

Issue 7: *Managing Crises*

Welcome to Evidence at a Glance No 7. This issue focuses on the study *Causes of crises and appropriate interventions: The views of people with dementia, carers and healthcare professionals*.¹

In a dementia related crisis events occur that disrupt a previously stable situation. There is a need to make decisions immediately to resolve the situation.² The NICE guideline on dementia recommends involving people with dementia in decision making; and ensuring people living with dementia “know how to get more information and who from if their needs change”.³

The Alzheimers New Zealand Dementia Services and Standards Model includes the service *Managing through a crisis* – averting, responding and recovery. The standard components for this service are that people living with dementia:

- receive appropriate information to avert, or minimise the impact of, acute events and/or crises.
- experience relevant and timely advice, support and response to acute (dementia related) events and/or crises.

The research discussed in this issue identifies factors leading to a crisis along with helpful interventions.

Methods

The English study *Causes of crises and appropriate interventions: The views of people with dementia, carers and healthcare professionals*¹ explored the perspectives of people with dementia, carers and health professionals using a focus group approach. In total 18 people with dementia, 15 family carers, and 19 healthcare professionals were interviewed. Participants were asked about the issues that could lead to a crisis, helpful support and what might be useful interventions.



¹Toot, S., Hoe, J., Ledger, R., Burnell, K., Devine, M., & Orrell, M. (2013) Causes of crises and appropriate interventions: The views of people with dementia, carers and healthcare professionals, *Aging & Mental Health*, 17(3), 328-335. doi: 10.1080/13607863.2012.732037

²MacNeil Vroomen, J., Bosmans, J. E., van Hout, H. P., & de Rooij, S. E. (2013). Reviewing the definition of crisis in dementia care. *BMC geriatrics*, 13 (10). doi:10.1186/1471-2318-13-10

³ National Institute for Health and Care Excellence (2018) *Dementia: Assessment, management and support for people living with dementia and their carers. NICE guideline*. United Kingdom: Author. Retrieved from <http://nice.org.uk/guidance/ng97>

Key Findings

Causes of crisis

People with dementia stressed:

- Risks and hazards in the home.
- Hazards with daily living tasks- leaving gas and taps on, cooking and fire hazards.
- Falls and physical hazards in the home.
- Outdoor safety - traffic, forgetting keys, garden accidents
- Inability to assess a possible risk like letting a stranger in the home.

Family carers talked about:

- Excessive family commitments.
- Mental health issues – depression.
- Distress and taking on intimate tasks such as helping with continence.

Other causes of crisis discussed by participants included:

- Changes in memory and behaviour such as inappropriate communication with neighbours, unsafe walking and physical aggression.
- Poor services and continuity of care such as problems not being investigated quickly or thoroughly enough, difficulties approaching community services, and inappropriately trained home care staff.
- Physical health issues e.g. incontinence, falls, infection, nutritional problems.
- Social/environmental changes including home adaptations causing confusion. family carer having limited knowledge about dementia, and changes in family structure.

Interventions in a crisis

- Home adaptations for preventing crises included prompts and reminders around the home, telephone access for communication, and assistive technology i.e. gas and movement detectors, personal safety alarm, alerts/pagers.
- Neighbours and friends keeping a watchful eye to make sure the person is alright.
- Specialist home care services during a time of crisis with knowledgeable staff.
- Emergency access to respite.
- Family carer education and training in dementia, first aid, moving and handling and how to prevent crises including attending family support groups.
- Professional health care support such as easy access to A&E and out of hours doctor service, regular physical health checks, medication reviews, multidisciplinary team assessments, specialist nursing support.
- Healthcare professionals need to be more reassuring and express greater empathy.
- Having a care plan and one main point of contact known to the family.



Summary

Aotearoa/New Zealand participants in the study *This is our story: A qualitative research report on living with dementia*⁴ talked about not being taken seriously when needing support and that they were only heard when a crisis happened. Families also talked about needing the right help and support at the right time. Proactive and tailored education and support can ensure people living with dementia are well informed about safeguards to prevent crises and have the information to make informed decisions if a crisis occurs.



Questions for discussion

- Are there other causes of crisis not covered in this article in the Aotearoa/New Zealand context?
- How about interventions? Do you know about crisis interventions in your area not mentioned in the article?
- What sort of advice do you give people with dementia and care partners about preventing crises?
 - When is the best time to provide advice?
 - Can you incorporate the findings of the research in your advice or do you already cover all the findings?
 - Do you have a written individualised crisis support plan for families as part of the overall support plan? Could that be developed in light of the research findings?

⁴ Smith, E., Lamb-Yorski, R., Thompson, A., & Grootveld, C. (2019). *This is our story: A qualitative research report on living with dementia*. Wellington, New Zealand: Litmus. Retrieved from <https://www.alzheimers.org.nz/our-voice/new-zealand-data/lived-experience-of-dementia-research>