

Should I go or should I stay? Deciding an 'optimal' time for people with dementia to move to a care home

Older People's Annual Conference 2019

Research team: Kritika Samsi, Jill Manthorpe, Laura Cole
Health & Social Care Workforce Research Unit

King's College London

7th March 2019

Acknowledgements and Disclaimer

We thank all participants for taking part in this research and sharing their views and experiences.

We are also grateful to our funders the NIHR School for Social Care Research. The views expressed in this presentation are those of the authors, and not necessarily those of the Department of Health & Social Care, the NIHR, the NHS or its arm's length bodies.



National Institute for
Health Research

School for
Social Care Research

Background to the study



Moving to a care home may be **difficult decision** for some people with dementia and their carers. Studies suggest people with dementia are often **not included in decisions**, which may negatively affect their ability to settle into the care home.

Determining **when (if any) is an “optimal time”** to make this move may be difficult.

Our review of the literature was completed in 2018.

Published:

Cole L, Samsi K & Manthorpe J (2018) 'Is there an “optimal time” to move to a care home for a person with dementia? A systematic review of the literature', *International Psychogeriatrics*, pp. 1-22. <https://doi.org/10.1017/S1041610218000364>

Aims of the study



3 year, 3 part, multi-methods study which is investigating:

1. **Factors** that affect decision to move
2. **Drivers** of this decision
3. What may be considered an '**optimal**' time to move

Method: What we did

- Face to face one-off interviews
- Audio-recorded, with permission, transcribed
- Analysed using thematic analysis (looking for repeated patterns in transcribed interviews)

Method: Who we spoke to

Criteria: Those who had supported people with dementia and family carers to make the transition to a care home move

Social workers (20): 2 men, diverse ethnicity, 5 worked in hospitals

Care home managers (20): 4 men, 14 White British

Criteria: People with dementia who had moved to a care home in the last 6 months, and their family carers

People with dementia (5): 3 men, all White British, residential, self-funding

Carers (21): 9 men, 20 white British, 1 sibling + 15 adult children + 4 spouses + 1 adult grandchild

Findings: Social workers

- Risk and safety + family carers' ability to continue with caring at home safely
- Wishes of person with dementia were very important
- Acting in the best interest of person with dementia necessary:
 - Even if over-riding their wishes
 - Reports of these having positive outcomes

So it's kind of constantly looking at the risk, I think and weighing up. Is that a risk that we would be willing to take? Is there something we can do to kind of prevent that risk to get them back home [from hospital]? But if we have kind of ruled out everything, then we will suggest that maybe a [move to a care home] would be the better option. (SWo8)

Findings: Care home managers

- Early moves beneficial as care staff can get to know likes/dislikes of person with dementia better
- Needs to be balanced against most older people's wishes to stay in their own homes for as long as possible
- Paving the path:
 - Respite suggested by social workers as stepping stone towards permanent move
 - Waiting lists used by relatives as a way of preparing for a permanent move

We write to people every three or four months and say “are you still interested and do you still want to be on the waiting list?” A lot of people say “we are managing all right at the moment, but we want to stay on the list”. But they don't actually say [that] they are making their own decision about [whether it is] the right time, really. (CHM05)

Findings: People with dementia and carers

- Decision was difficult and emotional experience
- Carers would have liked more support and knowing where to go – especially true for those who are self-funding
- Sometimes the move to a care home took time, and there could be many moves between home, hospital and other care homes
- Some continued to find the move stressful/difficult months after the move
- Many carers appeared to have limited awareness of finances

“She was not ready [then] to come into a home. She used to still go out to the shop and get her paper and do all that. Okay, used to leave her credit car all over the place! [laughs] But I think it was the right time for her to go into a home. I think, I suppose we could have done it a few months earlier, perhaps. I think it was alright. That was why it was November and we thought shall we wait until the New Year. No we won't. We have got to move her.” (RF01)

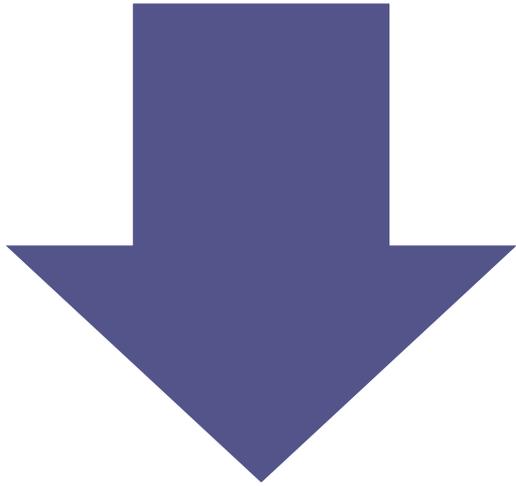
I feel that... we could have managed at home for another few months but the place [in the care home] was available, so I mean it was sensible to move... at the time.

Interviewer: Oh, okay. So a place became available [yeah, yeah] and you thought you'd take it?

Yeah, [yeah] yeah. (PDo4)

Is there an “optimal” (or best) time?

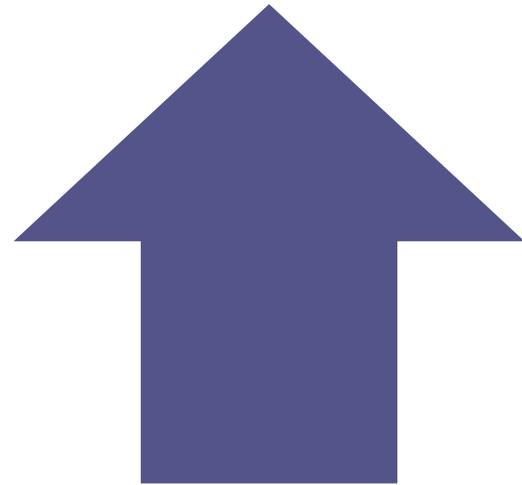
- Highly subjective, complex, personal decision
- When the person with dementia and /or relative is “ready” or when they realise they can no longer cope at home
- Hard balance to strike – lots to weight up



Move in
early?



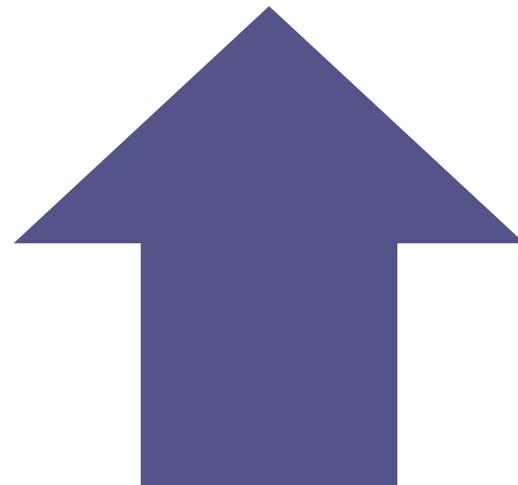
Move
during
later
stages?

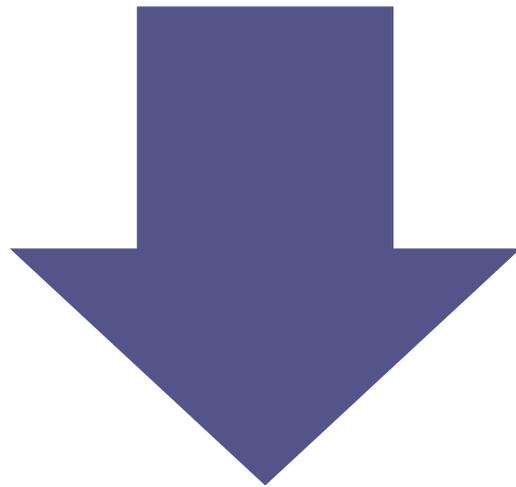


- The person with dementia is able to take part in the decision making process

“I think it's better to give them the opportunity to adapt into such an environment and they do, they do sometimes.”
(SW14)

Move in
early?





Move
during
later
stages?

- Limited awareness can be beneficial in minimising distress
- De-skilling environment for older people

“Moving in too early, you are de-skilling someone. A lot of homes, they do things for you. You are in a 24 hour living environment, where they get you up at a certain time, they make tea for you, they make lunch for you. You don't really have that independence.”

(SW10)

Impact of finances on “optimal” time

- Social workers and care home managers often provided information like savings thresholds worker
- Appeared to be limited choice of care homes if LA-funded

“I think people are a lot more aware these days that social care isn't free, and they're going to be financially assessed, and you know, savings are expected to pay for their own care. But understandably people do get very upset about that, and feel that it's very unfair.” (SW02)

Concluding comments

- There was no consensus on ‘optimal time’
- Relatives felt an enormous responsibility for making this decision on behalf of the person with dementia
- Care home managers provided substantial amount of support (informational and emotional), especially to those who are self-funding
- Costs shouldn’t include need or timing – but affected choice
- Respite often used as first step towards longer term permanent care home move

Thank you!

Any questions/thoughts?

kritika.1.samsi@kcl.ac.uk

jill.manthorpe@kcl.ac.uk

laura.cole@kcl.ac.uk