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Dying in care homes, when advance care planning requires wrap around care

As a baby boomer I have relatives in their eighties and nineties. They have survived a world war and led full and independent lives. They are part of the fastest growing section of the population and now episodes of ill health, cognitive impairment need for surgery and small accidents assume a particular significance. My experience of trying to initiate conversations about the future with these older relatives reflects research findings. Fleming et al's (1) interviews with people over 95 found that they were more likely to plan for death—funerals or wills than dying itself. They were aware of the inevitability and even proximity of death but talking openly about death was rare. A limited understanding of dying is not restricted to the oldest old, it applies too to those policy makers, commissioners and service providers who are responsible for their end of life care (2). Should we be talking more about what a systems based approach to support this population might look like?

Dying in advanced old age is increasingly common. Two recently published studies(3,4) drawing on English cohort data and national statistics argue that if current trends continue without a concomitant expansion in care home capacity, hospital deaths will start to rise. This is more than just an issue of funding. Alongside ensuring there are enough beds and an available workforce within care homes as important are discussions about how services are commissioned to work with and across organisations. How does care homes based end of life provision “fit” with commissioning palliative care services from hospices, hospitals and in individuals' homes?

Entry to a care home often occurs when other services are no longer appropriate. The older person is unlikely to benefit from curative treatments and their needs have exceeded what can be provided within their home. It also signals someone is in the last year(s) of life. There are growing programmes of research work that have articulated well the palliative care needs of residents and tested and developed education and training interventions that are context specific and dementia sensitive. Less well articulated is how the different configurations of services that work with and around care homes improve, sustain or hinder end of life care provision to care home residents. What kind of infrastructure and “wrap around” support is needed to ensure continuity, consistency and management of the inevitable uncertainties that arise when providing palliative care to this population? (5)

Care homes as standalone organisations often nurture relationships over time with visiting palliative care generalists and specialists including doctors, nurses, therapists and social workers. The quality of these associations however are highly variable and range from episodic, reactive resident specific encounters to those that have the capacity to discuss and jointly plan end of life care services. Evidence suggests that interventions that facilitate integrated working, that breakdown narratives of “them and us” can reduce duplication of effort, improve use of urgent and emergency services and foster reciprocal working (6,7).

A recent realist evaluation of care homes residents' (8) access to health care suggested four key characteristics of service delivery that, regardless of the model of care or service configuration could lead to improved resident and staff outcomes. These were, a sustained commitment to staff learning and working together, an environment where visiting practitioners and care home staff had a sense of common purpose and confidence in each other's skills, access to dementia specialist advice for care home and visiting health care practitioners and recognition from health and social care organisations that care homes are valued partners. This last characteristic was important for validating and legitimising the time, frequency and ongoing support care homes received from

external services. There is transferable learning when considering how palliative care is commissioned and organised.

Major challenges exist when providing good end of life care in settings that are already under resourced and struggling to recruit skilled staff. Advance care planning as a systems approach places care homes within an active network of end of life care provision. How a person's preferred place of care is achieved becomes an issue for commissioners and providers and so much more than a discussion between resident, family and practitioners. It is unhelpful to see the oldest and frailest of our population as packages who, in the last year(s) of life are carefully transferred between services, with the care home as literally the last resting place.

We need studies that can adapt, test and refine what is already known about integrated working to develop ways of working that address how an intervention maintains and strengthens links between the care home and the services that surround and support them. This kind of research will not solve issues of capacity but it does articulate and ultimately optimise how existing services can and should work together to provide end of life care to the oldest old in our society.

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