

Submission No. 182

(Inq into better support for carers)

A.O.C. 26/6/08

Sent: Sunday, 15 June 2008 9:09 AM
To: Committee, FCHY (REPS)
Subject: Inquiry into Better Support for Carers

Dear Committee Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

My Background Situation.

I am the mother and full-time carer of my 24 year old son, Zeke. I also became a widow after my partner died almost 18 months ago. Zeke is profoundly disabled. This was the result of a tractor accident when he was 2. Zeke is not mobile, he cannot communicate and he is blind. He has some use of his right side, he can hear in one ear, he can eat pureed food and he drinks thickened drinks from a baby's bottle. Zeke is also incontinent and needs incontinence pads. I also cared for my husband for 15 years particularly so in the last few years of his life. I am also a retired schoolteacher. I taught primary school at Cobargo for 30 years and was retired after Rex passed away.

I have had to think of the future in real terms. About 15 years ago we realised that there were no facilities to help us care for our son in the southern part of the state. Rex and I decided to give land and the idea of Nardy House came about. As you are probably aware that facility now caters for 6 profoundly disabled people at one time for respite and the permanent accommodation stage has begun. I am very proud of the work that the Nardy House committee has achieved. I can honestly say that it has only been the work of our committee that has recognised the need for profoundly disabled people. The State Government bureaucrats never included anything like the Nardy House facility in their planning. It has been a real battle to get our needs recognised and to make them understand that young people don't belong in aged care homes. In fact, that has been our major battle to get funding as in the past (hopefully not any more) it was cheaper for the State to ignore our needs and hopefully in the end we would use aged care facilities (or even hospitals for respite as one 2 service providers suggested once for respite!) because the aged care facilities were Federal funding and thus they could ignore them in their State planning. Caring for people with profound disabilities is a costly business. For years I have transported Zeke to Wollongong (600 km return trip) for respite. Now I have the support of Nardy House in my local area. I love respite (better than lollies)!

All regional areas should have a Nardy House to help families support people with profound disabilities. A place where families can become confident that the complex needs of the person they are caring for are understood and recognised and become a support for the families. When you are faced with a different form of respite or different carers all the time it becomes too overwhelming, too complex and also causes a lot of stress and in the end you give up and just stay home because it is easier. As well as a respite facility it is important to include the permanent accommodation because it becomes a natural transition from respite to accommodation when the carers can no longer give their support. When carers don't have this support they feel isolated, lonely and often become sick with worry. I have also had oesophageal cancer 6 years ago. Fortunately I am now free of the disease just minus a bit of stomach and oesophagus. My husband found the stress of caring, having respite in Wollongong, having people in the house all the time to help care for Zeke or himself so much so that he couldn't give up smoking. He also had epilepsy and had grand mal seizures. It finally killed him.

I have found the biggest obstacle to overcome is that bureaucrats and often the workers do not understand your needs. They don't recognise that everyone's needs are different and that people with disabilities have many and varied needs. They also don't plan effectively for the future needs. My biggest frustration at the

moment is the amount of "training " that I am required to do to make sure that people understand my son's specific needs. He has a sliding hiatus hernia and if not handled correctly suffers severe reflux and then chokes and has seizures. If people are not trained properly, they "twist" Zeke and then I get left "holding the baby" so to speak either through a sleepless night or he is often admitted to hospital when people caring for him don't understand and recognise his problems. I would be rich if I got paid for my hours of free training to support staff at his day program, at respite and at home through home care. That is the main reason that consistency of care, support and the workers is so vital. When its not there it is very stressful.

My other frustration comes from the fact that much staff training, fitting of wheelchairs etc., assistance eg home care all happens in my house. Sometimes I have had up to 9 people arrive! This is very difficult as not only do you have this chaotic scene in your house but it throws all of your routines into chaos. I hate the fact that sometimes my home is regarded as a "service facility" . And lastly, I would just like to comment on the fact that as a carer of someone with a profound disability there is often a lack of understanding and that I don't usually get any choice eg. Zeke goes to a day program which I have not been very happy with mainly due to the large turnover of staff at Tulgeen, but when enough was enough, I had no choice of service and sadly he is still there and I am still not happy with the level of care they provide. eg Last week it was very cold and when he required a complete change of clothes the staff were too lazy to put his singlet and tights back on and consequently he came home very very cold. The next day he dirties his tights and they sent them home "full of shit". They were too lazy to rinse them clean. I don't want Zeke to go there but I have no choice and I cannot look after him 24 hours a day. I need that time to prepare for his nedds etc.

Thankyou for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely
Betsy