JSNA Needs Assessment - End of Life Care

Introduction

End of life care is support for people identified as being in the last years or months of their lives, to help them live as well as possible and die with dignity[1]. Palliative care, to make people as comfortable as possible through managing pain and symptoms, is part of end of life care. End of life care should take account of people's needs and preferences and can take place in any setting.

As a result, EOL care is delivered across a wide range of services and many healthcare professionals provide end of life care as part of their roles. To support strategy development, the End of Life JSNA panel was commissioned to develop a shared understanding of what 'good' end of life care looks like and the key enablers to delivering this.

The current picture

In 2020, there were 9,376[2] deaths in Dorset, Bournemouth, Christchurch and Poole. Thirty-five percent of deaths occurred in hospital, 30% at home, 28% in care homes and 6% in hospices. Over the last few years, the leading cause of death has been from Dementia and Alzheimer's disease, followed by heart disease and stroke.

In Dorset we have an ageing population, living longer but with increasing co-morbidities. This can increase the support needs and complexity of health and care services required to manage people's conditions, make them comfortable and support their wishes and choices at end of life. Locally we've seen increasing rates of people on the palliative / supportive care register – there were 6,457 people registered in 2019/20 which is higher than England and South West prevalence (Figure 1).

This makes the need to have early conversations and understand what matters to people more important. Talking about death and our wishes is not a social norm, yet it is important in order to have a holistic view of the person and understand support needs for them and their loved ones[3]. National research[4] shows variation in our expectations and choices - nearly three quarters of bereaved people felt that hospital was the right place for their relative to die. However, only 3% reported their relative wishing to die in hospital and ratings of care quality were higher in other settings, such as in care homes, hospices or at home.

The proportion of people dying in hospital is reducing (Figure 2) and increasing in other settings and at home. Supporting choice and options for care emphasises the importance of consistent access and quality across settings and within the community, to ensure that everybody has the opportunity to experience the same 'good' end of life. The CQC reported that end of life care is variable for some groups, because of their diagnosis, ethnic or demographic characteristics. Not understanding or considering the needs of individuals or communities was a barrier to the provision of quality end of life care[5].
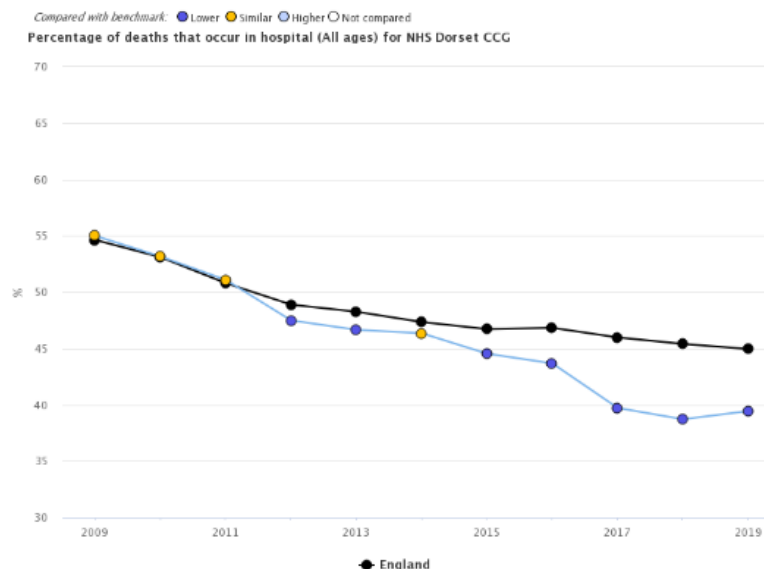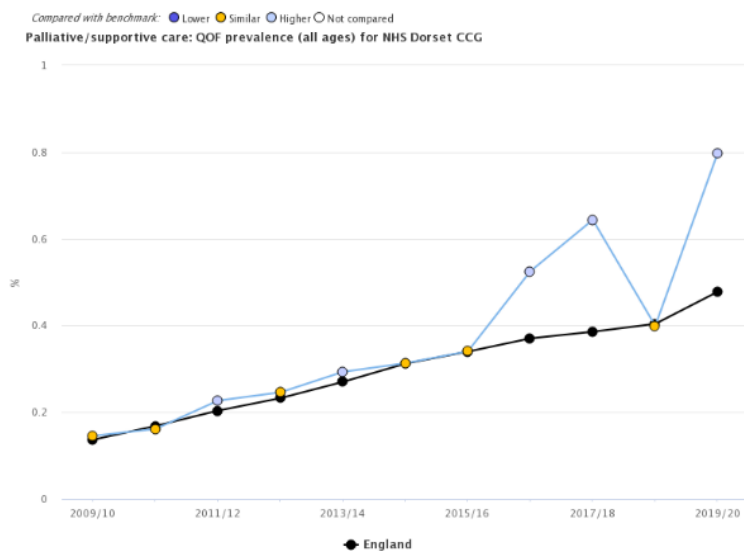
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[1] https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/?tabname=what-is-end-of-life-care

[2] During 2020, 605 deaths (6.5%) were related to COVID-19. Source: ONS death registrations

[3] New Stage Radicals (2020). Improving end of life care: what does good look like?

[4] ONS VOICES survey

[5] CQC: A different ending; End of life care review

Compared with benchmark: ● Lower ● Similar ○ Higher ○ Not compared
Palliative/supportive care: QOF prevalence (all ages) for NHS Dorset CCG

Compared with benchmark: ● Lower ● Similar ○ Higher ○ Not compared
Percentage of deaths that occur in hospital (All ages) for NHS Dorset CCG

The current picture - Local insights

Reflecting local and national data, the importance of these elements was re-iterated through workshops with local end of life care practitioners and health and care partners. When setting out to describe what 'good' end of life care looks like from their perspective, key elements included;

- **Personalisation of service and providing 'what matters'** is a central element to enabling a 'good' end of life
- **Relationship building and trust** is crucial to engagement and having early and open conversations with people, their families and loved ones
- **Partnership working and shared communication** between organisations allows them to build a 'full' picture of the person and co-ordinate care where multiple services may be involved to meet needs
- **Staff support and resilience** as supporting end of life care is emotionally demanding, particularly where this is not a regular experience in your day-to-day role.

In addition, workshop participants reflected on their experiences during the COVID-19 pandemic. Although experiencing many challenges through this period, it was felt the pressing need to discuss end of life options facilitated early and open conversations. In addition, the necessity to move to digital working facilitated communication and information transfer.

These local insights highlighting 3 key challenges for delivering end of life care (Figure 4);

1. Appropriate and timely End of Life care is dependent upon excellent inter-service relationships

2. Having a clear care plan, understood by all, is essential to support a good end of life and a sign that the system is well functioning.

3. Workforce wellbeing and resilience is fundamental to overcoming the socio-cultural norms that currently make end of life planning stressful.

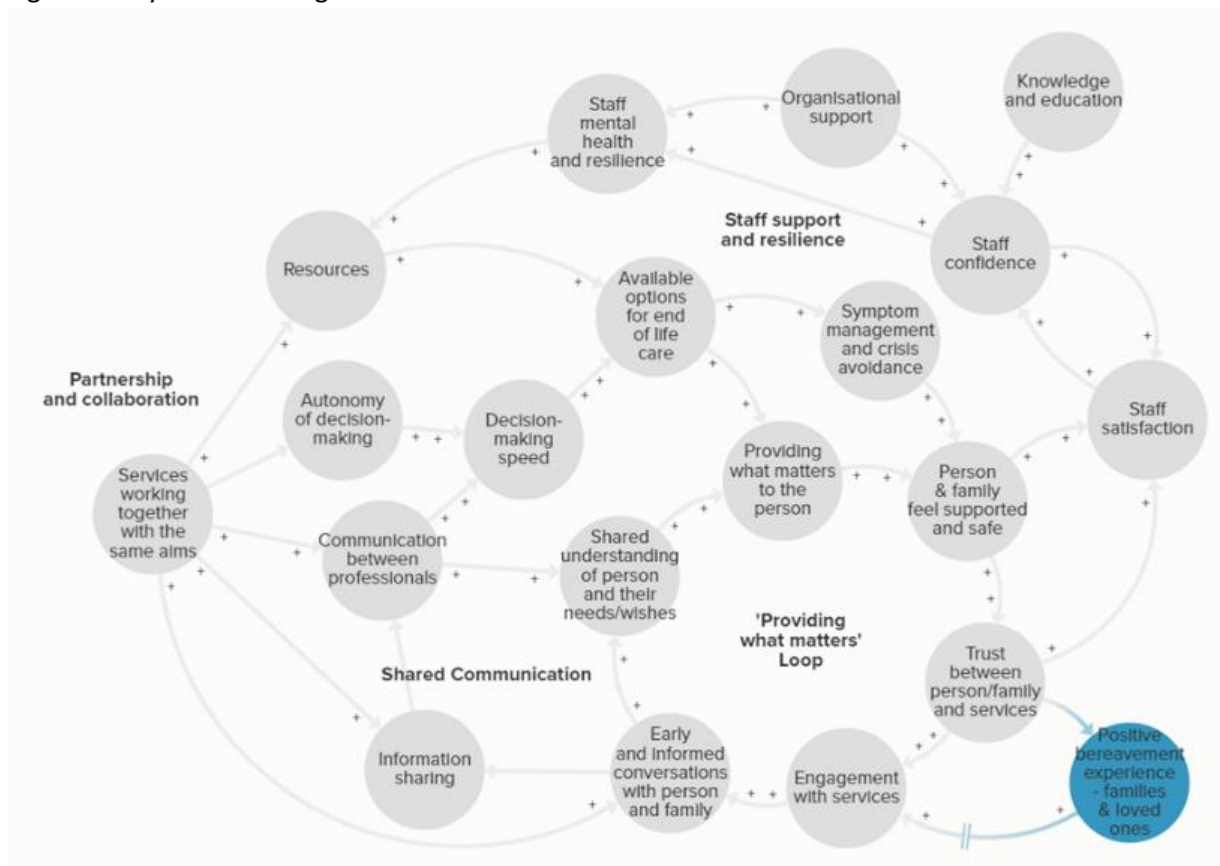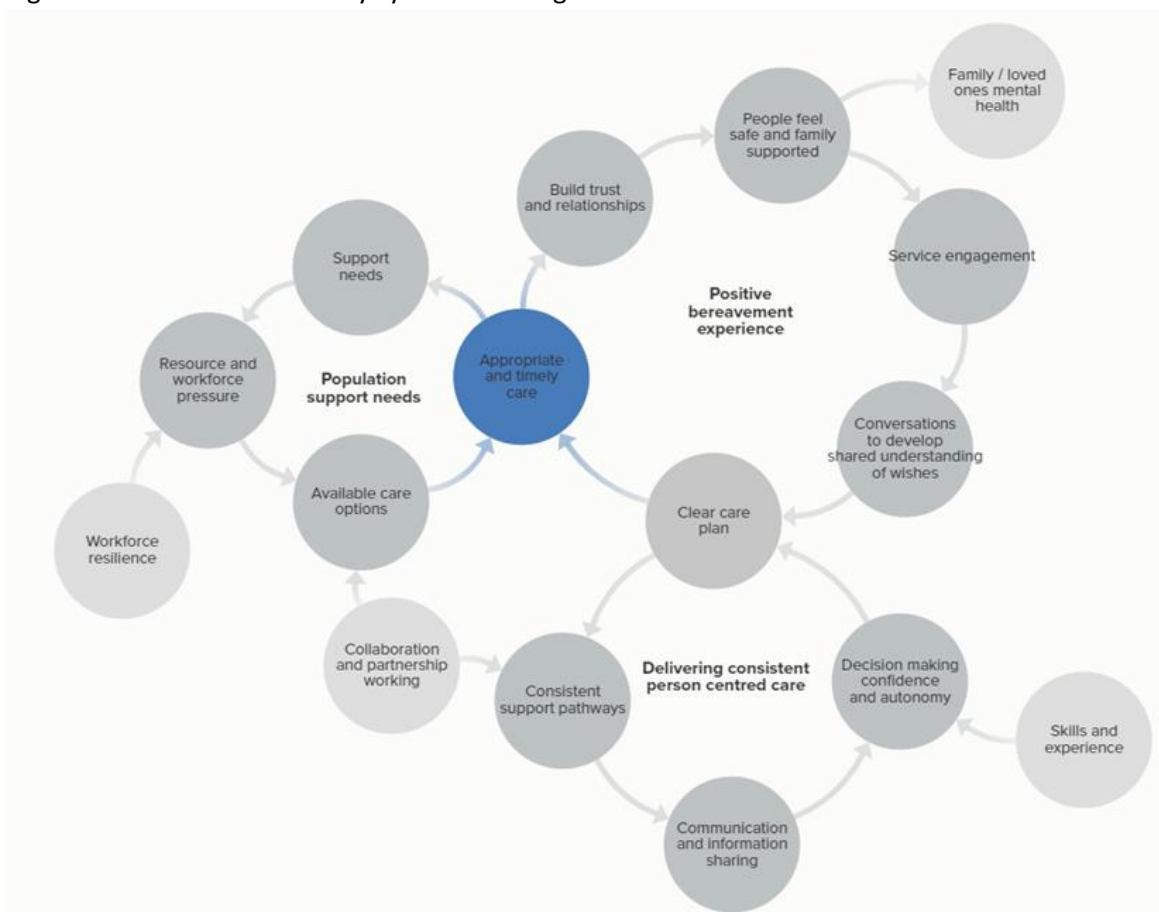Figure 3: Key enablers of 'good' end of life care

Figure 4: End of Life care – key system challenges

Future Vision

There are many policies and guidelines relating to end of life care and quality indicators. There are many overlaps and focus is on timely identification of someone approaching end of life, developing a holistic understanding of needs and supporting them to die well in a place and manner of their choosing through a multi-disciplinary approach[6].

The national palliative and End of Life Care Partnership also set out ambitions for end of life care. Their 6 ambitions focus on fair access to care for all individuals, co-ordinated care where all staff are prepared to support, and communities who are prepared to help support each other[7].

As depicted in our key challenges (Figure 4), supporting needs and providing care options places pressures on systems resources and workforce. National policy research[8] highlights focus on primary and community based end-of-life care generates longer term pay-off for the whole health and care system due to a) evidence this type of care is most effective b) is of lower cost than hospital based care and c) evidence of better wellbeing outcomes for the person receiving this type of care.

Locally, throughout the workshop process two desired outcomes were repeatedly raised;

- **Shifting system norms towards understanding 'what matters'** – making it the norm to ask people what matters to them and why
- **Developing a full understanding of the current system structure** – to clearly articulate the offer across the system and how this is accessed

Key areas that were identified as providing potential leverage to overcome the key challenges and achieve the vision for 'good' end of life care included;

- **Improving communication between agencies –** developing communication links and methods across the whole system, including community and voluntary sectors, building opportunities for working together and to build relationships
- **Increasing collaboration** across the whole system including the voluntary sector
- **Developing a shared End of Life Care strategy** through open discussions across all sectors and partners and looking at how to work better together

These are not insights exclusive to the End of Life Care system. Research with staff across a variety of 'front-line' roles highlighted, from their view, developing partnerships and collaborations being essential to mitigate system demands and pressures. Partnerships can take many forms, but to be effective need strategic level 'buy-in' to vision and processes alongside the development of trusting and communicative 'on the ground' relationships. Examples of success had both elements in place.

Closing the Gap

The JSNA End of Life Panel expressed interest in developing a shared vision for end of life care and progressing a shared strategy to approaching some of the raised challenges.

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[6] National policies; NICE guidance, GOLD Standards Framework, Department for Health End of Life care commitment
[7] Ambitions for Palliative and end of life care
[8] Institute for Public Policy Research; End of Life care in England, 2018

Additional Resources:

Public Health England Palliative and End of Life Care Profiles
Atlas of variation for Palliative and End of Life Care
Locality profiles
JSNA End of Life Care insights workshops
JSNA Insights from front-line workers