

AOC 16/7108

Submission – 1-7-08 – House of Reps - carers

The House of Representatives Standing Committee on Family,
Community, Housing and Youth
Enquiry into Better Care for our Carers

SUBMISSION

Background

My 38 year old daughter, Sam, has advanced, secondary progressive multiple sclerosis. Sam's disabilities are so severe that she has been assessed as 'at risk of admission to a nursing home'. She lives 'alone' in a Department of Housing home, with professional carers providing most of her weekday daytime care, private carers provide overnight care for 3-4 nights per week, and her parents provide the remainder. She is determined not to go to a nursing home, so her father and I will have an ongoing commitment to her care.

Caring role

While Sam has the maximum allocated personal care hours (per HomeFirst), better support for family carers needs to address the following issues:

- Unreliability of some carers: early this year we had many instances of Sam's care agency not arranging replacement carers when needed (and not notifying us), causing me such uncertainty that I had to make myself available to fill in at every shift change.
- Insufficient care hours: At present I do three – sometimes four - overnights per week and provide another 20 hours of day and evening care during weekends, in bridging time between carers, supervising Sam's medication and therapies, managing her household and in actual housework, and in helping her with her study and personal requirements.
- Standard of care, especially inadequate training of some carers: again, largely the fault of the agency that has sent inexperienced carers – for instance, they hadn't used a hoist before.
- Cost of overnight care: I retired two years ago at the age of 63, largely because of Sam's increasing needs. I have some superannuation and a part pension, but the financial outlay for overnight care is very difficult to find.
- Competent Case Management. I have no training in health or disability. However, by default, I am responsible for finding out about and organising therapies, resources and/or facilities that may assist my daughter.

Recommendations

I have no 'magic bullet' to suggest. However:

- The existing system needs to work as intended, with care agencies made accountable;
- More care hours would be a godsend;
- An efficient and reliable back-up system for replacement carers would enable me to maintain some sort of social life;
- An information base of services and resources is essential - something like the website that the Summer Foundation and the *my future my choice* program is setting up. At present, family carers have to rely on a network of informed people to find out what is available, where, and at what cost. (I thought case managers would do this, but on the personal level this has not happened.)

Thank you for the opportunity to present my views, and I look forward to your report.

Yours truly



Jan