Anonymous Publication: I agree to my submission being made public anonymously.

Royal Commission into Aged Care - Submission for my sister

What is my name: 
What is your email address: 
What is your preferred contact phone number:
In what State or Territory do I live: NSW
I live in a REGIONAL AREA
Date of Submission: 12/08/ 2019
Have I made a previous submission: I am submitting 2 submissions
Who are you making this submission for: ANOTHER PERSON – MY SISTER
What is the relationship to the person you are making the submission for:
SIBLING – MY SISTER
In which state or territory did the person live: NSW
The person lived in a REGIONAL AREA
The person had an Enduring Power of Attorney

WHICH OF THE ROYAL COMMISSIONS TERMS OF REFERENCE IS YOUR SUBMISSION ABOUT

1. Systemic failures and neglect in young onset dementia care in residential aged care facility:- management, staff education, ongoing care, palliative care, activities program, nutrition

2. Challenges and how best to deliver services to people with young onset dementia

3. Palliative and end of life care - Challenges

4. Examples of good practice and innovative models in delivering aged care services for people with young onset dementia

5. My Recommendations
WHAT SPECIFIC CONCERNS DOES YOUR SUBMISSION RELATE TO YOUNG ONSET DEMENTIA CARE AND SERVICES

1. Managers/ Directors of Residential Aged Care facilities, their education and training
2. Personal Care Staff - re-structuring training and education thru TAFE
3. Activities programme for people with young onset dementia
4. Neglect
5. No activities
6. Mental Health
7. Medication Management
8. Dental Health
9. Personal Care
10. Palliative Care and End of Life Care
11. Loneliness, disengagement, disconnection, and or boredom

WHAT TYPE OF AGED CARE SERVICES DOES YOUR SUBMISSION ADDRESS

1. Services of any kind to a person living with young onset dementia
2. Care for people with young onset dementia in an aged care home or residential facility
3. Entry level help or care in a person's own home.
WHAT WOULD I LIKE TO TELL THE ROYAL COMMISSION

Who I am:

- My sister lived with the condition of young onset dementia from age mid 50’s.
- My sister lived in an aged care residential facility in a NSW regional centre, from 2014 – 2018. From age mid 60’s.
- I was one of my sister’s local support people.
- Alzheimer’s Australia provided me with six (6) x 2 hour sessions to provide information and training to me about how to support my sister. Alzheimer’s Australia provided ongoing telephone support & information. Alzheimer’s Australia provided excellent support.
- I provided care and advocacy for my sister - through visiting, we read together, listened to music CD’s. I took my sister out for walks in parklands, to visit our mother, for drives and to the local indoor pool for exercise.
- Qualifications: I hold a Degree of Bachelor of Education, a Post Graduate Degree in Business Management.
- Work Experience: Teacher; Department Head Local Government; Co-ordinator NSW Government Regional Development Program.

The Aged Care Residence

Located in a NSW Regional Centre, owned and operated by a national Christian church organisation, a head office located locally. The Aged Care Residence comprised a number of purpose- built house like structures. Each house had a communal kitchen /dining room and lounge room. It is Dementia specific accommodation. Each house had a locked garden. 1 staff member to a house.

My sister

- My sister experienced head injuries at age 20. My sister recovered. My sister married, had children, worked, and was involved in sport. My sister started having memory difficulties in her 50’s. My sister continued working until approx. aged early 60’s.
- Aged in mid-60, my sister had paid carers come to her home to support her. In later 60’s, my sister needed urgent 24 hour care and support. A family member and with my sister had a meeting with a prospective Aged Care Residential Facility. The manager explained they could not accommodate my sister, as she was too young, too active and too fit.
Topic 1

Substandard or unsafe aged care services for young onset Dementia clients,

Background

In later 60’s age, my sister was offered a room in a house operated by Christian Denomination Aged Care residence. It was urgently needed.

All residents of the house lived with the condition of Dementia.

My sister had her own bedroom and en-suite bathroom in the house.

My sister was a strong, active person accustomed to daily exercise.

1. Systemic failures and Neglect - No Art therapy, No Music therapy, No Dance, No Exercise Program, No Gym. No Exercise Equipment provided for residents living with the condition of Dementia.

2. The residents were mobile, physically active and mentally able people confined day in and day out to a house and yard with no exercise program. This is wrong.

The activities provided were: - a weekly church service with singing of hymns, sometimes a morning walk.

There were no ‘active’ activities for residents.

Residents spent their whole time walking, constantly walking about the house and yard or sleeping in front of the Television.

Their constant walking was a way for the residents with dementia to release natural energy, a way to exercise themselves.

I felt it was a tragic, unhealthy, confining environment for my sister and for all residents.

There was no initiative or attempt by management to create a daily programme of physical and mental activities for the residents.

The environment was severe and prison-like. Head staff carried bundles of keys on their waists and seemed focused on containing residents. The Head staff demonstrated no understanding of resident’s abilities and energy levels.
1. Depression, isolation, boredom and no release of natural energy

- My sister was unhappy, depressed and did not want to be there.

- My sister relied on visits from family members and dear friends to survive. Family members played badminton with our sister at the Aged Care Residence house. My sister enjoyed this activity, as my sister had been a good tennis player. Family members took our sister out walking in parklands, to the pool and to a local children’s playground to relax and exercise. My sister was happy doing these activities.

- When I took my sister out for car drives and walks in nature she did not want to return to the Aged Care Residence house.

Progression of the medical condition. My sister’s condition deteriorated until in the last 8 months she was unable to walk.

2. Lack of uniform procedures in personal care

I observed no uniform procedures in this aged care residential facility.

Some Individual care staff members were outstanding in their work at my sister’s Aged Care home.

One female care staff member involved my sister in preparing meals, setting the table and clearing away dishes after meals.

My sister was a different person with this staff member. My sister was happy when concentrating and thinking while actively setting tables, putting out dishes.

I could see my sister was involved and thinking, and happy with this staff member and in doing these tasks.

Most of the care staff did not do this – most did not involve my sister or other residents in doing tasks. The residents were left to do nothing. This is wrong and inhumane.

DENTAL HEALTH CARE My sister’s oral dentures were not removed and cleaned each day. My sister had mouth infections and oral odour. The personal carers did not follow a uniform list of procedures for personal care including dental care.
3. Palliative Care

There was no palliative care offered over the last 8 months. Staff left my sister alone for hours in her room or in front of a TV in Residence lounge. This is wrong.

4. End of life care

Two weeks prior to passing away my sister deteriorated, I was notified by the Residence staff. I went to be with my sister

The final, end of life care was competent. The nurse on duty and care staff talked to me and explained fully about what was happening for my sister during end of life. The nurse seemed well trained in end of life care. My sister received morphine injections in the last 2 days. I think the morphine helped my sister. Some staff were caring and showed empathy. Their care helped me thru this time.
TOPIC 2 EXAMPLES OF GOOD PRACTICE AND INNOVATIVE MODELS IN DELIVERING AGED CARE SERVICES.

1. The Montessori Method of Aged Care as a model of best practice for people living with the condition of young onset Dementia.

- I visited another local aged care residence run by Uniting Care that followed the Montessori Method of Aged Care.

- The Montessori Method of Aged care is based on the correct foundation that people living with Dementia are capable of doing, thinking, learning & enjoying life.

- I concluded this residence was an example of good practice in aged care.

- I observed a purposeful, doing community at work

- The residents were engaged in doing things that made sense, tasks like peeling vegetables and preparing and setting the tables ready for lunch. The residents appeared purposeful and were socialising with each other while doing these tasks.

- I observed the staff in a team meeting.

- I was told about their thorough training program for volunteers at this residence. Volunteers worked one on one with residents with dementia in daily art activities.

- I noticed residents wore name badges and I was told residents had voted to wear first name labels so they could more easily socialise with other residents


I visited an Aged care Residence of 24 beds, which was co-located within a Retirement Village of 130 Units, 2 or 1 Bedroom Units.

This Aged Care Residence provides single rooms with en-suite bathroom, kitchenette, access to gardens or a courtyard from each room.
This Aged Care Residence provides a secure residence for people living with dementia. All levels of permanent and respite care are offered.

Here the Facilities provided are of a higher standard than offered by other Aged Care Homes I visited.
Facilities are available to both Retirement Village residents and the Aged Care Residence residents. This is a good system as facility costs are spread across many people.

The residents of this co-located Aged Care Residence were more active and healthy.

Facilities included:
Community Centre, Residents lounge
Indoor heated 15 metre swimming pool
Aqua exercise classes daily
Spa indoor heated
Gymnasium
Billiards Room
Indoor bowls area
Outdoor bowling green
24 hour on-site staff and manager

At this Aged Care Residence, family and friends are actively encouraged to participate in activities, meals and spend quality time with their loved ones. This is right.
3. **Aged Care Residences attached to a NSW rural District Hospital as a model of best practice**

I visit my 95 year of age relative at her Aged Care Residence attached to a rural District Hospital, NSW. I observe the Hospital nurses and care team members work in BOTH THE Hospital and the Aged Care Residence and are well trained and competent. My aunt is in a wheel chair. My aunt feels well cared for and safe.

The District Hospital nurse staff are providing quality care at this NSW District Hospital complex.

Also, the communication system used at the District Hospital Aged Care residence includes room bells directed to staff mobile phones. It is quiet and efficient. It is a peaceful calm environment.

However, this aged care environment would not be suitable for a person like my sister with young onset dementia unless more active leisure programs and exercise facilities were provided.

4. **Physiotherapy in aged care residences and playground equipment in the grounds as a model of best practice.**

My sister did not receive physiotherapy and did not maintain mobility. My sister had no access to play or exercise / activity equipment unless brought in by the family.

5. **Playground equipment in Aged Care Residence grounds as a model of best practice.**

In Europe Aged Care Residences have play equipment in the grounds.

This encourages visits from family members with children.

The play equipment is used by residents for exercise

The play equipment establishes a happy environment

The play equipment supports Aged Care residents to play and interact with grandchildren and great grandchildren.

The play equipment is successful in elevating aged care resident’s mood by its presence, colour and the possibilities it presents for residents and family members.
TOPIC 3 RECOMMENDATIONS

CHANGES I WOULD LIKE THE ROYAL COMMISSION TO RECOMMEND.

Number 1 Recommendation

a) I would like the Royal Commission to recommend that the Federal Government legislate and make it mandatory that Managers/ Directors of Australian Aged Care Residential Facilities must hold a University Level Management qualification.

b) I would like the Royal Commission to recommend that the Federal Government develop a Degree Level Aged Care Residential Facility Management Course in Australian Universities for this important community position of Manager of Aged Care Residential Facilities.

- I recommend to the Federal Government that accreditation of each Aged Care Residential Facility be dependent on the operator employing a Manager with a tertiary Management Qualification.

An Australian Aged Care Residence Manager POSITION has to have the skills and education to manage a large and varied team including responsibility for:

- Financial services
- Building Maintenance services
- Cleaning Services
- Gardening and Grounds services
- Food services,
- Activities & Recreation programme
- Personal care,
- Nursing Services
- Palliative Care Services
- Allied Health services
NUMBER 2 RECOMMENDATION

I would like the Royal Commission to recommend that the Federal Government urgently legislate to re-structure TAFE education in Aged Care to educate students in the Montessori Method of Aged Care

The Montessori Method of Aged Care supports people with Young Onset Dementia in being active and involved in their daily personal care and involved in meaningful life activities they choose, genuinely enjoy and find fulfilling.

When I asked my local regional TAFE educators of Cert 4 in Leisure and Lifestyle what activities they taught students to do with residents they said none. That it was up to students to devise activities. This is wrong.

Number 3 Recommendation - Legislated activities for residents with dementia

3(a) I would like the Royal Commission to recommend to the Federal Government that the Federal Government Legislate to make it mandatory that Aged Care Residences provide a programme of activities that must involve residents with Young Onset Dementia in art, music, dance and exercise and must include:

- Art sessions, daily, with residents painting and drawing sessions
- Music and Singing for pleasure sessions daily
- Dancing sessions where residents move to music daily
- Exercise sessions to maintain balance and strength with Gymnasium equipment and games equipment and physiotherapy led sessions of exercise
- Play- ground equipment in the yard to encourage play and interaction with young and older family members.
- Gardening sessions for resident with dementia to plant and water plants
- Daily Walking group, Badminton and Table tennis equipment provided
All these listed activities are proven by evidence-based research to engage people mentally, elevate mood and maintain mobility.

3(b) I recommend to the Federal Government that accreditation of Aged Care Residential Facilities be dependent on each Facility providing daily art, music, dance and exercise sessions and equipment.

No 4 recommendation - Palliative Care

I would like the Royal Commission to recommend that the Federal Government legislate to make it mandatory that every Aged Care Residence Facility employ a trained palliative care specialist. My sister passed away without trained palliative care support in her aged care residence. This is wrong and traumatising for the person and family and friends.

No. 5 Recommendation

I would like the Royal Commission to recommend to the Federal Government that the Federal Government pass legislation requiring all Aged Care Residential Facilities provide exercise equipment and playground equipment in their grounds for use by residents and their family members and friends.

In Europe Aged Care Residences have play equipment in the grounds.

This encourages visits from family members with children.

The play equipment is used by residents for exercise and relaxation.

The play equipment supports Aged Care residents to play and interact with grandchildren and great grandchildren.

The play equipment is successful in elevating aged care resident's mood by its presence, colour and the possibilities it presents for residents and family members.
No. 6 Recommendation – New Retirement Villages must include an Aged Care Residential Facility

I would like the Royal Commission to recommend to the Federal Government that the Federal Government legislate to make it mandatory that new Retirement Villages must include an Aged Care Residential Facility on site, limited to 25 beds.

This will provide Ageing in Place for Retirement Village residents, plus provide Aged Care beds available for people in the surrounding community.

From visiting Aged Care Residential Facilities I have observed that 25 bed Aged Care Residences seem better able to provide a high standard of care.

I have observed that larger 30 to 100 bed Aged Care Residences are too big and residents do not receive proper care or attention.

No. 7 Recommendation

I would like the Royal Commission to recommend that the Federal Government legislate to bring standards of nursing care, personal care, dental care meals, and room cleaning in Aged Care residential facilities to the same standard and quality as in Public Hospitals in NSW.

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