**Introduction**

Around 500,000 people die in England each year. The vast majority (around 99%) of deaths occur in adults over the age of 18 years. Most deaths occur in people over 65 years and this group is expected to increase in numbers over the next decade as our population ages. The majority of deaths occur following a period of chronic illness related to conditions such as heart disease, liver disease, renal disease, diabetes, cancer, stroke, chronic respiratory disease, neurological diseases and dementia.

The National Service Framework for Older People (Department of Health 2001) recognises that all those providing Health & Social care for older people with chronic conditions may need to provide end of life (EOL) care.

The Improving Supportive & Palliative care for Adults with Cancer (National Institute for Clinical Excellence 2004) defined service models required to ensure that people with cancer, their families and other carers receive support to help them cope with cancer and its treatment. In response to this, NHS South of Tyne and Wear developed a set of standards, adopting a coordination model. They supported the delivery of high quality end of life care in the care home setting, ensuring people living in a care home with ANY condition (including elderly frail and illnesses other than cancer) will receive the best quality care in the last 12 months of life.

In 2008, the Department of Health published the End of Life Strategy, aimed at improving the quality of end of life care for all people in all settings, including care homes. This is supported by a Route to Success (RTS) guide, which has been adapted by the North West End of Life Care programme in their Six Steps to Success Programme. Other guidance influences the quality of care delivered to people residing in care homes at the end of their lives, including core competencies for staff and quality and safety measures.

NHS South of Tyne and Wear’s Supportive and Palliative Care Standards for End of Life Care in Care Homes have been updated and mapped against the North West End of Life Care programme Six Steps to Success Programme. This reflects important publications to ensure local recommendations are aligned with national guidance. Furthermore, they complement the locally-owned document Supportive and Palliative Care Standards for End of Life in the Primary Care Setting.

**Completing South of Tyne and Wear’s Supportive and Palliative Care Standards for End of Life Care in Care Homes**

© Copyright NHS South of Tyne and Wear (covering Gateshead, South Tyneside and Sunderland Primary Care Trusts) Provider Services (April 2011)
The aim of the standards is to ensure that all residents in care homes receive equitable supportive and palliative care at the end of their lives, in keeping with their individual needs and that their family feels supported throughout the process.

The approach contains **Six Standards** which each care home should aspire to achieve.

The process begins with completion of a baseline self assessment of: **The Care Home End of Life Care: Baseline Assessment Questionnaire.**

In order to meet the standards the home will need to produce the evidence required. If the **Six Standards** are not being met the creation of an action plan of how this is going to be achieved will be developed.

The **Six Standards** are designed to be a work in progress, providing a benchmark for the care home to assess itself against. The aim is for the home to then work towards improving this baseline in an evidence-based framework, consistent with national guidelines.

Each of the **Six Standards** has an overall objective with goals attached. Each standard includes initiatives and measures to support achievement. Suggested evidence is also provided to give practical guidance. Each of the **Six Standards** have been mapped against the End of Life Care Strategy Quality Markers (2009) and Route to Success.

**A palliative care booklet** has been produced to provide information to support teams in achieving the recommendations of the Department of Health End of Life Strategy for adults (2008) and may be used in support of completion of the **South of Tyne and Wear Supportive and Palliative Care Standards for End of Life in Care Homes.**

**Definitions**

**Supportive Care:**

“Supportive care helps the resident and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the resident to
maximise the benefits of treatment and to live as well as possible with the effects of
the disease. It is given equal priority alongside diagnosis and treatment”.

Supportive care is fully integrated with diagnosis and treatment, encompassing:

- Self help and support
- User involvement
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- End of life and bereavement care

(Adapted from National Institute for Clinical Excellence, 2004)

Palliative Care

“Palliative care is the active holistic care of people with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for the resident and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments”.

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help residents live as actively as possible until death
- Offer a support system to help the family cope during the residents illness and in their own bereavement

(Adapted from World Health Organisation 2002)

End of Life Care

“Care for those with advanced, progressive and 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 management of pain and other symptoms and provision of psychological, social, spiritual and practical support”.

- Recognises that all health and social care professionals are involved in care for people nearing the end of life to some degree, rather than just palliative care specialists.
• Reliable comprehensive high quality care can only be achieved by everyone becoming engaged
• Since the development of the NHS End of Life Care Programme the term is used increasingly to include patients months and years before death, not just those in the final days

(Adapted from End of Life Care Strategy 2008<sup>5</sup>)

**Terminal Care**

“Care in the final days and hours of life, requiring the diagnosis of dying (as in Liverpool Care Pathway for the Dying).”

(Royal College of General Practitioners, End of Life Care Strategy<sup>12</sup>).

**Who Provides Palliative Care?**

Palliative care is provided by two distinct categories of health and social care professionals:
• Those providing the day-to-day care to the resident.
• Those who specialise in palliative care (for example consultants in palliative medicine and clinical nurse specialists in palliative care)

Those providing day-to-day care should be able to:
• Assess the care needs of each resident and their families across the domains of physical, psychological, social, spiritual and informational needs
• Meet those needs within the limits of their knowledge, skills, competence in palliative care
• Know when to seek advice from or refer to specialist palliative care services

Specialist Palliative Care services are provided by specialist multidisciplinary palliative care teams and include:
• Assessment, advice and care for the resident and families in all care settings, including hospitals and care homes.
• Specialist in-patient facilities (hospices) for people who benefit from the continuous support and care of specialist palliative care teams
• Intensive co-ordinated home support for people with complex needs who wish to stay at home.

(Adapted from National Council for Palliative Care 2008<sup>13</sup>)
Supportive and Palliative Care Standards for End of Life in Care Homes
Standard 1
Service Provision

There are clear, systematic approaches to the delivery of high quality palliative care for all residents, with effective assessment of their needs as appropriate to the individual.

Goals

People require supportive and palliative care at different stages of their journey and from a range of services.

People need to be central in any decisions about the care that they receive.

Continuity of care should be explicit in the philosophy of care.

Policies should include access to specialist palliative care in a variety of situations, including out of hours.

Initiatives

1. The care home has recognised in their Statement of Purpose/ Operational Policy that they deliver Palliative/ End of Life care.
   • End of Life Quality Marker 5.1
   • Route to Success: Step 4

2. There is a ‘Philosophy of care’ which incorporates supportive and palliative care; the staff are able to articulate the philosophy of care.
   • End of Life Quality Marker 5.1

3. Staff understand the “Surprise Question” and are able to identify residents that are in the last 12 months of life. But need to be mindful of dementia strategy
   • End of Life Quality Marker 5.3
   • Route to Success: Step 1

4. Delivery of care is focused on the resident and encompasses physical, psychological, social and spiritual dimensions.
5. *Continuity of care is an important aspect of the philosophy of the home, identified by the handover policy/process.*

- End of Life Quality Marker 5.2
- Route to Success: Step 3

**Measures**

1. **There is a Statement of Purpose/ Operational Policy which incorporates supportive and palliative care which all staff are able to articulate.**

2. **There is a mechanism for identifying residents potentially in the last year of life**

3. **The care home has a palliative care register.**

4. **There is a documented named professional (key worker) identified in the care home register, who responsible for the co-ordination of the care of the patient.**

5. **The Palliative Care plan, including psychological and spiritual support, is clearly documented.**

6. **The care home involves: a) residents in their treatment plan b) family in the treatment plan**

**Suggested Evidence**

- Care Home End of Life Policy
- Care Home Palliative Care Register
- Completed care plan in resident’s notes, showing holistic assessment.
- Documentation showing that all resident’s identified as being in the last 12 months of life have a named nurse/ key worker
- Audit of proportion of residents identified as being in the last 12 months of life who have a named nurse/ key worker
All staff are competent and skilled in delivering supportive and palliative care and have the necessary communication skills to enable them to inform, empower and support residents to make their own decisions / choices, appropriate to their specific role and function.

There is regular palliative care updates for all staff appropriate to their role.

A proactive approach to training is undertaken, supported by the Specialist Palliative care team.

The home's development plan incorporates palliative care

Staff training and education encompasses the 4 core common requirements for workforce development:

1. communication skills
2. assessment and care planning
3. advance care planning
4. symptom management

1. All residents will have a Named Nurse/ Key Worker who has attended Palliative care training within the last 2 years [minimum of a 1 day course].
   • End of Life Quality Markers 5.3, 5.4 (key worker), 5.9 and 5.10
   • Route to Success: Step 2
2. All senior staff [managers and qualified nurses] will have attended a 1 day Communication skills training course or equivalent.
   • End of Life Quality Markers 5.9 and 5.10
   • Route to Success: Step 1

3. All staff [nursing and care staff] will have attended a short course on Palliative & End of life care, incorporating the care of the dying pathway and Advance Care Planning [New staff within the first 6 months].
   • End of Life Quality Markers 5.9, 5.10 and 5.11
   • Route to Success: Step 5

4. Palliative care will be incorporated in all staff induction programmes.
   • End of Life Quality Markers 5.9, 5.10 and 5.11

5. The Nursing staff have been trained and are competent to verify death.
   • End of Life Quality Markers 5.9, 5.10 and 5.11

6. Agency staff receive training in Supportive and Palliative care.
   • End of Life Quality Markers 5.9, 5.10 and 5.11

---

**Measures**

1. Staff can demonstrate they have attended regular updates in supportive and palliative care as a key component of their personal development plan.

2. There are Palliative Care components to the care home training and development plan.

3. Palliative care will be incorporated in all staff induction programmes.

4. All staff can demonstrate they are competent in the delivery of End of Life Care eg: ‘Safer management and use of controlled drugs’
Suggested Evidence

- Certificates of attendance at educational sessions
- Competency based assessment documentation
- Documentary evidence of an educational needs analysis
- List of providers of relevant education to support end of life/palliative care
- New staff induction programmes
- Drug prescribing and administration documentation
Standard 3
Care Co-ordination

There is a clear process of how care is co-ordinated, with identified responsibilities.

Goals

A time commitment is given to the importance of a proactive planned approach to assessment and care planning with residents, carers and their families. This should include advance care planning and regular review of statements and wishes.

Professionals understand and respect the importance of a multidisciplinary approach.

Appropriate information is available for the resident and their family.

Note: Need to emphasise the importance of local authority/ social care/ Health care joint working.

Initiatives

1. Residents identified by the “Surprise Question” to be in the last 12 months of life are entered onto a palliative register.
   • End of Life Quality Markers 5.2 and 5.3
   • Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting

2. The home has regular meetings to review patients in the last 12 months of life.
   • End of Life Quality Markers 5.2, 5.3 and 5.4
   • Route to Success: Step 2
   • Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting

© Copyright NHS South of Tyne and Wear (covering Gateshead, South Tyneside and Sunderland Primary Care Trusts)
Provider Services (April 2011)
3. Care plans are up to date; residents are offered the opportunity of an advance care plan with regular reviews of their statement and wishes
   • End of Life Quality Markers 5.2 and 5.3
   • Route to Success: Step 2

4. Residents are reviewed following a significant event e.g. a new diagnosis, a hospital admission, disease recurrence.
   • End of Life Quality Markers 5.3 and 5.12
   • Route to Success: Step 2

5. The home works in a multidisciplinary team (MDT) manner.
   • End of Life Quality Marker 5.3
   • Route to Success: Step 3
   • Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting

6. Contact numbers and referral criteria for members of the MDT is easily accessible e.g. General Practitioner [GP], Specialist palliative care team, community matron, community pharmacy, Out of Hours services and any other relevant members of the Primary Health Care team
   • End of Life Quality Marker 5.2
   • Route to Success: Step 3

The GP (and any other relevant professional) is informed in a timely manner of any significant changes in the patient’s condition or circumstances.
   • End of Life Quality Marker 5.12
   • Route to Success: Steps 3 and 4
   • Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting

**Measures**

1. The home has a Palliative care register.

2. The home has documented evidence of residents review meetings.

3. Each resident has a relevant up to date care plan, including (if appropriate) an advance care plan.
4. There is evidence that each resident has been reviewed following a significant event e.g. a new diagnosis, a hospital admission, disease recurrence, deterioration of condition

5. There is a process of informing any other relevant health and social care professional of any updates/changes and following resident review meetings.

Suggested Evidence

- Care Home Palliative Care register
- Minutes from palliative care meetings
- Advance Care Planning protocol/documentation
- Care Home Palliative Care resource file
- Directories of other services required to support the home and resident
- Examples of documentation used to share information with other agencies (eg Out of Hours Proforma, hospital letters)
- List of local chemists stocking end of life care drugs for anticipatory prescribing.
- Evidence of how the named nurse/key worker has linked between services.
Standard 4
Symptom Management

All residents receive holistic, individualised assessment of their needs. There is effective multi-disciplinary team working to provide the highest quality of life possible for the resident.

Goals

All nursing staff will be able to deliver Level I support in line with NICE [2004] guidance:
- Communicate honestly and compassionately
- Treat residents and carers with kindness, dignity and respect
- Establish and maintain supportive relationships
- Inform residents and carers about the range of emotional and support services available to them.

All nursing staff will be able to identify spiritual distress and refer to the appropriate person.

All residents will have the best quality of life through effective management of pain and other symptoms and supportive care.

Note – make specific reference to situations where communication is impaired/difficult.

Initiatives

1. The home has an up to date Palliative care resource file.
   • End of Life Quality Marker 5.1
2. General guidance for pain & symptom management is followed.
   • End of Life Quality Marker 5.3

3. Nursing staff refer to appropriate members of the wider team if symptoms are not being managed.
   • Route to Success: Step 2

4. Staff are able to holistically assess symptoms (including distress) and provide appropriate intervention.
   • End of Life Quality Marker 5.3

5. It is demonstrated within the care plans that staff are able to recognise verbal and non verbal pain & distress and provide appropriate intervention.
   • Route to Success: Step 2

6. There will be a care plan for psychological support and spiritual care.
   a. Route to Success: Steps 2 and 5

Measures

1. Nursing staff understand general guidance for pain & symptom management, and know how to access this information.

2. There is evidence that Palliative care guidelines and prescribing guidance are being followed

3. Clinical staff refer to Specialist Palliative Care Clinician or appropriate member of the wider team if symptoms are not being managed.

7. Staff use validated assessment tools e.g. pain, mouth care.

Suggested Evidence

- Care Home Palliative Care resource file
- Documentation in resident’s notes showing guidance is being followed.
- Evidence of assessment tools used
- Evidence that resident has been assessed for specialist equipment (eg profile bed)
Residents will receive good quality end of life care, which is in keeping with their expressed wishes, and family will feel supported during this period.

Goals

People have the right to choose where they wish to die.

They should receive a speedy, effective and efficient service [There is no second chance to get it right]

Residents should have their dignity maintained at all times.

Residents should not die alone if at all possible.

Note: Need to make specific reference to families/ carers involvement

Initiatives

1. Residents are cared for and supported to die in the place of their choice and in a manner consistent with their wishes and preferences.
   - End of Life Quality Markers 5.2
   - Route to Success: Steps 1 and 5
   - Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting
2. **Staff are able to identify those residents approaching the last days of life and anticipatory drug prescribing is addressed**
   - End of Life Quality Markers 5.3
   - Route to Success: Step 4
   - Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting

3. **The home uses the Liverpool Care of the Dying Pathway**.
   - End of Life Quality Markers 5.5
   - Route to Success: Steps 3 and 5
   - Links with Supportive and Palliative Care Standards for End of Life Care in the Primary Care Setting

4. **The nursing staff will have attended syringe driver training within the last 2 years.**
   - End of Life Quality Markers 5.9

5. **The home will have a policy regarding how to access a syringe driver, if they do not own one.**
   - End of Life Quality Markers 5.1

6. **The staff will be familiar with the equipment required when using a syringe driver and how to obtain the equipment.**
   - End of Life Quality Markers 5.1 and 5.9

### Measures

1. **Resident’s wishes and preferences regarding end of life care are documented.**
   - (Advance care plan)

2. **There is a mechanism to assess the quality of care of the dying and implement change if necessary**
3. ‘Do not attempt resuscitation’ documentation is signed and accessible in the resident’s notes.

4. There is a retrospective analysis of the care given following the death of a patient (After death analysis)

Suggested Evidence

- Evidence of team decision that resident is in the last days of life
- Certificates of participation in Liverpool Care pathway training.
- Evidence that anticipatory prescribing has been addressed
- Syringe driver policy
- Guidance on reducing inappropriate admissions to hospital (eg within the home’s Operational Policy).
- Audit of hospital transfers and deaths.
- Audit of place of death (eg After Death Analysis)
- Evidence of rapid discharges from hospital to care home.
- Local DNAR guidance/ policy.
- Advance Care Planning protocol/ documentation
- Anonymous significant event analysis

Notes:
Mental Capacity Act – specifically referred to in Route to Success: Step 5
Standard 6
Care after death and bereavement

There is a system to assess bereavement risk and provide support to families, carers and other residents.

Goals

Informational needs of the bereaved have been considered.

Service development is examined regarding bereavement support.

There is equity in the approach to bereavement support.

Initiatives

1. Information, including bereavement risk, is shared with other professionals, for example the GP
   • Route to Success: Step 4

2. Families and carers will be supported during the residents dying phase and into bereavement.
   • End of Life Quality Markers 5.1 and 5.6
   • Route to Success: Step 6

3. Families and carers are signposted to local bereavement services.
   • End of Life Quality Marker 5.1
   • Route to Success: Step 6
4. Other residents are supported and allowed to show their respect following a fellow resident’s death.
   • End of Life Quality Markers 5.1 and 5.7
   • Route to Success: Step 6

5. Staff are supported when dealing with death & dying.
   • Route to Success: Step 6

Measures

1. Staff work to best practice guidance in the after care of a deceased resident, including verification and certification policies and procedures.

2. There is a policy/process to incorporate assessment of bereavement risk, and the sharing of information with other professionals.

3. The care home uses, where appropriate, a recognised ‘Bereavement Risk Assessment Tool’

4. The care home familiar with local bereavement services and will share that information with family/friends following death.

5. The care home will have a policy/protocol about how other residents are informed of a patient’s death and they will receive appropriate support.

6. Staff will be aware of what support is available to them when dealing with death & dying.

Suggested Evidence

- Care Home Bereavement Policy
- Care Home Palliative Care resource file
- Protocol for Last Offices
- Certificates of attendance at verification of death course
- Information leaflets (eg “What to do after a death?” leaflet)
- Evidence of remembrance activities
References / Bibliography

7. North West End of Life Care programme for Care Homes. Six Steps to Success Programme for Care Homes. NHS North West. Manchester
Authors

Louise Watson
Palliative Care Modernisation Facilitator
Louise.watson@sotw.nhs.uk

Jackie Richardson
Palliative Care Modernisation Facilitator
Jackie.Richardson@ghpct.nhs.uk

Dr Victoria Hewitt
Associate Specialist in Palliative Medicine
vicky.hewitt@sotw.nhs.uk

Gail White
Lecturer/Practitioner in Palliative care
gail.white@sotw.nhs.uk