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Placing death and dying The work of making place at the end of life





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Palliative care professionals consider place as part of the care they deliver. There is an increasing emphasis on home being the ideal place to die. Conversely, it is recognised that high quality palliative and end-of-life care can be delivered in a wide variety of settings.

The **Forms of Care** project explores palliative care practices through ethnographic methods (observation of inpatient and outpatient palliative care team meetings, one year of shadowing team members in their daily work, and 40 interviews with staff and patients).

Occupational therapist June visits Carl

— an older widower living alone in a supported living block in London — to enable him to stay at home longer. June explains that she first set out to decrease his risk of falling: They jointly filled 6 bags with 'paper' to be thrown away. When Carl did not want to throw away more, they compromised: they sorted things into boxes that June placed behind the couch. Instead of removing the rug, June taped it to the carpet. The hospital bed required a **trade-off**: June suggested which bulky furniture could be removed for the bed to fit.

Prompted by The Swan Initiative,

Janet's family put a sign on the door of the hospital side room saying: 'Only come in if you bring in love'. They also brought in personal items to make the room more 'her own space'.

Because a side room on the geriatric ward was the only one available, palliative care CNS Anne offered the ward team additional support for end of life care for a young person. Anne also stopped plans to move Janet to a different ward, enabling Janet and her family to have a sense of place and stability.

- Palliative care staff typified hospital as a place of **control**: known infrastructure, continuous staff presence, and constant monitoring. The home, in contrast, is understood as a place where professionals are **guests**, creating a shift in power dynamics.
- However, many cases extended beyond this binary: palliative care staff, patients and family members engage in **making place**. This work of 'placing' demonstrates how place is not merely a geographical location, but made through relations, interactions and activities. Our ethnographic material highlights the importance of understanding how placing gets done as a form of care.

The **Forms of Care** project team consists of Prof. Simon Cohn (LSHTM), Dr. Erica Borgstrom (OU) and Dr. Annelieke Driessen (LSHTM).

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