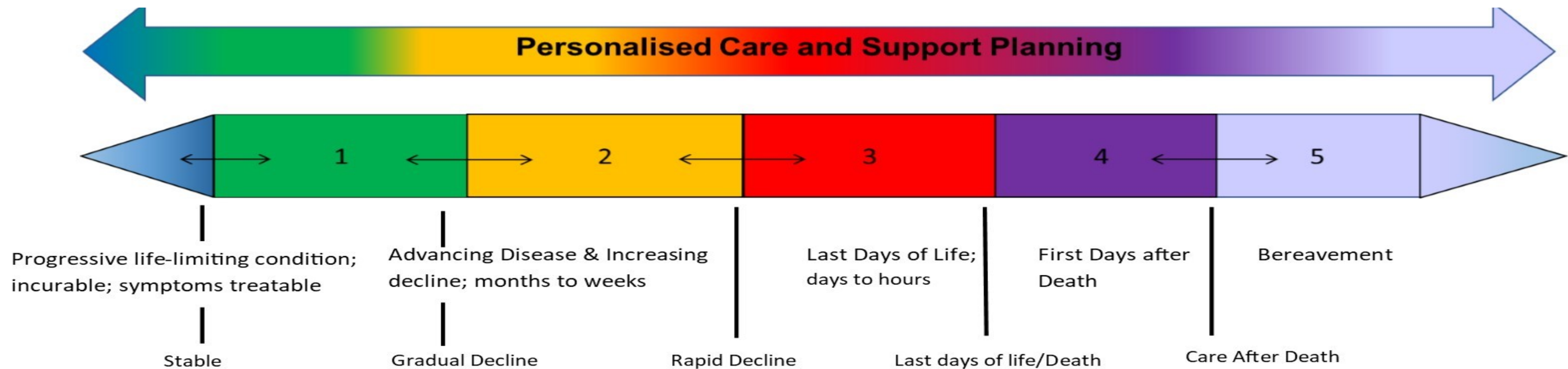
North West Model for Life Limiting Conditions

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 patient with life-limiting condition is about:

- ◊ Recognition and timely identification of patients 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 patients 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.

This model gives an overview of the assessment and planning process for patients 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.

Specialist Palliative Care (SPC) is the total care of patients 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.

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.

Stable

- **Person diagnosed with life-limiting condition; treatable symptoms, but incurable**
- Supportive care to help prevent or manage adverse effects of disease and/or treatment
- Offer ACP discussion to put PCSP in place; consider how soon/how likely capacity may be lost; ***may include*** *CPR discussion*
- Record EPACCS / equivalent, with consent
- Benefits review for person and carers: e.g. grants, prescription exemption, Blue Badge scheme
- Consider any possible crises; agree anticipatory clinical plan with the person / those important to them
- Monitor and support; consider timely referral to other specialist services
- ICD discussion about possible future deactivation, if applicable

Early Identification guides:

Primary care– EARLY

Care Homes—Six Steps / Shadow NEWS2

Gradual Decline

- **Person identified as deteriorating despite optimal therapeutic management of underlying medical condition(s)**
- Exclude reversible causes of deterioration; investigate and treat as appropriate
- Include on primary care supportive/palliative care register; review regularly
- District Nurse referral for assessment of care needs (if at home)
- 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
- Record EPaCCS or equivalent, with consent (Data Protection)
- Share important clinical and social information with all health and social care professionals
- Benefits review for person and carers: e.g. DS1500, attendance allowance
- Early identification of symptoms and holistic needs
- Consider referral to other services based on needs assessment
- Consider Continuing Health Care Funding
- ICD discussion, if applicable

Rapid decline

- **Person identified as in rapid decline despite optimal therapeutic management of underlying medical condition (s)**
- Exclude reversible causes of deterioration; investigate and treat as appropriate
- Review at supportive/palliative care meeting
- Discuss and prescribe anticipatory medication
- District Nurse referral for assessment of care needs (if at home)
- Enable rapid discharge to PPC/PPD (if in hospital)
- Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis
- Review, or offer, ACP discussion to put PCSP in place; record EPaCCS or equivalent with consent
- Consider Continuing Health Care funding
- Consider DS1500
- Assessment of equipment needs
- ICD discussion/deactivation, if applicable
- CPR considered/discussed; document conversation and decision
- Share information with OOH/NWAS, include CPR status and ACP; update EPaCCS
- Refer to other specialist services as needed

Last Days of Life

- **MDT agree person is in the last days of life—NICE guidance**
- Exclude reversible causes of deterioration; investigate and treat as appropriate
- Agree individual plan of care for the dying person, supported by local documentation, coordinated and delivered with compassion; review regularly Priorities for care of the dying person / One Chance to Get it Right
- Anticipatory medication prescribed and authorized for use by MDT
- Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis
- Implement care of the dying nursing interventions
- ICD discussion and deactivation if not previously initiated
- Community patients: share information about expected death with OOH/NWAS, include CPR status and ACP; update EPaCCS
- Sensitive communication with carers/family, including what to expect when someone is dying
- Respect and support cultural/religious faith customs

Care After Death

- **Verification of death**
- Medical Certification of death
- Respect and support cultural/religious faith customs
- Post death reporting: Notifiable diseases, Significant Event Analysis, Coroner referral
- Family, carers and those important to the person offered practical and emotional support (signpost to bereavement services)
- What to do after a death: https://www.gov.uk/when-someone-dies
- Update supportive/palliative care record and EPaCCS with date and place of death
- Inform all relevant agencies: CCG, GP, social care, ambulance service, OOH, Specialist Palliative Care Team, Allied Health Professionals, equipment store
- Timely debrief and identify if staff support required

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
OOH—Out of Hours
NWAS—North West Ambulance Service
PPC / D—Preferred Place of Care / Death
PCSP—Pesonalised Care and Support Plan
TEP—Treatment Escalation Plans

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