Commissioner's Guide to the NCEPOD Report
'Planning for the End'

A review of the care provided to adult patients towards the end of life.

INTRODUCTION

Each year over 600,000 people die in the United Kingdom[11] and many of these deaths occur in hospital, despite the majority of people saying that they would prefer not to die there.[5] Approximately 70% of people die from long-term health conditions that often follow a predictable course, with death anticipated well in advance of the event.[12] Improving people's experience of care as they approach the end of their lives will become increasingly important as our population ages. Improved treatment of long-term conditions combined with an ageing population mean the annual number of deaths in the United Kingdom is predicted to rise to 736,000 by mid-2035.[13]

The World Health Organization has defined palliative care as: '*An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial, and spiritual'*.[14] High-quality palliative care has a positive impact on patients and their families. Long-term conditions that are life-limiting represent an opportunity for palliative care to control symptoms and reduce suffering.

In 2008 the first national strategy for end of life care in England emphasised the importance of patient choice in terms of place of care alongside equity, cost effectiveness, planning for future increases in population and quality of care.[1] This strategy highlighted the variation in the quality of care delivered and received.

In 2014, the Leadership Alliance for the Care of Dying People published '*One chance to get it right'*, which outlined five principles to guide the delivery of high-quality end of life care: recognising imminent death; communication with the patient; communication with the family; the needs of families; an individual plan of care.[15]

In 2016 the Care Quality Commission's report '*A different ending: Addressing inequalities in end of life care'* highlighted variation in the quality of end of life care experienced by patients from minority backgrounds.[4] In the same year, the National Survey of Bereaved People (VOICES) highlighted much good practice but also a lack of continuity and communication between providers.[5] These issues also align with NICE guideline NG31 (2015) and NICE quality standards QS137 and QS144.[6-8]

In 2021 the National Palliative and End of Life Care Partnership; a partnership of national organisations with experience of, and responsibility for, palliative care and end of life care, refreshed the '*Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026'*. The framework sets out six ambitions for palliative care and end of life care: each person is seen as an individual; each person gets fair access to care; maximise well-being; care is coordinated; all staff are prepared to care; each community is prepared to help.[16]

The National Audit of Care at the End of Life, (NACEL)[9] has reviewed compliance with published standards and guidelines during the final admission of patients who died in acute and community hospitals in England and Wales. Whilst the quality of care has improved in many areas, there remains room for improvement: for example, in the provision of a seven-day specialist palliative care service, the use of individual care plans and in identifying the needs of those close to the patient.

For the full report and other support tools go to https://ncepod.org.uk/2024eolc.html

To add to the data provided by the NACEL audit, this study focused on hospital care provided in the last six-months of life as well as on the final admission. It was designed to identify opportunities to improve the provision of palliative care earlier in the disease trajectory and the impact of this on care at the end of life.

PATIENT POPULATION

All patients aged 18 or over who died in hospital between 1st April 2022 and 30th September 2022 with one or more of the following conditions: dementia, heart failure, lung cancer and liver disease.

A sample of people who died in the community was also identified. These were patients admitted to hospital during the study period with one of the included diagnoses who were subsequently discharged and died within six-months.

Exclusion criteria

Death due to suicides, homicides, or self-harm related

Death due to trauma, drowning, drug overdose or poisoning

Sampling

A maximum of eight patients were selected from each hospital.

CLINICAL AND ORGANISATIONAL ISSUES

- Where death was anticipated, clinicians identified opportunities to improve end of life care in the six-months prior to death for 139/444 (31.3%) patients. The reviewers believed that opportunities were missed more frequently, occurring in 153/285 (53.7%) patients..
- The most common areas for improvement identified were specialist palliative care input, treatment limitation decisions and communication
- Parallel care planning was used in the care of 135/439 (30.8%) patients
- 94/130 (72.3%) patients with parallel care planning had specialist palliative/end of life care team input compared to 120/290 (41.4%) where parallel care planning was not used
- 169/233 (72.5%) patients did not have their preferences for care at the end of their life recorded
- Training in end of life care was included in the induction programme in only 137/214 (64.0%) hospitals and in mandatory or priority training in 110/214 (51.4%) hospitals. There were 55/214 (25.7%) hospitals where this training was not included in the induction programme nor in priority training.
- Seven-day specialist palliative care services were only available in 125/210 (59.5%) hospitals

KEY FEATURES OF A SERVICE

1. Palliative care is not just about end of life care

Not enough patients had access to early palliative care alongside existing treatments to improve symptoms and quality of life. Earlier non-specialist palliative care will support people to make sure their life before death is comfortable and their wider needs are being met, while their underlying illness is still being treated. In addition to specialist palliative care, non-specialist palliative care should be a core competency for all healthcare staff.

2. Normalise conversations about death and dying

Death and dying was not discussed as often as it could have been. More people need to have their end of life care wishes recorded. The surprise question “Would you be surprised if this patient died within the next 12-months?" This can be used across all healthcare settings; and/or recurrent hospital admission of patients with advanced chronic disease as a trigger for conversations about palliative/end of life care, advance care plans, death and dying. These are tools designed to help identify people who will benefit from proactive discussions about their care and to identify their wishes, such as treatment escalation decisions, especially if they are approaching the end of their life. The 'surprise question' is a non-challenging way for clinicians to consider the possibility of patients being in the last year of life. Although the focus might be the advanced chronic disease, other factors, such as comorbidities/age/frailty/poor physiological reserve can influence a person's needs towards the end of life.

3. Have a named care co-ordinator

Care co-ordinators are an accepted standard in cancer services but were less common for other advanced chronic conditions. Care co-ordinators or key workers can help a patient, and their family/carers navigate the health and care system in hospital, the community and at home. They can help the patient and their family/carers access services to control symptoms, secure fast-track funding, and apply for benefits etc. The care co-ordinator may change but they should hand over to the next care co-ordinator. Clinical nurse specialists in cancer services would be a model to replicate.

4. Provide specialist palliative care services in hospitals and in the community

Specialist palliative care services were not always available in hospitals nor involved when needed. While early access to non-specialist palliative care and end of life care should be available to all who need it, specialist palliative care services should also be available when a patient's symptoms cannot be adequately controlled. We acknowledge the workforce issues that surround this, and local solutions will vary, some implementation suggestions are listed here.

Formal links with hospice services, increased use of clinical networks or partnerships between healthcare providers and commissioners to share knowledge, skills and advice may help.

One example of a current system involves an integrated inpatient palliative and end of life care jointly resourced by the NHS and the local hospice. The service was consultant nurse-led and had a dedicated discharge co-ordinator.

Dual training of clinical nurse specialists, e.g. respiratory and palliative care.

5. Palliative and end of life care should be a core competency for all healthcare staff

Training to identify when palliative or end of life care will help was not always provided or available. It should be included in undergraduate and postgraduate education; and as regular training for patient-facing healthcare staff. This will help healthcare staff understand the importance of recognising the need for, and early introduction of palliative care for advanced chronic diseases as well as when to involve specialist palliative care teams. Training should highlight the benefits of symptom control as well as care at the end of life.

SUPPORTING DOCUMENTS

- NICE Guideline [NG31], Care of dying adults in the last days of life, 2015
- NICE Quality Standard [QS144], Care of dying adults in the last days of life, 2017
- NICE Guideline [NG142], End of life care for adults: service delivery, 2019
- NICE Quality Standard [QS13], End of life care for adults, 2021
- Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026
- Universal Principles for Advance Care Planning

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- NHS England, Service specifications for palliative and end of life care: Adults
- Quality statement for palliative and end of life care for Wales, 2022
- National Audit of Care at the End of Life (NACEL)
- Leadership Alliance for the Care of Dying People – One Chance to Get it Right