

28th July 2004.

Mr. Elton Humphrey, Secretary, Senate Community Affairs References Committee, Parliament House, CANBERRA. ACT 2600.

Dear Sir,

Further to my conversation to your office, I am enclosing a book written by our daughter and an article written by my wife, which helps a little to explain our situation. This article was printed in InABIlity PossaBIlity. We do not have access to e-mail and your office assured me at this late date our submission would be accepted.

There are units being built in Bairnsdale at present (we live 15 k's from Bairnsdals) but these do not meet the needs of our situation. There is a great need for the victims individual requirements to be taken into account.

Should there be a public hearing held in Melbourne I would appreciate being invited to attend, subject to the time fitting in with our train service.

Yours faithfully,

(Ian Cox)

I am the mother of a severely disabled ABI person. Towards the end of February 2004, I had my 76th birthday. Three days later was the anniversary of our daughter Helen's accident, half her lifetime. It struck me that we're no nearer a solution than we were ten years ago as to her future despite numerous meetings we've attended. There has been a lot of talk, then we've received beautifully made up books and that's about it. Ian, my husband is 78, and has had two hip replacements recently. We're getting past our use by date.

Helen suffered severe brain injury when she tried to stop a bolting horse which charged into her and her horse, knocking them down. For five and a half months she lay in a coma, then started to come to. We were thrilled when we realised that intellectually she was "with it". It was the start of her pushing herself to regain ability. She is a hemiplegic, can walk with what she calls an excuse for walking, can speak quite well, has written a book and reached a stage of doing most things for herself. Sadly she now has Chronic Fatigue Syndrome (CFS) which became very evident during the 1990's and combined with ABI leaves her energy level at practically nil. She has to push herself to do the necessities.

Ian and I have three other daughters and Helen is the youngest. They were all able to help in the early days. Now two live in Tasmania and one in Moyston. They have their families and commitments but we are in constant contact. Ian was still working when the accident happened. He organised adding to our home so that Helen's life would be a bit easier. There was no insurance and it was hard getting any funding, so we limped our way through. Our way of life changed completely so that instead of getting to a stage of being able to do some of the things we wanted, we turned to helping our daughter and are still doing so.

One of the many results of brain injury, in Helen's case, is a chemical imbalance which in the main doctors diagnose as needing anti depressant tablets. They certainly help but aren't the complete answer. It's very difficult to get the balance right. In Helen's case too much of any drug causes the same problem as not enough, which means a nice person changes into someone you'd rather not know, through circumstances which are beyond her control. To us this is probably the worst part of ABI.

Until CFS, Helen with a helper, rode her horse most weeks, grew vegetables in raised boxes and made cakes to give away. She was always doing something. We were given a Getabout motor chair through PADP and she would set off with her dog on her knews to inspect her cattle. Since CFS she's not been able to do anything much other than her personal needs, and I help her now more than I have for years.

Living a life like our daughter's leaves a lot to be desired, for ourselves as well, because what involves her involves us all, and none of us are free. We have found putting the Serenity prayer into practice a real help in getting through. 'God grant me the serenity to accept the things I cannot change, Courage to change the things I can, and Wisdom to know the difference.'

It is becoming harder to get anywhere regarding suitable accommodation for younger disabled adults, particularly in rural areas, which is where we live. We need advocates who will take up the cause for families who are not able to keep up the struggle for themselves.

Natalie