A Joint Commissioning Strategy for End of Life Care for Adults in Cumbria 2016 -2021

1. Introduction

In 2009 the Joint Commissioning Strategy, for End of Life care for adults in Cumbria (See Appendix 1), was produced by a wide range of local partner agencies. The strategy described a five year vision for improving the quality and equity of End of Life Care across Cumbria. The strategy was influenced by: local issues; the national End of Life Strategy, the Darzi Review; the recommendations identified in Healthier Horizons for the North West, and Cumbria's End of Life base line review.

This refresh of the Cumbria strategy further builds on the progress made from implementation to date (as outlined in number 3 below) and describes our ambitions for end of life care services in Cumbria over the next five years. It also reflects national and regional direction as identified in the North West 'End of Life Strategy' and national documents such as 'The End of Life Ambitions Partnership' document

It is important to note that the Cumbria end of life care strategy underpins the three current adult programmes of work in Cumbria – 'Better Care together' in Morecambe Bay, "West, North and East Cumbria Success Regime" and the emerging countywide Mental Health programme, "Better Mental Health for All". Recognising the importance of end of life care in so many clinical care pathways it is critical that our strategy now reflects and is embedded within these. Consequently whilst the strategy presents the vision and ambitions for end of life care across Cumbria, implementation will be agreed by, and subject to the needs of, these three programmes. Implementation will be overseen by the Cumbria wide end of life workstream using clear goals that will allow us to define and measure success.

> *"Death and dying are inevitable. Palliative and End of Life Care must be a priority. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes*."
> (REF)

2. Vision

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

These services will respond sensitively to the dying person's wishes and preferences. Carers and families are provided with appropriate information and support to enable them to function effectively leading up to and after the death. (A Joint Commissioning Strategy for End of Life Care, for adults, in Cumbria 2009)

This is consistent with the over-arching vision of the Ambitions Partnership

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

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

It is therefore essential that Cumbria develops a whole systems approach to ensure the delivery of a fully integrated service.

3. Aim of the Cumbria Strategy for End of Life Care, For Adults

The aim of this strategy is to provide a framework for the delivery of services that will allow all adults in Cumbria who are approaching the end of their life, "to live as well as possible until they die[1]" in accordance with their own wishes and preferences.

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

- Opportunities available for people to talk about and record their wishes in relation to their own end of life.
- Provision of integrated, person-centred, needs led end of life services across Cumbria
- Equitable access to high quality end of life services across Cumbria, regardless of disease, condition, age, ethnicity, religious belief, disability, gender or place of care
- Consistent quality standards underpin the commissioning process
- Coordination of services that are seamless at the point of need
- Support for carers during a person's illness and after their death and through bereavement
- Increased public awareness and discussion of death, dying and bereavement
- All people are treated with dignity, respect and compassion at the end of their lives
- Pain and suffering at the end of life are kept to an absolute minimum with access to skilled symptom management to optimise quality of life
- All those approaching the end of their life have access to physical, psychological, social and spiritual care
- All staff (health and social care) at all levels are provided with the necessary education and training in end of life care

Who is this strategy for?

This joint commissioning strategy relates to the commissioning of End of Life Care services for all adults in Cumbria.
It is imperative that this runs in conjunction with an end of life strategy for children and young adults. We will work with children's services to enable this.

4. Context – End of life care in Cumbria

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

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

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

The problems experienced by people living in areas of high deprivation can lead to lower levels of life expectancy than those living in areas of low deprivation. This is a consequence of a number of issues including: lack of employment; high crime; low educational achievement; high alcohol use, obesity and smoking.

Deaths in usual place of residence has been traditionally used as evidence of good end of life care however, we need to recognise that this does not necessarily reflect the quality of care provided. Through implementation of this strategy we will develop robust data collection and quality measures that will provide assurance of end of life care provision in Cumbria.

There are still significant differences in access to end of life care, in Cumbria, during evening, night and weekends compared with normal working hours. We will endeavour to reduce this inequity by widening our end of life education programme and having greater access to specialist palliative care advise through improved use of innovation and technology – for example telemedicine.

We cannot defeat death. However, we can change the way we talk about dying, death and bereavement and prepare, plan, care and support those who are dying and the people who are close to them. We must strengthen and improve our ability to provide care whatever the circumstances of our dying.

5. What is End of Life Care ?

End of life care services are those services supporting people with advanced progressive illness in the last six months to year of their lives. These services should meet the end of life care needs of both patient and family throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support [5]

This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

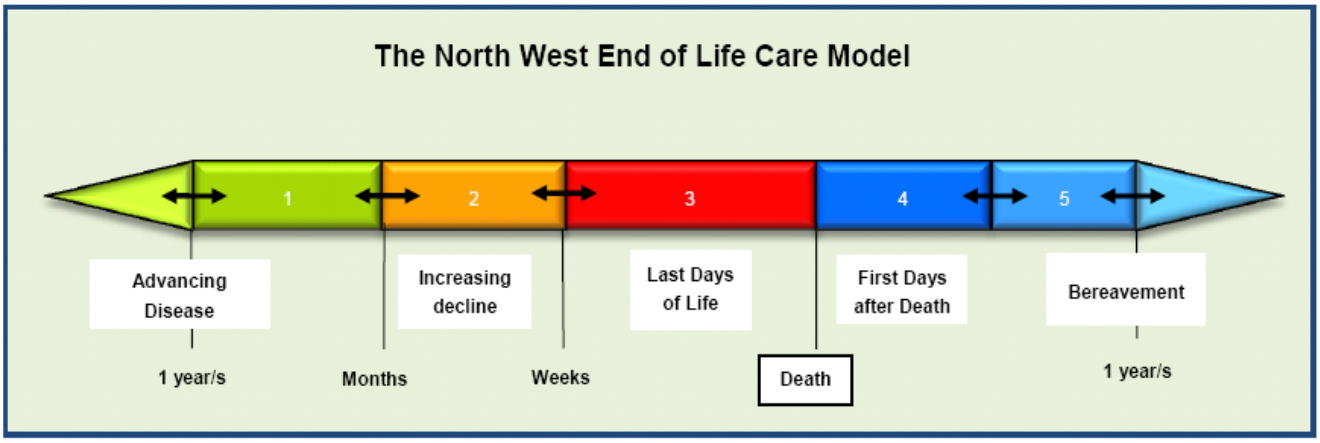
End of life care

- Is about the individual and those important to them
- Is about meeting the supportive and palliative care needs for all those with an advanced progressive incurable illness or frailty, to live as well as possible until they die'.
- Is about providing support in the last years, months or days of life as needed.

It will include:

- A person centred approach to care – involving the person and those closest to them in **all** aspects of their care including the decision making process around treatment and care
- Open, honest and sensitive communication with the patient and those important to them
- Care which is coordinated and delivered with kindness and compassion
- The needs of those identified as important to the person to be actively explored, respected and met as far as possible
- Discussions that follow guidance set within the Mental Capacity Act (MCA 2005)

This can be summed up best by the North West End of Life Care Model



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

- Identification of people approaching the end of life and initiating discussions about preferences for end of life care
- Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly
- Co-ordination of care by professionals within a caring community
- Delivery of high quality services in all
- Management of the last days of life
- Care after death
- Support for carers, both during a person's illness and after their death.
- A commitment to the delivery of culturally appropriate care
- Assessment of spiritual care needs at all stages of the pathway

6. The North West End of Life Care Model

The North West End of Life Model identifies five phases during which staff will be able to get an understanding of the needs of people who are approaching end of life and their carers – Advancing Disease; Increasing Decline; Last Days of Life; First Days after Death and Bereavement.

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

Advancing disease	**1 year or more**
Menu of services for Cumbria - Primary care services that are underpinned by the Deciding Right framework - Preferred priorities of care (PPC) plans recorded for all patients and carers - Out of hours (OOH) service providers with medical and nursing domiciliary visiting capacity and palliative care infrastructure and competencies - Robust communication between in and out of hours services - Easy access to medication - 24/7 access to basic palliative care/end of life information - Integrated information system across health and Adult Social Care - Integrated health and social care service provision - Choice and control – allowing people to direct as much as possible their own care - Access to appropriate services according to need regardless of diagnosis or care setting - Access to self-directed support mechanisms - Access to housing support, such as adaptations, to help people remain in their own homes as long as possible	
Increasing decline	**Approximately 6 months**
Menu of services for Cumbria As above PLUS: - Access to services that respond to the person's medical, nursing and personal care needs without delay (rapid response). - Access to pre-bereavement practical and emotional support - Coordination of documentation across service boundaries - Access to help with practical tasks (handyperson)	
Last days of life	**Last few days**
Menu of services for Cumbria As above PLUS: - Access to short periods of 24/7 nursing or carer input into the home according to criteria - Acute hospitals, care homes, hospices, residential homes and primary care services educated and skilled in Care of the Dying Patient. - Access to *Specialised* (Hospice at Home) Care - Rapid response services for appropriate equipment, aids, medical equipment, ambulance transfers, access to medication - Pan-Cumbria DNAR (Do not attempt resuscitation) policy	
First days after death	**First few days**
Menu of services for Cumbria Systems to guide/signpost bereaved in a compassionate/humane way through this process in all care settings, including:	

- Prompt verification and certification of death - Provision of D49 leaflet – what to do after a death - Provision of a list of local funeral directors - Access to family support and bereavement service - Access to spiritual support, as preferred	
Bereavement	**1 year or more**
Menu of Services for Cumbria: - Access to co-ordinated bereavement services - Signposting as required - Access to bereavement counselling where needed - Access to psychology/psychiatry services for complex bereavement reactions	

Social Awareness

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

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

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

Training

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

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

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

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

Group C
All staff who work within other services who infrequently have to deal with end of life care e.g. day centre, social care, prison service and domiciliary staff etc. should have a basic grounding of the

principles and practice of end of life care and should know when and how to seek expert support and information.

Skills for Care and Skills for Health have produced a national set of common core principles for end of life care. These competencies have informed the development of a Cumbria End of Life Care Education Strategy. Oversight of the implementation of the strategy will be managed by the Cumbria wide multi-agency End of life Care Education Group.

7. Achievements

Since the launch of the 2009 strategy there have been significant advances in End of Life Care in Cumbria. The launch of this strategy refresh will further build on these developments in order to ensure the delivery of fully integrated, high quality services across the county. The framework identified in *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (National Palliative and End of Life Partnership)* will underpin service developments and assist in the identification of areas for improvement.

Developments to date include:

- The use of 'Deciding Right' across Cumbria is common but not yet universal. Implementation of this advanced care planning framework is still patchy, within the normal practice, across primary and secondary care but has led to a significant improvement in the quantity and quality of End of Life discussions and decision making. Continuation of the 'Deciding Right' programme is critical to maintain and, further build on, its use across all care settings, it therefore forms one part of our Palliative Care Education Matrix.

- A greater understanding of Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) across all settings and the adoption of a universal policy and documentation in 2 of the 3 main healthcare providers.

- Registers of palliative patients in all GP practices. This has led to a greater identification of patients, who are likely to be in their last year of life, with emphasis on advanced care planning - ensuring that the patient is at the heart of decision making, improving access to appropriate services and key communication.

- Access to Palliative Care medication, in an emergency, has improved with the identification of named pharmacies and a unified approach to the prescribing of anticipatory medication, across Cumbria and Lancashire North has enhanced care. A new syringe driver control has also been launched to ensure further safety of medication at the end of life.

- Improvement in communication and joint working with Adult Social Care which has led to rapid, timely and appropriate discharges from our hospitals.

- Access to specialist advice 24/7 via the In-patient Hospices, although there is still only face-to-face contact with Specialist Palliative Care services five days a week.

- Improved integration of services through the introduction of shared patient records between GP, clinician, hospitals and hospices. Information is shared, with patient consent, on a need to know basis.

- Access to 24 hour, seven day a week, nursing care for palliative and End of Life patients. This is supported by Hospice at Home services run by the voluntary sector.

- The development of a Cumbria and North Lancashire End of Life Care Plan to ensure the delivery of personalised patient centred care during the last few days of life (following the publication of 'One Chance to get it Right' by the Leadership Alliance). A countywide education plan is supporting the ongoing roll out of this approach.

- Improved bereavement care within the Acute Trusts and prompt verification of deaths by District nurses. A comprehensive Bereavement Pack providing sign-posting for bereaved relatives has also been introduced across primary and secondary care.

8. Ambitions for Palliative and End of Life Care

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

We aim to build on our previous success by reflecting on national developments and in particular the "Ambitions for Palliative and End of Life Care: A national framework for local action 2015 – 2020" (National Palliative and End of Life Care Partnership 2015).

The six ambitions described in the document focus on the needs of the person who is approaching end of life, from their perspective, but also focus on the needs of carers and families. They emphasise the necessity for honest conversations and the importance of joined up care.

We intend to support Cumbria to become a compassionate community with an empathetic and competent workforce that is fully equipped to meet those needs.

The ambitions that will help us to achieve this are:

a Each person is seen as an individual
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon.
I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

b Each person gets fair access to care
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

c Maximising comfort and wellbeing
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

d Care is co-ordinated
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

e All staff are prepared to care
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care

f Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Each ambition is supported by a number of building blocks which make up the ambition and foundations which underpin delivery. (See Appendix A for Building Blocks description)

Foundations for the ambitions

Personalised care planning

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.

Shared records

To ensure the plan can guide a person centred approach it has to be available to the person and, with their consent, be shared with all those who may be involved in their care.

Evidence and information

Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence-base, will help to drive service improvements.

Involving, supporting and caring for those important to the dying person

Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person's caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves.

Education and training

It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish.

24/7 access

When we talk about end of life care we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'.

Co-design

End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die.

Leadership

The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers.

9. Achieving the Ambitions in Cumbria

A current state map, measuring Cumbria's position in relation to both the foundations and building blocks has helped to identify gaps in service provision and areas for further development. The recommendations made as an outcome of this exercise will inform the development of the commissioning strategy implementation plan.

Implementation will be managed by sub-groups of each of the Cumbria work programmes although core developments, for example education and interoperability will be managed on a countywide basis.

Effective performance measures, that will measure successful implementation of this strategy, will be developed by Cumbria End of Life workstream in partnership with key stakeholders.

I, the patient, receive the best possible care – first time, every time

Foundations			
What do we currently have?	**What is missing?**	**What do we recommend?**	**How are we going to measure success?**
Personalised Care Planning			
Deciding Right – county wide cross organisational roll out.	Varying degrees of implementation – ongoing cross agency education required.	-Adequate palliative and end of life care education across all health and social care settings - that is sustainable. To include audit and evaluation. **-Dependent on** cross organisational communication including IT.	- 90% of all patients on a palliative care register have a care plan in place. Baseline to be established. *To be monitored by the **Cumbria and Lancashire North End of Life Education Group.***
Shared Records			
All Group A providers have access to a shared electronic record with identified palliative care patients – supported by an information sharing agreement.	Data is not entirely transferrable and patients don't have access to their own record. Concern for the impact of one partner changing systems.	-Heavily dependent on interoperability across all systems and use of the Deciding Right framework to support the personalised care planning process. -All organisations required to communicate palliative and end of life decisions across all boundaries – as appropriate.	- All patients who die, and are on the palliative care register, have special patients notes in place. *To be monitored by the **Cumbria and Lancashire North EMIS reference group.*** - A reduction in the number of incidents of 111 being called and CHOC being alerted. Already being *monitored by **CHOC.*** Baseline to be established***.***
Evidence and Information			
Use of an electronic patient system	Inconsistent data capture using	-Development and implementation of simple	OACC tool introduced.

across all palliative care providers leading to a change in culture with regard to use off an electronic patient record.	numerous codes. Absence of a quality outcome measures.	standardised coding system and universal tool to capture end of life activity data and quality outcomes e.g. OACC. -Basic training of all support staff ensuring that they are equipped with the skills to manage the data.	*New group to be established.*
Involving supporting and caring for those important to the dying patient			
Pockets of support for carers via hospices, adult social care and clinical nurse specialists.	Inequitable access to a holistic assessment pre-bereavement. Difficulty in accessing appropriate timely finances including benefits; CHC etc. Comprehensive equitable post-bereavement support.	-Joined up approach to carers assessments, to include: • Recognised carer assessment tool; • Identified lead; • Documented outcomes and expectations; • Appropriate levels of patient support to allow the carer to maintain their previous relationship; • Ongoing review. -Joined up bereavement service across specialist and generic service that is accessible to the wider population of Cumbria.	-New group to be established to focus on carers and bereavement. Metrics to be agreed.
Education and Training			
Delivery of good quality end of life education across the county – mostly funded by MPET- but un co-ordinated.	Co-ordinated approach to the delivery of cross-organisational training and education. Little sustainable education resource – dependent on MPET funding. Evidence of impact.	-Refresh of education strategy to reflect the educational needs of generalist health and social care staff, carers and public. -Development of innovative education programme that encompasses the End of life core competencies. -Evaluation process to measure impact. -Commitment from all providers to mandatory training and ensure that all staff achieve the required competencies.	-North Lancashire and Cumbria education programme to be developed. Evaluation tool to be agreed. *To be monitored by the **Cumbria and Lancashire North End of Life Education Group.***
24/7 Access			
Countywide 24/7 access to medical and nursing support. Out of hours clinical advice from	No quality control of advice given on 24/7 help line. No 24/7 hours advice line for	-Establish of tele-medicine system that allows clinical support. -Establish countywide patient support service.	-All patients who are on the red stage of the end of life pathway to have "just in case" drugs in place.

inpatient hospices North and South but this is not commissioned. Adult social care out of hours facility. Strong ethos for just in case and pre-emptive prescribing – although gaps are unclear.	patients and carers. No 7/7 day face to face specialist team.	-Establish consistent approach to just in case prescribing across the county. -Develop a clearly defined end of life pathway that is easily identified within all other care pathways.	Baseline to be established. *To be monitored by the new **End of Life pathway re-design groups in North Cumbria and South Cumbria and North Lancashire.***
Co-Design			
Established Cumbria workstream. Good working relations across palliative and end of life care providers. Cumbria hospice alliance established.	No developed system to access patient/carer views.	-Scope of existing patient and carer groups with a view to establishing appropriate networks. -Build feedback into the end of life planning process.	-Introduction of patient and carer feedback into the end of life planning and implementation process. *To be monitored by the **Cumbria end of life workstream***
Leadership			
New clinical lead and commitment to consultant model across Cumbria. Accessible CCG with an interest in palliative care. Representation at regional groups.	Nursing leadership inconsistent. Adequate GP representation. Clear governance structure.	-Establish governance structure that links into key programmes of work ie BCT and Success.	-Establish clear links into the transformation programmes to ensure that end of life is recognised on each pathway. *To be monitored by the **Cumbria end of life workstream***