

SUBMISSION to the 2018 Senate Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia.

In summary:

- **It is imperative that the Aged Care Act is re-drawn to ensure that there are consequences, remedies and redress for failures of care under the Act.**
- **Aged care recipients are consumers and should have the same consumer rights as they did when they were not aged care recipients, guaranteed by the standard aged care contract. These should be upheld by the Complaints systems and the Quality Agency**
- **Aggregated bond money should be used to support Aged care residents genuinely without family members. This money should be given to an independent local individual or organisation, to advocate for the resident as would a family member, were one available.**

The information in this submission is not confidential.

The following submission will address each of the three terms of reference.

1. *The incidence of all mistreatment of residents in residential aged care facilities and associated reporting and response mechanisms, including the treatment of whistle blowers*

'Mistreatment' is not defined in aged care law. For the purposes of this submission, 'mistreatment' is defined as:

- Pressure sores
- Infected pressure sores
- Severe dehydration
- Severe malnutrition
- Aspiration pneumonia
- Medication error
- Falling & injury
- Scalding
- Toileting – delay and neglect
- Failure to ensure essential aids are available – glasses, hearing aids, television remote controls, tissues
- Dental neglect
- Failure to recognize/act on common conditions in an aged care setting – UTIs, pneumonia, falls risks, delirium, depression

It is not possible to calculate the incidence of all mistreatment of residents in residential aged care facilities, as government does not require this to be reported, let alone disclosed. 234,931 people live in aged care homes in Australia. Of those, 83% are classified as requiring high care. Qualitative data collected by Melbourne based Aged Care Matters indicates the aged care 'Living Longer Living Better' reforms have caused a decline in care and quality standards in Australian aged care homes.

While the Aged Care Act specifies that there will be a complaints mechanism established in every Service, (Section 56.4) this is frequently not backed up by action. In my father's aged care facility, written complaints can be ignored for weeks at a time. Telephoning the Service outside business hours is mostly unsatisfactory, with the telephone unattended, or a computerized message saying the message bank is full. I have made multiple requests to the Service (and to Complaints NSW) for this to be addressed, but the telephone message bank has never been fixed.

Verbal complaints are usually made to Personal Care Attendants (PCAs) who make up 68% of the aged care workforce. Complaints in person are invariably met with the response 'I don't know about that' or 'I have only just come on' or 'You'll have to ask someone else' or more ominously, 'I am not allowed to tell you that'. The undertrained PCA is something of a victim of circumstances also, without the skills or experience or supervision to undertake the range

of tasks expected of them. Often there are language deficits, making these workers' position difficult. Perhaps even more than language, there is a cultural dimension in responding to questions. In some other cultures, it is courteous to respond to a question with the reply the responder *believes the questioner wants to hear*. Hence, a simple question, 'How did my father eat this morning?' will often elicit a reply such as 'Oh, very well, he ate very well'. The same question, asked of an Anglo Australian on the same day, may be answered entirely differently. For this reason, the largely south Asian PCA workforce should attract less blame for failures in responding to complaints. That said, there remains a significant failure to address complaints in a factual and accurate way, and a tendency by PCAs to see themselves as not having any real responsibility for the frail aged in their care.

Complaints made to managers at the Service are in another category. Over the five and a half years my father has been in aged care in two different Services, my consistent experience is that Centre managers lie, blame the resident, attack the family member, cover up, cover up and cover up. I have absolute evidence that the Service withheld essential respiratory medication from my father, a lifelong asthmatic and COPD sufferer, for at least seven months. The evidence is from the pharmacy invoices and the testimony of three pharmacists, available on request. The Service told the pharmacy that they had a stockpile of Spiriva and Seretide (medications for COPD) and not to dispense these. Each medication lasts for one month, and there was no record of my father consistently refusing to take these medications, as there must be if a resident refuses. The Pharmacy had had no directive from the GP; their position was that they just dispensed what the Service ordered. My father is paying \$1000 a week for care. Yet he had essential medications withheld. In the face of absolute, explicit written and verbal evidence from three pharmacists, the management at my father's Service repeatedly asserted that there had been no change in my father's prescriptions.

My father's Service was formally sanctioned by the Department of Health between December 2016 and June 2017 due to 'an immediate and severe risk to the safety, health or well-being of residents.' Unbelievably, the nurse advisors were selected and paid for by the Service itself. (This is possible under government rules.) These women set about *preventing* residents and relatives from directing complaints to the Service *at all*. Their position was that the staff members were very distressed, and that all complaints should be filtered through the nurse advisors. The nurse advisors further insisted that no complaint should be in writing. All complaints would be by telephone only. Thus it cannot be discerned what complaints occurred during that time, or what happened as a result, as there is no independent record. The nurse advisors disappeared in March of 2017, and care patterns returned to the level they were before. My subjective observation is that staff members were not distressed by the sanctions. Staff members were stressed, however, by the risk to their jobs if they were caught speaking to residents and relatives. Although I hold my father's enduring guardianship, (and have done so since 2008) staff will no longer share medical information with me to this day, because they have been told they are not allowed to.

Whistleblowers tend to be relatives more often than staff. This is because staff are usually younger women, largely from a non-Western cultural backgrounds, and therefore less likely to speak out. My experience as a relative is that speaking out causes the Service to reach for their lawyers. I have been threatened with legal action, accused of 'rude and intimidating verbal communication' toward staff, (although with no evidence of this ever presented), directed to attend legal conferences with the Service's lawyers and further directed that, due to OH&S concerns, any complaint I make must be directed via the Service's lawyers.

The present lawyer, [REDACTED] has obediently followed the playbook of the Service's previous lawyer, [REDACTED] [REDACTED] said at an aged care conference presentation on the topic of 'How to Manage Difficult Families':

- *Use unfriendly third party*
- *Lawyer letter*
- *Conference with unfriendly*
- *give them 'bad cop'*
- *someone else to hate, bad news messenger*

[REDACTED] went so far to offer a suggestion that owners might *exercise rights as owner of premises - refuse entry to people who create a nuisance or disrupt your business.* [REDACTED]
[REDACTED]

As enduring guardian, my role is to advocate for my father. If I do not do so, I am not fulfilling my legal obligation to my father. If I *do* advocate for my father, I risk victimization by a hugely wealthy, taxpayer funded 'charitable' organisation with PBI status, that pays no tax, lacks transparency and enjoys freedom from all public accountability.

Residential Aged Care in Australia is legislatively weighted in favour of Service providers. From the point of view of care considerations, this is deeply immoral. The Act specifies that:

AGED CARE ACT 1997 - SECT 53.2

Failure to meet responsibilities does not have consequences apart from under this Act

(1) If:

(a) an approved provider fails to meet a responsibility under this Chapter; and

(b) the failure does not give rise to an offence;

the failure has no consequences under any law other than this Act.

That is, anything that is not strictly criminal will not attract any sort of censure or consequence. Some matters that are criminal such as assault are re-characterized by the Service as an injury done by the resident to himself. Legal advice suggests that the standards of care and quality assurances to be found in the Quality Assurance Principles are unenforceable. The present Aged Care Act effectively removes the common law rights of Australian citizens, when they are residents of aged care facilities. This position is unacceptable in a civilized society.

It is imperative that the Aged Care Act is re-drawn to ensure that there ARE consequences for failures of care under the Act.

The Minister must, at a minimum:

- insist that every aged care contract specify standards of care, and assert the resident's right to enforce the standards of care upon which their health and lives depend

- permit claims for negligence
- permit claims under the residential care contract
- permit claims for trespass (for treatment without consent)
- permit claims under Australian Consumer law
- permit application for a Coronial Inquest by families

2. *The effectiveness of the Australian Aged Care Quality Agency, the Aged Care Complaints Commission, and the Charter of Care Recipients' Rights and Responsibilities in ensuring adequate consumer protection in residential aged care*

The definition of consumer rights, broadly, is the right to receive goods or services in exchange for an agreed consideration. In residential aged care, the present system underpinned by the Aged Care Complaints Commission denies consumer rights in aged care; indeed, it *prevents* the consumer from achieving financial remedies or service redress. Presently the only way to seek enforcement of consumer rights in aged care is to go to the courts. The court system effectively prevents all but the very rich from even attempting to assure these rights.

The existence of the Aged Care Complaints Commission shoehorns frail aged residents and their families into a 'conciliation' system that does nothing to redress wrongs, or prevent wrongs from re-occurring. Together with Section 53.2 of the Aged Care Act, the Aged Care Complaints Commission effectively prevents the injured resident from a proper hearing and proper restitution, and does absolutely nothing to ensure that care failures will not occur in future. Legal advice suggests there are almost no claims discoverable in the decided case databases which refer to claims by residents for serious harm arising from poor care delivery service.

Given the experience of raising complaints with the Service as previously described, the next option is to make a formal complaint to the Aged Care Complaints Commissioner. This is a slow, bureaucratic and cumbersome process that is not useful when the victim is very old, frail, and may not be expected to live very long. The Complaints process takes months. Furthermore, extensive experience with the Complaints processes shows that the system is biased in favour of the Service. If the Service has failed to record a fall, say, even though a fall has occurred, the Complaints service will side with the Service. The Service rarely denies an event; it simply says there is no record. On the basis of 'no record', Complaints say without evidence, no finding can be made. In aged care, the complainant must have independent witnesses to prove an allegation. Victims of Aged Care have fewer rights than rape victims.

The system, however, makes claims about what the Complaints Scheme can achieve:

- **Resolve – To work with you and the service provider to acknowledge and resolve your concerns or complaint and make a positive difference for people receiving aged care**
- **Protect – To take timely action on issues raised through complaints to ensure people receiving aged care are well cared for and protected**

- Improve – To work with the aged care community to learn from complaints and act on opportunities to improve aged care

These fine words conceal the fact that Complaints does NOT resolve actual matters in the sense of finding out what went wrong and ensuring the Service takes steps so that it does not happen again. Complaints 'resolves', typically, by finding that the Service

a) did not actually do anything wrong

b) *may* not have done anything wrong

c) did something wrong but has agreed to institute 'processes' to ensure a better outcome in the future.

From the perspective of the family, our interest is rather less in 'improving the system' for some time in the future, but in getting real care for our frail aged parent NOW. The Complaints system does nothing to achieve this and is not interested in this as an outcome.

In dealing with a complaint the Complaints Principles [section 7] require the decision maker to take one of three possible actions, namely –

- to take no further action;
- to quickly resolve the matter by giving assistance and advice to the complainant;
- to undertake a resolution process

From the point of view of residents and relatives, these 'actions' are derisory. For serious and or repeated complaints, there is no satisfaction to be found in 'mediation' or 'advice' from the Complaints Officer. There are no remedies available to families whose relative has been injured, or who has died unnecessarily from an avoidable cause in an aged care facility.

ACFI Fraud: I alerted the Complaints Scheme to the fact that the Service was claiming ACFI monies for a condition my father did not have. The provider claimed ACFI monies for Parkinsons' Disease for two whole years after the condition was positively excluded by a professor of neurology [REDACTED]. The Complaints Scheme recommended assessment by the ACFI Compliance Section. The ACFI Compliance Section – faced with documentary evidence – did the only thing they could do. They did not respond at all. I went to the Ombudsman. The Ombudsman took six months to find out what had happened. They found that as soon as they received my original complaint, the ACFI Compliance Section had immediately sent an officer to the Service. There the Compliance officer simply unchecked the Parkinsons' box, and ticked another box 'dementia from other causes'. This, the Ombudsman told me, meant that my father's records were now accurate and that he found no wrong had actually occurred.

My father's care plan was updated by an ACFI bureaucrat with no doctor in attendance. The Service claimed for Parkinsons' Disease for two years when they had [REDACTED] letter on my father's file, and he had not been medicated for Parkinsons' for two and a half years. The entire bureaucracy colluded to find that no wrong had occurred. The Service had not defrauded the Commonwealth to the tune of \$20,000. The Aged Care bureaucracy is permitted to make medical judgments and put those judgments into the official record. The Ombudsman told me if I was still unhappy I could go to the Police.

The Quality Agency

The failures of the Aged Care Quality Agency have been well exposed in the press during 2017. Oakden and other facilities were fully accredited by the Quality Agency when horrendous outrages were discovered. There can be little doubt that the Quality Agency's understanding of its role is to maintain public confidence in the system by rather than the conduct of a true audit. At our facility the Quality Agency receives feedback from relatives and residents. In September of 2017, the feedback from residents and relatives was negative. However the Quality Agency found the Service met 44 of 44 outcomes. In December, the Department instituted formal sanctions. How is it possible that the Quality Agency passed this Service with 100% compliance, just three months before it was *sanctioned*?

When I reported the matter of the withholding of essential medication to a Quality Officer, her response was, 'but your father didn't die, though, did he?'

The Quality Agency claims it interviews 10% of residents and relatives. However the bureaucracy protects itself by putting distance between the site auditors and the decision makers. The site auditors do not make a decision. They write a report upon which the decision is made. This process is obviously designed to achieve deniability for the unnamed decision makers at the Quality Agency.

The Quality Agency generates a community perception that what happens in aged care facilities is separate and different than that which happens outside. What would be assault outside aged care becomes, at best, an occasion for 'a further audit to address specific issues raised by care recipients and their relatives to be undertaken as part of (our) usual processes.'

All aged care residents sign contracts that say they will receive 'appropriate care' in exchange for a bond and weekly fees. Aged care recipients are also consumers and should have the same consumer rights as they did when they were not aged care recipients, guaranteed by the standard aged care contract. *Appropriate care* should be specified.

Charter of care recipients' rights and responsibilities

The Act should be amended so that the User Rights Principles become enforceable.

The User Rights Principles should be amended to include arbitration into the aged care system. There should be a mandated alternative dispute resolution mechanism, written in to the standard contract, which allows the care recipient to require the Service to submit to arbitration. If the arbitrator thinks fit and if there is a finding in favour of the resident, awards may include or they may be limited to restoration and rehabilitation measures (such as various remedial therapies, medical procedures and support and social support, including additional nursing and community care) designed to improve the resident's enjoyment of life. These measures should not necessarily be limited by the award for money damages. Costs should be borne by the Service if there is an adverse award, or if no finding is made for the resident, costs should be borne by both parties.

3. *The adequacy of consumer protection arrangements for aged care residents who do not have family, friends or other representatives to help them exercise choice and their rights in care.*

There is no little protection for aged care residents whose affairs are managed by the Public Guardian and the Public Trustee. Unless adult protection organisations are diligent in visiting the aged care recipient and observing what happens, there can be no proper assessment of care and therefore no protection. As a rule the Public Guardian seeks assurances from the *Service* – the entity with an interest in claiming care needs are properly supplied. Those who maintain the paper record control the truth. The Public Guardian is assured by the Service that care is being given, the boxes are checked and everyone pays themselves a fee out of the care recipient's estate.

In the first instance there should be much more effort to determine whether there is, or is not, a family member or friend or other representative to assist the care recipient. At present, if one family member is deemed unsuitable, all family members are deemed unsuitable. There is no present system to identify friends or other representatives who might take on the responsibility. The overriding concern should be to protect the aged care recipient from the aged care system and the hospital system. This cannot be done remotely, but only by someone who is actually *present*, and able to consult with the aged care recipient as much as possible.

If it is the case that there is genuinely no family or willing friend to monitor care and manage financial matters, the Adult Protection agencies must be regulated very differently. Adult protection agencies should themselves be subject to scrutiny, and subject to prosecution if they fail to ensure care is delivered to their charges.

In June 2016, there was \$21.9 billion held by the Aged Care Sector in refundable accommodation deposits, and an overall increase between 2015 -2016 in the sector's net worth of \$42 million. It would appear that these monies could be utilized by an independent local organisation for the purpose of ensuring care for the frail aged without family.

It has been my misfortune, and my father's greater misfortune, to have been in the aged care system for the last five and a half years. Because of the unusually long time I have been observing the system, I have been able to recognize patterns. For example, it took me at least two years to realise that the routine claim my father had refused care was a tactic, a tactic to put off the family member and conceal the fact the Service simply did not have enough staff on that day. Because I have been doing this for five and a half years, I now know the signs of a UTI. More importantly I notice well *before* the aged care registered nurse does. She does not notice because she is rarely in the room. Our Service has one registered nurse for 74 residents. There are no resident to nurse ratios in aged care.

Because I have been in the system for five and a half years, I have done the rounds with the Complaints system. The first time, I discovered that Complaints audit food by checking the paper menu, rather than the food itself. They do not tell you this unless you have asked the right question. Having decided on the basis of the paper menu that the food is 'balanced' and 'nutritious' and 'varied', Complaints find that your concern cannot be upheld. When you complain that your parent has been left in the same clothes for four days and nights, and that the Service has lied about it (and can produce the photographs to prove it), Complaints reply that they have counselled the Service, which has put measures in place to correct past incorrect procedures. When those 'measures' fail to be implemented, Complaints invites you to put in a *new* complaint. When your parent is not attended to until 10.15 in the morning and soils himself because he is not mobile and cannot get to the toilet

on his own, Complaints simply repeat assertions from the Service that claim, on no medical evidence, that my father is faecally incontinent. Medically speaking, faecal incontinence is rare, being suffered only by those with a specific neurological condition or who are at the very last stages of dementia. Yet almost *every* aged care resident in Australia is forced into nappies in aged care facilities. *It means they do not have to hire sufficient staff to provide the appropriate care they contracted to do.* To justify this, they make unsupportable claims about residents' real care needs, and dishonestly claim ACFI funding.

The Commonwealth is in a bind. It does not want responsibility for aged care, and in previous years has set up an incredibly generous system for the aged care providers. Providers, being businesspeople, only ever want that generosity to increase. For government the only way forward appears to be to get the extra from individual citizens and families. Government and the aged care sector generate a set of false fears – that aged care providers will go out of business (they won't) that the aged care bubble is looming (entry into permanent care has stayed stable or reduced over the last two reporting periods) and that families are greedy and the frail aged must be protected from them (the take home message from last year's Australian Law Reform Commission report into Elder abuse). You are aware that the public is losing patience following outrage after outrage. You hold yet another enquiry. Like that which has gone before, whatever this inquiry recommends is unlikely to be implemented.

It is suggested that the Commonwealth look seriously into getting out of aged care altogether. Make aged care a local government matter. Deconstruct the massive and useless My Aged Care. Invite local authorities to partner with local general practitioners to set local standards. Have local inspectorates managed by local government for an aged care system that is local and therefore manageable. Abolish the Complaints Commissioner's office and the No-Quality Agency, and let local authorities determine how quality and complaints should be addressed.

The present system is a disaster, made all the worse by governmental authorities that do nothing but shore up the present aged care sector by protecting it from market forces and colluding in concealing its failures from the public.

If this were about children, it would not be happening.

My father is (still) an Australian taxpayer. He served his country twice overseas with distinction, with papers in the National Archive; he has met the Pope and had lunch with the Queen. For the last five years he has eaten sandwiches and ice cream twice a day (other food being unpalatable), has inconsistent personal and medical care. He watches television (when staff have not put the remote control out of his reach) and reads the newspaper (when I come, because otherwise no one cleans his glasses). He sees only the kitchen staff who deliver food. He has been assaulted, subjected to medication errors, he has been psychologically abused, he frequently does not receive the physiotherapy the Service claims to deliver, has been permitted to fall and his oral hygiene is appalling. His clothes have been stolen and money has been removed from his room. He has been sent to hospital when it was not necessary and *not* sent to hospital when it *was* necessary.

He might as well be in Guantanamo Bay.

This inquiry is about the authorities response to poor aged care standards and the lack of consumer protections in residential aged care.

In summary,

- **It is imperative that the Aged Care Act is re-drawn to ensure that there ARE consequences for failures of care under the Act.**
- **Aged care recipients are consumers and should have the same consumer rights as they did when they were not aged care recipients, guaranteed by the standard aged care contract. These should be upheld by the Complaints systems and the Quality Agency**
- **aggregated bond money should be used to support Aged care residents genuinely without family members. This money should be given to an independent local individual or organisation, to advocate for the resident as would a family member, were one available.**

Leonard Cohen wrote a song, 'Everybody Knows'.

Decision makers appear to be working on the assumption that in the end no one really cares about old people. This is incorrect. Not only does the public care about old people, there is a groundswell of anger about this matter that government would do well to take seriously. In the last year social media has exploded with sites about institutional aged care abuse.

Aged Care Complaints has relied on an assumption that it is dealing with individuals, individuals who do not talk to one another and who will be in the system too briefly to work out what is really going on.

Now is the time for Government to disabuse itself of that notion. We *are* talking to one another. That is why numbers in residential aged care are *falling*, in spite of an increase in the frail aged population.

Everybody knows.