**Submission for the ALRC Elder Abuse Issues Paper 47**

**Introduction** (Q4)(P5,7,8,9,11,12,15,17,18,19,21,22,24,25,26,29,32,46)

I have a particular concern about abuse of people diagnosed with Alzheimer’s and my submission is an attempt to address this. My concern is that they are not able to seek assistance if they do become victims of abuse, nor do they necessarily understand their experience, to be abuse.

I am committed to doing whatever I can to affect change to the laws underlying the EPOA instrument, as this fails completely in protecting a person diagnosed with Alzheimer’s.

Time is also an issue. From diagnosis to death is an average of about 7 years. If an abuse is identified by a concerned person willing to try to address the abuse, the time necessary to bring about a change to end the abuse can take far too long to do any good.

It is probable my father had no understanding of the commitment he made at the time he signed an EPOA because he was already suffering from the Alzheimer’s.

My father suffered abuse from his wife, my step-mother (M), and also from the aged care facility and the medical practitioner (Dr. P). The foundation on which M was able to be abusive, was her absolute authority with regard to all decisions regarding my father, and the complete privacy she was entitled to, regarding her choices. The foundation for the abuse he suffered from the care facility and the medical practitioner, was M’s attitude and actual communication with them about him.

The abuse he suffered occurred over a number of years and was a series and progression of actions and neglects (defined as omissions) which taken together, he experienced as “punishment”, and which collectively amounted to something much larger than the individual acts or neglects.

The following narrative is inevitably written with hind site and knowledge gained after the fact. I will try to convey my sister’s (WS) and my ignorance at the time. I need to point out this ignorance is normal as no one expects to encounter abuse, and coming to recognize it to be abuse, took time.

 I live in the USA and my relationship with my father is largely one of correspondence. During his illness the number of visits I made to Australia averaged 2-3 per year with each visit being for 20 days, and for four years prior to my father's death, my visits were specifically focused on spending time with him. While he was in the care facility, when I visited, I would often stay all day, leaving Dad to take rests whenever he needed them.

The following background history is derived from about 700-1000 emails, correspondence, photos and recorded conversation. These records support the fundamentals of this narrative. This concludes with a summary. Then I make suggestions for changes to prevent the abuses documented here, in order to help others in the future.

The submission is notated with Paragraph and Question numbers taken from the Elder Abuse Issues Paper e.g., (P99, Q99)

**Background History** (Q3,4,11)

***The Time before Diagnosis***

WS and I were aware that our father’s memory was failing well before 2009 but in March 2009 we received an email from him regarding a visit to a doctor specifically to do with his state of mind, M attended the consultation with him. He writes "since I cannot now expect to take in and remember what I am told”. He notes they are waiting on a diagnosis. At that time he and M lived in the Shoalhaven District. His emails over the next few months document plans to move closer to Sydney, the ups and downs of selling, then buying a house, and in addition the emails also discuss his wishes concerning personal possessions he cared about a lot, some of them heirlooms from his grandfather. On occasion, he specifically notes a young member of his family by blood - a child or grand-child - as designee for the possession.

***The Diagnosis, Legal and Chronological Vagaries*** (P8,30,129,131,134)

On November 20, 2009 WS receives a call from M, to communicate that my father has been diagnosed with Alzheimer’s. WS emails me and notes M’s anger and also delays to the communication.

A title search made after my father’s death in late March 2015, discloses that M and my father purchased a house on the Central Coast on December 2, 2009.

Also after my father’s death, the care facility informed WS that the Alzheimer’s diagnosis was made by a doctor (Dr. S) located on the Northern Beaches in mid-November 2009 near the residence of M’s daughter. WS contacted Dr. S by email, and her office responded that Dr. S has no record on file for my father.

According to M's lawyer, also located on the Northern Beaches, an EPOA was "prepared by, and executed in the presence of, the writer, immediately after the first diagnosis of the onset of Alzheimer’s Disease”. We have no date for the EPOA.

The only diagnosis of which we have been informed, and which is on record, is reported made by a doctor who has no record of seeing my father, and predates a real estate transaction that requires public registry of an EPOA with the NSW Sydney Office of Land and Property Information. When WS enquired of this office she was informed there is no record on file of an EPOA for M to manage my father’s affairs.

***Financial Abuse*** (Q29,P7,8,24,25,27,129,131,134,191)

In March 2011, I visit my father for lunch in company with WS and my brother (AJ). During the meal my father's conversation repeatedly turns to a wish to record, what is to be given to whom, from among his personal possessions. I am the eldest of his children and so set aside my reluctance and commit to assisting him with making determinations and records regarding these, and, following up on a suggestion of a friend whose mother suffered dementia, I decide the best way to help him is by recording our conversation. This assignment, the two of us working together in his office spans two more visits each about 4-5 hours long.

The first 2-3 hours of recording were erased by mistake, but captured in the balance of the recording, are two items of relevance here. In the first, Dad mentions that a painting has been sold, a painting of significant value to my family including my extended family. On the earlier visit for lunch, while WS was assisting M with moving furniture near M’s desk, WS saw a sales receipt for the painting from the ANMM for $10,000.00. After Dad’s death, enquiry of ANMM confirmed the sale was made by M in March 2011.

This is the first concrete sign that M’s behaviour with regard to my father is exploitive.

Other items of heirloom value to his family have also gone from the house, but we have no record of what happened to them.

In the second item of relevance, Dad offers me a painting of a ship that had been his father’s. I express my reluctance to take it because, as I say, I feel he needs to keep his things around him, they are important for helping maintaining his memory and quality of life, but I understand that the painting is a gift to me.

Up to this point we have not thought at all about the rights and workings of the law and the services intended to support people needing care. Dad trusts, we trust…. This begins to change.

***Psychological Abuse*** (P7,24,25,26,27,55,68,72)

It becomes evident over time that M does not share my view point regarding his quality of life. His office is dismantled so she can take it for her own office. I get to see Dad’s distress over this.

We listen as she reminds him frequently that he does not remember. Her conversations begin “Do you remember…” and then ended with “oh, but of course you don’t” and then she relates anecdotes about his forgetting, with the intention of humiliating him. Her manner toward him is consistently care-less.

More things go missing. One, another family important heirloom, is missing, and M tells us it is because Dad has tried to hide it. Others, valueless to both M and Dad, are later given to us by M. From her conversation it is evident she turns on and off Dad’s right to self-determination to suit her own purpose. This item she allows him to give away, something else to someone else is prevented.

She begins to restrict our access to him. AJ and WS are constrained to visiting him only when he is in respite care. She doesn’t inform them when he is going into respite care. She doesn’t inform about anything, they learn of things only when they call and ask a direct question. Her responses are vague and general. WS and I go through cycles of emails, and delayed responses, limiting, constraining and moving times I will be able spend with him. This culminates in a visit where, barely 30 minutes after I arrive, she is expecting me to leave, and she storms out in a huff because I ask to stay until WS comes to collect me. AJ is there, and Dad, who has not fully understood, now understands that she wants me to leave, and he says "I want you to stay, I love you”.

We are concerned we will offend her and that she will cut off all our contact with him or worse, take it out on him in some way. We hope for him to be moved to a care facility.

We are expected to take on trust what she says about him, descriptions of behaviour we never get to see, and that no one else reports, and that are not later reported by the care facility.

There is no doubt in our minds he is always happy to see me, AJ and WS and enjoys our visits. He is relaxed, loving and happy to spend time chatting over photos and cups of tea. He wants us to stay and then ventures out on to the street to walk with us when we leave.

***The Move to a Care Facility***

During my last visit to his home in November 2012, M informs me he has been diagnosed Stage 4 and she has made an appointment to be interviewed at a care facility around the corner, I offer to go with her, she ignores me.

I drop in on the facility and pick up brochures to learn what I can. On December 14, 2012 he moves to the care facility. M calls AJ, who lives over an hour away, and has him pick up bedding for him from her.

Shortly before this, M has called AJ’s home and spoken to my sister-in-law, telling her she has decided the painting of the ship is to go to the care facility to be hung. Though the painting had been singled out I assume it to be just one of many items to be moved there to make the place more of a home for him.

***Physical Abuse*** (Q11)(P64-68,74-78,179)

My first visit to the care facility is on March 4, 2013, WS is with me. I am shocked to find Dad much altered from the last time I saw him. He is thin, and so weak he can hardly feed himself, he is de-hydrated, his conversation a constant litany of complaint about aching. There seems to be no part of his body that doesn’t ache. His nails need to be cut and they are dirty, his toenails are also too long and broken. His hair and beard are too long and unkempt. His glasses have been missing since January and he is struggling with glare, a problem he had always managed by wearing a sun shade clip-on flipped up. When we enquire of the head nurse, he offers me a consultation with Dr. P.

The conditions of his living quarters are also distressing. There is no name label on the door of his room, unlike the other doors, and his very small, recent picture is hanging dog-eared from a single piece of tape. His room is untidy, detritus including spills and disposable cups, on a side “desk” and the bedside table. The painting of the ship hangs above the bed but aside from that and 3 photos – one of M, one of WS and one of Dad and M - there are no personal items at all. None of the letters I have been sending weekly are there, nor is the biography I had provided, “The Story of Me” as encouraged by the brochures I had read.

***Immediate Action to Mitigate Abuse***

WS calls M on the evening of March 12, to ask about any plan to replace Dad’s glasses, and repair his hearing aid. M responds that Dad is going to die soon and that she needs to get used to the idea.

Over the next few visits we see the staff feeding Dad.

I reprint the letters and biography, find family photos and frame them, and scan family photo albums to take back to the US for future letters. We tidy up his room and replace the name plate and photo on the door. I email the care facility manager to find out if there is a reason his room is so Spartan. There is not. I email M and request she provide some meaningful personal items to put in the room. On my next visit I take nail clippers and apple juice, and then I speak to one of the staff about his nails and much more.

All very polite, we are still trying to assess what should be considered normal.

***Chemical Abuse*** (P76,77,78,177)

During the interview with Dr. P on March 12, I ask for a copy of the “plan for his care”, as had been suggested to me by a friend. Dr. P does not understand my request and gives me a copy of his medication chart.

I asked why he is on osteoporosis medication as he did not have osteoporosis and why he is on blood pressure medication as he did not have a history of heart disease.

She responds that the osteoporosis medication is in case of a fall to reduce the risk of a hip fracture because caring for someone with dementia injured in this way is so much harder. Likewise the blood pressure medication is to prevent stoke because a stroke would make him harder to care for.

It comes as a surprise to her that we have not seen him aggressive at any time. Risperidone is being administered to manage aggression.

After this meeting there is no further communication from her to me, with one exception, in an email she backtracks on the aggression, and says the prescription is for agitation, but could not resist noting "though aggression can be observed in patients with dementia even if there hasn't been any past history of such behaviours.”

Dad is going to get Risperidone, Actonel, and Micardis, all, ”just in case”, and I have no say in the matter.

By this time both of us realize Dr. P has violated M’s right to privacy….

***Attempts to Mitigate the Physical Abuse*** (Q11)(P26,64,65,66,67,68,179)

I am now home in the USA, and WS and I start looking for information, answers and assistance. We contact Alzheimer’s Australia and others, and learn of the Aged Care Complaint System (ACCS) and other resources.

During this time WS learns from the head nurse that M will be leaving for an extended cruise in northern Europe. Requests to know the dates are ignored, then WS gets a “maybe it will be 3 weeks…maybe 5…” but no dates.

On April 15, 2013 AJ calls to tell me Dad’s teeth are missing. AJ advises we wait to see what M does about this. By May 8 we have heard nothing from M or the care facility.

I file complaints with the ACCS, citing the probability Dad is having a bad reaction to one or more of the drugs, as well as the need to replace both the glasses and the teeth and also repair the hearing aid, all of which, I offer to pay for.

The ACCS refer me to the Health Care Complaint Commission (HCCC) with regard to my concerns about the drugs. They inform me that although the care facility has lost the teeth and glasses, it is M who is responsible for replacements. They then begin the formal complaint process.

Everything is delayed while M is overseas, the only action being, to make an appointment with a dentist.

I am back in Australia at the end of May. By the end of June he has a new bottom denture and a plan is underway to replace the upper denture which does not fit properly. He was two and half months chomping down on gums with a denture that would not stay in place. The dentist marvels at the masticatory acrobatics involved.

There are a number of cycles though possible resolution and response, because M insists that store bought reading glasses will do. They will not, and, as she has been married to him for a long time, she knows this. He cannot see to walk when he is wearing them. He needs glasses for distance, and the right shape for the clip-on to work for him, and, although he no longer reads, he still needs to be able to see photos and his food, and that necessitates bifocals. At last, six months after they were lost he again has appropriate glasses.

***Attempts to Mitigate the Chemical Abuse*** (P7,76,77,78,131,177)

At the end of the day on June 10, while Dad is lying quietly, his jaw begins to shake uncontrollably, he is very frightened. I am with him. The care facility can offer only that his vital signs are normal and therefore there is nothing to be concerned about. The shaking eventually subsides after about 20-30 minutes.

The following day I put Dr. P and her Practice on notice I will be filing a complaint citing a probable bad reaction to a drug. All three drugs are being administered, not for his benefit, but for a current or potential benefit for the care facility.

My father is very sensitive to drugs and I quote him now to support my claim that M and Dr. P were not acting in his best interest by administering them. In his email of March 20, 2009 he writes “I rather forced a cut back on medication with the doctor, that seems to have helped.”

A family care conference is arranged following M’s return. This occurs in the first week of July, and a second one with Dr. F, the senior doctor from the same Practice, who has replaced Dr. P. It is agreed that informally WS will be considered to have the same status as M in regard to information and involvement in Dad’s care.

Dr. F reduces the Risperidone dose and discontinues the Actonel. By October on my next visit, Dad’s aching has subsided, and his weight has returned to normal.

The HCCC complaint is disallowed on the grounds that Dr. P has been following standard medical practice. I have not questioned the “standardness” of the treatment, only that the “standard medical practice” is bad for Dad.

***Making Complaints – Reporting Abuse*** (P31,79,82-84,169,182,191,192)

Filing complaints makes me very unpopular. I am fortunate there are two of us. Without my sister it would have been impossible to achieve any improvement for Dad.

While Dad is cared for at home solely by M, filing a complaint is out of the question, as we will put Dad at greater risk of abuse, especially if our complaint fails. Though our concerns grow over time they seem flimsy. I don’t know who we could have addressed our concerns with.

Only after he moves to the care facility and we determine Dad has nothing more to lose, and there is no other option available to us, are we willing to risk exacerbating the situation.

I reason that the care facility will be constrained by regulations and public image, and that the day-to-day staff will be largely unaffected by a complaint. With this in mind, I feel I can count on some improvement. I can also count on WS to be a buffer for me, and on several occasions she does need to come to my defense.

For me to file a complaint about the actions of an individual is much harder, and I reach a desperation point before I am able to file a complaint about the doctor with the HCCC. I include the Practice in the complaint to “spread the blame” and also because I think I am more likely to affect a change. There will be a group of people impacted and so it is more likely someone will act to protect them all. It is also the case that Dad’s treatment was initiated by Dr. F. Dr. P has acted only to perpetuate a treatment already in progress.

But we now feel we have achieved as much as we can hope for, without actually challenging the guardianship. So we settle into ensuring Dad will get the best care we can manage without actually being his “person responsible”. This never really works and we constantly cycle back to the possibility of applying to assume the guardianship.

We hesitate to take this step because an acquaintance, a professional in the field, has alerted us that in cases like ours the Guardianship Tribunal generally appoints a public guardian. As we cannot determine the practical outcome of applying, and whether or not Dad will benefit, it seems better to continue as we are.

***Push Back*** (P151-158)

The care facility insists M is to be the conveyer of information to WS. The care facility reasons, naively, that we can ask questions. We cannot ask about what we don’t know. Do we need to keep a check list and call everyday? Has he been seen by the doctor, for what reason and what was the outcome? Did he eat breakfast? Did my letter get read to him? And so on…. Can we trust the “information” M provides is true? This has not been the case in the past.

As before, information is either conveyed in such general terms it is not useful, or it is not conveyed.

WS struggles with false protocols regarding who among the staff can provide her with information.

M attempts to make a campaign out of her view that I “don’t like the care facility” and use this and other reasons to prevent or constrain my visits. WS has to respond several times to counter, what are essentially, lies.

After a while it becomes clear to M we are not going away, so she begins to follow our example in providing personal care and quality of life services. We are happy for Dad that this change occurs, but her purpose is to retain/regain control, and we are sad for him about that.

***More Physical Abuse*** (Q11)(P64,65,66,67,68,179)

Many of Dad’s clothes and shoes are unsuitable, besides the quality of life issue that they are not what he would have chosen to wear, they are also too hard to put on and not warm enough. When they wear out WS tries to replace them. At first M refuses to acknowledge they need replacing, and refuses to replace them, she then refuses to let WS give him new clothes. WS circumvents M and gives replacement clothing to the staff who oblige by also disposing of the worn out clothes.

On every visit we need to clean his nails, which are encrusted with dirt, often we need to cut them. Sometimes his hands are stained with faeces. We find encrusted dirt in and behind his ears. His hair and beard are often overlooked and become too long. There are food remains in his beard. He contracts conjunctivitis several times. Some of his remaining front teeth break and abrade his mouth, nothing is done. His room also, always needs attention.

On one visit Dad complains that his feet hurt. When we remove his shoes the stench is gut wrenching. It is evident his socks have not been removed for a long time. Between his toes there is a disgusting black mold, dirt and dried blood, the nails are seriously long and broken and cutting into the flesh of the other toes and the elastic of his socks is restricting the blood flow. We take photos, and then call in the head nurse. We are shown the podiatrist log reporting her visits. But we have already learnt that the logs are meaningless, a doctor or podiatrist may be on site and it is the site visit that is reported, not a service for a resident. His socks are replaced, his feet cleaned up and the tender flesh allowed to heal and a plan is put in place to address the issue. Despite the evidence, M insists she has been managing the situation satisfactorily all along, and will continue to do so. She feels confident in her view because of the input from the head nurse. Then the plan is neglected along with the feet.

His drugs are changed again and WS is not informed.

***He Knows He Is Abused*** (P31,79-84,181,182)

On another visit Dad asks me why he is being punished. I put my arm around his shoulder and stroke his back. I have no answer for him. His experience from 2011 to the end of his life, four years, is punishment. I would have experienced it as punishment. I feel helpless, and that I have failed to prevent this from happening.

Someone else hearing this question from him would, most probably, dismiss it as a delusion. This is why it is not possible for those with Alzheimer’s to act to protect themselves.

But Dad has not lost all his reasoning powers, or his ability to feel. It is memory and language that are missing. If he had been asked whether he was abused, he would not have understood the question. If, at this time, he still understood the meaning of the word at all, in his mind “abuse” would be defined as “cruel beatings”.

***His Death***

WS slowly gains the respect of the staff at M’s expense because M continues to use spiteful tactics to try to undermine our involvement with Dad and his care, right up until his death.

 At his death Dr. F asks us what he should put on the Medical Certificate of Cause of Death and suggests “Congestive Heart Failure”. I am disgusted, and tell the doctor he died of Alzheimer’s. The Certificate reports “dementia, years”.

***An Attempt to Address the Financial Abuse*** (Q25)(P7,8,24,25,27,121,122,127,128,129,103,131,134)

After his death WS and I return to the original issue – the sale and disposal of Dad’s personal properties, some of which are heirlooms that in someway belong to his extended family by blood.

Logically, we can address the question of whether financial abuse had occurred, only after Dad’s death. The law allows for the sale of personal property by an agent if it is in the best interests of the principal. Only after death can it be said for certain whether the sale and its proceeds contributed to the principal’s best interests at any time between the sale and death.

We seek legal advise, and then learn that an EPOA is essentially a Gerry-rigged instrument originally cobbled together from a standard POA without any consideration for the fact that the principal will be incapable of taking action for recompense against an exploitive agent and furthermore there is almost no way, and a very poorly defined right, for someone else to bring an action on the principal’s behalf. We also learn that the power of attorney ends with the death of a principal when the responsibility of the agent is discharged and that expunges any wrong-doing. In the USA an EPOA is now considered by many aged care professionals to be a “license to steal”.

Dad and M always lived in well appointed homes, and made overseas trips. Dad had a pension from his military service and we provided Dad with financial and other material support regularly. M maintained a personal account of $10K for pursuit of a hobby and “borrowed” from her mother, during the time her mother was in a care facility. Dad mentions more than once her skill at tapping into available government resources. All this and much more is in his emails. There was never financial need, and it is difficult to see what other “best interest” might have been served by the sale or other disposal of the things that mattered to him.

Perhaps there might have been the tiniest little possibility for us to bring remedial action before he died, but this was not a possibility in reality, not only because so much time was required to ensure his care was maintained at an acceptable standard, but also because such an action would have had the Dickensian quality of a dispute over property while the person was dying.

We found ourselves unable to act on what we knew to be his wishes. There was no legal recourse available.

**To summarize:**

The abuses we witnessed and which we tried to mitigate are as follows:

Financial abuse:

* The sale of his personal property by our step-mother, that was, in no way, for his benefit or in his interests
* Not until we offer to pay for necessary items is our step-mother willing to provide for him

Psychological abuse:

* Disrespect of his personal space and rights within his home
* Restricted access to persons who loved and cared for him and that he loved and cared for in return
* Intentional misrepresentation to professional carers regarding his state of mind and behaviour
* A disregard for maintaining a reasonable quality of life for someone suffering ill health
* The careless or capricious disposal of the personal property that had deep emotional value to him
* Humiliating and care-less discourse

Physical abuse or neglect:

* The non-replacement of teeth, items essential to his survival
* The non-replacement of glasses, essentially limiting safe mobility
* Refusal to consider that medication may be harming him
* Neglect of hygiene, and routine physical care

Chemical Abuse:

* The administering of drugs not for his benefit, but for the benefit of others
* The prescription of drugs after the diagnosis of Alzheimer’s, a disease that had taken away his right of self determination and that had the potential for side effects that could then be attributed to the progress of Alzheimer’s

We have learnt in conversations with friends and professionals who have shared experiences with us that some of these abuses are very common, in particular the following:

* Financial abuse of a parent by a step-parent
* Lost and non-replaced teeth
* The prescription of drugs for the benefit of a care facility

Sadly because they are common, we have noted a resigned “what can you do” attitude when they are mentioned. It could be that our informants witnessed only one of these abuses, and unlike us, could not act in time to mitigate the abuse.

Of these the lost teeth seems to be the most frequently mentioned and in someway is the most distressing as all recognize the ease with which the loss can occur and the potential impact for the person they care for. I wish to point out that after Dad’s teeth were replaced they were not lost again. I was willing to file a complaint again…

**Suggestions**

***EPOA:*** (Q13,14, 21,26,27,28,29,30,32,39) (P31,72,73,87,129,131,134,137-141,144-150,173,177)

The obvious one first: There needs to be a public registry for all EPOAs and Guardianship arrangements and guardianship agreements needs to be required for persons with dementia.

Also, interested parties need to be defined. There needs to be a requirement that, at least one, interested party be kept informed of decisions made by the agent before they happen. Also, those who can bring action need to be defined, and the right to bring action needs to extend beyond the death of the principal. All arrangements must specify two people for over-site. In a case, such as ours, where the agent is spouse and not the parent of the principal’s children, a child must be involved.

Where the care of people with dementia is involved, arguments for privacy rights are groundless. If the government expects that the care of the demented is to be managed at home by an unqualified, and possibly un-caring individual, and provides public resources to support this effort then the “carer” has a responsibility to the public. This is much too distressing an issue to allow concerns about paperwork burdens and costs to be considered. Forms need to be filled to get government subsidies, apply for scholarships and grants, how is this any different?

If this seems unworkable for all case, then there need to categories of EPOAs based on the need. Is the principal going to become demented? Or are they already diagnosed. Or are they physically disabled, young or old. Are the families complicated? It is a delusion to think the current legal environment is simple for people to navigate. Let’s accept that it is not, and make it work to protect and support. These qualities are more important than a veneer of simplicity.

***Aged Care Facilities:*** (Q14,15,17,18,19,33) (P74-78,86,155,156,177)

There needs to be an escrow account set up for the emergency support of a resident. The loss of teeth is every bit the emergency an injury is. Both can result in decline and death. I was the only witness of an accident resulting in an injury to a resident, and after tending to him the staff was very prompt in getting the report written. For lost teeth an “accident” report needs to be filed and after 2-3 days if the “person responsible” has not made an arrangement for a replacement, the care facility can draw on the escrow account.

I thought the ACCS worked very well. Though the complaint really needed to have been directed at M, they were content to compel the care facility to put pressure on M to address the issues.

I think there are a lot of things that need to be addressed with respect to aged care in a facility; some of what we witnessed would be fodder for Monty Python.

We were told Dad suffered from delusions, specifically that there were birds in his room and that there was gas in the air, this item they attributed to his war service (In the Navy in WW2 – no gas). There was a noisy parakeet in the public area right outside his room and the corridors had a strong odour of chlorine bleach. These were not delusions but a loss of language ability.

On another occasion Dad was given a test intended to determine his level of dementia (this was really for my benefit in case I had delusions about his dementia - which I did not). The test was a series of questions a nurse asked Dad. She had a strong Indian accent. Dad did not understand her at all, but had no trouble answering when I repeated the question to help the nurse in her task. It would be ridiculous to consider there was any validity to the result of a test administered by that nurse.

The staff are under-paid, the turnover is high, re-assignment is frequent and the shift rotation long. Almost all we met were caring and kind in a general way, (and there are some we will always remember with respect and affection) but from shift to shift, despite the logs, no-one really knew what had been attended to. The “not my yob” mentality prevailed. The person who dressed or undressed was not the person who washed who was not the person who fed, and it was no-ones job to tidy up the side tables, replace door signs, report or fix broken curtain rods and so on. The person on the Monday morning shift would not be on that shift again for two weeks. We had difficulty keeping track of staff names and functions, and for most part they did not wear identifiers. Is this a good environment for people with failing memories? Remarkably, Dad was, occasionally, able to retrieve the name of the head nurse almost to the end of his life.

There were long stretches of time when there were no staff to be seen in the public areas, and there was a progressive decline in over-all service from the time of Dad’s arrival to his death. The government audit had occurred in the June before Dad arrived and was not due again until last year. I have read the list of what is audited, and was impressed only by what the auditor would not know at the end of the audit. They would need to do some unscheduled, anonymous all day visits to really understand. Here is a role for a public advocate.

All of this means the care of a resident is only as good as the attention of the family to the resident. M may have understood that, or not, but she also actively didn’t care, and she acted to prevent others from caring. This was the foundation of the abuse.

Having a single point of responsibility and communication presents a risk in the same manner as the EPOA. Interested parties need to be defined and a second person included in the decision making process.

***Medical Practice:*** (Q16,18,19,20,35,36,38) (P76,77,78,87,161,162,166-168,177)

It is imperative, a third party (from among interested parties) be entitled to involvement in the medical care. Dad had children who loved and cared for him. One of us should have been entitled/required to involvement from the beginning, notified by the doctor, and not the guardian or agent or “person responsible”. This protects the doctor as well as the patient. Even if M had been a loving and caring person, she was not young and she was very willing not to question or enquire. This is not a healthy situation. Privacy must take second place after welfare.

Dr. P should have known her prescriptions were unethical; this is a matter of training. She also needed to have considered the possibility of a bad drug reaction. After a person is diagnosed with dementia the medical profession needs to actively work to reduce the number of drugs administered. Otherwise, how can one possibly sort out what symptom are a consequence of the disease, and what are symptoms from taking the drugs. There is no purpose to administering “maintenance” drug. Alzheimer’s is terminal. It is routine for the medical profession to discontinue all but prophylactic care in cases of terminal illness.

The HCCC needs to have a more negotiable standard than “standard medical practice” for initiating action on a complaint, and the actions available to them after a negative finding need to be less draconian. Using leaches was once standard medical practice. There is nothing unreasonable in a request to have a treatment reconsidered.

Also the care of those without self-determination needs to account for the risk of medical abuse not only by a medical practitioner but also by the “person responsible” and the care facility, or a combination of these. The standard needs to be different, to take into account that the patient, who is the person who usually communicates symptoms, is no longer able to, and that anyone else may misrepresent the symptoms. The doctor needs to have the skills of a vet, and also recognize that under-medication is the more ethical and cautious choice.

I am very grateful to the ALRC for this opportunity to contribute to the research on this issue and I hope it will contribute to meaningful change.