

Living and Dying in a Care Home – the stories we can tell

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Introduction

20% of the population die in care homes yet the lives of people living in, dying in, working in and visiting care homes is largely invisible beyond the walls of the care home itself. Photovoice is a participatory visual research method where participants take their own photographs and present their experience, joys and challenges, and share these with practitioners, the wider public and policy-makers.

Aims

To address the research questions:

- 1. What is the feasibility and acceptability of using photovoice methodology to explore end of life experiences of care home communities?
- 2. What experiences of the last year of life does photovoice methodology elicit in care home communities?
- 3. How can photographs and stories generated from this project, be used to inform the work of the Marie Curie Care Home Programme in Scotland and engage key stakeholders.

Methods

One resident, family member and member of staff from two care homes participated in this study. They took photographs related to what living well until the end of life in a care home meant to them and were interviewed about their photographs. Initial data co-analysis with participants enabled the selection of photographs and interview quotes for inclusion at an exhibition to take place in each care home.

Results

Each participant took 10 photographs capturing different aspects of their lifeworld within the care homes. This included considerations of a personalised environment, a sense of community, talking about death and loss, relationships being core, and managing tensions between personal care delivery within a communal setting.

Early Data Analysis identified the following themes

- 1. Being Seen and feeling affection
- 2. A wee community
- 3. Needing my own spaces
- 4. Bringing person centered care to the person
- 5. Songbook of my life - experiencing loss

Conclusion

Early results indicate that photovoice is a feasible and acceptable method for capturing end of life experiences of people within care home communities.

Impact

By visualising the lifeworld of different people within care home communities, there is potential to humanise and influence engagement with stakeholders, such as health and social care providers and policy makers. This will be explored with a further stage of analysis which is planned with exhibition attendees and external stakeholders in December 2025.

A selection of photos, taken by participants, with their themes



Theme: Being seen and feeling affection



A wee community



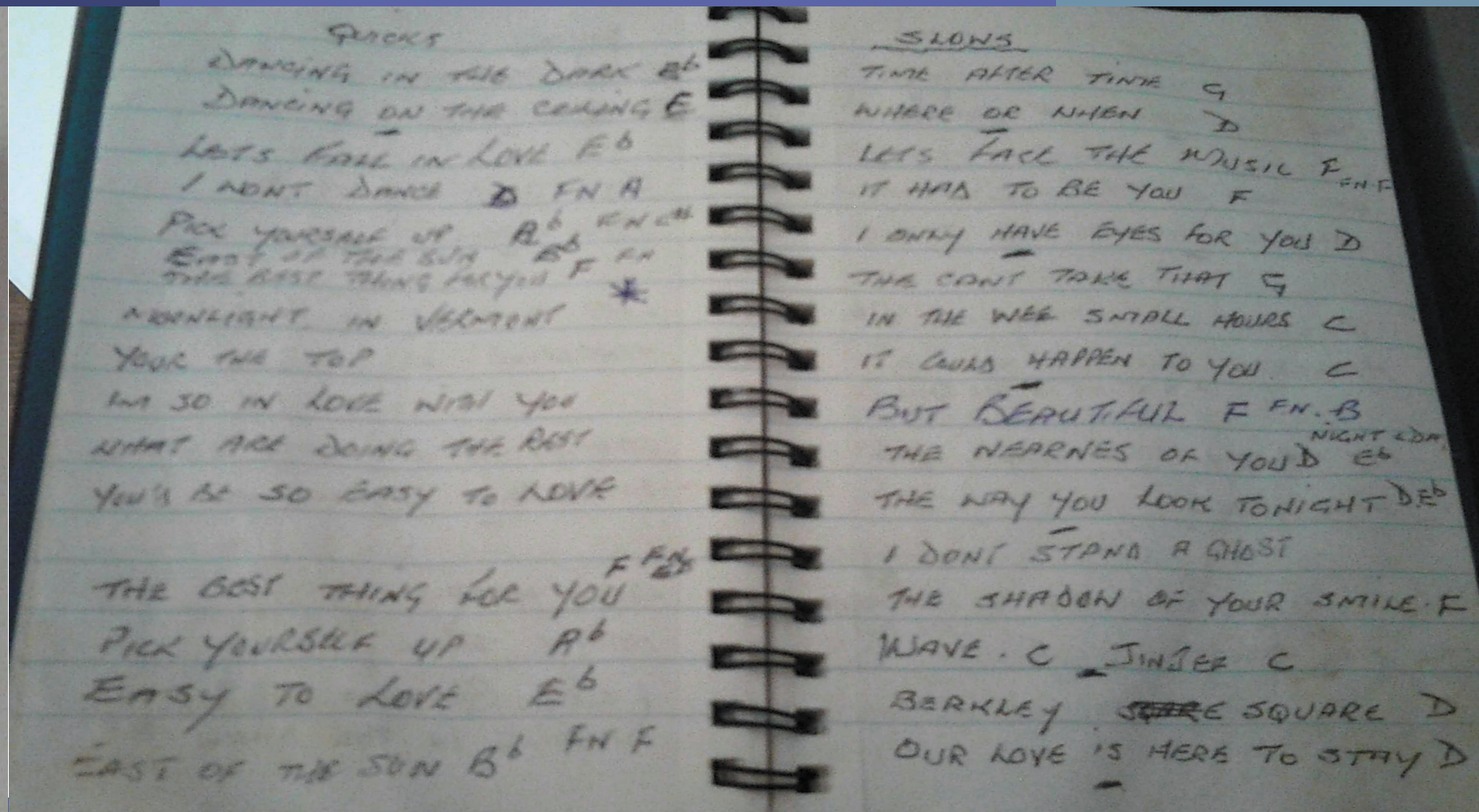
Bringing Person Centered care to the person



Needing my own spaces



Songbook of my life - experiencing loss



Open QR code to hear a participant's piano recital from the songbook of their life

