

## **My experience with Aged Care**

My mother used to live across the street from me, in a little housing complex, pottering around on her walking frame, and at that stage, with early signs of dementia – she couldn't sort the cutlery but would just throw it in the drawer, she would lose track of time, not knowing whether it was morning or night. She would take a nap after dinner, but sleep all night and on finding herself fully clothed when she woke, would assume that it was afternoon, and would be found eating cake for breakfast.

*{Her single storey house was in a complex where the houses at the front were two storied – whereas the active people at the front could run downstairs and jump into their cars and go, the frailer people in the single storey houses at the back were in total isolation. This is Council policy. Councils ought to change this policy, and demand that single storey houses should be at the front, as the housebound residents would be much better off, being able to sit on their porch watching the passing parade, particularly of school children, to keep a hold on the rhythm of the day and of the week.}*

She was still able to read books and to follow the plot, so most of her waking hours were spent in reading or in writing letters. Her meals came frozen from a community service, and she had a series of cleaners and 'support' staff, none of which were particularly effective and communications were dodgey- for example, I was told that someone would come and give her lunch and administer her medication; after a week I found that the tablets that I had put in a pill box, marked with the days of the week, were still there. Only when I raised the matter was I told that I had to get the chemist to pack them specially for the purpose. It is assumed that the public know these things.

I checked on her twice a day, every day, and one morning I found her lying on her bedroom floor, unable to get up, and she had no idea of how long she had been there.

She was taken to hospital, where she spent a week or so, but the social worker decreed that she could not go back home, but must go to a nursing home. And one was recommended.

## **Nursing Home No. 1**

I was invited to visit the nursing home around lunch time, when all the residents were tucked up in bed for their afternoon nap. I was shown a room on the upper floor, a single bed room with a window overlooking a sunny garden. The bathroom was next door and on the other side was a sitting room, a glassed-in verandah overlooking Botany Bay.

Food was cooked on the premises, and appeared pleasant and adequate.

My mother moved in.

### **Problems:**

She couldn't sit at the window of her room and read, because there was a hand basin fixed under the window (a detail I hadn't grasped on first visit)

She refused to use the sitting room because "*It is full of corpses*" she said in horror: - most of the time it was filled with 'baby capsule' beds, the very frail occupants staring at the ceiling with mouth open.

After a week she was moved downstairs to another room on the grounds that she was '*too mobile for upstairs*' ( the staff found it inconvenient to keep the gate, at the top of the stairs, closed.) The room she was then given was a dark and dingy room, the window of which opened into a covered courtyard where the staff ate their lunch, and I suspect, smoked.

When she was still living at home, she used to have a glass of sherry before her dinner, so after consulting the DoN, we supplied a bottle of sherry and a sherry glass, with instructions. After a week, there was no sign of the sherry, so I made inquiries and was told that she had finished the bottle – apparently the little glass had been lost, and the staff, unfamiliar with the sherry-drinking, had been giving her 200mls per night.

After a few weeks, a staff member came to me and told me in the strictest confidence that I should move my mother to another place, this place was inappropriate, as my mother and only one other resident were *not catatonic*.

I found her another place.

*{Relatives of prospective residents would be well advised to make a second visit to the nursing home, unannounced, in the middle of the afternoon, as a reality check.}*

## Nursing Home No. 2

This was a large nursing home on the side of a hill – ‘U’ shaped, with parking under one side, and gardens around linked by ramps and stairs. It appeared attractive, with wide brightly lit corridors, twin bed rooms, a large dining room, a large community room, with gardens visible from all windows.

The nursing home decreed that my mother was too unstable on a walking frame, and that she should be confined to a wheelchair. My mother preferred to roam outside in the garden in her wheelchair when weather permitted. One of the garden ramps had a top landing from which branched off a staircase.

When I drew the attention of the director to the risk of her falling down the stairs that ran from the ramp, the response was to stop my mother from going outside altogether.

*So I then paid for a gate to be installed, to buy her freedom of movement.*

My mother constantly went missing, abandoning her wheelchair if necessary to get through a gate by crawling, and often the staff and I would search the grounds for half an hour before tracking her down, often finding her covered in scratches and bruises.

And then one night, a nurse heard banging on the front door of the building in the middle of the night, and went to investigate – it was my mother.

How long had she been out of doors, in the street, unbeknownst to her carers? Who knows.

To make matters worse this was told to me by the nurse as a funny/amazing story “*Your mother is such a card! Do you know that I heard banging on the front door....!*”

So I moved her again.

### **Problems:**

The staff – few had good English, and most couldn’t read name tags, so my mother was often wearing someone else’s glasses or clothes.

This home had a mixture of residents – some with serious dementia, some merely with physical disability (in wheelchair) and all were thrown in together.

One male wheelchair-bound resident was a sexual groper who openly preyed on the frailest of women with dementia.

The residents were deprived of dignity and were made to wear bibs at meals, at tables with plastic cloths.

Doors leading to stairs and to the kitchen had signs that they were to be kept shut at all times, but were instead propped open.

Meals were timed to fit into one chef's single day shift. Dinner on Sunday night was packet soup and white bread.

At meal times the mentally alert were forced to share a table with the demented which often resulted in the table cloth being ripped out from under the plates, and everyone with their dinner in their lap.

The director had taken the sitting room with sunny aspect and view to the street as his office, instead of the space originally intended as his office, leaving nowhere for the residents to sit, other than in the huge entertainment room with blue vinyl chairs in rows like an auditorium. The residents took to sitting in the entry lobby as that was where interesting activity took place, but a fire safety audit decreed this an unsafe practice, and they were banned from the area.

My mother was often tied to her wheelchair, to stop her getting into bed. (But Houdini-like, she always managed to escape, and the chair would be found with her nowhere in sight).

At times she had an alarm device strapped to her body, supposedly to alert them if she went outside, but often if the alarm went off, it was ignored.

There was no protocol for collecting 'found' items in a central place – if I complained that my mother was missing three pairs of spectacles and her hearing aids, a staff member would open all the drawers and cupboards at the nurse's station to see what was there.

*{There was/is still? a problem with the Building Code, which, as far as nursing homes were concerned, focused mainly on the means of fire escape and fire-fighting, and appeared not to consider the day to day safety of the residents with their various disabilities.*

*This is why the ramps were permitted to have a staircase branching off them – the stairs are merely a means of escape, not a hazard. }*

### **Nursing Home No.3**

This was a beautiful-looking relatively new building in landscaped gardens, with large and bright bedrooms, spacious and comfortable living areas. Unfortunately, residents were not permitted into the garden without escort. The premises were secure, we thought, with automatic sliding doors and keypad control, although by coincidence my mother's previous neighbour had been living there and had escaped, twice.

#### **Problem:**

My mother was there less than 24 hours, when she approached the sliding exit door, looked at the key pad, read the sign above it - "*to exit, press 1618*", so she did.

The director phoned me and told me that my mother had been retrieved from the highway and would have to be put in the secure dementia wing – which at that time contained men who shouted and threw furniture around.

So, no thank you.

At this point, I was angry, distraught, and desperate; I phoned the Aged Care Hot Line, and was patiently, kindly, and frankly helped down from my tree by a wonderful woman, who gently managed to get me to accept my mother's dementia, to cope with my grief, and to face the relocation again.

She recommended a nursing home, where my mother (92 this year) has now been living for 6 years. I cannot fault it: only recently, as I sat with my mother, I watched a young male carer tending a Parkinson's disease sufferer, going off to find pillows and towels to pack around the man to make him comfortable, controlling the tremors, all gently and soothingly, competently.

At this nursing home, the owners are visible, they visit often, they know many of the residents by name. They are available to discuss problems, and deal with issues regularly. There are feed-back questionnaires for relatives, several times a year, as well as meetings.

The kindness, the consideration, the meals, the cherishing, the gentleness, the prompt addressing of concerns, even the ensuring of good language skills in all staff.....it brings tears to my eyes. It really does. Often.

**But**, the issue here is that we pay just under \$6000 per month for the privilege of this superb care. We have no regrets whatsoever, our mother deserves whatever it costs, we can afford it, but what of those who cannot afford the money, but are nonetheless entitled to be treated with similar respect and consideration? How many people suffer as we did, without the means to choose anything better?

And as a matter of interest, I received from a government department a booklet on choosing a nursing home – it contained a matrix with a list of criteria on the left hand side, and columns for each of the nursing homes visited, the idea being that by ticking boxes one could base one's choice by rating several nursing homes against each other.

I tried this, the criteria are so general that all of the nursing homes we tried rated exactly the same.