

To: The Secretary community.affairs.sen@aph.gov.au
Senate Community Affairs References Committee

Senate Inquiry into Aged Care
Submission re: younger people who fall within Aged Care fee models

I am writing a submission as an individual as I would like to comment on item (c) *“ the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which special needs such as dementia and mental illness are met under current finding arrangements”* .

I am commenting since I have personal experience as a carer for my husband who has had early onset vascular dementia for some years (he is now 60 years old).

My husband has suffered from early onset dementia for over 5 years. Even though he is under 65 his case is serviced by the ‘aged care’ system. I work full time out of financial necessity and he has no eligibility (because of my income) to any pension nor is he fortunate enough to have super of any sort. Current funding arrangements do not take into account the cost of providing care for him at home nor in an aged care facility. Our needs literally fall between the cracks and this has led to considerable personal stress for me and my family. It is agonising enough to watch one’s loved one decline from this debilitating illness and then to have to drag oneself through a system that actively **discriminates** against people who don’t fit all the pigeonholes is a very unfair ‘double whammy’.

My husband is sadly on the point of needing permanent nursing home care but the system simply does not cater (legislatively) for people in our circumstances. I would like to draw your attention to this anomaly, as it literally precludes his access to an aged care facility. I have had to write to my local member of parliament to try and progress this matter.

Recently, an offer of a place for my husband from a good local nursing home was withdrawn because the nursing home cannot levy an accommodation fee in his case, nor does the legislation allow the home to charge me (even if I could afford it). I have contacted other homes to be told the same thing. The advice of many has been to ‘pretend we are separated’ as the only way to get around the system. As the issue of the fees is very complicated I will not attempt to explain in this submission but am happy to provide specific details on request.

I have worked in various bureaucracies for 30 years and yet the fee structure system is so complex that it has challenged me significantly and many people within the system confess they do not understand it either. I cannot imagine how the average older person or someone not experienced with guidelines and bureaucracies would comprehend it. It needs to be made ‘user friendly’ and more simplified. The system is also designed to cater to those on an allowance or pension but the numbers of people who may not fit these criteria (with early onset dementia) are on the increase and I ask that their future need be considered in the Aged Care review.

I would also like to provide a general comment pertaining to training of aged care workers and medical professionals in general. I have spent the last few years trying to 'educate' people (that I have encountered as carer) even within the medical profession that dementias can be quite different and vascular dementia manifests itself very differently to Alzheimer's (much better known) for example. I believe it is very important when planning services and training that consideration is made to train even general aged care workers about different types of dementias.

I am happy to be contacted for further comments or information.

Yours sincerely,

Tanya Neill

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