

17 July, 2010

Caring for Older Australians
Productivity Commission
PO Box 1428
CANBERRA CITY ACT 2601

Dear Sirs,

Caring for Older Australians – Productivity Commission Enquiry

I am writing in response to the above enquiry with a background as a carer who has helped my mother go into aged care accommodation.

I have read your scope of the inquiry and I submit the following for your consideration. I have tried to organise the issues into groups but many of them overlap.

1. Financial

- 3 years ago after my father died, it was evident that he was the major carer for my mother and after 6 falls in 8 months after watching my mother bounce from home with a CAPs package to hospital several times and then into transitional care, we finally decided together that we should look at hostel accommodation.
- After seeing a number of villages we decided that should a room become available in Village X (name withheld) we would take it.
- My mother went in under respite care to see what it was like and I was pleased when she asked if there were any permanent rooms. She was told that there was a room for her to stay permanently and we set about working out the financials.
- Prior to my mother going into respite in this village I had enquired as to how much it would cost to buy in. I was told that “it depends on the asset test”. I said “what if my mother doesn’t want to do an asset test? Is there a maximum fee?” I was told it was \$600,000. This seemed rather a lot to me compared to other villages but I wanted my mother to be in the best place and this was the only well presented village I could find that had meals cooked on the premises.
- When the village said they had a room available for my mother I went to do the paperwork with management and was told that we had to do an asset test. I told them that my mother didn’t want to do this and asked what the maximum fee was. That is when the “fun” began. I was told that there was no maximum fee and that it depended on the assets. I asked if she had a house worth \$1,000,000 would they take all of that. I was told that would be very unusual but yes they would take that into the equation. They would not give me a “retail” price for the room.
- After calling the Government hotline for advice and 3 days of hard negotiation I eventually got the village management to agree to no asset

test and an accommodation bond of \$600,000 which in my view was extremely expensive compared to other villages I had seen.

- I sensed however that had I agreed to an asset test they would have taken even more money.
- We were in a weak negotiating position because:
 - (a) my mother was in an incredibly fragile state having just lost her husband and if she was happy with the place I wasn't going "to rock the boat".
 - (b) this place was the only village I could find that had freshly cooked meals on the premises. If it wasn't for the above two factors we would definitely have gone somewhere else. So we copped the hefty "out of line" payment on the chin and went ahead.
- My main point here is that I don't feel it is fair for villages to charge people on the basis of their assets with no limit as to what they can charge. It is contrary to the usual way in which our society operates. I am sure we would think it very strange if we went into Harvey Norman to buy a heater and the salesperson asked us how much money we had before he answered the question.
- If Villages or the Government is going to set up a scheme whereby people are going to be charged "**according to an asset test**" I foresee a number **of problems** such as:
 - (a) people who have worked hard to accumulate their wealth all their life will not take kindly to this discrimination and will resist going in to aged care when that would possibly be the best course of action for them; this type of reverse discrimination will affect more elderly as more prosperous baby boomers start to need aged care.
 - (b) it will take away money from the elderly person's family when there could be family members facing hardship or in trouble which the money would relieve.
 - (i) this could set up all sorts of inter-family conflict if the parent gives an early "inheritance" to the one who needs it and not to others. Or,
 - (ii) force the elderly to give an early inheritance to all their family which they may not really want to do (but would do it rather than be forced to give it to an institution.)
 - (c) it could force the elderly to lose their money prematurely which is there to provide for their future as they may need expensive and intensive care at some stage and the family or (deceased) spouse may have wanted to provide for this.

When I was involved in the Retirement Village Industry there were people who were unhappy in their current village and wanted to move or they wanted to move closer to their children but couldn't because they had paid too much initially and would have to surrender too much money to leave the village. They felt trapped and this of course limited their options.

(d) it sets up a feeling of “I’ve paid more than most people here and I don’t get anything for it.” This engenders a sense of injustice and discontent.

- There are two points from this experience:
(1) Every village should have a maximum set price in place and that price should be able to be justified in the market place particularly if the village is receiving government funding. It is against all normal conventions in society not to do so.
- (2) Both my mother and I were in a vulnerable place to carry out a tough negotiation such as this. We were both at a disadvantage because we needed the accommodation fairly urgently. I want to make the point that **there is no way that my mother could have negotiated this deal on her own** which is why I think maximum commercial rates must be in place and they should be set at prices that are **comparable and relevant to the proximity of the demographic. A tiny room should not cost as much as a 3 bedroom home in the same area.**
- As a baby boomer myself who has no children – who is going to be my **advocate** to negotiate on my behalf in the future?

2. Physical attributes of the village

- The village that my mother is in is in a very pleasant area but it is a long way from shops. Ideally, more land should be made available near shopping centres and transport. If they are not, it would be good to have a bus service available specialising in aged transport. My mother’s village has a bus but it only seats about 10 people so people have to take turns to go on outings. This could have something to do with bus driver’s licensing as well.
- My mother paid a bond of \$600,000 for a small room roughly 5 x 6 metres in size.
- The argument is that she has the rest of the hostel i.e. the corridors, 2 lounge areas and a dining room however she is not allowed to wear her slippers or her dressing gown in these areas and the lights are turned off in all these areas after dinner at 6.00 pm so it’s not really like her home. Essentially her room is her new home and it is tiny compared to the home that most people in. In fact her bedroom at home was bigger than the room she now occupies.
- There is barely enough room to fit a TV, a table and an armchair plus her single bed. And yet, I saw rooms that were smaller than this when I was doing my research. Who wants to live in something the size of a cardboard box after living in a house? These small rooms are a disincentive to anyone needing to move to greater care and the size certainly appears to have a depressing impact on my mother. Perhaps this is why the residents in my mother’s village call it “the jail” because the rooms are as small as a cell. The size of these rooms do not allow residents a sense of dignity.
- **I recommend that the Commission look at rooms in the future be a minimum size of at least 5’ x 8’ in recognition that it is their home as well as a bedroom.**

3. Policy and Staffing Issues

- As a general statement it appears to be that management of a hostel believe they are there to manage the residents. Residents buy into the village believing that it is their new home. There is the conflict.
- However, being forced to sit with the same people for 3 meals a day whom, given the choice, you wouldn't, and being showered by someone when you wouldn't even like your spouse to perform this function, all this reminds you that your environment is now out of your control.
- When we bought in to the hostel there were some excellent staff. Unfortunately most of them have gone now citing better job offers and better pay. My mother now often has relief staff caring for her at night time. "Strange" men whom she doesn't know.
 - The quality of the staff seems to have deteriorated. One carer I saw was so morbidly obese that she could hardly walk down the corridor. She told my mother that she couldn't pick her up when my mother had a fall and she had to get a machine to do it. Meanwhile my mother was stuck on the floor.
 - I fully understand issues of discrimination but I feel one should be sensitive to cultural and age needs. I am sure that there would be an outcry if a strange man walked into a Muslim woman's bedroom. Never mind discrimination issues – do these elderly women feel safe? That should be the question.
 - **I believe it is insensitive to force a non discrimination policy onto the elderly.**
- **Inadequate staffing** – my mother and her co-residents are constantly being told that they are "understaffed". This leaves them feeling that they don't want to be "any trouble" and they don't use their buzzers when they should.
- One woman who had a fall and broke her hip had to **lay on the floor for hours before her emergency call was responded to.**
- Many of these issues, I believe, revolve around the fact that villages are paying **very little money** or can't compete with regular services and so are attracting not enough staff and sometimes inferior staff.
- And yet, when I do a quick calculation of the money that this village should be making (having been in the industry myself) and subtract the likely overheads I can not but wonder where the money is going. Are they truly underfunded or are the profits being syphoned off from these "cash cows" to other parts of the owner's less profitable businesses?

4. Meals

- One of the reasons we felt that our choices of retirement villages was limited was because most of them served re-heated chilled meals. Everyone knows the boredom that quickly sets in when we are fed re-heated meals on an aeroplane so why should elderly people have to put up with them. Food is often one of the last pleasures left in life for the elderly.

- I understand the difficulty of having to provide kitchen staffing but surely villages should be able to provide **some** fresh meals every week.
 - My parents-in-law used to get frozen meals on wheels but they were losing weight. When we investigated the situation we found that they had lost their desire to eat because everything was “tasting the same”. When we organised for them to have fresh meals on wheels they started eating again.
 - The difference in my mother-in-law was amazing. She went from someone who appeared to have dementia when she wasn’t eating properly and then to completely coherent and normal once she started eating fresh meals again.
 - **Re-heating chilled meals should be a back-up in villages not a first and only option.**
- **Breakfast** – when I first enquired at my mother’s retirement village I was told that if she wasn’t feeling well someone could bring her breakfast. There have been periods when my mother hasn’t been well but it has been very difficult to get the staff to bring her breakfast.
 - It would be nice to think that residents can occasionally have breakfast a bit later if they want to. After all they have worked all their life – couldn’t they sleep in a few mornings? **This regimentation would I think make it very difficult for many people to accept hostel conditions. I suggest that there needs to be more flexibility.**
 - At the moment everyone has to get dressed at around 7.30 am and get to breakfast by 8.00 am every single morning.
 - Because they are not allowed to go to breakfast in their dressing gown or slippers they have to get dressed, have breakfast and then return to their rooms to get undressed and have a shower and then get dressed again.
 - I can understand the need for standards and neatness but I would like to see a bit more flexibility and breakfast would be the easiest meal to provide this flexibility.
- **Seating arrangements**
 - One only has to ask the question “how would you like it if you went from the freedom of your own home to being forced to sit with 1 or 2 other people that you didn’t like or who were deaf and you had to sit with them 3 meals a day, 7 days a week for the rest of your life?”
 - The residents at my mother’s village were asked if anyone would like to change tables and no one said “yes” and yet I am aware that there are a quite a few problems with seating arrangements in the village. I am guessing that they don’t want to upset the people at their table. There may be other people they would prefer to sit with but they don’t want to offend or be “that much trouble” so they put up with a very unnatural situation.
 - The seating arrangement has caused my mother periods of unhappiness and depression since she moved in and one can’t help but wonder if there is a better system. Why can’t they sit anywhere they like?

- I have asked management why the residents can't sit anywhere?
 - Their response was that "that was impossible". Apparently some residents have certain dietary requirements.
 - This reason doesn't make sense to me. The residents are permanent so the staff would know who is who and that would entail a fairly simple logistics adjustment.
 - What is far more important is that residents are happy and they can look upon the village as their home. That would involve being happy with whom they sit with at every meal.
 - I would also think that the right to wear slippers "in your own home" should also be acceptable especially for breakfast.
 - Surely residents could have breakfast in bed once or twice a week or a buffet breakfast could be arranged in order to give residents some flexibility.

5. Different Ideologies

- There needs to be consideration given to freedom of ideologies. The village where my mother lives is very medically conventional and will not allow any "alternative" or holistic treatments.
- My mother suffered from a medical condition which was progressively getting dangerously worse.
- I suggested an alternative treatment and offered to provide the therapist to assist.
- The village denied me this right stating that they were doing everything they could medically but she continued to deteriorate.
- Eventually I was so worried that I had to take my mother out of the hostel and take care of her myself. I employed all that I knew and her condition not only stopped but it reversed itself and completely healed up in only 5 weeks.
- It worked brilliantly and I couldn't help feeling more than a little annoyed when I took my mother back to the village to think that I was prevented from giving her this treatment by the head nurse.
- I would like to make the point that just because someone might move into a village shouldn't mean that one should have to submit themselves to Gestapo health treatments and be prevented from employing other therapies that they would in their own home.
- In this case they clearly dismissed a life saving treatment that they had little regard for.
- They changed their mind when they saw the results however and I am now "allowed" to employ these "alternative" techniques.
- Please consider **resident's right to freedom of therapies** when they move into aged accommodation.
- Shouldn't people still have the right to determine what is good for their body?

6. Deterioration of Services

- Since my mother moved into the retirement village, unfortunately, we have both noticed a deterioration in services.
- For example
 - The boutique and the reception areas are only open half the time they used to be.
 - The rooms used to be cleaned daily. Now they are cleaned weekly.
 - There used to be a family liaison person. Now there is none.
 - Laundry used to be done when needed. Now it is sometimes not done for over a week.
- This village was recently given accreditation and apparently it “passed with flying colours”. Perhaps whoever is accrediting should look at what services were being supplied 12 months ago and see if it has risen or deteriorated. They should also advise the resident’s families who I am sure would have an opinion on how the village is performing.
- Even though we had paid the equivalent price of a 3 bedroom home in the area for a tiny room, we had cheap fittings and fixtures that were inappropriate for elderly people.
- I also saw with dismay, a significant deterioration in the garden in the first 12 months. The reason given was that there was a lack of staff.
- It seems that villages are happy to take a lot of money from residents but don’t want to give anything back.
- It should be noted that during this last year the village would have earned approximately \$25,000 in deferred management fees just from my mother’s bond.
- **My feeling is that if a village is receiving funding from the Government then they should demonstrate that they are putting significant money back from the residents’ bonds and deferred management fees in to the village both for physical improvements and into staff.**

7. Security Concerns

- In the first 6 months of my mother moving into the village there were 3 break-ins. This was frightening to my mother who had never experienced a break-in at her home.
- I was alarmed as well and suggested that the village install cameras at the entry points but they told me that they **didn’t have the budget**. This was despite one of their carers being assaulted by an intruder.
- I was beginning to worry that we had made a huge mistake having my mother in aged care.
- **I believe that criminals will target the more vulnerable in our society and greater thought should be given to the inclusion of adequate security for residents.**

8. The necessity of an Advocacy Service

- There is no doubt that residents feel extremely vulnerable when they are in aged care and the opportunity for over zealous help or abuse of power is unfortunately only too obvious.

- My mother has been told with the best intention I am sure, that lights should be out at 9.00 pm. Staff need to be reminded that the village is people's home and not a boarding school.
- When I suggested to my mother that she advise management that she was not happy with something she said:
 - "Oh no I wouldn't like to do that ... they could get back at you."
 - I said "how would they do that"?
 - She said, "I've noticed when someone complains that they get served last at dinner You know – just little things like that".
- Even though I have pointed out to my mother that the staff are not allowed to discriminate the fear is there that they will.
- The other problem I have had is that my mother would not press the call button because the staff kept telling her "how short staffed they were". Not wanting to cause them extra trouble she won't press the buzzer.
 - I have of course brought this to the attention of the Manager.
- I therefore put to the Commission that **there is a much needed role for Advocacy Service for people who:**
 - Have no children or close representatives
 - Their children are geographically isolated from the resident.

A lot of the above seems critical and I do believe there is room for improvement in the care of this vulnerable sector of people. I would like to point out that the village that my mother stays at has many good aspects and there have been some wonderful and dedicated staff. They also provide a number of stimulating programs which my mother seems to enjoy and which make the days go faster. I am sure that there are many well-meaning people in the industry but perhaps some of the organisations are not good with money and there appear to be a lack of business skills.

Many villages seem to becoming "cash cows" for their owners (religious ones included) rather than safe and proper caring havens for the elderly. I was involved in the private enterprise retirement village sector and after a village had been operating for more than 10 years many of the villages didn't know what to do with the "avalanche" of money that was pouring in from deferred management fees. Villages that accept Government funding should be prepared to open their books to residents and prospective residents so that one could clearly see the re-investment they were putting back into the home.

Yours faithfully,

(name supplied and withheld)