

26th June, 2008

Mrs. Joanna Gash MP,
Box 1009,
Nowra 2541

Dear Mrs. Gash,

Re Federal Government's Carers Inquiry.

I am the carer for my husband, Jim who was injected with an illegal drug called myodil, in a myelogram some years ago resulting in him now being diagnosed with Adhesive Arachnoiditis, a hideous chronic disease. This is my submission for the above inquiry.

SALE OF FAMILY HOME; As this disease became worse we were forced to sell our home due to the many steps (14) and elevated land and move to a modest home with no steps, about three years ago, due to his mobility. This cost around \$50,000 to make the transition, for legal fees, stamp duties, real estate fees, removal etc. I had to borrow this money from the bank which means although I am of retiring age, I cannot stop work due to the financial pressures of a mortgage. Surely, with Government assistance, the banks could lend at a lower rate to help carers in similar circumstances (under very strict conditions).

DRUGS: Secondly, prescriptions for some drugs are not on the NHS causing financial hardship. I was paying \$122 a script for Lyrica for my husband, because it isn't on the free list. This put enormous pressure on me financially and we had to stop the Lyrica and take a drug on NHS. Not really acceptable.

PUBLIC TRANSPORT; As I work part time I only receive a carers allowance. I don't get concessions on public transport. I have told them my husband cannot travel alone, due to memory loss and poor mobility, but to no avail. I must pay full fare. Just a day out to Wollongong on the train costs me \$20, a 80 klm journey, which is grossly unfair. Day outings are not part of the agenda unless for medical reasons.

HOSPITAL FUNDS; I dare not stop my Hospital Fund due to his illness. I have the barest of covers—no frills, just no ancillary. This costs \$150 per month. Another financial burden.

EQUIPMENT: is very expensive for disabled, in our case hearing impaired. Ear phones to listen to TV normally cost around \$5 to \$10, BUT for ear phones for hearing impaired they are \$346. Same for smoke alarms, phones etc. To make life easier for the disabled these goods need to be a lot cheaper. Only a handful of programmes on TV are closed captioned and many channels don't include the news or current affairs programmes with CC..

RESPONSIBILITIES: as a carer of a disabled person, I am responsible for maintaining the house, garden and lawns, finances, meals, shopping, distribution of medications, medical appointments. The list goes on and on. I am in my 60's and work 4 days a week. When my husband was well, we shared jobs. Now I pay \$40 each time I get the lawns mowed, but more time than often I do it myself as I cannot afford the \$40. I asked the Council if anyone mows for pensioners etc, but to no avail. Am I supposed to live in a jungle of weeds and grass, just because I can't afford to maintain my yard?

Financially, mentally and physically I am continually under pressure to keep everything going. I worry how I will cope if I have to give up work due to health. What will happen to us, where will I get money for the mortgage. We live modestly and I thank God for each day we have together BUT the Government needs to realise it's the carers who are saving them millions of dollars by not putting their loved ones in hospitals, retirement village and homes. It's time they started listening to OUR NEEDS.

AS CARERS WE NEED HELP TOO.

Bronwynne

BRONWYNNE
Carer.