Mrs Valerie Little
Tathra NSW 2550

Australian citizen and member of concerned citizens for aged care- Victoria.

My points are from personal experience. I am not an expert, apart from my humanity and empathy for my 98 year old mother who died July 23rd 2010, after 6 months in an Australian High Care Facility.

I make these points with no knowledge of costs, regulations, requirements etc. of the NSW Aged Care System. My statements are based only on this one experience- which is, in a way, why our frail, older citizens' needs are inadequately met.

1. Most families have no knowledge of the Aged Care system until a family member needs the care. Many families never have a need of the Aged Care System, let alone the High Care System operating in NSW. The booklet and verbal information provided to our family did not adequately explain what physical and psychological changes may occur when a frail, still cognitively aware 98 year old parent can no longer, even with home nursing, meals on wheels, frequent family and retirement villager support and her own determination, live on her own.

2. Our family were delighted with the clean, pleasant environment available for our mother- room for herself with ensuite, and all within the confines of her Retirement Village location. We decorated it with her favourite treasures and many photographs. We felt she would adapt, as she had for the rest of her life. We had the phone put on; we visited her and took her on outings. As the home was within the confines of the retirement village many friends also visited, playing scrabble, cards, crocheting. We expected some anxiety. We did not expect Diazapan, Respiridone or physical restraint. We did not expect to have to sign a document to authorize restraint of our mother simply to keep her from using her walker, or to keep her in a chair when she wanted to go and sit outside in the sun and fresh air. We did not expect her to be institutionalized and that she would be diagnosed antipsychotics.

3. We asked to see our mother's care plan, or whatever records were kept to inform carers where our mother was at, what medication she was on. As we did not know what our mother's behaviour was like when we weren't there we were not given the chance to offer help if needed. Unless we requested a meeting with the director or emailed our concerns there would have been no communication between the family and the home. And when we were informed changes were being made- they rarely continued for long.

4. It is insufficient to classify people as either Low Care or High Care. It is wrong to think High care is a 'one size fits all' situation. Two carers for 15 high care

people is insufficient- if we are providing quality of life for our frail aged citizens. I thought I was back in a Dicken's Book when my mother would say, as we waited for someone to come and help her with toileting- 'stay in the corridor, don't go into my room- otherwise I will be ignored'; and she would spit it out.

5. It is wrong to put insurance, occupational health and safety and carer 'work to rule' considerations before the needs of a frail 98 year old person. 'Your mother has to wait to use her walker until we can be with her, incase she falls': 'your mother has to wait to use the toilet until there is another carer with us- I can't take her on my own.' When I offered to help- 'no you are not allowed.' 'Your mother was restrained because we had to finish the showering and she would not stay in her chair.' 'Use the pad darling, the other carer is having dinner.'

6. At no stage did we ever give permission for my mother to be given Respiridone- which is obviously a form of chemical restraint- at no stage did her doctor or the nurse explain the effects of respiridone. We were told what 'sundowning' after a couple of months- and is it any wonder people get 'restless' over the afternoon and early evening. They have learned what is in front of them from 4 o'clock- when family are not here: dressed for bed, dinner, dose of respiridone and a bed on the floor!!

As I have explained I am just a daughter- but I can assure you it was an extremely steep learning curve when my mother went into High Care. I have learned that a RN is not always on duty, although you think one is. I have learned that carers are paid a pittance and expected to do the impossible. I have learned that some carers do not care. At least 4 carers/15 people should be available to even start to give High Care people quality of life. I have learned that having so many different carers is very confusing. I have learned you can sign to have your mother physically restrained, but not to allow her the freedom of getting herself from A TO B. I have learned that ambulances are only called when it is almost too late- i.e. renal failure (hospital 'if we don't get your mother's potassium level down in the next 8 hours she will be dead.') and (hospital 'no we cannot operate and cut off your mother's 2 black dry gangrene toes, she is too old- they will eventually drop off, they will be very painfull, but we will give her something for that.'). My mother died 7 months after entering High Care.