his father died. How sad would that have been?

In Sydney there is no Slow To Recover program and a young man in his mid 20's lives in an aged nursing home. He shares his room with people in there 80's and 90's. He has no funding and his parents have had to do most of his rehab. which has come at a high cost to his parents, emotionally, physically and financially. And he is talking and improving all the time. He needs a full rehabilitation program. But with no funding he has no chance. Imagine if this was your son. Doesn't he deserve a chance?

Even at Gardenview Angela is one of 23 others mainly under the age of 65. Gardenview is under Aged care funding. Most of these residents need Physio, OT, Speech Hydro or have some other appointment, which they have to be up for. This places a great drain on the staff that does an excellent job under these conditions. The needs of younger people aren't being met. Gardenview tries to do activities and outings for all ages. But 18 year olds have different views; ideas and wants to someone aged 40 or 65. Example of this is music, food (young people eat differently to older people and usually more and at different times and more frequently, they like to graze.)

Young people may also want to be sexually active. They like to stay up late and sleep in some mornings.

They are not being catered for.

Most aged care facilities don't have the funds or resources for rehabilitation programs. So the chances of recovery and retuning to a life in the community are not good.

Another problem is when a young person is put in a nursing home, they are only allowed out overnight 52 times a year.

Some families can cope with having their loved ones at home a few days a week, but not full time.

This rule can also impact on their rehab. As young people need to be able to socialize with their peer groups, to enable them to mature. As we found with Angela when she started to communicate her memory had regressed to years before the brutal bashing, talking with her friends and going out has brought her up too date. They also need to keep in touch with their friends so if they can return to the community they have their support groups to help them settle in.

I think if each major city had facilities purposely built to accommodate younger people, also offering a rehabilitation program for non-compensationable people, this would help both parties. There would be more aged care beds available for the aged and young people may have the resources they need to recover and maybe one day return to their own community and give something back to society rather than being a burden all their lives. Young people need a home of their own.

When building an accommodation, young people need a place that will encourage their friends and families to keep in close contact. Nice grounds, maybe with a Basketball ring or rebound wall (which could also be used for rehabilitation purposes), also a BBQ area. I'm no talking big and elaborate, just purposed built to accommodate the needs of the young and the staff be trained in dealing with the needs of the young, not the aged.

All these things need to be looked at. Although maybe they can't all be met, they should be considered.

We would really love the opportunity to meet with you and discuss this further.

Yours sincerely,

Helen Barker