

## Opening Statement for Parliamentary Hearing.

I would like to thank the committee for giving me the opportunity to speak today. A very special thanks to Mr Coulton in arranging for this enquiry to be held outside a capital city so that issues pertaining to rural and remote areas can be highlighted.

Eleven years ago in mid 2001 after 27 years of not being well after contacting Ross River Fever in 1974 and Glandular Fever in 1990 my husband Ken almost 64 was diagnosed with Dementia most likely Frontotemporal. From 1990 when Ken was diagnosed with Chronic Fatigue until 2001 we had regular trips to Sydney to a GP specialising in Chronic Fatigue. He sent Ken to dozens of different specialist Drs for tests. One test was done by attaching electrodes to Ken's head to gauge his brain responses to the pulses sent through the electrodes. The report showed Ken's responses remarkably slow, but not once was the word "dementia" ever mentioned.

From 1990 onwards Ken would have been unemployable, for approx. 6mths of every year Ken would sit and do nothing. We have our own property and I was able to take over the management of same when Ken was ill. A much earlier diagnosis would have given me the knowledge that I should have taken over the decision making full time not just when Ken was not up to it.

By 2001 Ken was becoming very difficult to live with, very irrational and erratic towards the business and family. One day I had had enough of all the emerging inappropriate and unlike Ken behaviour the family and I were being subject too. I rang the GP in Brisbane Ken was seeing at that time and told him I was bringing Ken up and I wouldn't be bringing him home until somebody could give me some answers. Dr had Ken admitted to hospital and Ken was sent for scans. Three weeks and three scans later plus a lot of other tests we were told Ken had some vascular and atrophy problems within his brain – dementia – most likely fronto temporal. We were told to go home see Ken got his affairs in order and for Ken to enjoy life while he could. Then we were on our own. I would like to think any family given this diagnosis today would be given a lot more support and counselling, however I don't think this is always the case.

I still care for Ken at home and during the intervening years he has enjoyed many outings, trips, and family gatherings, the comfort of his own home and familiar surroundings and regular visits to and from our family and their unconditional love.

Ken currently receives an EACHD package and was receiving 3 x 8hr services weekly, this is now reduced to 5 x 8hr services a fortnight due to funding constraints and lack of staff Ken has only received approx. 50 % of his services this year. My main concerns are loss of services, not receiving value for money for Kens' package and earlier diagnosis of dementia .

Notes:

Services lost 1/3/11 until 1/3/12 47 days plus 3 days we were away and 18.75 hrs due to staff arriving late/leaving early.

Value of above: A. P. was receiving \$1023 per week value of each service \$341

Lost services and days:

50 days x \$341 = \$17050

18.75 hrs x = \$506

35 Wkly O/H = \$8305.50 35 weeks x \$237.30

Total \$25861.50

Ken received approx 51% value of package.

Provider received approx. 49% of package.

Services lost 1/3/12 until 31/7/12 27 days plus 3 days away and 17hrs, 20 mins.

Approved provider organised a Employed Carer's Respite Package for Jill, which to date I have not signed.

Provider now receiving \$2890 a fortnight and only providing 5 x 8 hr services a fortnight, value of each service \$578.

Lost services and days:

30 days x \$578 = \$17340

17 hrs 20 mins x \$27 = \$468

Weekly O/H \$2054.4

Total \$19862

Ken received approx. 34% value of package

A. Provider received 66% value of package.

Upon my receiving the ECRP package the Provider put their Case management cost up from \$12.50 a week to \$50 a week and their overheads and admin costs went from \$203 a week to \$293.66 a week, plus a surplus each week of \$147.87 All up approx. 59% of this package has gone in extra costs and surplus to the provider. Until very recently a R. Nurse had not seen Ken for 8 months.

Between the two packages the provider is receiving a surplus of \$204.50 a week in addition to all their overheads and expenses.

I feel they knew they could get this extra package when they were really giving me no choice I either had to accept less hours or they would find me another provider.

To arrive at the above figures for the value of the package lost to Ken I have taken the total weekly value of Ken's package he was receiving before Mclean obtained the ECRP (employed carers respite package) and divided it by 3 services a week in the first example above. In one costing sheet the McLean gave me they suggested that Ken's package was costing them approx. \$1300 a week. As I keep reiterating how can they know how much Ken's package was costing them over a period when up until last November they could not give me a list of days Ken did not receive a service in the past.

The second example I have worked out approx. from the latest costing sheets that I have been able to obtain from McLean. I have checked with them that they are receiving \$421.15 a week not a fortnight from ECRP and they have confirmed this is correct. The costing sheet I received show that Ken is receiving 9.25hrs a week from ECRP when in fact he is only receiving 4hrs actual service a week and the other 37.5 mins a week would be for payment whilst travelling. I have requested a new costing sheet reflecting these figures, however like all other matters if they don't wish you to know the truth they choose to ignore one's request.

When they first started on about the cost of Ken's package McLean told me several times "they did not intend cutting Ken's hours they just wanted to make his package more cost effective". Then a few months down the line they pushed me to sign an agreement that I would accept less hours, or else they would help me find another provider.

Their way of making the package more cost effective was taking services from a carer who had been coming to Ken for over three years and employing another girl who actually lives 10/12 ks further from our home. As a result of losing some days the original carer went off and got another job. At one stage the other girl who lives approx 80/90 ks from Moree was some Saturday and Sundays making two and three separate trips a day into Moree, They were not saving on Ken's package and certainly costing themselves a lot more every week in travel to service their clients in Moree. The original carer was one of the most reliable caring non smoking carers Ken has had in the all the years he has had a package.

I have been to the Complaints Scheme and not being satisfied with the outcome I appealed and took the issues to the Aged Care Commissioner, both parties wrote a final report and closed the case before I was given an opportunity to read and comment on the final report. At the moment I am considering my options do I take the issues up with the Commonwealth Ombudsman and even the media.

I do not consider any of the above conducive to assisting or making life easier in helping me to keep Ken in his own home. I understood that the packages were for Ken's welfare not to help nursing homes balance their books.