RECOMMENDATIONS

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These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations in this report support those made previously by other organisations, and for added value should be read alongside:

- 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
- 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

	The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives. The results which should be presented at quality or governance meetings, and action plans to improve care should be shared with executive boards. Suggested target audiences are listed under each recommendation
1	Ensure that patients with advanced chronic disease have access to palliative care alongside disease modifying treatment (parallel planning) to improve symptom control and quality of life. ***Primary target audience:*** *Integrated care boards and commissioners, hospital executive boards* ***Supported by:*** *Palliative care services, clinical directors, medical directors and directors of nursing, hospice services and local authorities, primary care, community care including care homes, nursing homes and social care* *This aligns with NICE Guideline [NG142], End of life care for adults: service delivery, 2019*
	RATIONALE and IMPLEMENTATION SUGGESTIONS
	Rationale: Palliative care should not be associated only with end of life care. 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. **Implementation:** Building this approach into normal hospital processes, such as a box on an admission proforma may help identify patients in need of palliative care and embed it into clinical practice. The *statutory guidance for integrated care boards* and *NHS England » Service specifications for palliative and end of life care: Adults* may help.

2

Normalise conversations about palliative/end of life care, advance care plans, death and dying. As a trigger to introduce a conversation which includes the patient and their family/carers, consider:

- 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.

Primary target audience: *Patients and their families/carers, all healthcare professionals, specifically members of the clinical team treating the underlying disease, primary care, community care including care home and nursing home staff*

Supported by: *Palliative care services, clinical directors, medical directors and directors of nursing, hospice services and social care*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: 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.

Implementation: By recurrent admission we mean more than once, so this could be set, for example, as two unplanned admissions in the previous 12 months for the same index condition or frailty.

Implementation: The conversations can be used as an opportunity to document an advance care plan.

3

Ensure all patients with an advanced chronic disease are allocated a named care co-ordinator.

Primary target audience: *Medical directors and directors of nursing in integrated care boards, health boards and trusts*

Supported by: *Palliative care services, clinical directors, primary care, hospice services and social care*

This aligns with NICE Cancer Service Guideline [CSG4] Improving Supportive and Palliative Care for Adults with Cancer

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: 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.

Implementation: Clinical nurse specialists in cancer services would be a model to replicate.

4

Provide specialist palliative care services in hospitals and in the community, to ensure all patients, including those with non-malignant diseases receive the palliative care they need.

Primary target audience: *Integrated care boards and commissioners*

Supported by: *Medical directors, directors of nursing, the Association for Palliative Medicine of Great Britain and Ireland, hospice services, primary care, and community care*

This aligns with recommendations from the National Audit of Care at the End of Life

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: 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.

Implementation: 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.

Implementation: 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.

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

Implementation: Multidisciplinary teams including consultants in palliative medicine and palliative care clinical nurse specialists, sufficient to provide a seven-day face-to-face service, 8.00am-4.00pm or equivalent, in line with the *NICE Cancer Standards 2004* could be applied to non-cancer conditions.

Implementation: Measure the number of cancer and non-cancer patients receiving specialist palliative care e.g. those coded on hospital systems or recorded on a cancer or palliative care registry. This would provide a baseline of current productivity to highlight where the gaps in service are.

5

Train patient-facing healthcare staff in palliative and end of life care. This training should be included in:

- Undergraduate and postgraduate education; and
- Regular training for patient-facing healthcare staff

Primary target audience: *Medical schools, schools of nursing and university departments who provide training for nurses, pharmacists, allied health professionals, primary care, community care including care homes, nursing homes, social care, post-graduate deaneries, medical directors and directors of nursing*

Supported by: *Executive boards, integrated care boards and commissioners, Care Quality Commission, Health Inspectorate Wales, Regulation and Quality Improvement Authority Northern Ireland*

This aligns with recommendations from the National Audit of Care at the End of Life

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: This training will help patient-facing 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.

Implementation: Embed palliative care and end of life care training as a core competency for patient-facing healthcare staff. A similar example would be *Basic Life Support (BLS)* training.

Implementation: Training requirements should be agreed through objective setting in appraisals. The frequency of this training might vary between different staff groups but should ensure a basic level for most patient-facing healthcare staff and enhanced training wherever possible.

Implementation: Focused training to a level appropriate to the job role with a clear job description and agreed core competencies may provide support for specialist palliative care teams.

6

Ensure that existing advance care plans are shared between all providers involved in a patient's care.

This aligns with recommendation 2 from the NCEPOD report looking at the in-hospital care of out of hospital cardiac arrests – Time Matters

Primary target audience: *Integrated care boards and commissioners*

Supported by: *Palliative care services, clinical directors, medical directors and directors of nursing, primary care, ambulance trusts, care home and nursing home providers, hospice services, social care, local authorities, patients, carers and family members*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: Documents frequently stay in one place if a patient is transferred, meaning their wishes are often not followed. This includes sharing of documents such as ReSPECT forms – *Resuscitation Council UK*, and universal / advance care plan / treatment escalation plans.

Implementation: Use electronic records or send the document with the patient when they are transferred, with consideration given to third sector (hospice), private (care and nursing home) and local authority providers.

7

Raise public awareness to increase the number of people with a registered health and welfare lasting power of attorney (LPA) well before it is needed.

Primary target audience: *Department for Health and Social Care, Welsh Government, Department of Health Northern Ireland, Office of the Public Guardian, the Office of Care and Protection*

Supported by: *Royal colleges, patient support groups, third sector organisations, hospice services, primary care, community care including care homes, nursing homes and social care*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: Early conversations are important to ensure that people's wishes are always considered specifically should they lose mental capacity to make their own decisions. Appointing trusted people to be an advocate when people cannot speak for themselves should be a normal part of this conversation.

Implementation: Information about a lasting power of attorney can be found here: *www.gov.uk/power-of-attorney.* This information could be provided to patients in GP practices, when people are admitted to hospital, hospice, care home or nursing home. Information could be provided by will-making services, or registrars when people get married/register a birth. A media campaign is needed, similar to organ or blood donation, to raise awareness.