

End of Life Care

A strategy for improving care for
people living with and dying from
long term conditions
2006 - 2011

V.final April 2007

Our vision is:

“To provide services in Bolton that are built around the individual, and that deliver high quality and effective, care of the dying and bereaved, irrespective of age and the cause of death.”

Until recently there has been a tendency to focus on the end of life and palliative care needs of people with cancer. Individuals with other conditions as a result have been overlooked.

Care services for the end of people’s lives must aim to provide appropriate care, where possible, for the, physical, psychosocial, emotional and spiritual well being of those who are not expected to live long, including those with illnesses such as dementia, chronic heart disease, chronic respiratory disease, strokes, progressive neurological conditions, AIDS and cell mediated immunodeficiency.

This document sets out, for service users, a five-year strategy to jointly develop end of life services throughout Bolton for people with long-term conditions in their last 6 to 12 months of life as determined by the Macmillan, Gold Standards Framework, prognostic Indicator Guidance Tool.

This strategy will be supported and implemented through the establishment of a local end-of-life network with all key partners.

It builds on the work carried out in specialist palliative care across the health economy of Bolton and has been prompted by the need to review the provision of services for end of life care within community health and care and the Royal Bolton Hospital Acute Trust.

It acknowledges that this service should eventually apply to persons of **all** ages and states of health dying from **any** cause and not just cancer.

Here's how we'll achieve our vision:

- One **Co-ordinated care** with better planning and sharing of information about patient needs between different parts of the health service and partner organisations, and a smoother, faster and more joined up care experience.
- Two **Better training and education** in all settings where care is delivered for people who are dying.
- Three **24-hour access** to a broad range of community services to enable patients and their carers to receive support when needed at end of life, including the period of bereavement, irrespective of age, disease, race or gender.
- Four **Dignity at the End of Life** to strive to ensure that whatever the cause of illness, and wherever care is provided, a dignified and, as far as possible, pain free death can be achieved.
- Five **Choice as far as possible** in where the patient would like to be cared for in the last days of life.

This document sets out how we will realise these 5 priorities and responds to the key requirements set out in the white paper - **Our Health, Our Care, Our Say: a new direction for community services (DOH 2006)**.

Index

	Page
1. Services currently provided	6-8
2. Case for change	9
3. Co-ordinated care at end of life	10-13
4. Training and education to support end of life care	14-16
5. 24-hour access to services to support end of life care	17-20
6. Dignity at the end of life	21-23
7. Choosing where you want to spend your last days	24-27
8. Commissioning care in the future	28-29
9. Glossary.	30-32

There is a **glossary** on page **30**, which explains any unfamiliar words and terms.

If you want to find out how to **access any PCT health service**, please contact our PALS (Patient Advice and Liaison Service) on 01204 360085.

For access to social care information and services contact **Access Bolton** on 01204 333333

If you have any queries or comments about what is in this document, please contact our Commissioning Manager for Older People, Tony MacKay on tel: 01204 547859 or e-mail: anthony.mackay@bolton.nhs.uk

What is End of Life care?

End of life care involves an active, compassionate approach that treats, comforts and supports any individual with a progressive life threatening condition and who is in the last 6 to 12 months of life.

It should be underpinned by evidence-based practice exemplified by the three key tools for end of life care – the Gold Standards Framework, Liverpool Care Pathway and Preferred Place of Care.

The aim of such care is to improve the quality of life of individuals and their carers and families, through the prevention and relief of suffering; through early identification and treatment of pain and other physical, psychosocial or spiritual problems.

End of life care should be tailored to personal, cultural and spiritual values, beliefs and practices of the individual and their family; and encompass support for family, friends and carers up to and including the period of bereavement. The PCT is committed to ensuring equity for all citizens of Bolton, in all aspects of care, and endeavours to improve access for all, with the support and feedback from patients and their families and carers.

SERVICES CURRENTLY PROVIDED

The General Practitioner and Primary Care Team are leaders in the provision of care at end of life. Though your individual needs may vary depending on the nature and stage of illness and your life circumstances, there is a range of other services, provided by **Bolton Primary Care Trust and its partners**, which are available at end of life, these include:

- District Nursing Service.
- GP Out of Hours services.
- Nursing care provided through evening and night services, and specialist cancer nursing services such as the Marie Curie Nursing Service.
- Rapid Response Team.
- Physiotherapy.
- Occupational therapy.
- Dietetic services.
- Podiatry.
- Continence advisory services.
- Speech and language therapists.
- Intermediate Care Services including Crisis Response Team.
- Access to Specialist Nurses.
- Palliative medicine consultants.
- Clinical psychologists and community mental health teams.
- Mental health inpatient provision for older people with dementia.
- Community pharmacists.
- NHS Direct.
- Carers Support Bolton.
- Voluntary services.
- The religious and faith communities of Bolton.

SOCIAL CARE

Social Care support forms part of the co-ordinated services to provide effective end of life care. Joint working and care management arrangements are being developed which will clarify professional roles, reduce the duplication of questions and help to ensure the timely delivery of the necessary services.

Social care input covers a range of care, from providing direct emotional support through counselling to, the more practical support in organising domiciliary care services to assist within the home.

The Hospital-based Social Work Team is regularly involved in supporting people and their families who have to come to terms with negative changes to their health or life expectancy. Three social workers based within the hospital team have been located in Bolton Hospice to offer a specific service to the people and their families who use the Hospice.

Social Care support also includes: Welfare Rights advice, general information and signposting to other relevant independent and voluntary agencies, Direct Payments (where cash equivalents, rather than services are provided), aids to daily living, day and residential care, minor and major home adaptations and access to home based respite care for carers. All direct services would be subject to an assessment of need and eligibility and a financial contribution towards their cost may be required.

The social care support services provide a complimentary addition to health care services and aim to create a simpler pathway for people in the end of life stage to enable them to obtain the assistance they need.

SPECIALIST PALLIATIVE CARE SERVICES

Specialist palliative care services - provide specialist patient care services and offer advice, training and support to other care providers.

Bolton Hospice – the hospice itself provides specialist care services, mainly to cancer sufferers but also a small number of patients with non-malignant disease.

- 14 inpatient beds.
- Consultant input.
- Day care.
- Out patients Clinics.
- 3 Social workers.
- Hospice at Home Team.
- Palliative Care Therapy Team, which includes physiotherapy, occupational therapy and social worker.
- Bereavement Service.
- 24 hour telephone advice service for professionals.

Macmillan Clinical Nurse Specialists in Palliative Care – 3 community nurses and 3 hospital based nurses providing specialist care for cancer patients and patients with non-malignant disease.

Marie Curie Nursing – Providing overnight care, and some care during the day, for patients at the end of life.

Access to specialist palliative care together with advice and support for both professional and non-professional carers is an essential component of the care that should be available to all. Ensuring that appropriate existing shared care arrangements are further developed and extended to cover all those with life-threatening conditions other than cancer should help to ensure that optimal use is made of specialist resources.

HOSPITAL CARE

Within the Royal Bolton Hospital, patients with end of life needs currently receive dedicated care on the palliative and continuing care ward H3, as well as general provision on all other wards within the hospital.

Other services include:

- Palliative Care Consultants
- Macmillan Nurses
- Specialist Nurses
- Hospital Chaplaincy service
- Hospital Social Work Department.
- Allied Health Professionals
- Bereavement officer

BEREAVEMENT

In the context of end of life care, death should not be regarded as the end point of care. Death results in bereavement. Support and understanding for spouses, relatives, friends and carers, and professionals in the period of bereavement can lessen morbidity and suffering. Chaplains and other church/faith groups, which offer help and support, also play an important role. Relatives and carers in circumstances of sudden death, suicide, the death of a child, miscarriage, stillbirth and perinatal death are likely to have particular needs, and skilled support may be required. Parents and bereaved siblings, in particular, may need specialist help.

CASE FOR CHANGE

The care given in hospitals, at home, and in care homes to people who are dying needs to be strengthened.

Staff do not always recognise or acknowledge impending death, and may lack education, training and knowledge of best practice in end of life care.

The Hospice model of excellence of care for people who are dying is one that this strategy aims to emulate in all settings and services, enabling all to have a dignified death, with family and other carers adequately supported during this time.

Many people experience deteriorating health and have distressing physical symptoms, in their last year of life, all of which are mostly amenable to treatment.

Good palliative care, underpinned by the three key tools:

- Gold Standards Framework,
- Preferred Place of Care,
- Liverpool Care Pathway

Will enable the provision of appropriate:

- Symptom control
- Social support
- Emotional support
- Spiritual support

Which in turn will improve the quality of life, and help individuals, their family and carers begin to come to terms with the end of life.

It is also important to acknowledge that there are groups with particular needs for example:

- Black and Minority Ethnic groups.
- People with learning difficulties.
- Adolescents and young adults.

The above list is not exhaustive and we recognise that these examples and many other groups needs may not always be recognised and addressed appropriately by existing services.

The special needs of children require different but overlapping skills for end of life care, and require services that can meet those needs. Those with learning disabilities and dementia may also have very specific needs relating to their understanding of their illness and its impact on them which need to be acknowledged and addressed in future planning for end of life.

Co-ordinated care at end of life...

Principles

- To provide a flexible and responsive '*package of care*' to meet patient needs and those of carers.
- To ensure that the care received is delivered seamlessly and efficiently and that continuity of care and minimal distress occur.
- To provide a model of care that ranges from care in the home to complex care in a special setting such as community hospital, nursing home, hospice or hospital.
- To acknowledge that patient and family/carer choice is an important element in the decision as to what should be provided and where.
- The Bolton End of Life Care Strategy will be seen to harmonise palliative care across the other major health and care work streams, both nationally and locally such as those relating to:
 - Primary Care and Community Health Services
 - Services for Older People
 - Mental Health Services
 - Acute Services
 - Cancer Services
 - Carers

Gold Standards Framework

The Gold Standards Framework enables those approaching the end of life to be identified, their care needs assessed, and a plan of care with all relevant agencies put in place. The framework focuses on optimising continuity of care, teamwork, advanced planning, including out-of-hours, symptom control, patient, carer and staff support.

Although initially developed for use in primary care it can be used in care homes and for all disease groups. For more information, visit the GSF website at: www.goldstandardsframework.nhs.uk

We already:

- Provide Active Case Management for 800 older people, where a health worker is assigned to an individual patient with complex health needs to help improve their quality of life, and to make sure they get the most from health services.
- Have 11 Active Case Managers
- Work closely with our out of hours GP providers to coordinate medical care.
- Are working with partners to develop integrated teams to coordinate your care better.
- Are working with partners to develop joint planned and funded initiatives.
- Provide specialist services for people with long-term illnesses in community e.g. rheumatology and diabetes.
- Have existing agreements with the hospice to provide palliative care services and a location for the PCT Palliative Care Therapy Team.
- Are working closely with other Primary Care Trusts and North West Ambulance Service to develop triage services to provide appropriate local signposting of services for those with non-life threatening conditions according to need.
- Have an agreed joint strategy between health and social care to ensure services for older people are well co-ordinated by further refinements to the single assessment process, to ensure all health and social care needs are looked at together. Within this process the needs and contribution of carers will be considered.

Local case study – Care Co-ordination, using the Gold Standards Framework in General Practice.

David developed lung cancer in his late 50's. He was treated initially with surgery that unfortunately was unsuccessful. Secondary cancers developed and David needed palliative chemotherapy and radiotherapy. Despite this treatment he still had some symptoms that were managed in conjunction with the Bolton Hospice Team. Another complication for him was the development of diabetes as a result of some of his treatment. Despite these quite complex problems, in the last 6 months of his life, David was managed at home (his and his family's expressed wish) where he died peacefully surrounded by his family.

Gold Standards Framework meant that the practice had a system in place for identifying people in David's position. This allowed a key health professional to be identified and be the first port of call for David or his family. David was consulted about his care at all times, and his wishes regarding where he would like to receive care and spend his last days were sought. At this stage he had time to discuss his wishes with his family and the team were able to plan for his needs and anticipate potential problems. His care was discussed within the team regularly; this meant that good continuity was obtained even when his main contact was unavailable.

The GP's had actively sought education regarding symptom control and so had the skills to deal with his complex problems and knew where and when to seek help. In the end phase of his illness, David's problems were anticipated so if they arose medicines and equipment were already available in his home. The Gold Standards Framework meant that there was a good relationship between the district nurses and the practice team and all worked together in a co-ordinated way to provide the best standard of seamless care. After David's death his family was able to continue to seek support from the practice, recognising that care needs for family and carers extend beyond the death to include the period of bereavement.

We will:

- **Ensure all individuals with end of life needs receive seamless, holistic care by allocating them an Active Case Manager trained to support and co-ordinate their palliative care needs.** *(Increase from 500 people in August 2006 to a target of 1840 people by April 2008 who will receive active case management. Increase the number of case managers from the current level of 11 in August 2006 to 23 by April 2008.)*

By:

- Identifying all people with end of life needs in Primary Care using the Gold Standards Framework, Prognostic Indicator Guidance Tool
- Supporting GPs through practice based commissioning for example, to develop their roles in the co-ordination of end of life care by agreeing the development of improved services for palliative care provision including the Gold Standards Framework
- Encouraging all 57 GP practices to participate in active case management and have a palliative care register as part of the new quality and outcomes framework
- Ensuring patients receive appropriate and consistent information together with opportunities for discussion at every stage in the journey
- Increase the completeness of ethnic monitoring data
- Ensuring access to a range of services that offer spiritual, emotional and psychosocial support appropriate to faith and beliefs and those of family and carers
- Ensuring that bereavement support services, including staff within existing National Health Services trained in bereavement counselling, are used appropriately within Bolton
- Working with partners and the voluntary sector to ensure existing services are further developed such as befriending and sitting services

Training and Education to Support End of Life Care for People with Long Term Conditions...

Principles

- Patients will feel confident and supported to manage their own condition, where able
- Patients will receive evidence based quality care from all staff involved in care.
- Carers, and staff involved with care, will be supported by specialists in palliative care.
- Patients will be fully informed and involved in decisions about treatment.
- Patients will be able to access generalist and specialist services, experienced in palliative care, in community settings, minimising the need for hospital attendance.

We already ...

- Provide education and support to help people live positively and manage their own condition as much as possible, including the generic Expert Patient Programme, and specific programmes for people with back problems and diabetes.
- Have an existing palliative care education programme.
- Have a full time Palliative Care educator in post.
- Are strengthening the support and care available in GP surgeries for people with conditions such as diabetes, respiratory disease and heart failure.
- Work closely with Bolton Salford and Trafford Mental Health Trust and Bolton Council to provide specialist services for older people with dementia.
- Ensure that Cardiac Rehabilitation services for people recovering from a heart attack or heart surgery, and neuro-rehabilitation for people with brain injuries and other neurological problems are available.
- Work closely with local voluntary sector support groups including Breathe Easy, Diabetes UK and the Bolton Cardiac Support Group, Over 50s Federation and Carers Support.

- Have the Gold Standards Framework in 2 GP practices in Bolton.
- Have recruited a Gold Standards Framework Facilitator to support implementation across Bolton.
- Are committed to the implementation of the integrated care Pathway for the last days of life in the community, hospital and hospice.

We will:

- **Ensure that all individuals with a long-term condition at end of life are cared for by staff trained in palliative care** (*baseline survey of all PCT staff, trained in palliative care, to be completed by June 2007 and all partner organisations by Dec 2007. Across health and care, 100% of staff trained will have received some training in palliative care by April 2011.*)

By:

- Working closely with agencies such as Macmillan to look at partnerships to improve the delivery and provision of training, education and resources to support end of life care for all.
- Agreeing shared goals and agreed outcomes for education and professional development with partners and all stakeholders.
- Encouraging providers of care, including GP practices, to offer all staff appropriate end of life training.
- Ensuring appropriate further development of existing specialist palliative care services around their key role in advising, supporting and training other providers of care.
- Encouraging early and appropriate use of the full range of services including self-help and support groups such as expert patients and support and training for carers, preferably in the home.
- Ensuring that existing staff trained in bereavement support and counselling are deployed appropriately.
- Working to ensure that all appropriate staff receive training and development so that they are skilled in the provision of palliative care and support.
- Ensuring that the wide range of information about the patient's condition is available to the people who need them at the appropriate time,

particularly materials for specific groups with particular needs e.g. black and minority ethnic groups and those with learning difficulties.

- Developing the role of Community Matron to champion end of life care in the community and care homes
- Ensuring that all staff receive adequate training and support in relation to breaking bad news and are sensitive to the needs and wishes of people.
- Contributing to education and training for voluntary agencies, families and carers.
- Planning care to reduce unnecessary routine follow-ups by improving how we organise our services.

24 Hour access to services to support End of Life Care...

Principles

- To ensure that twenty-four hour care in the community is not seen as a “health sector only” responsibility but a robust package of care to which a wide range of services contributes. This may include the use of:
 - Active Ageing Centres
 - Department of Work and Pensions
 - Education
 - Housing
 - Independent and voluntary agencies
 - Transport
 - Respite facilities.
- To ensure access to end of life care when it is required.
- To ensure care will be provided as close to home as the patient chooses unless hospital care is required for clinical reasons.
- To reduce inequalities in accessing health and social care at end of life, for people with long term conditions
- To improve the care that many patients and carers experience at end of life.
- To develop new ways of working that improve care at end of life for all

We already:

- Have A Gold Standards Framework Facilitator in post to support spread of the framework to all GP practices.
- Have a Palliative Medicine consultant in the PCT based at the Hospice.
- Liaise closely with the Bolton Hospice who provide a 24-hour advice line for palliative care needs.
- Provide some overnight nursing care through Marie Curie Nursing Service.

- Have 2 GP practices that have piloted and implemented the Gold Standards Framework.
- Have initiated a review of services currently provided across organisations for end of life care.
- Provide an interim Community Services Unit at the Royal Bolton Hospital.
- Make sure that GP services are available when needed outside ordinary surgery hours, through our Out of Hours provider.
- Provide an evening and night service within district nursing.
- Work to prevent unnecessary hospital admissions by responding quickly when someone becomes ill at home e.g. Crisis Response Team, Intermediate Care and Rapid Response Team.
- Work with voluntary and independent providers of services to support provision of existing palliative care services.
- Deliver services through a range of professional teams, to ensure that services are better coordinated and work around the patient's needs rather than those of professional groups.
- Carry out medication reviews to improve the effectiveness of prescribing, especially for older people and those taking many different medications.
- Provide an easily accessible Patient Advice and Liaison Service and Health Information Centre to give people advice and information about services, and to resolve any difficulties quickly.

Case Study (example from national report)

Robert, aged 19 had osteo-sarcoma. He later developed secondaries and declined specialist input. He stated that when his time to die came, he wanted to be at home. Robert was offered a Preferred Place of Care (PPC). One Friday evening his condition deteriorated, his parents called the out of hours district nursing staff who were reluctant to administer the anticipatory medicines. The out of hours GP service was contacted who visited and said he would have to be admitted to hospital, and contacted Paramedics. However, when they arrived, Robert's mum, Julie met them at the door, and forced them to read what Robert had written on the PPC. The paramedics requested that the doctor revisit, and a different doctor then called who set up a syringe driver. Robert settled after this; he was lucid and calm, with no complaints other than the dyspnoea. Robert died at home, as he wished, with all his family and friends in the room, his dog under the bed, and his beloved mobile phone still in his hand.

What patients can expect in 3 years time – 24-hour access to care

- If patients have end of life needs they will be able to access a range of services provided in the community rather than having to attend hospital: For example, respiratory services, rapid access clinics and telehealth monitoring of conditions.
- Patients will have a dedicated active case manager who has been trained to coordinate palliative care needs in a planned and proactive way using tools such as the Gold Standards Framework.
- The case manager will work closely with specialist teams, GP, district nurses and, if necessary, community palliative care consultant to ensure the plan of care is followed and that services are in place to support care at home 24 hours a day where appropriate.
- Part of care may involve the management of specific symptoms. The equipment and any medicines for this will be provided to keep in the home in advance of you needing them to avoid crisis in the middle of the night, for example.
- At night, patients will be able to access services in the planned Diagnostic and Treatment Centre including, for example, an enhanced night nursing service, which will provide clinical care and a night sitting service.
- If patients call 999 during the night and it is decided clinically that hospital admission is not required, local services, for example the Bolton night nursing service, could be contacted and asked to visit.
- Members of Bolton Community staff would come out to see patients promptly within an agreed time period. They would be able to provide a range of services from clinical care to blood tests and ensure that symptoms such as pain are well controlled. The individual patient care record would be updated.

We will:

Review the end of life provision within the Bolton Hospitals NHS Trust, (with the aim of reducing the number of people dying in hospital from 1530 in 2004/05 by 350 annually by 2011.)

By:

- Ensuring sufficient services are in place to provide a robust night sitting service to support people in their own homes.
- Providing 24-hour access to essential equipment, including transport.
- Reviewing and develop bereavement and sudden death support services for families, carers and staff.
- Reviewing the need for additional medical provision for palliative care management of long-term conditions in the community.
- Ensuring a range of care options is available from care at home to, if necessary, specialist care in a setting such as the hospice, community hospital or specialist nursing home.
- Working with all GP practices to develop good end of life care underpinned by the use of the Gold Standard Framework, Preferred Place of Care and Liverpool Care Pathway.
- Developing a “one stop shop” to access all health and care services in partnership with Bolton Council.
- Reviewing the capacity of the specialist palliative care therapy services to support end of life needs for people with long-term conditions.
- Working with NHS Trust and other providers of care in Bolton to redesign and reprioritise existing health services where appropriate.
- Reviewing provision within district nursing to assess the need to strengthen the existing services particularly in the evenings and at night.
- Developing robust and integrated pathways of care and access criteria using the three key tools.

Dignity at the End of Life...

Principles

- To treat all citizens of Bolton equally and with dignity and respect their human rights at all points in their care especially at end of life
- To adapt and implement the three key tools for best practice for end of life for people cared for in all care settings.
- To ensure best practice in commissioning, delivery and education for end of life care in all settings.

Liverpool Care Pathway (LCP)

The **Liverpool Care Pathway for the Dying Patient** was developed to take the best of hospice care into care for people in hospital and other settings including care homes. It is used to care for people in the last days or hours of life once it is known that they are dying. The LCP involves promoting good communication with the patient and family, anticipatory planning including psychosocial and spiritual needs, symptom control (pain, agitation, and respiratory tract secretions) and care after death. The LCP has accompanying symptom control guidelines and information leaflets for relatives.

For more information, visit the LCP website at: www.lcp-mariecurie.org.uk

We already:

- Provide quality care based on national and local guidelines such as the National Service Frameworks, National Institute for Clinical Excellence guidance, Bolton PCT Policies and procedures.
- Have robust clinical governance procedures.
- Have a complaints system that is responsive and rigorous.
- Have Older Peoples' Champions.
- Regularly audit and evaluate performance and quality of services.
- Ensure all our staff dealing with service users and carers have been vetted by Criminal Records Bureau.

- Ensure all our professional staff are registered with their professional bodies and adhere to codes of professional conduct.
- Engage with a wide range of patient and carer groups.
- Provide mandatory training and support for continuing education for all staff.
- Comply with Healthcare Commission and Commission for Social Care Inspection standards.
- Have a Nurse Consultant for Older People.
- Have active Patient and Public Involvement forums.

Case Study (example from national report)

Emily had been diagnosed with advanced heart failure and lung cancer and although she had repeated admissions to hospital with similar symptoms, she was significantly weaker on this occasion and did not respond to the usual interventions. The Specialist Palliative Care team was asked to get involved in her symptom management.

Although her pain and breathlessness settled with appropriate support and medication, she remained weak and fatigued and she felt she was too frightened to be nursed at home. The option of a care home placement was discussed and it was explained that support would be available at the end of life through the Liverpool Care Pathway.

Emily was transferred to the care home within two weeks. She died three months later.

A few days prior to Emily's death, the staff in the care home were able to recognise that Emily was deteriorating. In discussion with the family, it was agreed that she should not be admitted to hospital and the LCP was initiated. An assessment of Emily's needs was undertaken which included psychological, social, spiritual and physical aspects, and included stopping oral medication and prescribing medication by other routes for symptoms such as pain, breathlessness, nausea and vomiting.

Her daughter said, 'I think the culture of the care home was excellent and the Liverpool Care Pathway helped the staff to help my mum and me. I will miss her terribly but I know her care was the best it could be and that helps.'

Benefits of using Liverpool Care Pathway in this situation: The LCP provided a structure within which excellent care could be given in the final days of life without readmission to hospital. This meant that disruption was avoided for the resident and the LCP gave the care team confidence to manage the situation.

We will:

- **Reduce the number of deaths in hospital from a care home at end of life** (*establish definitive baseline figures for those at end of life on admission to hospital by January 2007. Currently 256 of the deaths in The Royal Bolton Hospital for 2004 were identified, by postcode, as residents of a care home. We will reduce this figure to 125 people by April 2009.*)

By:

- Working closely with regulatory agencies, care homes and independent care providers to improve standards and provide equity of care in Bolton.
- Reducing significantly the incidence of untreated symptoms through support, education and training in the use of LCP for all staff in nursing and care homes.
- Working with partners to develop a single system to enable patients and their families and carers, to suggest changes and improvements to services.
- Ensuring that quality assurance, audit and research are actively promoted and that all services adhere to policies and standards that support good end of life care.
- Developing the roles of Dignity Champions.
- Complying with Standards for Better Health (2004) this states that 'staff treat patients, their relatives and carers with dignity and respect' and 'appropriate consent is obtained when required for all contacts, with patients and for the use of any confidential patient information'.
- Identifying senior managerial leads within partner organisations and working across geographical boundaries to develop high quality, co-ordinated bereavement support, which is accessible for families and carers.

Choosing where you want to spend your last days...

Principles

- To ensure that patients and their carers are allowed a choice in the preferred place of death, taking into account individual needs and services available.
- To ensure patients receive the best possible care in any care setting chosen.

Preferred Place of Care (PPC)

The **Preferred Place of Care Plan** is a document that the individual holds for him or herself and takes with them if they receive care in different places. It has space for the person's thoughts about their care and the choices they would like to make, including saying where they would want to be when they die. Information about the family can also be recorded so that any new care staff can read about who's who and what matters to them too. If anything changes, this can be written in the plan so it stays up to date. For more information, visit the PPC website at: www.cancerlancashire.org.uk/ppc

We already:

- Provide a Community Nursing Service and a range of allied health professionals that support people at end of life in their own homes including residential care settings.
- Provide palliative care in the community through general practitioners and the primary care team. Many people with end of life needs already receive much good care from a wide range of hospital and community based services within Bolton.
- Work in partnership with Bolton Council, Voluntary Agencies, Bolton Hospice and the Royal Bolton Hospital to support people with end of life needs in all their care settings as well as at home.

Case Study (example from national document)

Derek was 62 and had been in a care home for three months. He was admitted following a stroke from which he never fully recovered. He was also suffering from dementia. His wife Betty had visited every day but had been looking increasingly tired. Derek had his own business but passed this on to his two sons when he started having difficulties due to dementia. Visits from their sons were rare as they lived in the South.

Derek had another chest infection for which the doctor prescribed antibiotics. One day Betty asked to discuss Derek's care; she cried as she spoke about her concerns. She asked that next time Derek developed a chest infection it should not be treated. She did not want him to be transferred to hospital, as he was last time, as this was traumatic and Derek's dementia seemed to worsen after this. Derek was very comfortable in the home and it was easier for Betty to visit. She felt that nature should take its course. She said that she had not discussed this with her sons but felt that after being married to Derek for so long, she knew him best and that previously when in good health he had talked of not wanting to end his days in dependence. She added that he would have hated to be like this and for their sons to witness his demise.

The benefits of using PPC in this situation:

The Preferred Place of Care provides a mechanism to facilitate discussions between the individual and their families earlier in the process of care. It records an individual's preferences and can initiate establishment of advance directives if the person wants to decline medical treatment. The PPC process includes the opportunity to regularly review options and to ensure that the difficult discussions about end of life care are recorded and available to all of the teams involved in the delivery of an individual's care.

What patients can expect in 3 years time - choice in care

- GP practices will use the three key tools:
 1. Gold Standard framework
 2. Preferred Place of Care
 3. Liverpool Care Pathway
- Condition and future prognosis will be discussed with the patient and their family/carers and a plan will be jointly agreed about choice of place of death.
- Patients will be allocated to the practice palliative care register and assigned an Active Case Manager to support and to help them coordinate care needs at end of life.

- Care at home will be provided round the clock as required by district nurse and home care staff, backed up if necessary by support and advice from specialist palliative care staff and others such as cardiac or respiratory specialist Nurses.
- Should it be necessary, admission may be arranged to a community facility for 1 to 2 weeks, for additional short duration treatment including therapy and respite care.
- After this period patients will be supported to return home and your planned care continued.
- As the patient's condition deteriorates care will be increased accordingly. This may include an increase in the district nursing and home care services. A night sitting service will be available to meet individual needs.
- Specialist equipment will be available as needed 24 hours a day from the joint community equipment store. This would include hospital type beds and special mattresses.
- The GP, district nurse, active case manager and, if necessary, specialist services will coordinate care to ensure that all your symptoms such as pain and breathlessness are controlled, where possible, and the Liverpool Care Pathway is used in the last few days to enable patients to die peacefully and with dignity in the place of choice.
- The family will be supported following the patient's death by a co-ordinated bereavement service in conjunction with the GP practice.

We will:

Increase the number of people, in agreement with their carers, who wish to be supported to die at home *(the baseline figures for people dying at home was 420 or 16% of deaths in 2004, we aim to increase this figure to 1330 or 50% by April 2011.)*

By:

- Implementing preferred place of care.
- Identifying current preferences of population through patient surveys and public and patient involvement (PPI).
- Developing increased bed capacity in the community for people at end of life. These beds may be in a community setting, Bolton Hospice or a specialist Nursing Home.
- Working closely with Bolton Hospitals NHS Trust to ensure that for those individuals that seek hospital care as their preferred choice or because the hospital is the only place that can deliver the care that is needed, that this decision is recognised as valid and supported.
- Reviewing the future role of community care providers, looking at opportunities for developing short stay bed options to support people with end of life needs.
- Increasing the use of assistive technology to support people in their own homes.
- Assisting the local authority to increase the uptake of direct payments and individual budgets.
- Contributing to increasing the uptake of health needs assessment for carers.
- Continuing discussions with other organisations such as Bolton Hospice around developing services for people with non-cancer end of life needs.

Commissioning Care in the Future...

Bolton already commissions different aspects of palliative health care for a growing number of its residents, through existing contracts.

The challenge for Bolton is ensuring that the balance of services and the quality of care provided meets the needs of its population appropriately, effectively and efficiently.

End of Life Network

In order to ensure that an appropriate range of services is available in Bolton, within available resources, Bolton Primary Care Trust will establish and develop an end of life care network with primary care providers, the Bolton Hospitals Trust, Local Authority, Bolton Hospice and other independent and voluntary sector organisations.

The care commissioned for Bolton should reflect:

- Its vision of a palliative care approach to all people with life threatening illnesses
- The right of individuals and their families to be consulted, their views to be respected and to be involved in all decisions about the care to be offered
- The resources available

However, the approach to providing high quality palliative care requires close multidisciplinary and multi-agency liaison and co-operation with services being able to:

- Anticipate users' and carers' needs and respond to them in a flexible, co-ordinated and timely manner.

What will be important in the future is to ensure that high quality palliative care, for end of life, is commissioned jointly within allocated resources for all those who require it and not just for selected groups of people. This will entail:

- Developing Quality Targets into Service Specifications with providers of palliative care services.
- Developing feedback mechanisms from users and carers to be used in the commissioning of new services and the redesign of existing ones.

- Establishing multi-faith forums as part of PPI developments to discuss spiritual needs of people with end of life needs in Bolton, and using this in the training and education of all staff.
- Linking the requirements of palliative care into any future planned investments in staff.

This strategy outlines what the PCT aims to achieve over the coming 5 years. An implementation plan and performance management framework, that will ensure effective delivery, will underpin the strategy.

This strategy and associated business plan and performance framework will be subject to ongoing review dependant on relevant local changes and developments in national policy.

Glossary ...

Palliative care – improves the quality of life of individuals and their families facing problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Provision of palliative care can be divided into 2 categories:

1. General – provided in, for example, primary care by GPs, district nurses and other allied health professionals.
2. Specialist – provided by consultants in palliative medicine, nurse specialists such as Macmillan Nurses and AHPs. People with unresolved symptoms or complex psychosocial, end of life issues access these specialist services.

Active Case Management

A service whereby people who have complex health needs and use health services frequently are supported by a health professional to manage their own health better.

Commissioning

The process whereby Primary Care Trusts and Local Authorities identify and plan the health and social care needed for a given population, arrange for that care to be provided by other organisations, and fund that care to meet requirements for quality and quantity.

Inappropriate hospital admission

Occasions on which people are admitted to hospital who would not need to be there if suitable alternatives existed that would allow them to be looked after or provided with a diagnosis in their own home or in a community setting.

Independent Contractors

Primary health care professionals who operate under contract to the NHS, often owning their own premises and employing their own staff. These include dentists, pharmacists, optometrists and GPs.

Independent sector

The term used to refer to private companies, voluntary organisations or charities providing services for NHS patients, funded by the NHS.

Intermediate Care Services

A range of services provided outside hospital as an alternative to hospital care – either to prevent hospital admission or to enable someone to leave hospital sooner. Intermediate care may be provided in a residential care setting or in someone's own home, and will include nursing, therapy and social care to enable the person to regain maximum independence.

Long Term Conditions

These are conditions that are progressive, such as heart failure, diabetes, emphysema, arthritis, and dementia. This type of condition requires long-term treatment and sufferers experience frequent “flare ups “or exacerbations.

Public and Patient Involvement (PPI) Forum

A group of independent volunteers with rights to make recommendations and comments on local health services based on the views of local people and their own monitoring and inspections. There is currently a PPI Forum for each PCT and NHS Trust in England.

Primary Care

Health services provided outside hospital mainly by GPs and other contractors, and the teams working alongside them including Health Visitors and District Nurses. The term may be used to include a range of services which patients can attend without referral (such as family planning clinics) and other community services for which referral is needed, such as physiotherapy.

Prognostic Indicator Guidance Tool

This is a tool developed by Macmillan Cancer Support that enables GPs to identify their patients with long-term conditions and who need end of life care.

Patient at Risk of Re-hospitalisation Tool

This is a method of identifying patients suitable for active case management and is based on number of admissions to hospital as well as a range of other criteria.

Respite Care

Services provided to give families and carers a break for short periods whilst their loved one is cared for in a community setting such as a residential home. This can also now be provided in the person’s own home.

Rapid Access Clinic

This is a facility for GPs to refer patients about whom they are concerned, when further advice and investigations are needed to give a diagnosis and the right treatment. This is an alternative to people being sent to hospital unnecessarily.

Standards for Better Health

National standards to which all NHS organisations must work, and which will be monitored by the Healthcare Commission. They cover the following seven areas or “domains”: safety, clinical and cost effectiveness, governance, patient focus, accessible and responsive care, environment and amenities, and public health.

Single Assessment process

A complete assessment of older people’s needs to which the different agencies providing care contribute.

Telecare/ Telehealth

A combination of equipment, monitoring and response that can help individuals to remain independent at home. It can include basic community alarm services able to respond in an emergency and provide regular contact by telephone as well as detectors which detect factors such as falls, fire or gas and trigger a warning to a response centre. Telecare can work in a preventative or monitoring mode, for example, through monitoring signs that can provide early warning of deterioration, prompting a response from family or professionals.

Unscheduled Care

Health care that is required unexpectedly, as opposed to planned or “elective” treatment. The term is used to include Accident and Emergency, out of hours primary care, and crisis response services.

Voluntary Sector

This term refers to non-profit-making organisations, usually with some unpaid staff, which work alongside NHS and other organisations to provide health and social care services.

For more information please contact

Tony MacKay Commissioning Manager
E-mail: anthony.mackay@bolton.nhs.uk
Tel: 01204 547859
Fax: 01204 547835
Address: St Peters House, Silverwell Street, Bolton, BL1 1PP

We recognise that not everyone will find this strategy document easy to read. We can arrange for large print or audiotape versions or for a summary in another language. We can also provide further explanation if required.

Please call 01204 907717 if we may be able to help in any way

Bolton Primary Care Trust
St Peter's House
Silverwell Street
Bolton BL1 1PP
Tel: 01204 377000
www.bolton.nhs.uk

**Health Information Centre
and Patient Advice and
Liaison Service**
Tel: 01204 360084
Minicom: 01204 360086
Email: PALS@bolton.nhs.uk

Feedback from End Of Life (EOL) Consultation **August 2006 to January 2007**

1. The key initial findings are that we ensure that integration between health and social care is a priority to ensure responsive joint working and robust co-ordination of care. That the standard of care is agreed amongst all stakeholders and that this is delivered seamlessly from the patient and carers perspective. End of life care should be planned in a proactive manner, be person centred, responsive and sustainable to be effective. End of life care should be seen as a priority and investment should be robust and sustainable based on realistic costings. The delivery of the strategy needs to be realistic and workable to be successful. It should be inclusive and involve all partners and stakeholders such as for example, PPI, voluntary sector, Benefits advice and Housing. Consideration also should be given to the relationship between Private health insurance and healthcare and that general awareness is taken into account of the potential impact of other services by changes in provision. The design of new services should involve partners from secondary care to ensure the development of an integrated model and to ensure that we don't underestimate the challenge of delivering 24/7 care.
2. We need to ensure that EOL care is truly person centred rather than target driven and that the education and support needs for families and carers is given priority and that more carers and people from BME groups are involved in the future commissioning planning and implementation.
3. A significant element of feedback from the consultation concerned carers. This related to issues around identifying hidden carers, GPs developing their registers of carers to enable support to be given when needed. There were issues raised about carers having key workers as first contacts and also the need to facilitate carer breaks through respite care. Any support needs to be available over a 24 hour period to be effective and that there should be a range of support for carers. It is also important that carers are involved in discussions about care whether directly or from a strategic planning perspective and that their views are respected.
4. More commitment needs to be given to the spiritual care of people at EOL and not skimmed over as appears at present. This is reflected in the following feedback:

It was felt that the document did not reflect that anyone has been consulted on spiritual care. It would be inadvisable for a non-spiritual professional to conduct assessments without extensive training. Parish priests and Religious Leaders generally do not have skills in this area of work, and may

not be appropriate anyway. There is a considerable difference between normal pastoral visiting and support of the sick, and the liaison with other health professionals in the extended care of the terminally ill. Using voluntary workers from the community raises also the problem of communication. Health workers could not share confidential, but essential information about the progress of the illness or the services provided to voluntary visitors. Similarly, there would be no formal referral mechanism, or ongoing return of information from the Religious Leader to the health professionals.

The possibility of 24-hour callouts for spiritual care would not be sustainable by Religious Leaders on a voluntary basis.

Spiritual support should also be available to members of the various disciplines who have input to these patients/clients. There seems to be no evidence that spiritual care is provided at any level in the PCT. It is suggested that the PCT consider funding a whole-time chaplain who would provide that service and expertise and that this person has a wide expertise in multi-denominational and multi-faith issues and requirements.

The Chaplaincy Dept. at Bolton Hospitals NHS Trust would be willing to assist the PCT in exploring and developing spiritual care.

5. The education and training for all staff and carers was seen as an essential and that the success of the strategy will rest on this being implemented broadly. In particular, good communication and awareness raising and education to promote strategy implementation was seen as essential. As was the need to ensure carers were recognised as having relevant knowledge and skills, which needs to be supported practically in the home by support and education. In relation to staff, it was felt that an audit of existing background knowledge of long term conditions should be undertaken as well as ensuring that all staff involved in assessments have good communication skills. Staff feedback related to the need to have a range of training for all grades, from very practical skills to more academic levels and that this study time must be protected. There should be a mentorship system for staff and that training should be developed on a multi-agency basis with adequate and sustained financial support. The basic education for nurses should include palliative care at end of life

6. Communication was seen as the other key requirement with emphasis on the use of Gold Standards Framework etc. across primary care and the links to single assessment process. The need to have robust information and IT systems that communicate with each other was also highlighted.

7. From a practical perspective the fundamentals within the draft strategy remain unchanged following consultation. This hopefully indicates we are approaching end of life in the right way. Some of the feedback relates to very operational issues such as:

- Develop processes and care pathways
- Advanced directives
- Equipment services collection fragmented
- Death certification process
- Sensitivity towards clinical staff
- Diagnosing last 6-12 months who and how
- Breaking bad news
- Avoid marginalising people
- Avoid defensive medicine

Other general comments were:

- Don't forget children's eol needs
- Obtain more detailed and accurate data on figures
- Supporting care homes in deciding who needs to be in hospital and who can remain in home
- Preferred place of care Vs mental capacity issues
- Community beds- ensure not care on the cheap.

The consultation process has included the following:

End of life Steering Group
Palliative Care Strategy Group
Bolton Hospice
Bolton PCT Management Team
Bolton PCT PEC
Bolton Hospitals NHS Trust Executive Team
Older Peoples Partnership Board
Adult Partnership Board
Health and Wellbeing Partnership Board
Health Overview and Scrutiny Committee
Health and Care Forum
Members of the general public.
EOL Conference Reebok Nov. 2006

Manifesto business plan We Will number: 7.4 Version Date: 19th March 2007

We will action	<ul style="list-style-type: none"> • Improve end-of-life care for people with a long term condition or cancer through better access to support and improved coordination between all services involved, for the patient and their carer.
We will measure	<ul style="list-style-type: none"> • Ensure <u>all</u> individuals with end of life needs receive seamless, holistic care by allocating them an Active Case Manager trained to support and co-ordinate their palliative care needs. • Ensure that all individuals with a long-term condition at end of life are cared for by staff trained in palliative care. • Review the end of life provision within the Bolton Hospitals NHS Trust, • Reduce the number of deaths in hospital from a care home at end of life • Increase the number of people, in agreement with their carers, who wish to be supported to die at home
Milestone actions for March 2007, 2008 and 2009	<ul style="list-style-type: none"> • Agree an end of life care strategy by February 2007 <p><u>This investment and development will deliver:</u></p> <p><u>Bereavement co-ordinator</u></p> <ul style="list-style-type: none"> • Ensuring patients and their families and carers have access to a range of services that offer spiritual, emotional and psychosocial support appropriate to their faith and beliefs. • Ensuring that bereavement support services, including staff trained in bereavement support and counselling are used appropriately within Bolton • Review and develop bereavement and sudden death support services for families, carers and staff • Identifying senior managerial leads within partner organisations and working across geographical boundaries to develop high quality, co-ordinated bereavement support, which is accessible for families and carers <p><u>2 WTE therapists and 2 band 4 technical instructors in the PCT Palliative care therapy team</u></p> <ul style="list-style-type: none"> • Review the capacity of the specialist palliative care therapy services to support end of life needs for people with long-term conditions • The O.T Physio and technical instructors could see a further 140 patients per year <p><u>Investment in 13 band 5 nurses and 10 band 3 nursing auxiliaries will support:</u></p> <ul style="list-style-type: none"> • reduce the number of people who are admitted to hospital from a care home to die, with a baseline and target agreed by June 2007. • increase the number of people who are supported to die at home if they choose from 16% of deaths in 2004 to 33% of deaths in 2009 • Ensure sufficient services are in place to provide a robust night sitting to support people in their own homes. • Provide 24-hour access to essential equipment, including transport • Review provision within district nursing to assess the need to strengthen the existing services particularly in the evenings and at night.

GSF/LCP Coordinator

- Supporting GPs through practice based commissioning for example, to develop their roles in the co-ordination of end of life care by agreeing the development of improved services for palliative care provision including the Gold Standards Framework
- Encouraging all 57 GP practices to participate in active case management and have a palliative care register as part of the new Quality and outcomes framework
- Ensuring patients receive appropriate and consistent information together with opportunities for discussion at every stage in your journey through implementation of the Gold Standards Framework, Liverpool Care Pathway and Preferred Place of Care.
- Increase the completeness of ethnic monitoring data (*from current baseline in 2005/06 ranging from 67% to 2% missing data to 100% completeness by April 2008, with the aim of increasing access to palliative care services for black and minority ethnic groups by 50% over the next 5 years.*)
- Planning care to reduce unnecessary routine follow-ups by improving how we organise our services.
- Develop robust and integrated pathways of care and access criteria using the three key tools .
- Reducing significantly the incidence of untreated symptoms through support, education and training in the use of LCP for all staff in nursing and care homes. (*Training needs analysis to be undertaken in conjunction with Nurse Consultant by Dec 2007*)
- Implementing preferred place of care.
- Work with all GP practices to develop good end of life care underpinned by the use of the Gold Standard Framework, Preferred Place of Care and Liverpool Care Pathway.)
- Identifying all people with end of life needs in Primary Care using the Gold Standards Framework, Prognostic Indicator Guidance Tool (*Roll out with GSF with full implementation by Dec 2009.*)

Project manager

- Developing implementation plan and performance managing developments.
- Identifying current preferences of population through patient surveys and PPI.
- Working closely with agencies such as Macmillan to look at partnerships to improve the delivery and provision of training, education and resources to support End of Life care for people with cancer and non-cancer needs (*first partnership agreement to look at developing ethnic minority outreach worker post by August. 2007.*)
- Ensuring that quality assurance, audit and research are actively promoted and that all services adhere to policies and standards that support good end of life care.
- Work with NHS Trust and other providers of care in Bolton to redesign and reprioritise existing health services where appropriate.

Education and training

- Working closely with agencies such as Macmillan to look at partnerships to improve the delivery and provision of training, education and resources to support End of Life care for people with cancer and non-cancer needs (*first partnership agreement to look at developing ethnic minority outreach worker post by Dec. 2007.*)
- Agreeing with partners and all stakeholders shared goals and agreed outcomes for education and professional development
- Encouraging providers of care including GP practices to offer all staff appropriate end of life training
- Ensuring appropriate further development of existing specialist palliative care services around their key role in advising, supporting and training other providers of care
- Working to ensure that all appropriate staff receive training and development so that palliative support is part of their normal skills and that this improves the quality of direct care
- Ensuring that all staff receive adequate training and support in relation to breaking bad news and are sensitive to the needs and wishes of people.
- Contributing to education and training for voluntary agencies, families and carers.
- Reducing significantly the incidence of untreated symptoms through support, education and training in the use of LCP for all staff in nursing and care homes.

Pulmonary Rehabilitation Service

- Provide support and maintenance for patients with chronic respiratory disease. Each course will comprise 2 sessions per week over 8 weeks followed by an exit strategy agreed during the course. There will be a break of 2 weeks between courses to enable review and follow up as well as course preparations and new patient assessments. Each of the three 8 week courses will cater for 10 patients giving 30 patients the benefit per 8-week course. Four courses will be run per year enabling 120 patients to benefit. The figure of 10 patients per locality is the baseline figure and it is intended to increase this figure once demand is established. Each of the three localities will run concurrently but will be staggered by one week.

Oxygen assessment service

Assessment of 100 patients with respiratory disease at EOL receiving LTOT. Active case management of this cohort.

- Non-recurrent
- Equipment - Pulse ox - £700.00
Concentrator - £42.89/month (rental & service)
- 12 month fixed term/ secondment (first 100 patients)
- 1 WTE Respiratory Nurse Specialist Band7 £37,924.00
- Clinic preparation - £894.00
- Concentrator consumables - £200.00
- Total - £39018.00

Other complementary developments contributing to delivery of EOL strategy.

- Encouraging early and appropriate use of the full range of services including self-help and support groups such as expert patients and expert carers courses (**Manifesto 10.5**)
- Ensuring that the wide range of information about your condition is available particularly materials for specific groups with particular needs e.g. black and minority ethnic groups and those with learning difficulties to the people who need them at the appropriate time. (**development of information prescriptions exploratory discussions taking place**)
- Developing the role of Community Matron to champion end of life care in the community and care homes **Manifesto 7.6** (*6 community matrons to be in post by 2008 one specifically for end of life care.*)
- Ensure a range of care options is available to you from care at home to specialist care in a setting such as the hospice, community hospital or specialist nursing home (**Manifesto 3.1 - 5**)
- Develop a “one stop shop” to access all health and care services in partnership with Bolton Council (**Access Bolton -project manager to be recruited integration timescale to be agreed.**)
- Reducing significantly the incidence of untreated symptoms through support, education and training in the use of LCP for all staff in nursing and care homes. **Manifesto 7.6 - 3 Community Matrons for Nursing Homes to commence April 2007 (Training needs analysis to be undertaken in conjunction with Nurse Consultant by Dec 2007)**
- Developing the roles of Dignity Champions, Complying with Standards for Better Health (2004) this states that ‘staff treat patients, their relatives and carers with dignity and respect’ and ‘appropriate consent is obtained when required for all contacts, with patients and for the use of any confidential patient information’. – **Joint working group established and a number of champions identified across health and care.**
- Increasing the use of assistive technology to support people in their own homes (**Manifesto 7.3**)
- Assisting the local authority to increase the uptake of direct payments and individual budgets (*70 older people in 2007.*) **Manifesto 10**
- Contributing to increasing the uptake of health needs assessment for carers **Manifesto 10.1**
- Working with partners to develop a single system to enable you to suggest changes and improvements to services. (**Manifesto 11.5**)
- Working with partners and the voluntary sector to ensure existing services are further developed such as befriending and sitting services. **Manifesto 8.1 and 8.3**
- Working closely with regulatory agencies, care homes and independent care providers to improve standards and provide equity of care in Bolton, reducing significantly the incidence of untreated symptoms through support, education and training in the use of LCP for all staff in nursing and care homes. **Community Palliative Nurse is to be appointed for assessment of patients with Non Malignant Conditions in care homes funded by cancer network plus Manifesto 7.6**

These issues from the EOL strategy will not be addressed within this phase of development and investment.

- Developing increased bed capacity in the community for people at end of life. These beds may be in a community setting, Bolton Hospice or a specialist Nursing Home (*7.3 specialist beds needed in Bolton for people with long term conditions at end of life based on Cancer Network needs analysis 2005*)
- Reviewing the future role of community care providers, looking at opportunities for developing short stay bed options to support people with end of life needs
- Continuing discussions with other organisations such as the Bolton Hospice around developing services to accommodate more people with non - cancer end of life needs.
- Review the need for additional medical provision for palliative care management of long-term conditions in the community.
- If the capacity within the proposed services in the patients own home is at risk of being exceeded, then it will be necessary to review existing bed based capacity and services within the PCT. This will necessitate providing support for end of life care provision until resources are available to invest in additional home support services or dedicated bed capacity.

Milestone measures	<ul style="list-style-type: none"> • Increase from 500 people in August 2006 to a target of 1840 people by April 2008 who will receive active case management. Increase the number of case managers from the current level of 11 in August 2006 to 23 by April 2008. • baseline survey of all PCT staff, trained in palliative care, to be completed by June 2007 and all partner organisations by Dec 2007. Across health and care, 100% of staff trained will have received some training in palliative care by April 2011. • aim of reducing the number of people dying in hospital from 1530 in 2004/05 by 350 annually by 2011. • establish definitive baseline figures for those at end of life on admission to hospital by January 2007. Currently 256 of the deaths in The Royal Bolton Hospital for 2004 were identified, by postcode, as residents of a care home. We will reduce this figure to 125 people by April 2008. • the baseline figures for people dying at home was 420 or 16% of deaths in 2004, we aim to increase this figure to 1330 or 50% by April 2011.
Lead director	Mike Maguire
Lead manager	Tony MacKay
Group responsible	
Risk rating	
Key risks	Impact – 3 Likelihood – 3 Total - 9
Financial requirements (including any financially quantifiable/ releasable savings made as a result of this work (i.e. reduced hospital admissions))	<p>Approximate full year costs £974k recurrent</p> <ul style="list-style-type: none"> • Bereavement co-ordinator 30k • 1 WTE Band 7 physio 40k • 1 WTE Band 7 OT 40k • 2- band 4 technical Instructors 50k • 13 - band 5 District Nurses 364k • 10 – Nursing auxiliaries band 3 190k • GSF/LCP coordinator post band 7 40k • Project manager 40k • Training programme 25k <p>Pulmonary rehab service</p> <ul style="list-style-type: none"> • 1 WTE Band 7 physio 40k • 1 WTE Band 7 OT 40k • 1 technical instructor 25k • equipment and non costs 10k <p>Oxygen assessment service</p> <ul style="list-style-type: none"> • 1 band 7 nurse including on costs and equipment 40k <p>TOTAL 974k (planning assumption)</p> <p>Recruitment has already commenced for the oxygen assessment nurse</p>

	<p>and so full year funding is required in 2007/08.</p> <p>The remaining staff are unlikely to be in post before mid October 2007 except the project manager who will commence in July 2007. This would mean the part year funding required in 2007/08, will be £499k including £40k for the oxygen post. The above investment is based on an invest to save proposal and anticipates the ability to deflect 175 admissions from 08/09 and increasing to 350 by year 10/11. The predicted net saving through deflections will be realised in 08/09 and amounts to 263k this will increase to 526k in 2011/12</p> <p>This is based on : Cost of episodes relating to all deaths in Hospital 2004/05 based on HRG costs = £5,606k. Further work is on going to determine cost of those episodes that would be deflected by these developments but initial figures based on a deflection plan of 350 PA say 50% @ average costs of 3k 175 x £1500 unit costs = -263k this would give a total recurrent cost of 711k</p> <p>Additional net funding in 2008/09 = £212k</p>
<p>Involvement of patients and the public</p>	<p>Bolton Carers Support and Over 50s Federation reps non steering group Consultation process has included members of the public via Bolton Evening News Consultation event 13th Nov. 2006 at Reebok stadium for 100 people. PCT Board, Overview and Scrutiny Committee, Health and Wellbeing Partnership, Older Peoples Partnership Board, Adult Partnership Board. Health and Care Forum</p>
<p>Map to HCC target or standard</p>	<p>Community matrons against plan Number of VHIU against plan Proportion of data with useful ethnic group coding Change in hospital bed days following emergency admission Delayed transfers of care Total time in AE Access to GP 48hours Access to PCP 24 hours</p>