



Caring for people with dementia in care homes

Managing behaviours that challenge within English care homes: an exploration of current practices

Summary of key findings

Phase Five: Relatives: An Alternative Perspective

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Background

It is important to describe the experience of living with dementia from the perspective of those who have experienced just that: this includes those people who care for their loved ones with dementia, whose voices are often unheard in research. Including relatives in research allows them an opportunity to share their stories and experiences. This report provides an overview of a study which tried to illuminate this alternative perspective of dementia care, by exploring the views and experiences of relatives of people with dementia.

What we did

We conducted interviews with relatives of residents with dementia who lived in three care homes in Kent. We asked them to tell us their story of dementia, and we asked about behaviour that challenges, about their feelings about views of care home staff that relatives could sometimes be a barrier, and finally about their views on research.

Who took part

Three relatives agreed to be interviewed; two husbands and one wife. Interviews lasted approximately half an hour. Interviews were collected and analysed together, and patterns in the data were searched for.

What we found

We picked out three main ideas from the interviews. These are shown in the table below.

Ideas	What it covers
Worsening of behaviours	Lack of awareness, attribution to old age , perception of 'behaviour that challenges' term, experience of behaviours
Lack of formal support	Nowhere to turn, changing support
The care home transition	Care home admission, behaviours, processes, care home family

1. Worsening of behaviours

Relatives' dementia journeys were unique in many ways, but also incredibly similar. Relatives talked at length about their experience of living with their spouse's dementia, and it was clear that caring for them at home, often alone, became increasingly difficult as time went on. All three relatives interviewed said they were unprepared for the diagnosis of dementia, despite knowing that unusual behaviours were increasingly occurring. These behaviours were sometimes attributed to other things, including old age and stress, and sometimes ignored all together.

'In hindsight the symptoms were there a long time ago. But being ignorant of it, we put it down to other things, or just getting on with it, things of that nature... I thought [her] lack of cognition I suppose for want of a better word, was umm, shook me... And I thought crikey, there's something really wrong here'.

Relatives were asked about their perceptions of the term 'challenging behaviour', and asked whether they felt it was an inappropriate term to use, when conducting research with people with dementia and their families. All of the interviewees supported the term, and showed understanding and empathy towards those people managing it.

'I don't find it offensive. Because you see here what happens to some of them, and they are challenging. Some of the staff here they end up with orange juice all down them, they're abused, hit. You can understand why they use that term.'

Relatives had experienced behaviour that challenges personally while caring for their spouses at home, and this is often what forced the transition to a care home, or in one case, hospital prior to moving to a home. A number of behaviours that challenge were experienced; in two cases, this took

the form of aggression and in one, dangerous behaviour. Relatives talked of the toll this had on them personally, including lack of sleep, panicking when their spouses tried to wander off, having to orientate their spouses when they awoke confused in the night, not allowing them to cook in case the gas was left on and being unable to leave them in the house alone.

'She was getting up in the night and moving all the furniture around, and walking around the house in the nude, and she'd put the gas stove on and nothing on top of it...I just used to bite my lip like, because you knew, she couldn't help it'.

2. Lack of formal support

One of the main topics discussed by relatives when talking through their dementia journey was the lack of formal support they and their spouses received after diagnosis and before the transition to the CH. They talked about their lack of knowledge, and sometimes being passed from pillar to post, because of staffing levels, staff difficulties in managing behaviours and frequent changes to staff within care provision services resulting in repeated changes of 'care managers'. One participant remembered her frustration in no one understanding her situation, and feeling that no one cared. Admiral Nurses are specialist dementia nurses, who provide support for both the individual with dementia and their family. They were introduced as a result of the experience of family carers, relatively recently. To family carers, they provide emotional, practical and psychological support to enable the individual with dementia to remain living at home. It is important to note that they may not have been in place when the relatives' residents were living at home, being cared for by their spouses. One participant discussed the information given by an Admiral Nurse, but felt it was provided at too late a stage.

'I only wish when it happened, they'd put us in touch with the admiral nurse. Because it took two years to learn for me, how people [care for their loved ones], have you done this, have you done that? The admiral nurse come in...and everything that had taken me two years to learn she told me in half an hour...That's what they should do, put you straight in touch.'

3. The CH transition

Once relatives had accepted or decided that their loved one could no longer live at home, they talked emotively about the difficulties in either getting into a care home, or even staying in one. Relatives had very contrasting views of different homes, and staff attitudes and willingness to cope with behaviour that challenges. One relative spoke of the three attempts it took to get his wife admitted to a care home, and how each time, his wife was refused on the basis of her having these sort of behaviours. He went on to remark how wonderful the current home was with regard to her behaviour, and why.

'They calmed her down. She calmed down pretty quickly within a matter of weeks of being here...In hindsight, because these people care what they're doing. They're very good, very patient.'

Another relative recounted with distress, an assessment that his wife was required to pass, in order to continue receiving her continuing care package. He was clearly displeased with the home and its assessment process; however he praised the other residents and their relatives, and talked about how they impacted on his life.

'I feel like they're my friends as well. I know the families...what's happening in their lives...which takes your mind off of what's going on with yours.'

One relative talked of her desperation for her husband not to be in a home, but also of her exhaustion from caring for him at home. She visited her husband daily, and was particularly praising of the care home staff and environment.

'Well I went every day you see. And sat with him, did the crossword, you know. I'd say the care home staff were wonderful, they worked so hard. And I know that it was the right place for him to be, but I hated seeing him there, like that. Wanting to come home with me...I wish I could've just said yes dear. But I couldn't, well you can't can you? But you know, they let us take him out, and they had beautiful garden, lots of flowers. He loved the garden. But the girls were just wonderful'.

Relatives' views of research

Two of the relatives talked about their view of research, one having experienced a research study previously with her husband. I believe their comments are particularly pertinent to this study, and warrant inclusion.

'He did take part in some research at the beginning, a drugs one, and it was lovely. But yes I would fully support anything that helps, especially in care homes, yes. Well it's so important isn't it? There are all these people, and we've got to get better at knowing how to look after them properly. Of course.'

Key conclusions

Overall, our findings confirm that relatives of residents living in care homes can provide an important alternative perspective on dementia care and therefore should be included in future research studies. In particular:

1. Relatives have experience of behaviour that challenges, including dangerous and aggressive behaviour, and in this study were able to discuss the unusual behaviours occurring. In retrospect they may have realised it was dementia, however they did admit to attributing the behaviours down to other factors including old age and stress, or being in denial about a potential diagnosis.
2. It is possible that this could have perhaps been avoided had more information or support been more widely available. A national Dementia Strategy was introduced in 2009, so it is possible that there was a lack of support and information at that time.
3. Relatives were understanding of and empathetic to the use of the term behaviour that challenges.
4. Being admitted into a care home may not be a straightforward process, particularly where behaviour that challenge are present, and residents' families required care and support from care homes and their staff, when struggling with unusual behaviours, consequences of a dementia diagnosis and the care home transition.
5. Relatives praised the care homes in which their spouses were cared for, and talked highly of the staff and the environment.
6. Two relatives discussed participation in research, and their wish to contribute. In particular they suggested that more research should be focused on caring for people with late stages of dementia, not just on preventing deterioration.

How you can use this information

Care home managers, owners and staff may find the results useful, particularly in helping relatives feel part of the care home community. They may want to consider how best to involve relatives in residents' care.

Relatives may find that the results are similar to their own experiences, and this may help them think about how they can be involved in their relative's care, and more generally life within the care home.