



Human Rights for People Living with Dementia: An Australian Anthology

Edited by Linda Steele, Kate Swaffer, Lyn Phillipson and Richard Fleming



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Research team:

The research team was led by Dr Linda Steele (UTS), with investigators A/Prof Lyn Phillipson (UOW), Prof Richard Fleming, (UOW), and Kate Swaffer (DAI, UOW and UniSA), and research assistant Ray Carr (UTS).

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This Anthology is an outcome of the 'Safe and Just Futures for People Living with Dementia in Residential Aged Care'.

Here we introduce the background, aims and findings of this project in order to provide some context for the necessity of this Anthology.

We then give an overview of the summit, which was the foundation for the Anthology.

Introduction: We need to talk about human rights of people living with dementia

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Project background

The 'Safe and Just Futures' project was a response to a variety of common aspects of the environmental design of residential aged care facilities (RACFs) that are detrimental to the quality of life and the exercise of human rights of people living with dementia.

RACFs often house older people and people with disabilities (including people living with dementia) in large numbers separate from the rest of the community. Locked fences and doors commonly prevent residents from coming and going from RACFs.

RACFs generally include dementia care units that only house people living with dementia, therefore segregating them. Dementia care units are generally locked to prevent those inside from accessing other parts of the RACF and the community beyond the RACF.

These aspects of RACFs can give rise to discrimination, exclusion and injustice, yet they are often overlooked or taken for granted as the defining and natural features of RACFs.

There has been a long focus in health and social science literature on 'quality' and 'safety' in aged care and this literature can be drawn on to question the impacts of these aspects of RACFs in relation to individual wellbeing. Yet, there has been little discussion across all academic disciplines of the social and political impacts on people living with dementia of common aspects of environmental design of RACFs.

People living with dementia and their international representative organisation 'Dementia Alliance International' have argued for many years that the environmental design of RACFs gives rise to confinement and segregation and constitutes human rights violations.

Historically people living with dementia have not been seen as bearers of rights. However, the past decade has seen increased human rights recognition in the coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD requires people with disability

(including people living with dementia) to enjoy the same rights as everyone else, including rights to autonomy in decision making, independent living and community inclusion, and liberty.

Internationally, there is increasing pressure to recognise human and legal rights of people living with dementia, in part by reason of the advocacy of people living with dementia and their representative organisations and allies.

In an Australian context, there is emerging recognition of the human rights of people living with dementia in the context of law reform and policy discussions, as evidenced in the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Moreover, the new Aged Care Quality Standards – including through reference to dignity, respect, freedom from abuse, choice and independence – are encouraging shifts in service provision consistent with human rights.

The extent to which human rights are realised in practice and in everyday life depends not only on the willingness of politicians and policymakers to change legal and regulatory frameworks, but on the support from civil society for human rights – the attitudes and enthusiasm of community members, people living with dementia and those who provide advocacy and support.

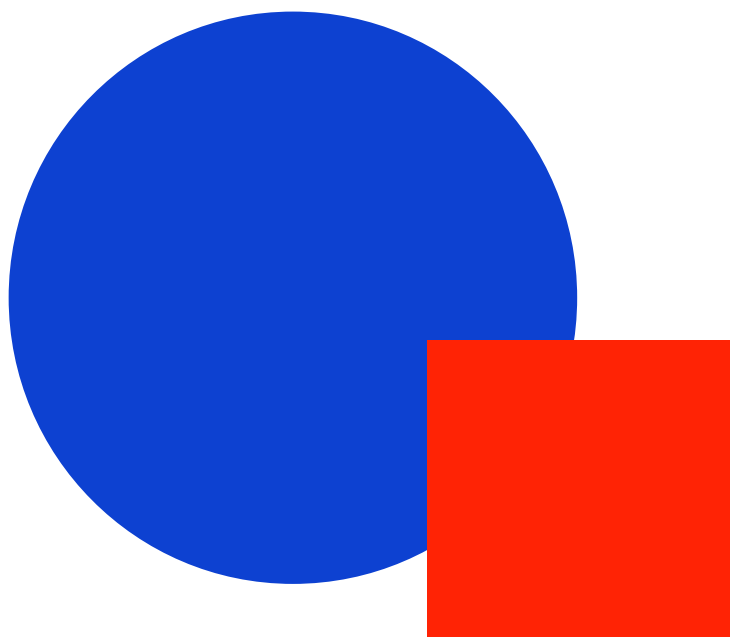
Aims of the project

The aims of our project were to explore:

- current barriers to liberty and community access for people living with dementia in RACFs, and
- the possibilities and challenges of utilising a human rights framework to transform the living and support arrangements of people living with dementia in RACFs.

We sought to contribute to policy and law reform discussions around aged care, and raise awareness amongst lawyers, advocates, human rights practitioners and policy makers about human rights of people living with dementia.

The project researchers constituted an interdisciplinary team traversing law, public health, dementia design, and psychology, and included a leading international advocate on rights of persons living with dementia who herself has younger onset dementia. The project was guided by an advisory group that included people living with dementia, care partners, care home professionals, and lawyers and advocates for people living with dementia.



Formative research

The project was in two stages.

Stage 1 involved developing a framework for understanding segregation and confinement in residential aged care as a human rights issue. We drew on the human rights contained in the CRPD and the jurisprudence and work of the United Nations Committee on the Rights of Persons with Disabilities

Stage 2 then involved exploring perspectives of stakeholders in relation to the human rights framework. This involved interviews and focus groups with people living with dementia, care partners, care home workers and lawyers and advocates. Aged care regulatory officials did not respond to our invitation to participate.

Ethics approval was granted for the interviews and focus groups.

Following extensive recruitment efforts, our final sample of participants consisted of n=5 people living with dementia, n=19 care partners of people living with dementia, n=12 care home professionals, and n=9 lawyers and advocates. Overall, this was consistent with our targets, with the exception of the low numbers of people with dementia who took part.

Findings

At Stage 1 of our project, we found that the CRPD can provide the basis for problematising confinement and segregation in RACFs as a violation of human rights of people living with dementia. The specific rights we identified are:

- rights to non-discrimination (Article 5);
- liberty and security of the person (Article 14);
- equality before the law (Article 12),
- accessibility (Article 9); and
- independent living and community inclusion (Article 19).

In developing the human rights framework, we found that human rights are useful in highlighting what is currently harmful and unjust with current practice. In addition they also provide principles to guide transformation of the aged care system and our communities. This is critical to bring about meaningful alternatives and appropriate supports to make choices from a range of alternative residency and support options, end institutional-style aged care, and build communities that are free from ableism, ageism and other systems of oppression that contribute to confinement and segregation.

These results can be read in full in our academic publication:

'Questioning Segregation of people with dementia: An International Human Rights Approach to Care Homes.'

<https://www.mdpi.com/2075-471X/8/3/18/htm>

In Stage 2 we found support for human rights of people living with dementia in our key stakeholder groups but also identified a number of barriers that impede the practical and everyday realisation of these rights.

Contrary to our initial understanding of confinement and segregation as primarily driven by environmental design of RACFs we learnt that beyond locked doors and restrictive practices there are micro-level interrelated and compounding factors that contribute

to human rights abuses of people living with dementia. These are related to limits on freedom of movement and community access that are, at times irrespective of the use of restrictive practices. They include:

- immobilisation and neglect of residents;
- limited and segregated recreational activities;
- concerns about duty of care and liability;
- apprehension of community exclusion;
- pathologisation of the responses of people with dementia to their circumstances; and
- subversion of the understandable resistance of people with dementia to the interventions, interactions and actions thrust upon them.

Overall, we also found that, across all participant groups, there was support at a general level for human rights for people living with dementia.

However, despite this, the overwhelming majority of participants identified barriers to realising human rights on a practical and everyday level. These barriers include:

- a lack of cohesive and supportive communities;
- the marketisation of aged care;
- perceived conflicts with safety and duty of care;
- the stigmatisation of people living with dementia, incapacity and epistemic negation;
- nihilism, and invisibility and dehumanisation.

Through these findings, we concluded that law and policy directed towards recognising human rights in RACFs must go beyond challenging environmental design and use of restrictive practices.

Critically, an effective response must also include issues relating to community access, social and recreational inclusion within and external to care homes, and physical mobility.

This includes individuals who were in the child welfare system, individuals who have experienced child abuse, sexual or physical violence in institutional, family or intimate partner contexts, older transgender, gender-diverse and intersex people who have experienced discrimination, and individuals who have been institutionalised in other contexts such as criminal justice, mental health and immigration systems.

It is vital to foreground the voices and experiences of people living with dementia in human rights scholarship and advocacy and support, and to amplify the work of consumer-led organisations such as Dementia Alliance International, and challenge the pathologization and subversion of their acts of resistance into further bases for confinement.

To help promote community discourse around these critical human rights issues, this project also supported a Summit on Human Rights for people with dementia living in residential aged care. People living with dementia, care partners, advocates, lawyers, academics and other interested community members gathered at University of Technology Sydney on Friday 22 November 2019. The summit provided an opportunity for knowledge translation in a number of key respects:

- to share our preliminary findings;
- to provide a forum to share other, existing work on human rights; and

- In their presentations care partners Lynda Henderson and Dubhglas Taylor supported these calls.



Yumi Lee (Older Women's Network NSW), Pauline Crameri (Val's LGBTI Ageing and Aged Care, La Trobe University) and Kate Kennedy (Senior Rights Service) emphasised the importance of taking an intersectional approach to understanding the identities, life histories, experiences and needs of people living with dementia. Diana O'Neil (Flinders University) discussed the experiences and circumstances of diverse populations of people living with dementia including LGBT, public housing residents, care leavers, and older women (notably those who are homeless, in poverty or experiencing domestic violence), including circumstances of inequality, discrimination and violence they might experience across their life courses that then shape their journeys into aged care.

Hamish Robertson (University of Technology Sydney) offered some theoretical reflections on the social views about dementia, ageing and disability that contribute to the devaluing of people living with dementia and inform policies and practices that expose them to greater risk of harm and death.



Bethany Brown presented via Skype from New York on the recent Human Rights Watch report on chemical restraint in Australian nursing homes and the need for the Australian government to shift from regulating to prohibiting this practice.

In a similar vein, Laura Grenfell (Law, Uni of Adelaide) argued that some harmful practices in residential aged care facilities might breach international human rights law relating to torture. Lawyers Karen Williams (ADA), Sonia Di Mezza (ADACAS), Linda Rogers (private practitioner) and Rodney Lewis (private practitioner) discussed the possibilities for and barriers to realising legal rights for people living with dementia.

Leonie Sheedy and Stewart Quinn from Care Leavers Australia Network spoke about the trauma care leavers (i.e. people who were in child welfare institutions, such as orphanages) have from their childhood and their fears of being institutionalised in aged care facilities – noting that many would choose suicide over aged care.



Kirsty Carr (Dementia Australia) suggested the current focus on aged care through the Royal Commission provides exciting opportunities for transformation of the aged care sector.

Ingrid Fairlie (consultant working with UTS Faculty of Health) discussed the ways in which the new Aged Care standards are informed by human rights values of dignity and autonomy.

Richard Fleming (University of Wollongong), Phillipa Carnemolla (University of Technology Sydney), and Claire Loughnan (University of Melbourne) offered academic reflections on the extent that we can achieve respect for dignity in aged care facilities through a facility's built environment and care practices.



This Anthology

Participants at the summit were invited to contribute to an anthology on human rights of people living with dementia. The aim of the anthology is to showcase diverse perspectives in support of human rights of people living with dementia in order to communicate to law and policy makers and the wider community the growing support for recognising human rights of people living with dementia.

The team is currently developing submissions to the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. These submissions will also include the anthology to show the views of the research team form part of a broader Australian conversation about the importance of human rights for people living with dementia.

Further reading:

Linda Steele, Kate Swaffer, Lyn Phillipson and Richard Fleming, 'Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes Laws' (2019) 8(3) *Laws* 18
<https://www.mdpi.com/2075-471X/8/3/18/htm>

The everyday violation of rights of people living with dementia

Bobby Redman
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Stigma is so strong around dementia that in many countries, people with dementia are hidden away by their families, never leaving their homes

Interestingly, even in 1st world countries people hide their own dementia as though it is something of which they should be ashamed. Why is this?

If we developed cancer, heart disease or any other type of debilitating illness, friends and family generally gather around us to encourage and support us on our journey; medical professionals offer medical treatments to cure us or to at least ensure that our health and well-being is maintained as well as possible.

Sadly, it is a very different story if we develop dementia. Here, friends and even family take a step back. We change because of our symptoms, but instead of receiving encouragement and support, people often turn away from us – perhaps not knowing what to say to us and how to manage the change in dynamics of our relationship; often frustrated by our various symptoms.

People, including medical professionals start to talk to our partners or other family carers rather than directly to us even though, in early to mid-stages and maybe even into late stages, we still can describe what is happening to us, what we are experiencing, how it feels!

Doctors avoid making a diagnosis, perhaps they too are filled with a sense of helplessness in not being able to offer a cure. Even when a diagnosis is made there is seldom any advice or recommendations made around where to go next, no information on the type of activities that research is identifying as helpful in maintaining function, basically most of us are told to go away and put our affairs in order.

Everyone gives up on us – we are alone and afraid. It is as if, at this point, we cease to be a human being, **this is a breach of our human rights.**

Over time, as our symptoms increase and our functioning reduces, decisions need to be made around our capacity to do various things.

Are we safe to go out into the community alone, to continue to drive, to maintain our own finances, to continue to live at home, to make decisions around our own health needs?

Of course, this needs to happen, but it is how this happens that is often questionable. These decisions need to be discussed with us whilst we are still able to make sound decisions.

Naturally, it can be hard for people to make decisions about their future, and so encouragement may be required to plan future needs. Everyone diagnosed with dementia should be encouraged and supported to develop a plan and identify their wishes for their own future.

Unless our wishes put ourselves or others at risk they should be respected and followed. This is often, not the case. The level of support offered to people living with dementia to maintain their ability to live at home and continue to participate in the Community is inadequate.

Assessments are often based on physical rather than cognitive needs. Because, until later stages, we do not require assistance with getting in and out of bed, showering, or eating, we are offered little in the way of support.

It is not recognised that although we can eat, we may not recognise hunger or fullness, and not remember whether we have eaten, so may not eat or alternatively eat several lunches.

We may be at risk of burns and of creating fires when we burn our pans.

We may flood our kitchens / bathrooms when we forget that we have turned on the tap.

We can still walk around in the Community but can easily become lost and confused. People with dementia need support to live in their homes, but it is a different type of support to those with a physical disability. **Lack of support or services is a breach of our human rights.**

Advance Care Plans are often ignored, dismissed by others who 'think' that we may feel differently now, to when the plans were made. This is not only disrespectful it is a total breach of our human right to make decisions that affect us.

Driving capacity assessments are necessary to ensure that people with dementia are safe to drive. Some doctors do not request or perform assessments they just say, 'You have dementia so must give up your driving licence'. In addition to this, not all driving capacity assessments are equal.

My own driving capacity assessment was a three hours endurance test. The first part made up of answering a range of questions; the second part some virtual experience driving completed on a tablet; the third part an hour on road driving test with a driving examiner and the occupational therapist.

Firstly, I question just how many people with or without dementia would be fully alert after three hours of testing, accompanied by the stress from knowing that your independence was dependant on your results.

Secondly, I question how fair it is to test people who may have limited technology skills and possibly no experience of using a touch screen, on a tablet. Thirdly, I would ask how many people would feel comfortable completing a driving test in a strange car that they have never driven before.

Driving tests to gain a licence are completed in the car in which you have learnt to drive, why then are these capacity assessment tests completed in the car provided by the examiner? I generally drive a Kia Picanto, one of the smaller cars on the road. I had to complete my assessment in a large SUV with electronic controls! Even though I told the examiner that I limit myself to a 20 minute drive, and was quite prepared to accept a limited licence to fit with this, my road test went for 1 hour, increasing the risk for all three of us in the car.

In case you are interested, YES I passed the test and retained a full licence, although I never drive out of my local area and limit myself to driving less than 20 minutes at a time. However I strongly believe that these tests would put the majority of people, undergoing this assessment, at an extreme disadvantage. They are designed for us to fail. **This, once again, is a breach of human rights.**

Finally, when talking about breaches of human rights for people with dementia we cannot ignore the situation for people living in residential care, where they still place us in locked facilities, indefinitely, which cannot happen in any other circumstances.

People who have committed a felony are locked up for a prescribed period of time; people diagnosed with a mental health condition may be certified and placed in a locked facility for a period of time, but this has to be reviewed on a regular basis – reviews generally do not happen for those living in dementia specific facilities.

Even in locked facilities it is common practice to chemically restrain people living with dementia to make us easier to manage – this practice goes back to the dark ages in mental health institutions. How can this still happen?

How can things be changed?

It needs a total change of attitude towards dementia by the whole community. Education is required for greater understanding; practices need to be reviewed in order that people receive the services and support that they require; and the law needs to be enforced to protect people from abuse. We don't cease to be human when we develop dementia, we too have the right to live the best life we can.

**Bobby Redman, Dementia Advocate
diagnosed with Dementia in 2015**

What happened?

Dennis Frost, Southern Dementia
Advisory Group

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In 2007, shortly after my mother's 80th birthday, she had a minor stroke. While she was still in hospital recovering, she was given a short 'mini-mental' and diagnosed with dementia. The medical experts advised that she should go into care.

It was very clear she wanted to return to her home of over 30 years, but, with some reluctance, we followed the medical advice and shortly found her a place in a care facility about 60 kilometres from her home.

The view from the front of the facility was spectacular, parkland and ocean views. Inside the only view the residents had was of walls and fences partially hidden behind shrubs.

When she was admitted, we were advised not to visit her for several weeks, so she could 'settle in'. Within that period, she fell from bed and broke her hip, and died a few weeks later.

In hindsight, what she wanted and needed was just some help at home from her family and friends. What the system gave was isolation, confusion and an untimely death.

I now ask was any medication or drugs involved? A question we didn't think relevant then but in the light of what is being revealed today a very important question.

Then, in 2013, I was diagnosed with Frontotemporal Dementia at age 59.

I was told that I had 3 to 6 years to live and to go home and retire, get an ACAT assessment and prepare for 'care'. All my friends tell similar stories.

A few years later my oldest sister was also diagnosed with dementia at the age 80. Her family placed her in a 'care' facility nearer to them and she is happy there. When I first visited her there, we noticed one of the residents was a bit agitated pacing around the gardens. My sister told me a few weeks later that he found a shovel and tried to dig his way out. He was then transferred to a more secure facility, where he succeeded in committing suicide. I now admire the persistence of this gentleman.

What I have observed at this and every other aged care and dementia care facility I have visited over the last 4 years is that there is a very inconsistent level of care, it really depends on who is on duty that day. There are some very good empathetic and caring staff, but they are far too few and far between.

What I see are fences and locks, all designed to keep people in and hidden from the outside world. This also has the effect of discouraging friends and family from visiting, further adding to their isolation and loneliness.

There are far too few meaningful activities for residents, with almost no intellectual stimulation associated with any of them.

There is exorbitant costs and very little value associated with all these care facilities. They seem to rely on families' perceived guilt to fill their beds and coffers.

I will never willingly live in any of these facilities and if I find myself incarcerated in such a place, I will honour the memory of my Grandfather who was a POW in WWI and consider it my duty to escape or die in the attempt!

What is wrong with living and dying at home?

Reframing dementia through the lens of human rights

Kate Swaffer, Dementia Alliance International and University of South Australia

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'Safety is what we want for those we love, and autonomy is what we want for ourselves.'

Keren Wilson (2013)

This quote is important in the context of residential dementia and aged care; having been an unpaid care partner and legal guardian for three people who died in nursing homes, it was safety and full time 'care' I had believed, and for which I had been promised for them, by each nursing home manager.

However, 'safety' was so far from the reality it remains something from which I still have guilt, and this reality fed my growing concerns about residential care. I wrote on my website in 2015:

'There is little doubt the view of the family care partners versus the person with dementia are vastly different.

We want autonomy. They want us to be safe.

We want freedom and a front door key. They want the doors locked to 'know that we are safe'. We see and feel like this as being in jail.

We want to walk. They see our walking as wandering, and want us to stop wandering, seeing our desire to continue walking as a 'challenging behaviour'.

By the time we probably do need residential care, we may not know we need care, and we certainly don't want to be in care. If we become angry or upset about being 'made' to move there, we are viewed as having 'challenging behaviours', rather than people who do not wish to go and live with strangers or leave our own homes.

We want to continue to live our lives, in our own homes, the place we are familiar with, and have always lived. However, we are sold the concept of residential care being our new home. So, if it is our new home, why are we not given the key to the front door of our new home, or at least the back door, out to a garden. How can it be our new 'home', if we can't get out?

On top of this, we are expected to live in a commune with strangers and eat in dining rooms with people we have never met and may not ever get to like.

We are told it is good for us to go to the activities room and participate in the various (or not) activities provided, at the times on the printed timetable stuck on the door in our single room with our single bed. More often than not, these activities are just 'time fillers', with no inherent value other than socialising, and with people we may not consider friends.

Meaningful activities don't only have to engage people, they have to have some value and inherent purpose, for them to be of any real benefit... a reason to want to get out of bed. This point is missed in almost all activity or lifestyle coordinator programs that I have read about or seen. Activities are for the most part, simply 'time-fillers'.

And then onto the topic of our bedroom, in our 'new home'. Yes, a single bed. If it was really our home, we would be in a Queen, King or at least a double bed. Oh, and this room, supposedly our personal, individualised private space, cannot be locked, nor do we have a key to it, and rarely does anyone knock to enter, they just come in when it suits them.

We might be resting, or wanting to be alone, but no, when it is time to eat, or to be bathed, or go to an activity, we are disturbed, often without the courtesy of the visitor in 'our home' asking if it suits us.'

<https://kateswaffer.com/2015/11/01/safety-vs-autonomy-in-residential-care/>

Although I have been a nurse (including working in a 'secure' dementia unit), and a care partner, I also have an insider's view. As well as speaking up to improve the post diagnostic care, including advocating for rehabilitation for all people with dementia, I have been writing and speaking up against institutional care and **segregation** for well over a decade.

My insider's view began more than 11 years ago when I was diagnosed with a rare form of young onset dementia, aged 49. It was an early 50th birthday 'gift' although I don't remember saying 'thank you'. Ultimately, my diagnosis has been the third greatest gift of my life and ironically, it has given me more clarity about life than I'd had before.

My accidental activism started after being asked to speak to a group of aged care staff in 2009, attending events about dementia and being told by people without dementia what I was feeling, and what was best for me! This resulted in me co-founding the first international advocacy organisation led by, and exclusively for, people living with dementia more than six years ago. We started with eight co-founding members, and now have members in 49 countries.

Dementia has also given me a much deeper purpose than I'd had previously, but the road has been very rocky, and definitely 'the' roller coaster ride of my life. Sadly, it is one that has highlighted so many breaches of the most basic of my human rights, and the rights of the more than 52 million others living with dementia around the world.

Since my own diagnosis I have been speaking up for the human rights and disability rights of all people living with dementia and in aged care, and have been saying since 2009:

'The only other group of people to be institutionalised, locked up and then segregated from others, are convicted criminals.'

I've now experienced what Dr Martin Luther King expressed as that sense of 'otherness', to the point on many occasions where I've felt that others have treated me as a 'non-human being'.

It is now time to reframe dementia as a condition causing acquired cognitive and other disabilities.

This is important, as until we do, most of the 'interventions' to improve care are little more than expensive band aids, that don't actually fix the problem(s).

My university immediately set me up with this approach to dementia about 12 months after my diagnosis, teaching me to accept and see the symptoms of dementia as acquired disabilities. This approach has allowed to continue living a positive, productive and meaningful life, and although I initially disliked the addition of another negative label, it helped me reframe dementia as a disability, and to claim my indisputable rights.

Thankfully I'm resilient and optimistic by nature, otherwise the reactions to being diagnosed with dementia may not have become a gift. With some help from my Back Up Brain (husband), and a lot of disability support, I still manage to live a good life.

Finally, for this anthology, I want to list a few of the daily breaches happening to most people with dementia globally, specifically in relation to the CRPD. They are more likely to be worse if the person is living in a residential aged care facility.

Human rights breach 1: Denial of health care and support

CRPD Article 25: Health

Article 26: Habilitation and rehabilitation

My doctor who diagnosed me told me there was nothing he could do, other than monitor the progression of the dementia symptoms. He said it was likely I'd progress quickly even though at no time was I advised dementia is a terminal illness, or referred to, or provided with, the same post diagnostic support as others with a terminal illness.

Human rights breach 2: Denial of social participation

CRPD Article 19: Living independently and being included in the community

Article 29: Participation in political and public life

Article 30: Participation in cultural life, recreation, leisure and sport

The whole of the health care sector, especially service providers and advocacy organisations told me to go home, get my end of life affairs in order, and start going to dementia day care once a month to get used to it. I trademarked this as **Prescribed Disengagement®** and 12 years later, it is still happening to most people who are diagnosed today.

Human rights breach 3: Denial of employment and reasonable accommodations

CRPD Article 5: Equality and non-discrimination;

Article 17: Work and employment

Article 29: Participation in political and public life

Article 30 Participation in cultural life, recreation, leisure and sport

When I failed my driving test, resulting in losing my driver's license, I 'lost' my job. No one, not even the dementia 'experts' told me I had a human right to be supported to stay at work, with Reasonable Accommodations, and which should have been automatically provided by my employer. Furthermore, almost no organisation has been willing to pay for my time or expertise since, which increases the stigma and discrimination, loss of self-esteem, and sense of 'otherness'.

Human rights breach 4: Denial of rehabilitation

CRPD Article 26: Habilitation and rehabilitation

The health care sector does not offer rehabilitation including allied health services such as speech pathology at the time of diagnosis, and nor is there adequate funding for it.

Human rights breach 5: Denial of health care

CRPD Article 25: Health

Health care professionals and service providers do not provide post diagnostic allied health services, or palliative care and counselling, in line with other terminal illnesses, at the time of diagnosis. Furthermore, and especially for older people with dementia living in residential care or in the acute setting, their other co-morbidities are not managed appropriately, if at all.

Human rights breach 6: Denial of disability support to living independently

CPRD Article 19 – Living independently and being included in the community

I was not provided with disability assessment or proactive disability support at any time by the health care or service providers, nor any proactive disability support to maintain my independence and live my life as well as possible, for as long as possible.

General human rights breaches: Denial of equality and non-discrimination

Since the time of my diagnosis, and across various aspects of my life, I have been treated detrimentally because of my acquired disabilities. Without self-managing, and without self-prescribing a number rehabilitative and other interventions, including being able to self-fund them, I would not have achieved universal health coverage, nor have a high quality of life.

These and other issues breach of many rights, and leaves me, and all people with dementia, behind in the 2030 Sustainable Development Goals (SDGs), which are the United Nations (UN) plan for achieving a more sustainable future for everyone, and they address the global challenges we face. These challenges include inequalities related to poverty, inequality, climate change, the environment, peace and justice; and they are all interconnected. The UN believes that in order to leave no one behind, it is important that we achieve all of the SDGs by 2030.

These, and many other breaches of my rights are part of the fuel for my continued activism, as governments and health care providers continue to deny us the most basic of services and support.

Sadly, living positively with dementia is very much based on a person's social economic status. Although note related to residential care, since my diagnosis, almost no one is willing to pay me for my time or expertise; I am thankful in this project, funding was provided, as the level of economic stigma heightens the experience of isolation, stigma and discrimination, and the loss of identity and self-esteem.


In my quest for human and legal rights for all people with dementia (and indeed every person living in residential aged care, irrespective of diagnosis), I have often felt like Mrs Rosa Parks. I will continue to refuse to be quiet about our rights, and to reflect on the work still needed to ensure everyone receives not only universal health coverage, but that they have all of their rights upheld.

May the work of others, past, current and present, continue to inspire us all to fight for change.

Further reading:

<https://journalofdementiacare.com/reinvesting-in-life-is-the-best-prescription/>

<https://journalofdementiacare.com/human-rights-disability-and-dementia/>



'The only other group of people to be institutionalised, locked up and then segregated from others, are convicted criminals.'

Dementia, disability and discrimination

Lynda Henderson

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Veda Meneghetti

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In March 2019, I testified at the Royal Commission into Aged Care Quality and Safety against a well-known provider's practice of employing untrained people, without any Senior First Aid or other qualifications, to walk into the homes and lives of people living with dementia, thereby taking over a third of people's individual care budget funding for their profit.

The 5 years of our lives that were dictated to by this provider were unspeakably frustrating and disempowering. Veda's diagnosis was incorrect on her file, although they promote their organization as the experts in dementia care in Australia, and there was no care plan developed.

We became known as 'difficult'. The organization was unable to retain their best staff and it became near-impossible to keep a consistent team of careworkers around my partner Veda, who lives with a rare form of Younger Onset Dementia and is losing language, read, written and spoken.

For the past 18 months, since Veda changed providers, we've been blessed with the support of an exemplary, innovative organization, and that has changed our lives.

Veda is not being cheated out of her entitlement to government-funded services, in fact she has saved 20% of her annual funding. I feel supported by a wonderfully flexible team and Veda is happy and healthy.

We were both lucky that Veda was diagnosed quickly. She was formally diagnosed in 2012 at the age of 61 and managed to get a Home Care Package (HCP) at the highest level of support 2 years later.

There are still 120,000 older people waiting on their entitlements in line with their assessed needs, and 16,000 died waiting this past year.

Meanwhile, Veda has been entitled to 63 days a year of 'respite' ('time out' from the usual domestic situation), but that can only be taken in a residential aged care facility. Over the 6 years that she's had a high-level HCP, she has missed out on the equivalent of 1800 hours of 'break time', and so have I.

Veda's worst fear is being locked into a closed dementia unit with very frail people a generation older than her, and there is no alternative. (By the way Veda is a retired singer-songwriter and rock musician).

We have continued to resist the 'dominant narrative', i.e. that the only 'survival' option is booking Veda regularly into an aged care home, so that she 'gets used to it'.

She will not be sedated, locked in, neglected or sexually abused on my watch. At home she lives healthily. She takes power walks, goes out to lunch with her companions (her careworkers), has some adventures and fun, while I'm free to do my own thing for 15 hours a week.

It's not enough: those 63 days a year should be able to be spent 'in home' while I take breaks away, and it wouldn't cost government a cent more.

I hold little hope that this government will clear the backlog of people waiting on a Home Care Package. I have self-referred for my own assessment, to get some subsidized services for me: so far I've waited more than a year to get help even with cleaning, and I'm still waiting.

I've lived with a spinal disability for 25 years: I've been on the Disability Support Pension for the past 14 years.

But Veda and I were both just a bit 'too old' to be eligible for the NDIS when it finally rolled out in our region. Her funding is capped, regardless of her increasing needs, and it has been for the past 6 years.

This inequity, between the Aged Care system and the NDIS, is age-discriminatory. It's people like us, still in our 60s, who have as little chance at enablement ('salutogenesis') as those who have told their terrible stories about neglect in residential aged care to the Royal Commission.

Note: I have read this to Veda and she is happy with it. We practise supported decision-making.

Further resources:

<https://youtu.be/Vco5L6wpWCK>

Even so, rights, if it has no action, is dead: Don't talk – ACT, don't say – DO, don't promise – PROVE!

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Throughout history, human beings have fought and died for their human rights.

Definitively, human rights recognize the inherent value of each person, regardless of background, where we live, what we look like, what we think or what we believe.

These rights are based on principles of dignity, equality and mutual respect, which are shared across cultures, religions and philosophies. They are about being treated fairly, treating others fairly and having the ability to make genuine choices in our daily lives.

Respect for human rights is the cornerstone of strong communities in which everyone can make a contribution and feel included.

As human beings, we seem to have an innate need to have the freedom of choice! Going back to the garden of Eden to the present time. When Adam and Eve questioned the rules and ate from the tree of knowledge of good and evil.

The struggle for human rights is a story of drama and persistent struggle, setbacks, and steady advancement, often against heavy odds.

It feels as if the rights and needs of older people seem to have a low priority in the national and global agenda. This has been highlighted by the abuse of older people in the Aged Care Royal Commission currently underway. Since our primary objective is the support of people living with dementia.

It doesn't take much to acknowledge that the abuse of rights of older people and people living with dementia are on a similar trajectory.

Estes (2003) says that:

'Critical social gerontology that examines power relations and structural inequalities in society that foster current understanding of aging can also be effectively applied to critical analysis of dementia.'

The history of human rights is a pattern of **gaining RIGHTS** and **losing RIGHTS**. This underscores the need for vigilance for **maintaining RIGHTS**.

The atrocities and violations that occurred in WWII led to the need to create a more peaceful world and to the launch of the Universal Declaration of Human Rights (UN, 1948). This initiative was to ensure human rights could be guaranteed for all.

An example of a human rights violation is the apparent age care systematic discrimination of persons on the ground of their age. As in other forms of discriminations, it takes various forms, ranging from stereotypes to mistreatment and abuse.

Sadly, it is often 'structural', i.e. sustained by our society and its institutions in laws, policies, practices or culture.

Such as the practice of restraining people – physically and chemically, stopped and started and minimized by providers but still in use with shaky questionable guidelines.

Such as the NDIS, It's okay if you're under 65 years but when you turn 65 you have a choice. You can continue with NDIS benefits or change to Aged Care. Only people who are unable to count would choose that!

For example, Eileen was under 65 when the NDIS was instituted, but by the time the roll-out happened she was over 65 and no longer eligible. Another serious example of discrimination in funding.

Yet another example can be made by the hype and great excitement that occurred in July of this year. This was when there was a revision of Aged Care Quality Standards. When the standards were drafted, people living with dementia were not considered at all in the Standards.

This abuse of human rights was address when Dementia Australia, along with several dementia advocates, went through the 'Quality Standards' to make them more inclusive of people living with dementia. Was this a convenient oversight since dementia is not exclusively an aged issue since one can develop dementia at a much younger age than 65 years.

We thought it would be eye opening for you to experience the YO-YO that many older people and people living with dementia face regarding the Standards which are supposedly based on human rights for aged care.

Exercise:

1. Choose a partner (preferable someone you don't know).
2. Briefly discuss the list of the eight Aged Care Quality Standards sharing what you think is the most important standards there.
3. Your choice? Now, cross off three standards on your list you think you can live without!
4. No choice! Now, give your list to your partner, and they have to do the same, cross off three standards but without discussing it with each other!
5. Serious violation of 'Rights' Hand your lists to the facilitator. The facilitator will read a few out from the things people are left with – no names are included!
6. What does it mean? Symbolically, this allows us to 'experience' what it might be like to lose out rights in aged care.

Questions following exercise:

1. What was it like surrendering those rights yourself?
2. What was it like to have three rights taken from you without any choice?
3. What is it like seeing the remainder of your rights being torn up?
4. What was it like to have not choice? Hence no rights?
5. What did you personally learn from this experience / exercise?
6. How might your learning help us to better understand the needs for vulnerable people and the abuse of their aged care rights?
7. What was it like not having anyone speak up for you?

You've just had a small taste of what it is like to gain rights and then lose them again. As with all loss there is a great emotional upheaval of mixed emotions ranging from dismay, denial, anger, sadness, bargaining, and acceptance (and sadly in some cases acquiescence or defeat).

Aged discrimination affects or will affect everyone. There is more evidence that aged discrimination is the most common form of discrimination. It does not only concern today's older generation, but every one of us, as we will all one day grow old.

Age discrimination is as harmful as other forms of discrimination. Unfortunately, it is often more acceptable than other forms of discrimination. For example, although it would be considered unacceptable to exclude someone from training based on their sex or race, age limits that impede particularly older people in training are still widespread today. We need to shed a light on the negative effects of age discrimination for society and for the individual

We must change our mindsets about aging. Countering age discrimination requires changing the way we think, feel and act about aging and older persons.

We all have the capacities and potential to contribute to society regardless of age, but often against ageism attitudes that limit opportunities to do so providing services and support for older generations is a right and an investment, not a cost.

'The road to hell is paved with good intentions' (wrongdoings or evil actions are often masked by good intentions; or even good intentions, that when acted upon, may have unintended negative consequences that don't become apparent for years).

In conclusion - 'Actions Speak Louder Than Words' (what we do has a stronger impact on people than what we say... people are more likely to believe what we do rather than what we say...).

In summary:

- It is difficult to avoid the conclusion that our society's Response to Human Rights thus far, specifically to our older population in Aged Care has been inadequate, if not shabby;
- A recurrent theme from people in Aged Care is that they lose their identity and sense of worth – they become invisible and anonymous; and
- It is well past the time for them to be seen and heard with action.

The importance of human rights: An interview with Eileen Taylor and Dubhglas Taylor

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Linda Steele (LS): Why do you think human rights are important for people living with dementia?

Eileen Taylor (ET) and Dubhglas Taylor (DT): Human rights are important for people living with dementia as they must be empowered to claim their rights rather than simply wait for policies, legislation or the provision of services.

As rights-holders, they should be able to exercise their rights in all circumstances. They must be able to enjoy legal capacity on an equal basis with others. Along with the right of recognition everywhere as people before the law and the right to choose the support that he or she may need or require. This needs to be enforced by laws that guarantee free and informed consent to treatment, supported decision-making, and procedures for implementing advance directives

LS: How are people living with dementia discriminated against and stigmatised?

ET & DT: People living with dementia often face discrimination and treatment that contravenes their human rights in three key areas:

- **Ageism.** For example people older than 65 years are often denied access to health services that are available to younger adults with the same condition as in the case of the NDIS;
- **Stigma** (language used to describe folk with dementia) and discrimination often based on the misbelief that a person living with dementia would not know any difference; and
- **Lack of capacity** to challenge and report incidents that occur – again based on lack of knowledge of the law, misconceptions and false beliefs about people living with dementia.

LS: Which human rights do you think are particularly important to recognise, so that people with dementia can stay living in the community?

ET & DT: There is a standard that must be equal for all people that allows people to live with dignity, freedom, equality, justice and peace regardless of race, colour, sex, language, religion, political opinions, property, birth, disability, including a person living with an illness like dementia in their local community. Guaranteed to everyone without distinction or discrimination.

LS: Which human rights are particularly important to recognise once people living with dementia enter residential aged care?

ET & DT: Ideally a person living with dementia in residential care must be ensured the right to be treated with dignity and

respect and to live without exploitation, abuse or neglect, the right to privacy, the right to live in a safe, secure and home-like environment, and to move freely, both within and outside the residential service, without undue restriction, and the right to live without discrimination.

LS: What is your advice to people living with dementia who are interested in being involved in human rights advocacy?

ET & DT: Human rights dementia advocates will need excellent interpersonal skills; and to feel comfortable working with people of varied socioeconomic, political, religious, and racial backgrounds and remain impartial. Other advice is to:

- learn as much as you can about dementia;
- reflect on your motivation for wanting to become an advocate;
- read material from Dementia Australia's web page as well as books and journals;
- have several conversations with other dementia advocates (including people living with dementia);
- complete a dementia MOOC course through the University of Tasmania;
- become an active member of the Dementia Alliance International (DAI) and the Dementia Awareness Advocacy Team (DAAT);
- have a plan for personal self-care and a support safe group / individual you can bounce off.

LS: What can the broader community do to support human rights of people living with dementia?

ET & DT: The broader community can support human rights of people living with dementia by making a choice to support rights in general. This requires a growing awareness of what dementia is and the needs of people living with dementia.

As such, know about, accept and respect, human rights, and trauma of discrimination. They must understand the concept of full inclusion and the right to citizenship. They must facilitate, promote, and provide dementia friendly environments through signage, physical changes, and learning about what it means to be dementia friendly and inclusive. In a dementia-friendly community people living with dementia are understood, respected and supported in such a way that people with dementia can continue to live in the way they want to and in the community they choose.

LS: Thank you Eileen and Dubhglas.

Human rights: Older people with dementia have a voice and a choice

Bethany Brown, Human Rights Watch

@Bethany_L_Brown

Human rights provide a crucial lens through which to view what it means to have dementia. There are other ways to look at dementia. Medical doctors are researching plaques and tangles and administering exams. Caregivers are exhausted without training or support. Policymakers are calculating health and support costs. But through a human rights lens, it's the person with dementia whose voice and choices matter.

Over the past year, I had the honour to partner with some of the powerful advocates who presented at the People Living with Dementia, Human Rights and Residential Aged Care Summit.

I crisscrossed Queensland, New South Wales and Victoria listening to people with dementia and their loved ones describe their experiences with chemical restraints in 35 aged care facilities across those states.

They told me how aged care facilities gave people with dementia drugs to quiet them, forcing them to sleep, rather than assessing and supporting their individual needs.

We documented their experiences, along with testimony from doctors, aged care facility staff, and experts in a Human Rights Watch report: *'Fading Away: How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia'*.

In some cases, people on the drugs had physical harm, like strokes, or painful muscle contractions and loss of functions such as swallowing. In all cases, people with dementia lost precious conscious life to connect with others, enjoy a meal, or listen to a song.

Human rights are for everyone. They are for people at risk of being viewed by others as non-entities. This includes those of us with dementia. Stereotypes and stigmas about people with dementia can make others blind to just how wrong chemical restraint is. Human Rights Watch's report puts the voices of individuals with direct experience of chemical restraint front-and-center.

People with dementia are the protagonists of their own lives. The human rights' solution to the problem of chemical restraint is partly about choice and informed consent. People with dementia are entitled to support to make decisions if they need it, and their informed consent should be required for any medical treatment. Their decisions about advance directives and their choices of those holding powers of attorney should be respected.

The United Nations Committee for the Disability Rights Convention has determined that treating an adult with medications without consent is a violation of the right to equal recognition before the law, the right to personal integrity, and the right to freedom from violent exploitation and abuse, as well as the right to freedom from torture and inhuman and degrading treatment.

Trained, supportive staff should give personal assistance, not drugs.

Ray Ekins, 78, has dementia and lives in New South Wales in an aged care facility. A previous facility gave him drugs to control his behavior, with side effects that made him depressed, unable to walk, and unable to swallow.

These symptoms were ignored by his aged care facility's staff until his daughter Susan stepped in and moved him to another facility. He now spends his days with daily visits from his daughter, doing crosswords, and chatting with other residents. Staff at the facility understand him and treat him as an individual.

Ray's story is a powerful illustration: with support, people with dementia can lead their own lives. Not everyone is so fortunate to have a daughter like Susan, and to have the option to move to a different facility.

The Australian government should revise its aged care restraint regulation to prohibit chemical restraint and require all people with dementia get the support they need, not a pill.

A human rights lens on chemical restraint shows it for what it is: the silencing of a group of people who are so often isolated and stigmatized.

The voices of people with dementia matter, and the world needs to hear them.

Further Reading:

Bethany Brown, *Fading Away: How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia* (2019, Human Rights Watch, New York) <https://www.hrw.org/report/2019/10/15/fading-away/how-aged-care-facilities-australia-chemically-restrain-older-people>

Older people, human rights, advocacy and supported decision making

Sonia Di Mezza, ACT Disability, Aged and Carer Advocacy Service

As we age, the chances that we will become more frail and vulnerable increase as does the probability that we may develop some form of cognitive impairment, such as dementia.

Human rights are universal and inalienable: we should be able to enjoy them by virtue of the fact that we are humans. However, in the case of older people, society can often forget that this is the case, and it becomes problematic and challenging for an older person to enjoy their human rights.

The human right of self-determination relates to our ability to make decisions about how we would like to live our lives. As people age, adult children or paid carers may decide that the older person no longer has the right to decide where they should live, be it at home or in a residential aged care facility; who the older person should socialise with; how they should manage and spend their money; etcetera.

The situation is exacerbated and compounded when the older person has cognitive impairment, such as dementia. Their ability to communicate their wants and needs can become even more comprised, if they struggle to verbalise what they want to say or perhaps suffer from memory decline.

Unfortunately, the consequences of this particular vulnerability may include that the older person with dementia struggles even more to be able to enjoy their fundamental human rights and live lives of dignity. By denying older people their human rights, the risk of exposure to elder abuse likewise increases.

Just because a person may struggle with communicating their needs doesn't mean that they have no right to make decisions about their own lives. But how can we support the older person faced with such a dilemma if someone struggles to articulate their wishes?

One way is via advocacy. Advocacy is the process of providing a voice for a person who may struggle to stand up for themselves and consequently access their human rights. Another way is via implementing a supported decision making (SDM) model.

SDM is a way of recognising that every person counts; and that every person has the right to access decision support, as stated in the United Nations Convention on the Rights of Persons with Disability at Article 12.

SDM places the older person at the heart of every decision, and supports them to access information, identify networks and supports, so that they can clearly work out what they would like to happen in their own lives and have those decisions become reality.

It is imperative that we, as a society, learn to stop devaluing older people, denying their human rights, including their right to stay at the centre of all decisions relating to their own lives.

Australia's population is ageing, and the reality is that we are all living longer as a consequence of improvements to medical technology. Thus, if we continue in the current vein of devaluing older people, it is highly likely that this is the future that will await all of us as we become older people ourselves.

Legal advocacy and human rights of people living with dementia: An interview with Karen Williams

Karen Williams, Aged and Disability Advocacy Australia

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Linda Steele (LS): From a legal advocacy perspective, in what ways are human rights useful tools for improving the social and political status and wellbeing of people living with dementia in residential aged care?

Karen Williams (KW): Human rights framework is a useful reference for people receiving dementia care in residential aged care. Somehow, there has been an automatic dehumanising process that upon entry to aged care, legal and human rights are forgotten.

It occurs to such an extent that people in that situation wonder what they can legitimately expect. For example:

- Can I expect to have a private phone call?
- Can I expect to have a visitor of my choosing?
- Can I expect to go out and have an appointment with a professional of my choice?
- Can I expect to leave the facility and visit friends of my choosing?
- Can I expect to receive a copy of my accounts?
- Can I see a copy of my own Enduring Power of Attorney document?

LS: In what ways is the enjoyment of legal rights by people living with dementia dependent on recognition of their human rights?

KW: Utilising a human rights framework puts residents on a balanced footing so that they can legitimately expect positive answers to these commonly asked questions that cause people so much angst when answered in the negative (which is often the case). Use of the human rights framework removes the ecological discrimination that occurs just because someone is in a facility, and

no longer seen as a member of a local community or citizen of the country.

LS: From a legal advocacy perspective and mindful of legal frameworks of substituted decision making and property ownership, how can family dynamics contribute to human rights abuses and what should be the roles and responsibilities of family members in realising the rights of people living with dementia, including in relation to the decisions made around entry into aged care facilities?

KW: Often, when family members become decision makers, they become confused in carrying out a dual role of decision maker versus a supporter for decisions to be made. When in the decision making role, family members need to know more about the United Nations Convention on the Rights of Persons with Disabilities and human rights framework, which is essentially an inclusive and not exclusive style of decision making.

LS: How can the legal profession better support the human rights of people living with dementia in residential aged care?

KW: If people cannot access basic information, such as:

- Do I have a decision maker and who is it?
- Can I have a private phone call?
- Can I see a doctor or lawyer of my choice?
- Can I leave this facility for an appointment?

Then Legal Rights are not useful as there is little opportunity to exercise these rights without these practical rights to have some level of privacy about some level of decision making.

Legal Rights would only be useful if your decision maker is 100% backing your views and wishes (as they should but rarely in practice).

Pathway to residential aged care is opaque and fraught with conflicted interests, that include family dynamics, patterns of behaving that are not upholding the rights of the older person.

Most residential aged care facility admissions occur through State or Territory based hospital system, whereby treating teams:

- listen to the views of most others and not the older person;
- are quick to notice deficits and seek an appointment of a guardian/financial decision maker, unless there is an attorney/enduring guardian whose views are aligned to the hospital, irrespective whether the person could go home with supports; and
- don't factor in co-morbidities (infections on top of dementia diagnosis), whereby people may recover their level of functioning.

The sale of property (usually the person's home) often means that the person is stuck in aged care even if they experience improvements in their health and functioning.

Role of lawyers, who act on the instructions of their clients, who have capacity for those particular instructions, is a great tool for having rights respected.

However, multiple barriers, as outlined above for people to access a lawyer, alongside health professionals giving unhelpful blanket/global capacity assessments – 'no capacity'.

Lawyers are well placed in highlighting issues that preclude clients being able to access their services.

For example, Queensland Mental Health Act 2016 funding was made available for certain matters before the Tribunal, such as ECT, so that people had legal advice and representation for their views and wishes in relation this treatment.

Lawyers are released from their role in relation to capacity as they are able to make submissions in relation to the views and wishes and/or best interests of their clients.

Lawyers have had minimal roles with older people in the health or aged care system. Health justice partnership models, combined with social workers, would be very useful to have rights respected.

LS: What can the disability advocacy sector do to support the human rights of people living with dementia in residential aged care?

KS: Disability advocates are well placed in understanding the power dynamics and tenaciously pushing for a human rights response, e.g. meetings with facilities, applying for Tribunal Orders against a rogue attorney, etc. Where issues can be resolved through advocacy, this then leaves lawyers to work on issues only able to be resolved within the legal framework.

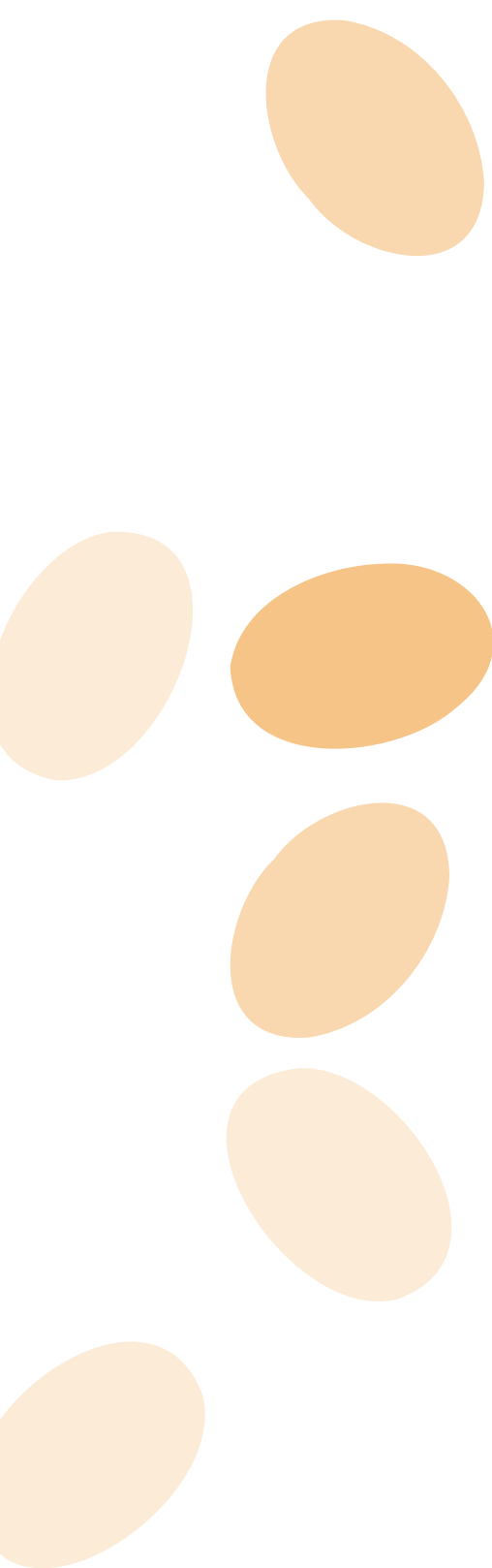
There needs to be a greater focus that people are people, irrespective of diagnosis, geography etc. Strong imaginative inclusion campaigns to remove the stigma!!!

LS: Thank you, Karen.

Human rights of Care Leavers living with dementia: An interview with Leonie Sheedy

Leonie Sheedy, Care Leavers Australasia Network

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Leonie Sheedy: As children, Australian Care Leavers were denied their human rights, leaving a lifelong legacy of trauma, pain, and suffering. It must be the highest responsibility of aged care providers and staff to treat adult Care Leavers with dignity and to respect their human rights in their adulthood.

Linda Steele: Child welfare and aged care systems might be thought by some to operate at either end of the lifecourse and thus be unrelated to each other. But, for care leavers this is often not the case. Can you please elaborate on the connections and similarities between these two systems and their institutions?

Leonie Sheedy: Every childhood lasts a lifetime if it was an extended experience of abuse and neglect which led to an adulthood of trauma. Childhood is an age of vulnerability and dependence. Old age is similar in many respects. This is no excuse to treat old people as if they are children again. Do not patronise them or speak down to them.

If an orphanage has become an aged care facility (even using the same name as when it was a children's home) many Care Leavers will be deeply distressed and may re-experience past trauma.

Institutional life is a life where bells and routine timetables control every aspect of every day, and no one wants to experience that again.

The connections and similarities between child welfare and the age care systems is that they are one and the same. The people running the age care industry today are the same people who ran the orphanages, children's homes, missions and foster care. The same churches, charities, the past providers of child welfare. They even call their nursing homes the same names as some of their orphanages. This can be highly traumatic for Care Leavers.

Most Care Leavers will be happiest in their own homes. We should provide as much support as we can to make that feasible.

Linda Steele: What are some of the common lifelong experiences and trajectories of Care Leavers through to aged care, and how might these impact on their experiences entering and being in aged care?

Leonie Sheedy: Poverty. Never being able to have any luxuries or personal indulgences because the budget won't cope.

Care Leavers are frequently unable to trust authorities. They are used to feeling and being abandoned, and never having a proper explanation as to why. No letters or family outings. Visitors must be strongly encouraged. They may have been subjected to being given drugs without ever being told what they were for.

Be alert to the fact that some Care Leavers didn't get an education. Some hide their literacy problems and don't want the stigma of illiteracy foisted on them.

Care Leavers feel vulnerable losing their independence and going into institutional life. It will remind them of what happened to them as a child.

Linda Steele: What the particular concerns and fears of care leavers entering aged care, and what kinds of experiences might they have once they arrive?

Leonie Sheedy: Care Leavers fear that they will be abused and or bullied by staff and peers as they were when they were children. That they will lose their prized personal possessions - staff took them off them because they didn't like individuality. Let them have their own CDs or DVDs and let them keep them where they want and use them when

they want. Terrible food is a common experience, and Care Leavers may have experienced being force-fed food they don't like. They need variety and some individual choice.

Avoid religious symbols, such as crosses on the walls, as these might trigger many who were abused in Christian homes.

Care Leavers may experience fears of being punished for making a mess, wetting the bed, spilling or breaking things. In the past they have experienced punishments that were brutal and swift.

They fear being locked into rooms or areas of the facility.

Time tables that are rigid and non-negotiable are a common experience. Allow people to eat and go to bed when they are ready!

Care Leavers may experience depression at Christmas time, birthdays, Mother's or Father's Day, and they may not have any visitors due to being disconnected to their children, or some having never married or had children, due to never learning to trust another human being.

Linda Steele: Are residential aged care facilities ever capable of realising the wellbeing and human rights of care leavers? What needs to change to residential aged care make this possible?

Leonie Sheedy: Respect for the rights of Care Leavers needs to be paramount in aged care. They need more personal and individualised care. Choice is important. Not everyone has the same likes and dislikes regarding food, clothing, and other aspects of their care.

Appoint independent people to listen to complaints, take them seriously, and advocate on their behalf. Being treated with dignity and respect is so important to Care Leavers

Let them have a say in the things that affect them. Care Leavers don't want to

lose all control over their lives again.

Empathy and respect don't cost a lot.

Linda Steele: What should the aged care sector do to improve the human rights of care leavers living with dementia?

Leonie Sheedy: Respect. All people, regardless of whether or not they live with dementia, deserve respect.

Allow them to have photographs, music, movies, and their own clothes. Find out what that person liked as a child and use the good moments to best advantage.

Aged care providers must remember that Care Leavers living with dementia still have emotions and want to enjoy life. Music, personal memorabilia, and other comforts may put them back in touch with those moments of their lives they have enjoyed.

Linda Steele: Taking a more longitudinal approach to addressing human rights of care leavers living with dementia, what should governments and the community sector do to support Care Leavers within the community prior to the onset of dementia and/or entry into residential aged care?

Leonie Sheedy: Realistic preparation is vital. Care Leavers must be given the best possible information at a time they can absorb it.

Make sure family and friends know about their situation, and give advice about visiting.

Be prepared for setbacks, because smells, food, and sights can trigger emotions from long ago. The number one priority is they need to be aware of what happened to children in orphanages, children's homes, missions and foster care. They had no human rights as children.

Connect Care Leavers and their families to Care Leavers Australasia Network so we can be a support and an advocate for those in aged care:

Telephone: 1800 008 774

Visit: <http://clan.org.au>

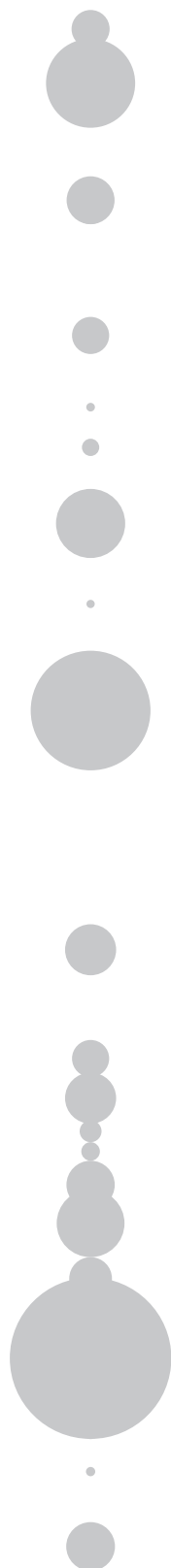
Human Rights for everyone.



Human rights of women living with dementia: an interview with Yumi Lee

Yumi Lee, Older Women's Network, New South Wales

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Linda Steele (LS): In what ways is residential aged care a gendered issue?

Yumi Lee (YL): This is an important question to pose because we still do not acknowledge that residential aged care is gendered. It is gendered on all levels, from the residents to the staffing and the management of these facilities.

Nearly 70% of people living in residential aged care facilities (RACF) are women, largely in part reflecting the fact that women live longer than men.

As you know, the Aged Care Royal Commission (ACRC) has highlighted the many problems in RACF and if our members are any guide, people do not go into these facilities by choice. 50% of those in RACF have dementia, and 90% have a disability. We're looking at a very vulnerable cohort. Do we recognise this in terms of having adequate staffing both in number as well as qualifications? The stories we have heard clearly indicate that this is not the case.

We also have to note that women make up over 80% of the residential care workforce. Unsurprisingly, the workers take home very low wages, reflecting society's undervaluing of caring work which is predominantly carried out by women. We have heard directly from the workers in these facilities who say that they have unreasonable workloads caused by understaffing.

If we are to look at the management of these facilities, I do not know what the latest figures are, but when I last checked, only about 40% of the CEOs are women, compared to 90% female workforce. It's just not good enough.

LS: What factors might shape the circumstances leading to women living with dementia entering residential aged care?

YL: There are so many factors which lead women living with dementia to enter residential aged care. For some of these women who have male partners, it could be because their partners are not able to take on the caring role. These are men who have spent their formative years at a particular time in Australia's history where gender roles were more rigid and they did not have the opportunity to take on caring responsibilities. It could also be because the men are themselves in need of care.

We have also seen women with dementia in RACF because there is no one to care for them at home. The expenses related to maintaining a family and a home are so significant that it is challenging for adult children to give up their paid employment to care for their parents.

We also do not value carers. If carers are compensated adequately for their work, we know of many adult children who would be prepared to care for their parents. Let us not forget that it is not only a sacrifice in terms of immediate wages, but also of superannuation when women take time out of the workforce to be a carer.

LS: Is intersectionality relevant to understanding the experiences of women living with dementia in residential aged care?

YL: There is so much research yet to be undertaken to understand how dementia affects us as individuals. However, if we accept the simple premise that we carry within us all the ages we've ever been, and that we are shaped by our cultures and our beliefs, then we cannot ignore intersectionality in understanding women living with dementia.

Women of colour, women from LGBTQI background, women who have lived with a disability, indigenous women, and women who are a combination of two or more of these categories, are all going to have different experiences of living and ageing. Unless we recognise this, our understanding of how these women experience dementia will be severely limited. And in turn, we will not be able to provide effective responses to manage their dementia.

LS: Why is it important to take a longitudinal and intersectional approach when addressing human rights of women living with dementia in residential aged care?

YL: As advocates for human rights of older women, the Older Women's Network believes that not enough is being done to protect the human rights of women living with dementia in RACF. We have heard, witnessed and understood from the ACRC what impact the sub-standard levels of care is having on the residents. They are being doped, restrained/shackled and neglected. It's inhumane to say the least. When we talk about human rights, we need to address why these abominations are being perpetrated against some of our most vulnerable. There are many layers to this.

On the macro level, we must admit that unless we put in the resources necessary, the abuses will continue. Older Women's Network believes in ratios. If we have ratios for childcare, why aren't there ratios for our vulnerable elderly in RACF? Then we need to have staff who are adequately trained in caring for people with dementia so they understand how intersectionality impacts dementia.

Where Older Women's Network is concerned, we also believe a longitudinal approach in dealing with dementia is critical. What has happened in the past impacts the present, and the present will impact the future.

Take the Forgotten Australians, for instance. Their experience of institutions was horrific and the abuse they suffered in the past as children continues to impact them in the present.

The same can be said for our Aboriginal people who live with intergenerational trauma. We cannot talk about the human rights of people with dementia without also addressing the human rights of these communities.

Longitudinal and intersectional approaches are meaningless without an acknowledgement of these issues, and the financial commitment to restore the dignity of these people.

LS: What should the aged care sector do to improve the human rights of women living with dementia?

YL: Women living with dementia are extremely vulnerable to abuse - not just physical abuse, but also financial and sexual abuse. We know that sexual abuse happens in RACF and abusers are not being called to account because it is too easy to dismiss the accusations of a woman with dementia as the rantings of an individual who has lost her mind.

We want to focus on this issue for now because we know that there has been an increase in the reported cases of sexual abuse in RACF and we also know that the real number is much higher. We need a national strategy and resources, policy, guidelines and training to build the capacity of aged care service providers to better respond to and prevent sexual abuse/assault.

We're working with Dr Catherine Barrett on this issue and we believe that so much more can be done to protect the human rights of these older women. And to date, despite Dr Barrett's submission to the ACRC, she has not been called to give evidence before the commission.

What does this signal to us?

There is also the issue of the human rights of women with dementia of LGBTQI background. We know that some facilities are not welcoming of them, and this makes it exceptionally difficult for their partners. They cannot have their freedom of expression in such facilities. We also have grave fears of how the proposed Religious Discrimination Bill will play out in such situations, not only for residents, but also for staff.

LS: Taking a more longitudinal approach to addressing human rights of women living with dementia, what should governments and the community sector do to support women within the community prior to the onset of dementia and/or entry into residential aged care?

YL: It is so critical to acknowledge that a patriarchal society perpetuates systemic disadvantage against women. This can be seen amongst others in the gender pay gap, the fact that women retire with less in superannuation, the killing of at least 1 woman per week from domestic violence and the small percentage of women in decision making positions, including in parliament.

What does this mean? It means that the new face of homelessness in Australia is that of an older woman. It means that 1 in 3 women are retiring into poverty. We know that stress and trauma increases the risk of dementia. We also know that poverty and violence increase stress and trauma. We therefore continue to pay the price for inadequate action to deal with these issues well into our advancing years.

Practically, it means that we must raise the level of Newstart because it is forcing people to live in poverty. We know that there is a growing number of women between the ages of 55 and 64 who are on Newstart, thereby creating a growing cohort of women who are continually stressed because they cannot make ends meet.

We also need to adopt the 'Housing First' policy and build more social housing so we can reduce homelessness. Australia is not a third world country, but we are forcing a growing number of older women into third world conditions.

We urge researchers and policy makers to also consider these issues when framing their responses to dementia.

LS: Thank you, Yumi.

Older people with vulnerabilities: The right to live safely with support in the community

Kate Kennedy, Social Worker Elder Abuse Program,
Seniors Rights Service
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Seniors Rights Service aims to build awareness of the needs and rights of older people to counteract societal attitudes such as ageism that further disadvantage older people. The organisation prioritises the rights of the older person and their voice over others who may want to speak for them.

Our services include:

- free and confidential telephone advice;
- aged care advocacy and social support;
- legal advice; and
- rights-based education forums to seniors across New South Wales.

As the social worker in the organisation, my role is to work with older people who are at risk of, or are experiencing abuse. The social work program is underpinned by a trauma informed, anti-oppressive practice framework. This relational approach can greatly assist all clients, including those who are living with a cognitive disability such as dementia, to feel acknowledged and safe. It is a good starting point when working with vulnerable clients who report abuse, usually by a family member, as they may have complex histories and experiences that further put them at risk.

Elder abuse is an increasing defined by the World Health Organisation (WHO) as:


'Any act that can cause harm to an older person and is carried out by someone they know and trust, such as a family member or friend. Elder abuse can take various forms such as financial, physical, psychological and sexual'.

Based on available evidence the prevalence of elder abuse affects 16.7% of older people over 60. It is however widely acknowledged that elder abuse is under reported and that prevalence rates are likely to be underestimates (WHO 2017).

Seniors Rights Service works collaboratively with key community and legal organisations on a number of projects aimed at mitigating older people's risk of elder abuse. One such project is in one Sydney's public housing developments. Overseen by the Department of Communities and Justice and supported by a number of well-recognised community organisations, the aim of the project is to offer direct services to vulnerable community members, in their neighbourhood.

Seniors Rights Service has been delivering a legal and social work outreach clinic every two weeks for over a year now. Our clinic is free and accessible for all community members who identify as housing tenants in the area. The model of a combined solicitor/ social work practice at the clinic puts vulnerable clients needs and wishes at the centre of the service.

Many resilient, independent older people live in this community and have visited the clinic since its inception. A booked appointment at the regular clinic very close to their home has helped clients to build a sense of trust and safety. The use of interpreters as required allows clients to tell their story in their own time and language.



Most identify significant challenges in their day-to-day life, including the daily risks of negotiating life in a large, old, sometimes unsafe public housing complex. These risks may include living next door to a violent neighbour, or negotiating four flights of stairs to their unit, whilst dealing with mobility issues, a walker and shopping.

Many in this community have experienced cumulative disadvantage throughout their life. Most have few social or family supports. English is often not their first language. Some have escaped a violent relationship at a time when little support was available. Others are living with a disability or a mental illness and have had experiences and histories that have resulted in ongoing trauma and a subsequent mistrust of any government or medical intervention or engagement.

Some may be living alone or may have an adult children still living with them. Sometimes this can result in the older person having a caring role, whilst needing care themselves. Elder abuse by family members can be an issue for older people, who may be living in fear or being financially exploited by a family member.

Accessing the legal and social work outreach clinic can greatly assist the older person to identify what is happening, learn about their rights and the options are available to them. The social worker can work with them to identify referrals or information about services that may assist them and this may include government funded home care.


We know that having community services and home care packages (for example, meals on wheels, domestic assistance and social support) can be a protective factor for older people and can assist them to stay independent and in their own home for longer.

However, many trauma survivors are hesitant to seek home help, as they confuse 'homecare' with being placed in aged care. In addition, there is a considerable wait for community care services especially in the inner city where demand is very high. This wait alongside a lack of family support to step in, can force people into aged care despite their wish to remain home.

Living in un-safe accommodation is a daily issue for many older people living in the public housing. Many are waiting years for a transfer to more appropriate housing. This lack of safe housing, coupled with few informal supports, also puts this cohort at greater risk of being forced into aged care against their wishes.

We know that vulnerable older people are much more likely to have had cumulative past experiences, such as abuse in institutions or homes that have resulted in longstanding trauma and mental illness. For these trauma survivors, entry into aged care can result in re-traumatisation and risk.

It is hoped that recommendations from the Royal Commission into Aged Care will include the provision of more flexible models of community based care that take a trauma-informed approach. One that allows older people, particularly those with complex histories and vulnerabilities, to live safely with support in their community for as long as they wish.



Dementia as a form of necropolitics

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Introduction

In this very short piece we offer a small provocation that has potential in the dementia care space, but which has roots in the patient safety arena, areas in which both authors have some experience. Our purpose in doing so is to point out that many types of harms in the wider social policy arena (health, justice, education, aged care, disability etc.) continue to be replicated over time and space, having a documentable history several centuries old. Thus, when you hear people describe their individual suffering and abuse at the hands of publicly funded services (although now often provided by non-governmental organisations), they are both tragically distinct and personal on the one hand, and surprisingly familiar and commonplace on the other.

Our premise accepts the axiom most often attributed to William Deming that 'every system is perfectly designed to get the results it gets', rather than the 'one bad apple' excuse proffered at each new instance of systemic abuse.

The results of inquiries in health and social care over several centuries, for example, are good evidence that the harm done to patients, and in particular specific patient groups (most consistently the elderly and people with disabilities, but also often women and children) are not aberrations but the inevitable consequences of systems and services that do not take accountability for the forms of violence that they perpetrate against vulnerable people.

In other words, they do harm because, for various reasons, they are designed to produce those harms.

Necropolitics defined

Given this perhaps unusual perspective, we suggest that one of the reasons such harms continue to occur in the environments they do is because we lack a necropolitical understanding of the way the modern state, its functionaries and 'services' actually operate.

The concept of necropolitics can be attributed to the Cameroonian intellectual and theorist Achille Mbembe (2003). His view, more broadly conceived than Foucault's 'right to kill' suggests that the state takes on that power with its '...capacity to dictate who may live and who must die'.

We suggest that in the context of public policy arenas such as health and dementia care that this 'capacity' can be seen in a slightly extended form to include not only who must die, but how they may die (e.g. withholding of food and drink, use of opioids, not-for-resuscitation orders and so on).

It also modifies the concept of 'who may live' to consider under what conditions they are permitted to live (e.g. physical and chemical restraints). In other words from a more strictly political theory perspective (sovereignty theory) we can see explicit examples of necropolitical practices in our everyday lives, played out through our institutions and how they treat various, often highly vulnerable, groups of people in our communities.

Thus, while we focus here on the concept of dementia and people who are diagnosed as having a 'dementia', the basic idea of permitted living and state-sanctioned dying, is clearly evidenced across many areas of society.

We need only consider issues such as deaths in custody or gross health inequalities/inequities as possessing a necropolitical dimension that, for the most, part goes largely unremarked. This fits well with a human rights critique but may not align well with the more commonly held 'enlightenment' view of human rights as a progressive developmental process by which previously stigmatised groups (eventually) acquire justice, representation and inclusion.

Dementia

To be clear, dementia is not a clinical disease state but a syndrome. As a syndrome, it is a category that can include a wide range of symptoms that often but do not always progress to a neurodegenerative state.

This is important to consider because medicine tends to impose categories of pathology on patients that have their own power and inevitable interventional consequences. Once you are defined as ill, you are increasingly enmeshed in the medical system's approach to health and illness. If you lose 'capacity' this situation can become more fraught because you will be the focus of several systems of power and potential intervention.

We suggest here that organisations that promote 'dementia' (or indeed population ageing more generally) as a crisis, while not promoting the humanity of those with a syndrome, are part of a necropolitical politics and not a solution to the problems experienced by the individual or the category of persons defined as 'dementing'.

Instead, what we are seeing is a continuation of past systems of social authority and regulation dressed up in the latest scientific knowledge.

Mild cognitive impairment (MCI) can also be seen in these terms, because the common understanding of MCI is of a long and deterministic precursor phase anticipating, even predicting, an inevitable neurodegenerative future of pathology and death. Loss of 'memory' and prior identity feature heavily in the horror stories in these spaces.

Deterministic thinking in healthcare

This sense of inevitable decline and deterministic thinking is common across the health sciences, if somewhat mediated in geriatric thinking.

Caution is required here because not all symptoms progress inevitably to a disease state and not all people with a dementia exhibit specific pathologies.

Deterministic thinking relies excessively on general categories and can elide the highly individual experience that people with a diagnosed dementia (such as Alzheimer's Disease, frontotemporal dementia, vascular dementia and dementia with Lewy bodies etc.), and their carers, may experience. This means that individual situations can be overly generalised and individual cases lost in the nature of the systems we already have in place.

Conclusion

Dementia is still framed as a deficit scenario with an often idealised 'normal' as the measure of a person and their humanity. Treatment aims to fix the person (fixing symptoms is the main option at present) not the system in which they find themselves, and those unable to be 'fixed' can experience highly variable care.

Innovation in the dementia care space necessarily requires a focus not only on the enduring rights of individuals with a dementia but an expansion of what it means to be human. To see dementia only through a quasi-medical lens of pathology, treatment and possible cure can only continue to diminish the lived experience of such people. To sit in judgement on the quality of those lives, including who may live and who must die, is a continuing form of necropolitics.

The need to strengthen the monitoring of residential aged care facilities in Australia using a human rights-based approach

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Recent inquiries indicate that residents of locked units in residential aged care facilities are at a high risk of torture or cruel, inhuman or degrading treatment. The limited mobility of many residents in these facilities combined with the high usage of restrictive practices (sometimes unlawfully) means that many residents are effectively detained (irrespective of whether they are in a locked unit) and at high risk of torture or cruel, inhuman or degrading treatment. Despite this, our current systems of monitoring residential aged care facilities are based on safety and quality of care approaches and hence are not equipped to address the human rights aspects of how residents are treated.

Australian parliaments and courts have recognised that aged care facilities with closed units can be places of (civil) detention where patients/consumers are deprived of their liberty. For example, a 2016 Senate Community Affairs References Committee report, *Indefinite Detention in Australia of People with Cognitive and Psychiatric Impairment* confirms that detention is taking place in aged care. Based on evidence presented to it, the Senate Committee concluded that:

'indefinite detention of people with cognitive or psychiatric impairment is a significant problem within the aged care context [. . .]. It is also clear this detention is often informal, unregulated and unlawful'.

A 2019 South Australian case (*The Public Advocate v C, B*) highlighted that, if a person is ordered to reside in a closed unit where their movement is restricted, they are subject to a form of detention, regardless of whether the restriction is total or partial. This detention must be lawful at all times.

The Court ordered the release of Mr C, a 95-year-old man with dementia of 'at least moderate severity', on the basis that the order for his detention was not made lawfully.

Current monitoring of residential aged care facilities is substandard and inadequate, as evidenced by the multiple federal and state inquiries into South Australia's Oakden Older Persons Mental Health Service and, more recently, Queensland's Earle Haven Retirement Home. In addition, the Royal Commission into Aged Care Quality and Safety has uncovered systematic abuses across Australian jurisdictions.

The 2017 federal independent report on Oakden stated that many of the practices at Oakden raised a 'human rights issue'. The 2017 Report of the South Australian Chief Psychiatrist went further in referring to the possibility that the use of restrictive practices at Oakden constituted torture.

Such high level usage of restrictive practices was also found at Earle Haven in mid 2019, where chemical restraint was being used for 71 per cent of the 69 residents and physical restraint for 50 per cent of the residents. These situations are facilitated by patchy framework of federal/state regulations, a lack of jurisdictional clarity and a culture of non-compliance where there are few, if any, penalties.

The Aged Care Quality and Safety Commission (ACQSC), established in 2019 in light of the Oakden inquiries, aims to ensure more stringent monitoring and complaint handling. However, the late 2019 Earle Haven inquiries indicate that the ACQSC is still struggling to perform these roles 'in a coordinated or concerted fashion'.

The monitoring of closed aged care facilities needs urgent strengthening via the use of rigorous, international human rights-based standards. The ACQSC does not use such standards in its monitoring or complaints handling roles.

The providers of residential aged care are focussed on meeting their legal duty of care (risk management) and hence insufficient attention is paid to ensuring residents can realise their human rights.

In Australia's existing legal framework, residents living with dementia are not generally understood as capable of enjoying or exercising agency and their rights to full participation (for example, the right to movement) are treated as a secondary consideration.

The urgency to improve the system of monitoring for this form of civil detention coincides with Australia's 2017 ratification of the Optional Protocol to the Convention Against Torture (OPCAT). Australia's commitment to OPCAT ushers in the establishment of National Preventive Mechanisms (NPMs) at the federal and state levels to strengthen monitoring of all places of detention in Australia. These mechanisms will use monitoring principles drawing on international human rights standards.

The Federal Government has stated that Australia's NPMs will initially focus on 'primary' places of detention. It has indicated that this initial monitoring will not extend to residential aged care facilities. While closed aged care facilities are less traditional places of detention, Oakden and Earle Haven indicate that the Federal Government should not delay strengthening its system of monitoring for these closed facilities where residents are detained, sometimes unlawfully.

Both the Australian Human Rights Commission and the Commonwealth Ombudsman (the nominated coordinating federal NPM) have called for residential aged care facilities to be included in NPM monitoring.

New Zealand's NPM (the Chief Ombudsman) has recently begun monitoring locked residential aged care facilities (both privately-run and public) as part of NZ's OPCAT obligations. This is in addition to its current monitoring of locked dementia facilities and psychogeriatric wards whereby it assesses 'the conditions and treatment of detained people to determine if there are any risks, poor practices, or systemic problems in the facility that could result in a human rights violation'.

At the global level, New Zealand is not alone in conducting this monitoring based on human rights standards. Australia needs to draw on New Zealand's approach and thereby show that it fully understands the systemic problems being uncovered by the Aged Care Royal Commission.

NPM monitoring of residential aged care facilities in Australia would be preventive in its focus – not simply a regulatory, compliance or reactive approach. It would likely lead to the drafting and implementation of stronger (human-rights-based) national principles and the ongoing expert monitoring of compliance with these principles.

This would benefit those made vulnerable in civil detention by removing risk factors and reinforcing protective safeguards. It could also help to ensure that all instances of civil detention in the aged care context are formally recorded.

The Public Advocate case may represent the tip of the iceberg, in that there may be hundreds of people like Mr C being unlawfully detained in closed aged care facilities. Monitoring should cover not only those held under guardianship and mental health laws but also those informally detained in closed units.

Further reading:

Australia OPCAT Network, The Implementation of OPCAT in Australia: Submission to the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (SPT) and the United Nations Working Group On Arbitrary Detention (WGAD) (January 2020) https://www.kaldorcentre.unsw.edu.au/sites/default/files/Implementation_of_OPCAT_in_Australia.pdf

Laura Grenfell, 'Aged Care, Detention and OPCAT', (2019) 25(2) *Australian Journal of Human Rights* 248, doi:10.1080/1323238X.2019.1642998 <https://www.tandfonline.com/doi/abs/10.1080/1323238X.2019.1642998>

Why human rights are important for people living with dementia and what we can do to achieve recognition of these rights

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People living with dementia have the human right to participate in all decisions which affect their lives and wellbeing. This approach should be embedded in practice as a foundational component of care to anyone receiving aged care, regardless of a dementia diagnosis.

One of the biggest barriers to a human rights approach to dementia is that dementia is not yet core business for the aged care sector. Another barrier is that dementia is still poorly understood or stigmatised by the community, and by many people working in the aged care sector. There is an obligation for all levels of government, the aged care sector and its workforce to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else.

The Royal Commission into Aged Care Quality and Safety has highlighted the poor outcomes experienced by many individuals receiving aged care, especially vulnerable Australians. The Interim Report makes it clear that fundamental and systemic change is required. The old system has to transform, and by extension this presents an opportunity to transform aged care to better meet the needs of people living with dementia, their families and carers, as well as ensuring their human rights are recognised and respected.

'If you can get it right for dementia, you can get it right for everyone else.'
Person living with dementia.

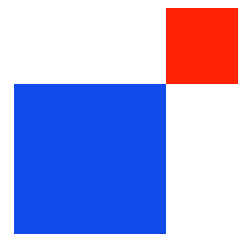
It isn't simply about the sector needing significantly more funding. It's about:

- allowing for inclusion, participation and decision making;
 - training and building the capacity of the aged care workforce to understand dementia and acquire the necessary skills, knowledge and capacity to deliver high quality dementia care;
 - involving carers, families and advocates as partners in care and supporting them with decision making and care planning;
 - eliminating the over prescription of medication and excessive use of physical and chemical restraints;
 - creating and delivering meaningful activities for people living with dementia to engage with or participate in;
 - building supportive environments that are dementia-friendly and create a sense of homeliness and familiarity;
 - having feedback and complaints systems that take people living with dementia seriously and facilitate their involvement;
 - having the right skills mix amongst staff to meet the needs of the person living with dementia; and
 - building an organisational culture that encourages an understanding of dementia and can respond effectively to the staff requirements that help meet the needs of the person living with dementia.
- innovation – thinking outside the box to allow for dignity of risk;

Visit:

<https://www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf>

'If you can get it right for dementia, you can get it right for everyone else.'



Through transparency, accountability, greater collaboration and awareness raising activities, these things can be achieved through existing structures, frameworks and policies.

This isn't just the perspective of Dementia Australia as an organisation, it's informed by the expert knowledge shared by members of 31 focus groups, comprising 137 people with a lived experience of dementia, and their insights about improving the quality of dementia care through the Aged Care Quality Standards. We asked them:

- What does quality dementia look like? Feel like?
- What are the key points of difference between quality dementia care and aged care more generally?

The culmination of this work was a Consumer Summit to discuss consultation findings and ratify a communique – *Our Solution: Quality Care for people living with dementia*.

The result was an unequivocal vision of holistic and person-centred care that is underpinned by strong leadership and a positive culture within and across the sector. And although the principles are framed within the context of the Aged Care Quality Standards, they speak to the need for sector-wide transformation using a human rights approach – the seeds for which have, in part, been planted by other capacity-building work, including the strategic vision outlined in the *Matter of Care Report* compiled by the Aged Care Workforce Taskforce in 2018, key work by the Aged Care Quality and Safety Commission, and by individual providers.

'There must be the five R's: Right People, Right Training, Right Place, Right Time and Right Pay.' Former care.

What became clear through consultations with people impacted by dementia was that there are two fundamental issues that need to be present to achieve quality dementia care and recognise human rights:

- A clear understanding of the clinical aspects of dementia and the disease trajectory; and
- A holistic and person-centred approach, including high-quality communication, with every individual.

'It is having the time to spend with people. Getting to know who they are, their likes and dislikes. That's what matters.' Carer

The concept of person-centred care has been around for many years, but it is clear from what people with a lived experience of dementia tell us that the mechanisms to achieve this – leadership, culture, regulation and workforce development – are still falling short and need to encompass some key domains:

- **cognitive health** – including a formal understanding of the clinical components of the disease and how it impacts care needs;
- **clinical health** – including flexible approaches to the delivery of – and recalibration of – care, especially as it relates to the use of medication;
- **functional health** – including ongoing assessment and care planning that involves families, carers and advocates;
- **cultural needs** – including understanding and recognising the diversity of dementia as it impacts individuals, their families, carers and advocates; and

- **living well aspirations** – including ensuring the participation of individuals in meaningful activities that improve their quality of life. Visit: Australia's Aged Care Workforce Strategy

<https://www.health.gov.au/resources/publications/a-matter-of-care-australias-aged-care-workforce-strategy>

The time for talking is over. It is time to leverage what already exists to deliver better quality care to people living with dementia, their families and carers.

It is time to recognise and promote the human rights of people living with dementia through innovation and cultural change.

It now requires governments, the aged care sector and workforce to step up to the challenge and change culture, behaviour and build capacity across the aged care sector. The tools are already there, now it is a matter of putting them into practice.

'It is having the time to spend with people. Getting to know who they are, their likes and dislikes. That's what matters.'

A human rights-based approach for people living with dementia: Aged Care Standards

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We all know that everyone, all people, are entitled to human rights but we also know that our world does discriminate in some shape or form against people living with dementia. This may be in a way that dignity is impacted, access is denied or society disempowers a person to exercise their right.

With the number of people living with dementia increasing there is a great need for education and understanding in society. The greater knowledge people have of dementia the more improved responses they will have to supporting a person living with dementia.

The stories that have unfolded through the investigations in the Royal Commission have raised the negative and challenging images of living with dementia perpetuating the stigma associated with dementia.

There is far greater benefit to provide education and information about the realistic image of dementia and the continued positive contributions that each person living with dementia provides to our society. This was the intent in the development of Standard 1 of the Aged Care Standards and the treatment of each consumer with dignity and maintaining identity.

There are times where carers experience burden when society discriminates against the person with dementia such as in a shopping mall. An attempt to find a quiet space to sit and be calm for a moment is almost near impossible in modern shopping malls, making the experience difficult for the carer and overwhelming for the person living with dementia.

The assistance of others too often results in the loss of dignity where attempts are made to 'move on' what they perceive is a disruption that is impacting others. This response perpetuates the society generated

'stigma' associated with dementia. The carer with a sense of guilt is no longer willing to go out and social isolation begins.

Let's educate urban designers and award building design for environments that support community participation and contribution of people living with dementia. Community designers should be encouraged to build shared spaces where carers and people living with dementia can participate together with the full community and learn from each other – that prevents social isolation. Provide safe environments where engagement can reduce the burden on carers and provide respite that protects the dignity of everyone involved.

Transitioning to an aged care environment, despite the introduction of new Aged Care Standards, there is minimal inclusion of human rights protections. People living with dementia may find themselves being placed in 'secure units' or living in the aged care community where other people will continue to discriminate by saying another person is disturbing them because of dementia related behaviours.

Staff, through lack of knowledge and understanding, are often observed to respond in a way that removes the rights of the person living with dementia.

Residential aged care brings together groups of people who may not have actively made a decision to live in close proximity with another person who may not share their values. We need to think differently about the solution of residential aged care and areas of locked units that are perceived as protecting the safety of people living with dementia. The residential aged care model is a past society response to caring for our elders and removes rights no matter how much good will is implied or Aged Care Standards are designed.

People living with dementia and their care givers are entitled to have their standard of living protected. With limited 'home care' services available at a high level of support, carers are making decisions when they can no longer afford supplementing for care needs or the burden of caring becomes too great to seek alternative care solutions in some form of residential aged care. Improved and smarter funding is required to support people living with dementia to continue to receive care in their own homes that minimises the impact on their standard of living and the burden on care givers.

Organisations, government, state and local and private bodies should be held accountable for the protection of rights of people reliant on care and services.

An outcome of the Royal Commission is an expectation that there are laws to allow people living with dementia to self-advocate at a greater level. Awareness raising is required to remove the perception that a person living with dementia is unable to make decisions.

In all proposed strategies, people living with dementia and their care givers should be empowered as active participants in decisions on policy and services. This will ensure the right of the person living with dementia is given equity of respect and to participate in decisions that affect them.

Critical design for autonomy, wellbeing and community inclusion

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I am an Industrial Designer and Senior Research Fellow at the University of Technology Sydney (UTS). I research the role design plays in supporting our autonomy.

We each interact with our surrounding environments in unique ways, and this uniqueness changes constantly across our life span.

In one stream of my investigations, I have researched the impact of housing accessibility on health-related quality of life and the amount of care needed in the home. I am particularly aware of the role our built environments play as people age, not only in maintaining an autonomous life, but in enabling caregiving to be provided safely and effectively. The design of places we live and receive care has a significant impact on how we live our lives – inclusive of any physical and cognitive changes.

The Interim Report of The Royal Commission into Aged Care Quality and Safety highlights the poor outcomes of people in the aged care system. It also calls for fundamental and systemic change to meet the needs of people living with dementia and their families.

One of the most critical shifts needs to take place is the design of our aged care facilities. Having worked across care/support environments in both the aged care and disability support sectors, I believe that there are a number of design-led shifts that can be made to drive innovations in support provision and improve the quality of life of people who live with dementia, both at home, and in higher care facilities, to live lives and receive care with dignity and autonomy.

Aged care providers will benefit from continuing to expand their thinking about design to include the sensory implications of physical built space, wayfinding, semantics, technology and

communication and critically – how design influences the quality of support provided to those who need it.

As a starting point, any new design of an aged care or specialist dementia facility must happen as part a participatory process – one which integrates those experiencing dementia, their family and carers into the design decision making from the very beginning through to the very end – including post-occupancy evaluation.

We should continue to drive research into alternate models to congregate care, which although available, are by no means a widely available or accessible dementia care environment– what is typically available is a 'Dementia-wing' facility with secured space and locked gardens and nurses quarters watching over.

Innovative ways are developing to approach independent living with support, and opportunities to apply principles of inclusive design that recognise the role of people's lived experience in guiding and informing the design process.

As a design researcher focused on the area of wellbeing and autonomy, I consider the following points critical for the Aged Care sector to consider, in order to improve outcomes for people with dementia and the quality of care and support they and their families, receive:

- considering how the design of built environments influence not only independence and autonomy of a person receiving care and support, but the quality of support that can be provided;
- value and listen to lived experience in all research and design stages;
- consider person-led, flexible support models and environments

that identify and re-balance the powerlessness experienced by those receiving care or support.

- Conduct research that develops our understanding of what helps to maintain and foster community participation. Does living in community necessarily maintain community participation?

I have always found it unsettling, as I have researched community and residential care settings, that once a person is in an aged care facility, they are no longer within the definition of community care. We are always living in community. The design of the places we live in when we receive higher levels of care and support should reflect and support this.

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Towards a restorative model in aged care

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Australia's Royal Commission into Aged Care Quality and Safety has drawn national attention to the systemic neglect and abuse in many of the country's aged 'care' homes.

A key question posed by the Commission has been: what are the best ways to help and care for people living with dementia? The report found that there was, and is, a

'poor quality of care right across the aged care system, but [that this is] most marked in the care provided to people with dementia and other cognitive disabilities' (2019: 68).

In light of damning evidence of abuse and neglect in aged care over many years, the report of Australia's Optional Protocol Against Torture (OPCAT) Network leading up to the visit to Australia by the UN Sub-Committee Against Torture, urges that Aged Care be included in the Sub-Committee's investigation of breaches of the Convention Against Torture, Cruel and Degrading Treatment in sites of control and confinement.

In numerous inquiries into institutional violence and neglect, we have seen calls for increased staffing levels, improvements in staff procedures and policies, and greater funding to support better trained staff. This is also a feature of the Interim Report of the Royal Commission into Aged Care Quality and Safety, titled simply *Neglect*.

This has been accompanied by an emphasis on the role that human rights monitoring plays in ensuring that our elders are respected and treated with dignity. Yet monitoring human rights is especially difficult among those who typically lack the agency to claim their rights, and can be subject to threats and intimidation for doing so.

Those with dementia are particularly vulnerable. The Royal Commission has also found that the failings of the aged

care system can be traced to its design 'around transactions, not relationships or care,' which 'minimises the voices of people receiving care and their loved ones,' Royal Commission into Aged Care Quality and Safety Interim Report, 2019: 255.

While more and better trained staff, and improved procedures and regulatory frameworks can make a significant difference, the underlying culture of aged care, especially for those with dementia and those with compromised physical capacity, tends to mitigate against human dignity. Our elders, and those living with dementia are typically subject to forms of confinement and control as a way of managing dementia. This is not care.

In an aged care home operated and managed by a religious order, and in which I conducted research over several months, I observed a culture of hospitality and respect which is not easily reducible to a procedural manual or to employing more and better trained staff. While training and adequate staffing are important, they are not the solution on their own. The culture I observed at this aged care home is informed by an ethical recognition of the uniqueness and particularity of the person.

As the Interim Report of the Royal Commission observed, a person in aged care 'is still a unique personality' regardless of whether they are living with dementia or cognitively impaired (2019: 4). As an example of this ethic of hospitality and in recognition of this uniqueness, staff and volunteers at this aged care home were reminded that they were to treat the 'facility' and those living in it, as they would their own home and family members.

On a festive occasion, a resident was offered a wine in a coffee cup. I was told that staff were advised that this was entirely inappropriate: the wine must

be offered in a wine glass. A simple thing, but an example of conduct which is shaped by mundane but compelling forms of respect.

Nursing and care staff were also given clear advice during induction sessions, on how to bathe someone, emphasising that a part of the person's body always be kept covered, even when other parts of the body were laid bare for bathing. This was a powerfully ordinary form of conduct aimed at preserving a person's dignity.

Similarly, management resisted calls by standards inspectors for additional signage in the interior, arguing for less, rather than more, signs of institutionalisation. The ethos of the home was encapsulated by this comment by one of the staff:

'There is no difference between who you are at work and who you are at home: the person you are is the same.'

The practices in this home were exemplary in many respects, evidenced by loving attention, laughter and a homely atmosphere, enticing food, including regular, freshly baked afternoon teas. However, an aged care home is not, and cannot be, a home in the usual sense. It is also a workplace, and a place of confinement, no matter how subtle. Over the time I conducted this research, I started to notice nuanced forms of control and confinement, often introduced with the welfare of residents in mind: to reduce their risk of falling, for example, by encouraging the use of 'walkers' and by limiting a person's independence while taking appointments and excursions outside the confines of the building.

Both practices were implemented for the safety of residents, to comply with a duty of care, even when excessive use of aids reduces independence.

The Royal Commission found however

that chemical and physical restraints are often inappropriately and excessively used, including without evidence of need for them to be applied. As it noted,

'The changed behaviours associated with dementia are often an expression of unmet need, including untreated pain, a desire to interact with the physical environment, and/or unmet psychosocial needs' (203).

Reflecting this view, I found that the home in which I conducted field research was mindful that signs of cranky, or 'difficult' behaviour must be understood and appreciated: people complain and become grumpy or 'non co-operative' for a reason, usually because their needs are not being met. Unmet needs are also often evident because there is an explicit and implicit assumption, particularly for those with dementia, that being elderly is the 'end of the road' and that their lives no longer matter. Reliance on restraint then becomes a management tool.

Exclusion, institutionalisation and subtle forms of control are often deployed in order to minimise risk. However, paradoxically, the increased reliance on walking 'aids' leads to diminished capacity. Risk minimisation through restraints can also accelerate the disablement of those with dementia.

This points to the limits of 'duty of care' models which are weighted towards liability rather than responsibility. While meeting regulatory standards is often critical to the protection of human rights, ensuring that care is delivered well and with care entails something much deeper and more complex than regulatory compliance. Neither is it reducible to designing spaces which are open, green and nurturing. Some of the worst examples of abuse of our elders have come from homes which appear to be places of beauty.

The answers are much more intricate

than those which can be found in a list of recommendations because such recommendations are attuned to the organisational and resource capacity of an institution to improve its standard of service delivery. Although this is with the primary aim of reducing neglect and abuse and enhancing the quality of life of those living in institutions, the underlying culture and framework are not always challenged. We don't, or should not, need a procedural manual to tell us that abuse is not appropriate, and that physical assault and intimidation are a breach of human rights. As researcher Yvonne Jewkes has remarked:

'For prisons, or healthcare settings, or homes for the elderly, to be humanistic, affirmative and generative, they depend on a concept of human persons as beings, with depth and complexity, functioning and developing in interactions with other persons and with other living things including plants and animals.' (2018: 328)

My participatory and observational experience has prompted me to reflect on the possibilities afforded by an ethical, restorative model of care, which is premised on individual, human capacity and growth, rather than living a diminished life.

For those who are aged, including those with dementia, I suggest that we need such a restorative approach, which sees our elders as people with potentiality and capacity, even if subtle. An obsession with a duty of 'care' model which is metrically driven reveals this to be a risk-based model which is premised on the actuarial (cost-based) risk to the organisation, and less with the fulfilment of human potential.

The 'care' exerted in pursuit of the 'duty of care' as a legal obligation, typically subsumes the ethical duty we have towards the complex specificity of the person. Over time, an acceleration of

direct and indirect forms of control undermines a person's autonomy and dignity. Those who are subjected to chemical and other restraints, become more dependent, less coherent and less interactive. Their relationships with others are diminished by this.

A restorative model would work towards improving physical, mental and social capacity and is important, not because it might minimise the cost to an organisation, but because it matters to the person, and because a person who is in the later stages of life, ought to have the ability to live with promise. An imaginative, restorative model would be characterised by the promotion of active, engaged, expansive interactions, a focus on relationality, sensory stimulation, and the nurturing of possibilities for independence which might also mitigate against loneliness. Dementia ought not be a condition which leads to the erosion of the possibility of relations with others.

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- Lynelle Briggs and Richard Tracey, Neglect. Interim Report of the Royal Commission into Aged Care Quality and Safety (2019, Commonwealth of Australia, Canberra) <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>

Epistemic justice and human rights

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All people receiving aged care services in Australia:

'have the right to be listened to and understood'

The Charter of Aged Care Rights, 2019.

Yet persons living with dementia who access these services often report that they feel ignored and misunderstood.

My current PhD research aims to explore this phenomenon from a social justice perspective.

Published in January 2019 by the Journal of Aging Studies, my PhD supervisors and I wrote a paper entitled: *Expanding current understandings of epistemic injustice and dementia: Learning from stigma theory*. This paper describes how persons with dementia are included in, or indeed excluded from, 'epistemic practices' (e.g., conveying knowledge to others by telling them, and making sense of their own social experience).

The concept of 'epistemic injustice' (Fricker, 2007) has proven to be particularly useful when exploring the partial or full exclusion of persons with dementia from these practices. Persons with dementia experience epistemic injustice when we assume that they are not credible reporters of their own experiences. It is widely assumed that persons with dementia, by virtue of their diagnosis and associated cognitive symptoms, are not credible.

We found that these assumptions often are fuelled by stereotypes of what it means to have dementia. Stereotypes of persons with dementia as dependent, incompetent, untrustworthy, unreliable, lacking of insight into abilities, and unable to speak for themselves all fuel the assumption of poor credibility.

These stereotypes are so powerful because they are created, maintained and perpetuated multiple ways, through:

- Language (e.g., describing someone with dementia as 'not all there')

- Metaphor (e.g., the metaphor of 'reverse childhood')

- The medical model (i.e., a focus on deficit and impairment)

- Compounding stereotypes (e.g., with ageism)

- Cultural beliefs (e.g., that dementia has a moral cause)

Given the wide and varied modes of spreading these negative ideas about what it means to have dementia, putting a stop to these stereotypes would require a multimodal approach, and this remains an ongoing challenge.

We also found that these stereotypes are so powerful because they don't discriminate. They are a part of a larger social conscience, and can therefore be internalised by anyone: physicians, family members, friends, persons with dementia, judges, etc. Such internalisation can cause 'others' (family, friends, health professionals) to exclude persons with dementia from epistemic practices and/or can cause persons with dementia to withdraw themselves from epistemic practices.

In this paper, we prompt readers to reconsider the role of persons with dementia in epistemic practices. We hope that these understandings can assist in identifying the root of epistemic injustices, so we can then challenge those attitudes and behaviours that act to marginalise and exclude persons with dementia from engagement in our communities.

The paper is hugely topical politically, given current global trends in health and social care promoting person-centred and consumer-directed aged care. We simply cannot provide care that is person-centred, if we do not seek to understand what it is that persons with dementia want for their care.

Similarly, in the local context of the Royal Commission into Aged Care, this paper contributes to an ongoing discussion in Australia about the multitude of ways we can do justice and injustice to older persons through the care we provide to them. This paper highlights the potential of a specifically epistemic type of injustice; an epistemic kind of harm, abuse or neglect.

Continuing our consideration of voice and inclusion, my supervisors and I conducted a systematic review, published in the *Journal Dementia* in July 2019, designed to explore how persons with dementia are involved in decision-making about their own care.

We searched existing literature for accounts from persons living with dementia of moving into long-term care (LTC). From a synthesis of these accounts, we established 5 preliminary principles for support provided to persons with dementia and their families throughout transitions to LTC:

Principle 1: Persons living with dementia and their families should be supported with respect to their unique, individual context.

Principle 2: Both the positives and negatives of transitions to LTC should be acknowledged and validated for persons living with dementia and for their families.

Principle 3: Input should be sought from persons living with dementia regarding decisions to transition to LTC. If the person lacks the capacity to make the decision independently, shared decision-making must be supported.

Principle 4: Persons living with dementia and their family and friends should be encouraged to maintain regular social contact throughout all stages of the transition.

Principle 5: Once in the LTC facility, persons living with dementia should receive support to integrate socially in the new setting.

In the accounts included in this review, persons living with dementia described systematic exclusion from involvement in decision-making about their own health and social care. Decisions to move to LTC were made on their behalf, by lay people, family members or legal guardians.

They described the negative personal impacts of such exclusion, which informed the development of Principle 3 in particular: Input should be sought from persons living with dementia regarding decisions to transition to LTC.

If the person lacks the capacity to make the decision independently, shared decision-making must be supported. Yet it may be the case that those making these (proxy) decision may not have the knowledge or resources to uphold this principle. Upholding Principle 3 depends on an understanding of:

1. how best to seek input from persons with dementia (who may have significant cognitive and communication difficulties);
2. how to determine capacity to make such decisions; and
3. how to go about making decisions together.

Continuing this program of work, I have interviewed people with dementia and their families about transitions to long-term care, with a view to exploring issues of power, injustice and prejudice throughout the care continuum. Dissemination of the findings from this research will commence in the coming months (mid-2020).

Summary:

The most basic human rights of persons with dementia simply cannot be upheld if we do not take the time to listen to, understand, and act on what they have to say. Exclusion from care decision-making, either active (ignoring) or passive (failing to seek their input), is unjust. We need to continue to develop our understanding of how best to challenge dementia-related stigma that fuels this exclusion, and to seek new and innovative ways to support persons with dementia to contribute to care decision-making.

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Reflections on the Summit: Fighting for human rights in dementia care

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I read an article recently that really piqued my interest, entitled: *'Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes'*.

In this paper, authors Linda Steele, Kate Swaffer, Lyn Phillipson and Richard Fleming challenge the practice of putting persons with dementia into residential care homes. In reference to the United Nations Convention on the Rights of Persons with Disabilities, the paper frames this practice as 'segregation', and ultimately as a human rights violation.

As a student focusing on transitions to long term care as they are experienced by persons with dementia, and as someone who is very keen to adopt a 'human rights' approach my own work, I got very excited about this paper.

This work relates very closely to my own. I can see how it could potentially help to support my critical work looking at:

1. how we do justice to the experiences and perspectives of persons with dementia; and
2. the injustice resulting from the exclusion of persons with dementia from care decision-making.


It also offers a really clear example of how the UN CRPD can be used to expose issues of injustice in dementia care. As you can imagine, given the relevance of this work to mine, I was very excited to hear more about it and to connect with these authors.

Shortly after reading this paper, I was sent an invitation to attend a Summit in Sydney, hosted by these authors (+ Ray Carr from UTS and UOW), and by the University of Technology Sydney (UTS) Law, University of Wollongong (UOW) and Dementia Alliance International: *'People Living with Dementia, Human Rights and Residential Aged Care'*.

Usually I try to attend as many professional development opportunities as I reasonably can, while realising that I can't possibly attend everything! But this one sounded too good to miss.

Last Thursday, I drove from Swan Hill to Albury, then caught the overnight train to Sydney for this extra special event on Friday. I decided to tweet throughout the day, as I have found this to be very helpful in the past. From those tweets (and from comments of others), below I have collated a simple summary of each of the presentations and some useful resources shared by presenters.

This contribution originally appeared (on November 28th, 2019) as a blog post titled *'Fighting for Human Rights in Dementia Care'* on Jessica Young's webpage: <https://www.jessicaanneyoung.com/blog-1/2019/dementiahumanrights>.



**'I have a right to health.
I have a right to habilitation
and rehabilitation!'
Bobby Redman**

Aged care and the built environment

Professor Richard Fleming from the University of Wollongong started the day with an introduction to the concept of environmental restraint as it relates to current, institution-based models of dementia care. He talked about how the current design of residential care, in particular the presence and use of gates, locks and sensors, poses a real threat to human rights of persons with dementia who live in those spaces. He said:

'It is not lawful to lock someone with dementia up!'

Yet there are currently approximately 50,000 people with dementia in secure (locked) 'dementia units' in Australia. He described how such practices (of locking people with dementia up) likely do more harm than good, often exacerbating dementia symptoms.

'Who gave you the right!'

Bobby Redman, Dennis Frost and Lynda Henderson are influential, active advocates for the rights of people with dementia. On Friday, we heard their perspectives on a human rights approach to dementia.

Dementia advocate Bobby Redman raised the issue of lack of access to rehabilitation of any kind:

'I have a right to health. I have a right to habilitation and rehabilitation!'

But she has never been offered this type of support, nor is it easy to access independently.

She spoke about how many current testing practices are unhelpful and may lead to restricting the human rights and independence of persons with dementia. She gave the examples of testing driving in an unfamiliar car, using new technology in the assessment of cognitive capacity (e.g., iPads for those who are unfamiliar with touchscreen tech). These practices effectively set persons with dementia up for failure.

Dennis Frost talked about the outcome of using fences and locks in residential care: they keep people locked in, hide them from the outside world, discourage friends and family from visiting, and

keep people from engagement in meaningful activities.

Dennis also told of his experience of moving his mother to long term care—told to 'stay away' for a few weeks to allow her to 'settle in'. Our recent review showed that both persons with dementia AND their families often find this practice incredibly distressing. Dennis' experience aligns with our findings.

I have been following Lynda Henderson on Twitter for a little while and have always found her perspectives to be incredibly thought-provoking. It was exciting to hear her speak on Friday. Lynda currently cares for her partner Veda in their home. Reflecting on their shared experience, she shared her current concerns:

'What scares me is that I don't know if I'm going to be able to be keeping on (as a care partner) for much longer.'

She asked: How do you maintain your own health while keeping up the care? What's the alternative?

'Even so, rights, if it has no action, is dead: Don't talk – ACT, don't say – DO, and don't promise – PROVE.'

Eileen and Dubhglas Taylor are dementia advocates and activists. On Friday they spoke of challenges they have experienced in accessing support.

Eileen, who is living with Familial Younger Onset Alzheimer's Disease, was no longer able to access NDIS funding when she turned 65. Eileen and Dubhglas framed this as age discrimination. They spoke of the experience of getting support and then having it taken away:

'You get given rights and those rights get taken away!'

They challenged us to familiarise ourselves with the 2019 updated Aged Care Quality Standards, and consider which of these rights we could live without.

They then told us that, in their experience, they have never had a choice. Often these rights are taken away without any say in the matter!

In a later discussion, Eileen passionately asserted:

'We don't need more carers, we just need people to be more caring!'

I thought this was too powerful to not share here!

Human rights and chemical restraint in Australian aged care facilities

Bethany Brown from Human Rights Watch in New York spoke about chemical restraint in aged care in Australia.

She recently published a report on: *How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia*.

She spoke of an overreliance on drugs, often sedatives, to control behaviour (without medical purpose) in Australian long-term residential care facilities. She spoke about how the current model of care limits choice to the point where people (persons with dementia, families and care providers alike) feel they have no choice.

'To have real choice, there have to be adequate alternatives!'

This mirrors what some of the participants in my PhD research have told me in relation to the transition to long-term care. They didn't feel that they made the decision to move to long-term care. They felt that there were no other options; they felt powerless to the system!

Bethany's work calls for immediate reform of the Australian aged care sector, prohibiting the practice of chemical restraint.

Legal rights, human rights and advocacy

Next we heard from Sonia Di Mezza from ACT Disability, Aged and Carer Advocacy Service (ADACAS), Karen Williams from Aged and Disability Advocates (ADA) Australia, and solicitor Linda Rogers.

What I took from these presentations (which mostly went over my head as someone with ABSOLUTELY NO understanding of legal studies or lawyering) is that the power to uphold the rights of persons with dementia can lie solely with unfamiliar others (guardians, tribunals), and not particularly with people familiar with or close to the person.

They spoke of the way in which family disputes and fractures can come to the fore when people living with dementia are going into aged care and this can mean that health and social care decisions are often shaped by these disputes rather than by what the individual with dementia wants.

It seemed to me that much of the work I am doing, around shared decision-making and listening to the voices of persons with dementia, could be applied in a legal setting. Maybe I'll become a lawyer next (ha ha)... listening to these presentations made me question next steps after my PhD!

Human rights of care leavers in aged care: connections across child welfare and aged care systems

Leonie Sheedy and Stewart Quinn from Care Leavers Australasia Network (CLAN) discuss the issues related to Care Leavers going into long-term residential aged care.

Care leavers (people who grew up in orphanages, children's homes, missions and foster care) often experienced abuse in these setting, and as a result fear re-abuse and re-institutionalisation as they age.

Entering care institutions can bring up memories of past traumas. Leonie spoke of how common features of orphanages can be triggers for care leavers going into long-term care: certain smells, being touched on the back, being touched in intimate areas (for assistance with toileting), being offered ice-cream scoops of potato.

As people who have not had this experience, we need to understand these triggers to be able to provide appropriate, trauma-informed care.


Dementia and aged care: a rights-based approach

Dementia advocate and activist Kate Swaffer, CEO of Dementia Alliance International (who I have written about and with before) spoke of a need for deinstitutionalisation and desegregation in dementia care.

'We all have rights and they are all inalienable rights!'

Personally, Kate always gets me so (rightfully) angry about the current state of dementia care! But I often feel so powerless to make positive change.

The system seems too big, the issues too deeply ingrained. But Kate's passion and persistence inspires me every day to work harder and with a sense of urgency that I simply did not have before I met her!



'We all have rights and they are all inalienable rights!'
Kate Swaffer

Diversity, intersectionality and human rights

Yumi Lee from Older Women's Network NSW spoke about issues at the intersection of dementia care, gender, poverty, loneliness and homelessness. She proposed that interventions targeting domestic violence and poverty may improve the outcomes for older women with dementia.

Pauline Crameri of Val's LGBTI Ageing & Aged Care spoke about the inclusion of older LGBTI people in our communities. She spoke of harmful myths that impact the wellbeing of older LGBTI adults with dementia, such as that an LGBTI person with dementia will 'revert' to their birth-assigned sexual orientation (hetero) and gender identity (cisgender) as their dementia progresses. Myth such as these, Pauline said, act as a barrier to appropriate, person-centred care that affirms and validates older LGBTI adults' experiences.

She shared a useful resource for planning sensitive care for LGBTI adults: *Safeguarding the End of the Rainbow*.

Kate Kennedy from the Seniors Rights Service spoke of her experience of working with older people who are experiencing or at risk of abuse. On accessing aged care, she says:

'Don't get me started about home care! People are dying waiting for care!'

Diana O'Neil from the University of South Australia and Flinders University shared resources and perspectives on how to better support 'Forgotten Australians' (or care leavers) and trauma survivors. She shared a useful resource: *Real Care the Second Time Around*.

What I took from this presentation, and the earlier presentation by representatives from the Care Leavers Australasia Network (CLAN) discussed above, is that institutionalisation and loss of rights has already been a huge part of these people's life experience, so we need to do as much as we can to protect them from systems and practices that may bring up these issues again.

Hamish Robertson from UTS spoke of the 'Necropolitics of Dementia'. Like any good researcher, I took a quick moment at the start of his talk to do a quick google search of the meaning of 'necropolitics'. In the meantime, Hamish shared a slide which helped me out.

Hamish asserted that we have inquiry after inquiry but the same thing keeps happening: people with dementia are treated poorly and eventually die.

In his work, he asks the provocative question: is our system designed for people with dementia to die because our society dictates that certain groups of people MUST die?

Human rights and regulating aged care

Laura Grenfell from the University of Adelaide spoke about the inquiries into Oakden Older Persons Mental Health service, as they relate to human rights and the regulation of aged care. In her work, A/Prof Grenfell looks at the application of the Optional Protocol to Convention Against Torture (OPCAT) to the Australian aged care context. She suggests that as people with dementia often are not in the position to make complaints (or as my work might suggest we often do not deem them to be credible reporters of their own experience, but that's a discussion for another time), monitoring schemes can be proactive and preventative when it comes to reducing rates of abuse.

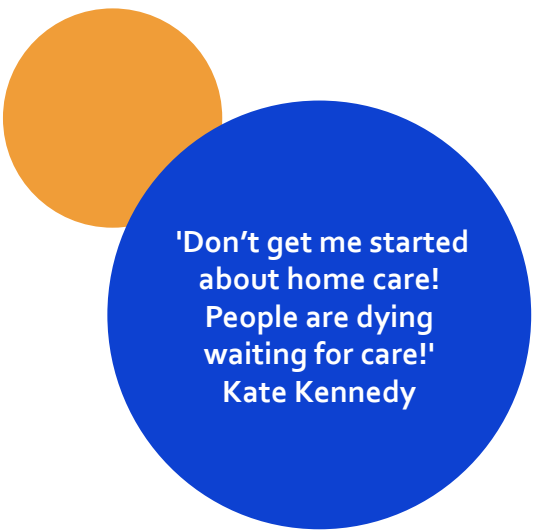
Ingrid Fairlie from UTS Health says the Australian Aged Care Quality Standards were well overdue for an update. The old standards were outdated and did not reflect contemporary practice. New aged care standards reflect, in part, a human rights perspective. These standards focus on consumer outcomes. And, Ingrid highlighted, these are only MINIMUM standards. They should not reflect an idealistic aged care sector, but the bare minimum!

Rodney Lewis from Elder Law Legal Services spoke about aged care through the prism of human rights. As I wrote earlier, I am not a lawyer so might have the terminology wrong here. My understanding is that, according to common law, restraint lawful under the following conditions:

- When there is imminent harm or risk of harm to oneself;
- When there is imminent harm or risk of harm to others; OR
- When lawful consent has been provided.

Outside of these conditions, Rodney told us, restraint is unlawful!

Rodney is the author of the legal reference book, *'Elder Law in Australia'*. The second edition was released in 2011 and the 3rd edition will be released shortly.



**'Don't get me started
about home care!
People are dying
waiting for care!'
Kate Kennedy**



Dignity, safety and human rights

Industrial designer Phillippa Carnemolla from the University of Technology Sydney looks primarily at two issues in her work: Inclusive design in cities and homes, and the influence of design on independence and autonomy.

She believes that relationships are changed by design. She suggests that if design can increase independence (in showering, toileting etc.), then people can focus on the more social aspects of shared lives- even if that just means having a cup of tea or going shopping together.

She also suggested that we consider the common terminology used: 'in the community' vs 'in long term care'. She asks, why do we treat these as mutually exclusive? Are long-term care facilities not in our communities? Amen, Phillippa! I wholeheartedly agree!

On a bit of a side note, Phillippa's work reminded me of a book I read recently called '*Joyful*' by Ingrid Fetell Lee. In this book, the author looks to define the aesthetics of joy, so that we may intentionally bring more joy to our everyday lives. I wonder if there is anyone out there looking at the use of these principles in the design of aged care homes?

Kirsty Carr, National Policy and Strategy Advisor from Dementia Australia, gave a rousing call for hope for a better future:

'We're so aware of the problems. But the system must crumble for us to be able to rebuild it!'

She shared with us an interesting report, entitled '*Our Solution: Quality Care for People Living with Dementia*'. The report is the product of the National Consumer Summit, hosted by Dementia Australia in June 2019, whereby people with a lived experience of dementia and their care partners were asked to reflect on what the new Aged Care Quality Standards meant to them:

The new Aged Care Quality Standards (the Standards) aim to:

'Focus on outcomes for consumers and reflect the level of care and services the community can expect from organisations that provide Commonwealth subsidised aged care services.'

However, people with a lived experience of dementia have expressed concern that the Standards will not necessarily ensure quality dementia care is delivered. This led to a series of discussions of what quality dementia care looks and feels like, and what the key points of difference are between quality dementia care and aged care more generally.

Claire Loughnan from the University of Melbourne says we need a restorative model in aged care. The current model of 'duty of care' (which is misunderstood by many) is weighted towards liability rather than responsibility. She asks: Who benefits from a model of care preoccupied with risk management?

Live scribe

A really novel aspect of this event was the involvement of a live scribe, the talented Devon Bunce. Throughout the day, Devon created three images/ collages/drawings reflecting the major themes of the summit. Her computer was projected to a screen, so we could watch the process from start to finish. It was very helpful to have a real-time visual log of the main ideas presented and how they might link to each other. What a fabulous access tool (this speech pathologist was impressed)! Check out more of Devon's work at her website: <https://devonbunce.com/>

Outcomes

The organisers of this fabulous event will be compiling an anthology from these presentations, the live scribe and from responses to the event, which will offer a more comprehensive discussion on the topic of dementia, human rights and aged care. The anthology will be compiled with the intent to submit it to the Royal Commission for Aged Care Quality and Safety. Once made public, I intend to share a link to the anthology at the top of this blog post.



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