Palliative and End of Life Definitions

NICE (2019) Quality Standard for End of Life Care for Adults recognises the importance of early identification to ensure that people have access to the right care, when and where they need it. This promotes shared decision making and allows time for planning and preparation to support quality at end of life.

Misconceptions about which patients need to receive palliative care may be an obstacle to meeting patients' needs for palliative care (Schreibeis-Baum HC, et al., 2016)

The Lincolnshire Voices survey (2023) highlighted differences and inconsistencies in patient experiences of palliative end of life with communication between services being one of the the biggest concerns. This is informed locally through conversations with health and social care professionals, who have varying definitions of palliative and end of life care.

Therefore this document brings together nationally recognised definitions, used within palliative and end of life care, to improve communication between professionals, through a shared understanding and consistency of terminology across Lincolnshire.

Palliative Care

- Palliative care is 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 impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

(WHO, 2002)

Although this is an older definition this is the one still used by NICE, GMC and other PEOL Guidance such as Ambitions 2021 - 2026.

- Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

(IAHPC, 2018)

A new up to date reference endorsed by multiple international groups following recommendations by a report in The Lancet (2018)

End of Life Care

- Patients are 'approaching the end of life' when they are likely to die within the next 12 months.
  This also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state
  (PVS) for whom a decision to withdraw treatment may lead to their death)

(GMC, 2022)

- Adults in the final weeks and months of life, although for people with some conditions, this could be months or years. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It also covers support for their families and carers.

(NICE, 2021)

Care of the Dying

- Care needed when a person is judged by the multi-professional clinical team to be within a few (2 to 3) days of death.

(NICE, 2015)

Best Supportive Care

Bowden et al, in their literature search state “Current cancer guidelines published by ASCO, ESMO, NICE and SIGN do not offer any consistent definition or standards of BSC. Consensus-based standards of BSC are needed to guide clinical teams, enable measurement of key performance indicators and reduce unwarranted variation in the quality of care that people with incurable cancer can expect” (Bowden et al, 2019)

In Lincolnshire, following consultation with healthcare professionals and patients, we would like to agree a definition for all healthcare professionals across the system to describe what Best Supportive Care means to both patients and those healthcare professionals caring for them. Thus it is proposed that the term:

- **Best Supportive Care** describes the time when a cure is not achievable with existing treatments such as surgery, chemotherapy or radiotherapy. The focus is on quality of life and symptom relief, supporting patients and their family/carers, to help them live well until they die. This could include transfusion of blood products or treating infections with antibiotics.

For patients/relatives

This is a suggested adaption for use on patient information sent by cancer services at the end of planned treatments:

- **Best Supportive Care** is a term mainly used in cancer care when a cure is not achievable with existing treatments such as surgery, chemotherapy or radiotherapy. The focus is on quality of life, supporting you and your family/carers, to help you live well until you die.

FastTrack

- Individuals with a rapidly deteriorating condition who may be entering a terminal phase may require ‘fast -tracking’ for immediate provision of **NHS continuing healthcare funding**. The completed fast-track pathway tool – which clearly evidences that the person has a primary health need arising from a rapidly deteriorating condition and the condition may be entering a terminal phase – is in itself sufficient to establish eligibility.

(Department of Health and Social Care, 2022)

Gold Standard Framework (GSF)

- GSF is a practical and evidence-based end of life care service improvement programme. The aim is to enable a ‘gold standard’ of care for everyone, with any condition, in any setting, given by any care provider, at any time in a person’s last years of life.

(Gold Standard Framework, 2024)

Special Rules and SR1

- The Special Rules allow people nearing the end of life to:
    - get faster, easier access to certain benefits
    - get higher payments for certain benefits
    - avoid a medical assessment

- Clinicians can be asked to provide medical evidence on an SR1 form to support a benefit claim made under the Special Rules.

(Department for Work and Pensions, 2024)

References

1. National Institute for Health and Care Excellence (2021). **End of Life Care for Adults: Quality Standard (QS13)**. Online at: https://www.nice.org.uk/guidance/QS13
2. Schreibeis-Baum HC, Xenakis LE, Chen EK, Hanson M, Ahluwalia S, Ryan G, et al. (2016) **A Qualitative Inquiry on Palliative and End-of-Life Care Policy Reform.** Journal of palliative medicine. Vol19(4): pp400–7.
3. Healthwatch Lincs (2023) **VOICES Survey. Post-bereavement views of palliative end-of-life care in Lincolnshire 2022 – 2023.** Healthwatch Lincs
4. World Health Organization (2002) National cancer control programmes. **Policies and managerial guidelines.** Online at: http://www.who.int
5. International Association for Hospices and Palliative Care. **Global Consensus based palliative care definition** (2018) Houston, TX: The International Association for Hospice and Palliative Care. Online at: https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/)
6. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. (2018) **Alleviating the access abyss in palliative care and pain relief - an imperative of universal health coverage: the Lancet Commission report**. The Lancet. 391(10128):1391-454.
7. General Medical Council (2022) **Guidance: Treatment and care towards the end of life.** Online at: https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/treatment-and-care-towards-the-end-of-life/guidance
8. National Institute for Health and Care Excellence (2015) **Care of dying adults in the last days of life (NG31).** Online at: https://www.nice.org.uk/guidance/ng31
9. Bowden, J., Gilmour, M., Boyce, S and Wilson, J. (2019) **Best Supportive Care in cancer: working models require both resource and accountability for delivery if patients are to benefit.** National Cancer Research Institute (NCRI)
10. Department of Health and Social Care (2022) **Guidance Fast-track pathway tool for NHS continuing healthcare guidance.** Online at: https://www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool/fast-track-pathway-tool-for-nhs-continuing-healthcare-guidance

11. The Gold Standard Framework (GSF) (2024). **The Gold Standards Framework Everyone deserves Gold Standard end of life care.** Online at: https://www.goldstandardsframework.org.uk
12. Department for Work and Pensions (2024) **Guidance. The 'Special Rules: how the benefit system supports people nearing the end of life** Online at: https://www.gov.uk/government/publications/dwp-factual-medical-reports-guidance-for-healthcare-professionals/e5b3b502-9067-4b20-93c0-1006d9cb0edb