

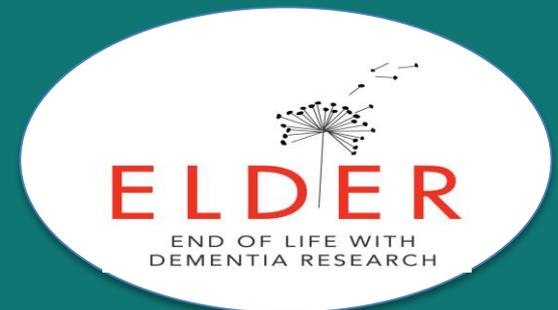
Can neurodegenerative end of life care be improved with individualised interventions?

ELDER: End of Life with Dementia Research

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**MEDICAL AND
HEALTH SCIENCES**



Project Aims:

Phase 1 aims to determine quality of death from the perspective of Aged Residential Care (ARC) staff.

Phase 2 of the study aims to determine the quality of death from families' perspective.

Phase 3 a palliative care guide for neurodegenerative conditions will be developed to translate evidence into practice.

***This project is co-funded by the
Guardian Trust - Ted and Molly Carr Trust***

Implementation Plan:

Phase 1:

- **September 2015:** Ethics approval completed
- **October 2015 to June 2016:** Recruit 60 randomly selected and stratified facilities (20 each Auckland, Wellington, Christchurch) 15 Auckland facilities recruited so far.
- **Jan 2016 to September 2016:** Death monitoring period
- **Jan 2016 to December 2016:** Staff quality of death questionnaires

Phase 2:

- **July 2016 to Mar 2017:** Recruit Family Participants
- **July 2016 to Sep 2017:** Family interviews and surveys
- **Jul 2017 to Mar 2018:** ELDER final analysis and report writing

Phase 3: Two-Way Public Engagment KPI:

- **Oct 2017 to Jun 2018:** Development of care guides for publication and distribution in collaboration with residential aged care providers

Linkages to other Ageing Well Projects:

- **Adding life to years for all older New Zealanders:** Excellent palliative care is important to maintain 'wellness' even in the face of dying, and promote quality of life and 'living until one dies'.
- Providing the evidence needed to enable ***age friendly environments*** that accommodate all disabilities and promotes the best quality of living possible even at the end of life.
- An important component to ***maintain wellness, independence & autonomy*** and ***reducing disability and the impact of disability***, both of which are achievable even in the face of incurable cognitive impairment.
- This approach also acknowledges that ARC is the 'de facto' hospice for a large proportion of older people and therefore, understanding and improving palliative care for this population is an important way to ***value older people in all settings.***



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Thank You



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