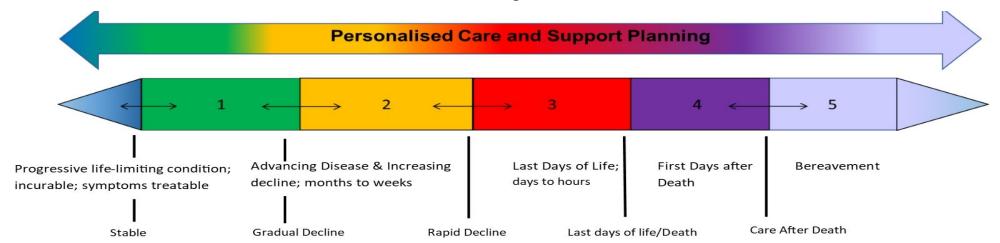
North West Model for Life Limiting Conditions

Supporting people in Wales 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 (<u>Proactive Identification Guidance</u>)
- ♦ 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 plan (PCP) 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 (SPC) (with consent) when needs or symptoms are difficult to manage.

Stable

- Person diagnosed with lifelimiting condition; treatable symptoms, but incurable
- Supportive care to help prevent or manage adverse effects of disease and/or treatment
- Offer ACP discussion to put PCP in place; consider how soon/how likely capacity may be lost; may include DNACPR discussion
- Record in individuals records with consent if relevant
- Benefits review for person and carers: e.g. Attendance
- Allowance, 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:

Care Homes—Six Steps

V4.0 wales

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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. Discuss and prescribe anticipatory medication.
- District Nurse referral for assessment of care needs (if at home)
- Consider if the care is still in line with PCP, or offer an ACP discussion to put PCP in place; may include TEPs and DNACPR discussions.
- Record in individuals records 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, include holistic & spiritual 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 and consider using Care Decisions Guidance (CDG).
- 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 PCP in place; record in individuals records with consent
- ♦ Consider Continuing Health Care funding
- ♦ Consider DS1500
- Assessment of equipment needs
- ICD discussion/deactivation, if applicable
- DNACPR considered/discussed; document conversation and decision
- Share information with OOH/WAST, include DNACPR status and ACP; update electronic records & other plans if appropriate.
- 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 CDG; review regularly <u>Priorities</u> <u>for care of the dying person</u> / <u>One</u> <u>Chance to Get it Right</u>
- Anticipatory medication prescribed and authorised 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/WAST, include DNACPR status and ACP; update individuals records
- 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/whensomeone-dies
- Update supportive/ palliative care record and individuals records with date and place of death
- Inform all relevant agencies: GP, social care, WAST, OOH, Specialist Palliative Care Team, Allied Health Care Professionals, equipment store
- Timely debrief and identify if staff support required

ACP—Advance Care Planning

ADRT—Advance Decision to Refuse Treatment

DNACPR—Do not attempt cardiopulmonary resuscitation

ICD—implantable cardioverter defibrillator

LPA—Lasting Power of Attorney

CDG- Care Decisions for Last days of Life Guidance

MDT—Multidisciplinary Team

OOH—Out of Hours

WAST—Welsh Ambulance Service Trust

PPC / D-Preferred Place of Care / Death

PCP—Pesonalised Care Plan

TEP—Treatment Escalation Plans