

**ARC East of England
Stevenage Dementia Involvement Group**

Living well with dementia in care homes



May 2022

Stevenage Dementia Involvement Group

Stevenage Dementia Involvement Group aims to provide opportunities for people with experience of dementia to have their voice heard and to have influence on research and the planning of new services. In each session the group will discuss a particular topic relating to living with dementia or health and social care services in Stevenage.

Stevenage Dementia Involvement Group met face-to-face on 12th May 2022. In attendance were three people with experience of living with, or caring for somebody with dementia in a care home.

Attending the group was Nicole Darlington from The University of Hertfordshire and Su Harvey from The Red Shed Project, Stevenage. Lisa Irvine from the University of Hertfordshire was the guest researcher, she joined virtually over Microsoft Teams.

The topic of discussion **living well with dementia in care homes** was introduced by Lisa Irvine. Lisa is working on the DACHA study (www.dachastudy.com) and presented about the different factors that make up quality of life.



Summary of discussions

Introduction

Lisa introduced the study she is working on called DACHA. Quality of life of residents in care homes is important but there is no straightforward way for researchers to measure it. Many different questionnaires exist, each focusing on different aspects of quality of life. These were grouped into 9 themes. No single questionnaire covers all the themes so we need to decide which themes are most important and which could potentially be dropped, before deciding which questionnaires should be used going forward.

Lisa presented 9 slides, one per theme, with group discussion for each.



1. Physical health:

Physical conditions and their related symptoms, pain, and perceptions of overall health

- Group agreed this was important to measure.
- Focus on 'pain'. Often residents can be in a lot of pain but do not want to make a fuss.
- The group felt that if reported by care home staff (rather than the resident themselves), they doubt it will be accurate.
- "Hearing loss" was flagged as important. Also issues with language barriers with staff – if resident does not understand they will simply say "Yes". Hearing aids may have dead batteries for a long time before anyone realises.



2. Mental health:

Mental and cognitive health conditions, and clinical symptoms which would indicate mental health problems

- There was little discussion on this theme. The group agreed it was important to measure.



3. Emotional state:

Experiences of positive and negative emotions, including feelings of calm, happiness, and loneliness, among others

- There was a long discussion on this theme.
- A key problem is “loneliness” and has been made worse by covid isolation. One group member suggested that their mother (who lives in a care home) would benefit from a buddying-up scheme with other residents, but staff are probably too busy to organise.
- Group members found there are often many residents sitting in the day room but with no one interacting or talking.
- One group member’s mother prefers to withdraw to her bedroom alone.
- Again, the group doubts that care home staff would be able to report on emotional state accurately.



4. Social connection

Frequency and quality of social interactions, including feelings of belonging, friendship, and support

- The group shared some examples of armchair keep-fit and singing.
- Many residents are unlikely to engage if they have low mood.
- Links back to loneliness.



5. Environment

Living conditions and deployable resources – also covers satisfaction with social care services

- ‘Feeling safe’ is really important.
- On the other hand, some residents can feel distrust and invasion of privacy inside the care home– e.g. from infrared cameras installed in their rooms to detect falls.



6. Personhood

Levels of satisfaction with personally and culturally meaningful activities which provide joy and a sense of identity

- Lack of activities in care homes reported by the group.
- One group member shared that their mother has left the care home only once in the past year, for a hospital appointment.
- Group members shared that, in their experience, the care homes are not making full use of the garden facilities.



7. Autonomy

Capacity and satisfaction with ones ability to manage activities of daily living

- The group had a long discussion on this theme.
- The main problem is lack of choice, probably due to understaffing.
- One group member shared that their mother is aware when she needs the toilet, but no staff are available to bring her, so incontinence pads are used instead of her being supported to go herself. This resident is private, and this lack of choice & independence leads to a lack of dignity. Later we discussed how their mother lost her ability to eat independently since entering the care home. It is Unclear if the care home staff were fully aware of this.
- Lack of independence is a big issue, but difficult to convey with questionnaires that are completed by staff.
- Feeling that staff do not keep such a close eye on residents as their immediate family would and cannot spot deterioration as quickly.



8. Spiritual Connection

Feelings of faith, inner peace, and involvement in religious or spiritual practices like prayer

- Interesting discussion about this theme – while residents may have strong religion/faith in earlier years, discussion

on how dementia seems to take that away. Lack of understanding of religion, or no longer important to them anymore. One anecdote of a neighbour who was a strong catholic, but ‘that was not part of her life anymore’ since developing dementia and moving to care home. A priest will occasionally visit, but it is not “*an important aspect of their quality of life*”.



9. Overall Quality of life

A single item asking respondent to rate their quality of life as a whole

- Problem with ‘overthinking measurement’ – the question is too subjective. All people have good days & bad days and this will affect results.
- The group felt that the question might be difficult for people living with dementia in care homes to understand.

Summary

Overall the group felt that the most important issues that contribute to quality of life were: **physical health** (especially pain); **loneliness**; **dignity & choice**; and **feeling safe**. Spirituality and an overall measure of quality of life were less important.

Conclusion and next steps

This group provided people with experience of living with dementia the opportunity to share their opinions and experiences about quality of life and living well with dementia in care homes. Members of the group have been invited to be involved with the project if they would like to. For the researcher, the session provided the opportunity to hear people’s experiences with care homes and to check that the measures they are using in the study will resonate with residents. This summary report has been read and approved by the group members who attended.

The next meeting will take place in June 2022 with the topic about **dementia friendliness in Stevenage.**

This group is organised by researchers from the University of Hertfordshire as part of the National Institute of Health Research Applied Research Collaboration (ARC) East of England. For more information, or if you are interested in joining or visiting the group, please contact Nicole Jones (Darlington), n.jones@cpft.nhs.uk or visit <https://arc-ee.nihr.ac.uk/stevenage-dementia-involvement-group>.