

Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study

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Plain English summary

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At the end of life, a move into or out of hospital, a care home or a hospice may be a disruptive event for an older person, with consequences for their health and well-being. Such moves are believed to be common in the months before death, costly to services and are not always of benefit to patients. This study combined the perspectives of a range of stakeholders with analysis of hospital data to understand the influences on, and consequences of, transitions at the end of life for older adults in England. Interviews were conducted with older patients in their last year of life, bereaved family carers of older people, and service providers and commissioners in primary care, hospital, hospice, social care and ambulance services.

Patients' and carers' experiences of transitions were of a disjointed system where the working of organisations often took priority over individual needs. Many family carers were co-ordinators and providers of care at home who perceived that they were overlooked during hospital stays. Good relationships and communication between professionals in different settings and sectors were recognised by families as one of the most important influences on transitions but this was rarely acknowledged by staff. Patients and carers manage many aspects of end-of-life care for themselves. Identifying ways to strengthen their voices, particularly in hospital settings, would be welcomed and may reduce unnecessary moves at the end of life. It is not clear why the experiences of carers appear to have changed little in recent years, despite the introduction of a range of relevant policies.

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