

## **A Joint Commissioning Strategy for End of Life Care, for adults, in Cumbria**

### **1. Introduction**

Cumbria has a number of organisations providing high quality services in different areas of the county however service delivery is patchy, sometimes not co-ordinated effectively and is not accessible to all. This strategy provides a vision and framework for the delivery of a needs led, equitable, accessible and high quality service, for adults, across Cumbria.

This strategy has been driven by the views of a wide range of partner agencies who came together as the End of Life Care Strategy Group and who contributed to the End of Life Care workshop that took place in early October. Participants included: clinicians; adult social care and public health leads; key providers and other community partners with an interest in end of life care. Collectively these agencies have identified a vision for the future that will improve the quality and equity of end of life care across Cumbria. Their views were influenced by their own professional experiences; the national End of Life Care Strategy<sup>1</sup>; the Darzi review High Quality Care for All<sup>2</sup>; the recommendations identified in Healthier Horizons for the North West<sup>3</sup> and Cumbria's End of Life Care Baseline Review<sup>4</sup>.

The strategy does not include an implementation plan – this will be agreed by, and subject to the needs of, each of Cumbria's six localities. Implementation will be overseen by the countywide End of life care strategy group

### **2. Aim of the Cumbria End of Life Care, for adults, Strategy**

The aim of this strategy is to provide a framework for the delivery of services that will allow all adults in Cumbria who are approaching the end of their life, "to live as well as possible until they die<sup>5</sup>" in accordance with their own wishes and preferences.

Delivery of the strategy will be underpinned by the following principles:

- Opportunities available for people to talk about and record their wishes in relation to their own end of life.
- Provision of integrated, person-centred, needs led end of life services across Cumbria
- Equitable access to high quality end of life services across Cumbria, regardless of disease, condition, age, ethnicity, religious belief, disability, gender or place of care
- Consistent quality standards underpin the commissioning process
- Coordination of services that are seamless at the point of need
- Support for carers during a person's illness and after their death and through bereavement

- Increased public awareness and discussion of death, dying and bereavement
- All people are treated with dignity, respect and compassion at the end of their lives
- Pain and suffering at the end of life are kept to an absolute minimum with access to skilled symptom management to optimise quality of life
- All those approaching the end of their life have access to physical, psychological, social and spiritual care
- All staff (health and social care) at all levels are provided with the necessary education and training in end of life care

### **Who is this strategy for?**

This joint commissioning strategy relates to the commissioning of End of Life Care services for all adults in Cumbria.  
 A commissioning strategy for End of Life Care services for children and young people in Cumbria will be developed in the Autumn/Winter of 2009. At the point of development, this document will be reviewed, alongside the draft children and young people's strategy to ensure continuity and consistency between the two.

### **What are end of life care services?**

End of life care services are those services supporting people with advanced progressive illness in the last six months to year of their lives. These services should meet the end of life care needs of both patient and family 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<sup>5</sup>  
 This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting. Appendix A provides a fuller definition of End of Life Care.

## **3. End of Life Care in Cumbria**

### **Population**

The population of older people living in Cumbria is predicted to rise dramatically over the next 20 years and by 2029 over 28% of the Cumbria population will be over 65.<sup>6</sup> This equates to an increase of 64,000 people aged 65 and over.

By 2031, it is estimated that over 5% of Cumbria's population will be over 85 years old, compared to 4% in England. Inevitably this is likely to result in an increase in the number of people requiring end of life care. This increase is significantly higher than the national average. (Appendix B Fig 1)

Within the county of Cumbria levels of deprivation range from one extreme to the other for example from Barrow, Carlisle and West Cumbria, which are ranked among the 20% most deprived of areas in England, to most of South Lakeland which is ranked amongst the 20% most affluent wards.

The problems experienced by people living in areas of high deprivation can lead to lower levels of life expectancy than those living in areas of low deprivation. This is a

consequence of a number of issues including: lack of employment; high crime; low educational achievement; high alcohol use, obesity and smoking – There is almost 20 years difference in life expectancy between somebody living in Moss Bay in West Cumbria and Greystoke in Eden.

#### **Deaths <sup>4</sup>**

Between 2002 and 2005 there was an average of 5597 deaths per year. The three most common causes of death are:

- Circulatory disease 39%
- Cancers 29%
- Respiratory diseases 13%

The most common place of death is within an NHS acute hospital but place of death varies according to diagnosis and district (Appendix B fig 2 and 3)

- Deaths at home are more common in cancers – 29% die at home
- The lowest percentage of death at home is in respiratory diseases with just 14% of people dying at home and 85% dying in an institution
- 75% of those whose main cause of death was a circulatory disease have died in an institution
- The likelihood of dying in an NHS acute hospital is almost 20% higher for residents in Barrow than in Eden or Carlisle

#### **4. The Vision and Framework for End of Life Care in Cumbria**

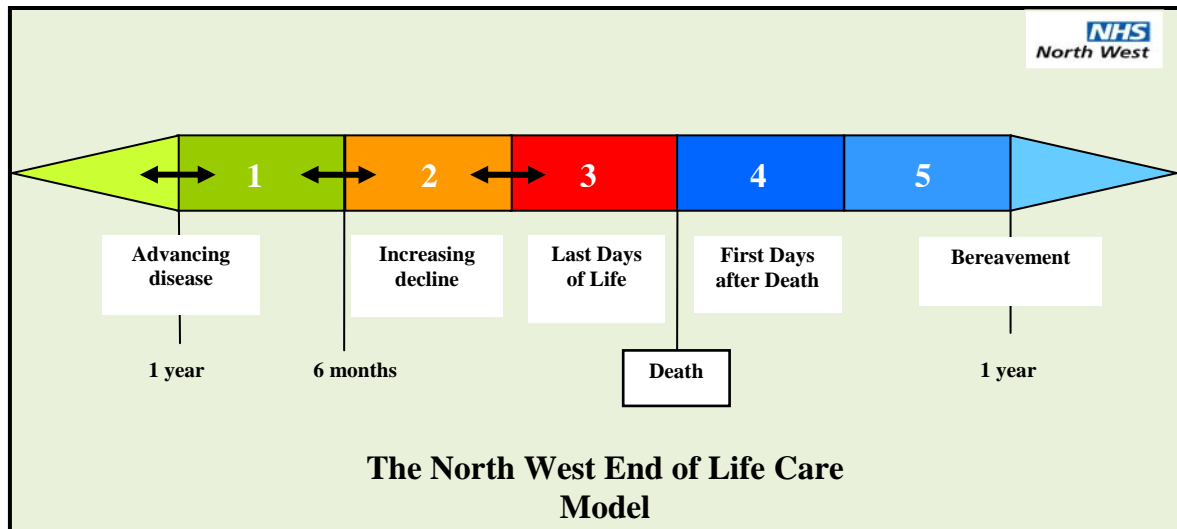
Our vision is that all people who die in Cumbria are treated with dignity, respect and compassion at the end of their lives and that regardless of age, gender, disease or care setting they will have access to integrated, person-centred, needs based services to minimise pain and suffering and optimise quality of life.

These services will respond sensitively to the dying person's wishes and preferences. Carers and families are provided with appropriate information and support to enable them to function effectively leading up to and after the death.

Both the national strategy and local consultation are clear that an important way to ensure delivery of quality end of life care services is through recognition that each individual has different needs and preferences. Wherever possible, provided this is congruent with the individual's wishes, these should be sensitively explored and recorded to allow the development of patient held **personalised care plans** that can be co-ordinated and delivered as and when required. Consideration should be given to the use of personalised budgets throughout this process.

Sometimes this will not be possible, either because of individual preferences (denial, reluctance etc.) or because death is untimely or unanticipated. The pathway will have the flexibility to accommodate entry at varying points, including last days/hours and point of death/after death. It needs to prioritise humane and dignified care, extending to families with compassion at its core, whatever the point of entry.

It is therefore essential that Cumbria develops a whole systems approach to ensure the delivery of a fully integrated service. The Cumbria Framework will adopt the model of care developed by the North West End of Life Care Clinical Pathway Group as it provides a whole system and care pathway approach.



Delivery of the model will need to be through the following functions:

- 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
- Co-ordination of care by professionals within a caring community
- Delivery of high quality services in all locations as required by the quality tools: Gold Standards Framework (GSF); Keep Improving the Experience (KITE); Liverpool Care Pathway (LCP); and the Preferred Priorities of Care (PPC) (Appendix C)
- Management of the last days of life
- Care after death
- Support for carers, both during a person's illness and after their death.
- A commitment to the delivery of culturally appropriate care
- Assessment of spiritual care needs at all stages of the pathway

The model identifies five phases during which staff will be able to get an understanding of the needs of people who are approaching end of life and their carers.

The phases are described below with a **menu of services for Cumbria**. This menu is not written as a comprehensive description of Cumbria's service but as a minimum level of service delivery for each phase.

<b>Advancing disease</b>	<b>1 year or more</b>
<b>Menu of services for Cumbria</b> <ul style="list-style-type: none"> <li>- Primary care services working to GSF or KITE standards</li> <li>- Preferred priorities of care (PPC) plans recorded for all patients and carers</li> <li>- Out of hours (OOH) service providers with medical and nursing domiciliary visiting capacity and palliative care infrastructure and competencies</li> <li>- Robust communication between in and out of hours services</li> <li>- Easy access to medication</li> <li>- 24/7 access to basic palliative care/end of life information</li> <li>- Integrated information system across health and Adult Social Care</li> <li>- Integrated health and social care service provision</li> <li>- Choice and control – allowing people to direct as much as possible their own care</li> <li>- Access to appropriate services according to need regardless of diagnosis or care setting</li> <li>- Access to self directed support mechanisms</li> <li>- Access to housing support, such as adaptations, to help people remain in their own homes as long as possible</li> </ul>	
<b>Increasing decline</b>	<b>Approximately 6 months</b>
<b>Menu of services for Cumbria</b> As above PLUS: <ul style="list-style-type: none"> <li>- Access to services that respond to the person's medical, nursing and personal care needs without delay (rapid response).</li> <li>- Access to pre-bereavement practical and emotional support</li> <li>- Coordination of documentation across service boundaries</li> <li>- Access to help with practical tasks (handyperson)</li> </ul>	
<b>Last days of life</b>	<b>Last few days</b>
<b>Menu of services for Cumbria</b> As above PLUS: <ul style="list-style-type: none"> <li>- Access to short periods of 24/7 nursing or carer input into the home according to criteria</li> <li>- Acute hospitals, care homes, hospices, residential homes and primary care services equipped to use the Liverpool Care Pathway (LCP) framework during the last few days of life.</li> <li>- Access to <i>Specialised</i> (Hospice at Home) Care</li> <li>- Rapid response services for appropriate equipment, aids, medical equipment, ambulance transfers, access to medication</li> <li>- Pan-Cumbria DNAR (Do not attempt resuscitation) policy</li> </ul>	
<b>First days after death</b>	<b>First few days</b>
<b>Menu of services for Cumbria</b> Systems to guide/signpost bereaved in a compassionate/humane way through this process in all care settings, including: <ul style="list-style-type: none"> <li>- Prompt verification and certification of death</li> <li>- Provision of D49 leaflet – what to do after a death</li> <li>- Provision of a list of local funeral directors</li> <li>- Access to family support and bereavement service</li> <li>- Access to spiritual support, as preferred</li> </ul>	
<b>Bereavement</b>	<b>1 year or more</b>
<b>Menu of Services for Cumbria:</b> <ul style="list-style-type: none"> <li>- Access to co-ordinated bereavement services</li> <li>- Signposting as required</li> </ul>	

- Access to bereavement counselling where needed
- Access to psychology/psychiatry services for complex bereavement reactions

## Social Awareness

Generally our society does not talk openly about preparing for old age, death and dying making it difficult to consider options and make choices for end of life care and also to discuss those choices with friends and family.

In order to improve end of life care the profile will need to be raised across all local communities. To ensure consistency a Cumbria wide plan for raising the profile of death and dying will be developed and implemented.

*“In the absence of open discussions, it is difficult or impossible to elicit people’s needs and preferences for care and to plan accordingly”*  
(End of Life Care Strategy – Department of Health, July 2008)

## Training

In order to deliver a high quality, needs led service, all staff working with people who may be approaching end of life need to be appropriately trained.

For training purposes, in line with the national end of life strategy, staff will be divided into three groups:-

### **Group A**

All staff who spend all of their working time working with end of life care e.g. palliative care nurses; hospice staff; specialist social care practitioners etc. should have the highest level of specialist knowledge, skills and understanding. These skills should include communication; assessment; spiritual, religious and cultural care; comprehensive knowledge of the range of community support that is available; advance care planning and symptom management as related to end of life care.

### **Group B**

All staff who frequently work with end of life care as part of their role, e.g. staff in A & E; care of the elderly; nursing and care homes; GPs; community and district nurses; community pharmacists; chaplaincy; social care practitioners; occupational therapists etc. should have some specialist knowledge and this should be built on. These skills should include communication; assessment; spiritual, religious and cultural care; comprehensive knowledge of the range of community support that is available; advance care planning and symptom management as related to end of life care.

### **Group C**

All staff who work within other services who infrequently have to deal with end of life care e.g. day centre, social care, prison service and domiciliary staff etc. should have a basic grounding of the principles and practice of end of life care and should know when and how to seek expert support and information.

To take this forward the Department of Health has commissioned Skills for Care and Skills for Health to lead a joint project to identify a set of common core principles for end of life care. These competencies will inform the development and commissioning of appropriate training programmes. This work should be completed by June 2009.

As with social awareness, to ensure consistency, a Cumbria wide training package will be developed as soon as the competencies have been agreed and compliance with the training requirements will be specified within service contracts.

## 5. Delivery of the Cumbria End of Life Strategy

<b>Service Area</b>	<b>What is needed</b>
<b>Identification</b>	A register for those approaching end of life in all GP practices
<b>Advice &amp; Information</b>	A directory of services that is accessible to all patients and staff and incorporates details of services and local faith organisations delivered in Cumbria and relevant information about services delivered elsewhere.
	Disease specific information and advice for patients and families
	Information about sourcing support on a 24/7 basis
<b>Preferences</b>	Consistent use of quality tools to identify wishes and preferences
	Written, person-centred care plans for all those approaching end of life with built in review.
	Appropriate training and use of the Mental Capacity Act for staff working with those who are unable to express wishes/preferences
<b>Patient Care</b>	A shared understanding of the end of life care pathway across all provider organisations that are involved in the delivery of end of life services, including but not exclusively: NHS providers; Adult Social Care Services; North West Ambulance Service; HMP Haverigg; Hospices; Residential homes; Nursing homes; Voluntary sector providers; Out of hours services; Pharmacy; Chaplaincy/spiritual care providers Local Housing Authorities Housing Providers
	Cross organisational information sharing
	Care co-ordination across all provider organisations
	Rapid response service available across the county
	Access to respite care both at a person's home and away from the home

	Rapid access to appropriate aids and equipment as required.
	Rapid access to medication and medical equipment
	Rapid discharge pathways including rapid access to equipment, medication, community services, and rapid access to ambulance transfer (including voluntary hospice settings)
<b>Carers/Family</b>	Access to carer's assessment to ensure the development of a support plan that will enable them to stay mentally and physically well. <sup>7</sup>
	Information, advice and Support network
	Care after death bereavement service
<b>Training</b>	Comprehensive training package for all three groups of staff to include: <ul style="list-style-type: none"> <li>evidence based workforce strategies to minimise burnout/build resilience</li> <li>a range of training methods including action learning and user experience</li> </ul>
<b>Social Awareness</b>	Open discussions around end of life and bereavement encouraged
	Increased profile of end of life
<b>Commissioning</b>	Comprehensive specifications including expected outputs and outcomes
	Three year contracts with all providers of end of life care
	Mechanisms established for measurement of outcomes and outputs against national quality standards (as they are agreed) and locally agreed indicators.
	Links with end of life care established across relevant care streams

## 6. Measuring progress

The following indicators will be used to identify progress being made. The list will be extended as national quality indicators are agreed, and the service and service monitoring mechanisms become more established.

<b>Service Area</b>	<b>Indicator</b>	<b>Measurement Tool</b>
<b>Quality</b>		
<b>Identification</b>	By 2013/14 95% of GP practices will hold end of life registers and be holding review meetings.	Quality outcomes framework
<b>Advice &amp; Information</b>	Directories in place	Locality commissioning groups
<b>Preferences</b>	Number of providers trained in and using the recognised quality tools	Various – to be confirmed by implementation group
	By 2010 100% of people approaching the end of their life will have a personalised care plan in place	Adult social care (ASC) business intelligence NHS Cumbria performance monitoring
<b>Patient Care</b>	Information sharing protocols in place	ASC and NHS Cumbria

	and implemented	Contract Management
	Rapid access to breaks for carers available across Cumbria	Monitoring of carers organisation contracts
	Rapid access to aids and equipment as required	ICES board
	NI 125 – 85% of people will be living at home 91 days after being discharged from intermediate care (locally set target)	Adult social care business intelligence
	Increase in the percentage of deaths that occur at home to 25% by 2013 (Vital Signs Indicator 15, NI 129 and WCC 54 <sup>8</sup> )	Coroners office via death certificates (NHS Cumbria gathering)
	NI 129 End of life care - access to appropriate care enabling people to be able to choose to die at home	
<b>Carers/Family</b>	Number of carers assessments completed	Cumbria Carers Organisations on behalf of Adult Social Care
	Number of carer support plans implemented	Cumbria Carers Organisations on behalf of Adult Social Care via carer questionnaire
<b>Training</b>	Evidence of appropriate end of life care training at all levels.	NHS Cumbria and ASC Workforce Development. Commissioning contract management
<b>Social Awareness</b>	Cumbria wide plan produced and agreed	Public Health Directorate
	Number of campaign resources produced – 9000 flyers and 1,000 posters by 2010	Contract monitoring
	By 2010, 200 members of the public attend awareness raising events	Contract monitoring
<b>Commissioning</b>	Three year contracts in place	Commissioning contract management
	All contracts specify expected outcomes and outputs	Commissioning contract management.
	Standardise monitoring processes across localities and organisations	
<b>Outcomes</b>		
People approaching end of life and their carers		
<b>Advice &amp; Information</b>	-receive advice, information and support that help them to make their decisions and choices.	Survey
<b>Preferences</b>	- are able to express their views and preferences in a personalised care plan.	Survey
	-are able to access the services that are identified in their care plan as and when they are required	Survey

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References:

- <sup>1</sup> Professor Mike Richards *End of Life Care Strategy; Promoting High Quality Care for all Adults at the End of Life* (2008) London Department of Health
- <sup>2</sup> Lord Darzi of Denham *High Quality Care For All; NHS Next Stage Review* (2008) London Department of Health
- <sup>3</sup> North West SHA *Healthier Horizons for the North West* (2008)
- <sup>4</sup> Ferguson J and Nuttall C *End of Life Care: Health and Social Care Service Baseline Review* (2008) Cumbria PCT
- <sup>5</sup> National Council for Palliative Care
- <sup>6</sup> Moving care closer to home: Integrating health and social care for adults in Cumbria NHS Cumbria and Cumbria County Council (2008)
- <sup>7</sup> Carers at the heart of 21<sup>st</sup> century families and communities – “ A caring system on your side. A life of your own”
- <sup>8</sup> NHS Cumbria Strategic Plan 2008 – 2013 Goal 6

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## **Appendix A**

### **A Working Definition of end of life care:**

End of life care has been defined as:

*“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 management of pain and other symptoms and provision of psychological, social, spiritual and practical support”.*

(National Council for Palliative Care)

“The definition of the beginning of end of life care is variable according to individual person and professional perspectives. In some cases it may be the person who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the person. In all cases, subject to the person’s consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

For some the start may be at the time of diagnosis of a condition which usually carries a poor prognosis, for example motor neurone disease or advanced liver disease. For others it will be at a point when there is a deterioration in a chronic illness and it becomes apparent that the likely prognosis is measured in months or possibly a year or two, for example a patient experiencing an acute episode on the background of longstanding chronic obstructive pulmonary disease. Some conditions, such as heart failure, have such a variable prognosis that whilst one patient may die within months of diagnosis another may survive for many years.

Alternatively, it could be an elderly person who is becoming increasingly frail and recognises that they need increased help to continue living at home, or makes the decision to become a resident of a care home or of sheltered or extra care accommodation.

It is important to remember that death may be sudden or violent, or as a result of a sudden outbreak of infectious disease that spreads rapidly through the population. In the latter case, whilst the NHS may have plans in place to be able to deal with such a pandemic, it is important to note the impact it may have on the provision of other services such as death certification, availability of coroners etc and the effect it will have on families’ and carers’ support requirements. It is essential that end of life care services are adaptable to all these scenarios”.

(End of Life Care Strategy – Department of Health, July 2008)

## Appendix B

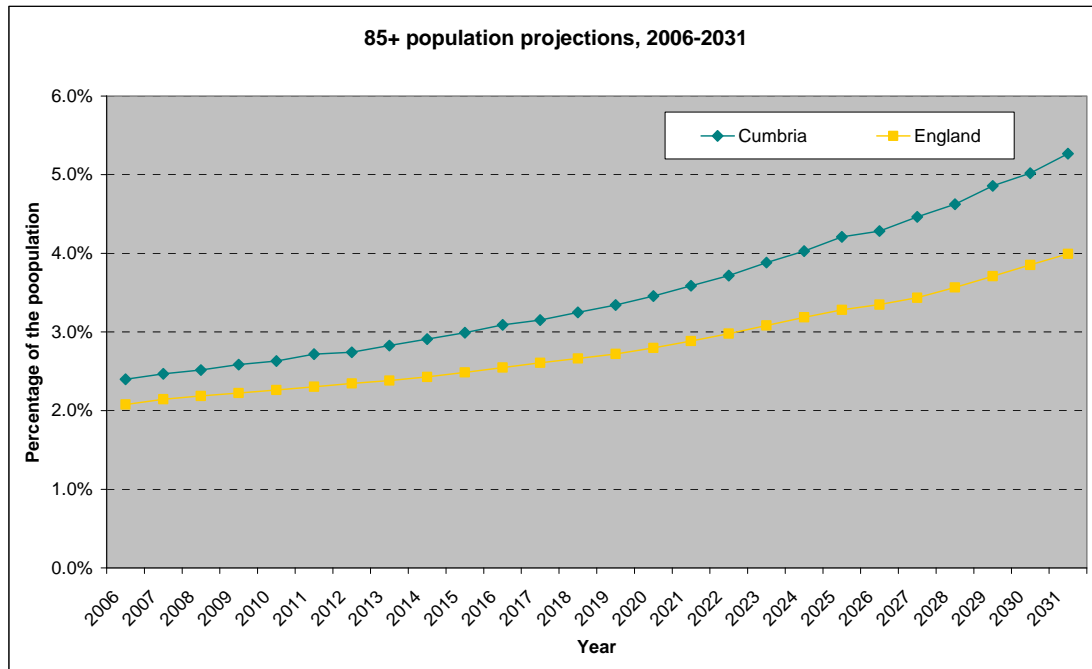


Figure 1 – 85+ projections 2006 - 2031

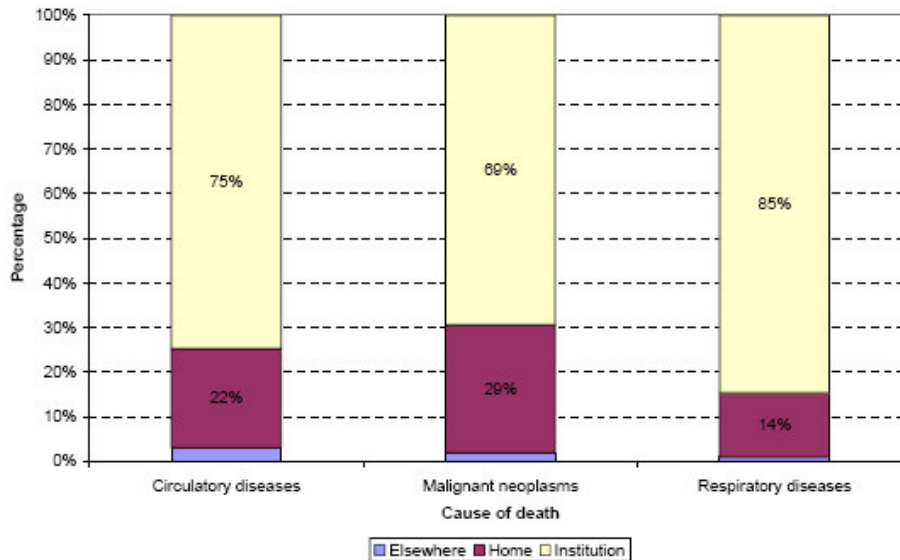


Figure 2 - Place of death

Place of death, all cause, by district, 2002-2006

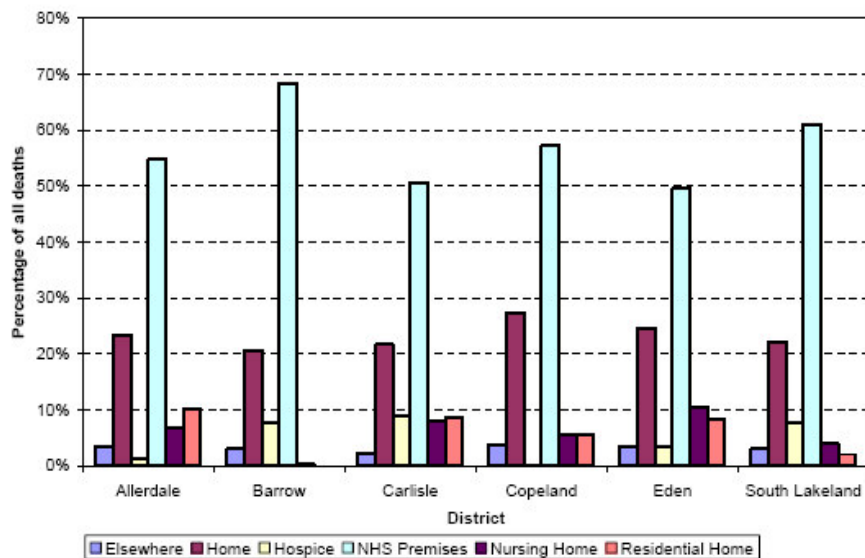


Figure 3 - Place of death by district, 2002-2006

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## **Appendix C**

### **End of Life Care Quality Tools**

#### **The Preferred Priorities of Care Plan (PPC)**

The PPC is intended to be a patient-held record that will follow the patient through their path of care into the variety of differing health and social care settings. The document provides an opportunity to record

- A family profile and carers needs
- The patients thoughts about their care, their choices and preferences
- The services that are available in a locality and being accessed by the patient
- Changes in care needs

#### **PPC - A Nationally Recognised Tool for Palliative Care**

The PPC originated from the Palliative Care Education Programme to evaluate the effectiveness of teaching on place of death.

Building on the Best suggested that the success of the initiative reaching non-cancer patients will depend on increasing the use of the Liverpool Care Pathway, Gold Standards Framework and the PPC in District General Hospitals, Primary Care and Care Homes resulting in

- Greater choice for patients in where they wish to live and die
- Decrease in number of emergency admissions of patients who wish to die at home
- Decrease in the number of older people transferred from a care home to a DGH in the last week of life

#### **Gold Standards Framework (GSF)**

The Gold Standards Framework (GSF) is a framework to enable a gold standard of care for all people nearing the end of their lives. GSF is a systematic evidence based approach to optimising the care for patients nearing the end of life in the community. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness.

**The aim of the Gold Standards Framework (GSF)** is to develop a locally-based system to improve and optimise the organisation and quality of care for patients and their carers in the last year of life.

#### **Keep Improving the Experience (KITE)**

The KITE framework encourages a self assessment process for practices by utilising a structured document. This is followed by external verification by a team of skilled professionals. There are 10 palliative care standards and 9 standards for cancer services.

#### **Key Goals**

To continuously improve quality and promote standards of care. To encourage multi-disciplinary team working at practice level by:

- enhancing communication
- ensuring continuity of care

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- anticipatory care
  - better symptom management
  - addressing the holistic needs of the patient and carers (spiritual, emotional, physical and psychological)

### **Key Outcomes**

- Identify training and development needs of teams from the evidence of practice accreditation data
- Ensure health professionals have the right education, training, skills and competencies to deliver care needs of patients and their carers.
- Self-assessment can be used by the practice to improve quality and standards of patient care.
- Promote and improve partnerships between clinicians and patients.
- Patients feel better supported through the disease process. They have a better knowledge and understanding of their illness and treatment
- Patients and carers benefit from a greater certainty about what is happening, thereby suffer less anxiety, stress and physical symptoms.

### **Liverpool Care Pathway (LCP)**

Developed for use within hospitals but equally can be used within care homes and in primary care. The LCP empowers generalists to care for dying patients in the last 48 hours of their lives.

The Liverpool Care Pathway for the Dying Patient (LCP) provides an evidence based framework for the delivery of appropriate care for dying patients and their relatives in a variety of care settings. It encourages a multi-professional approach to the delivery of care that focuses on the physical, psychological and spiritual comfort of patients and their relatives that has also been shown to empower generic staff in the delivery of care.

The LCP framework incorporates:

- 1: Aim  
To improve the care of the dying in the last hours/days of life
2. Key themes:  
To improve the knowledge related to the process of dying  
To improve the quality of care in the last days/hours of life
3. Key sections:  
Initial assessment  
Ongoing assessment  
Care after death
4. Key domains of care:  
Physical  
Psychological  
Social  
Spiritual