



East Kent Interagency Policy for End of Life Care Management

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1. Introduction

The National End of Life Strategy aims to ensure the delivery of high quality palliative care to everyone in the UK on the basis of clinical need not diagnosis, and according to established principles of equity and personal dignity. It sets out an agenda for improving the quality and effectiveness of services.

Defining end of life

The NICE commissioning guide uses the General Medical Council's definition of end of life: people are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

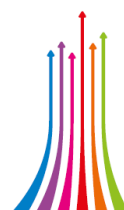
Defining when a person needs end of life care is individual and dependent on the person's perspective and that of their health and social care professional. It could be marked by diagnosis of a condition that has a poor prognosis, or by exacerbation of a long-term condition that has resulted in a sudden and marked deterioration, in the person's physical health and independence. End of life care needs coexist with other health and social care needs and are influenced by a person's religious, cultural and social circumstances. Consequently, end of life care services should be commissioned and delivered in an integrated and person-centred manner. (NICE)

The ambitions for palliative and end of life care (2015) documents highlights key ambitions for care

Six ambitions to bring that vision about



"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."



National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

Primary and community care teams deliver the majority of hands-on end of life care to patients and do this in a sound and effective way, especially when backed by specialist palliative care support. However, although there are many examples of good practice, national findings suggest end-of-life care can sometimes be uncoordinated, inconsistent and reactive, leading to a variable standard of care.

The Five Year Forward View intends to ensure decisive steps to break down the barriers in how care is provided between GP's and hospitals, between physical and mental health, between health and social care. Far more care will be delivered locally but with some services in specialist centres, organised to support people with multiple long term conditions, not just single diseases. Services need to be integrated around the patient ensuring patients are helped to get the right care in the right place at the right time. The care & quality gap will be addressed with reshaping of care delivery, harnessing technology and driving down variations in quality & safety of care

This policy has been prepared in response to the East Kent End of Life Strategy and relates to the NICE quality Standard (QS13) for end of life care and the Ambitions (2015) National framework. Please see section 9 where details of related guidance can be found.

2. Purpose and Scope

The purpose of this policy is to improve anticipatory care to help more people with palliative care needs, and at the end of their life to be cared for and die in the place of their choice. Improved anticipatory care will ensure patients receive timely symptom assessment and management. Facilitating improved anticipatory care has the potential to enhance patient care and aid the prevention of unnecessary crises and unscheduled hospital admissions.

The policy sets out the responsibilities of each care provider within and across the patient pathway in order that care is well coordinated and that patients, carers and families needs are assessed and appropriately met.

3. Statement of Policy

The aims of this policy are to:

- Clarify roles and responsibilities across care providers to ensure that care is well coordinated across the pathway
- An improved pathway for patients identified as requiring palliative care early on through the palliative care register ['end of life register', 'supportive care register'] held within general practice.
- Better co-ordination of the patient journey to assist people to die in their place of choice where possible.
- Assisting those at the end of life to live as well as they can until they die.
- Ensuring that the needs of both the patient and their families are identified and met throughout the last phase of life.
- Appropriate management of symptoms and access to social and practical support.
- Provision of a timely and appropriate response to all calls 24/7.
- Reduction in duplication of services and more effective and efficient use of limited resources.
- An improvement in liaison and transfer between service providers.

4. Duties of Care Providers - Responsibilities

The organisation of the care pathway is described in 'Tiers of Care'. This is to define what is expected to take place in support of the patient and their families and reduce fragmentation and blurring of care delivery responsibilities.

It is important to note that patients will often move between the Tiers of Care as appropriate to meet their individual needs and are as follows:

Tier 1 – General(ist) Palliative Care - Primary Care / District Nursing/Learning Disabilities (PC)

Tier 2 – Specialist Palliative Care – Multi-professional team with specialist palliative care training (SPC)

Tier 3 – Secondary (acute) Care (SC)

See **Appendix 1** for description of each Tier of Care and flow chart

However, other supporting services are available and each services roles and responsibilities are detailed within the policy.

5. Primary Care (Low Risk - General(ist) Palliative Care)

The patients GP, who holds ultimate responsibility as the lead clinician for the patients care, together with the community nurse team will:

- Work together to identify the patient group to be proactively case managed via Risk Stratification (Top 1%) and / or the palliative care register.
- Ensure all appropriate patients will be entered onto the palliative/end of life register within general practice and the supportive and palliative care (**SPICT**) indicator tool will be applied. At this point the patient's complexity will be considered and if deemed high risk will be referred to Specialist Palliative Care (SPC) Pilgrims Hospice (see **NB** below). At this point the most appropriate tools for example '**PEACE**', '**Frailty**' or

other appropriate tools must be applied See **Appendix 2 & 3** for PEACE & Frailty Tools as examples

- The community nursing team will ensure that if any of the patients identified have a learning disability the Community Learning Disability team are involved at the earliest opportunity
- Work with the patients GP and other clinicians including social services teams (if patient is already known to social services) to ensure care is coordinated.

NB: if the patient is deemed high risk and requiring specialist palliative care, the patient will remain under the care of their GP and Community Nurse team with support, guidance and input from the SPC team until such time as the patient requires inpatient care and management when they will be admitted to Pilgrims Hospice. This will be either for symptom control and will return home, or for end of life care, which preferably will be the last 72 hours if possible, in order that the patient stays within their own environment for as long as possible.

- The Community Nursing team lead will work with the GP to arrange a discussion with the GP, patient and carer / family in order that early conversation takes place regarding preferred place of care and also ceilings of care.

(Ceilings of Care – this discussion will be the responsibility of the GP supported by the Community Nurse).

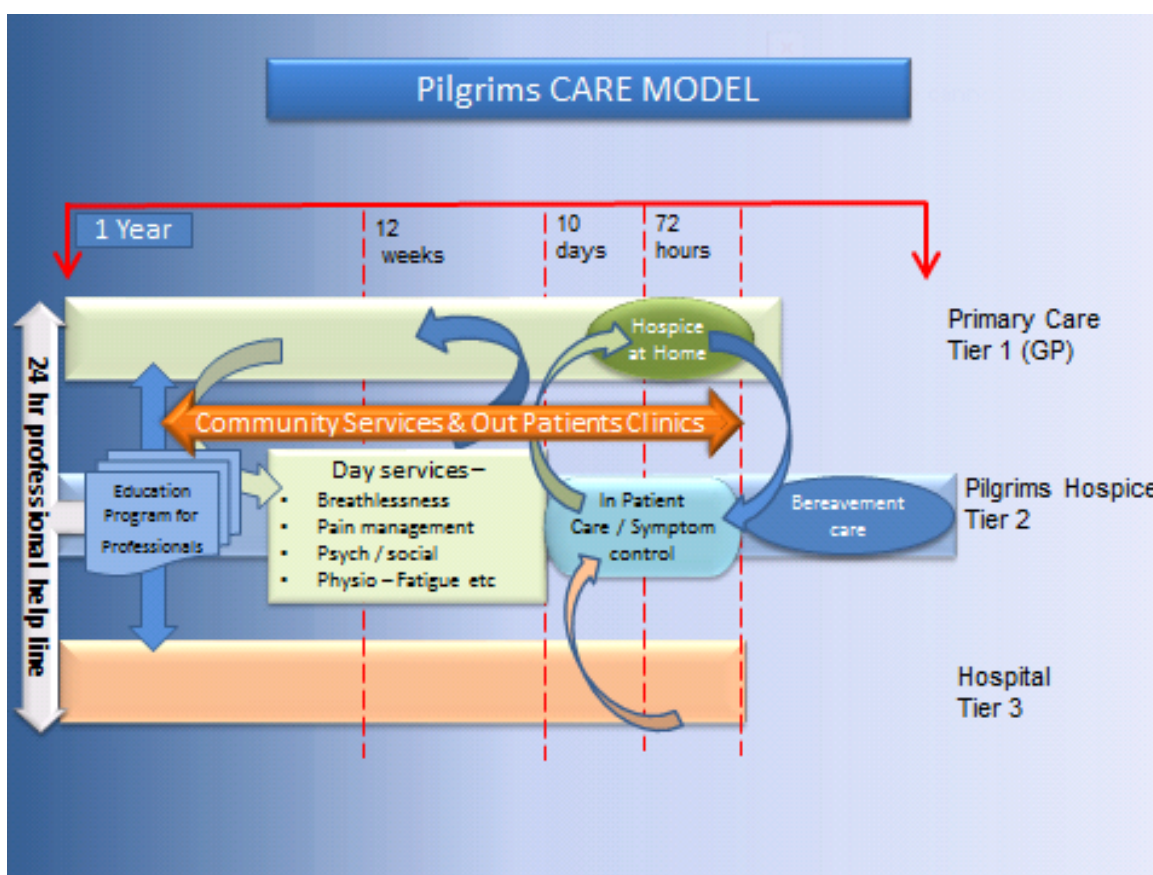
- When discussing preferred place of care, in line with the Ambitions guidance (2015) there should be a decision to ensure each person is seen as an individual. It is recommended individuals are asked for their 1st and a 2nd preference and the patients 1st preferred place of care will be the priority. The 2nd preference is required as towards the end of life as individuals may consider that as their health status changes they require further/extra support in a different care setting. An early conversation between the health care professionals, patient and carer/family in this regard can ensure that all parties are confident that the patient and family wishes have been fully explored and considered.
- A holistic assessment will be undertaken by the community nursing team and a personalised plan of care agreed. This will be reviewed regularly
- The GP and Community Nurse Team Lead or Deputy (in the absence of the team lead) will ensure that the anticipatory & advance care plan (ACP) (see **Appendix 4** for example of ACP) is completed and agreed with the patient, carer/family at the earliest opportunity.
- (A paper copy must be kept in patients home together with relevant documentation including DNA CPR status)
- The Community Nursing team will provide a contact number for day and night contact to the nursing service. This is in order that the patient and carers can seek advice and support if concerned or unsure, this can prevent an unexpected situation escalating to crisis point.
- The Community Nurses will ensure that any carers/ family members are identified and offered a referral for a carers support and carer assessment. . Appropriate information such as patient & carer pack should be provided, that meets the patients and carers need.

- The GP and/or Community Nurses will work in collaboration to ensure 'Just in case box' with emergency symptom control medication is in place at the earliest point appropriate.
- Community Nursing teams will ensure that spiritual and psychological support is in place for those who wish it.
- The GP and Community Nurse Team Lead will ensure Multi-Disciplinary Team meetings are held regularly in order that care coordination and communication is maximized. These can be physical or virtual. (virtual – through the use of 'Careflow' - if available)
- The Community Nurse Team lead will hold responsibility for patients on their case load, (each patient will have an identified lead clinician (GP), which will be detailed on the care plan) and continue to regularly review care and coordinate to prevent crisis, consider any care/support needs and mobilise services to include:
 - Referral and communication in regards Social care support
 - Continuing Health Care assessment
 - Assessing and prescribing equipment required and ordering via local policy
 - Liaising with lead clinician and providers to access 'Step-up beds'
 - Hospice support (Generalist) – Pilgrims Hospice will provide advice and guidance to GP's and Community Nurses in the general management of patients at the end of life.
- The Community Nursing Team/GP will ensure that care after death takes place and take the following actions:
 - Ensure the Medical Interoperability Gateway (MIG) is updated if not already undertaken by GP
 - Bereavement visit / contact
 - Highlight to lead clinician if relatives may require future bereavement support
 - Timely verification of death where appropriate and where death meets criteria where a nurse can verify
 - Timely certification of death (GP)
- Request provider of equipment to collect items

5.1 Specialist Palliative Care (SPC) (High Risk- Multi-professional team with specialist palliative care training and competence)

Vision of the Pilgrims Hospices Service

Our vision is of a community where people with a terminal illness and their family and friends are supported and empowered to live well in mind and body until the very last moment of their life



Aims of the Pilgrims Hospices Service will:

- Provide Specialist Palliative Care services alongside existing primary and secondary care services to patients in their last year of life who have specialist palliative care needs.
- Support Primary care (tier 1) and East Kent Hospitals University Foundation Trust (tier 3) services by providing a 24/7 professional helpline where Healthcare Professionals from all tiers, patients and their carers, can get advice and guidance
- Support Primary care (tier 1) and East Kent Hospitals University Foundation Trust (tier 3) services by providing a time limited programme of education, care and support to patients and families to enable them in their last year of life
- Support Primary care (tier 1) with decision making and symptom management by providing outpatient appointments for patients and carers to assess requirements and plan care
- Support Primary care (tier 1) with decision making and symptom management by providing home visits, if appropriate, for patients and carers to assess requirements and plan care
- Support East Kent Hospitals University Foundation Trust (tier 3) services by providing on site visits to inpatients to assess patient requirements and plan care
- Support primary care (tier 1) services when they are managing patients in the last hours or days of life with additional support to carers in the home environment between 730am and 930pm 7 days per week
- Provide inpatient care to patients that require Specialist Palliative Care for symptom management and at end of life, should the hospice be their preferred place of death.
- Support Primary care (tier 1) and East Kent Hospitals University Foundation Trust (tier 3) services by coordinating a programme of education for all healthcare professionals in best practice in End of Life Care

Eligibility Criteria

The patient remains under Primary Care services at all times.

Referral can be made from

- Primary Care (Tier 1)
- Secondary Care (Tier 3)

All patients who are referred

- Will have agreed to referral or, if lacking capacity, a decision has been made in line with the Mental Capacity Act
- Are expected or at risk of dying in the next year
- Exacerbation of symptoms that cannot be effectively managed within Tier 1 and who require specialist input from Tier 2

Indications for referral to Day Services

The aim of the service is to empower patients and carers through education and support to improve their symptoms (physical, psychological, spiritual or social).

A full service specification will be launched throughout the year and will include:-

- Advance care planning
- Counselling
- Complementary therapies
- Physiotherapy
- Occupational Therapy
- Breathlessness management
- Fatigue Management
- Therapeutic classes (such as music/Art)
- Support groups for Patients and Carers

• **The service is for:-**

People whose death is expected within a year and have any of the following that cannot be managed by Tier 1:

- Symptom Control needs
- Psychological needs
- Carer support needs
- Rehabilitation needs
- Agree to the referral

Indications for referral onto full Tier 2 services includes patients who:

- Are expected to die in the next 72 hours and their preferred place of death is the hospice or requiring rapid response help to die in their place of care
- Have physical, psychological, social or spiritual needs related to their illness that are beyond the scope of primary or secondary care (Tier 1 or Tier 3) services to meet
- Are identified as being at risk of physical, psychological, social or spiritual need over the course of their illness that would benefit from Specialist Palliative Care input

Crisis admission criteria for patients

- Patients not on current hospice caseload (Tier 1)
- A sudden and rapid decline

Indications for admission (in order of priority) of patients on caseload (Tier 2)

- Patients with a range of needs related to their illness, none of which can be met in other settings
- Patient with single need scoring as severe or overwhelming related to their illness, which cannot be met in other settings
- Patients with mild or moderate needs which cannot be met elsewhere
- Patients with no specific needs but their preferred place of death is the hospice and they are expected to die in the next 72 hours

If there is difficulty in establishing priority then the patient with the shorter prognosis will usually take priority if all other factors are similar.

Indications to refer onto other services from Tier 2

- Patients where their condition improves such that their prognosis is greater than a year
- Patients declining Pilgrims Hospices Services input
- Patients whose informed decision is to follow active care pathways and not engage in a palliative approach
- Patients who no longer have specialist needs

If the improvement is likely to be only temporary then the patient can be offered “patient or care led follow up”. Pilgrims Hospices Services will no longer be actively following them up but they will be able to ring and re-activate input during the following 6 months.

Referral processes

A referral can be made by using the hospice electronic referral proforma only. Letters will not be accepted

Completion of a referral form must be undertaken by a healthcare professional with the agreement of the patient’s supervising consultant or GP.

Exclusion criteria

- Patients who are under 18 years old
- Not registered with an East Kent GP
- Respite admissions, defined as a planned break for a carer, **are not offered**.
- Medical provision Out of Hours not related to Specialist Palliative Care will be provided by the Out of Hours service provided by IC24 at this time
- Transportation of patients to and from either Tier 1 or Tier 3 and between Hospice sites (this is part of the patient NHS transport service commissioned by east Kent CCGs)

5.2 Service description/care pathway

The service will provide Specialist Palliative Care as outlined in the Tier 2 framework this will include the following;

- Advice and guidance to Tier 1 (Primary Care) & Tier 3 (secondary care) as part of MDT
- 24/7 hour Professional Helpline for patients carers and HCP– access to advice and guidance to Tier 1 & Tier 3, patients under the care of Tier 2 SPC
- Education of carers/patients/ health care Professionals
- Advise on general symptom control (all patients Tier 1 and 3)
- Access to day services (all patients)

- Complex symptom control (at home Tier 2)
- In-patient complex symptom control
- Update Primary Care Team with any change to patients care to update MIG asap
- Spiritual, Psychological and Social Support
- In-patient end of life care
- Care after death
 - Ensure MIG updated by informing patients GP Practice
 - Bereavement services
 - Timely verification/certification of death

5.3 Service Model

An inpatient provision will be provided from:

- Pilgrims Hospice in Thanet
- Pilgrims Hospice in Canterbury
- Pilgrims Hospice in Ashford

Discharges

Patients will be discharged as per admission and referral criteria back to Tier 1

Withdrawal from Tier 2 services –will be made in accordance with the East Kent Multiagency Policy for end of life care.

5.4 Response time and prioritisation

Pilgrims Hospices will respond to referrals within 3 working days of receipt unless urgent when response will be expected within 24 hours.

5.5 Days/hours of operation

Inpatient care is provided 24 hours a day 7 days a week as per Tier 2

Hospice at home is provided from 7.30-21.30 7 days a week

Day services are provided and are available Monday –Friday

Palliative Specialist nursing team providing Outpatient assessment and follow-up and community home visits as required Mon-Fri.

5.6 Population covered.

The service will cover the Population of East Kent

5.7 Secondary (acute) Care

East Kent Hospitals NHS University Trust (EKHUFT) consists of 3 acute hospitals; William Harvey Hospital, Ashford (WHH), Kent and Canterbury Hospital, Canterbury (KCH) and Queen Elizabeth Queen Mother Hospital, Margate (QEQMH)

EKHUFT will ensure:

- EKHUFT will work together with Tier 1 to identify the patient group at risk of dying in the coming year using the supportive and palliative care (SPICT) indicator tool
- EKHUFT will ensure all these patients are identified to the primary care teams so they can be entered onto the palliative/end of life register. At this point EKHUFT will complete the anticipatory care plan if one is not already in place.

- If the patient or those close to them are deemed high risk, EKHUFT will refer to Specialist Palliative Care teams at the appropriate hospices after informed consent.
- End of life care is the responsibility of all staff at EKHUFT - a principle that is fully endorsed by the End of Life Board and forms part of the philosophy to deliver safe, effective, well led care and monitoring of standards for those in their care.
- Management of an acute episode should an end of life care patient require it
- Provide planned treatments (i.e. blood transfusions, chemotherapy, radiotherapy)
- Access and follow Anticipatory/Advance care plan (AAP) via the Medical Interoperability Gateway (MIG), including access to the DNACPR
- Early identification of patients for who require specialist palliative care (SPC) from the hospital SPC team, supported by the Consultants from Hospices
- That there are discussions with patients/families /carers regarding current prognosis and ceilings of care
- Update Primary Care Team to ensure AAP is updated on MIG as soon as possible
- That care needs are still met with current levels of support at home (where ever that may be) if not make appropriate referrals
- That referral for 'fast track' to preferred place of care takes place as per AAP
- Offer patient/carer information pack
- Register unregistered patients with a GP in patient's area of choice
- Care after death (if death takes place in hospital)
 - Bereavement discussion with families/carers
 - Patients GP is informed within 3 days of the patients death
 - Timely verification/certification of death
- Provision of a specialist palliative care (SPC) team (NB: this is an EKHUFT team and not to be confused with Pilgrims Hospice SPC – Tier 2 service) in the hospital. A team of specialist nurses and medical consultants led by a nurse consultant in palliative care who will also support and advise the generalist staff regarding end of life care.
- Provision of access to counsellors, chaplaincy, allied health care (AHP) professionals, discharge co-ordinators, site specific CNSs and acute oncology matrons who through a co-ordinated approach aim to meet the needs of the palliative/ dying patients and carers in the hospital setting.
- That generalist ward doctors, nurses and AHPs are supported and guided to provide end of life care through link nurses with a specialist interest in promoting end of life care, facilitated by the SPC nursing team.

The aim of the SPC hospital team is to provide an effective specialist palliative care service for adult hospital patients who have a life limiting condition including supporting dying patients who may wish to go home or transfer to the hospice for their end of life care and to support those important to them.

The Hospital SPC team will ensure that the following takes place:

- Assessment and advice on holistic management of symptoms where palliative care needs are complex and cannot be met by the hospital generalist teams.
- Indirect patient care through advice and education of generalist colleagues in order to empower generalist hospital staff in managing non-complex end of life care in accordance with local guidelines to support communication and care planning.
- Liaison between community services, local hospices, extended team (as above) and with multi-professional teams within the Trust.
- Improving co-ordination of the patient pathway to meet their identified needs and choices as best as possible, including consideration to family and carers' needs.

- Facilitating complex, complicated transfers out of hospital and rapid discharge home to die.
- Empowering generalist hospital staff in discharging patients home to die; in accordance with local guidelines.
- Providing formal and informal education and training in palliative care and end of life care for hospital staff.
- Encourage student health professionals to 'shadow' a member of the SPC team for a day to gain insight into the role of palliative care teams and enhance their generalist palliative care skills.
- They are responsive to clinical trials and studies by assisting in the recruitment of patients as appropriate.
- Support to other Clinical Nurse Specialists involved in the care of patients with a life limiting illness.
- Implementation of local and national policies and guidelines.
- Referral to financial benefit services.
- The SPC on-site service will be available Monday to Friday 9am-5pm (although hours may vary slightly on each site).
- Support to patients under the care of other clinical nurse specialists by accepting referrals for patients with complex symptoms requiring specialist palliative care assessment and advice. This may be a singular episode or longer term involvement, depending on complexity and irrespective as to where the patient is in their pathway.
- Will aim to see all urgent referrals within 1-2 working days provided there is a member of the team on site. At weekends hospital ward staff may phone the pilgrims hospice for advice or request admission if the situation is appropriate for a transfer.
- Hold a local weekly MDT meeting on each site where all patients on the caseload are discussed.
- Hold a monthly Trust-wide Palliative MDT meeting (video-linked across the 3 main hospital sites) takes place to discuss complex cases.
- That end of life care features in the 'Quality Improvement Hub' that takes place one day a week on each hospital site. The hubs are a central point to cascade information and promote new initiatives for all staff to improve delivery of EOLC across EKHUFT.
- That a website is in place at EKHUFT with EOL care tools and resources to enable and support staff electronically 24/7.

5.8 Kent County Council (KCC) Adult Social Care – Responsibilities and Provision

KCC will ensure:

- Communication with the End of Life Lead and other agencies involved in the patient's end of life care.
- Support to the patient to organise the right balance of care and communicate with other agencies to support the service user with this.
- Support access to an independent advocate if the person has substantial difficulty in being involved in the assessment and planning process and has no appropriate person available to assist them.
- Completion of an assessment, and application of the national minimum eligibility criteria, to consider whether the person has eligible needs for care and support. If the patient has eligible unmet needs for care and support services.
- Support the person to remain in their own home and Develop a care and support plan with the person and if appropriate their carer to meet their needs and outcomes. The support plan will be reviewed on a frequent basis to ensure it continues to meet the person's needs and outcomes
- Provision of a named worker for each service user to ensure and enhance effective communication on the person's journey.

- Information and advice on Care Homes and paying for care where care home has been agreed as the way to meet that person's needs where the person does not meet the criteria for NHS Continuing Health Care..

KCC will provide services such as:

- Enablement – a time limited service aiming to assist people to remain independent and maintain their quality of life in their own home.
- Ongoing care services to assist and support with personal care where appropriate. There may be a charge for some services which will be based on a means tested financial assessment.
- Equipment – to assist and support with daily living within the person's home.
- Assistive Technologies – these include personal alarms and monitoring services e.g. Telecare.
- Referrals on to other organisations' such as Carers Support and Crossroads who will provide additional support

5.9 Carers Support

Carers Support will:

- Ensure that Carers' Support work in partnership with other organisations' to identify Carers and offer information, support and assessment.
- Ensure that Carers' Support signpost/refer to other organisations'/services as appropriate.
- Ensure provision of carer information pack

5.10 Crossroads Care

Crossroads Care will:

- Ensure provision of support for Carers of people at end of life; in exceptional circumstances for people living alone.
- Ensure provision of trained 1-1 social care workers attending to patient's personal care needs 24/7 for up to 48 hours.
- Ensure a response within 2 hours of professional referral,
- Ensure provision of emotional and practical support for Carers
- Ensuring capacity for service within agreed expectations
- Ensure social care/personal care needs of patient and Carer are met at home within agreed expectations
- Ensure clear lines of communication with referrer and other providers involved in pathway
- Ensure provision of Carer/Patient information pack

5.11 Community Learning Disabilities Team (CLDT)

Following admission to the General Practice EOL register, any patients with a learning disability will be referred to the local CLDT (Community Learning Disability Team)

On receipt of referral the CLDT will complete an initial screen/assessment to ascertain learning disability and then following the guidance from the national EOL Programme will “read the road ahead” using a suite of specialist assessments which may include :-

- DisDAT (Disability Distress Assessment Tool)
- Communication passport
- Hospital Passport
- Assessment of capacity to understand the diagnosis
- Breaking Bad News framework
- When I Die doc.

The CLCT will support the patient referred using steps from the following pathway:

- Discussion of diagnosis, consequences and treatment options
- Discussion with family/carers
- Develop an ACP (Advanced Care Plan) in conjunction with relevant agencies e.g. GP, hospital consultant, primary care team
- Introduce the ACC (Anticipatory Care Calendar) to help carers / family record and respond to symptoms
- Develop and adapted NEWS (National Early Warning Score)
- Develop other adapted resources to enhance understanding
- Involve advocates, if appropriate
- Liaison/facilitation activities with family/ carers/ acute/ primary care/hospice/palliative care team
- Interpretation of information provided
- Identify and signpost to other specialist Learning Disability support across health/social care/voluntary sectors

5.12 Kent & Medway NHS Partnership Trust

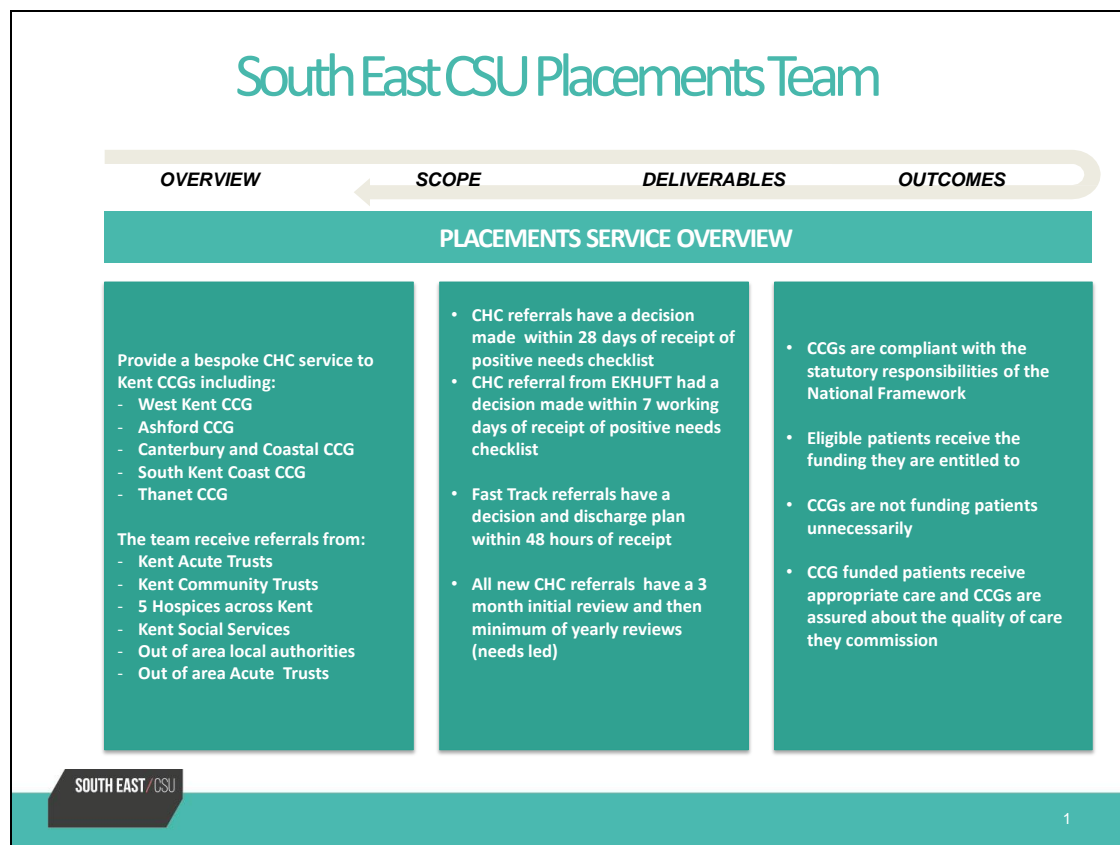
Based on The Five Priorities of Care explain that if a person is identified as being at the end stage of life:

- That this possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.
- The nurse in charge must make a prompt referral to their local hospice.
- If it is deemed appropriate for the to use a syringe driver to assist with symptom control whilst in the care of KMPT, staff will make an immediate referral to access District Nurse input via the Kent Community Health Foundation Trust (KCHFT).
- Within many religious traditions it is important that in the period leading up to death, appropriate rites of passage are conducted. KMPT staff are to make arrangements at

the beginning of this period, to follow up the wishes of the patient where they have been recorded or to seek advice from members of the family.

- Good end of life care does not stop at the point of death. When a person dies, all staff needs to be familiar with good practice for the care and viewing of the body and be responsive to carer and family wishes and cultural or religious and spiritual needs.
- A lead professional must be identified who is responsible for coordinating shared decision making between all involved

5.13 Continuing Health Care



Fast Track Definition for NHS Continuing Healthcare

Individuals with a rapidly deteriorating condition that may be entering a terminal phase, may require 'fast tracking' for immediate provision of NHS continuing healthcare. The Fast Track Tool should be completed by an appropriate clinician, who should give the reasons why the person meets the criteria required for the fast-tracking decision. 'Appropriate clinicians' are those professionals who are responsible for an individual's diagnosis, treatment or care and who are medical practitioners (such as consultants, registrars or GPs) or registered nurses.

The purpose of the Fast Track Tool is to ensure that individuals with a rapidly deteriorating condition that may be entering a terminal phase are supported in their preferred place of care as quickly as possible.

The completed Fast Track Tool should be supported by a prognosis, if available. However, strict time limits that base eligibility on some specified expected length of life remaining should not be imposed: it is the responsibility of the appropriate clinician to make a decision based on the needs of the person.

This overall process including how personal information will be shared between different organisations and healthcare professionals involved in delivering care, should be carefully and sensitively explained to the individual and (where appropriate) their representative.

NHS continuing healthcare assessments, care planning and commissioning for those with end of life needs should be carried out in an integrated manner, as part of the individual's overall end of life care pathway and should reflect the approaches set out in the national End of Life Care Strategy, with full account being taken of patient preferences, including those set out in advance care plans.

5.14 OOH Medical Services

Integrated Care 24 Ltd (IC24) will ensure:

- Support to all organisations and clinical teams in providing seamless care of the patient in the out of hours setting in the evenings overnight at the weekends and on bank holidays.
- Utilisation of special information to enable the clinician out of hours to provide consistent and appropriate advice aligned to the individual's care plan.
- All consultation details are entered onto the Electronic Patient Management System (CLEO, Adastra or SystmOne) and electronically transferred to the patient's registered practice by 8am the following day.
- Appropriate follow up by the GP of any End of Life patients via fax as well as electronic notification.
- Full support to the use of anticipatory prescribing and highlight to the GP any patients where further review is necessary.
- Active encouragement and empowerment all patients to make informed choices and decisions regarding their care.
- Links with Local Hospices ensuring all IC24 clinicians access telephone specialist advice and support throughout the out of hours period.
- IC24 will provide medical assessment to hospice inpatients
- That IC24 Call Centre staff are trained to be specifically responsive to the needs of End of Life patients and their families and carers.
- Understanding of the importance of taking accurate patient demographics.
- Calls regarding any End of Life patients are always streamed to a clinician and are routinely assessed as having an urgent disposition
- Adequate and timely response for all end of life patients by holding a comprehensive palliative care bag in all cars which is stocked with the most frequently used end of life care drugs as per our formulary (In most cases end of life patients should have a 'Just in Case' box in place).
- Provision of injectable Diamorphine in all cars to ensure that if there are any unpredicted

needs of our end of life patients that this can be administered or supplied in order to reduce any unnecessary suffering and reduce the distress to the family and carer.

- Regular audits of a random selection of all clinicians' calls by the Medical Director supported by the Locality Associate Medical Directors. These audits include the assessment of end of life care and whether hospital and 999 admissions are appropriate to the needs of the patient. Will also have the option of contacting the GP surgery directly if there are any particular concerns to be discussed.
- **That if a death takes place in a patient's own home.** Will attend if requested unless a phone call ascertains that own GP has made alternative arrangements, or a community nurse able to confirm, or the patient's own practice will be open within a reasonable timescale. Always treat sensitively, and go if it would make the process significantly easier for the family.
- **That if a death takes place in a Residential or Nursing home.** Will attend if no appropriately qualified staff are available to verify death. If the suitably trained clinician is satisfied with circumstances of death and the patient's own GP has seen the patient within the last two weeks, and there is a strong indication that the patient was near the end of their life, the home staff should contact an undertaker, in the anticipation that certification will be undertaken by the patient's own GP when next available

5.15 South East Coast Ambulance

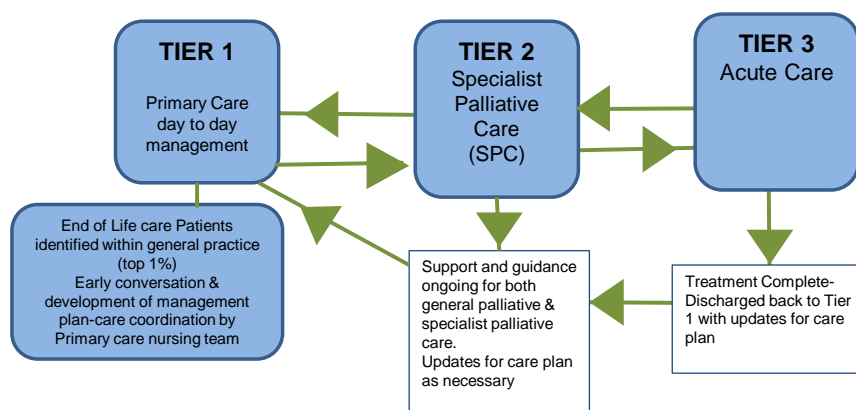
South East Coast Ambulance will ensure:

- SECAmb clinicians will provide urgent and emergency care to patients who call 999 or are referred to 999 through 111. Paramedics are able to administer 'Just in Case' medications which are provided in the patients home/care setting and appropriately prescribed to the patient.
- Ambulance Clinicians can manage patients with a wide variety of conditions without admitting to the acute hospital, in context to the patient's preferences within their care plan.
- Ambulance clinicians are recommended to share decision making with the patient's existing team (Tier 1) should they note any changes in symptoms or other coexistent issues (e.g. falls, breakthrough pain) which in turn may suggest a deterioration in their whole condition.
- SECAmb is responsible for providing urgent and emergency assessment and referral at the point of call they can also recognise the need for acute admission They must meet the duty of care of their patients and aim to meet the needs of their patients and to work the patients' own team. (Tier 1 and/to Tier 2)
- SECAmb staff will also access existing information about patients either via IBIS directly or via other interoperable clinical registers GP or care teams.
- Staff registered health care professionals (paramedics and nurses) will be required in line with their scope of practice and professional registration to access the Just In Case or anticipatory drugs available to end of life and palliative care patients.
- SECAmb paramedics and nurses are required to review a patient's symptoms, in line with their specific care plan and will administer medications as provided; even if the drug in question is not detailed on the exemptions list or as a Trust Patient Group Directive. These medicines are prescribed under a Patient Specific Direction (PSD) to manage their symptoms effectively whilst referring to the patient's palliative care support

services.

6.

End of Life Care Management Pathway



See Tiers of Care definitions for expectations of each Tier of care provided across the pathway

Date: 09/10/2015

7. Process

8. Training

Health and care staff must demonstrate kindness as well as the skills, confidence and the application of knowledge in the care of those at the end of life.

Early identification of End of Life Care need is the most important factor in maximising the chance for patients and health professionals to plan adequately and ensure that those needs and preferences of individuals are met. (Links to EK EOL Strategy) (One Chance to get it right)

This will facilitate a culture of care that is compassionate, recognises the individual needs of patients and their families and carers, as well as being open and transparent by respecting the duty of candour to which the patient is entitled.

There is widespread agreement on the importance of workforce development for all staff who come into contact with patients at the end of their lives. The focus therefore relates more to training and development issues across all the statutory, voluntary and independent sectors involved in end of life services.

Achieving this requires :

- Commitment from all staff
- Employers and commissioners to make learning time and resources available
- Employers to undertake regular staff performance reviews

There must be a focus on integration so that high quality End of Life Care is the norm for everybody.

Priorities of Care are outlined for when a patient is at the end of their life :

1	The possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes and these are regularly reviewed and decisions revised accordingly
2	Sensitive communication takes place between staff and patient and their family/carers
3	The patient, their family and carers, are involved in decisions about treatment and care and may include Ceilings of Care, DNA CPR
4	An Advance Care Plan which includes psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion. <i>Links with Anticipatory Care Planning and Anticipatory Prescribing (Just in Case Boxes)</i>

Education and training for palliative and end of life care should be made available across Health and Social care and the voluntary and private sectors for both clinical and non-clinical staff supporting patients, families and carers. The education resource toolkit can be seen in **Appendix 5**

Related Policies

Table 1 - Quality Standard (GS13)

Quality Standard (GS13) & Related National Guidance Best Practice	GS 13 -what is expected of Commissioners	GS 13 -what is expected of Providers (Health & Social Care)	Tiers of Care & Education Framework for End of Life Care – matched to quality standard	GS 13- What Patients/families /Carers can expect
Quality Standard 1 – Identification	Ensure commissioned services identify people approaching the end of life in a timely way and have the capability to record identification	Ensure that systems are in place to identify people approaching the end of life in a timely way Act to identify people approaching the end of life in a timely way.	Identify patient group via Risk Stratification (Top 1%) Add all appropriate patients to the palliative/end of life register with general practices	Identification at the right time to receive care and support to meet their needs and preferences.
Quality Standard 2- Communication & Information	Ensure they commission services with systems in place to communicate with, and offer information to, people approaching the end of life and their families and carers, in an accessible and sensitive way, in response to their needs and preferences.	Ensure that systems are in place to communicate with, and offer information to, people approaching the end of life and their families and carers, in an accessible and sensitive way, in response to their needs and preferences. Communicate with, and offer information to, people approaching the end of life and their	Early conversation with patient/family/GP/Nurse Lead regarding preferences at the end of life and ceilings of care Completion of an Anticipatory/Advanced Care Plan (ACP) with patient/carer/family – include MCA	Communicated with and offered information in a sensitive way, at a time when it is helpful and with respect for their needs and preferences.

		families and carers, in an accessible and sensitive way, in response to their needs and preferences	<p>Patient and carer pack</p> <p>Plan A – Patients agreed preferred place of death</p> <p>Plan B – 2nd choice agreed of preferred place</p> <p>Community lead nurse/Hospice/Hospital teams continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include</p>	
Quality Standard 3 – Assessment, Care Planning & Review	Ensure they commission services that carry out comprehensive holistic assessments with people identified as approaching the end of life, in response to their changing needs and preferences, which include the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment	<p>Ensure that systems are in place to ensure comprehensive holistic assessments are carried out with people identified as approaching the end of life, in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.</p> <p>Offer or contribute to comprehensive holistic assessments with people identified as approaching</p>	<p>Completion of an Anticipatory/Advanced Care Plan (ACP) with patient/carer/family –include MCA</p> <p>Holistic Assessment undertaken by nursing team (Community)/Hospital/Hospice</p> <p>Ensure MDT's are held regularly – physical or virtual</p> <p>Complete DNACPR and review regularly</p>	Offered full assessments to ensure they are getting the best care and support for their circumstances. During these assessments, they have the opportunity to discuss their needs (for example, physical, psychological, social, spiritual and cultural needs) and preferences. This includes the opportunity to develop and review a care plan detailing their preferences for current and future support and treatment.

		the end of life, in response to their changing needs and preferences, including giving them the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.	Community lead nurse/Hospice/Hospital teams continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include Ensure spiritual and psychological support is in place	
Quality Standard 4 – Holistic Support-Physical and Physiological	Ensure they commission generalist and specialist services that are able to meet the physical and specific psychological needs of people approaching the end of life, including access to medicines and equipment, in a safe, effective and appropriate way at any time of day or night	Ensure that services are available and systems are in place to meet the physical and specific psychological needs of people approaching the end of life, including access to medicines and equipment, in a safe, effective and appropriate way at any time of day or night. Manage physical and specific psychological symptoms in people approaching the end of life, including provision of medicines and equipment,	Lead nurse continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include: <ul style="list-style-type: none">- CHC if appropriate-care home/support at home- Social care support- Equipment required- Access 'Step-up beds'/care home/community hospital Hospice support (Generalist) Ensure 'Just in case box' is	Receive treatment and care to manage their physical and psychological needs, which may be at any time of day and night.

		in a safe, effective and appropriate way at any time of day or night. This may include contacting specialists for advice	in place Identify high risk patients and involve SPC Provide a contact number for day and night contact to the nursing service 24/7 Single Point of Contact – access to advice and guidance to Tier 1 (primary/community) & Tier 3 (acute hospital), patients under the care of Tier 2 Specialist Palliative Care	
Quality Standard 5 – Holistic Support – Social, Practical and Emotional	Ensure commissioned services that provide timely personalised support to people approaching the end of life for their social, practical and emotional needs. Support should be appropriate to their preferences, and maximise independence and social participation for as long as possible	Ensure that systems are in place to provide timely personalised support to people approaching the end of life for their social, practical and emotional needs. Support should be appropriate to their preferences, and maximise independence and social participation for as long as possible. Follow local policies and procedures and signpost to relevant national or local services, to ensure that people approaching the end of life are offered	Lead nurse continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include: <ul style="list-style-type: none"> - CHC if appropriate –care home/support at home - Intermediate Care Therapeutic Support - Social care support - Equipment required - Access 'Step-up beds'-community hospital 	Are offered social, practical and emotional support tailored to their needs and at the right time to help them feel supported, retain their independence and do things they enjoy for as long as possible.

		timely personalised support for their social, practical and emotional needs. Support should be appropriate to their preferences, and maximise independence and social participation for as long as possible.	Patient & Carer information pack provided Access to day services (Hospice)	
Quality Standard 6 – Holistic Support – Spiritual and Religious	Ensure commissioned services with adequate provision for offering, facilitating and providing (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to person's needs and preferences.	Ensure that systems are in place to offer, facilitate and provide (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to the person's needs and preferences. Offer, facilitate and provide (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to the person's needs and preferences	Offer Spiritual, Psychological and Social Support	Offered spiritual and/or religious support appropriate to their needs and preferences.
Quality Standard 7 – Holistic Support – Families and Carers	Ensure commissioned services that offer comprehensive holistic assessments in response	Ensure that systems are in place to offer families and carers of people approaching the end of life	Identify carers/ family members offer assessment and carer support	Families and carers of people approaching the end of life have their own needs fully assessed as

	to their changing needs and preferences, and holistic support appropriate to their current needs and preferences	comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.	Patient & Carer information pack provided	appropriate for their changing needs and preferences, and are offered support to help them cope.
Quality Standard 8 – Coordinated Care	Ensure commissioned services with appropriate systems in place (including those for information sharing) to ensure that people approaching the end of life receive consistent care at all times of day and night, that is coordinated effectively across all relevant settings and services and that is delivered by practitioners who are aware of their current medical condition, care plan and preferences	<p>Ensure that systems (such as those for information sharing) are in place, to provide consistent care at all times of day and night to people approaching the end of life, that is coordinated effectively across all relevant settings and services and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.</p> <p>Provide consistent care for people approaching the end of life at all times of day or night that is coordinated effectively across all relevant settings and services. They follow local policies and procedures for information sharing so that care is delivered by practitioners</p>	<p>Complete Anticipatory/Advanced Care Plan (ACP) will be held at General Practice via Medical Interoperability Gateway (MIG) –(include MCA and carer/family) – will be accessed by all providers involved in patients care.</p> <p>Use of Careflow (when available)</p> <p>Ensure MDT's are held regularly – physical or virtual (use of careflow)</p>	Receive care whenever they need it (day or night) that is consistent, smoothly coordinated and delivered by staff who are aware of their medical condition, care plan and preferences

		who are aware of the person's current medical condition, care plan and preferences.		
Quality Standard 9 – Urgent Care	Ensure commissioned urgent care services that provide people approaching the end of life who experience a crisis at any time of day or night, with prompt, safe and effective urgent care, appropriate to the person's needs and preferences.	<p>Ensure that systems are in place to provide people approaching the end of life who experience a crisis at any time of day or night, with prompt, safe and effective urgent care, appropriate to the person's needs and preferences.</p> <p>Respond appropriately to crises experienced by people approaching the end of life, at any time of day or night, by providing prompt, safe and effective urgent care, appropriate to the person's needs and preferences.</p>	<p>Community/Primary Care:</p> <p>Complete Anticipatory/Advanced Care Plan (AACP) -will be held at General Practice via Medical Interoperability Gateway (MIG) –(include MCA and carer/family) to be accessed by all providers</p> <p>AACP – will contain detail of ADRT & Ceilings of Care</p> <p>Lead nurse continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include:</p> <ul style="list-style-type: none"> - CHC if appropriate – care home/support at home - Intermediate Care - Therapeutic Support - Social care support - Equipment required - Access 'Step-up beds'-community hospital <p>Specialist Palliative Care :</p>	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care that takes into account their needs and preferences.

			<p>-Complex symptom control (at home)</p> <p>-In-patient complex symptom control</p> <p>-Advice and guidance to Tier 1 (Primary Care) & Tier 3 (secondary care) as part of MDT</p> <p>-24/7 Single Point of Contact access to advice and guidance to Tier 1 & Tier 3, patients under the care of Tier 2 SPC</p> <p>Acute Hospital:</p> <p>-Management of an acute episode</p>	
Quality Standard 10 – Specialist Palliative Care	Ensure commissioned specialist palliative care services with sufficient provision and capacity to provide timely specialist palliative care and advice at any time of day and night for people approaching the end of life who may benefit from specialist input. Care should be appropriate to	Ensure that systems are in place (such as shift patterns and on-call rotas), to provide timely specialist palliative care and advice at any time of day and night for people approaching the end of life who may benefit from specialist input. Care should be appropriate to the person's needs and	<p>Specialist Palliative Care (Hospice):</p> <p>Advice and guidance to Tier 1 (Primary Care) & Tier 3 (secondary care) as part of MDT</p> <p>24/7 Single Point of Contact – access to advice and guidance to Tier 1 & Tier 3, patients under the care of Tier 2 SPC</p>	Offered specialist palliative care if their usual care team are unable to relieve their symptoms adequately. It is offered at the right time for them and is appropriate to their needs and preferences at any time of day or night.

	<p>their needs and preferences</p>	<p>preferences.</p> <p>Provide timely specialist palliative care and advice at any time of day or night for people approaching the end of life who may benefit from it, or know who to contact for specialist palliative care and advice. Care should be appropriate to the person's needs and preferences.</p>	<p>Holistic Assessment undertaken and reviewed regularly</p> <p>Patient & Carer information pack provided</p> <p>General symptom control (all patients)</p> <p>Access to day services (all patients)</p> <p>Complex symptom control (at home)</p> <p>In-patient complex symptom control</p> <p>Access and follow Anticipatory/Advanced care plan (ACP) (AACP – will contain detail of ADTRT & Ceilings of Care) via MIG, include access to the DNACPR</p> <p>Use of 'Careflow' (when available)</p> <p>Update Primary Care Team with any change to patients care to update MIG asap</p> <p>Offer Spiritual, Psychological and Social Support</p> <p>In-patient end of life care</p>	
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<p>Quality Standard 11 – Care in the Last Days of Life</p>	<p>Ensure commissioned services that identify people who are in the last days of life in a timely way, and that coordinate and deliver care in accordance with their personalised care plan. Services should provide rapid access to holistic support, equipment and administration of medication</p>	<p>Ensure they have systems in place to identify people who are in the last days of life in a timely way, and that care is coordinated and delivered in accordance with their personalised care plan. Systems for rapid access to holistic support, equipment and administration of medication should be in place</p> <p>Identify people in the last days of life, and coordinate and deliver care in accordance with their personalised care plan. Local procedures should be followed to ensure rapid access to holistic support, equipment and administration of medication.</p>	<p>Ensure MDT's are held regularly – physical or virtual</p> <p>Apply supportive and palliative care indicator tool</p> <p>Identify high risk patients and involve SPC</p> <p>Apply the PEACE tool</p> <p>Holistic Assessment undertaken by nursing team and reviewed regularly</p> <p>Provide a contact number for day and night contact to the nursing service</p> <p>Complete Anticipatory/Advanced Care Plan (ACP) -will be held at General Practice via Medical Interoperability Gateway (MIG) (AACP – will contain detail of ADTRT & Ceilings of Care)– include MCA and carer/family</p> <p>Use of 'Careflow' (when available)</p> <p>Ensure 'Just in case box' is in place</p> <p>Offer spiritual and psychological support in place</p> <p>Lead nurse Communtiy/Hospital/Hospice</p>	<p>People in the last days of life are identified and receive care according to their care plan, which takes into account their needs and preferences, and ensures they can have rapid access to all the support they need, including equipment (such as a pressure-relieving mattress) and medication</p>
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			<p>continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include:</p> <ul style="list-style-type: none"> - CHC if appropriate – care home/support at home - Intermediate Care Therapeutic Support - Social care support - Equipment required - Access 'Step-up beds'- community hospital <p>Hospice support (Generalist)</p> <p>Hospice support (specialist)</p> <p>Complex symptom control (at home- Specialist))</p> <p>In-patient complex symptom control (Specialist)</p> <p>In-patient end of life care (Specialist)</p>	
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Quality Standard 12 – Care After Death – care of the body	Ensure commissioned services that provide culturally sensitive and dignified care of the body after death.	<p>Ensure that systems are in place for culturally sensitive and dignified care of the body after death.</p> <p>Care for the body of a person who has died in a culturally sensitive and dignified manner.</p>	Care after death: <ul style="list-style-type: none"> - Body is cared for in a culturally sensitive manner - Bereavement visit/discussion with family /carer - Ensure General Practice informed within 3 days - Ensure MIG updated - Equipment collection 	The body of a person who has died is cared for in a culturally sensitive and dignified manner.
Quality Standard 13 – Care After Death – timely verification and certification	Ensure commissioned services that ensure timely verification and certification of death	<p>Ensure that systems are in place to ensure timely verification and certification of death</p> <p>Follow local procedures to ensure timely verification and certification of the death.</p>	Care after death: Timely verification/certification of death	Carers and family members of people who have died receive verification and certification of the death as soon as possible.
Quality Standard 14 – Care After Death – Bereavement Support	Ensure commissioned services for people closely affected by a death that include sensitive communication and provision for immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs	Ensure that systems are in place for people closely affected by a death that include sensitive communication and provision for immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs	Care after death: Bereavement visits / discussion with the family and carers Support self- referral for Bereavement counselling	People closely affected by a death are communicated with in a sensitive way and offered bereavement, emotional and spiritual support appropriate to their needs and preferences. This may include information

	and preferences	and preferences Communicate sensitively with people closely affected by a death and offer them immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences		about practical arrangements and local support services, supportive conversations with staff, and in some cases referral for counselling or more specialist support.
Quality Standard 15 – Workforce – Training	Ensure commissioned services that provide and assure education for all health and social care workers appropriate to their role. This should enable them to develop the knowledge, skills and attitudes necessary to be competent to provide high-quality care for people approaching the end of life and their families and carers.	Ensure that systems are in place to provide and assure education for all health and social care workers appropriate to their role. This should enable them to develop the knowledge, skills and attitudes necessary to be competent to provide high-quality care for people approaching the end of life and their families and carers Participate in appropriate training and engage in evaluation and supervision to ensure they have the knowledge, skills and attitudes necessary to be competent to provide high-quality care for	East Kent End of Life Care Education Toolkit as a resource for training programmes available to health and social care staff across the tiers of care framework End of Life education post (Pilgrims Hospice) to be appointed to assist in implementation of the EK education toolkit	People approaching the end of life and their families and carers are cared for and supported by staff with the knowledge, skills and attitudes needed to provide high-quality care.

		people approaching the end of life and their families and carers.		
Quality Standard 16 – Workforce - Planning	Ensure they commission generalist and specialist palliative care services with a multidisciplinary workforce sufficient to provide high-quality care and support to people approaching the end of life and their families and carers.	<p>Service providers (generalist or specialist) ensure that systems are in place to provide a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support to people approaching the end of life and their families and carers.</p> <p>Work as part of a multidisciplinary workforce that provides high-quality care and support to people approaching the end of life and their families and carers</p>	<p>Development of an new model of provision of home care support to delivery end of life care (in and out of hours)</p> <p>Development of the east Kent end of life care needs assessment to assist with planning workforce in conjunction with CCG workforce facilitators</p>	People approaching the end of life and their families and carers receive high-quality care and support because there is enough staff with the right skills to meet their needs.

Table 2 – Related National Guidance & Best Practice References

<ul style="list-style-type: none"> • Ambitions for Palliative and End of Life Care-National Palliative & End of Life Care Partnership • Actions for End of Life Care 2014- 16 - NHSE • Priorities of Care of the Dying Person-Duties & Responsibilities of Health & Care Staff- with prompts for practice -Leadership Alliance for the Care of Dying People • Every Moment Counts-The National Council for Palliative Care • The Gold Standards Framework • Delivering Better Care at the End of Life – Kings Fund • The Route to Success- the key contribution of nursing to end of life care- Royal College of Nursing and NHS Improving Quality • Six Steps End of Life Pathway- NHS Improving Quality • Commissioning for Community Nursing-NHSE • Commissioning for Specialist Palliative Care- Association of Palliative Care Medicine • NICE Quality Standard (QS15) Patient Experience in adult NHS services 	<ul style="list-style-type: none"> • NICE End of Life Commissioning & Benchmarking Tool • NICE Commissioning Services for End of Life Care for Adults • Queens Nursing Institute –Voluntary Standards for District Nurse Education & Practice • Fit for Frailty – Developing, commissioning & managing services for people living with frailty in community settings (RCGP) • The National Survey of Bereaved People –Voices (ONS) • 6 Steps end of life care pathway - NHS Improving Quality • A long & winding road-improving communications with patients in the NHS – Marie Curie • More Care Less Pathway –Independent review of the Liverpool Care Pathway • One Chance to Get it Right-Leadership Alliance for the Care of Dying People • What's important to me- A review of Choice in End of Life Care-The Choice in End of Life Care Programme Board • Care of dying adults in the last days of life -NICE
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Appendices

Appendix 1

End of Life Management - Tiers of Care

<p>Tier 1: Low Risk Management – Generalist Palliative Care</p> <p>Primary Care (GP / Nurse Lead / EOL Lead / Practice Co-ordinator)</p>	<ul style="list-style-type: none"> • Identify patient group via Risk Stratification (Top 1%) • Add all appropriate patients to the palliative/end of life register with general practices • Ensure involvement of community learning disability team at this time • Ensure MDT's are held regularly – physical or virtual • Apply supportive and palliative care indicator tool • Identify high risk patients and involve SPC • Apply the PEACE tool • Apply Frailty Tool (TBA) • Early conversation with patient/family/GP/Nurse Lead regarding ceilings of care • Holistic Assessment undertaken by district nursing team and reviewed regularly • Provide a contact number for day and night contact to the district nursing service • Complete Anticipatory/Advanced Care Plan (ACP) - will be held at General Practice via Medical Interoperability Gateway (MIG) (AACP – will contain detail of ADTRT & Ceilings of Care)– include MCA and carer/family • Use of 'Careflow' (when available) • Plan A – Patients agreed preferred place of death • Plan B – 2nd choice agreed of preferred place • Paper copy to be kept in patients home together with up to date DNACPR • Patient & Carer information pack provided • Complete DNACPR and review regularly • Identify carers/ family members offer assessment and carer support • Ensure 'Just in case box' is in place • Offer spiritual and psychological support in place • Lead nurse continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include: <ul style="list-style-type: none"> - CHC if appropriate –care home/support at home - Intermediate Care Therapeutic (OT /Physiotherapy) Support - Social care support
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	<ul style="list-style-type: none"> - Equipment required - Access 'Step-up beds'-community hospital • Hospice support (Generalist) • Care after death <ul style="list-style-type: none"> • Timely verification/certification of death • Ensure the patient's body is cared for in a culturally sensitive manner • Bereavement visit • Support self- referral for Bereavement counselling • Ensure MIG updated • Equipment collection
Tier 2 : High Risk Management - Specialist Palliative Care (SPC)	<ul style="list-style-type: none"> • Advice and guidance to Tier 1 (Primary Care) & Tier 3 (secondary care) as part of MDT • 24/7 Single Point of Contact – access to advice and guidance to Tier 1 & Tier 3, patients under the care of Tier 2 SPC • Education of carers/patients/ health care Professionals • Holistic Assessment undertaken and reviewed regularly • Patient & Carer information pack provided • General symptom control (all patients) • Access to day services (all patients) • Complex symptom control (at home) • In-patient complex symptom control • Access and follow Anticipatory/Advanced care plan (ACP) (AACP – will contain detail of ADTRT & Ceilings of Care) via MIG, include access to the DNACPR • Use of 'Careflow' (when available) • Update Primary Care Team with any change to patients care to update MIG asap • Offer Spiritual, Psychological and Social Support • In-patient end of life care • Care after death <ul style="list-style-type: none"> • Timely verification/certification of death • Ensure the patient's body is cared for in a culturally sensitive manner • Bereavement visit/discussion with family /carer • Ensure General Practice informed within 3 days • Equipment collection

<p>Tier 3: Secondary Care</p>	<ul style="list-style-type: none"> • Management of an acute episode • Holistic Assessment undertaken and reviewed regularly • Offer Spiritual, Psychological and Social Support • Planned treatments (i.e. blood transfusions, chemotherapy, radiotherapy) <p>Access and follow Anticipatory/Advanced care plan (AAP)(AAP – will contain detail of ADTRT & Ceilings of Care) via MIG, include access to the DNACPR</p> <ul style="list-style-type: none"> • Use of 'Careflow' (when available) • When an inpatient, identify if reaching EOL via SPICT and inform Tier 1 via EDN discharge summary • Early identification of patients for Tier 2 -SPC • Discussion with patient/family/carer regarding current prognosis and ceilings of care • Update Primary Care Team to ensure ACP is updated an MIG asap • Involve Tier 2 services if appropriate for SPC (Hospice- Tier 2) • Ensure care needs are still met with current levels of support if not more appropriate referrals • Ensure 'fast track' to preferred place of care as per ACP • Provide patient/carer information pack • Register unregistered with a GP in patients area of choice • Care after death <ul style="list-style-type: none"> • Timely verification/certification of death • Ensure the patient's body is cared for in a culturally sensitive manner • Bereavement discussion with family/carer • Support self- referral for Bereavement counselling • Ensure General Practice is informed within 3 days • Equipment collection
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Appendix 2 – SPICT Tool



Supportive and Palliative Care Indicators Tool (SPICTM)



The SPICTM is a guide to identifying people at risk of dying within the next 12 months.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

Unable to communicate meaningfully; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Assess and plan supportive & palliative care

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

Appendix 3 – Frailty Tool-example

Clinical Frailty Scale*



1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



3 Managing Well – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being "slowed up", and/or being tired during the day.



5 Mildly Frail – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



7 Severely Frail – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. Terminally Ill - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Appendix 4 – Anticipatory Care Plan example

Anticipatory & Advance Care Plan

[NAME OF PRACTICE] [PRACTICE
ADDRESS]

[PRACTICE TELEPHONE NUMBER] [PRACTICE BYPASS NUMBER]

Ensure all fields are completed throughout the form.

(Sections with black writing are to be completed. Blue text is for guidance only)

The location of this ACP in the patients' home is also important to discuss with patient/carer/relative.

THE PATIENT DNAR STATUS NEEDS TO BE CLEARLY DOCUMENTED AND ANY NECESSARY DOCUMENTATION MUST BE INCLUDED WITH THE CARE PLAN

MENTAL CAPACITY ACT

- Remember all patients are assumed to have mental capacity
- Assessment of capacity is time specific on individual decisions
- Record rational and outcomes for any mental capacity assessments relating to this ACP
- Please record details of any Lasting Power of Attorney for the patient's health and welfare
- Please record details of Independent Mental Capacity Advocate (if appropriate)

PATIENT INFORMATION

Patient name:	Title:	NHS Number:
		Date of birth: / /
Address:		
Post code:		
Contact details:	Key safe door access code:	
	Accommodation Status: (ie lives alone,in care)	
Gender:	Need for Interpreter: Yes / No	
Named accountable GP:	Care coordinator (if appropriate): This can be the GP/Practice Nurse/etc Must include name and contact details	
Date Plan Created :	Date Plan to be Review to include Version No:	
to include Version No:		
Other named professionals (e.g. care coordinator, other healthcare professionals or social worker) involved in patient's care, if appropriate e.g. Community Nurse must include name/tel. Mental Health worker: must include name/tel Social worker: must include name/tel		

Mental Capacity Assessment (MCA): (at time of initiation of care plan)	
MCA Review date:	
Has information been shared on the patient's behalf?: YES / NO If YES, by whom: name and designation (i.e. wife, sister, carer, etc) (only applicable where the patient does not have the capacity to make this decision)	
Patient (or other allowed individual) consent to share information:	
<ul style="list-style-type: none"> • with other healthcare professionals involved in the patient's care, e.g. carer, OOH etc: YES / NO • with the multi-disciplinary team: YES / NO 	
Smoking Status: (ie smokes/never smoked/ex-smoker)	
Functional Status:	
Frailty Score: (if the score is > 4 refer for a falls risk assessment)	
Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) Order in place: Yes /No Discussed with patient: Discussed with Carer:	
Equipment in place:	
Catheter/Continence Products at Home:	
Preferred Place of Death (if relevant):	
1 st Choice:	
2 nd Choice:	
Religious, Spiritual and Cultural Requirements:	
NEXT OF KIN / CARER / RESPONSIBLE ADULTS INFORMATION	
Name:	Title:
Address (if different from above):	
Post code:	
Contact details:	Relationship:

Names and Contact details (1 and 2) that the person wants to be involved in decisions about their care 1) 2)	
Additional emergency contact (if appropriate): Name: Contact details:	
Relationship:	
Is the patient a carer themselves: Yes / No Plan in place to support patient as a carer: If not why not:	
Carers assessment carried out: Yes / No If not why not:	
Has DS 1500 been completed: Yes / No	
Has the person been accepted for Continuing Health Care: Yes / No	
Name & Contact details of Lasting Power of Attorney: <ul style="list-style-type: none"> • without authority to make life-sustaining decisions • with authority to make life sustaining decisions 	
Name & contact details of Power of Attorney Personal welfare: Yes/No	
PATIENTS MEDICAL INFORMATION	

<p>Relevant conditions, diagnosis, latest test results and baseline observations:</p> <p>List all active problems here. (This could include recurring UTIs, Diabetes, LVF, COPD, Asthma, RA etc.)</p> <p>Primary End of Life Care Diagnosis (if relevant):</p> <p>List patient's baseline data here: Sats, BP, pulse, relevant blood results, height, weight, respiratory rate, ECG if CVD patient etc. – what is normal for the patient.</p> <p>Significant past medical history: Other co-morbidities need to be listed here</p>
<p>Current Medication (to include any end of life medications and syringe driver medication):</p> <p>Essential information to include dosage. In addition include information such as patient's previous history of GI bleed so no anticoagulation prescribed.</p> <p>Date of planned review of medications:</p> <p>'Just In Case' medication prescribed: Yes / No If not why not (please state):</p> <p>Where is the Just in Case medication located:</p>
<p>Allergies:</p> <p>If no known allergies state NKA</p>
<p style="text-align: center;">KEY ACTION POINTS</p>
<p>For example: guidance on intervention / deterioration, unmet need to support patient (specify), agreed plan in emergency (ICE)/ useful situation etc.</p> <p>1. Here it should state what patients can do to self-manage if appropriate. E.g.</p> <ul style="list-style-type: none"> If weight increases by 2 kilos over 24 hours increase Furosemide by 1mg and review etc. Advice on self-management by patient, i.e. step up ICOs to 2 puffs QDS if symptomatic etc. If blood glucose levels exceed agreed target of 7-9mmols pre-prandial increase insulin by 2 units OD. First line therapies i.e. start Amoxicillin 500mgs TDS, Prednisolone 30mgs OD ETC. <p>2. It should also detail what a health professional should do i.e.</p> <ul style="list-style-type: none">
<p>Person Has made an advanced decision to refuse treatment (ADRT)</p> <p>1) Whether the a decision has been made: Yes / No</p> <p>2) Date the decision was made:</p> <p>3) Location of documentation:</p>

- **First line treatment:**
 - Amoxicillin 500mg TDS for 5/7
 - Increase use of short acting β_2 agonist (Ventolin QDS/PRN)
 - Commence oral steroids – prednisolone 30mg od – if wheeze present. (Only need reducing dose if takes steroids more than twice a year)
 - Review every ... 5/7
- **Second line treatment:**
 - Continue oral steroids if appropriate
 - Obtain sputum sample treat with result of this.
 - Review every...
- **Third line treatment:**
 - Antibiotic of choice
 - X-ray if indicated
 - Liaise with GP/Consultant
 - Consider need for hospitalisation for IVAB's

If a patient is in a care home here you will need to detail the steps care home staff will need to take to support the early recognition of a deteriorating resident.

Examples of care plan standards for various conditions can be found on the SKC CCG Intranet page.

OTHER RELEVANT INFORMATION (if appropriate)

Preferred place of care: Here it should state if patients do not want admitting to hospital/preferred place of death if appropriate.

Other support services e.g. local authority support, housing

Identification of whether the person is themselves a carer (formal or informal) for another person

Anticipatory care plan agreed: YES / NO/ N/A Anticipatory drugs supplied: YES / NO/ N/A

Must be completed along with details including 'Just in Case' meds.

Emergency care and treatment discussed: YES / NO

If yes, please specify outcome:

Here it could include DNACPR status as well as preferred treatment option (linked back to key action points).

IF PATIENT CHOOSES DNACPR PLEASE ENSURE DNACPR FORM HAS BEEN CLEARLY COMPLETED AND IS WITH THIS CARE PLAN.

Date of assessment: / /

Date of review(s): / /

Any special communication considerations (e.g. patient is deaf or language communication differences):

Any special physical or medical considerations (e.g. specific postural or support needs or information about medical condition - patient needs at least x mgs of drug before it works etc): e.g.

- **Has ICD in Situ.**
- ? Needs deactivation
- ? Discussions been had already
- Link back to key action points
- Give details re mental capacity

SIGNATORIES (if appropriate and / or possible)	
Essential all of these fields are completed.	
Patient signature:	Date:
Carer (if applicable) signature:	Date:
Named accountable GP signature:	Date:
Care Coordinator signature (if applicable):	Date:

Possible Developments Specific to the Patient	Actions
Not eating or drinking	Encourage oral fluids: If insufficient focus on comfort measures at home with support of GP/Community Nurse
Increased agitation or confusion	GP to review and treat reversible causes of delirium eg: constipation/UTI/pain at home Provide comfort care if deteriorates
Clinical pneumonia/UTI/or any infection	GP to consider oral antibiotics Provide comfort care if deteriorates
Problem swallowing	Food/Fluids as tolerated by patient Oral intake to be maintained if possible for quality of life
Breathlessness	GP to treat infection if chest infection Provide comfort care if deteriorates
Serious unexpected event eg: significant GI bleed	End of Life medications to minimize distress
Patient has no signs of life	Do not resuscitate if DNACPR in place

Guidance Notes

If the patient deteriorates and has a suggested action of 'intensive' or 'hospital' treatment, then the appropriate action is to ring the GP/Community Nurse/Pilgrims Hospice Advice Line, if Out of Hours (OOH) the OOH medical provider and if necessary arrange admission to hospital.

Summary of suggested action categories:	
Intensive:	Transfer to hospital for treatment if appropriate. Intubation, ventilation etc. should be considered.
Hospital:	Transfer to hospital for treatment if appropriate. Avoid intubation and ventilation
Home:	Treatment medication and comfort measures within home with support from GP/Community Nurse/Pilgrims Hospice Advice Line if Out of Hours Medical provider Admission to hospital should be avoided unless comfort measures fail.
Comfort:	Palliative Medication - subcutaneous, oral or per rectal route. Ensure attention to positioning, wound care, mouth care, continence management and other measures to relieve suffering. Admission to hospital should be avoided unless comfort measures fail

If your patient deteriorates and has a suggested action of 'comfort' or 'home', you may find the following grids helpful. In order to carry them out, you may need to ask the GP or Community Nurse to come to see the patient and to prescribe as appropriate, and involve the support of the Palliative Care Teams. Contact the patient's significant others as stated on the front of this form.

	Home	Comfort
Feeding	Oral food as tolerated (eg pureed). If required involve community SALT.	Oral fluids or food as tolerated.
Hydration	Oral fluid as tolerated. If required follow SALT advice. Where possible/appropriate you may use sub-cutaneous fluids in the care home.	Oral fluids or food as tolerated and as often as tolerated. Low intake is very likely.
Infection	Contact GP for diagnosis and treatment with antibiotics if required.	Treat symptoms as required. Fan therapy for temperatures.
Pain	If new pain, GP may need to consider the diagnosis, and treat	Call GP/Community Nurse to consider medication – oromorph or

	accordingly.	sub-cut morphine may be required.
Breathlessness	GP will need to consider cause of breathlessness and what treatment medications are appropriate.	Call GP/ Community Nurse to consider medication – e.g. oromorph or sub-cut morphine. Consider oxygen, normal saline nebulisers.
Agitation	Ensure no urinary retention/ constipation/ pain or other unmet need. If necessary call GP to prescribe sub-cut midazolam.	Ensure no urinary retention/ constipation/ pain or other unmet need. If necessary call GP to prescribe sub-cut midazolam.
Nausea/vomiting	Check no constipation/ urinary infection and treat accordingly + anti-emetics.	Check no constipation. GP will need to prescribe anti-emetics, e.g. cyclizine oral or s/c.
Diarrhoea	Check not overflow constipation (PR). Stool samples for c.diff and treatment if positive. Encourage fluids. Loperamide only if continues for more than 3 days and risk of skin breakdown.	Check not overflow constipation (PR). Stool samples for c.diff and treatment if positive. Encourage fluids. Loperamide only if continues for more than 3 days and risk of skin breakdown.
Drowsiness/ confusion	Check no constipation/ urinary infection/ dehydration. Consider medications which could be causing this. The GP may need to do blood tests to guide therapy.	Check no constipation/ urinary infection/ dehydration. Consider medications which could be causing this.
Fall	Examine for injury. If fracture suspected may require admission to hospital for adequate palliative management. Give analgesia prior to transfer. If no injury, consider cause of fall. Consider need for crash mats, low bed, increased supervision and assistance with toileting and transfers.	Examine for injury. If fracture suspected may require admission to hospital for adequate palliative management. Give analgesia prior to transfer. If no injury, consider cause of fall. Consider need for crash mats, low bed, hip protectors.
Medications		Ask GP/ District Nurse /SPC to review medications – especially to stop unnecessary medications.
Pressure area care	Pressure area care is based on risk assessment and is fully documented. Patient repositioning should be maintained ensuring that pain issues are also addressed. Pressure sores managed at home with review by TVN and GP.	Pressure area care is based on risk assessment and is fully documented. Patient repositioning should be maintained ensuring that pain issues are also addressed. Pressure sores managed at home with review by TVN and GP.

Appendix 5- Education resource toolkit

Guidance – Toolkit for End of Life Care Education

Date of Issue	December 2015
Date for Review	December 2016
Version	11.0
Prepared by	Developed by the East Kent End of Life Workforce and Education Working Group

Contents

1	Introduction
2	Why we are developing the Guidance
3	Aims and Objectives
4	End of Life Care Management – Tiers of Care
5	Tiers of Care – Minimum Skills and Knowledge
6	e-ELCA Modules matched to Principles of Care for EOLC
7	Conclusion

1. Introduction

Health and care staff must demonstrate kindness as well as the skills, confidence and the application of knowledge in the care of those at the end of life.

Early identification of End of Life Care need is the most important factor in maximising the chance for patients and health professionals to plan adequately and ensure that those needs and preferences of individuals are met. (EK EOL Strategy Sept 2014 & One Chance to get it right)

This will facilitate a culture of care that is compassionate, recognises the individual needs of patients and their families and carers, as well as being open and transparent by respecting the duty of candour to which the patient is entitled.

There is widespread agreement on the importance of workforce development for all staff who come into contact with patients at the end of their lives. The focus therefore relates more to training and development issues across all the statutory, voluntary and independent sectors involved in end of life services.

Achieving this requires:

- Commitment from all staff
- Employers and commissioners to make learning time and resources available
- Employers to undertake regular staff performance reviews

There must be a focus on integration so that high quality End of Life Care is the norm for everybody.

Priorities of Care are outlined for when a patient is at the end of their life :

1	The possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes and these are regularly reviewed and decisions revised accordingly
2	Sensitive communication takes place between staff and patient and their family/carers
3	The patient, their family and carers, are involved in decisions about treatment and care and may include Ceilings of Care, DNA CPR
4	An Advanced Care Plan which includes psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion.

Education and training for palliative and end of life care should be made available across Health and Social care and the voluntary and private sectors for both clinical and non-clinical staff supporting patients, families and carers.

The aim, in line with the Gold Standards Framework (GSF) is to improve the:

- **Quality** of care for people in the final years of life
- **Co-ordination and communication** of care across boundaries

- **Outcomes** for people- reducing time in hospitals and enabling more to live and die where they choose in line with their needs and preferences.

Quality improvement

- Through ensuring training programmes are offered in many settings and subjects
- Improved quality of care for people nearing the end of life, their carers and families
- Significant reductions in costs by reducing unnecessary hospital admissions
- Quality outcomes for commissioned contracts
- Improved cost effective provision of services and communications across health and social care.

Quality assurance

- In line with GSF / Pilgrims Hospice recommendations for training programmes, with evaluation and benchmarked audit measures according to each CCG's action plan
- The outcomes will report into the Integrated Planned Care Board, whilst linking with the Integrated Urgent Care Board and Quality committees across east Kent CCGs
- To ensure training and education all provide a quality assured approach to end of life care across health and social care and meet targets i.e. CQUINS, QIPP, NICE standards, DH Quality Markers, CQC
- Meets National policy i.e. *End of life Care – Francis Report* recommendations.

Quality recognition

- Recognition as example of best practice in the field of End of Life Care
- Recognised by the general public, commissioners, national policy and regulators
- It aims to raise the standard of independent providers, empowering staff, patients and their families.

CQUINs

A further route into supporting the implementation of this Guidance could be via a CQUIN as set out in the national CQUIN Guidance for 2016/17 (Local CQUIN Templates) for End of Life Care Pathways :

Indicator weighting (% of CQUIN scheme available)	To be agreed locally
Description of indicator	Multi-disciplinary and multi-agency monthly meetings of cases to identify causes of patients not dying at their preferred place of care and to develop suitable action plans to support people to die at their preferred place of care.
Numerator	Number of patients who actually die at their preferred place of care
Denominator	Number of patients who die having a recorded preferred place of care
Rationale for inclusion	To help deliver person-centred End of Life Care through improved integration within and between providers of healthcare along the pathway. The goal is to ensure that people are asked what their preferred place of care is and that those preferences are met. This CQUIN encourages providers to assess and resolve issues that prevented people receiving care in their preferred place.

The goal is to ensure that people are asked what their preferred place of care is and that those preferences are met.

This CQUIN encourages providers to assess and resolve issues that prevented people receiving care in their preferred place.

“Every organisation involved in providing end of life care will be expected to adopt a co-ordination process such as the GSF”

- Department of Health End of Life Care Strategy 2008

The objectives include increasing knowledge, confidence, awareness and communication skills, including the Gold Standards Framework (GSF), Advance Care Planning and DNA CPR (Do Not Attempt Cardio Pulmonary Resuscitation).

Investment in training for staff will ensure that End of Life Care supports patients to remain independent where possible and in their preferred place of care.

2. Why we are developing the guidance

Early identification of EOLC need is the most important factor in maximising the chance for patients and health professionals to plan adequately and ensure the needs and preferences of individuals are met.

A major opportunity to address some of the key issues outlined in the East Kent End of Life Strategy is through adoption of the new Long Term Conditions Agenda that incorporates the themes of risk-stratification, integrated teams and self-care. The vision is for a unified data hub that integrates activity across all health and social care and a fully functional system which will enable early identification for those at risk of death, enable more accurate EOLC planning across a population and ensure health and social care are better co-ordinated and integrated with each other.

3. Aims and Objectives

This guidance can be used by providers and by individual professionals to continue and further develop mandatory education and training to support care for patients at end of life.

The purpose of this guidance is to implement the recommendations from the East Kent End of Life Strategy which states that patients within East Kent have the best possible end of life experience, ensuring that they are treated as an individual, with dignity and respect, and are able to be cared for in their Preferred Place of Care.

The patient's needs should be identified as early as possible and discussed to include :

- Advance Care Planning
- DNA CPR
- Preferred Place of Care
- Ceilings of Care

The East Kent vision for end of life care has as its key goals:

- **Each person is seen as an individual** and has the opportunity for honest conversations about dying, for access to an effective person centred care system, to have clear expectations of health and care services, rapid access to needs based social care and for ensuring palliative and end of life care is part of the new models of integrated health and social care.
- **Each person gets fair access to care** regardless of who they are, where they live or the particular circumstances of their life.
- **Comfort and wellbeing to be maximised** by regular review of care, recognising distress whatever the cause may be, skilled assessment and symptom management, development of individualised plans of care and access to Specialist Palliative Care when needed.
- **Care that is co-ordinated**, resulting in the right help at the right time from the right people by means of shared records, setting out clearly the roles and responsibilities of service providers and joined up care for patients, families and carers.
- **That all staff are prepared to care** and that end of life care is everyone's business
- **Communities that are prepared to help** and are compassionate and resilient.

Advance Care Planning

Advance Care Planning is a voluntary process of discussion and review with the aim of helping someone who has the capacity to indicate what their preferences and wishes are for future care. If the individual wishes, they can record choices about their care and treatment and an Advance Decision to Refuse Treatment (ADRT) in specific circumstances. These choices can then be referred to by those responsible for care and treatment if, as the illness progresses, the individual loses capacity to make decisions for themselves.

Anticipatory planning should be robustly discussed, documented and shared with other health professionals involved in the patient's care. Families, carers and professionals involved in the patient's care should be aware of the Advance Care Plan and be clear on the actions which should be undertaken when the patient's health significantly deteriorates. This includes the use of medication, resuscitation, ambulance call-outs.

Anticipatory Care Planning

The Advance Care Plan is the conversation that takes place with the patient to inform the Anticipatory Care Plan, which is a plan that anticipates significant changes in a patient (or their care needs) and describes action which could be taken to manage the anticipated problem in the best way. It is used by healthcare professionals to record decisions agreed with patients about their anticipated care needs and wishes. These discussions should include family, carers, and representatives whenever possible.

Medicines management plan (Anticipatory prescribing)

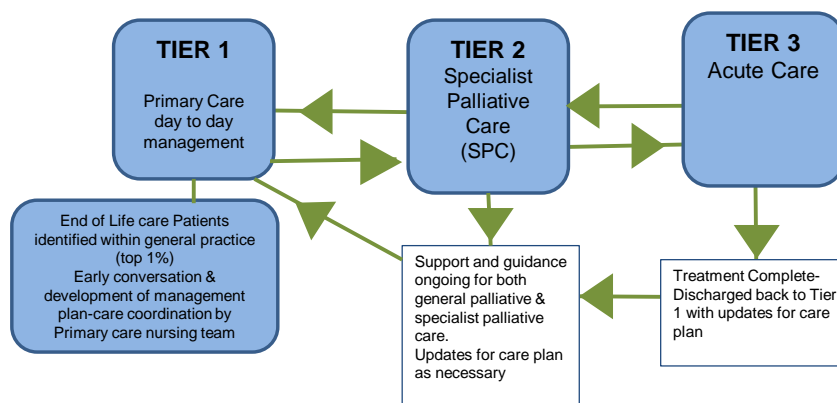
Anticipatory prescribing at the end of life should be initiated as the patient enters the last few weeks of life. Medication should be made available before there is the need to administer it to the patient, to ensure that in the last hours or days of life there is no delay in responding to

a symptom if it occurs. To this end a 'Just in Case Box Policy' has been implemented as part of the recommendations.

The EK EOLC WG has discussed the need to provide relevant education for GPs as well as the need to ensure a robust template is in place across the health economy.

4. End of Life Care Management - Tiers of Care

End of Life Care Management Pathway



See Tiers of Care definitions for expectations of each Tier of care provided across the pathway

Date: 09/10/2015

Tier 1

Low Risk Management – Generalist Palliative Care

Primary Care

Tier 2

High Risk Management – Specialist Palliative Care (SPC)

Tier 3

Secondary Care (Acute Trust)

Details of the minimum skill and knowledge level for each Tier of Care are set out on the following pages, together with the resources and courses available.

For further information on courses available online and other helpful resources, please see the following web pages :

- Pilgrim's Hospices : <http://www.pilgrimshospices.org/training>
- Macmillan :
<http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/macmillansprogrammesandservices/macmillansprogrammesandservices.aspx>

Links to Online Courses : <http://learnzone.org.uk/courses/>

- Marie Curie : <https://www.mariecurie.org.uk/professionals/commissioning-our-services/why-marie-curie/nurses-training>

5. Tiers of Care - Minimum Skills and Knowledge

Tier 1 Primary Care : Staff working within other services who are frequently involved with care and support to the dying person and those closest to them	Need to be enabled to develop or apply existing skills and knowledge to the principles and competencies for the care and support of the patient, family/carers at the end of life. Some healthcare professionals may require additional specialist training on their roles and responsibilities and place of work.
--	--

TIER DEFINITION	Minimum Skill and Knowledge Level	RESOURCE	STAFF GROUP
Tier 1 Primary Care : staff working within other services who are infrequently involved with care and support to the dying person and those closest to them	<ul style="list-style-type: none"> Identify patient group via Risk Stratification (Top 1%) 	<ul style="list-style-type: none"> SPICT/ GSF 	All Healthcare and Social Care Professionals
		<ul style="list-style-type: none"> e-ELCA assessment modules 	
		<ul style="list-style-type: none"> End of Life Training (KCC) 	
		<ul style="list-style-type: none"> Principles and practices in EoLC for non/registered practitioners (PH) 	
	<ul style="list-style-type: none"> Apply supportive and palliative care indicator tool 	<ul style="list-style-type: none"> SPICT 	All healthcare and social care professionals
	<ul style="list-style-type: none"> Apply the PEACE tool 	<ul style="list-style-type: none"> PEACE Training (PH) 	All Healthcare and Social Care Professionals
	<ul style="list-style-type: none"> Apply Frailty Tool (TBA) 	<ul style="list-style-type: none"> Dalhousie Tool 	All Healthcare and Social Care Professionals and Voluntary Sector
	<ul style="list-style-type: none"> Early conversation with patient/family/GP/Nurse Lead regarding ceilings of care 	<ul style="list-style-type: none"> e-ELCA Communications modules 	All Healthcare and Social Care Professionals
		<ul style="list-style-type: none"> Sage and Thyme 	
		<ul style="list-style-type: none"> Open University 	
		<ul style="list-style-type: none"> Macmillan 	
		<ul style="list-style-type: none"> Compassion awareness 	

	<ul style="list-style-type: none"> Complete Anticipatory/Advance Care Plan (ACP) (or MIG) 	<ul style="list-style-type: none"> Advance Care Planning 	All Healthcare and Social Care Professionals Senior clinicians and senior advanced healthcare professionals
		<ul style="list-style-type: none"> Anticipatory Care Planning 	
		<ul style="list-style-type: none"> CCCU Online training 	
		<ul style="list-style-type: none"> e-ELCA advanced care planning modules 	
		<ul style="list-style-type: none"> Macmillan leaflets 	
		<ul style="list-style-type: none"> Advanced communications 	
	<ul style="list-style-type: none"> MCA and DOLS 	<ul style="list-style-type: none"> Online training 	All Healthcare and Social Care Professionals
		<ul style="list-style-type: none"> Face to face 	
	<ul style="list-style-type: none"> Awareness of DNACPR 	<ul style="list-style-type: none"> <u>DNA CPR Awareness training (PH)</u> 	All Healthcare and Social Care Professionals and Voluntary Sector
	<ul style="list-style-type: none"> Complete DNACPR form and review regularly 	<ul style="list-style-type: none"> DNA CPR Training 	Clinicians : GPs, Consultants, Advanced Nurse Practitioners, Band 7 nurses and above
	<ul style="list-style-type: none"> Symptom control management (Just in Case boxes) 	<ul style="list-style-type: none"> e-ELCA Symptom management modules 	All qualified nurses, GPs and consultants
		<ul style="list-style-type: none"> Just in case policy and competencies 	
		<ul style="list-style-type: none"> Macmillan symptom control 	
	<ul style="list-style-type: none"> Ensure spiritual and psychological support in place 	<ul style="list-style-type: none"> e-ELCA Spirituality modules 	All health and Social Care professionals
		<ul style="list-style-type: none"> <u>Macmillan modules</u> 	
		<ul style="list-style-type: none"> <u>Touch therapy (PH)</u> 	

	<ul style="list-style-type: none"> Lead nurse continues to care coordinate to prevent crisis, consider any care/support needs and mobilise services to include: <ul style="list-style-type: none"> CHC if appropriate Social care support SECAmb 		
		<ul style="list-style-type: none"> e-ELCA CHC Module 5.22 	
		<ul style="list-style-type: none"> e-ELCA Module 6 (Social Care modules) e-ELCA Ambulance call to the home 	
	<ul style="list-style-type: none"> Hospice support (Generalist/Specialist) 		Teachers and Family Liaison Officers
	<ul style="list-style-type: none"> Care after death <ul style="list-style-type: none"> Bereavement visit Timely verification/certification of death Equipment collection 	<ul style="list-style-type: none"> e-ELCA Bereavement modules 	
		<ul style="list-style-type: none"> e-ELCA Verification of Death module 	
<ul style="list-style-type: none"> <u>The Forgotten Mourners</u> 			

Other Courses available to support Tier 1 care include :

- End of Life Skills Workshop (KCHFT) – Provides new RNs and HCAs with key EoLC knowledge
- Gold Standards Framework Care Homes Programme
- Dementia and end of life care (To support dementia patients/carers)
- CCCU – commissioned PH input – Foundation Degree Complex Care (Assistant Practitioners)
- CCCU – commissioned PH input – Paramedic training – complex Paramedic practice – Trainee Paramedics#
- Symptom Control Guidelines - Useful Technical Guidance (Pilgrims Hospice website) :
<http://www.pilgrimshospices.org/wp-content/uploads/Symptom-Control-Guidelines-5th-Edition.pdf>
- Care Certificate Standards (HEE, Skills for Care) – For Health and Social Care non-regulated staff (15 Care Standards)

<p>Tier 2</p> <p>Specialist Palliative Care/Hospice : Staff who are working entirely focused on the care and support to the dying person and those closest to them in the last days and hours of life.</p>	<ul style="list-style-type: none"> • Advice and guidance to Tier 1 (Primary Care) & Tier 3 (secondary care) as part of MDT • 24/7 Single Point of Contact – access to advice and guidance to Tier 1 & Tier 3, patients under the care of Tier 2 SPC • Education of carers/patients/ health care Professionals • General symptom control (all patients) • Access to day services (all patients) • Complex symptom control (at home) • In-patient complex symptom control • Update Primary Care Team with any change to patients care to update MIG asap • • Spiritual, Psychological and Social Support • • In-patient end of life care • 	<p>SPICT / GSF</p> <p>e-ELCA assessment modules</p> <p>Principles and practice in EoLC for registered practitioners</p> <p>Principles and practice in EoLC for non registered practitioners</p> <p>PEACE training</p> <p>e-ELCA communications modules</p> <p>Sage & Thyme</p> <p>Advanced Communication Skills Training</p> <p>Compassion awareness</p> <p>Advanced Care Planning</p> <p>Anticipatory Care Planning</p> <p>CCCu on line module</p> <p>e-ELCA advanced care planning</p> <p>DNACPR competencies training</p>	
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	<ul style="list-style-type: none"> Care after death <ul style="list-style-type: none"> Ensure MIG updated Bereavement visit Timely verification/certification of death Equipment collection 	<p>McKinley Syringe driver training and competencies</p> <p>e-ELCA Symptom management</p> <p>Advanced symptom control management</p> <p>Bereavement Risk Assessment</p> <p>Verification of Expected Death</p>	
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Tier 3

Secondary Care : staff who frequently deal with the care and support for the dying person and those closest to them in the last days and hours of life as part of the role	Need to be enabled to develop or apply existing skills and knowledge to the principles and competences for the care and support of the dying person and those closest to them in the last days and hours of life. May require additional specialist training.
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TIER DEFINITION	Minimum Skill and Knowledge Level	RESOURCE	STAFF GROUP
Tier 3 Secondary Care : staff who frequently deal with the care and support for the dying person and those closest to them in the last days and hours of life as part of their role	<ul style="list-style-type: none"> Identify and undertake assessment of patient group at end of life 	<ul style="list-style-type: none"> <u>SPICT</u> <u>PEACE Tool</u> <u>Frailty Tool</u> 	All Healthcare Professionals Administration Staff Reception Staff Hospital Porters
		<ul style="list-style-type: none"> <u>e-ELCA assessment modules (Modules 02.01, 02.02, 02.14 – Assessment of Dying Phase and after death)</u> 	
		<ul style="list-style-type: none"> Link Nurse EOLC Training Programme 	
	<ul style="list-style-type: none"> Apply supportive and palliative care indicator tool 	<ul style="list-style-type: none"> <u>SPICT</u> 	All healthcare professionals
	<ul style="list-style-type: none"> Apply the PEACE tool 	<ul style="list-style-type: none"> PEACE Training (PH) 	All Healthcare Professionals
	<ul style="list-style-type: none"> Apply Frailty Tool (TBA) 	<ul style="list-style-type: none"> Dalhousie Tool 	All Healthcare Professionals
	<ul style="list-style-type: none"> Early conversation with patient/family, consultant and MDT regarding ceilings of care 	<ul style="list-style-type: none"> e-ELCA Communications modules : (Modules 03.01, 03.02, 03.09 – Skills which facilitate good communication) 	Healthcare Professionals : Clinicians Doctors Senior Nurses
		<ul style="list-style-type: none"> Link Nurse Training Programme 	
		<ul style="list-style-type: none"> Advanced Communication Skills for senior Consultants 	
		<ul style="list-style-type: none"> <u>Sage and Thyme</u> Record of EOL Conversation 	

		<ul style="list-style-type: none"> • <u>Macmillan</u> 	
		<ul style="list-style-type: none"> • Compassion awareness 	
	<ul style="list-style-type: none"> • Complete Anticipatory/Advance Care Plan (ACP) (or MIG) 	<ul style="list-style-type: none"> • Advance Care Planning 	All Healthcare Professionals
		<ul style="list-style-type: none"> • E-ELCA - Dying in Acute Hospitals (Module 05.12) 	
		<ul style="list-style-type: none"> • Anticipatory Care Planning 	
		<ul style="list-style-type: none"> • HEKSS Online training 	
		<ul style="list-style-type: none"> • e-ELCA advanced care planning modules 	
		<ul style="list-style-type: none"> • Link Nurse EOL Training Programme 	
		<ul style="list-style-type: none"> • Advanced communications 	
			Senior clinicians and senior advanced healthcare professionals
	<ul style="list-style-type: none"> • MCA and DOLS 	<ul style="list-style-type: none"> • Online training 	All Healthcare Professionals
		<ul style="list-style-type: none"> • Face to face 	
	<ul style="list-style-type: none"> • Awareness of DNACPR 	<ul style="list-style-type: none"> • <u>DNA CPR Awareness training (PH)</u> • EKHUFT Mandatory Training (DNA CPR) 	All Healthcare Professionals
	<ul style="list-style-type: none"> • Complete DNACPR form and review regularly 	<ul style="list-style-type: none"> • DNA CPR Training • EKHUFT Mandatory Training (DNA CPR) 	Clinicians only
	<ul style="list-style-type: none"> • Symptom control management 	<ul style="list-style-type: none"> • e-ELCA Symptom management modules – Last months and days of life (Module 04.23) 	All qualified nurses and clinicians/ consultants
		<ul style="list-style-type: none"> • F1 and F2 training for doctors (EOL) 	

		training undertaken once/ twice per year)	
		• Link Nurse Training Programme	
		• Face to face training	
		• Macmillan symptom control	
	• Ensure spiritual and psychological support in place; communication skills for care after death and bereavement	• e-ELCA Spirituality modules (Module 2.14)	All Healthcare professionals
		• Sage and Thyme	
	• Care after death	• e-ELCA Modules (Module 2.14)	All Healthcare professionals
		• Advanced communication skills (2 day course)	Consultants and Clinical Nurse Specialists (linked to Peer Review)
		• Hospice UK – Care after Death : Guidance for Staff	
		• <u>The Forgotten Mourners</u>	

Other Courses available to support Tier 3 care include :

- Symptom Control Guidelines - Useful Technical Guidance (Pilgrims Hospice website) : (<http://www.pilgrimshospices.org/wp-content/uploads/Symptom-Control-Guidelines-5th-Edition.pdf>)
- Syringe Driver Training – e-Learning (McKinnley)
- Skills for Health – Core Skills for End of Life Care (scheduled for roll out in 2016)

ELCA Module	Unit
ELCA 01 - Advance Care Planning	<p>01_01 Introduction to principles of ACP</p> <p>01_02 Cultural and Spiritual Considerations in ACP</p> <p>01_03 Benefits and risks of ACP to patients, families and staff</p> <p>01_04 ACP in practice: using end of life care tools</p> <p>01_05 Advance Decisions to Refuse Treatment: Principles</p> <p>01_06 Advance Decisions to Refuse Treatment in Practice</p> <p>01_07 Mental Capacity Act - Aims and Principles</p> <p>01_08 Mental Capacity Act in practice</p> <p>01_09 Approaching ACP when capacity is uncertain, fluctuating or likely to deteriorate</p> <p>01_10 ACP and different trajectories</p> <p>01_11 Introduction to conducting conversations about advance care planning</p> <p>01_12 How to get started and get the timing right</p> <p>01_13 How to handle patients' questions and concerns</p> <p>01_14 How to Document Conversations About Advance Care Planning</p> <p>01_15 How to Negotiate Decisions Which May be Difficult to Implement</p> <p>01_16 How to review previous ACP decisions</p> <p>01_17 Developing ACP in your organisation</p> <p>01_18 Developing your practice: clinical supervision, further reading.</p>
ELCA 02 - Assessment in End of Life Care	<p>02_01 Introduction to principles of assessment in end of life care: Part 1</p> <p>02_02 Introduction to principles of assessment in end of life care: Part 2</p> <p>02_03 Assessment of Physical Symptoms</p> <p>02_04 Assessment of physical function</p> <p>02_05 Assessment of psychological well-being</p> <p>02_06 Assessment of Social and Occupational Well-being</p> <p>02_07 Assessment of spiritual wellbeing</p> <p>02_08 Context of assessment: cultural and language</p>

	<p>02_09 Bereavement assessment and support</p> <p>02_10 Carer assessment and support</p> <p>02_11 Assessing through proxies</p> <p>02_12 Assessing those with fluctuating mental capacity</p> <p>02_13 Assessing Urgent Situations with Limited Information</p> <p>02_14 Assessment of dying phase and after-death care</p> <p>02_15 First assessment: meeting the patient</p> <p>02_16 Identifying the patient's goals and priorities</p> <p>02_17 Documentation, communication and coordination</p> <p>02_18 Following up Assessments and Evaluating Outcomes</p> <p>02_19 Uses and limitations of assessment tools</p>
ELCA 03 - Communication Skills	<p>03_01 The importance of good communication</p> <p>03_02 Principles of communication</p> <p>03_03 Communicating with ill people</p> <p>03_04 Talking with Ill People Considering the Surrounding Environment</p> <p>03_05 Culture and Language in Communication</p> <p>03_06 Communication skills for administrative staff, volunteers and other non-clinical workers</p> <p>03_07 Self awareness in communication</p> <p>03_08 Understanding and Using Empathy</p> <p><u>Communicating with Empathy</u></p> <p>03_09 Skills which facilitate good communication</p> <p>03_10 Things which block good communication</p> <p>03_11 Face to face communication skills</p> <p>03_12 Telephone communication</p> <p>03_13 Written communication skills</p> <p>03_14 Information Giving</p> <p>03_16 Communicating with non-English speaking patients</p> <p>03_15 Breaking Bad News</p>

	<p>03_17 Communicating with people with speech and hearing difficulties</p> <p>03_19 Request for organ and tissue donation</p> <p>03_18 Communicating With Children and Young People</p> <p>03_20 Request for euthanasia</p> <p>03_21 Legal and Ethical Issues Embedded in Communication</p> <p>03_22 Am I Dying How Long have I Got Handling Challenging Questions</p> <p>03_23 "Please Don't Tell My Husband" - Managing Collusion</p> <p>03_24 "How dare you do this to me!" - managing anger</p> <p>03_25 "I don't believe you, I'm not ready to die!" Managing Denial</p> <p>03_26 What Will it Be Like Talking About the Dying Process</p> <p>03_27 "Why can't I stay here" "I don't want to stay here" - when preferred place of care cannot be met</p> <p>03_28 "I'm not loveable anymore" - discussing intimacy in end of life care</p> <p>03_29 "Why me?" - discussing spiritual distress</p> <p>03_30 Discussing 'Do Not Attempt CPR' Decisions</p> <p>03_31 Discussing food and fluids</p> <p>03_32 Silence: The Withdrawn Patient</p> <p>03_33 Distress: the crying patient</p> <p>03_34 Dealing With Challenging Relatives</p> <p>03_35 Challenging communication with colleagues</p>
ELCA 04 - Symptom Management	<p>04_01 General approach to assessment of symptoms</p> <p>04_02 Agreeing a plan of management and care</p> <p>04_03 Communicating the Plan of Management and Care</p> <p>04_04 Individual preferences and cultural influences on symptom management</p> <p>04_05 Influence of Transition Points and Crises on Decision-Making in Symptom Management</p> <p>04_06 Recognising Your Own Limitations in Symptom Management</p> <p>04_07 Assessment of Pain</p> <p>04_08 Principles of pain management</p>

	04_09 Drug management of pain: core knowledge
	04_10 Opioids in pain management: advanced knowledge
	04_11 Managing Different Types of Pain
	04_12 Assessment of breathlessness
	04_13 Drug management of breathlessness
	04_14 Non-drug management of breathlessness
	04_15 Causes of nausea and vomiting
	04_16 Assessment of nausea and vomiting
	04_17 Management of nausea and vomiting
	04_18 Assessment of Constipation
	04_19 Management of constipation
	04_20 Management of Bleeding
	04_21 Management of seizures
	04_22 Recognising and Managing Malignant Spinal Cord Compression
	04_23 Recognising the Last Months and Days of Life and Verifying Death
	04_24 Managing Death Rattle
	04_25 Agitation and Restlessness in the Dying Phase
	04_26 Managing distress during the dying phase
	04_27 Using Syringe Drivers
	04_28 Non-drug intervention in symptom management
	04_29 Symptom Management in People with Learning Difficulties or Mental Health Problems
	04_30 Symptom Management Complicated by Coexisting Conditions
	04_31 Management of symptoms associated with wounds
	04_32 Assessment of Mood
	04_33 Assessment and Management of Anxiety
	04_34 Management of Depression
	04_35 Assessment and Management of Agitation
	04_36 Recognising and managing fatigue
	04_37 Assessment and management of weight loss and loss of

	<p>appetite</p> <p>04_38 Management of Sore Mouth and Other Oral Problems</p> <p>04_39 Assessment of physical and cognitive deterioration in function</p> <p>04_40 Management of physical deterioration</p> <p>04_41 Management of Cognitive Deterioration</p>
ELCA 05 - Integrating Learning in End of Life Care	<p>05_01 Initiating Conversations about End of Life Care: COPD</p> <p>05_02 Initiating conversations about EoLC: cancer</p> <p>05_03 Initiating Conversations about End of Life Care: Dementia</p> <p>05_04 Initiating conversations about EoLC: long term neurological conditions</p> <p>05_05 End-stage Cardiac Disease</p> <p>05_06 Case Study Motor Neurone Disease</p> <p>05_07 Case study: COPD</p> <p>05_08 Case study: End-stage Renal Disease</p> <p>05_09 Case study: dementia</p> <p>05_10 Ambulance Called to Home</p> <p>05_11 Scenario: terminal agitation - patient in a care home</p> <p>05_12 Dying in Acute Hospitals</p> <p>05_13 When the dying process is protracted or unexpectedly fast</p> <p>05_14 Sudden unexpected death</p> <p>05_15 Dying As A Prisoner</p> <p>05_16 Dying as a homeless person</p> <p>05_17 Dying in Intensive Care</p> <p>05_18 Treatment and Care Towards the End of Life Good Practice in Decision Making</p> <p>05_19 Care After Death I Introduction to Care After Death</p> <p>05_20 Care After Death II Providing Personal Care After Death</p> <p>05_21 A Unified DNACPR Policy</p> <p>05_22 Using the NHS Continuing Healthcare Fast Track Pathway Tool</p> <p>05_23 Framework for End of Life Care in Advanced Kidney Disease</p>

ELCA 06 - Social Care	06_01 Supporting People to Live and Die Well 06_02 Palliative Care Social Work 06_03 Assessment in End of Life Care 06_04 Support and Care Planning at End of Life 06_05 Hospital Social Work 06_06 End of Life Care in Care Homes and Domiciliary Care Settings
ELCA 07 - Bereavement Care	07_01 Talking About Death and Dying 07_02 Assessment of Carers' Needs 07_03 Practical Support After a Bereavement 07_04 Sudden Death and Bereavement 07_05 Emotional Support and Signposting 07_06 Children and Bereavement
ELCA 08 - Spiritual Care	08_01 Spirituality and the Philosophy of End of Life Care 08_02 Understanding and Assessing Spiritual Need and Spiritual Distress 08_03 Spiritual Care and Models of Spiritual Intervention 08_04 Spiritual Resources and Quality of Life 08_05 Spirituality and the Multidisciplinary Team 08_06 Spirituality in the Community
ELCA 09 - Priorities for Care of the Dying Person	<p><u>Priorities for Care of the Dying Person Core and Additional Sessions</u></p> e-ELCA Priorities for Care of the Dying Person Training Needs Analysis e-ELCA Priorities for Care of the Dying Person Learning Paths for Doctors e-ELCA Priorities for Care of the Dying Person Learning Paths for AHPs e-ELCA Priorities for Care of the Dying Person Learning Paths for Social Care - Managers e-ELCA Priorities for Care of the Dying Person Learning Paths for Social Care Workers e-ELCA Priorities for Care of the Dying Person Learning Paths for Healthcare Managers e-ELCA Priorities for Care of the Dying Person Learning Paths for

	Healthcare Administrators
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7. Conclusion

Every professional needs to be competent and up to date in the knowledge and practice that enable them to play their part in good end of life care.

It is vital that every locality and every profession has a framework for their education, training and continuing professional development, to achieve and maintain this competence. That framework must allow expertise and professionalism to flourish in the culture of every organisation and every caring contact.

It should offer practical examples of how care can be delivered in a way that is tailored to the person.

If our ambitions are to be achieved there must be a consistent and common use of such educational resources for palliative and end of life care.

The Local Education and Training Boards must support educational and service providers to use to their full potential, the opportunities for learning and development that exist locally, and, where needed, to develop new opportunities.