

Dying well at home

Commissioning quality end-of-life care

Overview

- Increasingly people are dying at home rather than in hospital and this trend is set to continue. This raises questions about whether there are the right staff with the right skills to support people in their home at the end of life, and whether the health and care system is prepared for changing levels of demand.
- We interviewed NHS commissioners in 10 areas of England, and social care commissioners in a further 5 areas, to find out how they assess need, plan services and assure the quality of care for people who die at home.
- Commissioners had limited ability to assure the quality of care for people who die at home. They were not making full use of available data or national resources for assessing local needs, and were not monitoring quality across health and social care.
- All commissioners recognised the importance of inequalities in end-of-life care, but none had yet started taking action to reduce them.
- There is a moment of opportunity for commissioning end-of-life care. Developing integrated care systems (ICSs), a new statutory duty for commissioning end-of-life care, and new ways of working create potential for commissioners to develop end-of-life care as an integrated service with patients and carers' needs at its heart. We make recommendations for commissioners, integrated care boards (ICBs) and national bodies to ensure the opportunity is grasped.

Why we did the research

For the increasing number of people who die at home, there is inadequate data at a national level to understand how well services reflect population needs and the quality of care people receive. We set out to find what information about care quality and needs exists at a local level, and how it is used.

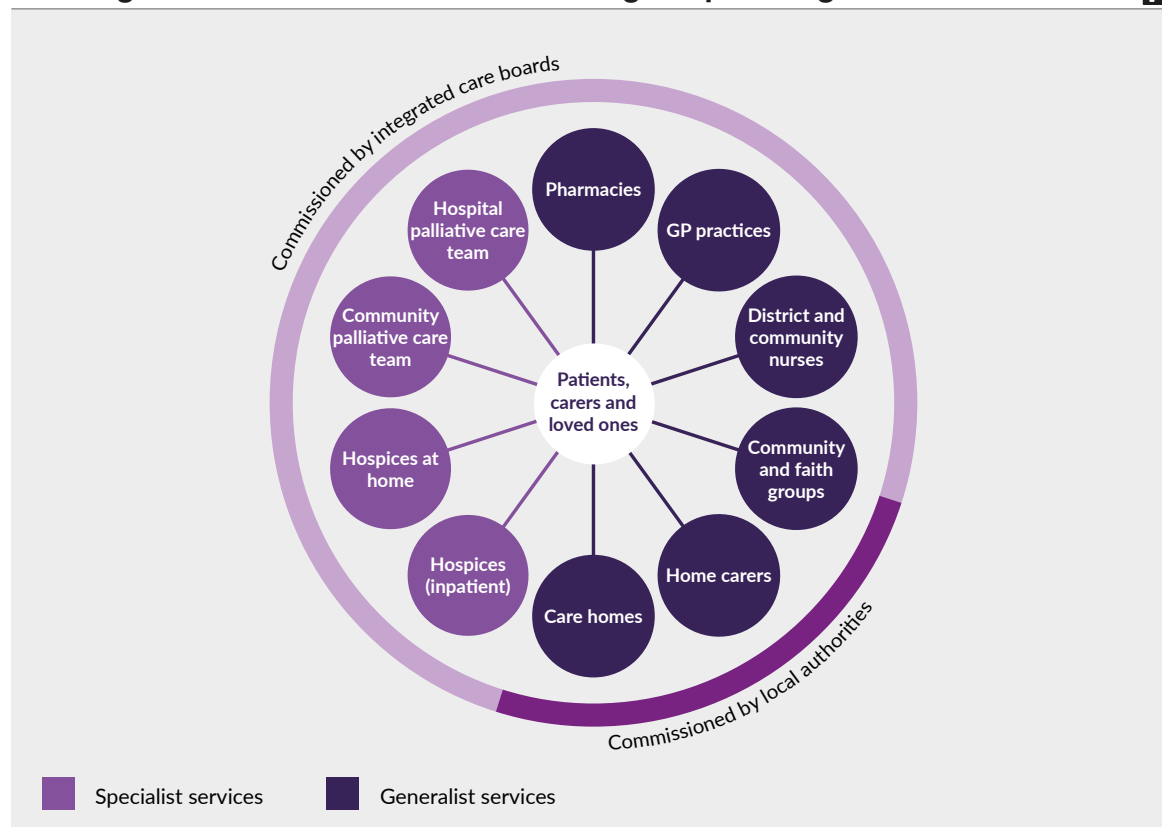
We focused on the role of NHS commissioners, including how they work with social care commissioners in local authorities. Commissioners have a unique view across the complex mix of both specialist and generalist health services and social care involved in supporting people who die at home (see figure below).

What we did

We reviewed literature and engaged with stakeholders to build up a picture of end-of-life care at home. We then asked recently bereaved families and carers to help identify the issues that we should focus on.

Families and carers told us that good quality end-of-life care includes: consistently caring, as well as clinically competent, staff; good communication and involvement, for example, in care planning; information about what to expect, what services are

Main organisations involved in commissioning and providing end-of-life care



available and how to access them; and seamless, co-ordinated care that adapts as people's needs change.

If the services available are to correspond to local needs, they said commissioners should: reflect the specific needs and preferences of people from different ethnic minorities and religions; involve people in saying what is needed; and take an overview of all the services as a whole and how well they fit together.

We interviewed commissioners from 15 urban and rural areas with differing levels of deprivation across England. We presented our findings back to the stakeholders, families and carers to help us understand their implications.

What we found

How commissioners measure and monitor care quality

Commissioners we talked to understood what constitutes high-quality care at the end of life, but mostly did not have specific quality assurance measures for people who die at home and had little or no information on end-of-life care in generalist services.

Commissioners often relied on whatever data providers were able to share with them. As a consequence, they had a fragmented view of quality in individual services rather than one that reflected people's experience of the care pathway as a whole.

They used process indicators of care quality for people who die at home, such as the number of hospital admissions in the past three months of life, and did not routinely collect data on the outcomes of care or people's experiences. Although local authorities had mature systems for quality monitoring in social care, they were not joined up with quality monitoring in health care in any of the areas we spoke to.

How commissioners use data to understand population need

Most commissioners did not have a complete view of needs across their local area. Need was often understood based on levels of demand reported by providers for each service separately, making it difficult to build a complete picture or identify unmet need. Only one place in our sample was making extensive use of the available data across services to understand local needs, and none of the commissioners described using national resources available for needs assessment. Some areas lacked basic data such as accurate palliative care registers.

How commissioners identify and address inequalities

Commissioners recognised the importance of reducing inequalities in end-of-life care. However, only one commissioner in our sample was taking steps to collect more data on inequalities, and none had started actions to reduce them.

New roles for commissioners

Our research took place just as ICBs were established. Commissioners' roles were starting to become more facilitative and strategic, convening providers to work together on system-wide approaches to improving services.

What this means

Commissioners need to improve their ability to measure and assure the quality of end-of-life care at home, including through better information about people's experiences. They should make better use of data to assess current and future needs, and to focus on inequalities.

These improvements are feasible because the ways in which commissioners' roles are developing, the creation of ICBs, current national priority for end-of-life care and staff motivation after experiences in the Covid-19 pandemic, all combine to create a moment of opportunity. Our report makes recommendations for commissioners, ICBs and national bodies to ensure that the opportunity is taken.

About this report

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To read the full report, *Dying well at home*, please visit www.kingsfund.org.uk/publications/dying-well-home-commissioning-quality-end-life-care.

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