



CONTINUING TO CARE FOR PEOPLE WITH DEMENTIA

Irish family carers' experience of their
relative's transition to a nursing home

Garden Shed



My Father's Cap



My desk





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CONTINUING TO CARE FOR PEOPLE WITH DEMENTIA

Irish family carers' experience of their
relative's transition to a nursing home

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MAKING KNOWLEDGE WORK

Why this research?

- Grassroots led research agenda/small niche pieces of research/impact on policy and/or practice
- Anecdotal - listening to people and their stories; majority of people who leave our services to go into NH
- Some major milestones on the dementia journey
- Making the transition to long term care = major event for family carers
- Wanting to understand the experience/respond

Purpose of the Study

- Describe carers' experiences of the transition of their relative who has dementia to nursing home care
- To provide evidence based guidance for the development of initiatives to support carers

Find answers to the following questions:

- What are key influences in making the decision?
- What are the carers experiences of the transition?
- How has the family carers role changed?
- What roles do carers want?
- How can they be supported in these roles?

Method

- Carers recruited by ASI/St. Luke's Home (currently experiencing/recent experience)
- Qualitative approach using
 - ✓ *semi structured, one-to-one interviews incorporating 'photo voice' methods (5 people/3 occasions)*
 - ✓ *focus groups (3 groups/9 people)*
- Data analysed using grounded theory approach

Findings – 5 themes emerged

Theme 1: key Influences in Decision Making

- Accumulation of a range of factors; commonly shared; professionals KEY prompt
- Lack of community supports (formal and informal)
- Demands of 24 hour caring at home; providing personal care/safety
- Declining health of carer/person with dementia
- Conflicting roles and responsibilities
- Independent financial means



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Findings: Themes – cont'd

Theme 2: Process of Transition

- Mixed emotional responses (relief/guilt/loss/new roles)
- Influences on the experiences of transition (spouses/adult children/negative attitudes/adaption over time)
- Facilitators to adjustment (quality of care, stimulating environment, familiarity, incremental formal support, emotional and spiritual support)

Findings: Themes – cont'd

Theme 3: Carer's Role

- **Continuity** (spending time/performing tasks) and **change** (monitoring quality of the care rather than being provider)
- Changed relationship with family member (+/_)
- Carer's loss of identity post transition

Findings: Themes – cont'd

Theme 4: Carer's Desired Role

- All wanted to be involved in the care of their family member
- participate in wider life of home
- 'resume' own life
- Some unsure how to remain involved and how receptive the care home staff would be

Findings: Themes – cont'd

Theme 5: Supporting Carers in Transition

- Good lines of communications with staff, information and education about dementia and dementia care and on-going emotional support
- Utilising their expertise
- Mentor schemes peer support groups
- Recognise the diversity of carers

Recommendations

- Enhance community based services so that NH admission is a proactively planned choice, not crisis driven; case management model
- Need to guide and support people through the system/pre and post transition
- Challenge stigma of dementia and NH care
- Professional practitioners adopt proactive and preventative approach/prompt and gradual input of appropriate support

Recommendations/2

- Dementia specific training for staff in NH
- NH support carers to be facilitated (HIQA standard 20); accessible environment open visiting policy, opportunities to participate
- Information, education and emotional support to carers at the various stages of the transition process
- Further research needed

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My Dog



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THANK YOU!

