# Royal Commission into
# Aged Care Quality and Safety

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## Introduction

The Oxford English Dictionary defines "abuse" in this way: "use badly or wrongly; treat a person with cruelty or violence; the wrong use of something".

Any abuse in aged care implies a lack of quality and safety.

If a competent sensate human being is placed without effective choice, or against their choice in circumstances which they find undesirable, intolerable, or even repugnant, and essentially restrained there until they die, which they are predictably going to do within 6 to 24 months, is that not abuse?

It is essential to recognise that persons entering high-level aged care, whether with capacity or with dementia, are terminally ill, have either serious chronic physical medical conditions, or grave cognitive disturbance. As a consequence, there needs to be a substantial relationship with ongoing basic medical care and with palliative care.

Regarding life expectancy of those admitted to high-level aged care, Professor John McCallum found that: "The median time to death in a nursing home was 10.5 months for men and 9 months for women. Dementia patients took longer to die." This latter fact skews the figures for competent persons. In 2015, the Australian Commission on Safety and Quality in Health Care issued a consensus statement titled *Essential elements for safe and high-quality end-of-life care.* It defined end of life as:

> The period when a person is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. ... People are approaching the end of life when they are likely to die within next 12 months.

Consequently, **a significant number of persons entering high-level aged care are terminally ill.**

## Admission into Aged Care – Who Decides?

The fundamental reason for admission to an aged-care institution is somebody's decision that another individual is unable to safely care for, or look after, themselves. This constitutes a loss of independence and involves a grave decision regarding personal freedom and potentially quality of life. **People should be able to choose between quantity of life and quality of life**.

The predominant reasons for this situation are:

1. Dementia
2. Frailty associated with old age
3. Chronic illness and disability
4. Terminal illness (progressing too slowly for admission to palliative care, or having outstayed their time in inpatient palliative care).

The majority of those with dementia will not have mental competence (capacity), but the majority of the aged frail will have competence, though with varying degrees of cognitive impairment, which may progress after admission.

Who makes the decision regarding admission to aged care? It is rarely the individual him or herself (and there are far higher admissions for females, because they have a longer life expectancy, and have spent time caring for their male partners).

These are predominantly medical or family decisions.

Medical decisions are commonly made in hospitals when people have suffered a severe medical event (e.g. stroke, heart attack, fracture, or poor outcome from surgery), often following a period of medical decline. The patients are either unlikely to ever recover the ability for independent living or are thought to need rehabilitation prior to returning home (which commonly is not the outcome). Families and social workers are placed under considerable pressure to move such people from an expensive hospital bed into aged care. **The affected individual has no effective say**.

Medical decisions also occur at the GP level regarding a frail elderly person who is either living alone or being looked after by a relative. In many cases that relative is also elderly and finding it increasingly difficult to cope. Close family members are commonly behind such assessments, as they fear the likelihood of domestic, pedestrian or traffic accidents, falls and fractures, and poor nutrition and cleanliness. These relatives may not have the accommodation, time, proximity, commitment or financial resources to provide a safe level of care in their own home. Sometimes the ‘victim’ fights determinedly to remain in their own home but, ultimately, they succumb, or they may accede meekly, having little remaining energy for the fight.

## The Frail Aged – How do they feel?

What are the attitudes of those who are threatened with being coerced into institutional living?

They are commonly leaving a family home of great familiarity, and maybe a partner of many years whom they know and trust. They have previously been free to make all their own personal decisions and meet and talk with whomever they choose.

The Australian Government Productivity Commission document No. 53 (2011) *Caring for Older Australians* stated: “Older Australians generally want to remain independent and in control of how and where they live; to stay connected and relevant to their families and communities; and be able to exercise some measure of choice over their care.”

It continued, “A number of participants presented their visions of a future system of care and support for older Australians. While the visions varied, they had many common themes including that: focus should be on wellbeing; services should promote independence; and people should be able to make their own life choices, even if it means they accept higher levels of risk. Older people should be treated with dignity and respect and should be able to die well. Carers of older people should be adequately supported."

Further, "There is strong empirical evidence that consumer choice improves wellbeing, including higher life satisfaction, greater life expectancy, independence and better continuity of care"; and "Many, especially those not suffering from dementia, are deferring entry into residential high care until they reach greater fragility."

Professor John McCallum, leader of the 15-year Dubbo study into ageing Australians, found that about a quarter of Australians who survive over 85 years of age can expect to end up in a nursing home, but "few regard this as their preferred option".

Occasionally an elderly person living alone will make their own considered decision to enter 'care' but, in the vast majority of circumstances, the decision is effectively made by someone else, consent is not strictly given, or only under considerable duress, and sometimes deception. Suggestions that admission is temporary for rehabilitation or 'respite' commonly turn into permanent placements.

## Respite Care – Who Benefits?

As a younger doctor I naively thought that respite care was to allow a more intensive form of temporary assistance for the struggling older person. Now that I have been caring for my wife with Alzheimer's disease, initially on my own, but latterly with significant family help, I realise that the respite is for the carer. The demands on time, patience and tolerance of such a situation are increasingly demanding. There are new skills to be learnt (cooking and cleaning), new habits to develop, and old pleasures to be foregone. It is no wonder that many find they can't cope, and accept a placement on behalf of their non-consenting partner.

A further comment on respite is to recognize the increased dangers to frail aged persons entering homes for a short period with inadequate background information. There is documentation that they receive poorer care than more permanent residents.

Recognised Causes of Death - Dementia but not Old AgeDementia is recognised as a medical diagnosis, and a cause of death. It is now recorded by the Australian Bureau of Statistics as the second leading cause of death, even though no-one actually dies of dementia per se; they die of the complications of progressive dementia, namely, infection (pneumonia, kidney, septicaemia), bedsores (related to immobility and contractures), and wasting (inanition) due to a complete lack of interest in food and fluids (despite forced spoon feeding).

Yet despite dementia being recognised as a cause of death (on obvious clinical rather than scientific diagnostic criteria), old age and frailty are not recognised as causes of death, although commonly similar factors are causative. Old age is measureable though not necessarily accompanied by frailty. Neither old age nor frailty is readily definable medically, though they are clearly recognisable, and comparable to changes in dementia in their effects on life expectancy and quality of life.

The critical difference between these two populations is retained mental competence with the ability to verbally express pain and suffering. The competent frail aged person may suffer from one or more of the six horsemen of the ageing apocalypse, namely loss of sight, loss of hearing, loss of mobility, loss of continence, loss of cognition, and the development of psychological and existential suffering. These are typical accompaniments of ageing.

## Where do people want to die?

Linda Foreman and colleagues (*Palliative Medicine)* analysed 2052 residents re preferred place of dying with a terminal disease. 58% expressed a desire to die at home, but only 14% did so. The proportion of respondents stating preferences for respective places of death were: home 70%, hospital 19%, hospice 10%, nursing home 0.8%. Some changed their minds about dying at home when they realised how prolonged and difficult it might be, but **why should it be so difficult for a terminally ill person to die at home?**

The maximum effort should be made in the use of aged-care resources to keep people at home as long as possible. They should also be able, if competent, to accept the risk of complications rather than face unwanted incarceration.

## Managing the Frail Aged

What are the associated criteria of frailty? Frailty is well recognised medically, but defies measurement by any simple test. It is known to affect the morbidity and mortality of surgery, to prolong recovery, and impede rehabilitation. It is the critical factor in aged-care admission.

It is important for the Commission to be aware of the extremely difficult task that aged care assumes. Many of the persons with dementia are unco-operative at best, and may be abusive and physically aggressive, needing either physical or chemical restraint, to allow reasonable management and protection of other residents. Managing such persons can receive virulent criticism, and rightly so if it is overused.

Definitive proven advice for the management of behavioural and psychological symptoms does not exist; yet these are perhaps the commonest complication of dementia syndromes. The best recommendation is 'distraction, redirection, reassurance and reorientation' – all of which are time-consuming. They may be effective when applied by someone known to the resident, but very difficult for someone unknown to the resident (the institutional carer) particularly in an unusual environment.

To protect the community, police and security forces use physical and chemical (capsicum spray) restraint to subdue and control violent and uncooperative offenders, and the community approves that proper use. Residents in aged care are not criminals and the use of physical or chemical restraint is an abuse of an innocent person's freedom. There are clearly circumstances where, to protect the safety of other residents or staff (or even the individual themselves), some restraint is justified. Sometimes physical restraint is necessary in order to be able to provide more acceptable chemical restraint. These can be extremely difficult situations for aged-care staff – they should be provided with clear guidelines and required to report incidents for assessment or further training.

This is a classic 'Catch 22' situation – the 'best' solution is difficult and time-consuming, while the solution to be avoided (restraint) is quick and cheap but potentially dangerous (increased risk of falls, adverse cerebro-vascular events, and death). There is no doubt that financial restraints on quality of staff and numbers of staff must inevitably lead to poor care. Doctors, staff and homes are between a 'rock and a hard place' in this respect. Abuse of other residents and staff can occur without effective intervention, but abuse and harm can also occur with restraint!

A 2013 Australian study of psychotropic use in 9000 institutional residents found 27% (excluding those with schizophrenia and bipolar disorder) were on antipsychotics, while 41% were prescribed benzodiazepines. The authors stated that such findings were not new, having been reported for nearly 20 years. Following the revelation of a gross instance of physical restraint in January 2019, the Minister for Aged Care responded that “draft changes to regulations are expected to be released within weeks”.

Even those with capacity may have significant anger and fear as a result of their feeling of abandonment by family at a time, and in circumstances, that they have not chosen. In addition, they commonly have multiple chronic illnesses which are difficult to manage. Without great elaboration, **one can assert that the aged-care population is a very complex and difficult group to care for – to expect perfection in outcomes is thoughtless and selfish on the part of relatives and the community at large.**

In my opinion, there are few more difficult and thankless tasks in the health system than looking after (I deliberately do not use the word ‘caring’) for these unfortunate people. Under current staffing and funding arrangements, it is extremely difficult to provide high-level and safe care. In addition, more frequent and honest communication with relatives regarding their family member’s prognosis would be likely to deal with many complaints.

Let me make it absolutely clear that I am not critical of the workers providing ‘care’. This is extremely hard physical work, it is emotionally demanding, and often takes ‘carers’ to the limits of their emotional endurance – complete absence of any co-operation plus physical attack by clients would test the restraint of many critics. Combined with low pay, limited training and heavy work schedules, it is not surprising that occasional adverse events occur.

## Aged Care – Who is Responsible?

The Commission can take a limited view of abuse in aged care – of kerosene baths, of occasional sexual and physical abuse by individual ‘carers’, and occasional systemic lack of care in particular institutions. However, I suggest you lift your sights to the abuse inherently involved in the currently accepted structure of aged care, which ignores the choice of individuals to be incarcerated in aged care, and have their subsequent lives constrained by institutional rules, and forced to live in a communal environment with people they have not chosen and may not like – in other words, a totally alien environment in which to end their lives – as they assuredly will.

This structure has slowly evolved over the last 60 years while modern medicine has extended human life to a point where families, struggling with modern culture, are simply unable to look after their aged parents in their own homes (to put it kindly – perhaps the aged home is a more convenient and accepted option now). Research shows that immigrant families make less use of aged care.

There is a culture of fear of complaint – by residents, families, but more significantly by administrations – a cloak of obfuscation, silence and delay, or ultimately using the financial power of the institution to bury the complainant.

Gradually, Australian (and most other Western) societies have come to accept the aged-care industry as the answer to an increasing tide of ageing parents as a consequence of modern medicine, in the same way that they have come to accept palliative care as the solution for suffering in the dying patient. Neither have proved, on their own, to be a sufficient answer to these serious modern problems. Both problems, but more particularly aged care, are too complex to have a singular solution. This is partly because the nature and variety of human thought and values is so diverse, and the nature of physical, social, psychological and existential circumstances of the aged population is so diverse, that simply applying one solution has failed.

For the aged, to herd them all into one environment and expect a good solution is fatuous, and it is surprising that it has survived so long, except that it has been so convenient, and aged persons have been so amenable and readily coerced. Let me repeat the OED definition of abuse: “use badly or wrongly; treat a person with cruelty or violence; the wrong use of something”. The Commission should apply this to the information it receives.

Aged care is an essential public health service. I deplore the entry of for-profit companies into this field – there is evidence that profit comes before care. The major cost on the aged-care sector is staff; if profit needs to be sustained, staff levels decline. If, for political and economic reasons, there is no alternative to for-profit entry, there should be government-mandated staff/resident ratios, and a restraint on profits should be imposed if possible.

## Recommendations

1. Recognise the very significant increase in the need for aged care in the future.
2. Recognise that two different streams of residents: (i) aged and fail but competent; and (ii) incompetent with dementia. These two groups have different circumstances and requirements.
3. Recognize that a significant majority of those in aged care did not themselves decide to be there, and do not want to be there or die there.
4. Recognize that inadequate numbers of properly trained staff lead to overwork and frustration, and thence to poor quality care and abuse.
5. Recognize that improved care will require a significant increase in funding.
6. Recognize that aged care is an essential public health service, and that for-profit providers are a poor compromise to quality – profit comes before care.
7. Recognize that if, for political and economic reasons, private providers cannot be ignored, place the restraint on profits, and mandate minimum levels of staff.
8. Mandate increased minimum staff/resident ratios, as in our public hospitals.
9. Recognize that residents in aged care have significant medical morbidities and require regular medical assessment and care. This requires improved medical care in aged care. Medical funding is based on time. Recognize the time of travel to institutions and recognize the complexity of end-of-life consultations with increased funding.
10. There should be mandatory reporting of selected events involving abuse.
11. Recognize the importance of better communication and understanding of future expectations by family. Many complaints are based on poor information re prognosis and unrealistic expectations re outcome.

12. There should be improved documentation of individuals' wishes through advance-care directives, through emphasis on these documents of persons with an early diagnosis of dementia before admission (in government-funded senior-health checks), and especially on admission to aged care.
13. Visual educational aids should be developed regarding the more advanced circumstances of dementia, in order to improve the level of information regarding dementia in the community and improve informed consent regarding future limits of care.
14. Recognize that residents in high care are terminally ill, and there is a need for improved palliative care in aged care. At least one staff nurse must have training in palliative care. Create a terminally ill section in high care in order to improve the care of dying residents. Currently there is a vacuum between aged care and acutely ill/ terminally ill residents who need more than basic care but do not need hospital care.
15. A palliative-care-trained nurse must be on staff or one available on urgent call.
16. Improved documentation of residents' wishes through advanced care directives on admission, placing notice of the existence prominently on the front of the residents' record and ensure that a copy of the resident's directive travels with them to hospital.
17. Recognize that much aged care is provided to people who do not want it.
18. Clarify the law regarding refusal of unwanted in advanced dementia.
19. There should be a choice not to enter aged care or to leave it if it does not meet needs and to request a choice of voluntary assisted dying as an alternative.

Detailed documents regarding many of these recommendations will be made by others with more detailed experience in aged care; so, I do not enter those arguments in detail, but I wish to address items 13 to 19 in more depth.

**Item 13:** We recommend the development of visual educational aids with respect to the more advanced stages of dementia in order to improve the level of information re dementia in the community and improved informed consent. Such visual aids have been developed and used in the USA (Volandes et al.; BMJ 2009) with significant reduction in competent older persons making requests for futile and life-prolonging care, opting rather for comfort care. There is very strong evidence that such visual documents change uninformed opinion with respect to treatments in end-stage dementia.

**Item 14:** Residents in high level aged care are terminally ill. Professor John McCallum found that "the minimum time to death in a nursing home [in high-level care] was 10.5 months for men and 9 months for women." He emphasized that the large group with dementia take longer to die because they are cognitively impaired rather than physically impaired. This skews the figures for the frail aged competent group. If they are terminally ill, they have significant medical problems and require frequent medical assessment and particularly palliative-care assessment. Medical practitioners attending nursing home patients should have basic levels of palliative-care training.

There is a large body of evidence that people in aged care (particularly those with dementia) have a significant level of under-diagnosed and undertreated pain and other distress. Commonly this is due to under-reporting of incidents by poorly trained carers (those who are in the closest contact with residents). Even when pain and distress are recognised they are undertreated because of fear on the part of medical and nursing staff of accusations of 'hastening death'. So residents suffer the abuse of under-treatment of pain when they are dying, despite the established legal doctrine of 'double effect', enunciated by Justice Devlin. He stated "the giving of drugs to an elderly patient to alleviate pain was lawful even if incidentally it shortened the patient's life". Sixty years later, the medical and nursing professions are insufficiently aware of this determination, with tragic implications for residents. This should be addressed.

At present, due to the lack of trained palliative-care staff, and inadequate response from the medical profession in general practice, many people in aged care who develop a critical situation requiring good palliation, are almost automatically transferred to an acute hospital for 'treatment'. This is inappropriate and futile and a very expensive solution to the problem. These people commonly end up in intensive care when in situ palliation would have been appropriate (refer to frequent comment by intensivists (Peter Saul, Ken Hillman and Charlie Corke). The establishment of a small palliative-care section in all large aged-care homes would prevent most of these unnecessary admissions.

**Item 15.** Recommend that a palliative-care-trained nurse be on staff or one available on urgent call. Terminally ill people are the target population for palliative care. A palliative-care emphasis in aged care is essential in the training of both the medical and nursing personnel involved in high-level care.

**Item 16.** Recommend improved documentation of residents' wishes through advance-care directives (ACDs) through emphasis on these documents before admission (in senior citizens health assessments) or of persons with an early diagnosis of dementia or, especially, on admission to care.

Good communication is essential to prevent unwanted treatment and the prolongation of completed life and of suffering. The medical professions' response to illness is to provide treatment unless it is refused. The earlier discussion via an ACD (a directive, not a plan) allows better informed consent of possible refusal of treatment. As CJ McDougal (NSW Supreme Court) stated in 2009 "if an advance care directive, made by a capable adult and is clear and unambiguous, and extends to the situation at hand, it must be respected". Effective ACDs are of great benefit to patients, families and doctors in preventing unwanted and futile treatment, providing they are visible to doctors and carers.

**Item 17.** Recognise that much aged care is provided to people who do not want it. Most decisions for people to enter aged care are made by hospital staff after treatment has failed to restore independence, and/or by families who can no longer provide sufficient support to keep a relative at home. They are rarely made by the aged frail or demented person. The evidence overwhelmingly indicates that the vast majority (99%) of people do not wish to die in nursing homes, yet that is exactly what happens to about 20%. This is a deprivation of liberty (confinement against one's wishes) and of autonomy (the right to choose when, where and how to die).

**DWDV would assert that this is one of the major abuses involved in the aged-care system – the incarceration of people in aged care against their will and without any choice.**

**Item 18.** Recommend clarification of the law regarding refusal of unwanted spoon/hand feeding in advanced dementia. Competent persons have a legal right to refuse fluids and food, even if such refusal would result in the loss of the person's life, and must be provided with appropriate palliation

(CJ Martin, WA Supreme Court, 2009 in Rossiter). Artificial (tube) feeding can be refused in dementia via an advance directive. The alternative to tube feeding is spoon feeding, but its status re refusal by advance directive is not clear. Many residents with advanced dementia have their lives (and their suffering) prolonged by such feeding, which in many cases becomes forced feeding. Many aged-care institutions have a significant dilemma in relation to this matter.

**Item 19:** Recommend a choice not to enter aged care or to leave it if it doesn't meet needs and, in these circumstances, there be an ability to request voluntary assisted dying as an alternative.

There is a recognised right to have one's autonomy respected, so long as that does not harm others. Incarceration in an institution against one's wish is a clear breach of liberty and autonomy. The right of frail aged but competent persons to avail themselves of voluntary assisted dying laws should be formally acknowledged.

You may see this as outside the terms of reference of your Commission, but it is by far the greatest abuse in the aged-care process: the deprivation of freedom and choice with regards to admission and incarceration in the system.