North West Model for Life Limiting Conditions

Supporting people to live well in the last years of their life before dying in the place of their choice with peace and dignity; supporting families and carers through bereavement.

Caring for a person with life-limiting condition is about:

- Recognition and timely identification of individuals with a life limiting illness (Proactive Identification Guidance)
- The person, their carers and those important to them.
- Meeting the supportive and palliative care needs for all those with a progressive incurable illness or frailty, to live as well as possible until they die.
- Support in the last year(s), months and days of life and through to bereavement.

Care should be:

- Individualised and person-centred; “What matters to me and my priorities”
- Underpinned by shared decision making that involves the person, and those important to them;
- Education and empowerment of individuals and their carers to support self-care and wellbeing
- Collaborative, coordinated, and delivered with kindness and compassion;
- Delivered by a competent, confident and capable workforce
- Underpinned by continuity of care through good communication across all systems
- Supported through compassionate communities.

Specialist Palliative Care (SPC) is the total care of individuals living with progressive, advanced disease and limited prognosis. The care is provided by a multi-professional team who have specialist palliative care training. SPC includes (but is not limited to) physical, psychological and spiritual assessment and management of symptoms; analysis of complex clinical decision-making challenges applying ethical and legal reasoning alongside clinical assessment; care and support to those important to the person, including bereavement care; specialist advice and support and education and training of the wider care team providing core palliative care.

This model gives an overview of the assessment and planning process for individuals with a progressive incurable illness or frailty. The Good Practice Guide on page 2 identifies key elements of practice within each phase to promote individualised, personalised care and support planning, with core principles that apply to all phases.
CORE PRINCIPLES (MAINTAINED FROM STABLE THROUGH TO THE LAST HOURS OF LIFE AND INTO BEREAVEMENT)

- Communication should be sensitive and unambiguous;
- Offer an Advance Care Planning (ACP) discussion; personalised care and support plan (PCSP) to be put in place; could include TEP / PPC / ADRT / LPA / Making a will;
- Needs of those identified as important to the person are explored, respected and met as far as possible;
- Assessments should be holistic to include physical, psychological, spiritual & social aspects, rehabilitation and quality of life. Review when condition changes or as required;
- The principles of the Mental Capacity Act 2015 must underpin all practice;
- Review Prescribing;
- Access Specialist Palliative Care Services (with consent) when needs or symptoms are difficult to manage.

<table>
<thead>
<tr>
<th>Stable</th>
<th>Gradual Decline</th>
<th>Rapid decline</th>
<th>Last Days of Life</th>
<th>Care After Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>◊ Person diagnosed with life-limiting condition; treatable symptoms, but incurable</td>
<td>◊ Person identified as deteriorating despite optimal therapeutic management of underlying medical condition(s)</td>
<td>◊ Person identified as in rapid decline despite optimal therapeutic management of underlying medical condition(s)</td>
<td>◊ MDT agree person is in the last days of life—NICE guidance</td>
<td>◊ Verification of death</td>
</tr>
<tr>
<td>◊ Supportive care to help prevent or manage adverse effects of disease and/or treatment</td>
<td>◊ Exclude reversible causes of deterioration; investigate and treat as appropriate</td>
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<td>◊ Medical Certification of death</td>
</tr>
<tr>
<td>◊ Offer ACP discussion to put PCSP in place; consider how soon/whether likely capacity may be lost; may include CPR discussion</td>
<td>◊ Include on primary care supportive/palliative care register; review regularly</td>
<td>◊ Review at supportive/palliative care meeting</td>
<td>◊ Review at supportive/palliative care meeting</td>
<td>◊ Respect and support cultural/religious faith customs</td>
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<tr>
<td>◊ Record EPaCCS / equivalent, with consent</td>
<td>◊ District Nurse referral for assessment of care needs (if at home)</td>
<td>◊ Discuss and prescribe anticipatory medication</td>
<td>◊ District Nurse referral for assessment of care needs (if at home)</td>
<td>◊ Post death reporting: Notifiable diseases, Significant Event Analysis, Coroner referral</td>
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<tr>
<td>◊ Benefits review for person and carers: e.g. grants, prescription exemption, Blue Badge scheme</td>
<td>◊ Consider if the care is still in line with PCSP, or offer an ACP discussion to put PCSP in place; may include TEPs and CPR discussion</td>
<td>◊ Enable rapid discharge to PPC/PPD (if in hospital)</td>
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<td>◊ Family, carers and those important to the person offered practical and emotional support (signpost to bereavement services)</td>
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<tr>
<td>◊ Consider any possible crises; agree anticipatory clinical plan with the person / those important to them</td>
<td>◊ Record EPaCCS or equivalent, with consent (Data Protection)</td>
<td>◊ Monitor frequently, consider any possible crises; ensure people have contact details of those to call in time of crisis</td>
<td>◊ Monitor frequently, consider any possible crises; ensure people have contact details of those to call in time of crisis</td>
<td>◊ What to do after a death: <a href="https://www.gov.uk/when-someone-dies">https://www.gov.uk/when-someone-dies</a></td>
</tr>
<tr>
<td>◊ Monitor and support; consider timely referral to other specialist services</td>
<td>◊ Share important clinical and social information with all health and social care professionals</td>
<td>◊ Consider Continuing Health Care funding</td>
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<td>◊ Update supportive/palliative care record and EPaCCS with date and place of death</td>
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<tr>
<td>◊ ICD discussion about possible future deactivation, if applicable</td>
<td>◊ Benefits review for person and carers: e.g. DS1500, attendance allowance</td>
<td>◊ Consider DS1500</td>
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<td>◊ Inform all relevant agencies: CCG, GP, social care, ambulance service, OOH, Specialist Palliative Care Team, Allied Health Professionals, equipment store</td>
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<tr>
<td>◊ Early identification of symptoms and holistic needs</td>
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<td>◊ Assessment of equipment needs</td>
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<td>◊ Timely debrief and identify if staff support required</td>
</tr>
<tr>
<td>◊ Consider referral to other services based on needs assessment</td>
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<td>◊ ICD discussion/deactivation, if applicable</td>
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<td>◊ Consider Continuing Health Care Funding</td>
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<td>◊ CPR considered/discussed; document conversation and decision</td>
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<td>◊ ICD discussion, if applicable</td>
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<td>◊ Share information with OOH/NWAS, include CPR status and ACP; update EPaCCS</td>
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</tbody>
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Early Identification guides:

- Primary care—**EARLY**
- Care Homes—Six Steps / Shadow NEWS2

ACP—Advance Care Planning
ADRT—Advanced Decision to Refuse Treatment
CPR—cardiopulmonary resuscitation
EPaCCS—Electronic Palliative Care Coordination System
ICD—implantable cardioverter defibrillator
LPA—Lasting Power of Attorney
MDT—Multidisciplinary Team
OHN—Out of Hours
NWWA—North West Ambulance Service
TEP—Treatment Escalation Plans

NICE—National Institute for Health and Care Excellence
NWAS—North West Ambulance Service