Submission No 120

INQUIRY INTO INQUIRY INTO ELDER ABUSE IN NEW SOUTH WALES

Name: Ms Susan Henderson

Date received: 21/03/2016

Submission to the NSW Legislative Council Inquiry into Elder Abuse

submission of: Susan Henderson

I would like to thank the Committee for the opportunity to make a submission regarding my late mother's experience, in order to contribute to the discussion about elder abuse. This submission focuses on abuse within residential Aged Care facilities, both by staff and other patients, rather than abuse by family members, which is often the focus of attention.

I am happy to speak to anyone concerned, and to provide additional information if requested. I have substantial records pertaining to the incidents relating to my mum.

There is legalised elder abuse occurring in aged care facilities across Australia. Federal legislation provides facilities with discretion in relation to reporting abuse by other patients and leaves the management of facilities up to the owners, who run them like businesses [the Aged Care Act 1997, Section 63-1AA(2) and the Accountability Principles 2014, Part 7, Section 53, subsections 1 (a), (b), (c), (d) and 2 (a) and (b)].

Abuse of dementia patients in aged care facilities is the perfect storm because:

- Approved providers ("providers") of aged care facilities essentially self-manage and self-police. Providers decide who they employ and their level of training. Providers also decide whether or not abuse has occurred, whether to report abuse, and what is done about it (e.g. standards of care implemented, actions taken regarding injuries and changes to staffing numbers). However, the owners of these facilities have incentives to minimise bad publicity, because they are businesses. As businesses, the focus is staying in business, cost-effectiveness and profit, not protecting vulnerable residents.
- The current legislative environment provides too many choices to providers. When non-compliance occurs, the consequences are minimal. The focus of the legislation is on supporting providers to comply with their requirements.
- The current legislation does not support knowledge of events in care, by families. Families of residents are legally kept in the dark as to the danger to their loved ones and actual events, because of the aforementioned legislative arrangements, and associated legislation in regard to privacy. Many families are also relatively uninvolved once their loved ones enter care. They may not know what is happening to their loved ones, and the provider doesn't have to tell them.
- Dementia patients are often unable to speak for themselves. Many cannot speak coherently and so cannot complain. Not all dementia patients are passive though. Dementia units include people who are potentially abusive, and people who are potentially victims of abuse.

My mother suffered abuse as a consequence of this perfect storm. This abuse was enabled by self-managing and self-policing facilities with poorly trained staff, an incentive not to report incidents, and my legal inability to make them do something about it. That providers are allowed to decide what to report, and that they are legally allowed the excuse of ignorance of Accreditation Standards and of what constitutes proper and quality care, enables abuse to continue.

There needs to be accountability and consequences brought into the Aged Care system.

I have been advised that recommendations would be appreciated with submissions to this Inquiry.

I am asking that the Committee make the following recommendations to the Australian Law Reform Commission Inquiry on Protecting the Rights of Older Australians from Abuse:

- that changes be made to the *Aged Care Act 1997, Section 63 1AA(2)* and the accompanying *Accountability Principles 2014, Part 7, Section 53, subsections 1 (a), (b), (c), (d) and 2 (a) and (b),* to ensure that all abuse is reportable, including all assaults, whether or not the assailant is deemed competent or otherwise responsible, and
- that changes be made to the *Aged Care Compliance Policy Statement 2015-2017*, such that the compliance and Accreditation Standards are mandatory for providers.

sincerely,

Susan Henderson

My (now deceased) mother was a dementia patient for 6½ years in residential Aged Care dementia-specific units, in regional NSW (2007-2009) and then in Victoria (2009-2013). She was the victim of abuse, of different forms and degrees, in both facilities. In NSW, my mother was the victim of financial abuse, psychological abuse and neglect; in Victoria, my mother was also the victim of unreportable assault by another patient. Had the Victorian facility in which the assault occurred been in NSW, the results would be the same: I could not protect my mother due to restrictions in federal law.

This submission outlines: the issues, as I see them, in relation to the current environment; and example outcomes, taken from my mother's experience. These include:

- changing of her needs status to satisfy placement (and subsequent financial abuse);
- unattended injuries (neglect);
- unreportable physical abuse;
- failure to care for her in relation to specific personal needs (neglect); and
- infringements on her autonomy and human rights (neglect and abuse).

Some of these consequences were illustrated in several ways; for the purposes of brevity, this submission highlights key exemplars only. The unreportable assault in the Victorian facility is included, as the process and its consequences are also relevant to NSW, given the scope of the federal legislation.

I am asking that the Committee make the following recommendations to the Australian Law Reform Commission Inquiry on Protecting the Rights of Older Australians from Abuse:

- that changes be made to the *Aged Care Act 1997, Section 63 1AA(2)* and the accompanying *Accountability Principles 2014, Part 7, Section 53, subsections 1 (a), (b), (c), (d) and 2 (a) and (b),* to ensure that all abuse is reportable, including all assaults, whether or not the assailant is deemed competent or otherwise responsible, and
- that changes be made to the *Aged Care Compliance Policy Statement 2015-2017*, such that the compliance and Accreditation Standards are mandatory for providers.

The issues

There is legalised elder abuse occurring in aged care facilities across Australia. Federal legislation provides facilities with discretion in relation to reporting abuse by other patients and leaves the management of facilities up to the owners, who run them like businesses [the Aged Care Act 1997, Section 63-1AA(2) and the Accountability Principles 2014, Part 7, Section 53, subsections 1 (a), (b), (c), (d) and 2 (a) and (b)].

Abuse of dementia patients in aged care facilities is the perfect storm.

Providers of aged care facilities essentially self-manage and self-police. Providers decide who they employ and their level of training. Providers also decide whether or not abuse has occurred, whether to report abuse, and what is done about it (e.g. standards of care implemented, actions taken regarding injuries and changes to staffing numbers). However, the owners of these facilities have incentives to minimise bad publicity, because they are businesses. As businesses, the focus is staying in business, cost-effectiveness and profit, not protecting vulnerable residents.

The current legislative environment provides too many choices to providers. When non-compliance occurs, the consequences are minimal. The focus of the legislation is on supporting providers to comply with their requirements. Legislation emphasises the provision of chances to improve, and ignorance and lack of intent as a defence – perhaps a reference to the criminal law concept of mens rea, but inappropriate in this context. Recent changes to the policy landscape, specifically the new "Accountability Principles" reduce the onus on providers to report assaults. The

previous "Compulsory Reporting Guidelines" encouraged providers to report assaults, and made specific reference to the severity of assaults to guide providers' decisions; the new Accountability Principles does not have these references.

The current legislation does not support knowledge of events in care, by families. Families of residents are legally kept in the dark as to the danger to their loved ones and actual events, because of the aforementioned legislative arrangements, and associated legislation in regard to privacy. Many families are also relatively uninvolved once their loved ones enter care. They may not know what is happening to their loved ones, and the provider doesn't have to tell them.

Dementia patients are often unable to speak for themselves. Dementia symptoms and complications include agitation, confusion, paranoia, memory loss, delusions and hallucinations. Many cannot speak coherently, cannot put their thoughts together, cannot defend themselves, cannot put in their own complaint. Not all dementia patients are passive though. Dementia units include people who are potentially abusive, and people who are potentially victims of abuse.

My mother suffered abuse as a consequence of this perfect storm. Much of this abuse was due to the inexperience of staff and the ignorance of general medical, physical and psychological care needs, and of dementia needs specifically. Abuse was enabled by self-policing facilities with an incentive not to report incidents, and my legal inability to make them do something about it. That providers are allowed to decide what to report, and that they are legally allowed the excuse of ignorance of Accreditation Standards and of what constitutes proper and quality care, enables abuse to continue.

My mother's abuse continued for the 6½ years because I could not stop it. I sought assistance, and made complaints to the then *Complaints Investigation Scheme* (known as *the Scheme*) in both states. In NSW, the result was that *the Scheme* advised me that the provider and facility staff assured them that I was mistaken and that they had acted appropriately at all times. In Victoria, *the Scheme* monitored the provider's attempts to comply over 6 months, identified provider non-compliance and eventually issued a *Notice of Intention to Issue Directions*, to no effect.

Victorian police could not respond to my mother's assault, because of the restrictions of federal law. NSW police cannot respond to such abuses either. The emphasis of the federal law is on the assault by a person with a cognitive impairment, which leaves the assault on a victim inadequately addressed. Discretionary reporting hides the incidence and severity of assaults, particularly in residential Aged Care dementia units. It has been my experience that the priority of providers is as any business: staying in business, cost-effectiveness and profit, and accordingly, avoidance of negative publicity. Reporting abuse is not good for business.

Whether or not State policies are reviewed and implemented, the monitoring of these policies is in accordance with the (Federal) *Aged Care Compliance Policy Statement 2015-2017*, which "encourage(s) and support(s) compliance" ("the conventional 'regulatory pyramid' model", Part 2, p.5) and emphasises continual chances for the providers to improve their performance, by "(m)onitoring the provider's return to compliance... for a period of time" (Part 3, p.11). For my mother, that "period of time" was 6 months, during which time Accreditation Standards continued to be breached. My mother ran out of time; she died.

Example outcomes (from my mother's experience) Changing of her needs status to satisfy placement, and subsequent financial abuse

My mother suffered financial abuse in NSW. The abuse stemmed from her reassessment as low care (from high care) to enable placement in the only aged care facility with a bed available. This reassessment made my mother eligible for the payment of a \$250,000 bond. The provider then overcharged. As well as the basic daily care fee, monthly charges included an "accommodation charge" (not legally chargeable in addition to the former) which turned out to be the interest on the

bond (due on the sale of the house). Facility owners demanded the bond payment of tens of thousands of dollars, and threatened legal action and eviction of my mother if the bond remained unpaid, despite previous agreements as to the payment method (paid in full plus interest upon the sale of her house).

It is my belief that these practices constituted financial abuse of my mother, and psychological abuse of me, as her representative and family member, and until residential placement, her primary carer. One of the consequences for my mother was that I was spending time on the phone, writing letters and sending faxes, seeking advice and trying to resolve this, rather than spending time with my mother, who had no other regular visitors. Re-assessment as low needs also enabled neglect. My mother had high care needs. However, these needs could not be enforced or complained about as not being met – since they did not officially exist. I put in complaints to *the Scheme* to no avail.

My family were fortunate in that we had her home to sell in order to cover the bond. Other families do not have such a financial resource, and this must be a problem for them, particularly in regional areas where residential Aged Care facilities are few and restrictive in regards to level of care available. People with high care needs are not supposed to have to pay a bond. I believe that it is reasonable to anticipate that placement options for high care patients become a bigger problem, with extended home care resulting in higher needs on entry into residential care.

Example 1: February – March 2007, ACAT assessment altered to enable placement; bond

14th February 2007, there was an assessment of my mother, in her home. She had been receiving home and community care; I also cared for her and visited at least twice a day. Primary disease/ disorder was identified as short term memory loss (STML). *Extended Aged Care at Home (EACH)* and respite care were recommended. The "living environment... most appropriate for long term care needs" was identified as "residential aged care service – high level care".

19th March 2007, I took with my mother to the local regional hospital, after her condition and behaviour had escalated to the point where I could no longer care for her myself. I had kept her out of residential care for as long as possible, since diagnosis 1995. The ACAT assessor wanted 8 days to observe her away from me, to reassess.

After 3 days in acute care, the hospital staff could no longer provide adequate care; my mother was twice found on the road outside the hospital, and staff were concerned that she would meet and conflict with a psychiatric patient who had been admitted. I was advised that the only available facility with the only available room was a private facility with a secured (locked) dementia unit classified as dementia specific low care and that they would only take my mother if she was assessed as low care. I was told I had 3 hours to make up my mind: either agree to reassessment and placement with this provider, or my mother would be transferred by police to the psychiatric hospital 180km away as the hospital could not cope with her behaviour.

I agreed to the reassessment. Thyroid Disorder replaced STML as the primary condition of concern. Appropriate long-term living environment was identified as "residential aged care service – low level care". My mother's care needs were classifiable as low in some respects and high in others; there was the option for the ACAT assessment to identify specific levels of care, but many of her dementia behaviours and her subsequent distress (e.g. wandering) would be managed purely by being in residential care. Assessment as low care meant a \$250,000 bond was payable to the provider.

Example 2: 2007-2008, the facility Director requested full interest payment to date

In the initial meeting with the Director of Nursing (DON) of the facility, it was agreed as understood that

- my mother's house would need to be sold in order to pay the bond;
- accrued interest would also be paid from the sale of the house, or as a reduction in the refund of the bond, whichever came first; and
- an additional basic daily care fee would also apply.

Over a period of months, the DON phoned me, requesting that the "outstanding account" be paid in full.

Example 3: 2008, the provider demanded full and immediate interest payment to date and threatened to evict my mother

The facility changed hands. My mother's house was still on the market despite several agents and several reductions in price. The head office of the new provider phoned me (and my brother) several times saying that full payment of "the outstanding debt" (the accrued interest) was required immediately. They demanded I pay if my mother could not, and advised me to reverse mortgage my mother's home; they gave me a phone number to call to organise the reverse mortgage.

They told me that the provider would evict my mother with 42 days notice if \$20,000 was not paid within 14 days and claimed that they could demand the whole amount within 14 days, but that they were being lenient as I had already paid \$20,000 off the bond.

I consulted a broker who advised me that a reverse mortgage was not only inadvisable, but impossible, given the amount of money involved.

Example 4: 2008, continued letters of demand, advice from TARS

I received a letter from the provider demanding payment of the full amount of accrued interest stipulated as \$45,050.19, within 7 days or "further action" would be taken.

I contacted The Aged Care Rights Service (TARS) and was advised that there was provision in the *Residential Care Manual* for interest on the bond (the "outstanding debt") to be subtracted from the refunded bond – as per my agreement with the DON.

I phoned the head office of the provider and advised them of this, and was told "that would be fine if there was a bond paid to subtract it from". I replied that if the bond were paid, then there would be no interest.

I received another letter from the provider demanding payment of the full amount of accrued interest within 7 days or "further action" would be taken.

A further letter from the provider threatened me with debt collection within 7 days if I did not agree to full payment within 30 days.

Example 5: November 2008, debt collection agency, and threatened legal action

I received a letter from a debt collection agency on behalf of the provider, demanding full payment of \$31,194.63 "or a satisfactory arrangement made within **5 business days** (original emphasis)", lest there be "further action which may include **LEGAL ACTION** (original emphasis) and result(ing) in additional costs together with interest being charged".

These issues were resolved with TARS' representation and intervention. My mother was granted Financial Hardship Assistance.

Interaction with care recipients' rights and responsibilities, and accreditation standards Aged Care Act 1997, Schedule 1 User Rights Principles 2014, 1: a) d) e) n) u) Accreditation Standards 1.2, 1.8

Unattended injuries

My mother had several shoulder dislocations which remained unnoticed, sometimes for several days. The delay in care had consequences for the injuries and my mother's ability to heal, and finally, the complications of an unattended injury in Victoria resulted in her death.

Example 1: November 2007, dislocation of right shoulder after reported fall

In 2007, my mother dislocated her right shoulder following a reported fall. Her fall was noted by staff and was documented, but her dislocated shoulder was not noted for several days. When it was noticed, she was sent by ambulance to the regional hospital, where I was required to hold her down while manual reduction (resetting) of the shoulder was attempted by a doctor and a male attendant, by pulling towels wrapped around her arm and shoulder in opposite directions. My mother screamed throughout, and the doctor had tears running down his face. My mother then required emergency after-hours emergency surgery to relocate her shoulder.

Example 2: December 2008, dislocation of right shoulder after reported falls

In 2008, my mother again dislocated her right shoulder following two reported falls two days apart. Again, staff failed to notice (or advise me at all) for several days, until I arrived from Victoria for a visit on Christmas Day. At the local regional hospital Christmas morning, I was advised by the doctor that he feared my mother's neck would collapse, leaving her head unsupported, and so endangering her life. He considered transportation by air ambulance. Following unsuccessful surgery, she was taken by road ambulance to Canberra (2½ hours), and was required to wait until evening for more surgery. This time, her shoulder was not only dislocated but also fractured and a bone fragment was loose in her shoulder.

Interaction with care recipients' rights and responsibilities, and accreditation standards Aged Care Act 1997, Schedule 1 User Rights Principles 2014, 1: a) b) c) d) g) p) Accreditation Standards 1.3, 1.6, 1.9, 2.3, 2.4, 2.5, 2.6, 2.7, 2.8, 3.3, 4.3, 4.4

Unreportable physical abuse

My mother was the victim of assault by another patient while in care in Victoria 2013. The man who assaulted her was an 84 year old ex-army man with dementia and PTSD. Other residents were also assaulted by the same man; it was continued abuse within the facility.

I am a psychologist trained in and working with trauma. I had concerns about what I saw as unsuitable and inadequate measures and requested that a suitably qualified professional be consulted regarding my concerns. This did not happen and unsuitable and inadequate measures continued to be implemented to keep residents safe. I continued to request that Standard 4.4 ("provide a safe environment") be addressed, to no avail.

It is my belief that:

- These failures were due to a lack of trained and qualified staff within the facility to know what strategies were necessary in order to be effective, and to the lack of outside consultation with suitably trained and qualified professionals.
- The discretionary option to not report assaults enabled continual lack of care and neglect, leaving my mother vulnerable to further assault. This is also applicable to NSW as the relevant legislation is federal. The relevant legislation is the Aged Care Act 1997, Section 63-1AA(2) and

- the Accountability Principles 2014, Part 7, Section 53, subsections 1 (a), (b), (c), (d) and 2 (a) and (b).
- The responsibility for monitoring this being essentially given to the provider [as per federal policy the *Aged Care Compliance Policy Statement 2015-2017* and federal legislation *Aged Care Act 1997, Section 63-1AA(2)*] further enabled continual lack of care and neglect, leaving my mother vulnerable to further assault. This, too, is also applicable to NSW.

Below I have mapped incidents relating to the assault on my mother (punching in the chest and attempted suffocation) onto the current Compliance Policy model. This is the revised policy of 2014.

point of compliance re previous assault(s), when the assault on my mother took place

Example 1: 20th March-July 2013

point of compliance re my mother's assault, after the assault on my mother

Examples 4&5; March-June 2013

The highest point reached after the assault on my mother

Example 7; July-September 2013

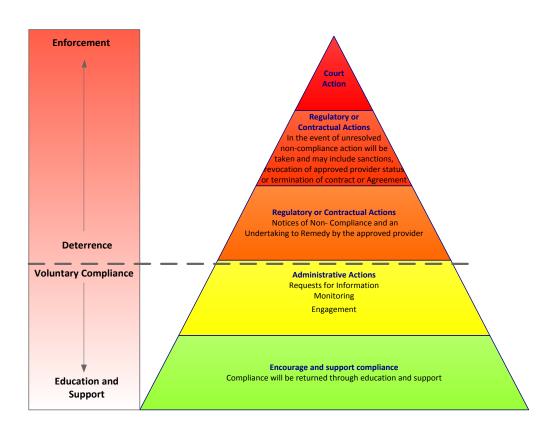


Figure 1"the conventional 'regulatory pyramid' model" of the Aged Care Compliance Policy (p.5)

Example 1: prior to 20th March 2013, assaults, strategies in place

20th March 2013, the Director of Care advised me that there had been previous assaults by the same man, at least one involving attempted suffocation with a pillow.

15th April 2013, *the Scheme*: "behavioural strategies were in place following the previous incident, but immediately prior to your mother's assault it was quite clear that they weren't working" and "it was clear that the strategies in place were not adequate because the assault on your mother took place".

Example 2: prior to 20th March 2013, assailant identified as potentially dangerous to residents and staff

There had been an APAT assessment following a previous unreported assault. The man was described as delusional, paranoid, and verbally and physically aggressive and violent to residents and staff.

Example 3: March 2013, assault, after previous assaults, and with strategies in place

20th March 2013, a staff member heard my mother call out (from bed, around 9pm), found a man punching her in the chest with one hand and holding a pillow over her face with the other. She pulled the man off my mother, preventing suffocation. The RN on duty advised me that there were no obvious injuries, that it was a mandatory report incident, as it was an assault. Management used discretionary power to not report as per the *Aged Care Act* 1997, Section 63-1AA(2) and the [then] Compulsory Reporting Guidelines for Approved Providers of Residential Aged Care (Office of Aged Care Quality and Compliance June 2008) section 5, 5.3 and 5.3.1 [now: Accountability Principles 2014, Part 7, Section 53, subsections 1 (a), (b), (c), (d) and 2 (a) and (b)].

Example 4: March 2013,

22nd March 2013, the initial suggestions put to me as strategies regarding the assault on my mother: (i) I take my mother home (ii) pay for extra care or (iii) move in myself to keep her safe. Other strategy suggested: laminated photos of residents to be put on their doors to remind them which was their room, and so stop the assailant from entering the wrong one.

Example 5: March 2013, personalised army photos on assailant's door

There was a poster-sized collection of personalised army photos on the man's door, including march-pasts of soldiers with rifles, and four individuals in combat uniform sitting in front of a tank.

March 2013, I advised the provider and facility staff and *the Scheme* of the possible role of these as triggering combative behaviour each time the man left, entered, or passed his room. I was told that they would remain, as this was his right.

9th April 2013, a *Scheme* officer conducted a site visit at the facility. She suggested removal of the personalised army photos.

I continued to request the removal of the photos, and of consultation with an adequately and suitably qualified person. I was told the photos would remain, that his family "would not permit" their removal.

Example 6: April 2013, inadequate strategies in place

As at 30th April (6 weeks after the assault) the strategies in place were:

- (i) denying my mother access to her room during the day and leaving her in the common lounge/dining (with the assailant)
- (ii) placing a red satin ribbon across her doorway with blu tac
- (iii) sighting her every 15 minutes (not in her care plan)
- (iv) sighting him every 10-15 minutes
- (v) phone calls to me at the end of every shift

Example 7: July 2013, provider issued with a Scheme Notice of Intention to Issue Directions

31st July 2013, I was advised by *the Scheme* that they had issued the provider with a *Notice* of *Intention to Issue Directions*, given that *the Scheme* continued, since 18th April, to have

- concern that the male care recipient involved in the incident has an underlying psychiatric condition and is therefore inappropriately placed in the Service
- concern that staff did not adequately manage his behaviours prior to the incident and immediately afterwards
- concern that management at the Service failed to communicate with you as next of kin in a timely manner immediately after and subsequently to the incident
- concern that as the legislation allows the approved provider the discretion not to report an assault when the offender has a cognitive deficit, that these types of incidents are going undetected

Interaction with care recipients' rights and responsibilities, and accreditation standards Aged Care Act 1997, Schedule 1 User Rights Principles 2014, 1(Rights): a) b) c) d) e) f) g) h) j) l) n) q) r) s) t) u); 2(Responsibilities): a) b) c) Accreditation Standards 1.2, 1.3, 1.6, 1.8, 1.9, 2.1, 2.2, 2.3, 2.4, 2.5, 2.6, 2.13, 3.2, 3.3, 4.2, 4.3, 4.4, 4.5

Failure to care in line with specific personal needs

My mother's care plan was made available to me following the assault in Victoria; there were omissions and inaccurate information. This resulted in neglect of my mother's specific needs.

It is my belief that this was at least in part due to failure of the NSW facility to forward complete and accurate information in regard to my mother's history in that facility, her needs and her care.

Example 1: 2009, broken dentures

October 2009, my mother arrived in Victoria from the NSW facility. One set of her dentures was missing. After several phone calls to the NSW facility, her dentures were eventually found in a staff drawer. They arrived in the post, securely packed but badly broken – seemingly pre-packing. I had them repaired, and in the meantime my mother's food was pureed. I do not know for how long my mother had been without her dentures, and so on an inadequate diet.

Her gummy appearance and her affected eating, drinking and speech robbed her of dignity, and raised comments from staff and other residents, and she at times reacted with frustration and distress.

Example 2: 2009, medical records and accurate Care Plan not supplied by NSW to Vic facility

April 2013, my mother's personalised care plan was made available to me. There were over 50 inaccuracies in her care plan, many of these applicable to her NSW care plan. For example: i) it was recorded that she did not wear glasses when my mother had worn glasses for 40 years, and had multi-focals from the 1990s; and ii) records of NSW hospital visits and surgical procedures whilst in NSW residential Aged Care were not included, nor referred to.

There were 19 additional conditions/ injuries/ incidents of which both the NSW and the Victorian facility had been advised, and which the care plan did not specify and of which the Director of Care stated he was unaware, for example, past shoulder dislocations and advanced Degenerative Disc and Facet Disease.

Interaction with care recipients' rights and responsibilities, and accreditation standards

Aged Care Act 1997, Schedule 1 User Rights Principles 2014, 1: a) b) c) d) g) h) l) m) n) p) q)
r) s)

Accreditation Standards 1.3, 1.6, 1.8, 1.9, 2.1, 2.3, 2.4, 2.5, 2.6, 2.8, 2.10, 2.11, 2.14, 2.15, 2.16, 3.1, 3.2, 3.3, 3.4, 3.9, 4.1, 4.3, 4.4

Infringements on autonomy and human rights

The biggest infringement here was to my mother's right to safety. Ultimately, I was never able to keep my mother safe.

In addition, my mother experienced several incidents that in light of what happened to her are relatively minor, but which do constitute the denial of her basic rights.

These included loss of clothing, loss of glasses, collecting glasses of all residents in the unit and then handing them out to match clothing, broken dentures, dentures kept in NSW, loss of property (including clothing and music discs), and medical and physical restraint.

Example 1: October 2009, physical restraint from the NSW facility

October 2009, a physical restraint was in with her clothing, when my mother arrived by ambulance with me at the facility in Melbourne. I didn't know what it was. It was identified and disposed of by the RN on duty.

Example 2: 2007, over-medication, contraindicative medication and psychotropics

March & April 2007 – My mother was given excessive and contraindicative medication (I was alerted by pharmacist accounts): Mirtazapine (tetracyclic antidepressant), Codapane Forte (paracetamol and codeine), Risperdal (anti-psychotic), Temazepam (benzodiazepine – tranquiliser and hypnotic). The pharmacist advised me that the facility "requests meds without speaking to the doctor". The doctor dismissed my concerns.

18th May, I organised a Canberra geriatrician who advised the Aged Care Facility that my mother was being over-medicated, and that this was the cause of multiple falls, mood and behavioural changes, and psychological distress. The geriatrician apologised to me for "going off at them" in front of me, saying this was not at all the 1st time that morning she'd seen the same thing from the same place. She instructed cessation of the medications. My insistence of a tapering plan stopped the facility ceasing all medications cold-turkey.

Example 3: 2007-2009, loss of clothing

Throughout my mother's residential care, clothing went missing. My mother was proud of her appearance, and loved and owned quality brand-name clothes. Such clothing was rare in that regional area of NSW. She entered residential care with these, and I would occasionally buy more for her, and launder them myself. All of these "disappeared".

Example 4: removal of disc player and music discs

My mother had sleep problems throughout her life. She had difficulties both going to sleep and staying asleep, and her sleep pattern for decades was 4-6 hours with late nights and early mornings. She loved her music. I bought her a disc player and discs of her favourite music to help her sleep in residential care. In 2008, my mother's disc player was taken from her room by staff and used in the common lounge/dining room. Of the accompanying discs of my mother's favourite music, only 3 out of 15 were ever recovered. The player was not.

Interaction with care recipients' rights and responsibilities, and accreditation standards
Aged Care Act 1997, Schedule 1 User Rights Principles 2014, 1: see all above
Accreditation Standards: see all above

There is a fine line between responsible management and autocracy.

I found this line to be repeatedly crossed by residential Aged Care management and approved providers from the day my mother needed placement in NSW until the day after her death in Victoria, when at 9am, 12 hours after my mother's death, I missed a call from the facility. They then phoned my distraught sister in NSW and said she needed to have our mother's body removed as they needed the room for a new dementia patient – psychological abuse of the family.

I had forgotten the phone call from the NSW DON on the afternoon of my mother's admission. She had forgotten to ask a question, so identified herself and then immediately asked "Burial or cremation for your mother?" I thought my mother had just died.

sincerely,

Susan Narelle Henderson

20/03/2016