

# **Supporting people living with dementia, their carers and surrogate decision-makers**

## **Background**

### **General**

- In Western democracies, where autonomy is respected, individuals make decisions about their own lives and have the right to have their choices respected by others
- Ability to make decisions and have decisions upheld is central to self-determination
- Positive relationship between involvement in decision-making, sharing preferences and opinions, and quality of life
- Respect for a person's right to make decisions is fundamental to the provision of person-centred care

### **People living with dementia**

- Important for people living with dementia to remain involved in decision-making
  - Everyday decisions
  - Life changing decisions
- People living with dementia may not be able to make decisions about how to manage their finances but they are able to make decisions about their everyday care
- Cognitive impairment in dementia is not uniform
- Decision-making for a person living with dementia is unique to that person
- Onus on others to prove that someone does not have capacity to make decisions
- Verbal communication only a small part of communication - ? whether the inability of a person living with dementia to verbally communicate is taken as an inability to participate in decisions
- Attitudes of others (i.e. health professionals, family, researchers) towards a person living with dementia because of their diagnosis can be a barrier to their involvement/participation in decision-making

### **Professional carers of people with dementia in residential aged care**

- Have a role in facilitating involvement of people living with dementia in everyday decision-making
- Barriers/enablers?

## **Surrogate decision-makers of people living with dementia**

- Prior to diagnosis of dementia person living with dementia had capacity to make their own decisions
- As dementia progresses the capacity of the person to make decisions diminishes until a time when someone else has to take over
- Emphasis on appointing substitute decision-makers/power of attorney but not on how to support them in making decisions on behalf of someone else

## **ACEBAC program of research – decision-making and dementia**

1. What is the essence of decision-making for people living with dementia?
2. How do family carers facilitate remained involvement in decision-making for people living with dementia
3. How do paid carers decide about people living with dementia and their participation in decision-making?
4. How do surrogates make decisions for people living with dementia - precedent autonomy or best interests?

### **1. What is the essence of decision-making for people living with dementia?**

'I am still here!'

Decision making for participants living with dementia was a constant negotiation between:

- subtle support versus taking over. Subtle support involved sitting down with the person living with dementia and establishing a plan, making suggestions and forming strategies that would enable them to do as much as possible independently i.e. shopping lists, lists of jobs etc. The best form of subtle support was when carers were a 'backup' for the person living with dementia.
- hanging on versus letting go. Participants wanted to hold on to their decision-making for as long as possible but required constant renegotiation and compromise as to what decisions to relinquish and what to hang on to. Some participants developed strategies to facilitate this i.e. diaries, alarms, reminders etc. Recognised that if they didn't allow others to be involved in their decision-making they would not be able to get the support they needed that was integral to maintaining some independence.
- being central versus being marginalised or excluded. Participants acknowledged the importance of feeling central to decisions that involved them and strongly resented when their input was ignored or when they were excluded or marginalised.

(Fetherstonhaugh et al, 2013)

### **2. Family carers and supporting people living with dementia to make decisions**

- Majority of people living with dementia reside in the community and family members are involved in their care.

- Fine line between developing strategies to assist decision-making for people living with dementia and taking over

Findings suggest that supporting and facilitating decision-making for people living with dementia relates to the caregiving relationship (which for participants was longstanding and familial and for most, intimate)

- Importance of decision-making to the humanity of people living with dementia – carers believed that supporting their spouse to be involved in everyday decision-making contributed to the person’s sense of self and maintained autonomy and independence for as long as possible; also provided some empowerment and dignity. Part of caring for someone they love. Decision-making for carers and the person living with dementia had always been a shared enterprise.
- Knowing the person and working together. Facilitating and supporting decision-making often involved negotiation and communication – acknowledgement of a life spent together – knowing the person, understanding their current abilities, respecting their likes and dislikes and being sensitive to things that distressed them; love and respect despite a diagnosis of dementia. Carers encouraged and supported the person living with dementia to make decisions by: making suggestions; explaining things repeatedly and finding the right time and; setting or environment to enable decision-making. Strategies were invariably revised as person’s cognitive ability declined.
- The paradox of care – how spousal carers can, with the best of intentions, act contrary to their desire to support and respect individual decision-making, by being too risk adverse or allowing their own beliefs and values to override a decision made by their spouse living with dementia

(Fetherstonhaugh et al, 2016 in press)

### **3. Paid carers and everyday decision-making for people living with dementia**

Utilise a number of strategies in their intention to support decision-making for people with dementia

- Keeping it simple – restricted choices ‘the red dress or the blue’ – showing them the choices (visual cues/prompts); using simple unambiguous language; showing consistency of expression; allowing the person time to decide; avoiding an environment that was distracting or noisy
- Knowing the person and how they communicate; individual expressions of choice and preferences; ensuring a relationship of trust; finding out information from the person’s family
- Negotiating a compromise

#### Barriers

- Organisational barriers – having to work within the system – finding time (task oriented – routine), competing rights (family), not knowing (i.e. whether the facility had a policy etc.)
- Risk aversion – a responsibility to protect
- Duty of care – what does this mean?

(Fetherstonhaugh et al, 2014; Tarzia et al, 2015)

#### **4. Surrogate decision-making for people living with dementia**

Process of decision-making

- Knowing the person's wishes - ? formal documentation, verbal conversations – could prove difficult when having to make decisions
- Consulting with others – family, health professionals, other caregivers
- Striking a balance between respecting the known wishes of the person living with dementia and looking after their perceived 'best' interests by keeping them safe, comfortable and well looked after.

(Fetherstonhaugh et al, 2016)

Majority of participants reported that the person for whom they made decisions did not have an advance care plan – research highlights the importance of the advance care planning process in helping surrogate decision-makers clarify their role and expectations in the decision-making process. Advance care planning can also help the surrogate decision-maker understand any previously stated wishes of the person with dementia and guide discussions so that goals of care and treatment decisions reflect these wishes.

How surrogate decision-makers can be supported in making decisions:

- increasing community awareness and understanding of the impact of dementia
- intervening early in cognitive decline
- health professionals acting as empathic guides
- having consistent and ongoing professional support
- getting input from carer organisations and other carers
- seeking and using support from wherever is relevant for each person.

#### **Future research/education**

- Education for both family and paid carers
- Support strategies and interventions for surrogate decision-makers
- Exploring 'duty of care' in residential aged care

## Journal articles

### **Published**

1. Fetherstonhaugh, D. McAuliffe, L. Bauer, M. & Shanley, C. (2016) 'Decision-making on behalf of people living with dementia: How do surrogate decision-makers decide?' *Journal of Medical Ethics* doi:10.1136/medethics-2015-103301
2. Tarzia, L. Fetherstonhaugh, D. Bauer, M. Beattie, E & Nay, R. (2015) 'We Have to Work Within the System!: Staff Perceptions of Organizational Barriers to Decision Making for Older Adults With Dementia in Australian Aged Care Facilities' *Research in Gerontological Nursing*. doi: 10.3928/19404921-20150413-01
3. Fetherstonhaugh, D. Tarzia, L. Bauer, M. Nay, R. & Beattie, E. (2014). 'The Red Dress or the Blue?': How do staff perceive that they support decision making for people with dementia living in residential aged care facilities? *Journal of Applied Gerontology*. Published online doi: 10.1177/0733464814531089
4. Fetherstonhaugh, D. Tarzia, L & Nay, R. (2013) 'Being Central to Decision Making Means I am Still Here!: The essence of decision making for people with dementia'. *Journal of Aging Studies* (27) 143-150.

### **In press**

Fetherstonhaugh, D. Rayner, J & Tarzia, L. 'Hanging on to some autonomy in decision-making: How do spouse carers support this?' *Dementia*

### **Revisions under review**

Shanley, C. Fetherstonhaugh, D. McAuliffe, L. Bauer, M & Beattie, E. Providing support to surrogate decision-makers for people living with dementia: healthcare provider, organisational and community responsibilities. *Health and Social Care in the Community*