My father, Kohn Keith McWhirter lived in two residential aged care facilities and spent some time in acute care hospitals in Melbourne, until he died.

As I live in Canberra, long distance organisation was a constant worry because, in spite of long phone conversations and frequent visits to discuss problems, few of the changes agreed were ever implemented. Staff at a facility in Surrey Hills Victoria and a small western suburbs local hospital seemed unable to look beyond my dad's stoic lack of complaint to offer simple help - sufficient assistance to eat, dress and toilet, which was required.

I have also recently been involved with distressing aspects of care for a friend's mother who was placed in an extremely well known facility in Canberra. This friend had to buy in carer hours to ensure that her dementing mother was showered, dressed and fed each day. The family had expected that this basic care was paid for in the fees.

My father had a DVA Gold Card and sufficient financial means and family support to purchase whatever care was needed.

My father was a very happy, sociable person, active and energetic but frail after serious surgery for throat and stomach cancer. A widower for 20 years, he married at 80 largely to avoid placement in a nursing home, but unfortunately the arrangement did not work out as he had hoped

After a violence incident when both my father (82) and his wife (83, and a long standing family acquaintance) were in stages of early dementia and she was beating him with his walking stick, it was clear that he required care. The first placement was at Surrey Hills, where he was accepted quickly.

This place, a delightful looking old mansion, was chosen because of its proximity to his grand-daughter and her beloved family, near shops, the RSL, and because they purportedly offered social stimulation and assistance to go out on group activities.

No such stimulation or assistance to go out was ever provided. The food seemed initially ok in the trial period, but deteriorated after 3 weeks – eg instant noodles, packet soup or bread and jam for dinner. My father (who always has disliked cats) complained about the cat always wanting to get on his bed. Over several weeks, he was left alone in his room and he grew very unhappy. His clothes disappeared slowly, and he looked slovenly.

After 4 months and many complaints to management, the family decided to move him to Gwennapp, in Kingsville, closer to a daughter who had recently become involved in his care. He lived at Gwennapp very happily for several years, with excellent care appropriate to his needs, reasonable food, and a variety of activities which gave him a good sense of independence and a feeling of some control of his life.

After a fall on a weekend outing with a relative, he sustained a #neck of femur, and was transferred to Heidleberg Hospital where repair surgery and rehabilitation was

undertaken. He was making excellent progress, and it was decided to move him to a small local hospital, closer to his daughter.
He was most unhappy there - probably disoriented - and constantly distressed about poor nursing care, uneatable meals and, particularly, lack of assistance to eat. From this hospital he phoned me in Canberra, in distress several times to say, "They are killing me … starving me to death. I can't eat any of the food here and no-one will help me." I called the hospital on 3 occasions in 3 days to try to work out how best to get the assistance required, and was reassured each time that staff would attend to my concerns. I also spoke with my sister who tried to get bed rails, assistance with eating and a friend to bring in food that he could eat. He died 2 days after a fall, when trying to get to the toilet, at this hospital. The death certificate says cause of death was cardiac failure but should, in my opinion, blame neglect.

After these unhappy recollections, I make the following critical observations about our family's aged care experience:

- There are no mandatory staff resident ratios so that most staff seemed overloaded and often harassed, also frustrated because they can never have time to do a proper job
- Unhappy workers: low pay rates for aged care workers means we may get only the desperate for work, hence low standards
- Lower pay for RNs – see above
- Lack of knowledge of geriatrics by RNs and DONs may explain the nonchalant attitudes to what appeared to me to be life threatening illnesses or behaviour (as was the result at the small acute care hospital)
- Poor level of treatment in aged care facilities for acute illnesses
- Inadequate knowledge of dementia in aged care facilities and acute care hospitals,
- poor building and landscape design for dementia care in aged care facilities and acute care hospitals
- inadequate supervision of care staff managing residents with dementia – supervisors need to be familiar with individuals
- little regard for family concerns ("We know better" attitude)
- inappropriate, uninteresting diet, and
- lack of assistance to eat
- I was very surprised, after working in aged care for 20 years and knowing how it all works, at how little I could influence "the system" to effect changes to improve my father's care. I now know that I should have whisked him out of the small hospital (as my cousin Bruce did with his mother some weeks later)

Recommendations:

1) Please reintroduce genuine, regular, standards monitoring, with resident and family evaluations not just window dressing
2) greater emphasis on wellness and prevention of decline, maintaining dignity and independence. These should be a central goal of ALL aged care services.

3) more assistance for people to remain at home – streamlining Assessment and community care services to enable earlier assessment and intervention which can be preventive in early stages
4) separation of accommodation and care so that people can purchase service. This would involve aligning payments for people living at home (or in a hotel) with people in residential care so that they can get what they prefer eg food from Meals on Wheels or the local Italian restaurant; council garden help or Jim's
5) better acute hospital management: Ageing people, particularly with cognitive impairment, do poorly in hospital and often have bad outcomes. Better staff education in geriatrics, greater respect for older people and better building and landscape design are needed in acute care hospitals.
6) better medical care in aged care residences: Some fully qualified staff seem to act as though poorly trained, sometimes taking a palliative approach rather than active treatment. The current arrangement of residents having individual GPs means that there appears no consistent approach and access can be difficult – a dedicated doctor with interest and knowledge in geriatrics could be better
7) staffing in residential care facilities requires:
    a. staffing ratios that allow proper time for care of individuals
    b. wage levels that attract good workers
    c. selection of people who have respect for and like working with older people
    d. ongoing training so that staff have appropriate knowledge and skills to do their jobs
    e. accreditation from this training across disciplines to assist career path development

8) increase access to specialist assessment and medical care in country and remote areas.
9) ensure local input, including Indigenous, into planning aged care infrastructure. No small community has exactly the same needs as others so a national approach can be wasteful; and
10) cross disciplinary research into ageing, prevention of decline and best practice (often what many practitioners know "works best.") Research and evaluation should have links to policy development so that new information, technologies, medical advances and social change are reflected in statutory frameworks,

Marjory Kobold