# One Devon end-of-life care

## Summary

This paper provides an overview of end-of-life care provision and the duties of local commissioners.

## Background

There are wide reaching reforms within the Health and Care Act 2022, including the legal foundations for integrated care boards (ICBs) like NHS Devon.

An amendment has also meant that 'palliative care services' is included in the section which specifies that ICBs have a legal responsibility to commission health services that meet their population needs.

Integrated Care Systems (ICSs) have a key role to play in ensuring that people with palliative and end-of-life care (PEoLC) needs can access and receive high quality personalised care and support and there is a duty for ICBs to commission palliative care services within ICSs'. (Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) (2022)).

One Devon is committed to commissioning end-of-life care services across Devon that are sustainable and consistent in terms of access, experience and outcome for individuals, their families and those delivering end-of-life Care.

## National guidance

**Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) (2022)** People with palliative and end of life care needs should be supported by a whole system approach.

- People's palliative and end of life care needs, and the complexity of their needs, will fluctuate throughout their journey, and this means that a flexible model of care is required
- There must be sufficient workforce in place across all settings, with the knowledge to deliver the care required
- ICBs should have a clear vision of how the package of services they commission locally deliver against the Ambitions Framework (see below) and should actively seek out commissioning resources to achieve this.

**Commissioning and Investment Framework for Palliative and End of Life Care (2020-2021)** Professionals work as part of multidisciplinary teams providing the service directly to the person with need, and those important to them, and/or supporting other care teams to do so.

- 2020-21 and 2021-22 will be a year of development including:

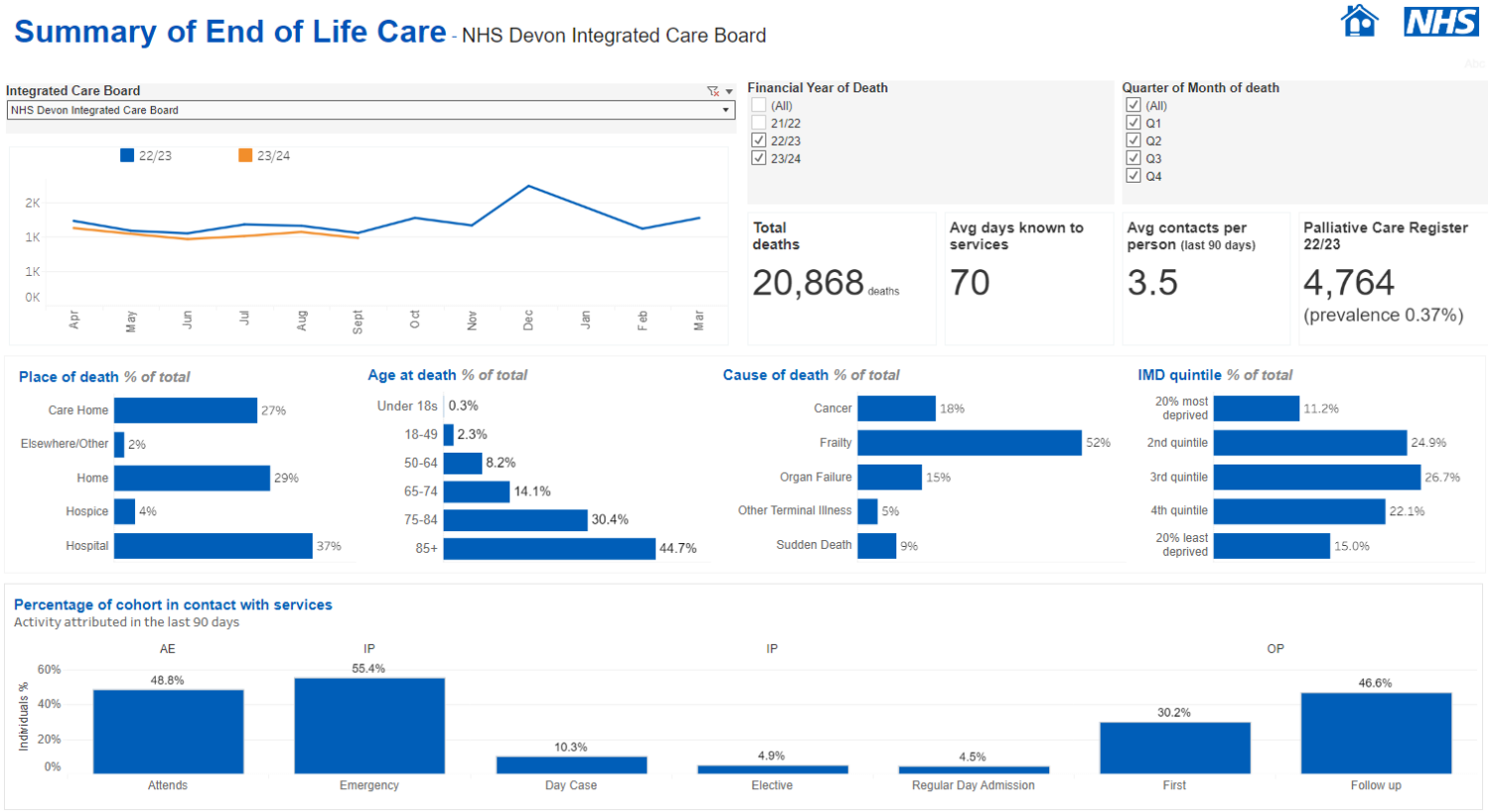
- Collaborative working at regional and ICS level
- Development of end-of-life care networks
- Service specifications are under development

**Ambitions for Palliative and End of Life Care: A national framework for local action (2021-2026)**

| | |
|---|---|
| 1. Each person is seen as an individual | 4. Care is coordinated |
| 2. Each person gets fair access to care | 5. All staff are prepared to care |
| 3. Maximising comfort and wellbeing | 6. Each community is prepared to help |

## Devon overview

This section provides an overview of key metrics in relation to PEoLC.




The corresponding information from neighbouring counties show that there isn't significant variation in their place of death when compared with Devon. There is a slight variation in that there are 3% more care home deaths in Devon but a lower overall percentage of hospital deaths.

However, there is significant variation within the recognition and recording of End of Life. Dorset ICB shows 0.82% of people on a palliative care registers, compared to

Devon's 0.37%. This is nationally recognised to be 1% of the GP-registered population)

## Promoting integration

Locally, Devon has an established county-wide multi-organisational, multi-Disciplinary end-of-life care steering group. The Devon end-of-life care steering group
oversees, monitors, and makes recommendations to NHS Devon on the delivery of end-of-life services across Devon.

In doing so, it uses its decision making, advisory and facilitative functions to deliver end-of-life care services that meet national, local and best practice guidance. Each of Devon's four localities have an established end-of-life care locality meeting, which brings together representatives from multiple sectors to discuss local and county wide issues, guidance, and best practice and delivery of end-of-life services.

## Commissioned end-of-life provision

**Devon inpatient hospices:**
NHS Devon currently has grant arrangements in place which offer financial support to the four adult hospices operating inpatient beds within the NHS Devon footprint. These arrangements are historic, having been established and evolved over many years, pre-dating the creation of the ICB.

These grants contribute to their clinical services, providing a mixture of inpatient and community care, as well as holistic interventions and general running costs.

**Marie Curie:**
NHS Devon also directly commissions a service from Marie Curie. This offers a night care service by non-registered staff who have training in end-of-life care. This service is supported by an in-hours Marie Curie nursing overview team. It is a hospice at home service aiming to enable patients with advanced illness to be cared for at home, and to die at home if that is their preference.

Care may be provided to prevent admission to, or facilitate discharge, for crisis management or for longer periods of care. In Devon, Marie Curie provides a pro-active bereavement service to the next of kin to all patients supported through the overnight service. The charity also offers a proactive bereavement service to the next of kin of all patients who die in the Royal Devon and Exeter Hospital site, which expanded to the North Devon District Hospital site in 2023.

Other services involved in end-of-life care include:

**Primary care services (GP practices)** aim to offer comprehensive general holistic care for patients and those closest to them. Care spans from as early as the time of diagnosis through to treatment, to later managing symptoms and maintaining their quality of life when no more treatments are available to supporting patients and their families with end-of-life care and bereavement.

A significant proportion of end-of-life care is provided by general services and can be supported by specialist care providers. There are models of hospice at home services, which provide interventions to stabilise an individual's care and provide support to families.

The model of provision across Devon varies. Not all of Devon's, geographical footprint has in place hospice at homes services. These services can enhance care coordination. Other models have considered working with independent care providers to flex the model of service provision according to individual and family needs. Education in end-of-life care is a key component of enhancing the service offer across general and specialist provision. There is scope in each of Devon's localities to build on exiting practice and re-shape services to deliver a more targeted/coordinated offer for end-of-life care.

## All ages approach

One Devon is committed to achieving an all-ages approach to palliative and end-of -life care. As part of the Devon End-of-life Commissioning review, it was recommended that a Devon Service Specification was designed that would focus on equity of access and experience for all residents and their families when requiring PEOLC.

## Advance care planning

NICE (NG142) recommends consideration of advance care planning (ACP) for every person with a palliative diagnosis. This is a process of person-centred discussion between the individual and their care providers about their preferences and priorities for future care, while they have the mental capacity for meaningful conversations about these.

Advance Care Plans (ACP) and Treatment Escalation Plans (TEP) are an integral part of an individual's journey and can ensure that they receive the care they want to meet their needs, and in a setting of their choice.

Devon has established a shared TEP form with Cornwall and has created a digital solution that will be accessible by health and social care colleagues via the Devon and Cornwall Shared Care Record (DCCR).

Supporting ACPs and TEPs is the need to plan and manage individuals at end-of-life in a timely and appropriate manner, that includes anticipatory prescribing and putting in place the necessary infrastructure for when an individual's care escalates and requires an urgent intervention. Including family members and carers in the discussion is vital to ensuring all wishes are recorded, communicated, an understood by those who will be involved within the process.

For urgent care during the out-of-hours setting, the documentation and coding in an individual's primary care record is crucial in enabling out-of-hours providers to understand the diagnosis and needs of the individual at end-of-life. Good in-hours

planning enables an individual to receive timely and appropriate care in all settings, including in the out-of-hours setting. Variable practice in the in-hours care setting creates delays in timely and appropriate care, leading to distress and confusion for families, as well as likely unnecessary and unwanted admissions to acute hospitals.

Ensuring Just In Case (JIC) Medications are appropriately prescribed, recorded and stored is of vital importance for end-of-life patients and their families. These medications can support symptom management at a time that is very stressful for all involved.
Through monitoring patient safety event reports at an ICB level, NHS Devon has highlighted the administration of these medications as a Devon-wide issue. To support this, a review of the administration process in underway with an aim of amending the literature that accompanies the medication. This will ensure that the correct advice and contact details are provided to patients and their families directing them to the most appropriate teams when the JIC medications are required.

## Recommendations on end-of-life care

The following recommendations are areas where members of the committee may be in a position to influence

**Care home education:**

- Support the rollout of educational material and opportunities for staff training
- Co-ordinate an equitable approach to training and education
- Support the launch of NHS Devon's new end-of-life Webpage

**Packages of care / fast-track continuing healthcare (CHC)**

- Ensure the funding and packages of care are made available in a timely way to ensure the following
- Speedy and safe discharge
- Support to individuals and family to ensure their loved ones are cared for
- Review and amendment to package as needs change

**System wide projects: e-TEP / Advance Care Planning / JIC meds**

- Promote the use of TEPs and ACP documentation within care homes
- Support staff to ensure they are confident to have these conversations
- Ensure appropriate medication and stocks are available for PEOLC residents / patients

**End-of-Life Care service specification**

- Contribute to the end-of-life care service specification and the aim of an equitable service across Devon

**Equipment**

- Appropriate equipment is available when required (syringe drivers, falls hoists)

ENDS