

# Reparations for Harm to People Living with Dementia in Residential Aged Care

## DEMENTIA REPARATIONS PRINCIPLES

by **Linda Steele and Kate Swaffer**

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## About this document:

This document provides a summary of the Project Report of the project 'Redressing Abuse and Neglect of People Living with Dementia in Residential Aged Care' funded by a Dementia Centre for Research Collaboration – Dementia Australia Research Foundation Pilot Grant.

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## Further information about the project:

**Project Report:** Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Project Report* (University of Technology Sydney, 2023).

**Executive Summary:** Linda Steele and Kate Swaffer, *Reparations for Harm to People Living with Dementia in Residential Aged Care – Executive Summary* (University of Technology Sydney, 2023).

**Project website and blog:** Dementia Justice: Dementia Redress Project [www.dementiajustice.org](http://www.dementiajustice.org).

# Preamble

People living with dementia in residential aged care are harmed. This harm has diverse and ongoing impacts on people living with dementia and their care partners and family members.

Governments and justice and complaint systems are failing to recognise, redress and repair the harm and hold people and organisations accountable for this harm.

Human rights provide for equal access to reparations and justice, and people living with dementia must enjoy these rights as much as everyone else.

**Therefore, reparations must be grounded in, and recognise and advance human rights of all people living with dementia, noting that people with disability have equal rights.**

Public knowledge of truthful accounts of harm and of perpetrators is central to holding them to account.

The necessary centring of the needs and perspectives of those who have been impacted by harm must not result in ignoring who has caused this harm.

**Therefore, reparations must be directed towards holding all parties to account for harm, including governments and residential aged care providers.**

Reparations will be futile if they are not trying to stop current harm and prevent future harm.

The past can't be changed, but the past can inform how we change for the future.

**Therefore, reparations must be directed towards stopping and preventing people living with dementia being harmed in residential aged care, in a wider context of advancing equality and dignity of people living with dementia.**

Many people living with dementia and care partners and family members who participated in the Royal Commission into Aged Care Quality and Safety shared personal experiences at great personal cost to them. It is important to recognise and honour these experiences.

The Royal Commission into Aged Care Quality and Safety made important recommendations about how to improve the aged care system, but omitted to consider or recommend systems for redress or reparations.

The Australian Government must act and implement the recommendations of the Royal Commission into Aged Care Quality and Safety.

Reparations are critical to prevent future harm in residential aged care, even though redress or reparations were not mentioned or recommended by the Royal Commission into Aged Care Quality and Safety. However, reparations must not undermine everything that was learned through the Royal Commission into Aged Care Quality and Safety.

**Therefore, reparations must be informed by the experiences of people living with dementia and their families and care partners shared at the Royal Commission into Aged Care Quality and Safety, and support implementation of the Commission's recommendations.**

People living with dementia and their care partners and family members experience physical, psychological, emotional and economic suffering and mistrust of and anger towards the aged care system, governments and health and legal professions.

Harm in residential aged care has caused broken social and moral relations.

Reparations must provide tangible repair for individuals, families and society.

**Therefore, reparations must be an opportunity for healing and moral repair.**

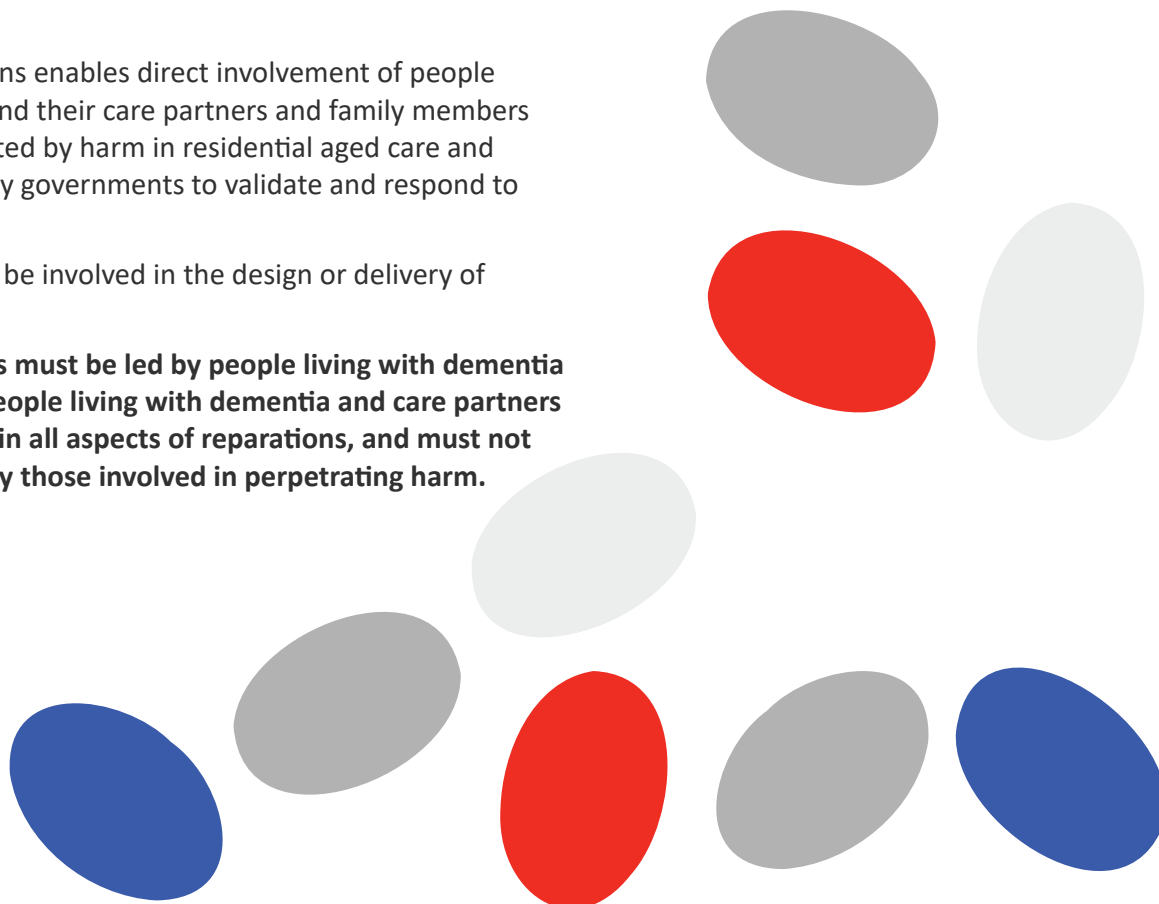
People living with dementia are often excluded from involvement in policy design and implementation because they are considered to lack capacity.

Co-design is one way to challenge paternalism and ableism towards people living with dementia and realise equality and self-determination.

Co-design of reparations enables direct involvement of people living with dementia and their care partners and family members who have been impacted by harm in residential aged care and reflects direct action by governments to validate and respond to their experiences.

Perpetrators must not be involved in the design or delivery of reparations.

**Therefore, reparations must be led by people living with dementia and co-designed by people living with dementia and care partners and family members, in all aspects of reparations, and must not be led or influenced by those involved in perpetrating harm.**



# Principles

## Necessity and scope of reparations

### Principle 1: Human rights

Reparations are critical to realising and protecting the human rights of all people living with dementia.

### Principle 2: Recognition

Reparations are critical to officially recognising that the harm to people living with dementia is unlawful and wrong and that this harm has ongoing and longer-term impacts on people living with dementia and their family members or care partners.

### Principle 3: Validation

Reparations are critical to ensuring the experiences of people living with dementia who have been harmed in residential aged care and their families and care partners are listened to, validated, and acted on, so these experiences are drivers of change which governments and residential aged care providers will be held accountable for making.

### Principle 4: Accountability

Reparations are critical to ensuring all parties are held to account for harm, including governments and residential aged care providers.

### Principle 5: Prevention

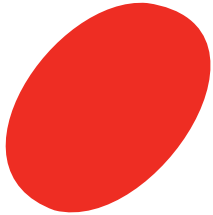
Reparations are critical to ensuring systems and structures are changed and that the harms experienced in the past are not repeated, now or in the future.

### Principle 6: Justice and regulatory failure

Reparations are critical because of failures of existing justice, regulatory and political systems to acknowledge and respond to this harm.

### Principle 7: Profit

Reparations are critical because people living with dementia have been harmed in a profit-driven industry.



# Forms of reparations

## Principle 8: Rehabilitation and improved living conditions

Reparations must include counselling, rehabilitation and restorative care, including support and resources to move out of one's existing residence and into the community.

## Principle 9: Truth-telling

Reparations must include publicly available, truthful accounts of harm to people living with dementia and the wide-ranging impacts of that harm, which validate the experiences of people living with dementia and their families and care partners and are followed by actions to prevent future harm.

## Principle 10: Apologies

Reparations must include apologies by residential aged care providers and governments which are followed by actions to prevent future harm.

## Principle 11: Monetary payments

Reparations must include monetary payments to provide symbolic recognition of harm to people living with dementia, reimburse payments for residential aged care, cover cost of rehabilitation and restorative care, and fund advocacy and legal costs.

## Principle 12: Sanctions

Reparations must include sanctions to hold residential aged care providers (including board and staff members), governments (including public servants), and medical and legal professionals accountable for harm.

## Principle 13: Human rights-based reform

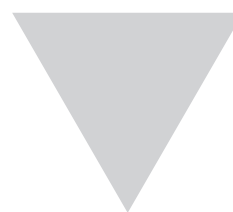
Reparations must include human rights reform of aged care governance, laws and practices led by people living with dementia and their families and care partners, in order to prevent future harm.

## Principle 14: Staff and board training

Reparations must include training and education on dementia to healthcare and legal students and residential aged care providers and all staff and board members, including on human rights and dementia as a disability.

## Principle 15: Empowerment and advocacy

Reparations must include measures to empower people living with dementia to realise their human rights and provide resources to advocate.



# Reparations processes

## Principle 16: Recognise diversity

Reparations processes must be centred on individuals' diverse identities and experiences, including individuals' gender, sexuality, disability, Indigeneity, cultural and linguistic diversity, and histories of institutionalisation, incarceration and victimisation.

## Principle 17: Trauma-informed

Reparations processes must be trauma-informed and culturally safe.

## Principle 18: Disability inclusion and access

Reparations processes must be inclusive and accessible to all people with disability, including disability associated with dementia.

## Principle 19: Inclusive, accessible and equitable

Reparations processes must be inclusive, equitable and accessible to all people who have been harmed or impacted.

## Principle 20: Promote reparations

Reparations processes must be supported by dissemination and accessibility of information about reparations, including to people who are socially isolated or have cultural, language or literacy barriers.

## Principle 21: Collective applications

Reparations processes must include an option for collective applications.

## Principle 22: Independent advocacy

Reparations processes must include access to free, independent and experienced advocacy.

## Principle 23: Safe, timely, independent and transparent

Reparations processes must be safe, timely, independent and transparent, without risk of retaliation.

## Principle 24: Communication and enforcement of outcomes

Reparations processes must include communication of outcomes to individuals and monitoring and enforcement of outcomes.

## Principle 25: Reform justice and complaint systems

In addition to reparations, individuals must have equal access to criminal justice, civil justice and complaint systems, and governments must make reforms to ensure these systems are safe, accessible and inclusive.

