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**Reparations for People Living with Dementia: Recognition, Accountability, Change, Now!**

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## **Introduction**

People living with dementia experience significant harm in long term care institutions ('LTC institutions', referred to by others as 'care homes', 'nursing homes', 'long term care', 'residential aged care facilities'), including violence, abuse, neglect, segregation, and detention. Yet, this harm is rarely the subject of redress. Harm experienced by people living with dementia can be trivialised, pathologised and ignored by reason of dehumanisation of people living with dementia and stigma associated with dementia, or concealed through the institutional, closed nature of LTC institutions. Some harm – such as restrictive practices and segregation – is legally, medically and socially authorised and is viewed as therapeutically necessary and beneficial (Chelberg 2023; Spivakovsky & Steele 2022). People living with dementia in LTC institutions, as well as care partners and family members advocating on their behalf, encounter ineffective and traumatising complaint, prosecutorial and court processes when they seek justice in response to harm. Harm experienced by people living with dementia and lack of redress for this harm violates human rights, including freedom from violence and torture, and equal access to justice. While recent government inquiries into LTC institutions have acknowledged harm occurs, recommendations typically focus on improving service quality within existing institutional status quo, rather than centring justice for individuals and their families and transforming service systems. Ultimately, laws, practices and systems that allow harm to occur remain unchanged and further harm is perpetrated. People living with dementia and their support networks await accountability, justice and change.

This article provides an overview of key findings of an Australian project that developed an evidence-base for redress in the form of reparations as a response to harm of people living with dementia in LTC institutions. Focus groups were conducted with people living with dementia, care partners and family members, advocates and lawyers to explore perspectives on why and how to redress harm experienced by people living with dementia in Australian LTC institutions (referred to in Australia as 'residential aged care facilities'). The project found unanimous support for a reparative approach to redress amongst research participants. Research participants favoured an approach that guarantees holistic and systemic reform to improve living circumstances and political status of people living with dementia and prevent further perpetration of harm.

While people without dementia in LTC institutions also experience harm, this article specifically focuses on people living with dementia. People living with dementia are a particularly marginalised group within LTC institutions, because of stigma, ableism and ageism surrounding dementia and laws and systems that enable segregation, detention and restraint on the basis of cognitive impairment. However, this article's call for reparations is relevant to responding to harm experienced by all residents in LTC institutions. Indeed, as a matter of equal access to justice, reparations should be available to anyone in LTC institutions, irrespective of disability. Although focused on Australia, the article has broader relevance. The article provides an empirical evidence-base for reparations in many other nations in which people living with dementia also experience human rights violations (see, e.g., De Albuquerque Green et al. 2021; Hardwick et al. 2022). Reparations is an important aspect of responding to calls for a fundamental reimagining of the future of LTC institutions that involves deinstitutionalisation (see, e.g., Kontos et al. 2021; Herron, Kelly & Aubrecht, 2021; Quinn & Campbell 2020) and growing recognition in United Nations and regional international human rights systems of the need for equal access to justice and remedies for people with disability and older people (see, e.g., Committee on the Rights of Persons with Disabilities 2022; Devandas-Aguilar 2020; Mahler 2022; Quinn & Doron 2021; Ruškus 2023). The article also contributes to an empirical evidence-base to support the work of disability rights activists who have long advocated for reparations for people with disability harmed in institutional settings (Frohman & Sands 2015; Katterl et al. 2023; Minkowitz 2021).

## **Background**

Data reported in academic research, multiple formal inquiries (Phillips 2018) and the Royal Commission into Aged Care Quality and Safety (2021a; 2021b) indicate that harm is a significant and persistent problem in Australian LTC institutions. For example:

- 39.2% of people in LTC institutions experience elder abuse in the form of neglect, emotional abuse or physical abuse (Royal Commission into Aged Care Quality and Safety 2020, 1).
- There are estimated 2,520 alleged incidents of unlawful sexual contact in LTC institutions per year (Royal Commission into Aged Care Quality and Safety 2021a, 140).

- Levels of poor nutrition and low hydration in LTC institutions are high (Bernoth, Dietsch and Davies 2014).
- There is low reporting of inappropriate use of antipsychotic agents in LTC institutions especially regarding initial dose and excessive duration of treatment (Shin et al. 2016).
- Some people's deaths in LTC institutions involve high-risk medications (Jokanovic et al. 2019).
- There is an overuse of antipsychotics prescribed for people living with dementia in LTC institutions (Ervin et al. 2019).

Impacts of harm on people living with dementia are diverse and wide-ranging. People living with dementia can experience physical and psychological injury, trauma, increased disability and greater need for support, and even death. For example, one woman described the impacts of sexual assault on her mother: 'she was repeatedly subjected to sexual assault by the night staff. She was so terrified of them that she would not tell me at first about what was happening. The men involved had threatened to kill her if she spoke about what they were doing.' (Royal Commission into Aged Care Quality and Safety 2021b, 97) Another woman described the profound impact on her grandmother after she was subjected to chemical restraint: 'Everything about her, her health, her spirit, declined after that drug. We went to see her after the meds, and she couldn't hold a conversation, she was dropping off to sleep, [just] like that.' (Brown 2019, 1). Australian media has reported on deaths of people living with dementia in LTC institutions. For example, in one media report, a woman was given excessive levels of a sedative which caused her to fall and contributed to her death by pneumonia caused by rib and pelvic fractures (Connolly and Stewart 2019). Another media report, detailed the story of a 91 year old man whose foot wound was not checked for five days, during which the wound developed into a necrotic foot ulcer which resulted in death by septicaemia (Turner 2021). Families and care partners can experience moral injury and ongoing loss, guilt, betrayal of trust, trauma and anger from witnessing and intervening in harm experienced by the individual with dementia, and times from realising they have been complicit in the harm (e.g., by arranging for someone to move into a LTC institution or by agreeing to use of restrictive practices).

Harm experienced by people living with dementia in LTC institutions is a systemic and structural problem. It is facilitated by environmental factors (including geography and

architecture), economic, legal and regulatory frameworks, and taken for granted aspects of how LTC institutions operate (Steele et al. 2019; Loughnan 2022). It is grounded in stigma towards dementia and ableism and ageism towards people living with dementia (Steele et al. 2023). For example, some scholars have drawn attention to the construction of people living with dementia as ‘wandering monsters’ and ‘zombies’ which in turn legitimates their subjection to exclusion, violation and death (Behuniak 2011; Chelberg 2023).

Harm experienced by people living with dementia received greater public visibility in Australia and in other countries during the COVID-19 pandemic, when there were media reports of people living with dementia in LTC institutions being socially isolated, denied necessary personal and medical care, receiving substandard food and in some instances being abandoned by LTC institution staff and left to die. These acute circumstances surfaced longer-term systemic and structural problems in LTC institutions and the pervasiveness of ageism and ableism (Dehm et al., 2021). Indeed, greater public visibility during the COVID-19 pandemic of conditions in LTC institutions has provided more urgency for demands for justice and change internationally, with scholars and advocates calling for deinstitutionalization of LTC institutions (Kontos et al., 2021; Herron et al., 2021; Luterman 2020; Quinn & Campbell 2020).

Harm experienced by people living with dementia violates their human rights under international instruments such as International Covenant on Civil and Political Rights, Convention Against Torture, and Convention on the Rights of Persons with Disabilities. Specific human rights violations include violations of rights to freedom from violence and torture, liberty, personal integrity, health, rehabilitation, legal capacity, independent living, and equality (Maker & McSherry 2018; Steele et al. 2019; Steele et al. 2020; Steele et al. 2023).

Existing justice, regulatory and political systems have failed to recognise and redress harm, hold perpetrators accountable and ensure transformative systemic and structural change to prevent harm from continuing. At an individual scale, there are limited examples in Australia of successful litigation providing court ordered remedies to people living with dementia harmed in nursing homes or to care partners and family members impacted by that harm (Dehm et al. 2021). There are well-documented problems with LTC complaint processes (internal and external to LTC providers), including that they are difficult to navigate, slow to act, focused on keeping LTC institutions operating, unsafe, and not transparent or

independent in their operation (Brown 2019: 34–5, 46–7, 49–50; Royal Commission into Aged Care Quality and Safety, 2021b: 95, 206–8, 209–10). People living with dementia and care partners and family members advocating on their behalf experience significant barriers to accessing justice through courts (see, e.g., Burns 2021). And, regardless, achieving judicial redress can be difficult because many types of harm experienced by people living with dementia are legally authorised (Spivakovsky & Steele 2022). To date, redress in the form of reparations have not been implemented or even explored in relation to people living with dementia in LTC institutions, in Australia, overseas or in UN and regional human rights systems (Steele & Swaffer 2022). The response to people living with dementia harmed in LTC institutions contrasts with harm experienced by people in other institutions of ‘care’ and ‘welfare’ where redress schemes have been introduced. Australian examples include the National Redress Scheme for survivors of institutional child sexual abuse and reparations schemes for members of the Stolen Generations and their surviving family members. Internationally, there is a rich body of scholarship and practice on reparations and truth-telling in relation to gross human rights violations against other marginalised communities, across diverse contexts such as racial apartheid, slavery, colonialism, internment, and sterilisation (Bhaba, Matache, & Elkins 2021; de Greiff 2006).

The Australian Government, LTC providers, their staff and board members, and legal and health professionals who work within this system are largely unaccountable to people living with dementia, their care partners and family members, and broader society. Failure to deliver recognition, redress, and accountability to people living with dementia in the wake of this known harm violates their rights to equality and equal access to justice. There should be equality in the process of accessing a remedy and in the outcome delivered by the remedy itself.

## **Methods**

The scarcity of existing research and practice on redress for harm experienced by people living with dementia in LTC institutions provided the research team with a unique opportunity to develop a foundational conceptual and empirical knowledge-base on the topic driven by perspectives of people living with dementia and their care partners and family members who advocate with or for them.

The project utilised a disability human rights methodology. This methodology involves research directed towards emancipation rather than marginalisation of people living with dementia and prioritising them as leaders and participants in research (Arstein-Kerslake et al. 2020). People living with dementia were involved at all stages of the project, and in various capacities including researchers, co-authors, research participants, project advisors. The primary research method was qualitative research with people living with dementia (who do not necessarily live in LTC institutions or have personal experience of harm), care partners and family members of people living with dementia who have been harmed in LTC institutions, volunteer advocates (individuals who, in an unpaid capacity, advocate for improved rights and quality of life for people living with dementia and who generally had experience as care partners or family members of people living with dementia), and formal advocates (e.g., lawyers and individuals or organisations working in a paid capacity in disability rights, older people's rights or human rights more broadly).

The project was led by authors Steele and Swaffer. The project was supported at all stages by project organisational partners Dementia Alliance International and People with Disability Australia and by a project advisory group of people living with dementia, care partners, disability and dementia rights advocates and lawyers, and social justice lawyers (including authors Mitchell and Kobier), which included representatives from the project organisational partners. Input included recruitment of research participants, format of focus groups and stakeholder roundtables, analysis of design and lived experience of Australian redress schemes, wording and presentation of the Dementia Reparations Principles (Steele & Swaffer 2023), and knowledge translation. The project received approval from the University of Technology Sydney Human Research Ethics Committee (ETH21-6114).

The project involved four stages. Stage One involved gathering an evidence-base for the necessity for redress in response to harm experienced by people living with dementia in LTC institutions, and forms of and processes for redress. Focus groups were promoted through a project website, social media and legal, advocacy and support organisations. Noting the importance of participation of people living with dementia, focus groups were promoted through disability, dementia and carer advocacy organisations, and through StepUp for Dementia platform (Jeon et al. 2021). Following extensive recruitment efforts, the final sample of research participants consisted of: people living with dementia (n=6), care partners and family members (n=13), volunteer advocates (n=8) and advocates and lawyers (n=11).

Overall, this was consistent with targets, with the exception of lower numbers of people living with dementia. One difficulty recruiting people living with dementia is the topic was not considered personally relevant to people approached (e.g., they did not live in LTC institutions or have experience of harm, or the topic was too confronting due to the prospect of being in a LTC institution), even though such personal experience was not a requirement for participation. Personal experience of living in a LTC institution and/or harm was not a requirement for participation because of difficulties of recruiting people living with dementia currently in LTC institutions (e.g., gatekeeping by LTC institution management and staff or family members). Nine focus groups and 1 interview were conducted. Due to sensitivity of discussions and importance of maximising psychological safety and ensuring everyone had an opportunity to speak, research participants were organised into separate focus group sessions. In order to facilitate prefigurative and creative engagement with redress, focus groups took a step back from discussing existing forms of redress (such as redress schemes that operate in the context of institutional child sexual abuse) and explored research participants' understanding of 'redress' in its verb sense as fixing or righting wrong. Focus groups explored questions such as:

- Is it necessary to right the wrongs of abuse and neglect of people living with dementia in residential aged care? And, why?
- What does 'fixing' or 'righting' abuse and neglect mean in relation to: (a) specific victims of abuse and neglect and (b) care partners, family members and close friends of specific victims of abuse and neglect, including if the victim is no longer alive?
- What form should redress take for people who are abused or neglected?
- What should be involved in the process through which redress occurs, and who is involved in this process?

Authors Steele and Swaffer facilitated the focus groups. A trained counsellor supported focus groups in which people living with dementia and care partners and family members participated.

Focus group recordings were transcribed and deidentified. Transcript data were thematically analysed using a coding schema that was applied to identify aspects of the 'who', 'what', 'why', and 'how' of redress:



- **Who** is involved in receiving or making redress,
- **What** form should redress take and what types of harm is the subject of redress,
- **Why** redress should be available, and
- **How** redress should be delivered.

The coding schema was initially developed by author Steele, drawing on her experience utilising a similar coding schema in a different research project on disability and redress (Steele et al. forthcoming), and then workshopped with author Swaffer. Transcripts were uploaded into NVivo 12 to support systematic coding by author Steele. Author Siciliano then coded all transcripts, and regular meetings were held between authors Steele and Siciliano to identify any alterations to the coding schema and any differences between them in coding. Author Siciliano's involvement in coding was central to the rigour of the analysis because she was not involved in the focus groups.

Stage Two involved development of draft Dementia Redress Principles. The draft principles were primarily informed by findings from Stage One as well as analysis of international human rights norms on access to justice and reparations and analysis of design and lived experiences of other Australian redress schemes.

Stage Three involved workshopping the draft Dementia Redress Principles. A series of stakeholder roundtables explored research participants' views on content and wording of each specific draft principle and identified gaps in the draft principles. Following extensive recruitment efforts similar to Stage One, a final sample of stakeholder roundtable research participants consisted of: people living with dementia (n=10), care partners and family members (n=11), volunteer advocates (n=9) and advocates and lawyers (n=11). Overall, this was consistent with targets. Notable increase in participation by people living with dementia compared to Stage One focus groups may have been due to stakeholder roundtables concentrating on a policy document rather than more abstract discussion in Stage One focus groups of a topic that was either too confronting, or perceived as removed from personal experience. All focus group research participants were invited to participate in the stakeholder roundtables, and some stakeholder roundtable research participants had also participated at Stage One, but this was not a requirement. Authors Steele and Swaffer facilitated the stakeholder roundtables, and a trained counsellor supported stakeholder

roundtables in which people living with dementia with dementia and care partners and family members participated. On advice of the project advisory group, research participants had the option of participating in a mixed session or a session only with individuals from their specific participant category.

Stakeholder roundtable recordings were transcribed and deidentified. Transcript data were thematically analysed using a coding schema structured by reference to each draft principle in order to identify themes that could inform changes to specific principles. In order to ensure rigour of the analysis, Stage Three utilised a process similar to Stage One involving authors Steele, Swaffer and Siciliano.

Stage Four involved production of a final set of principles, now titled ‘Dementia Reparations Principles’ in light of Stage Three findings confirming preference for a reparative approach to redress. This stage was informed by findings from stakeholder roundtables and feedback from the project advisory group and international human rights experts.

In reporting the data, research participants were de-identified and allocated a code and number reflecting the participant group to which they belong: PLWD is person living with dementia, CPFM is care partner or family member, VA is volunteer advocate, and AL is advocate or lawyer. For example, PLWD04 indicates the research participant is the 4<sup>th</sup> person living with dementia to register their participation in the project.

## **Findings**

The project found unanimous support among research participants for redress. Participants also emphasised importance of inclusive, accessible and safe processes for design and operation of redress. Research participants supported a reparative approach to redress, as is evident in three key features of redress emphasised in focus groups and stakeholder roundtables. Participants indicated that redress must be multi-faceted and consist of a range of complementary measures that can be flexibly tailored to meet individual needs. Redress must respond to impacts of harm as experienced by specific individuals while also responding to impacts of harm on people living with dementia as a collective. Redress must turn to deal with what has happened in the past while also proofing future laws, systems and practices against repetition of such harm.

This section discusses four key themes that should guide justification and design of a reparative approach to redress (hereafter referred to as ‘reparations’), and were threaded through the Dementia Reparations Principles (Steele & Swaffer 2023). These four themes are: recognition, accountability, change, now.

### *Recognition*

Recognition was identified by research participants as the foundation of reparations – recognising harm experienced by people living with dementia in LTC institutions and wide-ranging and ongoing impacts of this harm on these people living with dementia and their care partners and family members.

LTC institutions are, by their very name, labelled as places of ‘care’. Yet LTC institutions are also, by their institutional nature, places of harm. Harm is diverse and has wide-ranging impacts on people living with dementia and their care partners and family members. The full scope of harm experienced by people living with dementia in LTC institutions has not been recognised as wrong by governments, LTC providers or broader society. Moreover, LTC providers have ignored harm or denied any responsibility for harm. Thus, reparations are necessary at a foundational level to recognise that harm occurs and is wrong. Through recognition, reparations can provide opportunities for individuals with dementia, as well as care partners and family members, to heal. Additionally, reparations can provide opportunities for moral repair and restoring trust and hope by mending familial and social relations and building trust in governments and service systems.

Recognition is particularly important for five reasons. First, people living with dementia are devalued and are often not believed. For example, PLWD05 spoke about a current lack of recognition of harm as linked to cultural attitudes towards dementia: ‘a lot of people would not see it as abuse [...] well, that person’s got dementia, they need to be locked up, they need to be restricted, they need to be limited in everything they do.’ CPF02 explained that harm experienced by a person living with dementia can be dismissed as part of that individual’s dementia, using excuses such as hallucinations or imagination, ‘so it’s not taken seriously [...] they’re not a reliable witness’. PLWD01 spoke of her own experiences of being silenced and marginalised in the LTC institution where she lives: ‘[...] I get myself probably into a little bit of strife because I do speak up.’

A second reason is that care partners and family members who seek to advocate against harm are silenced, often because they are positioned as problematic and disruptive. Failure to validate ongoing trauma care partners and family members experience confirms people living with dementia do not matter. VA08 reflected on advocacy efforts of CPFM13 in the aftermath of her husband's death: '[CPFM13] got completely marginalised [...] the way in which she was treated over her complaints for the last four years has been a continued attempt to marginalise her. Oh, your husband's dead. [...] Oh, you are the grieving widow [...] Oh, everything is kind of justified. And in that sense, the anguish that people are feeling, the grief and the anger is just compounded by these responses.'

A third reason is that existing justice, political and regulatory processes have failed to acknowledge and provide people living with dementia, care partners and family members with the material resources and supports needed to address these impacts. PLWD09 explained that reparations need to extend to moving a person living with dementia who is harmed from their existing residence: 'when the harm has happened for us, we're left with the feelings, not the facts. So, for example, if I was sexually assaulted, I would still have the feelings of that, but I wouldn't necessarily know why. And the only type of redress that would be meaningful for me would be the costs of moving me to a safe place, where that was not going to happen again. [...] And so, it's not just the money [...] it's the support to go and move the person to somewhere that they will feel safe. [...] it's like a [domestic violence] and staying with your partner, you're always going to be triggered and on edge.' VA11 identified the importance of trauma support to family members in the course of reflecting on her experiences of being diagnosed with post-traumatic stress disorder associated with what she had witnessed of her mother's treatment in a LTC institution.

Fourth, recognition sends the message that harm is wrong and that lives of people living with dementia matter. VA07 stated that care partners and family members want 'recognition that the person was valuable and their life was valued, and even if at the end, that it ended so tragically, that the person was a human being'. CPFM11 explained the importance of reparations that recognised the death of the person living with dementia. Relatedly, there is a need for recognition of people living with dementia as full human rights subjects through having equal access to justice. VA02 saw reparations as central to recognising people living with dementia as equal because reparations 'implies we're saying society recognises these people as citizens, as equal citizens.'

Finally, recognition is a prerequisite for change. AL02 explained that recognition is central to not repeating that harm: ‘without knowing your past, everything that you’re doing now is not based on concrete acceptance, that what was done in the past shouldn’t be repeated. You really need to acknowledge the wrongs before you move forward.’

Recognition must be reflected in forms of reparations – such as truth-telling and apologies – that provide opportunities for public acknowledgement of, learning about and action in response to harm and its impacts. PLWD12 stated the importance of truth-telling through public transparency: ‘I like the shame [...] Putting up some sort of shame list and a naughty list.’ AL01 noted the importance of public learning: ‘to acknowledge suffering and make it part of our history, when it’s currently not written at all.’ AL16 spoke about the possibility of truthful accounts of harm to educate family members who might be considering encouraging a person living with dementia into a LTC institution: ‘If there was something that stood alongside the stories that talked about what those people should have experienced, it might help [care partners and family members] to understand what they should expect in care’. Recognition can also be reflected in the symbolic power of monetary payments. AL02 explained that a monetary payment can indicate the value of people living with dementia, signalling everyone matters, and there is a price to pay for harming people in LTC institutions: ‘Currently [...] we are all disposable, dispensable and completely not valued’.

Recognition must also be reflected in reparations processes that centre experiences and voices of people living with dementia shaped by their individual circumstances and identities. Their participation enables direct involvement by people who have been impacted by harm and those living in or facing the possibility of living in LTC institutions, which in turn reflects direct action by governments to validate and respond to their experiences. Participation of people living with dementia also enables reparations to be informed by their deep knowledge, expertise and experience of what works for them. They are often excluded from direct involvement in policy and service design and implementation, or their inclusion is tokenistic, because they are considered to lack capacity. Their exclusion can reflect a paternalistic approach that assumes others know best, whether those others are care partners and family members, service providers, academics, legal and health professionals or public servants.

## *Accountability*

Accountability for harm is the second key theme for framing reparations that emerged. Reparations are necessary to ensure moral, legal and economic accountability, in relation to governments, LTC providers and all other parties (such as legal and health professionals) who perpetrate or are complicit in harm. Reparations directed towards those who are harmed or impacted by that harm must be accompanied by explicit recognition and condemnation of actions of perpetrators and holding them to account. Otherwise, their behaviour will continue, accepted practices will remain unchallenged and established systems and structures will not change.

Accountability must extend to everyone involved in LTC institutions. Health professionals working in LTC institutions, including medical professionals, have an ethical responsibility to review existing practices and protocols to ensure they are not repeating past harm, as well as not coercing family members or guardians to place someone into a LTC institution. Legal professionals, who might be physically distanced from LTC institutions where harm is perpetrated, need to be held accountable for their role in enabling that harm (e.g., their role in appointment of substitute decision-makers, forced or coerced movement into LTC institutions pursuant to guardianship arrangements, use of authorised restrictive practices). AL02 explained that reparations must constantly foreground wrongdoing of perpetrators in reparations, because focusing only on recognising and responding to experiences of harm can slip into erasing responsibility of perpetrators and, in turn, overlooking accountability of those who have caused harm: '[Y]ou see the word 'people with dementia', you see the word 'family', you see 'care partners', but you don't see the words 'government' or 'governance' and 'providers' '. Similarly, VA08 explained: 'redress obviously has to deal with responsibility and nobody in this system takes responsibility. No one. The doctors don't. The nurses don't. The providers don't. The government doesn't. The hospitals don't. [...] So the idea of redress is going to be rendered actually nonsensical in the system in which there is no accountability.'

Holding accountable individuals and organisations who have perpetrated harm is particularly important for several reasons. First, existing justice, regulatory and political systems have failed to recognise wrongfulness – and, at times, illegality – of perpetrators' conduct in turn enabling harm to continue. AL02 explained this in the context of the Royal Commission into Aged Care Quality and Safety: 'I feel a great sense of despair after spending over 90 million

[dollars] on the Aged Care Royal Commission, after the last full stop, the abuse continues, so what is the point really? [...] it's just going to carry on.'

Second, perpetrators and other individuals and organisations have benefited – financially or otherwise – from harm. VA08 noted a profit model that runs throughout LTC institutions, including in charities: 'there is no doubt that the [for-profit providers] are looking after shareholders, they're not looking after residents. [...] And not-for-profits are building empires. [...] Why should aged care be reduced to [...] commodification.' AL04 also observed that it 'seems like people, harm, abuse and neglect, they are just externalities within that corporate model, that are embedded within it'. VA03 pointed out that 'the medical and legal profession [...] also profit from harm'.

Third, current absence of accountability legitimates ongoing perpetration of harm. CPF15 explained that 'a lot of providers see [...] compensation and redress as something that is ridiculous' and as an expense to write off rather than as a means to stopping harm.

Accountability must be reflected in forms of reparations that reckon with and sanction wrongdoing, require forgoing of financial benefit gained through harm, and ensure action that will stop ongoing perpetration of harm.

Accountability must also be reflected in reparations processes that are safe, transparent and independent. Concrete action entails not only forms of reparations that facilitate an initial commitment to action but also include processes for regular monitoring of what action has indeed been taken and enforcement if action is not taken. PLWD09 referred to this monitoring and enforcement in terms of a 'loop': 'we are only [the] first step in the loop. We make the complaint, but we don't get the outcome [...] But unless it's built in that the organisation is forced to be accountable, and this is what we've done to make sure it doesn't happen again. [...] that 360 feedback is super important, from both whoever's dealing with the complaint, and also, the institution [...] Because that's the only way you'd get some closure.'

### *Change*

Ultimately, reparations must be directed towards bringing about structural and systemic change. While reparations are necessarily responding to what has already happened, this must always be connected to preventing further harm at the individual and structural levels.

PLWD05 who was not in a LTC institution explained: ‘[O]ne of our greatest fears is that we’re going to end up in one of these places and it’s still going to be going on. [...] that this isn’t just a few cases [...] that it’s fairly commonplace, that it has been addressed, and will continue to be addressed and that moving forward, there’s going to be greater awareness and much better treatment of us when we’re in those circumstances.’

There are four reasons for the importance of change. First, in the immediate term, individuals need to be removed from sites of harm, as those places will continue to be triggering.

PLWD09 explained: ‘[T]he only type of redress that would be meaningful for me would be the costs of moving me to a safe place, where that was not going to happen again. [...] it’s about this restorative justice, restoring someone to a state comparable to what they had before [...] I just want to be gone from where it happened because otherwise you’re just living in a trigger point.’

A second reason is that reparations, if not followed up with meaningful action, can be experienced as empty words and people being ‘paid off’. Using the example of CPFM13 (whose husband died in a LTC institution), VA08 noted that validation must equate to the individual who shares their story being able to see lessons learned from that story reflected in changes to LTC institutions; otherwise listening can be a tokenistic process: ‘[R]edress for [CPFM13] would be a recognition that at least some of these things had been taken on board. In other words, it’s not all about compensating her personally for what she’s been through, but a sense that she has been able to have an impact on change. [...] and feel that she has been heard because there are real changes that she can see.’

A third reason is that harm arises from structural and systemic dynamics of LTC institutions, and thus these conditions for continued perpetration of harm need to be addressed. CPFM10 argued for deinstitutionalisation of LTC institutions: ‘Any redress, I still think does need an apology from a provider group, but I think we do want to look at deinstitutionalising aged care.’

Finally, while the past cannot be changed, using lessons of the past to change the future is critical. CPFM02 explained that the past cannot be fixed but it can be a lesson for preventing further harm: ‘Learning from problems so that you can prevent them recurring [...] I don’t think money and payment for problems that have arisen is going to fix it [...] So it’s not about money and therefore it’s not even about an apology, which could be a hollow apology



anyway, it's more about, 'Okay, what are we going to do to fix this', and prevent it recurring.'

Change must be reflected in forms of reparations that are directed towards human rights-based changes to laws and practices in LTC institutions, and each form of reparations having a clear connection between past harm and changes to prevent further harm of people in LTC institutions. This was particularly apparent in relation to participants' views on monetary payments. Participants expressed that money was not a priority. Some research participants were ambivalent about the significance of monetary payments, noting that money cannot fix or change the past, particularly where the person living with dementia has since died. Thus, if available, monetary payments must operate in the context of a broader commitment to and action on changing systems and preventing further harm, or used to provide relocation and support for people who are harmed. Change must also be reflected in reparations processes that include people living with dementia in paid leadership roles and monitoring and enforcement of action to stop ongoing perpetration of harm.

#### *Now*

A fourth key theme was 'now' – not to delay urgent action on reparations. There is already abundant historical and current evidence of widespread harm experienced by people living with dementia and its ongoing impacts on people living with dementia and care partners and family members. There was a sense that inquiries had failed because they had not acted.

The importance to act now is underscored by the urgent need of rehabilitation and support for people living with dementia who have been harmed and are still alive; many who have been harmed are older and the risk they will die before they can access reparations is high. VA11 explained that reparations must be 'done in a timely way' and 'you need that process to start really quickly' because otherwise people might die before they receive any reparations. This is particularly so in a context where LTC providers might strategically try to delay processes, as VA07 explained from her mother's experience: 'And they spin it out. Mum couldn't get access to her own health files. I got them a week before she died.'

#### *Limitations of project*

This project was a small-scale project conducted over 18 months with modest funding. Moreover, with no previous empirical, legal or conceptual literature on the specific topic, its

priority was to take an exploratory and prefigurative approach to define and map out key issues as a foundation for further research. With this in mind, there are four limitations of the project.

First, focus groups and stakeholder roundtable sample sizes were small. Further empirical research is required in order to continue to enrich the evidence-base on reparations for harm to people living with dementia in LTC institutions, notably of specific forms of reparations and the processes through which reparations are delivered. Continuing to prioritise participation of people living with dementia is vital in any future empirical research on reparations.

Second, there was insufficient scope in the project to fully explore intersectional issues, such as experiences of harm among and reparations needs of specific communities of people living with dementia (e.g., women, First Nations people, and people with earlier experiences of institutionalisation and incarceration). Future empirical research must engage with specific communities in recognition that their procedural and substantive needs will vary.

Third, in light of the focus on centring voices of people living with dementia and those who are close to or advocate with or for them, this project did not involve empirical research with other stakeholder groups whose interests will likely shape the design and operation of reparations, such as government and LTC providers. It is important for future empirical research to engage with these other stakeholder groups in order to gain a fuller understanding of barriers to implementation.

Fourth, the project focused on the bigger picture of reparations and did not explore the finer level of detail. Considering the implementation of reparations and technical aspects of its operation in specific cultural, legal and service contexts is important in future research.

## **Discussion**

There is growing interest in dementia scholarship and practice in engaging human rights to support community inclusion and political equality of people living with dementia (see, e.g., Dixon et al. 2020; Kontos et al. 2016). Findings from this empirical study add to this scholarship and calls for action, by broadening the debate beyond an existing focus on establishing relevance of human rights to people living with dementia and articulating human rights violations, towards reparation as one dimension of a way forward from these violations in terms of redressing harm, facilitating social repair in the wake of widespread harm, and

building more inclusive, equal and just communities. As the first empirical study on this topic, much more research needs to be done.

In light of the absence of dementia scholarship on reparations, and an absence of reparations scholarship on dementia, it is vital that there be more scholarship at the intersections of these two fields. There is a vast body of scholarship critically reflecting on experiences of reparations in more conventional transitional justice contexts (Bhaba, Matache, & Elkins 2021; de Greiff 2006) – such as post-conflict or authoritarian contexts – and a growing body of scholarship on the potential use of reparations in institutions of ‘care’ and ‘welfare’ (albeit not LTC institutions) (Gallen 2023; O’Donnell, O’Rourke, & Smith 2022). Drawing on this scholarship, further comparative research could learn from existing reparations practices, including when these have been unsuccessful or criticised. Moreover, dementia scholars could stage critical interventions into this reparations scholarship, particularly in terms of how reparations more broadly can be imagined and practiced in ways that are inclusive and accessible to people living with dementia and attentive to dementia-specific harm.

In advancing research on reparations for people living with dementia, there are three areas of particular relevance.

First, greater attention needs to be given to engaging the LTC industry in reparations. Responsibility for delivery of reparations conventionally falls on governments. In part this is because the obligation to respect and ensure human rights – including to deliver access to justice and remedies – falls on the state (rather than nonstate actors such as corporate or charitable LTC providers or private medical professionals). However, the obligation of governments to protect against human rights violations clearly extends to taking steps to regulate behaviour of corporations and charities and requiring these organisations to provide remedies for violations (Steele & Swaffer 2022, 74). As such, LTC providers must see themselves as actors in reparations and governments must hold LTC providers accountable as a matter of public procurement when they fail to meet these expectations (Methven O’Brien & Martin-Ortega, 2020).

Second, dementia scholarship must consider the role of dementia clinicians and practitioners – including geriatricians, psychiatrists, general practitioners, pharmacists, registered nurses and allied health professionals – in reparations for harm they perpetrate or in which they are complicit. Such research could draw on scholarship on the role of the medical profession in

reparations in other contexts (e.g., Gilmore & Moffett 2020). Such consideration must extend to critically examining and challenging common professional practices. Care partners and family members are often advised by another family member, a friend, medical doctor or clinic nurse to place the person they are supporting into a LTC institution. Society generally sees this as acceptable too, but because there are so few alternatives to institutional settings, people are coerced into them, and it is a decision which is often initiated and supported by the family's medical doctor, conceivably with more power over patient outcomes, and who society generally believes knows what is best for them. In turn, consideration of knowledge production and pedagogy that sits behind and legitimates professional practice is also essential. Research and practice on reparative pedagogies (Zembylas & Keet 2019) can provide tools for how to deliver education to future dementia practitioners and researchers in ways that prevents further perpetration of harm through education and facilitates educational institutions, academic associations and individual teachers and researchers reckoning with past injustice.

Third, dementia scholarship can explore the role of dementia activism and allies in reparations. Indeed, it might be possible to conceptualize a dementia reparation movement as a form of activism. Our empirical research has highlighted the importance of allies – care partners and family members, volunteer advocates and professional advocates and lawyers – in realising justice for people living with dementia who experience harm in LTC institutions. However, because people living with dementia have been marginalised and experienced epistemic invalidation and some care partners and family members have contributed to harm, prioritising of the interests, needs and perspectives of people living with dementia in ensuring a balance between different groups' 'justice interests' is essential. While all participants in our research supported reparations, people living with dementia had a stronger focus on material and individual support whereas many of care partners and family members and volunteer advocates (who had experiences with someone who had now died and so often their perspective was less on how to deliver reparations in the context of someone alive but rather when the person has died) had a focus on systemic change in a context of honouring the memory of individuals with dementia who have died. In exploring these complexities and tensions, scholars can draw on literature on activism in the context of dementia (e.g., Swaffer 2018), as well as in contexts of families of people with disability (Carey, Block, & Scotch 2020), and development of redress in other institutions of 'care' and 'welfare' (e.g., Lundy 2022).

The project also identified a series of unique challenges to realising reparations which could provide a basis for further research on the complexities of reparations in the context of LTC institutions. First, stigma associated with dementia can undermine reparations because it sustains the inevitability of institutionalisation of people living with dementia in LTC institutions, as necessary and even benevolent, making it inconceivable that LTC institutions are sites of harm and injustice. Moreover, there is a presumed futility and irrelevance of providing reparations in the form of material support based on the view that such people are near death and their lives are thus not worth saving or enriching.

Second, care partners and family members have a complex role in harm, being central to advocating for a person living with dementia when they experience harm – often experiencing ongoing impacts both from witnessing harm and engaging in complaint processes – and contributing to that person living with dementia moving into a LTC institution and their negative experience in the LTC institution often in circumstances of a lack of community options and lack of knowledge of the reality of LTC institutions. Thus, there is a need for a nuanced and sensitive approach to reparations, because of the complicated boundaries between victim and perpetrator and between healing and accountability.

Third, the institutional model of LTC is deeply entrenched in legal, economic and service systems and is often the only and inevitable option when people living with dementia are unable to receive the care and support they need in their home in a context where there are almost no non-institutional alternatives for a person living with dementia requiring supported living outside of their current home. The ongoing existence of LTC institutions may undermine the capacity of reparations to effect systemic change given that reparations are typically premised on a transition away from oppression.

## **Conclusion**

This project is a call to action for governments to implement reparations for harm to people living with dementia and others in LTC institutions. This call is made not only by researchers, but by people living with dementia and care partners and family members themselves. Additionally, this project is the first step in a longer-term program of work to support recognition of and action on reparations for people living with dementia in the UN human rights system and international human rights practice; and development of an international field of scholarship on reparations and dementia.

## References

- Arstein-Kerslake, A., Maker, Y., Flynn, E., Ward, O., Bell, R., & Degener, T. (2020). Introducing a human rights-based disability research methodology. *Human Rights Law Review*, 20(3). 412–413.
- Behuniak, S. (2011). The living dead? The construction of people with Alzheimer’s disease as zombies. *Ageing & Society*, 31(1): 70–92.
- Bernoth, M., Dietsch, E., & Davies, C. (2014). “Two dead frankfurts and a blob of sauce”: The serendipity of receiving nutrition and hydration in Australian residential aged care. *Collegian*, 21(3). 171–177.
- Bhaba, J., Matache, M., & Elkins, C. (eds) (2021). *Time for reparations: A global perspective*. University of Pennsylvania Press.
- Brown, Bethany. (2019). “Fading away”: How aged care facilities in Australia chemically restrain older people with dementia. Human Rights Watch. [https://www.hrw.org/sites/default/files/report\\_pdf/australia1019\\_web.pdf](https://www.hrw.org/sites/default/files/report_pdf/australia1019_web.pdf).
- Burns, K. (2021, June 1). The forgotten injured: Recovery for injuries in aged care. Griffith News. <https://news.griffith.edu.au/2021/06/01/the-forgotten-injured-recovery-for-injuries-in-aged-care/>.
- Carey, A.C., Block, P., & Scotch, R.K. (2020). *Allies and obstacles: Disability activism and parents of children with disabilities*. Temple University Press.
- Chelberg, K. (2023). Vulnerable monsters: Constructions of dementia in the Australian Royal Commission into Aged Care. *International Journal of Semiotics of Law*. <https://doi.org/10.1007/s11196-023-09979-w>.
- Committee on the Rights of Persons with Disabilities. (2022). *Guidelines on deinstitutionalization, including in emergencies*. United Nations. <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>.
- Connolly, A. & Stewart, J. (2019, January). Aged care home resident strapped to chair for total of 14 hours in one day. ABC News. <https://www.abc.net.au/news/2019-01-16/elderly-dementia-patients-given-anti-psychotics-and-restrained/10621658>.
- De Albuquerque Green, C. E., Tinker, A., & Manthorpe, J. (2022). Human rights and care homes for older people: a typology of approaches from academic literature as a starting point for activist scholarship in human rights and institutional care. *The International Journal of Human Rights*, 26(4), 717–739.
- de Greiff, P. (ed) (2006). *The Handbook of Reparations*. Oxford University Press.
- Dehm, S., Loughnan, C., & Steele, L. (2021) COVID-19 and sites of confinement: public health, disposable lives and legal accountability in immigration detention and aged care. *University of New South Wales Law Journal*, 44(1), 60–103.

- Devandas-Aguilar, C. (2020). *International Principles and Guidelines on Access to Justice for Persons with Disabilities*. United Nations.  
[https://www.ohchr.org/sites/default/files/Documents/Issues/Disability/SR\\_Disability/GoodPractices/Access-to-Justice-EN.pdf](https://www.ohchr.org/sites/default/files/Documents/Issues/Disability/SR_Disability/GoodPractices/Access-to-Justice-EN.pdf).
- Dixon, J., Laing, J., & Valentine, C. (2020). A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia*, 19(2), 221–236.
- Ervin, K. et al. (2019). Time for Australia to revisit antipsychotic use in dementia in residential aged care. *Australasian Medical Journal*, 12(5), 138–142.
- Frohman, C., & Sands, T. (2015). Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings. Australian Cross Disability Alliance. <https://dpoa.org.au/acda-submission-senate-inquiry-violence-abuse-neglect-people-disability-institutional-residential-settings/>.
- Gallen, J. (2023). *Transitional justice and the historical abuses of church and state*. Cambridge University Press.
- Gilmore, S., & Moffett, L. (2020). Redressing forced sterilisation: the role of the medical profession. *BJOG: An International Journal of Obstetrics and Gynaecology*, 127(8), 923–926.
- Hardwick, N., Marriott, J., Mason, K., & Steinbrecher, M. (2022). Human rights and systemic wrongs: National preventive mechanisms and the monitoring of care homes for older people. *Journal of Human Rights Practice*, 14(1), 243–266.
- Herron, R., Kelly, C., & Aubrecht, K. (2021). A conversation about ageism: Time to deinstitutionalize long-term care? *University of Toronto Quarterly*, 90(2), 183–206.
- Jeon, Y.H., Shin, M., Smith, A., Beattie, E., Brodaty, H., Frost, D., Hobbs, A., Kotting, P., Petrie, G., Rossor, M., Thompson, J., Vickers, J., & Waters, D. (2021) Early implementation and evaluation of StepUp for Dementia Research: An Australia-wide dementia research participation and public engagement platform. *International Journal of Environmental Research and Public Health*, 18(21), 11353.
- Jokanovic, N. et al. (2019). A review of coronial investigations into medication-related deaths in residential aged care. *Research in Social and Administrative Pharmacy*, 15(4) 410–416.
- Katterl, S. et al. (2023). *Not before time: Lived experience-led justice and repair*.  
<https://static1.squarespace.com/static/64509ef54c074f6f4dfb7138/t/648d31203bcc9152fbc2588f/1686974898046/Not+Before+Time+-+State+Acknowledgement+of+Harm+2023+-+FINAL+RELEASE.pdf>.
- Kontos, P., Grigorovich, A., Kontos, A.P., & Miller, K-L. (2016). Citizenship, human rights, and dementia: Towards a new embodied relational ethic of sexuality. *Dementia*, 15(3), 315–329.

- Kontos, P., Radnofsky, M. L., Fehr, P., Belleville, M. R., Bottenberg, F., Fridley, M., Massad, S., Grigorovich, A., Carson, J., Rogenski, K., Carpenter, K. S., Dupuis, S., Battalen, J., McDonagh, D., Fassbender, K., & Whitehouse, P. (2021). Separate and unequal: A time to reimagine dementia. *Journal of Alzheimer's Disease*, *80*(4), 1395–1399.
- Loughnan, C. (2022). The scene and the unseen: Neglect and death in immigration detention and aged care. *Incarceration*, *3*(2).
- Lundy, P. (2022). Pathways to justice: Historical institutional child abuse and the role of activist research. *Journal of Human Rights Practice*, *14*(2), 535–553.
- Luterman, S. (2020, August). It's time to abolish nursing homes. *Nation*.  
<https://www.thenation.com/article/society/abolish-nursing-homes/>.
- Mahler, C. (2022). *Older persons deprived of liberty: Report of the Independent Expert on the enjoyment of all human rights by older persons*, Claudia Mahler. United Nations.  
<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G22/447/00/PDF/G2244700.pdf?OpenElement>.
- Maker, Y., & McSherry, B. (2018). Regulating restraint use in mental health and aged care settings: Lessons from the Oakden scandal. *Alternative Law Journal*, *44*(1), 29–36.
- Methven O'Brien, C., & Martin-Ortega, O. (2020) Human rights and public procurement of goods and services. In S. Deva, & D. Birchall (Eds.), *Research handbook on human rights and business* (245–267). Edward Elgar Publishing.
- Minkowitz, T. (2021). Reparation for psychiatric violence: A call to justice. In M.A. Stein, F. Mahomed, V. Patel, & C. Sunken (Eds.), *Mental health, legal capacity and human rights* (44–55). Cambridge University Press.
- O'Donnell, K., O'Rourke, M., & Smith, J.M. (eds) (2022). *REDRESS: Ireland's institutions and transitional justice*. University College Press Dublin.
- Phillips, J., Parker D., & Woods, M. (2018, September 20). We've had 20 aged care reviews in 20 years – will the royal commission be any different? *The Conversation*.  
<http://theconversation.com/weve-had-20-aged-care-reviews-in-20-years-will-the-royal-commission-be-any-different-103347>.
- Quinn, G., & Campbell, A. (2020, May). Nursing homes must be made a thing of the past. *The Irish Times*. <https://www.irishtimes.com/opinion/nursing-homes-must-be-made-a-thing-of-the-past-1.4257422>.
- Quinn, G., & Doron, I. (2021). *Active social citizenship for older persons: The current use and future potential of the European Social Charter*. Council of Europe.  
<https://www.coe.int/en/web/european-social-charter/-/against-ageism-and-towards-active-social-citizenship-for-older-persons>.



- Royal Commission into Aged Care Quality and Safety. (2020) *Experimental estimates of the prevalence of elder abuse in Australian aged care facilities*.  
<https://agedcare.royalcommission.gov.au/sites/default/files/2020-12/research-paper-17-elder-abuse-prevalence-aged-care-facilities.pdf>.
- Royal Commission into Aged Care Quality and Safety. (2021a). *Final report: Care, dignity and respect* (volume 1).  
[https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1\\_0.pdf](https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf).
- Royal Commission into Aged Care Quality and Safety. (2021b). *Final report: Care, dignity and respect* (volume 2). <https://agedcare.royalcommission.gov.au/publications/final-report>.
- Ruškus, J. (2023). Transformative justice for elimination of barriers to access to justice for persons with psychosocial or intellectual disabilities. *Laws*, 12(3).
- Shin, H. et al. (2016). The use of antipsychotics among people treated with medications for dementia in residential aged care facilities. *International Psychogeriatrics*, 28(6), 977–982.
- Spivakovsky, C., & Steele, L. (2022) Disability law in a pandemic: the temporal folds of medico-legal violence. *Social and Legal Studies: An International Journal*, 35(2), 175–196
- Steele, L., & Swaffer, K. (2023) *Reparations for Harm to People Living with Dementia in Residential Aged Care – Dementia Reparations Principles*. University of Technology.  
<https://opus.lib.uts.edu.au/bitstream/10453/166674/2/Dementia%20Reparations%20Principles%20FINAL%20UTS.pdf>
- Steele, L., & Swaffer, K. (2022). Reparations for harms experienced in residential aged care. *Health and Human Rights Journal: An International Journal*, 24(2), 71–83.
- Steele, L., Carnemolla, P., Spencer, R., Kelly, J., Naing, L., & Dowse, L., (forthcoming) Listening to people with intellectual disability about institutions. *International Journal of Disability and Social Justice*.
- Steele, L., Carr, R., Swaffer, K., Phillipson, L., & Fleming, R. (2020). Human rights and the confinement of people living with dementia in care homes. *Health and Human Rights Journal: An International Journal*, 22(1), 7–19.
- Steele, L., Phillipson, L., Swaffer, K., & Fleming, R. (2023). Segregation and incarceration of people living with dementia in care homes: critical disability and human rights Approaches. In L. Sandberg, & R. Ward (Eds.), *Critical dementia studies: an introduction* (151–167). Routledge.
- Steele, L., Swaffer, K., Phillipson, L., & Fleming, R. (2019). Questioning segregation of people living with dementia in Australia: an international human rights approach to care homes. *Laws*, 8(3), 18.

Swaffer, K. (2018). Human rights, disability and dementia. *Australian Journal of Dementia Care*, 7(1), 25–28.

Turner, R. (2021, February) Children of Regis aged care facility residents who died speak out about ‘culture of neglect’. ABC News. <https://www.abc.net.au/news/2021-02-19/concerns-remain-over-regis-nedlands-aged-care-home/13168320>.

Zembylas, M., & Keet, A. (2019) *Critical human rights education: Advancing social-justice-oriented educational praxes*. Springer.