

RASAIID



GOOD NEWS STORIES for DADHC

18th August 2009

If you have just read this month's DADHC newsletter, you will have seen what Northcott has submitted as "Good News Stories". You will read about Valerie, the devoted lifelong carer of her 46 year-old son. She suffers with glaucoma and doesn't drive, but the Northcott worker takes out her son, Derek, one afternoon each week to play golf, which he enjoys. Valerie is "grateful" and the "break" allows her to get her shopping done (that would be for groceries, I think). Later in the year, when she visits her sister in the country, her son will go with her and she will avail herself of the respite service in the town. Maybe this is her choice or maybe she is unable to access a longer period of respite and take a holiday from caring.

The next story tells of camps run by Northcott that allow ageing carers a "well-deserved quality break of a lengthy duration". These camps have been devised by an NGO in response to a need for centre-based respite that they do not have. Many ageing carers think that three hours per week of in-home or out-of-home is more trouble than it is worth. Because the NGO has no venue at which centre-based respite can be provided, it resorts to camps. But to call a weekend or a five day - four night camp a "lengthy duration" just leaves me breathless. I think what Eddie Ozols just took in long-service leave is a "lengthy duration," and although he has been with DADHC for a long time, it isn't as long as these ageing carers have been on the job.

These stories perpetrate the myth that it is OK to have ageing carers of sons and daughters with a disability in this wealthy nation. It is OK to congratulate ourselves that at least we are doing something for them - three hours of respite each week, the carer's bonus, a counselling session with the national joke known as Carers Australia or that panacea for all ills, the laughter workshop. Yes, we are providing supports for them that they didn't have before.

Let's make no mistake about it. It is no good news story that people like Valerie are still caring for their sons and daughters in this lucky country. A parent who has raised a disabled child has worked far harder than any other parent. That parent reaches retirement age and is told that there can be no retirement and that the caring role must continue. There can be no gradual transition away from home, no plan for the future and no peace of mind for the parent. The person with a disability is allowed little independence or autonomy over his/her own life and often wishes to move out of home in an age-appropriate way. There is an earthquake waiting to happen in the lives of all the sons and daughters who live at home until their parents can care no longer. In one breath, they lose their home, their primary carer and almost certainly the known community. This is the disability system that we preside over, that we pretend does not exist, that we gloss over or look away from. It is inhumane and a disgrace and we all know it. Why don't more of us say so?

Instead we think up good news stories. It was tried in state parliament a few months ago, if you remember. It was suggested that people like Valerie were given "amazing support" which is rhetoric for "three hours". It is very important that we don't get sucked in with all this good news. It is easy to keep reality at arm's length, especially when the department uses its scarce resources to promote a talk-up. Never let us forget that people like Valerie are permitted to put their feet up in most other developed countries, having done a good job. In our country, the Valeries use their three hours of respite to rush out to do their shopping before coming home to care for their sons or daughters for the remainder of their lives.

Estelle Shields