Home Alone With Dementia

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Dementia

• The cognitive decline that happens with dementia makes it difficult for a person to live independently.

• As the severity of dementia increases, so does the difficulty of living independently.
Living Alone

• Living in community:
  – 70% of people with dementia live in community
  – 12% of these people live alone
  – More females with dementia live alone than males

2012, AIHW, Dementia in Australia
Research

• However, there is still only limited information available about the challenges faced by this group of people
Study Method

• Purpose
  – Explore the challenges faced by people who have dementia and live alone in the community

• Methodology
  – Qualitative descriptive

• Sample
  – Health and social care professionals who support people with dementia in the community

• Data collection & analysis
  – Interviews and focus groups
  – Thematic analysis
Results

• 9 major areas of challenges identified
  – Caring for self
  – Caring for the house
  – Keeping safe
  – Managing money
  – Coping with technology
  – Driving
  – Family, neighbours and other people
  – Disconnection
  – Maintaining adequate nutrition
Caring for Self

• Concerned three main areas:
  – **Hygiene**
    Not washing, changing clothes or washing clothes
  – **Incontinence**
    Increasing severity of dementia may exacerbate problem, many lack the capacity to manage the situation
  – **Health care**
    Attending appointments, taking prescribed medicines and managing other health problems
• Incontinence:

Margaret believed she was coping fine with her incontinence, and beside, she didn't want people getting involved in that part of her life. However, community care staff would often find soiled underwear put neatly away in her drawers. (Interview 6)
Caring for the House

• Poor house care:
  – Inadequate cleaning
  – Lack of regular home maintenance

• Problem exacerbated by:
  – Urinary and faecal incontinence
  – Dogs and cats, rats, mice and pigeons
Vignette

• Care of the house:

Susan was having many problems trying look after her home. Eventually it reached such a poor state of cleanliness that she had rats in her bed.

Some community service staff would not enter the house because of concerns about occupational health and safety. (Interview 3)
Keeping Safe

• Keeping safe is a broad area of challenge

• Concerns:
  – Fires
  – Locked doors
  – Falls
  – Wandering and getting lost
Vignette

• Risk of fire:

*Linda was cooking a meal, she got distracted and then forgot all about it. The food started to burn and the smoke alarm went off. Linda did not notice the smoke or hear the alarm. The fire that started was eventually detected by a neighbour who saw the smoke.*

*When the neighbour entered the house, Linda was sitting at the kitchen table oblivious to the alarm and to the house full of smoke* (Interview 5).
Managing Money

- Managing money and finances is difficult for people with dementia who live on their own.

- Challenges include:
  - Not being able to manage their finances (loans, ATMs, and using money at shops)
  - A soft touch
Vignette

- Financial management:

  *Samantha took over her mother’s finances when she was no longer able to manage them. She discovered that her mother had recently taken out multiple high interest loans for a TV, heater and other household items. So her financial state was very poor* (Interview 4)
Coping with Technology

• Technology challenged people with dementia, and they found it difficult learning how to use new appliances

• Technologies that were challenging include:
  – Phones
  – Household appliances
  – ATMs
• Using ATMs:

Rachael found ATMs tricky to use because you only get three goes before it disconnects and keeps your card. To overcome this, she would sometimes ask strangers to help her use the machine to withdraw her money (Interview 7)
Driving

- Driving is a particularly challenging area for people with dementia, families and GPs.
- Gophers were also identified as a risk because of the lack of guidelines or restrictions on their purchase and use.
Vignette

• Gophers:

Bob drove his new gopher to the health centre. He had an accident while there, he went through the front door, into the lift and came out the other end and then smashed into big double glass doors because he didn’t know how to stop it

(Interview 7)
Family, Neighbours & Other People

• Support from family is critical for the wellbeing of the person with dementia, but sometimes things can go astray
  – Family not understanding the dementia
  – Family not supportive
  – Their vulnerability means that they are an easy target for unscrupulous people
  – Abuse of trust
Vignette

• Family not supportive:

_Cheryl assisted her mother by doing her shopping._

Early in the morning Cheryl would enter her mother’s house, deliver the shopping and then leave while her mother still slept unaware of the visit because she didn’t use her hearing aids at night (Interview 5)
Disconnected

• Having dementia and living alone brings with it a risk of becoming disconnected
  – Isolation
  – Keeping the dementia a secret
  – Coping when things go wrong
  – Living alone
Vignette

• Hiding the dementia:

Ruby hid her dementia from her family. She had labelled all of the cupboards when she started to become forgetful. Eventually, everything in the house was labelled. She had a whiteboard next to her phone and used a diary to aid her memory. She didn’t let her family visit, she always visited them for family functions. She was in the latter stages of dementia before her family finally realised (Interview 2)
Maintaining Adequate Nutrition

• One of the most common challenges is maintaining an adequate nutritional intake

• Challenges include:
  – Forgetting to eat
  – Unable to prepare food
  – Unable to shop
  – Poor food storage
  – Poor meal selection
Forgetting to eat:

Paul will tell community care staff “oh yes I’ve had lunch” but he hasn’t. However, if he has food placed in front of him he will eat it. He needs to be prompted by visual cues (Interview 6)
• Unable to preparing food:

*Joan cooked her own food, but sometimes half way through the meal preparation she would forget what she was cooking and so would have to abandon the meal.

Other times she would put the food in the oven to cook and then forget all about it*  (Interview 8)
Vignette

• Unable to shop:

When Nancy goes shopping she buys the same things each time but not necessarily the things that she needs”
(Interview 8)
Vignette

• Poor food storage:

Sarah lacks the insight to be able to safely store her food. The meat in her refrigerator is 4 weeks old, the vegetables were all shrivelled up and other food was rotting. The food in her pantry was years past its use-by-date.

(Interview 8)
Vignette

• Poor meal selection:

*Betty had less than 5 minute recall, so she would eat biscuits and all the easy stuff, all the snacky stuff and then she would be hungry so she would wander and knock on neighbours doors* (Interview 7)
Implications

- The challenges suggest three broader issues:
  - Vulnerable population
  - Hidden problems
  - Disconnected

- Also issues surrounding the concept of ‘living alone’
Vulnerable

• People who have dementia and live on their own in the community are a very vulnerable group of people

• Normal daily activities can pose a greater than normal risk to these people

• But each person:
  – has their own unique set of risks
  – responds in their own unique way to the challenges
Hidden Problems

Malnutrition & Dehydration

Not Eating
- Forgetting to Eat

Poor Nutrition
- Poor Meal Selection
- Unable to Cook

Decaying Food
- Unable to Shop
- Poor Food Storage
Vulnerability & Hidden Problems

Critical Event

- Caring for self
  - Hygiene
    - Incontinence
      - Health
- Caring for Home
- Nutrition
- Safety
- Money
  - Can’t Manage Money
- Technology
  - Appliances
- Driving
- Family & Other people
  - Not Understanding
  - Living Alone
- Disconnected
  - Not Supportive
  - Isolated
  - Neighbours
  - Secret
  - Abuse of Trust
  - Coping When Things Go Wrong
Disconnected

• There is a risk that the person increasingly becomes disconnected from the community:
  – Living alone
  – Isolated
  – Secret

• Disconnection brings its own challenges:
  – Coping when things go wrong
Living Alone

• Living alone takes many different forms:
  – Alone during day
  – Alone at night
  – Temporarily loss of support
  – Limited or no support from family
  – Difficult domestic situation
  – Unexpectedly alone
  – Hiding the dementia
  – Two people with dementia
Thank you