

1. What happens in the case where only one of the partners needs care, in this case, high care, and the other is perfectly fit and healthy but ends up living a lonely life at home, due to their partner needing to go into a nursing home?

I suggest a new arrangement be set up where the couple moves into accommodation - a cross between retirement living and nursing home care.

When trying to find a place for my father in law, who fell over and broke his hip, and ended up needing full time care but was mentally ok, the closest we found that would suit both him and his wife was at Drummoyne Scalabrini - that has both retirement apartments and the nursing home. However, even here, each would have been put into the different areas. He was not able to live in the apartment with his wife, because he would not have access to full time nursing care. This seems odd to me when it is available within walking distance.

2. The other area of concern is the limited number of beds available, esp in new facilities that have been purpose-built. I speak about St Mary's Concord, where we put down my father-in-law's name on the waiting list over two years ago. I stressed the urgency of a placement for him as he was close to 90 yrs of age. Every 4-6 months, I call for an update (I never receive a call from them), only to be told they only have 6 (6!!!) beds available for men, and he is still on the list.

What is frustrating, is that no mention was made of this at the time of our interview. We were shown plans and models of the new site, which all looked great. And indeed, the new premises is hotel-like in its decor etc. But at no time was it indicated to us, that it would be highly unlikely we would get a spot.

3. Lastly, the size of the rooms need to be carefully looked at. At St Mary's Concord, each room only has one person, which I am told, is the new law. Each room is enormous. Considering how limited land is, and how few rooms are available, why is it necessary to have such large rooms?? Perhaps some people don't want to be on their own. As a suggestion, why not offer a choice of either a single room or sharing with one other person? If the rooms at St Mary's had two people per room, there would be another 10-20 beds available without encroaching on space. Is this part of the phenomenon where we are building bigger and bigger houses, but with fewer and fewer people living in them?

As a sign off, my mother in law, who was perfectly healthy has recently undergone a bowel cancer operation and has been moved into the nursing home section of Balmain Rehab hospital. So our days are spent driving from one nursing home to another in order to keep our parents' wellbeing positive. I wonder what the procedure will be now, should she require long term nursing home care? Will it be automatic that she goes where her husband goes, or will we have to jump through more hoops and wait on endless (and hopeless) waiting lists?

I do hope my concerns are taken seriously and some thought is put into finding solutions to the issues I raise.

I have read some of the draft report which has made me think of other issues:

1. the institutionalisation of patients in nursing homes, as per our experience. It seems to me, once they are in a nursing home, they have pretty much lost their independence altogether. Just because they are infirm, doesn't mean they should lose their right to choose when they want to get in and out of bed, when to have a meal, etc. And rarely, do I see any of the patients outside enjoying the fresh air. They are all sitting in their same spots, doing not much of anything.

2. the weak become weaker

On many occasions, I have asked my father in law why doesn't he walk/move around more? He says, he is not allowed to walk without a nurse by his side. Obviously, resources are scarce, but what it means is that, patients become weaker, and these places really become waiting rooms for them to die. Quality of life is severely reduced.

3. Care at Home services

We found that the government assistance provided - one hour a day, in rare cases, twice a day - was not suitable, as the help was often needed during the night. So we looked into care at home options which ended up being almost non-existent. The one we did find was very expensive (close to \$100 an hour) and didn't provide physical care such as helping with showering, dressing etc. And they required a minimum of two hours for any one visit.

Interestingly, in countries like Italy, where they have high numbers of extra-communitaries as they call them, probably like our refugees, they often hire them as live-in-help so they are 24 hr attendants to older people, providing all their needs including but not necessarily doing housework. Wouldn't that be an interesting idea to investigate with our own refugee issues??

4. Changes to Superannuation regarding Aged Care

Perhaps part of a person's super could be specifically set aside to help fund their aged care accommodation of their choice, whilst they still have a say, and not once dementia sets in.

5. Respecting and Valuing Older Australians

Looking at other cultures inc the Aboriginal culture that places a higher value on their older generations, and keeping them connected to society and the workforce in general. At the moment, they simply become invisible and voiceless.

Over the years, I have tried to engage with a number of groups and organisations inc Tafes, community groups, interest magazines and charity organisations to engage with nursing homes, not only providing hobbies etc to them, but rather, utilising the skills and talents of the aged people themselves. There is much knowledge and other ways of doing things, that will simply be lost once these people pass on.

I realise feedback is required by today, and that the report is over 500 pages long. I have read some of it, which seems to reflect what I have thought of so far.

Kind regards