

23/6/08

A.o.e. 2/7/08

Submission No. 447

(Inq into better support for carers)

To whom it may concern,

I'm better handwriting this than attempting it on computer.

our story is as follows... Alice is our beautiful 19 1/2 yr old daughter who is profoundly intellectually and physically disabled. She has done extremely well in life considering how poor she looked in the early days. We were told she wouldn't survive past infancy. but oh how she has proved the medicos wrong.

She is having a great life. She is a very happy and content girl as long as all her needs are met. My husband and I are her full time carers - both tag teaming her care around our part time jobs. We are not big money earners. I work as a nurse and he has his own small laminating run. He can manage to work his hours around her care.

Her care just during waking hours over a week long period is more than 40hrs duration. That in itself is a full-time job with no payment at all.

We only ever have small 2-3 day breaks from her care while she's at respite... the most we've had is one full week in her 19 1/2 years of life.

We have 2 sons - one older one younger than her... both boys still live with us and all we ever do together now they are older is

share an occasional meal. Having a disability in the family affects so much the "normal" dynamics.

My fear is when I cannot keep caring for her - even now that I've reached age 50 I am finding her physically too big and heavy a lot of the time. My husband still manages a little better than I but we just can't keep this amount of care up ongoingly.

The powers that be need to address the accommodation situation as a matter of urgency. Our families are at breaking point literally. . . . we can never dream of even a 2-3 week holiday let alone semi-retiring. . . . the workload will always be there as long as we live.

I have thoughts at times of putting us all to sleep together one day which is the only easy solution I see to our burden.

Yes we love our daughter very much but we cannot keep up the amount of care required FOREVER. . . . she will have to be placed into a group home with around the clock care because physically we cannot keep up the energy required to look after her.