

Improving palliative and end of life care: strategic commissioning plan 2013 – 2018

FINAL



'Helping people live well at the end of life'

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Executive summary

The purpose of this document is to provide commissioners with a five year strategic plan that will improve the commissioned service for patients with palliative care needs and are progressing towards their last year (s) of life.

Our vision is to ensure;

‘the care and provision meets the individual requirements of people identified with palliative needs and those living with increased need in their last year(s) of life’.

The plan identifies the commissioning and service developments needed to ensure that the populations of County Durham and Darlington receive the best possible care, in the place where they want to receive it, when they are progressing towards the end of life.

By 2030 the number of people living longer and living with diseases will have increased across County Durham and Darlington. Increased incidence of dementia will bring additional complexities in the management and advanced care planning for people with palliative and end of life care preferences and this will have an associated impact on health and social care systems.

The proposals documented in this plan have been developed through continued widespread engagement across health and social care systems. The pathway below has been developed with input from patients, carers, Local Authority partners and other key stakeholders and is designed to support patients and their carers/families through every step of their palliative care journey through to end of life, making sure their symptoms are managed and their quality of life is maintained as long as possible.

Pathway and end of life model

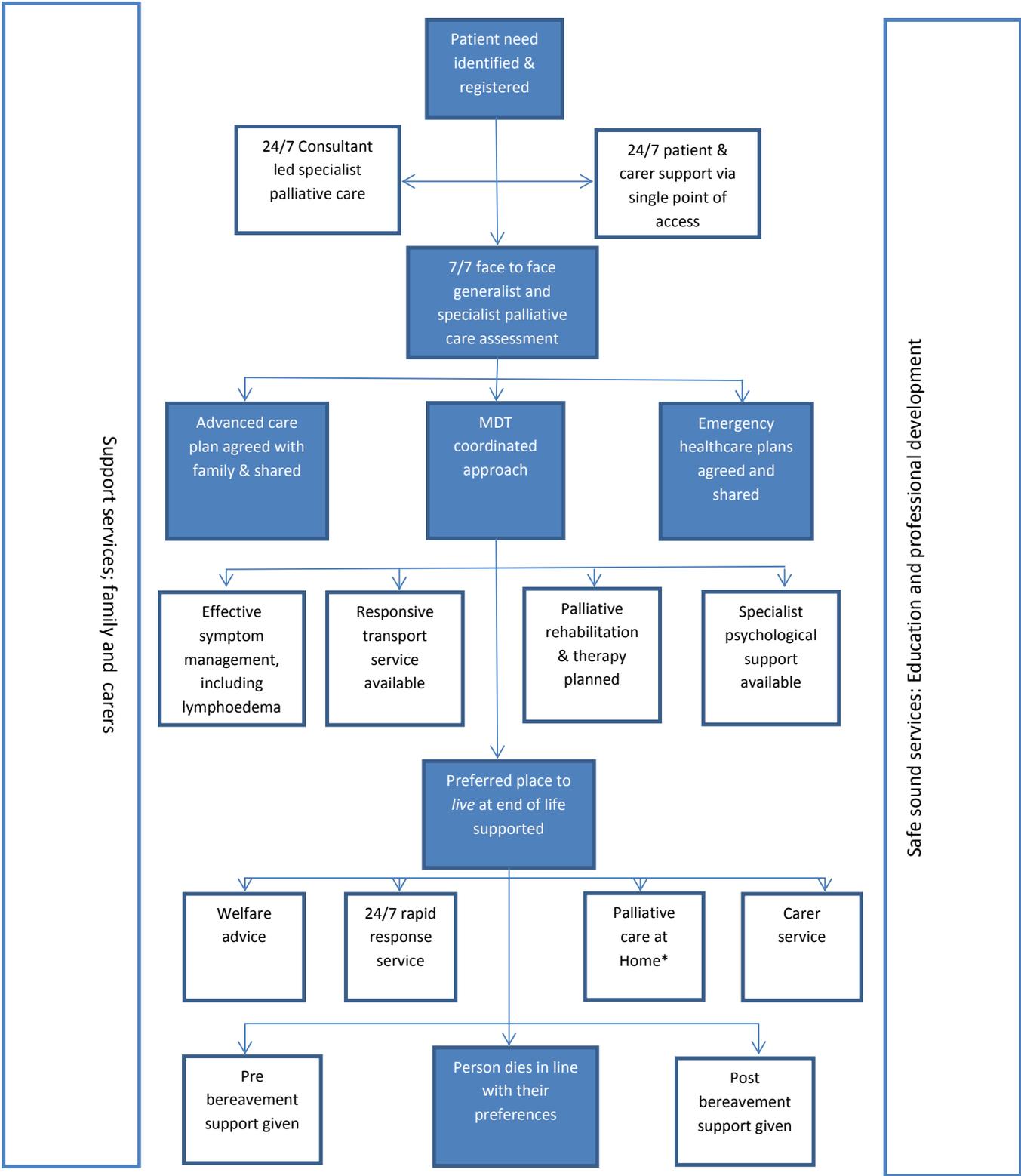


Figure 1: Single palliative and end of life care pathway

Home can be classed as any location other than hospital

To demonstrate the measurable impact of this pathway will have:

- Improved the *life* people live in their last year(s) of life.
- Ensured all patients have the opportunity to contribute to their advance care plan and their changing preferences.
- Ensured people are supported to achieve their preferred place of care.
- Met the requirements of patient's physical, social, psychological and spiritual needs.
- Supported family and carer social, psychological, spiritual and bereavement needs.
- Effectively planned for transitions of care delivery

The overarching aim of this five year plan is to allow us to deliver high quality sustainable services to our patients, regardless of the setting they have chosen to live in. Delivery against the plan does present its challenges and does require significant investment both in terms of financial resource and a willingness to work very differently, in a more integrated way across multiple agencies, to maximise the limited specialist resources available. For it to work effectively all parties have to take ownership in their respective service area.

The total investment over the next 5 years is £5,607,439*, an increase of £2,455,821 on existing commitments. It is recognised that in the current economic climate full investment in year one would be unrealistic. We are therefore recommending a phased approach to delivery with patient safety and positive experience being the primary responsibilities. For these reasons the following developments take precedence:-

1. 24/7 consultant led palliative and end of life care provision, including out of hours at a total cost of £937,161
2. Single point of contact at an indicative cost of £120,000*.
3. Keeping people at home; rapid response/palliative care at home/carers support at an indicative cost of £575,871* (over and above the existing investment of £688,318.)

Other elements of this plan can be progressed through greater collaboration and joint working. These will form the basis of the palliative and end of life care steering group's work plan and will be implemented in parallel.

(* subject to figures for some of the proposed services being finalised and validated)

Our primary goal will be to:

- Increase death in usual place of residence by 10%
- Reduce number of cancer emergency admissions by 10%
- Reduce number of palliative care emergency admissions by 10%

It is anticipated that this will achieve savings of £997.795. Although immediate savings would not be seen in ready cash terms, changing practice as a result of these initiatives would ultimately reflect in future healthcare tariffs and release of funds for reinvestment.

1. Introduction and context complexities

The drive to improve the patient and carer experience for people diagnosed with life-limiting conditions is morally not difficult to understand. It is the intricacies of how services are involved in the delivery of care and support, that adds complexity. Nationally the end of life care programme (NHS, 2004) has provided guidance and model pathways that can improve the delivery of quality care, and yet across County Durham and Darlington, our patients still experience less positive pathways of care; in part due to the variation in how services have been commissioned in years gone by.

In the last 12 hours of Mr C's life, he was discharged from an acute care setting to his usual place of residence, which was a nursing home, without his liquid morphine. On arrival at his home he was agitated and distressed. Despite a planning meeting earlier in the day with the care home, he was discharged without essential information to allow continuation of care. The home had to ask Mr C's GP to visit and re-prescribe the liquid morphine, while the hospital sought to arrange delivery of the missing information and medications. Mr C's pain was alleviated 4 hours post discharge. Mr C died 8 hours later.

In many respects, the NHS landscape provides us with an opportunity to work together and harness the changes to benefit patient and carers across the health social care system as a whole.

The national bereavement survey (2012), undertaken by VOICES, showed that of those who expressed a preference, the majority preferred to die at home (81%), but only half of these actually died at home (49%). The most common reported place of death was a hospital (52%). In order to achieve such a shift, the workforce looking after people in the setting of people's homes need to be accessible, capable, competent *and* supported to meet the care needs and preferences of people in a planned way.

Issues surrounding choice of place of death:

- Between 50-90% of patients with cancer wish to die at home but only 22% achieve this.
- Approximately a quarter of people express a preference to die in a hospice, but only 17% of those with cancer and 4% overall die there.
- Dying at home is associated with low functional status, an expressed preference (and carer agreement), home care and its intensity, living with relatives and dependable extended family support.

It is therefore critical, that this piece of work looks to consider the concept of 'home' and that there are appropriate care and carer support mechanisms in place to deliver such choices in alternative settings to that of the family home.

2. Understanding and measuring palliative and end of life care?

In order for us to understand patient, and therefore service needs, we first need to understand the 'definitions' that underpin palliative and end of life care.

We must also remember, that the majority of patients who die, will not require specialist support or specialised interventions: their care needs are successfully managed by the clinical teams with community and primary care. We do know however, that everyone facing life-threatening illness *will* need some degree of supportive care, in addition to treatment for their condition.

To provide us with a clarity, we have used the narratives from the National Palliative Care Council (2006) alongside National Institute for Clinical Excellence (NICE, 2004) who have provided helpful definitions of 'supportive and palliative care' for people with cancer, which, with some modification, can be used for people with any life-threatening condition.

Supportive Care

Supportive care helps the patient 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 patient 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 should be fully integrated with diagnosis and treatment. It encompasses:

- 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

Palliative Care

Palliative care is part of supportive care and can be defined (NICE, 2004) as:

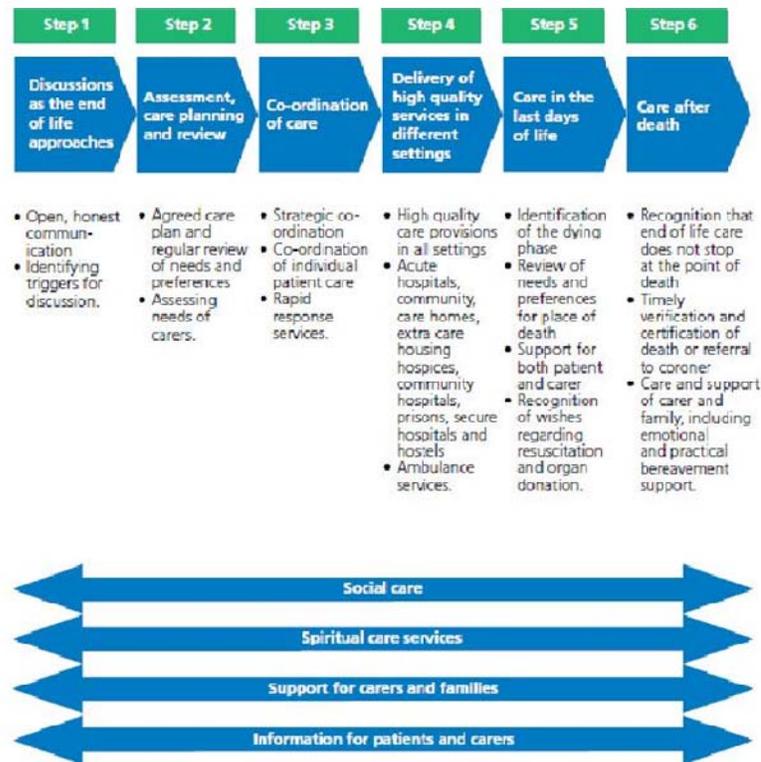
Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. 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 patients live as actively as possible until death
- Offer a support system to help the family cope during the patient’s illness and in their own bereavement

End of Life Care

End of life care 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. The six step care pathway development by the NEoLCP is shown below, and forms the basis of good quality patient experience and care for all.



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 patients and carers in their homes and in hospitals.
- Those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example).

Those providing day-to-day care should be able to:

- Assess the care needs of each patient and their families across the domains of physical, psychological, social, spiritual and information 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
- Access continuing health care funding to cater for the increased care need in the last few days of life, where it is appropriate to do so

Specialist Palliative Care Services

These services are provided by specialist multidisciplinary palliative care teams and include:

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes.
- Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home.
- This may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home.
 - Many teams also now provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'.
 - Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies.
- Advice and support to all the people involved in a patient's care.
- Bereavement support services which provide support for the people involved in a patient's care following the patient's death.
- Education and training in palliative care.

The specialist teams should include palliative medicine consultants and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

The revised NICE Quality Standard for End of Life Care was published November 2011. In response, the End of Life Care Quality Assessment Tool (ELCQuA) (2012) provides organisations with a standard methodology in which to 'keep track' of delivery standards and outcomes. Helpful to both commissioners and providers, the ELCQuA is viewed as the foundation on which we should measure the quality standard of care for end of life for adults, and includes:

- Reducing inequalities and improving identification
- Improving the quality of care
- Increasing choice and personalisation
- Ensuring care is coordinated and integrated
- Improving the psychological, physical and spiritual wellbeing
- Timely access to information and support
- Timely provision of continuing NHS healthcare
- Supporting carers and ensuring access to an assessment of need
- Timely access to generalist and specialist palliative care services
- Reducing unnecessary hospital admissions
- Improving cross-boundary and partnership working,
- Improving knowledge and skills

What will good palliative and end of life care look like?

At a national level, good commissioning of end of life care services will be achieved when the following, as outlined in the DH NEoLC Strategy, can be demonstrated:

- all patients approaching the end of life, and their carers:
 - have their physical, emotional, social and spiritual needs and preferences assessed by a professional or professionals with appropriate expertise
 - have a care plan
 - have their needs, preferences and care plan reviewed as their condition changes
 - have access to bereavement support
 - know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff
 - dignity and respect for the individual is maintained
- all the services the person needs are effectively co-ordinated across the sectors
- there is optimal delivery of care across all relevant services in hospitals, hospices, and care homes and in the community
- there is good quality care in the last days of life
- there are effective processes for the verification and certification of death, and care after death
- the quality and effectiveness of care can be robustly measured

- there are equalities in access to, and provision of, end of life care services

Measuring the impact of our work

The measurement of palliative care diagnosis, preferred place of death and place of death has historically provided us with a challenge, due to the coding and interpretation by providers across primary and secondary care. However, in order to demonstrate the impact of this work, we will measure the picture using the following indicators:

- Number of patients recorded on a practice palliative care register
- The frequency of practice multidisciplinary case review meetings, where all patients on the palliative care register are discussed
- The uptake of gold standard framework
- Where our patients die; hospital, hospice, care home
- The number of patients who are expected to die with care plans in place, that include where they want to die
- Cause of death
- What interventions our palliative and end of life care received
- What support has been provided to our patients and families

3. An Ageing Population.

County Durham and Darlington's increasing ageing population will continue to present challenges for health and social care.

Dementia

Dementia presents a significant and urgent challenge to health and social care in County Durham and Darlington in terms of both numbers of people affected and costs. One of the main causes of disability in later life, it has a huge impact on capacity for independent living.

Local GP data (QOF), 2011/12 indicates:

- a prevalence of 0.6% for dementia in County Durham and 0.7% in Darlington against a regional and national average of 0.5%.
- In County Durham dementia prevalence is predicted to rise by 78% by 2030.
- In Darlington dementia prevalence is predicted to rise to 7.5% by 2020 as the population ages.
- The number of people with learning disabilities with increased longevity will impact on dementia prevalence in the population – it is estimated nationally that 25.6% of people with Downs Syndrome aged over 60 will suffer dementia.

Premature mortality

Premature mortality can be used as an important measure of the overall health of County Durham and Darlington's population, and as an indicator of inequality between and within areas. Reductions in premature mortality over time can demonstrate improvement in the health status of the population as a whole.

Mortality rates from the major causes of death have fallen significantly over time in County Durham, in many cases faster than nationally, but they remain significantly higher than England. *Longer Lives*, recently launched by Public Health England (PHE) provides us with local insight into the top causes of avoidable early death, ours being; heart disease, stroke and cancer.

Early death in County Durham is worse than average across a number of areas and ranks 105th out of 150 local authorities for early deaths, whilst Darlington, ranks 94th out of 150.

Measuring the gap in premature mortality

Local analysis of premature deaths (2007-2011) at small area level within County Durham concluded:

There is significant inequality in premature all-cause mortality within County Durham. The distribution of premature mortality within County Durham is unequal. It is greater in the more deprived wards.

People in Darlington are living longer. However life expectancy remains slightly less than the average for England.

Significant inequalities in life expectancy exist within Darlington. A man living in the most deprived area can expect to live 14.6 years less than a man living in the least deprived areas. For women it is 11.6 years less.

Social Isolation

There can be many reasons why a person becomes isolated in their later years. Some elderly people may have small families or families that live far away. There are also people who have become more isolated due to increasing frailty. Some elderly people find it difficult and frustrating to socialise because they are deaf or have poor eyesight. It may also stem from no longer being able to drive to see friends and family. When a person is isolated and lonely they are at risk of depression. People in this situation may also not eat well. They are therefore at risk of illness which can lead to further pressure on health and social care services.

- Information provided from Self Directed Support Questionnaires as part of direct payments, highlights that social isolation could possibly be an issue in County Durham as most service user groupings identified that they need daily support to help maintain their relationships.
- In Darlington the number of older people receiving direct payments has increased by 49.7% since 2010-11.
- Retired (aged 65+) group is predicted to rise from 30,500 households in 2011 to 35,800 in 2021 and then to 40,100 in 2030, increases of 10.6% and 23.8% respectively from 2011. In numbers this increase will account for 72.3% of the total increase in single person households by 2030 and could lead to an increased number of older people becoming socially isolated.
- There are approximately 18,570 people currently living in Darlington who are aged 65 years or over. This figure is projected to increase to over 22,306 by 2021.

Older Carers

The definition of a carer is someone who: *“spends a significant proportion of their life providing unpaid support to family and potentially friends”* (Carers at the Heart of 21st Century, Families and Communities, Department of Health, 2008). It also highlights that people who provide unpaid care are twice as likely to be in poor health themselves, and need to be supported both in their own right and in their role as carers.

The *Projecting Older People Population Information System*, which provides projections based on population increases, suggests that within County Durham and Darlington the future local carer profile of older people who are carers will be as follows:

- The number of carers aged 65 and over providing unpaid care is set to increase by 33.6% by 2030 (from 10,624 in 2012 to 14,194 in 2030).

By 2030, the number of carers aged 65 years and over providing care between:

- 1-19 hours per week is set to increase by 31.3% (from 4,544 to 5,967);
- 20-49 hours per week is set to increase by 33.7% (from 1,363 to 1,826);
- 50 or more hours per week is set to increase by 35.7% (from 4,717 to 6,402).

Support for carers has been a key aspect of improvement in maintaining independence, and preventing family breakdown. Better support for carers helps prolong independent living and quality of life.

End of life care

The National End of Life Care Strategy aims for all adults to receive high quality end of life care regardless of age, condition, diagnosis, ethnicity or place of care.

In County Durham around 5,300 people die each year from all causes, around two thirds of these are aged over 75 years (similar to the national experience). The 2012 National End of Life Care profile for County Durham states that for the period 2008-2010:

- 54% (8474) of all deaths were in hospital
- 22% (3511) occurred at home
- 19% (2991) occurred in a care home
- 3% (475) were in a hospice
- 3% (427) were in other places.

Between 2008 and 2010 in County Durham:

- 29% of all deaths (4580) were from CVD
- 29% of all deaths (4531) were from cancer
- 28% of all deaths (4392) were from other causes
- 15% of all deaths were from respiratory diseases

In Darlington around 1100 people die each year from all causes, almost two thirds of these are aged over 75 years (similar to the national experience). The 2012 National End of Life Care profile for Darlington states that for the period 2008-2010:

- 50% (1593) of all deaths were in hospital
- 20% (648) occurred at home
- 24% (747) occurred in a care home
- 4% (123) were in a hospice
- 2% (66) were in other places.

Between 2008 and 2010 in Darlington:

- 28% of all deaths (882) were from CVD
- 28% of all deaths (879) were from cancer
- 30% of all deaths (972) were from other causes

- 14% of all deaths were from respiratory diseases

Information from the Office for National Statistics (PH England, 2013), indicates that since Q4 2010/11 Darlington have been showing a steady increase in the % of patients dying in their usual residence. Rising from 45.3% in Q4 2010/11 to 50.7% Q4 2012/13, bringing them to within the top 10 – 20 CCGs in the country in respect of death in usual place of residence.

Planning for the future

The quality and provision of end of life care is now being monitored via the National End of Life Intelligence Network (NEoLCN) and VOICES study of bereaved relatives (2011). This national study found that the majority of patients (71%) would have preferred to die at home. However, only 21% achieved this with significant geographical variation in this outcome. NEoLCN determined the North East underperformed in all measured outcomes; 54% of patients died in hospital with only 20% at home, (14% higher than the national average), 16% died in care with only 3% in a hospice. There were 14% more terminal emergency admissions with each admission averaging over 13 days – 5.7 bed days more than the best performing areas.

In view of the ageing trend of our population and the increasing trend of long-term conditions, unless we make sure that the whole system is geared up for accommodating and caring for people with health needs in a *proactive* way, the trend of people of dying in hospital will not change. We need to be working closely with our partners to allow people to be able to live in a place of their choice that allows them to live well and have a normal life in their last years of life, but also make provision to meet a possible increase in nursing need.

4. Services we currently commission

Because of the way services have been funded and commissioned by health in the past, we have a legacy of variation. Not only is this in relation to 'actual services' available to patients and carers, but also in the experience of patients. The following table provides a visual overview of what is currently in place (or not) and where elements of the funding are derived from.

Current Service Provision

Health contributed Funding	Non-recurring funded	Third sector funded	No provision

	Darlington CCG	Durham Dales, Sedgefield Easington CCG	North Durham CCG
Hospice provision	St Teresa's Marie Curie	Butterwick St Benedict's Marie Curie Hartlepool & district	St Cuthbert's Willow Burn Marie Curie
District nurse Palliative care			
Consultant led palliative service	CDDFT 2.5wte posts		
24/7 consultant advice			
Middle grade/nurse consultant provision	Nurse consultant St Teresa's (0.5 WTE) GPwSI St Teresa's (0.2 WTE)	GPwSI – St Cuthbert's (0.2 WTE) Doctor – Butterwick (0.2 WTE)	GPwSI – Willowburn Hospice (0.1 WTE)
	Nurse Consultant – St Teresa's (0.5 WTE)	Specialist Grade - St Cuthbert's (1.0 WTE) GPwSI – St Cuthbert's (0.1 WTE)	
		Clinical Assistant – Sedgefield Community Hospice (0.3 WTE)	GPwSI – Willowburn Hospice (0.1 WTE)
5day community specialist palliative care nurses			
7day specialist assessment			
Specialist psychology	CDDFT 1wte Consultant		
Inpatient hospice beds	6 beds	St Benedict's -12 beds Hartlepool – 10 beds	St Cuthbert's – 10 beds Willow Burn – 4 beds
Community hospital inpatient beds			
Hospice at Home			
Hospice palliative home care team			
Out of hours palliative care nursing		St Benedict's	

	Darlington CCG	Durham Dales, Sedgefield Easington CCG	North Durham CCG
Planned overnight nursing service			
Hospice palliative rehabilitation			
Community palliative rehabilitation		Easington only	
Specialist Lymphodema	CDDFT 1.6 practitioners		
Non housebound Lymphodema		St Benedict's	
Hospice Family support		Hartlepool District	
Hospice Carer assessment & support			
Hospice Driver support			
Hospice Bereavement support			
Hospice Day care			
Hospice Outpatient care			
Welfare support			
Hospice led Complimentary therapy			
Hospice Spiritual care			
Rapid response palliative care			
Hospice Counselling			
Hospice Social worker			
Macmillan carers		Easington	Durham & CLS
Hospice 24hour advice line		St Benedict's	St Cuthbert's

4.1 Current commissioned spend

A review of hospice and palliative care services in 2012-13 demonstrated that the delivery of palliative, specialised palliative and end of life care is managed through a range of

commissioned services across health, social and third sector organisations and that there is wide variation of the level of services delivered across our geographical areas.

Across County Durham and Darlington, the current recurrent health-spend on palliative and end of life care is £6,225,412 with a contracted spend value of £3,020,412 across the 7 hospice care providers and £3,205,000 on the main consultant-led palliative care provision managed through the community contract of County Durham and Darlington NHS Foundation Trust. This includes supplementary palliative care specific services, also managed through the community contract of County Durham and Darlington NHS Foundation Trust.

In addition, £1,566,342 has been made available on a non-recurring basis (2013/14) to enhance service delivery and test new ways of working – the evaluations of which have been considered as part of the commissioning proposals in this plan.

Appendix 3 provides a high level summary of the current funding arrangements aligned to palliative and end of life care both on a recurrent and non-recurrent basis.

4.2 Gaps in service delivery

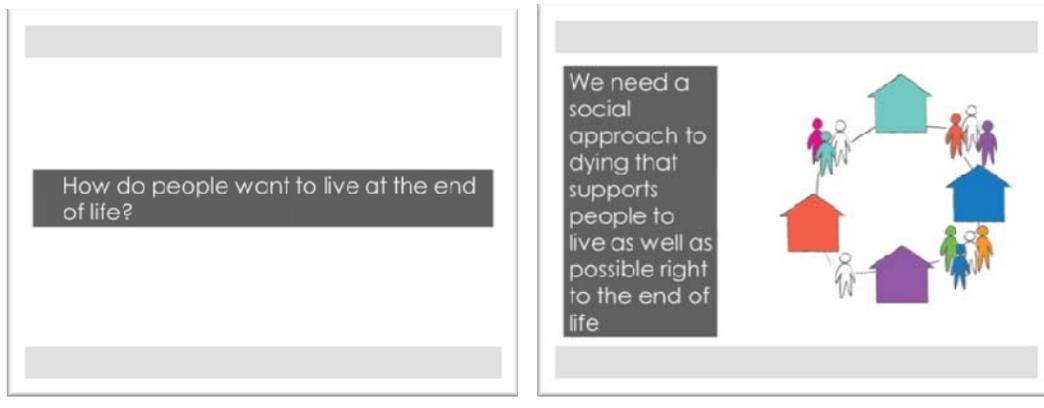
The review of hospice and palliative care services in 2012-13 also demonstrated a number of gaps in the delivery of quality palliative and end of life care services. Benchmarked against local geographical delivery, best practice and NICE quality standards, the following headline issues were shared at commissioning development sessions in November 2012 and January 2013:

- No continuity re Hospice at Home services.
- 24/7 Consultant-led support across primary and hospice provision.
- Inequity in GP cover for out of area patient placements.
- Uptake and regular use of the Gold Standard Framework for End of Life Patients
- Understanding and application of Deciding Right, particularly in primary care.
- The absence of specialist carer support skills for people living with relatives with Dementia.
- Effective working relationships between acute, primary community and end of life teams looking after the palliative care needs of those living with and dying because of their long term condition (s).
- Lack of lymphoedema provision/funding across area especially in the East of the locality.
- Inpatient capacity and on-going funding to cope with increasing activity demands.
- The rapid response service is complementing district nurse service, but is not funded recurrently.
- Variation in funding of Family support.
- Variation, inequity and ability to share information via IT systems.

5. Creating the model pathway: external challenge

As commissioners of health care, we often limit our access to knowledge and experience to 'what is happening on our patch' or 'what those on our patch know'.

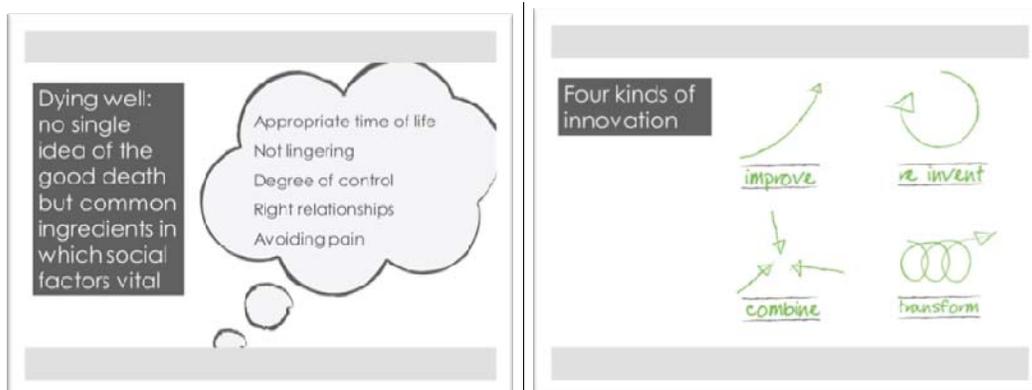
As part the commissioning development process, we accessed national expertise (Charles Leadbeater), in both end of life care experience, innovation and change, to stimulate a different debate, aspects of which are captured below:



We should aim for a social approach to dying that supports people to live as well as possible right to the end of life.

- Only 9% of people want to die in hospital or in a care home but about 85% will
- Two thirds of people want to die at home but by 2030 only 1 in 10 will

Make home and the community the focus rather than institutions – 'with' and 'by' not so much 'to' and 'for'.



Four kinds of innovation:-

- Improve – Advance care plans, non-specialist palliative care, patient involvement. Long haul – what is point of improving how we do the wrong thing?
- Transform – Not better versions of the institutions we have now but a viable alternative to them. A social approach which draws on medical knowledge.
- Combine – Increase support from within the home – care leave, Training, Technology
- Re-invent – Work with the home – Key relationships, telephone support, volunteers. Support to the home – medical/nursing support, Hospice at Home

Social system for dying is different, better and cheaper.

6. Our vision for a new social systems that delivers improved palliative and end of life care

As result our collaborative development work, our vision is to ensure;

‘the care and provision meets the individual requirements of people identified with palliative needs and those living with increased need in their last year(s) of life’.

The measurable impact for patients and their carers will ensure we have;

- Improved the *life* people live in their last year(s) of life.
- Ensured all patients have the opportunity to contribute to their advance care plan and their changing preferences.
- Ensured people are supported to achieve their preferred place of care.
- Met the requirements of patient’s physical, social, psychological and spiritual needs.
- Supported family and carer social, psychological, spiritual and bereavement needs.
- Effective planning of transitions of care delivery

The establishment of a *new social system* for palliative and end of life care, which operates for the best interest of the patient and works together to deliver the best care possible, will improve collaborative working, strengthen joint ownership and reposition patients and their carers at the centre of our work.

Although not radical in nature, Figure 1 places all the valuing-adding components of a ‘model’ social system for palliative and end of life care in one place. Commissioning of its component parts as whole parts across the health population will eventually manage out the variation and reduce pressures elsewhere in the health care and social care systems.

The main areas of change are:

- * Single point of access for patients and cares who are registered on GPs palliative care register
- * Multidisciplinary approach to advanced care planning and emergency care planning
- * Standard application of Deciding Right
- * Information sharing
- * Dedicated palliative and end of life care transport provision
- * Palliative care rehabilitation
- * 24/7 specialist palliative care advice
- * 7/7 face to face specialist assessment
- * Keeping people at home through, rapid response, palliative care at home, carer services

The remainder of the components in the pathway relate to the spread of good commissioning practice, improved communication and sustained workforce development.

Pathway and end of life model

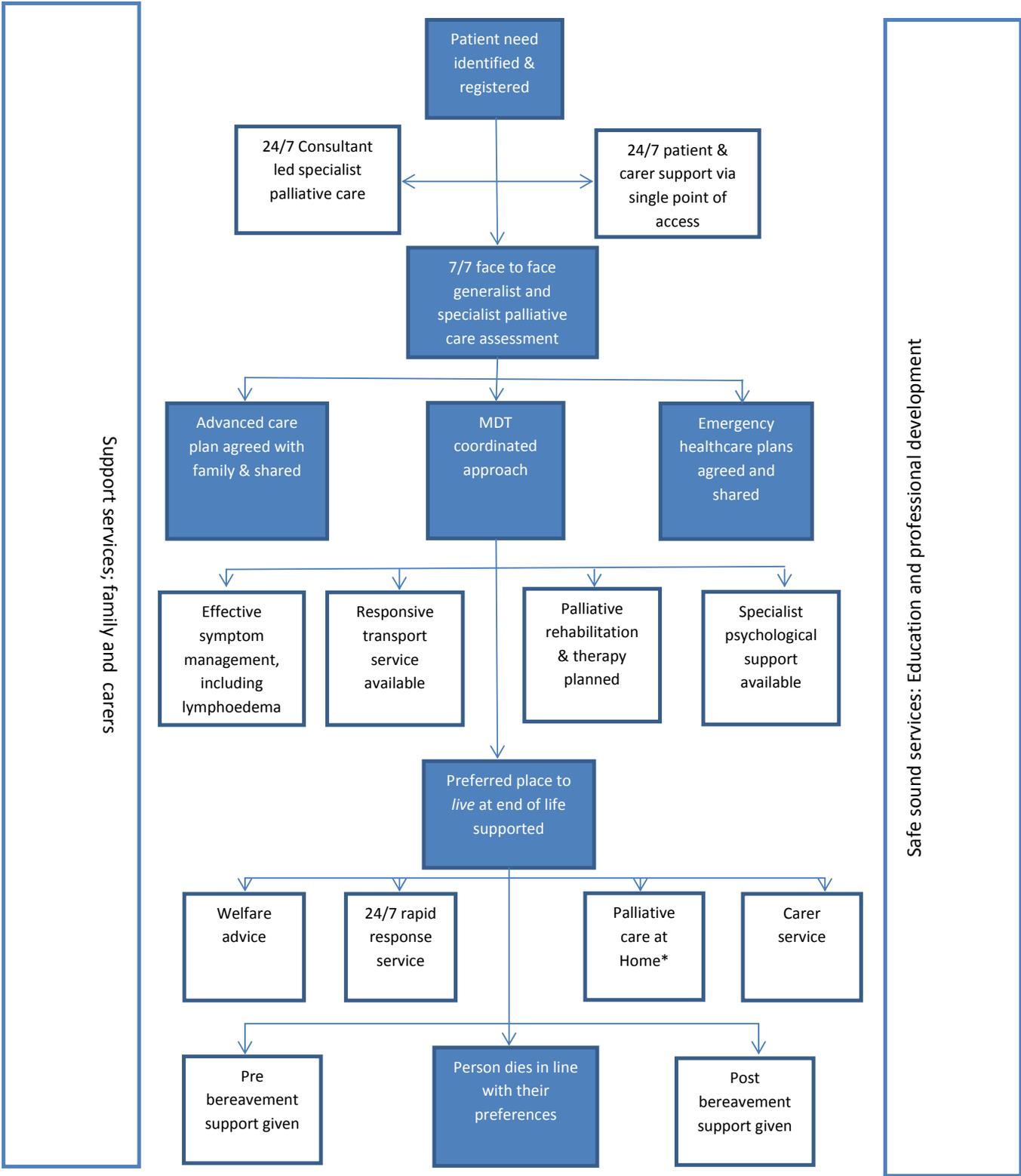


Figure 1: Single palliative and end of life care pathway

* Home can be classed as any location other than hospital

Pathway stage	Delivery approach
Patient need identified & registered	<p>Making the most of GP practice palliative care registers</p> <p>Global use of the Gold Standard Framework (GSF), across primary Hospice and care homes, and MDT</p> <p>Key worker identified for all</p>
Single point of access for patients & carers	<p>Knowledgeable about palliative and end of life care needs and services</p> <p>24/7 access</p> <p>Directory of support services</p> <p>Available to people on GP palliative care registers</p> <p>Provides knowledge able carer support and advice</p>
Dedicated transport	<p>24/7 skilled and compassionate workforce</p> <p>Short notice service</p>
Joint assessment & care planning	<p>Greater alignment of health & social care processes</p> <p>Avoiding duplication</p> <p>Single patient hand held record</p>
Consultant led & supported on-going assessment & management of symptoms	<p>Right level of specialist knowledge to support and advice complex management</p> <p>Supervision of practitioners with specialist interest</p> <p>Visibility in practice</p> <p>Last days of life supported by safe protocols of care</p> <p>Access to interventions and treatment in the right place, including hospice at home</p>
Advanced care planning	<p>Making best use of Deciding Right</p> <p>Patient choice, at a time when patients are able to contribute to the decisions</p>
Rehabilitation & therapy	<p>Equitable access to allied health professionals in their localities</p> <p>Allowing people to live well at the end of life</p> <p>Reducing the impact of care on carers</p> <p>Timely access to equipment in all 'home settings'</p>

Pathway stage	Delivery approach
Mental well being	Access to the spectrum of psychological support in a community setting Access to specialist psychological support when required
Emergency healthcare plans agreed through MDT approach	Making best use of Deciding Right Regular MDT meetings Best use of GSF Anticipatory care
Preferred place to live at end of life	Positioning the concept of 'home' away from that of the family home. Patients choice – linked to advance care planning
Pre and Post bereavement support	Range of support to be available for all family members, at a time when the need it
Family support	Proactive approach, to prevent predictable stresses Accessible and available for all who need it Helping people with their manage their social and economic welfare
Capable and competent workforce	Consultant led service 24/7 Increasing skill set in disease specific pathways, eg dementia, liver disease Introduction of junior Dr roles and GP trainees

6.1 Looking at improvement from the view point of the patient

Whilst there is a national framework for 'assessing' the effectiveness of commissioned services (ELCQuQ, 2012), it was important for us to describe the expected benefits from the view point of the patient and their families.

As part of the commissioning development sessions, the viewpoint of the patient was considered using the locally adapted 'no needless framework' (IHI, 2001). The results of which should be a reminder of what it is we have set out to deliver for our patients.

No barriers to health and wellbeing

- The ability to live well at the end of life
- Access to specialist palliative care, in the place patients want it
- A single route for communication across health, social, charity and voluntary sectors

No avoidable deaths, injury or illness

- A skilled workforce capable of caring for people with palliative care needs at end of life
- A specialist palliative consultant led service 24/7

No avoidable pain or suffering

- Anticipatory approach to care
- 24 hour access to expertise
- Prescribing at the point of care decision-making
- A knowledgeable workforce that understand the needs of patients, carers and family members

No feelings of helplessness

- Patients and families to be knowledge about their condition
- Patients, carers and professionals know how to access specialist advice and guidance
- Family support is available regardless of the care setting
- Named key worker for all

No unnecessary waiting or delays

- No delay in the transfer to patients' preferred place of care
- No delay in the verification of death
- 24/7 access to specialist palliative care advice and access to assessment and treatment interventions
- Delivery of agreed interventions and packages of care

No waste

- No duplication of patient histories
- Single patient held record
- Right skill caring for the right patient and carer need

No inequalities

- 24/7 access, regardless of care setting or diagnosis
- Single register of need and multi-professional approach for all
- Provision based on need, not on capacity and time
- Common assessment framework used in the patient's best interest

In addition, we have determined a set of operating principles (Appendix 4) for all agencies, to avoid organisational and professional boundaries impeding patient experience and closely

link to the on-going commitment and engagement of all parties in the palliative and end of life care group (Appendix 2) that will hold partners to account in working together to make a difference for patients.

6.2 Deciding Right

All care decisions must come from a shared partnership between the professional and the child, young person or adult. But for those who do not have capacity for their choices, or may lose that capacity in the future it is important that the right choices are made.

*It is our aspiration that everyone, through effective engagement and planning, is able to **decide right** their preferences at end of life.*

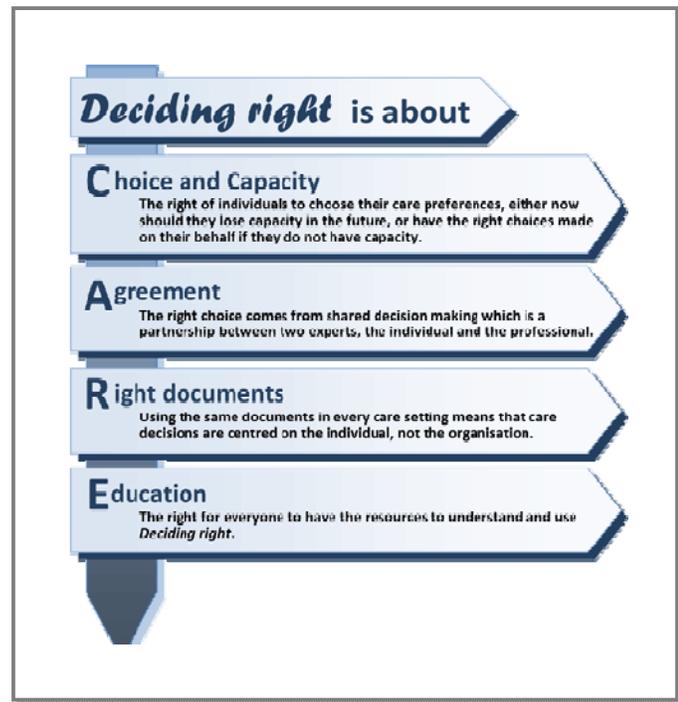
Deciding Right is a north east wide initiative - the first in the UK - to integrate the principles of making advance care decisions for all ages. It brings together advance care planning, the Mental Capacity Act, cardiopulmonary resuscitation decisions and emergency healthcare plans.

Written by health and social care professionals, Deciding Right identifies the triggers for making care decisions in advance, complying with both current national legislation and the latest national guidelines. At its core is the principle of shared decision making to ensure that care decisions are centred on the individual and minimise the likelihood of unnecessary or unwanted treatment.

Still considered to be the foundation of good practice, there is a drive to improve the understanding of its use in practice across all care settings, so that patients and families can benefit from advanced care decisions.

Learning from our own patient stories, we need to work across our organisational boundaries to ensure that all parties understand and have easy access to essential information, to prevent unnecessary conversations and actions that we know distress patients and their families.

An elderly gentleman with dementia, who had a very successful package of care and advanced care plan in place, that was supported by the family, general practice and nursing home staff, had an unnecessary admission to hospital via accident and emergency, because the 111 call handler failed to recognise the



information being provided by the health-care worker seeking an out of hours GP visit to address his increasing pain. Fortunately through the rapid response of the hospital staff, and accelerated interventions, the gentleman was discharged back 'home' and died in his and the family's preferred placed of care. However, the last 16hours of his 24hours, involved unnecessary anxiety and distress for the family and their father.

7. Commissioning and service developments to bring about change

In order to deliver improve care and experience to all patients across County Durham and Darlington, a number of the aspects of the revised pathway require:

- Investment
- Spread of good practice
- Commissioning of new services

A number of working groups, led by CCG commissioners, have worked across County Durham and Darlington, to develop high level business cases to show:

- Rational for change
- Current patient experience
- Service change required
- Expected service activity
- Patient and system benefits
- Indicative costs

The working groups have also been tasked with developing the service specifications, performance indicators and information requirements that will be used to procure services against.

7.1 Knowing who our patients are

Good primary care is about caring for individuals from 'cradle to grave'. Providing good palliative care to individuals in the community can be one of the more rewarding aspects for care. The multidisciplinary team responsible for such delivery can be large and, most often, the district nurses are key players in orchestrating services around an individual's changing needs.

In addition to the standard primary and community healthcare teams, specialist palliative care teams' input is necessary to support the management of complex care needs or difficult conversations with patents and their families.

Guidance to improve community palliative care has come from a number of sources over the last decade, including NICE and the Gold Standards Framework. Key messages include:

- Patients with palliative care needs are identified using common criteria and management plans instituted after discussion with the multidisciplinary team.
- Regular assessment of patients and carers using validated assessment tools.
- Anticipated needs should be planned for.
- Patient and carer needs are communicated within the team and to specialist colleagues, where appropriate.
- Preferred place of care and death are openly discussed and noted and measures made to facilitate an individual's preferences where possible.
- There should be a named person within the primary care team to co-ordinate care.

- Relevant information should be available to out-of-hours carers, and drugs that may be needed should be left in the home.
- Care in the dying phase should follow a protocol, to ensure that no aspect is overlooked.
- Carers should be involved, educated and supported to care for their loved ones in the ways they choose. Information is critical - whether medical, financial or on bereavement support.
- Audit, reflective practice, developing practice protocols, etc. are encouraged in order to promote individual and organisational development.

Locally, implementation has been variable and further work is needed to assess the direct impact on patients and carers. The Qualities and Outcomes Framework (QOF) for 2009-2010) included two indicators for palliative care (each worth 3 points) requiring a practice to have, but does no longer encompasses the standards for coordinated care. They are:

- A complete register of all patients in need of palliative care or support, irrespective of age.
- Regular (at least 3-monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

It is our aspiration that all practices across County Durham and Darlington will have comprehensive palliative care registers in place that include dementia patients and are managed using a systematic approach, as described by the Gold Standard Framework.

7.2 Effective information sharing

The information on the registers will be seen as a helpful guide in supporting anticipated packages of care, in all care settings, and avoiding crisis management. Currently, most of our practices have less than the suggested 1% on their palliative care registers (0.1-0.4%), meaning that potential benefits from improved case management and preventative interventions and support are being missed. The function and use of the information within the palliative care register is essential to us knowing who are patients are and the care that people have planned and arrangements in place at times of sudden deterioration (emergency health care plans). However unless we share this information and have effective communications mechanisms in place across organisational boundaries we will be unable to guide safe care.

It is predicted that the North East (population 2.6million) has 22,419 patients with palliative care needs. Only 1600 palliative patients (7%) have so far been flagged to our NHS 111 provider. Even when identified, North East ambulance service (NEAS) struggle to manage those with acute needs in the community, the result is invariably an acute admission. Data from 'flagged' patients indicate they make 432 calls per year, with the average length of stay for a palliative patient being 13.9 days (UK MDS 2008/9). This would result in a cost of £1,792.200 and 3336 hospital bed days. As 'flagged' patients represent 7% of predicted palliative usage then the total potential cost to North East Commissioners is £25.5 million.

Increased usage of the palliative care registers and sharing of information via an effective system would result in:

- Improved patient identification
- More appropriate specialist triaging
- More efficient utilisation of existing community services
- Patients preferred place of care being acknowledged
- Shared understanding of patient's wishes in respect of advanced care planning i.e. DNAR, advanced decisions to refuse treatment and emergency health care plans (EHCP's)

It is our intention, so that all patient's benefit from their plans of care being communicated to relevant agencies, that a locally mechanism to communicate effectively across boundaries will be put into place. It is important that patients don't endure duplicated conversations with healthcare professionals and that any patient who leaves a hospital or hospice will do so with a palliative care / end of life plan of preferences.

7.3 Summary of services to support pathway implementation:

The pathway in figure 1, page 27 depicts the journey patients requiring palliative and end of life support may follow. High level case for change documents have been developed to support the various elements of the pathway and these have been included in the appendices. In summary the areas requiring investment are as follows:-

Topic	Detail
Single point of contact	Appendix 4.1
Consultant led Specialist Palliative care	Appendix 4.2
Rapid Palliative care response	Appendix 4.3
Palliative Care at Home	Appendix 4.4
Palliative Care Transport	Appendix 4.5
Specialist Psychological Support	Appendix 4.6
Palliative care Rehabilitation	Appendix 4.7
Lymphoedema	Appendix 4.8
Supporting dementia carers and professionals	Appendix 4.9
Family Support	Appendix 4.10
Welfare support	Appendix 4.11
Workforce Education	Appendix 4.12

8. Impact of commissioning proposals

8.1 Social care arena

As the strategy suggests, care at end of life has historically been focussed very much to a medical model. The assurance of symptom control has rightly been prioritised in order to maintain the individual's dignity, reduce their suffering and minimise their and their family's distress. The recognition that balancing towards a more social model does not detract from this, but is intended to enhance the experience of all concerned.

This shift inevitably has an impact on the associated social care provision - not only for residential and domiciliary care providers but also more broadly to welfare benefits and carers support services.

To ensure that the changing focus is embedded, social care commissioners are involved and signed up to progressing this agenda through ensuring the services they commission are appropriate and capable of delivering high quality care during the palliative stages and at end of life.

Reflecting the aspiration of the strategy for the expansion of the Gold Standard Framework (GSF) and to ensure that the paid care workforce is able to deliver this high quality care, Durham County Council (DCC) have committed to offer Nursing homes contracted to provide care in the County, the opportunity to access training that will bring them to a standard of care that will enable them to apply for accreditation for GSF. This training opportunity will commence in financial year 2014/15.

In addition the Council is committed to supporting the work of the workforce capability work stream for this strategy. Development of workforce is not isolated to commissioned providers.

The shift to a more social model will require social work professionals to rebuild their skills and knowledge which have been diluted through the dominance of a medical approach. In recognition of this, DCC have worked with Macmillan to secure a 2 year post that will embed end of life care in social work practice, act as an expert resource and through partnership working streamline processes and pathways to improve the experience of clients and families at this most distressing of times.

8.2 Primary Care

Changes in working practice within Primary Care are key to the effective delivery of this pathway and an improved patient and carer experience.

Development and investment will be needed to support the implementation of new concepts in care management:-

- A named accountable clinician will be assigned to each patient aged 75 or older
- GP's will have to coordinate multi-disciplinary care packages for these patients which will, where necessary interface into a care home setting

Improved management of this patient group starts with knowing who our patients are – making sure they are recorded on the practice palliative care registers when it is appropriate to do so. The proposed changes are orientated around Gold Standards Framework and Deciding Right principles.

There will be cost implications in the way we commission services. Raised awareness and application of the Deciding Right principles will mean a greater number of patients are identified as requiring palliative care. These will require a named clinician, will require discussion at MDT and will require the proactive development of individual care plans at end of life.

Implementation in Primary Care will therefore require support in process development and associated investment.

8.3 Financial

It is our aspiration to finance care providers to a level that enable high quality palliative and end of life care that meets local requirement and national standards. In achieving this we are mindful of the additional and different funding streams that all contribute to the provision of good palliative and end of life care. Those being:

- Local authority and care homes
- Local authority carer and family support
- Hospice and their charitable status
- NHS main-stream commissioned services

In particular, it is not anticipated that our hospice colleagues will request 100% funding support from health, but we should be aiming to have equity of health commissioned services across all our hospices.

Development	Current health investment	Current non-recurring funding	New health investment	Total investment required from health
	(Column 1)	(Column 2)	(Column 3)	(Column 1+3)
Single point of access (Option 2)			£120,000	£120,000
24/7 Consultant advice including additional consultant	£270,000		£149,000	£419,000
Medical model, with middle grades	£187,000		£271,161	£458,161
Palliative care rehabilitation	£76,000		£280,000	£356,000
Specialist palliative care nurses, admin & specialist lymphoedema	£1,773,000		Inclusive in other developments	£1,773,000
Lymphoedema expansion to include specialist and non-housebound			£110,262	£110,262
GP Training posts			£60,000	£60,000
Rapid Palliative care response	£688,318	£295,871	£295,871	£984,189
Palliative Care at Home*		£280,000	£280,000	£280,000
Palliative care transport		£35,000	£203,755	£203,755
Specialist psychological support	£110,000		£179,433	£289,433
EOl dementia support			£110,263	£110,263
Family support	£147,300		£10,000	£157,300
Welfare support		£25,000	£236,076	£236,076
Sustained workforce development			£50,000	£50,000
Totals	£3,251,618	£635,871	£2,355,821	£5,607,439
Items shown in red above are still to be confirmed				
*home can be classed as any location other than hospital				

8.4 Understanding the QIPP potential

With England facing an increasingly aging population, end of life care is rooted within the Department of Health's QIPP agenda as a prime example of how a structured, coordinated approach can deliver both better quality and more cost-effective care. In 2005, 58.3% of deaths were in hospital, which may not have been the choice of the dying person or the best use of hospital resources. By 2011, this had fallen to 51%.

Providing the best possible care for a dying person can also lead to improved quality, productivity and efficiency gains. Unnecessary emergency hospital admissions in the final year of life, delays in discharging people home to die in accordance with their wishes and inappropriate or unwanted interventions have a significant financial as well as human cost. (NEoLCP, 2012)

The following data for County Durham and Darlington for 1Q 2012/13 – 4Q 2012/13 (www.endoflifecare-intelligence.org.uk/data_sources/place_of_death), indicates death in usual place of residence in our area is variable:-

- Darlington CCG 50.7% (532)
- DDES CCG 44.1% (1281)
- North Durham CCG 45.6% (1070)

The NEoLCP publication 'Reviewing end of life care costing information' identified the mid-point of End of Life care when provided as an alternative to dying in hospital at £2107. However estimates for the cost of an end of life care episode in hospital varies from study to study:-

1. £2,506 is used by NICE and is the basis of QIPP calculations. This gives a saving of £399 per saved admission ending in death.
2. £3,056 is the mid-point in the 'Reviewing end of life care costing information' report noted above. This gives a saving of £958 per death outside hospital.
3. £3,587 is the latest evidence as the average cost of an unscheduled admission ending in death as taken from Economic Evaluation of the Electronic Palliative Care Coordination Systems (EPaCCS) Early Implementer Sites report published in February 2013.

NICE advise that if a 10% reduction in the number of admissions that end in death could potentially result in a saving of £52 million nationally. However using the figures above against a number of saving scenarios the potential in our area is as follows:-

	Number of deaths in usual place of residence as at 1 Q1 2012/13 - Q4 2012/13	Potential savings (using option 2 above)	10%	15%	20%
Darlington	532	£958	£50,966	£76,448	£101,931
DDES	1281		£122,720	£184,080	£245,440
North Durham	1070		£102,506	£153,759	£205,012
			£276,191	£414,287	£552,383

In addition implementation of many of the services in this plan would contribute to a reduction in unnecessary emergency admissions. Using data from the period April 2012 – March 2013 these savings have the following potential:-

Cancer emergency admissions April 2012 - March 2013	No of admissions	Avg cost of cancer emergency admissions	Potential savings		
			10%	15%	20%
Darlington CCG	326	£3,148	£102,625	£153,937	£205,249.60
DDES CCG	822		£258,766	£388,148.40	£517,531.20
North Durham CCG	577		£181,640	£272,459.40	£363,279.20
			£543,031	£814,545.00	£1,086,060.00

Palliative Care emergency admissions April 2012 - March 2013	No of admissions	Avg cost of cancer emergency admissions	Potential savings		
			10%	15%	20%
Darlington CCG	137	£3,235	£44,320	£66,479.25	£88,639.00
DDES CCG	293		£94,786	£142,178.25	£189,571.00
North Durham CCG	122		£39,467	£59,200.50	£78,934.00
			£178,573	£267,858.00	£357,144.00

Our primary goal will be to:

- Increase in death in usual place of residence by 10% £276,191
- Reduce number of cancer emergency admissions by 10% £543,031
- Reduce number of palliative care emergency admissions by 10% £178,573
- Total £997,795**

Although immediate savings would not be seen in ready cash terms, changing practice as a result of these initiatives would ultimately reflect in future HRG tariffs and release of funds for reinvestment and/or savings.

There is much work still to do to develop robust cost information to support the continued development of high quality, cost effective end of life care - See more at:

<http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/qjpp-costings-report.aspx#sthash.SrzINxYO.dpuf>

Our primary goal will be to:

- **Reduce the number of deaths within 48hours of admission by 10%.**
- **Reduce the number of cancer and palliative care emergency admissions by 10%**

The cost savings from this change of activity can be redirected to service delivery in other care settings

9. Commissioning Summary

The developments and rational captured in this five year plan, are such that commissioners can see the breadth of service change and investment needed to secure the best patient experience and their ability to live well towards the end of their lives.

The total investment needed over the next five years is £ 5,,607,439*. However this is specific to the elements of the pathway documented in this plan and does include existing pre-committed investment. (* subject to figures for some of the proposed services being finalised and validated)

It is recognised that the lead in time for a number of these changes are longer than others, and a phased approach can be considered, whilst other developments are new to commission. On considering the proposals reached, it is important that patient safety and positive experience are the primary responsibilities for us to commission against first. For these reasons the following developments take precedence:

3. 24/7 consultant led palliative and end of life care provision, including out of hours at a total cost of £937,161, broken down as follows:-
 - 24/7 consultant out of hours - £25,000
 - Additional consultant post - £124,000
 - Medical model including middle grades – £271,161
 - Training posts - £60,000
 - Current investment in existing consultant and middle grade posts - £457,000
4. Single point of contact at an indicative cost of £120,000.
3. Keeping people at home; rapid response/hospice at home/carer support at an indicative cost of £575,871 (over and above the existing investment of £688,318.)

There are many elements of this strategic plan that can be progressed through greater collaboration and joint working. These will form the basis of the palliative and end of life care steering group's work plan.

10. References

Institute of Healthcare Improvement (2001) Pursuing Perfection (P2) Framework,

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End of Life Care Quality Assessment Tool (2012),

Gold Standard Framework (2013) <http://www.goldstandardsframework.org.uk/>

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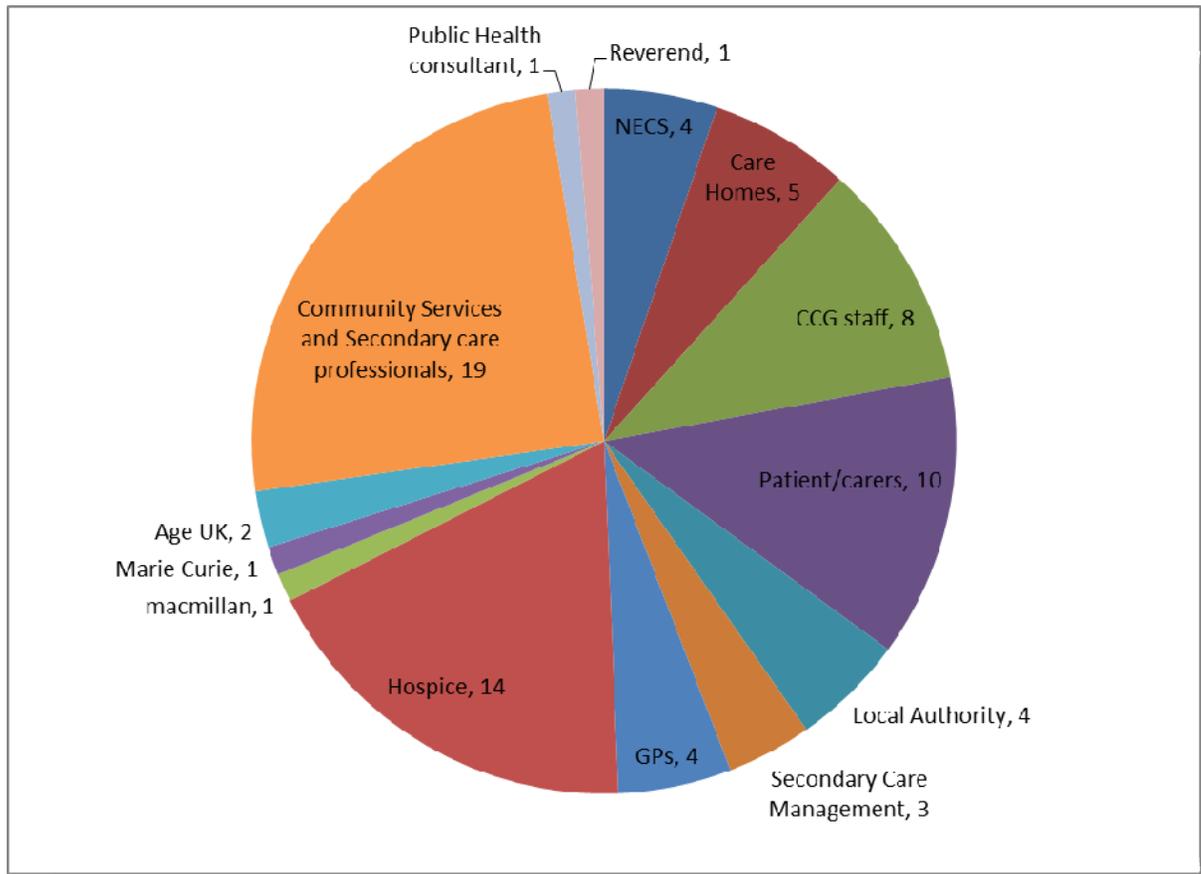
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Appendix 1: Partner and Stakeholder involvement



Appendix 2: Palliative and end of life care group – Terms of reference

Terms of Reference

Palliative and End of Life Care Group

Sub Group of:

Community Services and Care Closer to Home Group

1. Purpose

The Palliative and End of Life Care Group ('the Group') is a sub group of the County Durham and Darlington Community Services and Care Closer to Home (CSCCH) group.

The Group will have reporting arrangements into the Community Services and Care Closer to Home Group, which is itself a sub group of the Health and Wellbeing Boards and the Clinical Programme Board ('the Boards').

The primary objectives being '*to ensure the care and provision meets the individual requirements of people identified with palliative needs and those living with increased need in their last years of life*'.

The Group will develop an aligned vision and direction across the health and social care system in line with the Health and Wellbeing strategies of the Boards. The Group will lead on a number of priority work areas that will lead to the delivery of the strategic aims of the CSCCH Group and the respective Boards, and determine the minimum standards that provide quality of life and patient preference through:

- Improving the *life* people live in their last years of life.
- Ensuring all patients having the opportunity to contribute to their advance care plan and their changing preferences.
- Ensuring people are supported to achieve their preferred place of care.
- Meeting the requirements of patients physical, social, psychological and spiritual needs.
- Supporting family and carer social, psychological, spiritual and bereavement needs.
- Effective planning of transitions of care delivery

The Group will have no commissioning mandate, but there is an expectation it will regularly communicate with the local commissioning structures of CCGs, Darlington Borough Council (DBC), Durham County Council (DCC) and NHS England to inform the debate and commissioning decisions.

2. Remit

- 2.1 To deliver a shared vision of service models that promotes the improved life of people who are palliative and in their last years of life.

This vision will include the agreed priorities of:

- avoiding unnecessary admissions/readmissions,
- timely and safe discharges from hospital,
- joining-up services across health and social care.
- Timely transport of patients

- 2.2 To use this shared vision to deliver a model of care that enables delivery of equitable palliative and end of life care in the patients preferred place of care, including residential and nursing homes.

- 2.3 To provide clarity on the defining levels of expertise associated with palliative care delivery.

- 2.4 To use the shared vision to recommend the optimal configuration for specialised palliative care provision and hospice care, including hospice at home.

- 2.5 To maintain a partnership approach to identifying and understanding existing gaps in provision

- 2.6 To use the partnership approach in ensuring that resources that become available are used to fill the gaps in provision based on knowledge of evidence based best practice

- 2.7 To make CCGs and local authorities aware of commissioning options needed to deliver the whole system model, including the provision of 24/7 specialised palliative care, advice and guidance across the health and social care system.

- 2.8 To ensure that the appropriate engagement and involvement is undertaken with patient and carers using existing and new structures as appropriate.

- 2.9 To develop an effective system for the safe and timely handover of children to adult services

- 2.10 To develop effective information flows, including system-wide information sharing protocols, to avoid duplication, maintain continuity of care and safe decision-making.

- 2.11 To standardise training and education across the health and social care system to ensure delivery of minimum standards of general and specialized palliative and end of life care.
- 2.12 To recommend mandatory levels of staff education and training for integration into provider contracts.
- 2.13 To assure alignment of the Groups action plan with the NHS, social care and public health outcomes frameworks.

3. Membership

Membership of the palliative and end of life care group assumes a mandate to represent the views of peers and your respective organisation. It also assumes a commitment to attend the meeting or send a named deputy.

Organisation	Lead member	Named deputy
Patients and public		
Carers		
Volunteers		
Darlington CCG		
Durham Dales, Easington, Sedgefield CCG		
North Durham CCG		
Primary Care GP leads		
Durham County Council		
Darlington County Council		
County Durham and Darlington NHS Foundation Trust (CDDFT) – palliative care clinicians		
CDDFT – service lead		
CDDFT – Community nurse		
CDDFT – community matron		
Community hospital ward		
Allied health professionals		
Butterwick Hospice		
St Cuthbert's Hospice		
Hartlepool & District Hospice		
St Teresa's Hospice		
Willow Burn Hospice		
Marie Curie		
Macmillan Care		
Care Home managers		

Organisation	Lead member	Named deputy
Dementia UK		
HealthWatch		
North East Ambulance Service Foundation Trust		
Public Health Consultant		
NECS – Service Planning and Reform		
NECS – Provider Management		

Members will co-opt additional members to operate within defined working groups

4. Quoracy at meetings

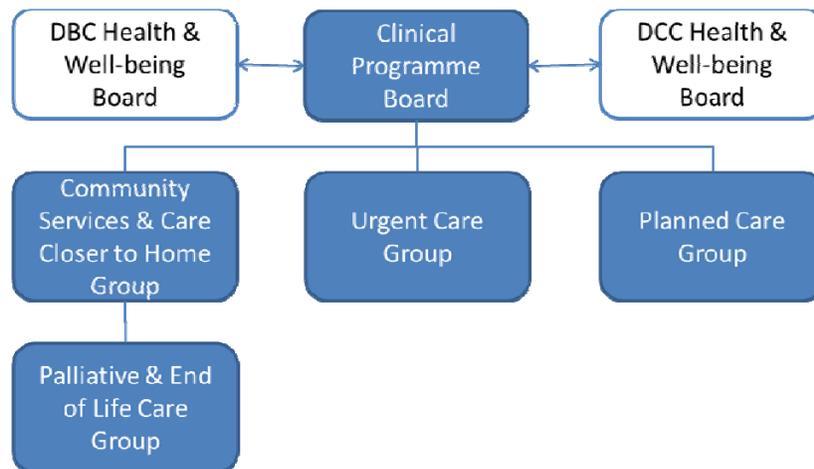
For a representative from each service/organisation to be present

5. Frequency of Meetings

The group will meet monthly as a minimum until April 2014 (excluding December 2013) where the frequency will be reviewed.

6. Accountability arrangements

The Group is accountable to the Community Services and Care Closer to Home Group.



The Chair of the Palliative and End of Life Care Group will be expected to update the Community Services and Care Closer to Home Group on progress on a quarterly basis or more frequently if requested.

7. Interactions with other Groups/Structures

The Palliative and End of Life Care Group will regularly communicate with the Community Services and Care Closer to Home Sub Group to inform the debate.

- 8. Meeting review date**
April 2014

Appendix 3: Current funding arrangements

Recurring funded services

	Hospice Contract Value	Family Support Contract Value	Neurology Contract Value	Nursing Service Contract Value	Total Contract Value
Butterwick Hospice Care	383,398	36,825	45,000		465,223
Hartlepool & District Hospice	227,240				227,240
St Benedict's Hospice	134,950				134,950
St Cuthbert's Hospice	807,268	36,825			844,093
St Teresa's Hospice	549,269	36,825			586,094
Willow Burn Hospice	446,488	36,825			483,313
Marie Curie Cancer Care	74,750			204,749	279,499
CDDFT palliative care					3,205,000
Specialist clinical psychology					
Grand Total	£2,623,363	£147,300	£45,000	£204,749	£6,225,412

Marie Curie Services are provided on a tariff basis so the actual spend is dependent on patient numbers, hours of nursing care provided etc. The contract value for Marie Curie above is the maximum expected cost to the CCGs

Non-recurring funded services

	Welfare support	Rapid response palliative care	In patient costs	Hospice at home	Transport	Other
Butterwick Hospice Care						
Hartlepool & District Hospice						
St Benedict's Hospice						
St Cuthbert's Hospice					35,000	25,000 34,883
St Teresa's Hospice			126,914			

	Welfare support	Rapid response palliative care	In patient costs	Hospice at home	Transport	Other
Willow Burn Hospice				280,000		55,356
Marie Curie Cancer Care		984,189				
CDDFT						
TEWV						
Local Authority	25,000					
Grand Total	£25,000	£984,189	£126,914	£280,000	£35,000	£115,239

Appendix 4: Case for Change

Appendix 4.1 Single point of contact

It is not unusual for patients and families to need support and information in their last year and days of life. People are living with difficult situations and symptoms, often in their own homes. The concept of a single point of contact for patients and families is not new, and is recognised by the national end of life care programme as best practice, but acts as a gateway to knowledgeable support and information.

Current patient and carer experience

County Durham and Darlington are the only area within the North East without access to a single point of contact for Palliative Care and end of life patients and their carers. This results in local patients and their families/carers being disadvantaged in terms of support at a time when they are in greatest need.

Service change

A central resource would act as a single point of access for patients to access advice, guidance and support in navigating the health system, to ensure that the needs of patients are met at whatever time of the day or night. The single point of access offers two individual services:-

1. A specialist helpline
2. A co-ordination centre

Specialist helpline

The specialist helpline will be manned by staff with specialist knowledge and skills in palliative and end of life care 24 hours a day 7 days a week. This central specialist team will be able to offer direct advice and guidance to patients, carers and/or other professionals. It would also act as point of triage and offer, where required direct contact with:-

- Rapid Response Teams
- On Call GP's
- NHS 111
- North East Ambulance Service

The service would be a central point for the co-ordination of information regarding palliative care services across County Durham and Darlington and would therefore offer a signposting function to professionals. If necessary the helpline would also link in with the co-ordination centre to initiate the development of an appropriate care package.

Co-ordination Centre

The centre will act as a central point for the co-ordination and provision of packages of care for patients at the end of their life and their families to enable them to be cared for and die in the place of their choice.

As this is not currently a commissioned service, this would be a new development for the patients of County Durham and Darlington. The commissioning options being to commission:

- a bespoke service locally or,
- buy into an existing service.

Expected activity

Limited data is available in respect of anticipated demand for the service and need will vary from patient to patient. Of the 1600 patients 'flagged' on NEAS system's as palliative care, data was extracted from the system for a 5 month period between January – May 2012. 182 calls were made during that period. Of these 159 (83%) were attended by ambulance and 101 (53%) conveyed to hospital. The remaining 23 calls (17%) were dealt with by telephone only providing advice. Annualising these figures indicates a total of 60 calls per annum could be anticipated for the known palliative care patients or 27 calls per annum per patient (1600/60). However this only represents 7% of those believed to have palliative need in the North East. CDD equivalent - NE palliative care patient 22,419 x 25% (CDD population) = 5604 patients. 5604 patients x 27 = 151,308 calls per annum requiring telephone advice.

Data collated by the Marie Curie delivering choice programme is available for the Co-ordination Centres that have been established as part of the partnership programme. Length of calls and time needed to arrange care packages will vary significantly. Evidence from previous co-ordination centre interventions suggests that the average call/time to arrange a package of care is 3-4 hours and is dependent upon complexity and individual needs of the patient. In addition to this estimation the average length of call for first referral is approximately one hour. There will also be 1 hour per month for maintenance of each package and additional time factored in for maintenance of the register etc.

Patient and system benefits

The key benefits to patients include the following:

- Improved continuity of care for the patient through a coordinated approach to care provision
- Improved communication relating to packages of care between organisations and the patient and their carers /families that will potentially reduce anxiety.
- Better organisation and coordination of packages of care will benefit discharge processes and community care, that potentially will have an impact on avoiding unnecessary hospital admissions and reduce length of hospital stay
- Palliative care/EOL helpline (governed by knowledgeable palliative care workers) available that provides specialist care and signposting

- Direct access to District Nursing support
- Core team that coordinates/understands all services that are available so patients can be appropriately signposted.

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				Option 1 61,000 Option 2 £100,000 + £20,000 set up costs (approx.)

Option 1 Buy-in to an existing service

Option 2 Set up own coordination centre based on Marie Curie model

Appendix 4.2 Consultant led specialist palliative and end of life care provision

Consultant led service

Consultant led palliative medicine provision for County Durham and Darlington will be available to all patients who would benefit (in any setting) and supporting the delivery of excellent outcomes in palliative care for all patients.

The model

The principle of the model will be a tiered consultant led group of clinicians working as a resource for the population of County Durham and Darlington across all care settings.

Patients will receive the right advice, support and symptom control. Much of this will be provided by hospital staff, primary care teams, together with specialist palliative care nurses and other members of the palliative care services.

Advice and assessment will be available from consultants in palliative medicine available in all settings including care homes when needed – responsive to patient need.

These consultants are supported by middle grade staff (often specialty grade doctors but also nurse consultants in palliative care), supporting inpatient palliative care beds across the community but also able to work across organisational boundaries - a provision that should match the consultant workforce.

The palliative care consultants and services will support training posts in palliative medicine for GP vocational trainees, developing capacity in palliative medicine within County Durham and Darlington and enabling consultant and middle grade time to be used more effectively.

Staffing levels

National guidance for provision of palliative medicine suggests 1 WTE per 160,000 population (http://www.rcplondon.ac.uk/sites/default/files/palliative_medicine.pdf). For County Durham and Darlington this equates to 3.75 consultants. In addition there is a recommendation for an equivalent number of middle grade staff (specialty doctor, staff grade doctor or palliative medicine specialty trainee).

The service will be able to support up to 4 training posts in palliative medicine

The overarching proposed model would comprise:

Consultants in palliative medicine work within multi-professional teams and services. In hospitals and the community, the role of these teams is advisory – the overall responsibility for medical care remains with the hospital consultant or the general practitioner. In specialist palliative care units, palliative medicine consultants have overall medical responsibility for the patients. Because palliative care services are funded by a mixture of NHS and voluntary sector money, consultants in palliative medicine often have a major role in local strategic planning of services and in negotiating with commissioning bodies. <http://www.rcplondon.ac.uk/specialty/palliative-medicine>

1. 24/7 access to specialist palliative care advice from consultants in palliative care

Consultants in CDD would seek to join a consortium of other palliative care consultants in the area (possibly the Tees Valley) to create a joint on call provision with a sustainable rota commitment. Because of the geographical extent this could only be an advice only service.

Essential Supporting elements are:

2. Effective consistent face to face assessment (by OOH, hospice or community staff)

The provision of advice is only helpful if linked to accurate assessment of the clinical situation. There may be training needs identified for clinical staff in other services.

3. Electronic access to key palliative care information for each patient (ePACCS, emergency care summary or equivalent)

Effective palliative care services work in conjunction with each other. Another key commissioning intention is the development of an effective system for communicating clinical information about patients in the palliative phase. This is an essential component of a sustainable advice service.

4. 7 day face to face availability of specialist palliative care nurse assessment

As the consultant service (due to the large geographical area) will be restricted to advice only, it is important that next day follow up and assessment is available. NICE Quality Standards for palliative care indicate the need for 7 day availability (9am to 5pm) of face to face specialist palliative care nurse assessment. 7 day availability of specialist assessment is an essential component of an effective consultant level advice service.

NICE Guidance Improving Supportive and Palliative Care for Adults with Cancer

9.32 The team should be staffed to a level sufficient to undertake face-to-face assessments of all people with cancer at home or in hospital, 09.00-17.00, seven days a week. In addition, there should be access to telephone advice at all times (24 hours, seven days a week). This is considered a minimum level of service. Provision for bed-side consultations in exceptional cases outside the hours of 09.00-17.00, seven days a week is also desirable.

9.55 The availability of a 24-hour telephone intervention (when combined with a specialist nurse co-ordinator, home care team linked with hospital, home care dossier and care protocols) has been shown to reduce re-hospitalisation, to improve patients' quality of life and to enable more patients to die at home. Systematic reviews also suggest that specialist palliative care teams facilitate access to other services and co-ordinate care.

24/7 specialist palliative care consultant advice

Context and evidence base

Both the End of Life Care Strategy and NICE Guidance identifies 24/7 access to specialist palliative care advice as an essential component of palliative care provision. 24 hour telephone advice improves patient's quality of life and enables more people to die at home.

Current patient and professional experience

Currently there are no formal systems for access to specialist palliative care advice except 9-5 Monday to Friday. Although there are many health professionals working during the other three quarters of the week who have excellent palliative care skills, there is no provision for support or advice when they require expert help.

For patients this may lead to:

- Poor symptom management
- Delays in accessing the correct medicines
- Admissions which are not required
- Additional distress for patients and carers

Professionals are left with the consequences of these patient experiences making the best decision they can in difficult situations.

National Guidance would indicate the need for 3.75wte consultants in palliative medicine for the population of County Durham and Darlington.

Currently there are 2.5WTE consultants in palliative care commissioned and budgeted by CCGs in County Durham and Darlington. There are 2.5 WTE consultants in post (2.1 substantive and 0.4 locum), which is a gap of 1.25wte against the national standard.

Service change

To deliver this service change a 1.25wte expansion in consultant posts is required, thus allowing the out of hours provision to be resourced, seven days a week.

Patient and system benefits

Access to advice for complex symptom and other palliative situations would lead to:

- Improved symptom control
- Fewer unnecessary admissions at end of life
- Better supported and trained staff
- Reduced carer and family distress
- Achievement of key palliative quality markers

Indicative costs

The cost of an additional consultant to match the national standard is £124,000 including on-costs, based on 10 sessions (Pa's)

The costs for the consultant for out of hours cover would be for four availability supplements (tier 2) and 1 session of consultant time (estimated activity at a cost of £25,000).

The current gap for middle grade provision is 2.50wte, as an element of which already exists to support inpatient beds. It is likely there is a need to increase the provision to match the consultant model.

This might most easily be split evenly between the three CCGs or, more equitably by population.

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£420,161

Based on Band 9 middle grade cover

7 day specialist palliative care 'face to face' assessment

Context and background

In order to ensure that no patient is disadvantaged, NICE (2004) quality standards state that face to face specialist assessment should be available 7days a week. Different to that of the consultant led service, the nurse led specialist palliative care assessment is an essential element of a 24/7 service.

Current experience

Face to face specialist assessment is currently funded in a number of ways across County Durham and Darlington; substantively through CDDFT community contract where a team of 17.4wte is available Monday to Friday to support patients, carers and professional. In addition, there is a small amount of capacity within the hospices that is able to support this function to their patients.

The results from the palliative care rapid response pilot also showed the added value of patients having access to specialist palliative care assessment when it was needed, to prevent admission and secure additional patient and family support.

Service change

In order for the consultant led service to be utilised effectively, it is essential those services that surround it, are resourced to the same level. Whilst it is not necessary to solely extend the community specialist palliative care team to weekend working, it is viewed that a number

of the commissioning developments in this strategic plan will contribute to a sustainable model of specialist assessment across County Durham and Darlington. Essential elements of these services is that the nursing staff are autonomous practitioners (equivalent to band 7) with prescribing capability, to ensure that decisions made can be acted on at the point of care. This level of specialist assessment will form part of the commissioned developments within:

- Hospice at home
- Rapid response palliative care
- Supporting weekend working in hospice facilities

Patient and systems benefits

- Seven day access to specialist assessment
- Admission avoidance
- Better supported staff and patients
- Right care first time
- Achievement of key palliative care quality markers

Indicative costs

These will be taking into account as part of the above commissioning developments

Training posts in Palliative medicine

Context and evidence base

There is a need to improve palliative care skills of many doctors. Within County Durham and Darlington, there is an opportunity to develop up to 4 training posts in Palliative medicine.

General Practice vocational training is normally a 3 year rotational training programme with (normally 6 month) posts in different specialties and in general practice. In County Durham and Darlington there are no training posts in palliative care – in contrast to all other areas of the north east where there is at least one foundation or GP specialty training post. Some areas have several posts. As many GPs take up permanent posts in the area in which they trained, the absence of palliative medicine training posts results in fewer GPs with experience of palliative medicine.

There are excellent local palliative care services with consultant palliative medicine support which would make ideal locations for training. The North East Deanery has identified a need for additional training posts in palliative medicine and would consider joint (50/50) funding of such posts.

Current patient and professional experience

There are very limited opportunities at present to gain experience of Palliative medicine within this area. It has been difficult to recruit doctors to speciality grade (staff grade) posts in

County Durham and Darlington. This contributes to poor access to palliative doctors for patients in all settings. The existing palliative care specialty doctors are mainly located in hospice inpatient units and some of their time is spent on tasks that could be performed by more junior staff.

Staff cannot always access assessment and advice when it is required resulting in:

- poorer symptom control
- difficulty establishing clear robust plans for complex patients.

Service change

We propose the creation of two or more GP Specialty Training posts in Palliative medicine located within a palliative care service and supported and supervised by a palliative care consultant. Staff/Specialty Grade time would be released and utilised to support palliative care in a range of settings.

Joint funding has been sought from Health Education North East and is very likely to be available.

Patient and system benefits

Training posts would support succession planning and create a larger group of general practitioners with knowledge and experience of palliative care.

A training post in each hospice would free more experienced clinical staff to deliver care to more patients at a level more appropriate to their expertise and experience.

Indicative costs

Training posts would provide the most cost effective way of augmenting palliative medicine availability in County Durham and Darlington, at a cost of £60,000.

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£60,000

Appendix 4.3 Rapid palliative care response

The drive to enhance care at the end of life when it is needed is not a moral dilemma. The challenge for commissioners is how that is best delivered. The current district nurse specification includes an urgent response standard of within two hours and on out of hour's services. Across County Durham and Darlington, the rapid response pilot with Marie Curie Cancer Care has been testing another mode of delivery for people with life threatening illness and those in the last days of life.

Current patient and carer experience

Because of the two pilot services currently running in County Durham patients are benefiting from a dedicated service to patients with palliative care needs in crisis situations within palliative care, thus avoiding unwanted hospital admissions, assisting with supported and rapid discharge to enable patients to be cared for in their preferred place of care.

Service change

The proposal is that we continue to commission a single rapid palliative response team across County Durham and Darlington, using the learning from the evaluated pilots to inform the service specification we procure against.

The service would be commissioned as an independent service, measured against its own quality standards, that is responsive to patient need, able to:

- 24/7 specialist face to face assessment
- Support remedial care and intervention
- Competent care planning and handover to community nursing/care home teams
- Prescribe at the point of need
- Interact with all agencies to ensure comprehensive sharing of information

The district nursing specification will need to reflect this service change and reduction in demand on their service to ensure we don't pay twice for the same provision.

Expected activity

Activity will be dependent on the pattern of referrals and will be informed from the results of the evaluation on the two pilot services. During the period April 2012 – March 2013, a total of 737 patients were seen across County Durham and Darlington with a total of 7,257 visits and 3,654 hours of care.

Patient and system benefits

- Care delivered against patient preference
- Greater patient control
- Response times in accordance with patient need
- Plans of care that travel with the patient
- Avoided admissions into secondary care
- Preferred place of death supported

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service	£295,871		£688,318	£984,189

Figures based on full year effect budget for pilot service

Appendix 4.4 Palliative Care at home*

(*home can be classed as any location other than hospital)

The evidence base for change is driven by reducing pressure and changing funding profiles across health and social care as a whole.

Voices 2011 found that the majority of patients (71%) expressed a preference to die at home but only 21% achieved this. In reality the highest percentage of people still die in hospital. England's highest % of deaths at home was 27.2% whilst the North East average was only 20.87%.

Current patient and carer experience

Currently County Durham and Darlington benefit from Palliative Care at Home, except in North Durham where aspects of the service are supported by non-recurring funding.

DDES patients don't have the benefit of local access to inpatient facilities and so their need to access Palliative Care at Home is greater.

Service change

The proposal is to expand the provision of hospice at home so this it is capable of supporting:

- On-going care, as determined through agreed patient care plans
- High standard of quality care and patient outcomes
- Specialist assessment and amendment of care
- Prescribing at the point care decision making
- Interagency working to give the best care and support to patients and their families

Actual activity

The current service is delivered as part of the Hospice service, but there is no separate contractual information flow to capture the activity in the service. This will need to be addressed in the 2014/15 contract discussions.

Patient and system benefits

- Patients will receive planned palliative and end of life care in their usual place of residence
- Patients will receive practical care and emotional support
- Patients will receive respite visits negotiated by means of a specific respite agreement with the patient
- Patients who are at the end of life will be supported to achieve their preferred place of care and death in a context of dignity and comfort
- Patients will receive home support whilst waiting for appropriate hospice or hospital admission in collaboration with other services

- Patients who wish to be discharged from hospital/hospice to home at the terminal stage will receive the support and care needed to enable this
- Patients will have a comfortable and dignified end of life when their preferred place of care and death is their own home

Indicative costs

The main gap in service delivery is within North Durham CCG.

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service			TBC 2014-15	

Appendix 4.5 Palliative care and end of life care transport

In the last weeks or days of life, people often need specialised intervention to help manage progressive symptoms of their illness. In many situations this cannot be delivered in the persons preferred place of care home.

Current patient and carer experience

Patients who require access to enhanced care at end of life do not currently benefit from a transport provision, with skilled staff, that allows them to receive care and symptom management in different care settings and return them to their preferred place of care.

The reality for most patients, due to the nature of their condition, means they need to access resources from the emergency ambulance crews. The calls to which, prioritise 'life-saving' calls. But in addition, patients also experience an inability to achieve day time admissions to Hospice settings.

There is no commissioned standard to support this patient group, often patients have long waits into and out of hospitals, which have sadly resulted in patients dying in hospital.

Service change

The proposal is to commission a dedicated transport services for this patient group.

The aims of which would deliver:

- a dedicated transport resource supported by staff with additional clinical and support
- a flexible and responsive service to patients registered with a GPs across County Durham and Darlington
- short notice to requests for transport of palliative and end of life care patients
- Improve the provision of transport for patients at the end of life, enabling them to be cared for and die in the place of their choice.
- Hours of availability 7 days per week, 08:00 – 18:00 hours

The service will work as an integrated part of health and social care provision across effectively managing transport resources to ensure equity of access to services, equity of available services and value for money. It will also provide robust and timely management information on service utilisation.

Expected activity

Limited data is available in respect of anticipated demand for the service. Of the 1600 patients 'flagged' on NEAS system's as palliative care, data was extracted from the system for a 5 month period between January – May 2012. 182 calls were made during that period. Of these 159 (83%) were attended by ambulance and 101 (53%) conveyed to hospital. Annualising these figures indicates a total of 240 calls per annum could be anticipated for

the known palliative care patients or 7 calls per annum per patient (1600/240). However this only represents 7% of those believed to have palliative need in the North East. For County Durham and Darlington this equates to - NE palliative care patient 22,419 x 25% (CDD population) = 5604 patients. 5604 patients x 7 = 39,228 calls per annum requiring transport.

Patient and system benefits

- Equitable access to transport services at the point of need
- Independently managed services against set standards of service delivery
- Reduced demand on emergency transport services
- Accelerated discharge from hospital
- Skilled and compassionate workforce commissioned for this patient groups needs
- Avoidance of admissions considered as untimely

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£203,755

Costs based on current Urgent Care Transport model

Appendix 4.6 Specialist psychological support

Psychological distress is common among people affected by cancer and life threatening illnesses as it is an understandable and natural response to a traumatic and threatening situation. Patients at every stage of their patient pathway can find themselves dealing with difficult and distressing issues. They can develop problems ranging from sadness or worry to psychological symptoms sufficiently intense to interfere with their ability to function on a day-to day basis.

Around the time of diagnosis, approximately half of all patients experience levels of anxiety and depression severe enough to affect their quality of life adversely. About one quarter continue to be so affected during the following six months. Among those who experience recurrence of disease, the prevalence of anxiety and depression rises to 50% and remains at this level throughout the course of advanced illness. In certain cancers e.g. pancreatic cancer there is an increased biological risk of depression.

In the year following a cancer diagnosis, around one in ten patients will experience symptoms severe enough to warrant intervention by specialist psychological/psychiatric services. Such symptoms can also be seen in 10-15% of patients with advanced disease (NICE, 2004).

NICE guidance for Improving Supportive and Palliative and acute Care for Adults with Cancer, recommends a 4 level model of professional psychological assessment and support, with mental health specialists (clinical psychologists and liaison psychiatrists) working at level 4 to provide direct clinical assessment and intervention to manage moderate to severe mental health problems. Provision of indirect clinical care is also integral to the model e.g. Health and social care professionals providing psychological support to patients, at all levels of the model, require training, education, and ongoing support and supervision. Psychological support serves to enhance the ability of health and social care staff to provide good quality care. It has a role in managing occupational stress and in the recognition and prevention of “burn-out”. NICE (2004). Clinical Psychologists working at level 4 are well placed to provide this indirect clinical service.

The Cancer Reform Strategy (2007) reiterates that cancer patients and their families need good psychological support which “can be as important as any other aspect of their treatment” and requires “all service providers to have established pathways to enable patients to access specialist level three and four support as and when they need it.” The Cancer Reform Strategy also highlights the very important role played by Clinical Nurse Specialists, such as Macmillan nurses, including their role in psychological support. The strategy further acknowledges the importance of providing adequate supervision and support for specialist nurses in performing these roles e.g. the current provision of regular support by Dr Margaret Jack (Consultant Clinical & Health Psychologist, CDDFT) to the Breast Care specialist nurses.

Current patient and carer experience

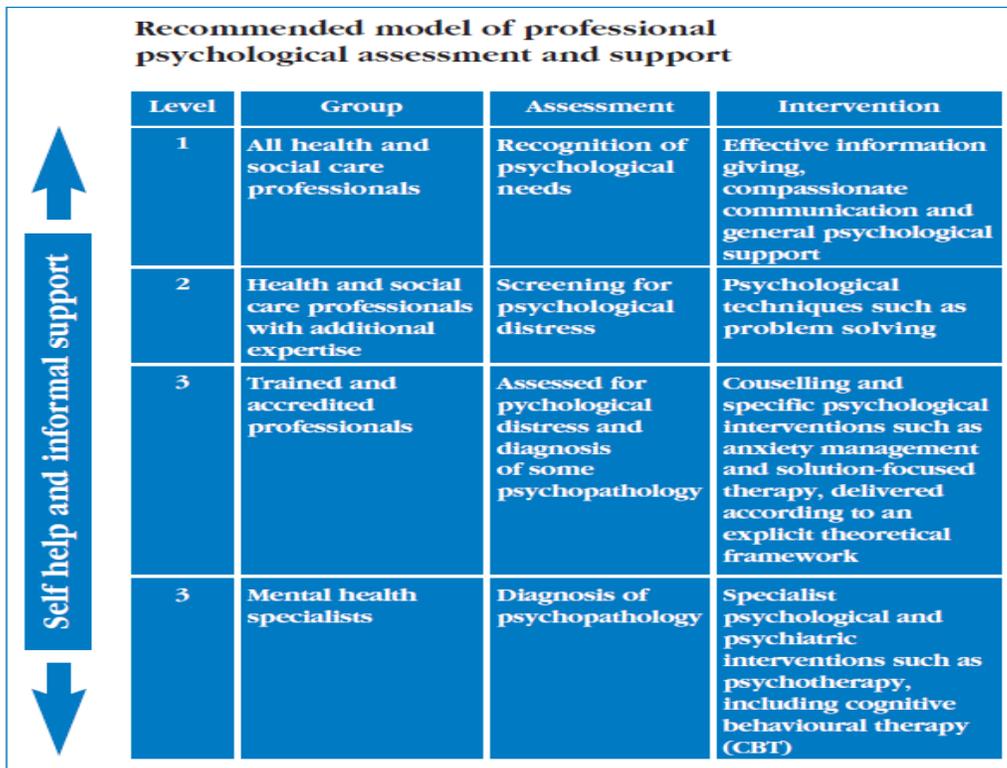
Currently patients with cancer, or long term conditions, are not benefitting from NICE compliant pathways of care. This is because there is no dedicated resource available to look after the psychological needs of these patient groups. This is because no stepped model has been commissioned and patient and professionals only have access to a single consultant in clinical psychology.

Also, the professional teams who are working with and managing this patient group, are not supported by professional expertise to assist patients live well with their life threatening illnesses.

This has been a gap in service for 10years.

Service change

In response to the Department of Health (DH) request for an action plan to address the NICE guidance, the former Northern Cancer Network (NCN) developed a proposed model for psychological care, included within its implementation plan. The plan, including the proposed model for psychological care was endorsed by the NCN board on 21/9/04 and approved by the DH on 4/2/05. The new clinical psychology service for palliative and acute care patients with cancer and life threatening illness across County Durham and Darlington represents a significant development towards achieving equitable referral pathways, shown below.



Locally, it is important that we maintain the consultant led services with increased capacity to support level three and four interventional support, through the investment in additional clinical psychologists and therapy support.

General psychological support, alongside effective information giving and compassionate communication, would be provided by all healthcare professionals at level 1. Screening for psychological distress should be carried out by a range of healthcare professionals, with additional training at level 2. People with mild levels of distress can also be supported and monitored at this level. People with moderate levels of psychological distress can be treated by professionals trained and accredited in specific psychological interventions at level 3 and those patients with more severe levels of distress should be referred on to level 4.

The recruitment of three clinical psychologists, 2wte at band 8b and 1wte at band 8a, will provide sufficient capacity to increase care to patients and support for staff, as well as provide the platform for the stepped model of care with support workers in future years.

Expected activity

The greatest causes of death and early death across County Durham and Darlington are due to cancers and long term conditions. The absence of service does not mean that there is no demand, but the gap is being filled by specialist nurse and general practice who are, at times, ill-equipped to deal with complex issues often associated with these patient groups.

Patient and system benefits

- Patient's will have symptoms of depression and anxiety alleviated
- Patients, families and carers will have access to the psychological support they need
- Level 3 training and support will be available for health care professionals regularly caring for this patient group.

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£179,433

Costs based on 2 * AfC band 8b and 1 * AfC band 8a

Appendix 4.7 Palliative care rehabilitation

The drive to improve the quality of provision of rehabilitation services for cancer and palliative care patients stems from the NICE Guidance on '*Improving Supportive and Palliative Care for Adults with Cancer*'. This addressed the nature of the care that should be provided to help patients and their families to cope with cancer and its treatment throughout their experience of the disease. 1.2 The NICE Guidance identified four key objectives for the provision of rehabilitation care:

1. All patients should have their need for rehabilitation services assessed
2. Patients should receive an active and planned approach to rehabilitation
3. Patients should be able to access rehabilitation services they need without undue delay
4. An education and training programme should be made available to all staff providing rehabilitation services for cancer and palliative care patients

Current patient and carer experience

Provision of specialist palliative care rehabilitation services across County Durham and Darlington is variable. Only patient in Easington currently have access to a palliative rehabilitation service, assisting them to live well at the end of life.

Service change

To commission a comprehensive palliative rehabilitation service across all areas of County Durham and Darlington.

A specialist palliative care rehab service will provide:

- Assessment of rehabilitation needs
- Agree rehabilitation care plans with patients covering:-
 - Physiotherapy
 - Occupational therapy
 - Speech and language Therapy (SALT)
 - Dietetics

The service will enable patients to undertake activities of daily living and maintain as much independence as possible. The service will be delivered in community settings, including the patients own home, residential and nursing homes and community hospitals. The emphasis of the service will be on quality of life, not quantity and it will affirm that dying is a normal life process and not a medical disease process.

Expected activity

The current service is delivered as part of CDDFT community contract, but there is no separate contractual information flow to capture the activity in the service. The work done during 2012/13 needs to be incorporated in the 2014/15 contract discussions.

Patient and system benefits

- 100% of patients receiving direct care to have a written care plan
- 90% of families/carers to be satisfied with their experience of using the service
- 100% of patients to report they felt the service treated them with dignity and respect
- 90% of patients to be satisfied with their experience using the service.
- 100% of families/carers to agree the service helped reduce distress suffered by the patient and their family/carer

Indicative costs

The current service is only within the area of Easington, at a cost of £76,000. But it does not include the breadth of service needed for patients.

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service			TBC 2014-15	

Appendix 4.8 Lymphoedema

Nationally the provision of care for patients with lymphoedema is inadequate, often as a result of under recognition of this chronic debilitating condition of highly diverse aetiology. Many patients are not properly diagnosed and there is often an impression that the condition is rare, causes few problems, is not life threatening and cannot be treated (Rockson, 2007).

Current patient and carer experience

Access to lymphoedema services is variable across County Durham and Darlington. There are insufficient specialist services available and historically funding has been on a non-recurrent basis.

Currently, 1.6wte specialist practitioners are employed via CDDFT community contract, along with additional resources provided by St Teresa's and St Cuthbert's hospices.

The generalist element of service, was provided by the district nursing team. However, since the service now focuses on the 'housebound' patient, the service is variable for those who don't come under the district nurse case load.

Service change

The provision of lymphedema management needs to be resourced for both specialist and generalist assessment and early intervention.

Orientated around a tiered model, the specialist lymphoedema element will ensure that patients with primary or secondary lymphoedema who cannot be managed by appropriate primary, secondary, community or general practitioner services have access to a service that offer treatment, support and on-going management where required. This service will also provide and maintain the education standard.

The current level of provision is would benefit from two whole time equivalents to support the generalist model and increase service resilience, together with 1 WTE dedicated admin resource.

The generalist service for people with simple primary and secondary lymphedema needs to be commissioned, but as a single service across County Durham and Darlington, to ensure equity and delivery against an agreed set of quality standards.

Expected activity

Based on specialist activity during the period April - December 2012, there was an average 9 patients per month for Darlington and 62 per month for County Durham. This makes an annual demand of 852 cases across County Durham and Darlington. This is based on activity data from the CDDFT service.

It is difficult to ascertain actual prevalence for Lymphoedema as much of the research to date has concentrated on different Lymphoedema classifications particularly for cancer, and

it's widely recognised that Lymphoedema is grossly underestimated. Primary Lymphoedema is cited to have a prevalence of 1:6000. Based on these estimates and average GP list of 2000 patients may have between 2 and 40 patients with Primary Lymphoedema.

A study into secondary Lymphoedema in 2003 found prevalence of 1.33/1000 population although other studies have shown a prevalence of 2/1000.

Extrapolating these figures to the over 18 population of County Durham and Darlington (518,274 population) would give the following possible prevalence (these figures should be treated with caution as its well documented prevalence is underestimated.)

Primary Lymphoedema = 86

Secondary Lymphoedema = 689

Total = 775

Patient and system benefits

- Improved quality of life for patients
- Avoid unnecessary hospital admission
- Enable management within primary services where possible
- Complex symptoms will be relieved and management

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£110,262

Based on 2 WTE Specialist practitioner – AfC band 7 – £88,732 (pay point 31)
and 1 WTE Admin staff - AfC band 3 - £21,530 (pay point 9)

Primary lymphoedema service for the non-housebound is yet to be modelled, but in part is dependent on the community nurses service re-commissioning developments

Appendix 4.9 Supporting dementia carers and professionals to allow people with dementia to live well in last years of life

A growing number of the population are living longer with more co-morbidities, including dementia. Sadly dementia sufferers do not fare well in hospital as the unfamiliar surroundings exacerbates their condition. More often, children live some distance from elderly parents and are unable to care for them as they would wish, which often results in care home admissions. This leads to feelings of guilt by family members/carers.

There are misconceptions that hospital admission from a care home is always appropriate. Poor communication between GPs and families living at a distance often results in care homes having no choice but to admit to hospital if the resident is acutely ill since advance care planning communication between the GP and the family is incomplete.

Incidence of dementia in the UK is expected to grow from 800,000 in 2012 to 1,000,000 in 2021 (Alzheimers UK, 2013). NICE Dementia Guidance recommends that dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.

In addition we need to set an expectation that at the point of diagnosis memory clinics initiated the use of 'This is Me' and encourage people with dementia and their carers to take it with them whenever they access health and social care services and ensure staff in those care settings ask to see it.

Current patient and carer experience

The opportunity to discuss end of life care plans with patients living with dementia, is currently left too late, and the process captured within Deciding Right is not benefiting the patient or their families.

Our workforce position to meet the care needs of these patient, are not skilled in looking after people with dementia and the end of life – neither is the end of life care processes and documentation reflective of accommodating end of life discussions in the last years of life.

Caring for the carers is an essential part of looking after people with dementia in the care setting which is most familiar to them. However, focused and expert support for dementia carers is not in line with the national dementia strategy.

Service change

To commission additional dementia practitioner expertise to support professionals, 'patients and carers deliver a coordinated approach to advanced and emergency care planning and communicate the benefits of early discussions, including that of DNA/CPR.

It is expected that the service provision will also;

- Input into MDT and GSF discussions
- Access to knowledgeable practitioners for carers support and those agencies who can deliver it.
- Education to health and social care practitioners, in all patient settings

The input of dementia support at end of life is the last stage of the dementia patient pathway. Any such commissioning development needs to be considered as part of the entire pathway for early detection, through diagnosis and management of care and support.

The service would be delivered across the health and social care systems, regardless of the care or home setting a person resides.

The introduction of a GP dementia champions at each practice and for each care home would support better coordination and delivery of EOLC for people with dementia.

Expected activity

The incidence of people living with dementia will increase by 78% by 2030. Of these, an increasing number will also have long term conditions and cancer, meaning that there will be an increased need for specialist palliative care and end of life support for carers and professions. Although the actual demand is difficult to predict, our workforce is not yet equipped to deal with this patient group at this stage of their lives.

Patient, carer and system benefits

- Relatives/carers satisfaction with EOL outcomes
- Reduction in hospital dementia deaths
- Increase in dementia deaths at home/care home
- Reduction in unplanned admissions for dementia sufferers
- Uptake of 'This is Me' document
- Gold standards framework/palliative care register
- Provider compliance with CQC quality standards

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£110,263

Costs based on 2 * AfC band 7 nurses and 1* AfC band 3 Admin

Appendix 4.10 Family support services

NICE national guidance recommends that all bereaved people are provided with comprehensive, trustworthy and easy to understand information about the practical and emotional aspects of dealing with death. With the appropriate information and awareness that additional support is available if needed, the majority of bereaved people are able to work through their grief using their own coping mechanisms and with support from friends and family.

For some however, additional support may be required which will include therapeutic and structured bereavement interventions from a trained professional. The NICE guidance recommends a tiered model which provides comprehensive bereavement care to cover a range of needs.

Current patient and carer experience

How people die lives on in the memories of those left behind and this alone can have a significant health and psychological impact on friends, family and carers of the deceased. This area of care is one of the least available support services nationally and needs to be addressed from a countywide perspective to ensure adequate provision and coverage within County Durham and Darlington.

In extreme cases lack of support in the grieving process has resulted in suicide of friends or family members following bereavement.

Service change

A Bereavement Support Service is proposed that will deliver care that meets the tiered model approach in line with NICE guidance. This will be delivered as follows:-

- Population/organisation level (Education/Awareness raising/information)
- Level 0 (Pre-bereavement information and signposting)
- Level 1 (Immediately post bereavement – proposed to be delivered in Hospice bases by nursing staff)
- Level 2 (Post bereavement low to moderate intensity support)
- Level 3a (Post bereavement high intensity, structured support services)
- Level 3b (Post bereavement specialist services)

Expected activity

The current service is delivered as part of the Hospice service, but there is no separate contractual information flow to capture the activity of the service. This will need to be addressed in the 2014/15 contract discussions

Patient and system benefits

- Patients will receive practical, timely and sensitive support as they approach end of life which meets their needs
- Families, carers and others affected by bereavement will:-
 - Receive timely, sensitive and relevant information in a format that meets their needs
 - Receive coordinated, effective support and care to enable timely access to assessment and advice from the right agency at the right time (including pre-bereavement support where appropriate.)

Indicative costs

The contribution to Family Support Services previously was quoted as £36,825 per hospice (£147,300), but this is now amalgamated into the base contract. However, Hartlepool currently has no contribution from health.

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service	-	£10,000	-	-

Appendix 4.11 Welfare support

Nine out of ten UK cancer patients' households experience loss of income as a direct result of cancer. This financial strain may be compounded by the additional costs associated with cancer. Evidence suggests that many people with cancer and their carers do not have easy access to the welfare benefits to which they are entitled and that expert knowledge is needed to negotiate the welfare benefits system.

Current patient and carer experience

Currently non-recurring funding has been made available across County Durham and Darlington, to provide benefit support until March 2014. Linked to the importance of carer support, we need to ensure that families do not experience additional stresses brought about by financial concerns and that access to grants, benefits and support is secured.

Service change

The Department of Health's Cancer Reform Strategy (DH, 2007) highlighted the importance of information and advice including financial assistance, to those affected by cancer. The welfare rights service in County Durham has shaped the provision and delivery of advice and information to meet the ambitions of the strategy, with the service embedded within social care and health structures.

Given the importance of the service provided, the proposal is for welfare support services to be funded through mainstream commissioning.

The proposed service would require 3 Welfare Rights Officers with Admin support.

Expected activity

The current service opened 1689 cases in 2012/13 with 1502 claims for benefit being made of which 1481 were successful (99%) and unlocked £4.84m for clients through casework and representation, bringing financial security for many. In addition 214 grants were awarded for vulnerable clients amounting to £224, 394.

This expansion in service will allow:

- Annual social security benefit gains of £2million to people and families living with cancer and other life limiting conditions
- Advice surgeries to be delivered in both primary and secondary settings e.g. cancer information centres
- Seamless service delivered to patients to receive advice regards Social Security, Tax credits and charitable gains.
- A commitment to build capacity in the community by delivering training and support to local hospices and Macmillan cancer Support volunteers.

Patient and system benefits

The income of people affected by cancer and other life threatening illnesses is maximised by providing casework and representation for those affected. In doing so the service will offer:

- Tribunal representation is given to those who require it
- Support groups are offered information, guidance and advice on benefit and tax credit issues
- Social Care and Health staff and volunteers are provided with training and information
- Welfare Rights Staff campaign on and contribute to social policy issues on behalf of those affected by cancer and life threatening illnesses, where these matters pertain to benefits and tax credits
- People in hard to reach groups are identified and offered a service by a welfare rights officer and referred on to other agencies who offer services to those affected.
- Patients will be better placed to make informed choices about their care and where it is delivered given their increased disposable income.

Indicative costs

	Darlington	DDES	North Durham	County Durham & Darlington
Delivery of service				£236,076

Appendix 4.12 Workforce education and capability to deliver high quality of care

Workforce capability is an essential part of delivering this strategic commissioning plan. Not only those of that operate as pour specialist services, but also those care staff that transport, support and care for people on a day-to-day basis. Without their capability and confidence to use their knowledge the system-wide and patient benefits described in this plan will fail.

It is our aspiration that 100% of care staff feel equipped to understand the needs of palliative care and end of life patients, and their carers, and are capable of delivering high quality care.

The government in responding to the NHS Future Forum report (DH, 2012, p13) requires that 'participation between stakeholders to ensure the health workforce access excellent education, are competent and capable, adaptable and flexible'. Therefore, collaboration between health care organisations and education providers needs to be responsive and evolve innovatively, to ensure quality and outcomes of care. The shared focus will be critical to developing the scope of workforce skills required today.

Capability in workforce requires different skill sets i.e. clinical and communication but with competence and confidence (self-efficacy) to use these skills effectively. Critical to greater understanding and investment in the development capability amongst the workforce is the prevention of burnout. 'Capability' requires personal qualities and evidence suggests that workforce need to be resilient as skilled carers and in an ever-changing healthcare environment, the resilience to commit to 'life-long learning': all of which need to be taken in to account when we plan our approach.

The National Cancer Peer Review Programme, which is led by the National Cancer Action Team and includes expert clinical and patient/carer representation, provides important information about the quality of clinical teams and a national benchmark of cancer and palliative care services across the country. In addition, the peer review measures for Palliative Care were published in 2012 and include the need to have a network training and education strategy. Any such education strategy should include key education and training requirements in palliative care for health and social care professionals outside specialist palliative care services.

A systematic strategy for developing capabilities in palliative and end of life care for the whole healthcare workforce, regardless of where they operate, is integral to the provision of high quality and sustainable services for people who are dying. This strategic plan requires all parties to develop an appropriate educational response for all levels of staff.

Our approach to education

In order for our health and social care professionals to be able to deliver high quality palliative and end of life care that is measurable to the national standards, we need an education programme deliverable in a number of ways and accessible to all staff groups

which includes awareness raising, basic training, post-qualification study and specialist qualifications.

In practice, this means that education in the principles of palliative and end of life care should be available to and undertaken by every; primary care team, community teams, hospital team, hospice and by care home staff dealing with patients with cancer or other advanced, life-limiting diseases.

In principal, County Durham and Darlington palliative and end of life care group supports the model of workforce education developed by the North of England Cancer Network (NECN) which describes four key groups of staff and the level of training and education they require. They are:

Group A - Specialist Palliative care staff and their Specialist Training

Group B – Includes hospice staff, cancer centre staff, link nurses for palliative care, district nurses, care home staff, community and acute sector health professionals, medical staff

- Communication Skills
- End of Life Care Pathway
- Holistic Needs Assessment
- Deciding Right
- Palliative care awareness
- End of Life Tools (ACP, LCP)

Group C – Includes district nurses, care home staff, community and acute sector health professionals, medical staff

- Communication Skills
- End of Life Care Pathway
- Holistic Needs Assessment
- Deciding Right
- Palliative care awareness

Group D - All Health and Social Care Staff

- Equality and Diversity training
- Communication Skills

Current situation

Education on palliative and end of life care is currently not delivered in a coordinated way, neither is it seen as an essential field of personal and professional development for all staff. As a result, there is variation in staff ability to care for and signpost patients and carers to the services that are available to them. It is not that staff don't see the importance, but the current delivery of this subject area is fragmented.

Service change

For education and workforce development to be effective, it is envisaged that a coordinated approach is needed to put all requirements of palliative and end of life care education under

one umbrella that all care staff can access, or be signposted to the right post graduate education programme to meet their needs.

Within the role of the specialist practitioners is their remit to educate and support other care workers. Whilst that may be the case, they also have a role in assessing and advising on patients and families with complex needs. It is our intention to make best use of their knowledge in the development of a meaningful model and programme of education for the following care settings:

- Care and nursing homes
- Community nursing
- Primary care
- Hospice
- Acute hospitals – mental and physical health
- Transport services

System wide and patient benefits

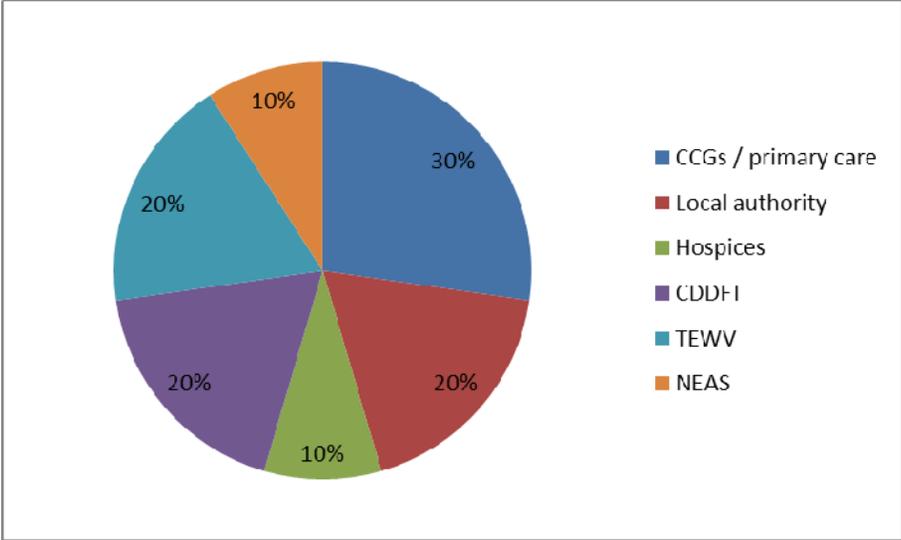
The measured outcomes of having a coordinated approach to education will contribute to the aims of this plans and the professional and continued development of staff. We would look to measure the impact of our education programme against the following measures:

- Retention of specialist knowledge and practitioners
- Improved annual appraisal and professional re-registration
- Increased confidence of staff to care for people in their preferred place of care
- Appropriate escalation for specialist assessment and management of additional care needs
- The numbers of staff trained against each group and the setting they operate in
- A reduction in the tendency to call ambulance staff
- A reduction in the numbers of secondary care admissions in last days of life

Financing education

We envisage that all parties across the social system of palliative and end of life care will benefit from a structured and quality assured programme of education, we means we would look to a contribution model of funding from all parties, similar to that of our local safeguarding board.

The annual programme of education is proposed to be a proportional annual amount from each commissioner and their commissioned providers, using a suggested model of that below.



Appendix 5: Palliative care and end of life operating principles

The establishment of a new social system for improved palliative and end of life care, means that partners will sign up to a common set of operating principles that will deliver patient aspirations.

Principles of a new social system for palliative & end of life care

The patient is the 'owner' of their experience	<ul style="list-style-type: none">•The hand-held patient records allows the patients to remain in control•Patient views travels with the patient, removing duplicated conversations
Service based on the importance of relationships	<ul style="list-style-type: none">•The patient and their family are at the centre, not the organisations from which care is delivered•Knowledge travels to the patient
Services measured against patient and family experience	<ul style="list-style-type: none">•It is about experience, not just about outcome and interventions
Anticipatory, not responsive	<ul style="list-style-type: none">•Advanced and emergency care planning, will provide access to symptom control and equipment at the point of need
Standardisation	<ul style="list-style-type: none">•Build on Deciding Right, to establish a common language across the system•Information travels with the patient via hand held record
Service delivery based on evidence	<ul style="list-style-type: none">•Service standards and outcomes are measured against best practice and evidence
Equitable and cost effective	<ul style="list-style-type: none">•Services are commissioned against the optimum critical mass to ensure patient safety
Best value commissioning	<ul style="list-style-type: none">•Reducing the need to admit to secondary care•No duplication of provision where not substantiated