



## Evidence at a Glance

### Issue 4: Shared Decision-Making

Welcome to *Evidence at a Glance No 4*. In each issue we use a research report to focus on an issue of relevance for member organisations.

This issue focuses on shared decision-making, defined as “a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences”<sup>1</sup>.

The NICE guideline on dementia<sup>2</sup> recommends that people with dementia are involved in decision making:

- “Encourage and enable people living with dementia to give their views and opinions about their care.
- If needed, use additional or modified ways of communication (for example visual aids or simplified text).
- Consider using a structured tool to assess the likes and dislikes, routines and personal history of a person living with dementia” (p.11).

The [United Nations Convention on the Rights of People with Disabilities](#) states that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (Article 12). Aotearoa New Zealand has ratified this convention.

### Shared decision-making: A systematic review

The paper *Shared decision-making for people living with dementia in extended care settings: A systematic review*<sup>3</sup> explores how people with dementia can be included in day to day decisions about their health and care. The review<sup>4</sup> identified 19 papers, most qualitative, on shared decision-making and people with dementia in either the community or supported living.

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<sup>1</sup> Coulter, A., & Collins, A. (2011) *Making shared decision-making a reality: No decision about me without me*. London, England: Kings College. Retrieved from <https://www.kingsfund.org.uk/publications/making-shared-decision-making-reality>

<sup>2</sup> 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>

<sup>3</sup> Daly, R.L., Bunn, F., & Goodman, C. (2018). Shared decision-making for people living with dementia in extended care settings: A systematic review. *BMJ Open*, 8, e018977. doi:10.1136/bmjopen-2017-018977

<sup>4</sup> A systematic review is a review, critique and synthesis of several original research papers on a defined research question using an articulated methodology

Although the intention was to focus on extended care situations most studies were conducted in the community. The majority of decision-making processes involved the person with dementia and the care partner, or in a group of three which included a health care worker as well.

### **Key findings**

- Understandings vary of what shared decision-making means and how to carry it out depending on the context.
- In one study people with dementia felt that it meant they were supported and were central to the process rather than side-lined.
- Many people with dementia felt participation in the process was more important than the decision itself.
- There were examples of ‘substituted decision-making’ excluding the person with dementia by the care giver or staff and some people with dementia reported unhappiness with this.
- Characteristics of shared decision-making included
  - “information received,
  - being listened to,
  - ability to express an opinion,
  - time allowed for reflection
  - and opportunity to change the decision” (p.7).<sup>3</sup>
- Care partners underestimated the desire of people with dementia to take part in decisions. One study using a vignette found that while 72% of care partners thought that the person with dementia wanted to participate in a decision about taking a disease slowing medication, 91% of people with dementia wanted to participate in the decision.
- In one study the characteristics of care workers in extended care that facilitate shared decision-making included warmth, encouraging use of memory and routines.
- Care worker characteristics impeding shared decision-making included discouraging independence, impersonal care, and being risk adverse. Routines could also discourage decision making if dominated by task-orientated behaviour.
- Three studies showed that optimal decision making was achieved by recognising the abilities and rights of a person with dementia to take part in decision-making through offering support and reinforcing behaviours.
- Several studies looked decision making tools such as visual aids such as [Talking Mats](#) and computerised tools.

- Benefits of ongoing participation in decision-making included improved self-esteem, a sense of self-worth, reduced symptoms of depression and the maintenance of everyday functioning.

## **Conclusions**

The New Zealand study *This is our story: A qualitative research report on living with dementia*<sup>5</sup> supports the findings of the systematic review. There is increasing awareness that shared decision-making is as important in day to day situations as in major events such as change of treatment or living situation. People with dementia want the opportunity to take part in decisions about both their day to day life and more noteworthy events. This has social and health benefits for both people with dementia and care partners.

## **Questions to discuss**

- Is your organisation promoting shared decision-making?
- If not how might you promote shared decision-making?
- How do you create opportunities for people with dementia to participate in shared decision-making in your organisation and everyday activities?
- Do you include advice on the importance of shared decision-making with care partners and in presentations to health professionals? If not what might be a good start?

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<sup>5</sup> 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>