

I am here in a private capacity and I was a carer for our late mother who had dementia.

Thank you for the opportunity to have input into this important issue. My interest is in the first terms of reference to which I am adding 'specifically in rural and remote areas' as I would like to highlight some of the challenges that people with dementia face in rural and remote areas – the main ones being respite and delivery of services.

I cared for my late mother who had Alzheimers for 10 years until her death aged 93 in 2002. I kept our mother in her own home on a rural property 30 km from Wandoan in Queensland. Mother received a CACPs package and because of my own physical disability (severe Rheumatoid Arthritis) I engaged live-in carers to assist me. I continue to live on the family property and now I require the assistance of a carer 24/7. I am receiving an EACH package and employ two carers for whom I provide separate accommodation on the property. This is at considerable cost to me.

About the age of 84, our mother was becoming forgetful and the GP said "Oh, it's just old age." Then there were strange behavioural changes like leaving a tap running as the sink overflowed while she tried to mop up the water. A nursing friend told me about a Geriatrician in Toowoomba some 300 kms away so I took Mum to see him. He did the usual MMSE (Mini mental state examination) and said she was early stage dementia – nothing could be done as it was just 'old age'.

I never considered putting Mother in a nursing home as I believe it is vitally important to keep people with dementia at home in a familiar environment for as long as possible as there are benefits from enabling them to keep their independence and being with loved ones. I relied on other family members for respite as there was no respite available nearby. The only support I had was through Alzheimers Australia with their Tele Support Group. They organised a teleconference with their facilitator and five or six other carers monthly. Yes, it does place increased burdens both emotional and financial on family and loved ones but these burdens can be lightened by better support services and improved and more efficient delivery of services, especially in rural areas.

The system is failing our dementia sufferers and in fact anyone else who receives a package. I don't believe the answer is throwing more money at the current services. We need more efficient use of the funding so the client gets better value for money. Perhaps the answer is more accountability and transparency of service providers. This is probably a contradiction of terms but they are constricted by regulations.

CARERS: Dementia specific training. Some of our most vulnerable people are being cared for by the least qualified people. It should be the responsibly of governments to provide learning. I realise this will increase costs as they will then be paid higher wages but what price do we put on our dementia suffers. Even hospital staff up to Registered Nurses do not understand the dementia sufferer if they require a stay in hospital. We were required to

stay with Mother 24/7 when she was in hospital to ensure her safety. A national training scheme could be considered.

RESPIRE: Needs to be flexible. In SW Qld now Blue Care has a rural respite service where they go on the farm while the carer can go away. More short term respite, say for a couple of days/nights or over a weekend is required. Respite like delivery of services has to be flexible. Studies have shown that people with dementia are better with respite in their own home.

EACHD packages: One size does not fit all. The delivery of a package has to be designed for the individual depending on needs and location. Service Providers seem to lack the ability or desire to do this. The attitude is 'here is a package and this is what you will be given for it'. There is definitely a need for an attitudinal change within the service provider industry. As a start they could listen to the needs of the care recipient and design some creative delivery models.

TRAVEL: The government should consider the travel for rural recipients separately from the direct care funding component of a package. Packages have to be tailored to meet the needs of the individual and that means flexibility – something which I have found Service Providers do not have.

HOME MODIFICATIONS: I was recently advised when I needed to modify my bathroom for carer safety that as a recipient of an EACH package I do not meet the criteria to receive Home Modification assistance and will have to meet the cost myself. At the same time I am only utilising 50% of my EACH package on direct care.

CONSUMER DIRECTED PACKAGES: Care recipients or perhaps their family should be given more control over the delivery of the package. A case in point was a person with a disability in my district who received a Lifestyle Package. His wife who was also his carer set up a Pty Ltd company into which the funds were deposited and she maintained the accounts and submitted monthly reports to the Dept. thus ensuring value for money. Currently, it is not uncommon for some Service Providers to use up to 50% of a package in administrative and delivery costs.

RURAL ADVANTAGES: Believe it or not there are advantages in rural and small town communities as you basically know most of the people in the town including the health professionals and what services are in the town.

RURAL DISADVANTAGES: No access to specialist services thus necessitating long distances and overnight stays which is disturbing for dementia sufferers who become easily disorientated when out of their own environment; no or limited respite; travel costs for care workers.

People with dementia need to be treated equally whether they choose to live in a rural and remote area or in an urban area – this is a human right. Just like with any other illness, they

deserve an early and accurate diagnosis. They are not only vulnerable people but valuable people.

**Rural and remote dementia sufferers deserve equal care in every respect.**