# SUPPORTING FAMILY CARERS IN PROVIDING HOME-BASED PALLIATIVE CARE

**An Implementation Study** 





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### What's the aim of the study?

This work aims to support family carers in providing home-based palliative care by implementing an educational resource (the 'Caring for Someone with Cancer' booklet) in partnership with community nurses and care assistants.

#### What we did

- Phase 1 explored how the booklet has been used by a Trust involved in its development.
- Phase 2 actively implemented the booklet in 4 sites 2 nursing homes; 1 district nurse team and a Hospice@Home team. Observations and interviews were conducted with adopters of the booklet, and documents were collected.

#### Why is it important?

The majority of people die in acute care, although most prefer to be cared for and die at home. Family carers are crucial to enabling this preference. Interventions offering practical information to prepare carers for this role are required. Luker and colleagues developed and evaluated such an intervention: the 'Caring for Someone with Cancer' booklet. The booklet received positive responses from family carers and district nurses, but raised questions regarding how it should be implemented. Further feasibility work is require to explore how the booklet can be used to support family carers in the future.



- Nurses and care staff felt they had to "get to know" the family carer before giving them the booklet. Nurses would then "pick up on signs" and may not give the booklet if they thought it would "open Pandora's box".
- Teams not interacting with each other and a high turnover of staff acted as a barrier.
- Family carers were critical of 'paternalistic practices' and thought every carer, caring for someone at home towards the end of life, should receive the booklet.
- Everyone interviewed thought with a few tweaks the booklet could be used for other conditions.