Palliative Care

Information and guidance to support professionals in the care of patients with palliative care needs in all care settings
Introduction

This information has been developed to support teams in achieving the recommendations of the Department of Health End of Life care Strategy for Adults (2008) and may be used to support completion of The South of Tyne and Wear Supportive and Palliative care Standards for End of Life.


The End of Life Care Strategy for Adults from The Department of Health 2008 states all services who provide palliative care and support should be carefully co-ordinated.

Coordination of the care needs of individuals and their carers need to be considered on three levels:

1. Coordination within an individual team e.g. Primary Care Team
2. Coordination between teams e.g. Primary Care Team and Specialist Palliative Care Team
3. Coordination across organisational boundaries (DH2008)

South of Tyne and Wear Supportive and Palliative care Standards for End of Life provide a mechanism to improve quality and promote standards of supportive and palliative care. This is a structured framework to providing a holistic approach with key measurable outcomes to enhance communication, continuity of care as well as symptom management and anticipatory care.

Included in the South of Tyne and Wear Supportive and Palliative care Standards for End of Life are key definitions for the following:

- End of Life
- Supportive care
- Palliative Care
- Who Provides Palliative Care?
- Specialist Palliative care Services

Other recognised models for improving coordination of care with an individual team or location are:

- Gold Standards Framework (GSF)
- KITE Standards (Keep Improving The Experience)
Who is the Key Worker?

Each patient should be appointed a Key Worker (with the agreement of the patient). This is the most appropriate person to co-ordinate that patients care. The key worker may change at any time depending on the needs of the patient. A person who acts as ‘key worker’ may be the GP or lead clinician or defined for example as a community nurse, allied health professional, nurse specialist or social worker (NICE, 2004). Contact details of the key worker are provided to patients and carer and this information is recorded in the patients’ case notes or documentation.

The role of the key worker
(With the patient’s consent)

- Provide practical and emotional support to the patient and family
- Provide a point of contact to the patient
- Act as a patient advocate
- Co-ordinate the patient journey ensuring interventions take place timely.
- Co-ordinate the provision of information and ensure that it is timely, tailored to the individual’s needs and understood
- Liaise with all appropriate health care professionals in the hospital and community including the primary care team
- Case manage the care needs of the patient as they move between care settings along the relevant pathway. This may mean changing key worker according to agreed protocols

Show patient the Key worker Card and complete all relevant sections:

- Your contact details
- Out of hours
- People responsible for care
- Relevant Support Groups

Transfer of key worker:

- Must be discussed and agreed with the patient and with the proposed new key worker.
- All changes to be documented

Key Worker Card:
While the perceptions of patients, carers and health and social care professionals may differ, the process of assessment can produce a common understanding of the needs and preferences of patients. Some studies have reported that the assessment of physical symptoms and psychosocial needs is often inadequate. Patients’ needs and preferences will change as they progress through different phases of the patient disease pathway; re-assessment at regular intervals and along critical points on the pathway is therefore essential (Department of Health 2004).

The aim of the holistic assessment Tool is to provide those health professionals, who are often named as ‘key worker’, with a tool which can be used along the palliative care pathway which can enhance the patient holistic assessment.

The tool for measuring concerns aims to:

1. Provide a brief holistic (i.e. bio-psycho-social-spiritual) assessment of patients at any stage of their illness, to identify areas of concern or distress.

2. Indicate the patient’s: Physical state, experience of treatment side-effects (e.g. pain, nausea, fatigue etc)
   Psychological and emotional well-being (e.g. anxiety, depression), relationship, sexual or family concerns, etc
   Social/practical/personal concerns (e.g. housing, finances, relationships, body image etc)
   Existential/spiritual concerns

3. Indicate services and resources that may help to resolve the patients’ concerns.
Holistic Assessment

**Critical Points on the Pathway for holistic assessment:**
At diagnosis and initial treatment
At remission / disease control / maintenance therapy
At relapse / recurrence or deterioration
Further intervention / modification or disease progression
At terminal phase and death
At bereavement

**Holistic assessment includes:**
Taking a patient history
Physical assessment
Psychological assessment
Nutritional assessment
Assessment of physical adaptation and coping mechanisms
Rehabilitation needs
Spiritual needs
Existing support
Social assessment
Information needs
Speech and language difficulties
Patients/Carers awareness of the range of services that they may be referred to
End of Life Care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

The End of Life Care Strategy (July 2008) aims to improve end of life care for patients with life limiting illnesses, regardless of their disease or the care setting.

Available evidence suggests that whilst more than 50% of patients wish to spend their final days at home, fewer than 20% are actually able to do so.

The strategy focuses upon providing greater choice for patients in their place of care and place of death; decrease the number of emergency admissions for patients who have expressed a wish to die at home; decrease the number of patients transferred from a care home to a district general hospital in the last week of life.

**Key Recommendations**

All professionals in all care settings need to effectively provide good quality care and there are key recommendations that can assist teams to fulfil the expectations of the strategy with the ultimate aim to improve end of life care for all patients with life limiting illnesses.

Although every individual may have a different idea about what would, for them, constitute a ‘good death’, for many this would involve:

- Being treated as an individual, with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings;
- Being in the company of close family and/or friends.
Whole systems and care pathway approaches

The end of life care strategy was developed over a period of a year by an advisory board and six working groups and over 300 stakeholders were consulted. From this process a consistent message has emerged that a whole systems approach is needed. Within this, a care pathway approach both for commissioning services and for delivery of integrated care for individuals has been strongly recommended.

The care pathway involves the following steps:

- **Identification of people approaching the end of life and initiating discussions about preferences for end of life care**
- **Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly**
- **Coordination of care**
- **Delivery of high quality services in all locations**
- **Management of the last days of life**
- **Care after death**
- **Support for carers, both during a person’s illness and after their death**
Identification of people approaching the end of life

Prognostic Indicator Guidance

Who should be on Palliative care register?

Three triggers for supportive care/palliative care.

To identify these patients we can use any of the following methods:

1. **The surprise question** – “Would you be surprised if this patient were to die in the next 6-12 months” – an intuitive question integrating co-morbidities, social and other factors

2. **Choice/need** – The patient with advanced disease makes a choice for comport care only, not ‘curative’ treatment, or is in need of supportive/palliative care

Clinical indicators – Specific indicators of advanced disease for each of the three main end of life patient groups – cancer, organ failure and elderly frail/dementia (For Prognostic Indicator Guidance see pages 14–17)

**Examples of prognostic indicators used as part of patient needs assessment**

Patients have differing requirements at varying stages of their illness. Some Teams (i.e. GP practices and Care Homes) categorise their patients on the Palliative Care Register according to estimated prognosis and need, and colour code them accordingly.

Although only a rough guide, this helps teams ‘awareness of patients’ varying needs, focuses care to ensure that the right care is directed at the right time, ensures regular review, and triggers key actions at each stage. A needs/support plan is therefore developed. Suggested prognostic coding could be:

- **A** – ‘All’ Stable Blue
  - Years + prognosis
- **B** – ‘Benefits’ eg DS1500 Green
  - Months prognosis
- **C** – ‘Continuing Care’ -Yellow
  - Weeks prognosis
- **D** – ‘Days’- Terminal phase Red
  - Days prognosis

The use of means of estimating approximate prognosis and need i.e. the intuitive ‘surprise’ question, needs/choice based care, and these clinical indicators, may help to ensure that patients with advanced illness receive higher quality proactive care and support as they near the end of their lives.
The End of Life Journey

Patients have different requirements at varying stages of their illness. It can therefore be useful to categorise patients on the Palliative Care Register according to estimated prognosis and need and colour code them accordingly. This helps raise awareness of patients’ varying needs, focuses care, ensure that the right care is directed at the right time, ensures regular review and triggers key actions at each stage.

**Prognosis < 1**
- Single Assessment of needs completed
- Carers Needs Assessment completed
- Prognosis communicated
- Keyworker team nominated
- Put on to Palliative Care GP register
- Advance Care Plan initiated
- Information prescriptions issued for patient and carer

**Prognosis < 6 months**
- DS1500 completed
- Advance Care Plan initiated/reviewed
- OOH informed of ACP via special patient notes
- Respite care arranged
- DNAR Initiated by GP

**Prognosis few weeks**
- Anticipatory medication supplied
- Fast track to full Continuing Care
- Support arranged
- Provision of telehealth
- ACP and DNAR
- OOH update

The following will be provided at the appropriate time according to individual patient needs:
- Specialist care (condition-specific and/or palliative)
  - Spiritual support
  - Respite care
  - Psychological support services
  - Self-help and support services
  - Equipment
  - Bereavement Support
Verification and Certification of death

Bereavement booklet (Help for the Bereaved) given to relatives/carers

ACP data base form completed and returned to Audit Dept

After death analysis at GP MDT

Inform all health and social care providers of patient death

LCP initiated

OOH, updated on patients condition via special patient notes

Prognosis < 1 week

medications

fully funded care completed

 ged for terminal care at

R reviewed

patient and carer needs:
Identification of people approaching the end of life

Prognostic Indicator Guidance of end stage illness

General predictors
Multiple co-morbidities
Weight loss – greater than 10% weight loss over 6 months
General physical decline
Serum Albumin < 25g/l
Reducing performance state/Karnofsky score (KPS) < 50%.
Dependence in most activities of daily living (ADLs)

Cancer Patients
Metastatic disease not amenable to treatment (with some exceptions)
Reduced performance status

Organ Failure Patients
Heart Disease (at least 2 of the indicators below)
CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
Patient thought to be in last year of life (surprise question)
Repeated hospital admissions with symptoms of heart failure
Difficult physical or psychological symptoms despite optimal treatment

Chronic Obstructive Pulmonary Disease (COPD)
Disease assessed to be severe e.g. (FEVI <30% predicted)
Recurrent hospital admissions (> 3 admissions in 12 months)
Fulfils Long Term Oxygen Therapy Criteria
MRC grade 4/5 – shortness of breath after 100 metres on level ground
Sings and symptoms of Right sided heart failure
Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression
Patient spending 50% of their time in bed/lying down
Identification of people approaching the end of life

Renal Disease
Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant
Frail with co-morbidities
Patients thought to be in last year of life by care team (surprise question)
CKD stage 5 (eGFR <15 ml/min)
Symptomatic renal failure (anorexia, nausea, purities, reduced functional status, intractable fluid overload)

Neurological Diseases
– Motor Neurone Disease
  MND patients should be included onto palliative care register from diagnosis as it is a rapidly progressing illness

Indicators of deterioration include:
  Disturbed sleep related to respiratory muscle weakness
  Signs of dyspnoea at rest
  Barely intelligible speech
  Difficulty swallowing
  Poor nutritional status
  Needing assistance with ADLs
  Medical complications e.g. pneumonia, sepsis
  A short interval between onset of symptoms and diagnosis
  A low vital capacity (below 70% of predicted using standard spirometry)
Identification of people approaching the end of life

**Parkinson’s Disease**
Presence of 2 or more of criteria
- Drug treatment is no longer as effective / an increasingly complex regime of drugs
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with “off periods”
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

**Multiple Sclerosis**
Significant complex symptoms e.g. pain
Communication difficulties e.g. Dysarthria +/- fatigue
Cognitive difficulties
Swallowing difficulties/poor nutritional status
Breathlessness +/- aspiration
Medical complications e.g. recurrent infection

**Patients with Frailty and Dementia**

**Frailty**
- Multiple co morbidities with signs of impairments in day to day functioning
- Deteriorating Karnofsky score
- Combination of at least 3 symptoms of: weakness, slow walking speed low physical activity, weight loss self reported exhaustion

**Dementia**
- Unable to walk without assistance and
- Urinary and faecal incontinence and
- No meaningful verbal communication and
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform activities of daily living
Identification of people approaching the end of life

**Plus any one of the following:**

- 10% weight loss in previous six months without other causes
- Pyelonephritis or UTI
- Serum albumin 25 g/l
- Severe pressure score stage III/IV
- Recurrent Fevers
- Reduced oral intake
- Aspiration pneumonia

**Stroke**

- Persistent vegetative or minimal conscious state / dense paralysis / incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / post stroke dementia

**Karnofsky Performance Status Score**

**Score Function**

- **100**  Normal, no evidence of disease
- **90**  Able to perform normal activity with minor symptoms
- **80**  Normal activity with effort, some symptoms
- **70**  Able to care for self but unable to do normal activity
- **60**  Requires occasional assistance, cares for most needs
- **50**  Requires considerable assistance
- **40**  Disabled, requires considerable assistance
- **30**  Severely disabled
- **20**  Very sick, requires active supportive treatment
- **10**  Moribund

Access Barthel and Karnofsky Performance Status Score taken form Gold Standards Framework
Palliative Care Multidisciplinary Team Meetings

The aim of having a regular MDT is to review and discuss the management plan for patients who are on the supportive and palliative care register.

To ensure each patient has a management plan as defined by the practice team and are acted upon by the most appropriate member of the team.

To ensure that the management plan includes preferences for place of care.

To ensure that the support needs of carers are discussed and addressed wherever reasonably possible.

A regular forum structured with a framework or protocol where an agreed plan of care for people in the last year of life can be discussed can be far more effective than ad hoc arrangements.

Once well established the MDT can be more fulfilling and lead to more people dying a good death, in the place and manner of their choosing.

For the practice this is a real opportunity to focus more on patients nearing the end of their life and to integrate with the appropriate members of the primary health care team.

There are 3 QOF points for holding a MDT at least 3 monthly. This is a minimum recommendation but meetings held more frequently, e.g. monthly, provide improved communication and co-ordination of care.

There are max 52 points available for cancer and other long-term conditions relevant to palliative care.
Coordination of care has also been supported by the development of GP practice registers of people who are approaching the end of life. These registers help to ensure that care given by the multidisciplinary primary care team is well coordinated. The registers are a key element featured in *South of Tyne and Wear Supportive and Palliative care Standards for End of Life*, The End of Life Care Strategy Quality Markers [EoLCS QM] and attract points with the Quality and Outcomes Framework (QOF).

General Practices should **all** have a register of **all** patients with supportive or palliative care needs, incorporating patients with cancer and non-cancer illnesses identifying that patients may be in the last year of life. Use of the prognostic indicator guidance will assist the identification and prediction.

This is an opportunity to focus on this important group of patients, to identify and collate significant information using a register and to discuss individual management plans as a team, this is the first step to improving palliative care organisation within your practice team, adopting a more proactive approach.

Effective communication needs to take place providing handover of information and alerts to the out of hours medical and Nursing services or duty doctor of people who wish to die at home; Do Not Attempt Resuscitation orders, medication regimes and any other significant information.

An example template of a Palliative care Register is provided over the page:
## Primary Care MDT – Palliative Register Form

| Patient’s Name Or Identifying Ref. | Diagnosis | GP | DN | Coordination of Care – Concerns / Needs | DS 1500 | E  
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<td>In brief – detail in patient record</td>
<td>Date</td>
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<tr>
<th>Macmillan Nurse/CNS</th>
<th>Specialist Pall. Care</th>
<th>OOH Form</th>
<th>Care Pathways ACP / LCP</th>
<th>Death &amp; Bereavement Care</th>
<th>Review/ comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name &amp; Date involved</td>
<td>Contact &amp; Date sent</td>
<td>Date(s)</td>
<td>Date and note of care</td>
<td>Event reviewed</td>
<td></td>
</tr>
</tbody>
</table>
Palliative Care Multidisciplinary Team Meetings

Suggested format and involvement -
May be combined with your other Primary Care MDT meeting or held separately – depending on number of palliative patients on register

Minimum every 3 months; consider monthly meetings

Palliative Register Form (with specific headings to aid discussion) available for use with meeting

For Cancer patients, this review may be considered as part of ‘Cancer 3 – ongoing management’ patient review

  Core Members Include -
    o GPs
    o District Nurses
    o Practice Manager
    o appropriate admin staff

Extended Members include –
  o Specialist Palliative Care nurse
  o Social Services (as appropriate)
  o Community Matron
  o Other Health Care Professional

Suggested meeting structure –

New patients –
  o Coming onto the register – initial discussions; reactive interventions to concerns/issues; anticipated needs, advance care planning, carers needs,
  o Those eligible for DS1500, or suspected to be in last year of life

Existing patients –
  o Current care and plans; Advance care planning and patient preferences; communication with others (social services, spiritual support); anticipating future needs and proactive planning; Liverpool Care Pathway

Review patient deaths –
  Reflection Positive or negative
  Significant Event Analysis
  After Death Analysis
  o Bereavement follow up for family and carers

Action points –
  o Specific to individual patient(s)
  o Learning needs; commissioning issues; practice protocols and procedures

Date of next meeting
Advance Care Planning

Planning future care (Advance care planning) This is the process of making clear a person’s wishes, preferences, beliefs, values and feelings in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. This may lead to making an Advance Statement, an advance decision to refuse treatment (ADRT), a Do Not Attempt Cardiopulmonary resuscitation (DNACPR) decision, or other types of decision (such as appointing a Lasting Power of Attorney). This has been known as Advance Care Planning in England & Wales.

Advance decision In the Mental Capacity Act this applies specifically to Advance Decisions to Refuse Treatment (ADRT)- see next

Advance Decision to Refuse Treatment (ADRT) A legally binding refusal of specified future treatment by a patient or client with capacity regarding their future care should they lose capacity for this decision. It is made by the individual who has capacity to make these decisions. It may be made with support from a clinician. However, it cannot be made if an individual lacks capacity to make these decisions, and only becomes active when the patient or client loses capacity for these decisions.

Advance Statement A statement written by a patient or client with capacity describing their preferences, wishes, beliefs, values and feelings about their future care. It may be written with support from professionals, and relatives or carers. It cannot be written if the individual lacks capacity to make these statements, and only becomes active when the patient or client loses capacity for these decisions. It is not legally binding, but must be taken into account when deciding the best interests of a person who has lost capacity.

Best interests A process required under the Mental Capacity Act to enable decisions to be made in a patient or client who has lost capacity for those decisions.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Only covers decision about withholding future CPR. Completed by a clinician with responsibility for the patient. Patient consent is sought only if an arrest is anticipated and CPR could be successful. Can be completed for an individual who does not have capacity if the decision is in their best interests.
Advance care planning: five point plan for primary care

(1) Identify patients who may be in their last 12 months of life and add them to the practice’s palliative care register

(2) Assess their current health and social needs

(3) Sensitively raise the following points with patients and their family or carers
   - What elements of care are important to you and what would you like to happen?
   - What would you not wish to happen?
   - Do you have a person who is willing to be a proxy or have lasting power of attorney?
   - If your condition deteriorates, where would you like to be cared for (first and second choices)?
   - Have you any other special preferences, requests, comments?
   - Do you have a view on resuscitation if your heart suddenly stops?

These preferences should then be communicated to other services

(4) Provide proactive personalised care and review this regularly with the patient and family or carers

(5) If patients do not want a specific treatment should incapacity arise, seek specialist help to initiate a legal “advance decision”

(Murray et al 2006) Advance Care Planning in Primary Care

The South of Tyne and Wear Advance Care Planning Statement Process

- Initiation of discussion by patient or professional
- Time for consideration by patient
- Completion of document with patient
- Complete summary document
- Dissemination of information to other professionals
- Register plan with database
- Review plan with patient (no longer than 6 months)
- Further sharing of review
- Further ongoing reviews
- Complete after death analysis and register with database
Care in the last days of Life

The Liverpool Care Pathway (LCP) for the Dying Patient is a multi professional document that provides an evidence based framework of best practice for the dying phase (Ellershaw and Wilkinson 2003). This is based on the standards of care delivery in the hospice environment which have been adapted to most care settings that was recommended by the national Institute for Health and Clinical Excellence (NICE 2004). The Government White Paper “Our Health, Our Care, Our Say: A New Direction for Community Services” (DH 2006) states:

“We will ensure that all staff who work with people who are dying are properly trained to look after dying patients and their carers. This will mean extending the roll-out of tools such as the Gold Standard Framework and the Liverpool care Pathway for the dying to cover the whole country.”

The LCP is outcome based and designed to enable the easy extraction of data for audit purposes.

The goals of care focus on ensuring the physical comfort of the patient, psychosocial (insight) and spiritual aspects (for both patients and carers), communication, information (giving and receiving) and policy and procedure. It is organised into three discrete sections.
Care in the last days of Life

1. The Initial Assessment Section
This section is completed on commencement of the LCP and is primarily concerned with ensuring that the care delivered (both to patients and carers) is optimum in light of the changing condition of the patient. It includes ensuring that medications are reviewed and any medication deemed unnecessary is discontinued, and appropriate regular and PRN medications are available for the five most common symptoms in the dying phase. It is also concerned with ensuring that appropriate communication takes place with patients (wherever possible), carers and other health professionals.

2. The Ongoing Assessment Section
This section documents the patient’s continual condition and level of physical and emotional comfort as assessed by health professionals at a minimum of three reviews in 24 hours. It is a requirement that a formal MDT review takes place every 3 days where appropriate or at a minimum of twice weekly. It also provides information regarding the continued well being of carers in this phase.

3. Care after Death Section
This section documents the care and procedures to be followed after the death of a patient, including following appropriate procedures for the care of the body and the giving of information and support to bereaved relatives (Help for the Bereaved Booklet) in the period immediately following the death.
References


http://www.goldstandardsframework.nhs.uk/


