

How can we make more services age appropriate?

Younger Onset Dementia Summit

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My journey began some ten years ago, while I was still teaching and it was as a result of working that I became aware that something was wrong. I didn't know this was to be the beginning of a long road; the most difficult aspect was to be correctly diagnosed. I won't elaborate on this aspect as I'm sure it will be familiar territory to many here, although in Western Australia this is probably more significant.

I live in a rural section of WA, about an hour's drive from the nearest town of consequence and an hour and a half from Albany. Living in regional WA made the path to diagnosis long and frustrating with many trips to Perth over about three years. Being younger not only made the diagnosis more difficult, as it seemed that GPs were more likely to look at other issues, but also convincing my husband and family that it was a real issue that gave me serious concern. So much so that this in turn led to a degree of stress that I could do without. You don't need to be told by others that ***'Oh yes that happens to me too, I've been forgetting this or the other'***. These days my husband is a little peeved; he feels that he should get away with telling me that I had promised this that or the other, but it never seems to work for him.

With younger people or those that are more or less still active, some of the available services seem inappropriate and at times I feel left out or that I don't quite fit. This is exacerbated by living in a rural area. Making the support service for either younger people or those with a spark of enthusiasm still there has to be something more than basket weaving, not that this has been offered to me, but it should be stimulating and challenging not sedentary. How this is achieved I'm not sure, but I imagine there are those among you more qualified to pursue this.

We have the good fortune to live within striking distance of Albany and the respite centre of Hawthorn House, the general manager there, Elizabeth Barnes, has not only been an inspiration but a single source of comfort, in that I know that no matter what my problem is I would find an open door and sympathetic ear there. The staff at Hawthorn House are aware of the difficulties with transport and have arranged for a weekly meeting at Mount Barker which for me is only an hour away. This resulted in finding a good friend there. It is refreshing to be able to meet with people who either have a similar problem, or with whom you are close enough to talk at ease without

the anxiety of wondering how many times you have either told the story before or if you are repeating yourself.

Let me finish here before I start to repeat myself.

Thank you for your attention.