

# Home death is associated with better patient and caregiver outcomes - but requires wider support

**New research carried out by the Cicely Saunders Institute at King's College London and published by BMC Medicine show that:**

- Patients who die at home experience more peace and a similar amount of pain in their last week of life compared to those who die in hospital, and their relatives also experience less grief.
- Some conditions are almost essential to enable patients to die at home: patient's preference, relative's preference, receipt of home palliative care and district/community nursing.
- Patients who discuss preferences, have home visits from their GP and whose relatives take more days off work have greater odds of dying at home.

## Summary of policy recommendations

- Ensure all areas have access to a comprehensive home care package, including specialist palliative care services and 24/7 district/community nursing. There are regions where the workforce providing essential elements of this care package is being reduced.
- Facilitate family caregiving, considering social programmes or employment insurance benefits, similar to maternity leave, aimed at supporting families to provide care for their dying relatives.
- Encourage discussion of preferences within the clinical setting. End of life conversations take time and training; they are currently not paid for and do not happen as often as they should.

## Background

Most patients with advanced cancer would prefer to die at home<sup>1,2</sup>, but many do not achieve this. In addition, the quality of death for people who die at home versus hospital is unclear.<sup>3</sup> The QUALYCARE study aimed to determine:

- whether people who died at home experienced more or less pain and peace than those who died in hospital;
- whether the family carers of people who died at home experienced more or less grief;
- the factors needed to enable death at home.

## Methods

QUALYCARE was a case-control study using a mortality followback survey methodology. Bereaved relatives were identified from death registrations and completed a purpose-built questionnaire including validated measures of patient's quality of death and relative's own grief intensity, and recollection of the services used.

The study included 352 patients with incurable cancer who died in hospital (n=177) or at home (n=175) in London (UK) during a 1-year period (2009-10).

## Research findings

Patients who died at home experienced more peace in their last week of life than those who died in hospital. There was no difference in pain levels. Grief was less intense for relatives of patients who died at home, both around the time of death and at questionnaire completion.

Four factors explained >91% of home deaths:

- home death preference by the patient;
- home death preference by their relative;
- receipt of home palliative care in the last three months of life;
- receipt of district/community nursing in the last three months of life.

In addition, patients who died in hospital were less likely to have had Marie Curie nursing; only seven patients who received care from these nurses died in hospital.

Death at home was more likely when the relative was aware of incurability and the patient discussed his/her preferences with family. Dying in hospital was associated with more hospital days, fewer GP home visits, and fewer days taken off work by relatives.

### Policy recommendations

In order to meet patient preference and ensure the best possible outcomes, we recommend:

- **Ensure access to comprehensive home care**

For patients who want to die at home, receiving a comprehensive home care package makes a big difference. Specialist palliative care services and community/district nurses are essential to help achieve death at home. GPs and Marie Curie nurses are also important.

Healthcare commissioners must ensure all areas have coverage. There are regions where the workforce providing key elements of this home care package is being reduced. Commissioners should adjust service levels to meet need, considering cost implications alongside choice, experiences and outcomes. For example, receiving two GP home visits in the last 3 months of life (which in England represents a cost to the National Health Service of about 200£, at a cost of 60-120£ per visit depending on time) is associated with 3 times greater odds of dying at home compared to having none or only 1 visit. This should be balanced with the costs of emergency department visits and hospital days.

In most cases ensuring access to a comprehensive home care package will require investment and expansion of existing community services, but not a major service reconfiguration.

- **Facilitate family caregiving**

Some governments, for example, in Canada, the Netherlands, Norway and Sweden, have set up social programmes or employment insurance benefits, similar to maternity leave, aimed at supporting families to provide care for their dying relatives. We urge consideration of similar schemes where they do not exist, with the necessary caution associated with complex public health interventions – careful development, piloting and testing, prior to implementation.

- **Encourage discussion of preferences within the clinical setting**

Preferences being one of the most influential factors on actual place of death, encouraging discussion is critical to ensure planning. End of life conversations take time and training; they are currently not paid for and do not happen as often as they should. Situations where dying at home is not feasible or people change their minds must be accommodated.

### References

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