NHS
Berkshire East

End of Life Care

Executive Summary

This paper outlines the key areas for improvement identified in the national *End of Life Care Strategy* (2008) and the progress that has been made across health and social care locally within east Berkshire.

National context

In England around 500,000 people die each year, 99% of deaths occur in adults over the age of 18 years, and most occur in people over 65 years. The majority of deaths occur following a period of chronic illness related to conditions such as heart disease, liver disease, renal disease, diabetes, cancer, stroke, chronic respiratory disease, neurological diseases and dementia.

The place where people die has changed over the past century with most deaths no longer occurring at home but in hospital. In 1900 approximately 85% of people died in their own homes, by the mid twentieth century this decreased to around 50% and in the early twenty-first century acute hospitals have become the most common place of death. The majority of people express a preference to die at home but at present about 60% actually die in hospitals.

The National Strategy

The End of Life Care Strategy was published in July 2008, promoting high quality care for all adults at the end of life. It aimed to provide people approaching the end of life with more choice about where they would like to live and die and encompasses all adults with advanced, progressive illness and care given in all settings. It positively promotes those at the end of their life:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

A total of £286 million has been committed to improving end of life care over 2009/10 and 2010/11 with the majority being devolved directly to PCTs.

The key areas identified in the End of Life Care Strategy are:

1. **Raising the profile** - Improving end of life care will involve Primary Care Trusts (PCTs) and Local Authorities (LAs) working in partnership to consider how best to engage with their local communities to raise the profile of end of life care.

2. **Strategic commissioning** - As the services required by people approaching the end of life span different sectors and settings, it is vital that an integrated approach to planning, contracting and monitoring of service delivery should be taken across health and social care.

3. **Identifying people approaching the end of life** - Many health and social care staff have had insufficient training in identifying those who are

approaching the end of life, in communicating with them or in delivering optimal care. Workforce development including the provision of communications skills training programmes and other programmes based on the competences is needed by different staff groups.

4. **Care planning** - Anyone approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan. This may include an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. Care plan should be subject to review by the multidisciplinary team, the patient and carers as and when a person's condition, or wishes, change and should be available to all who have a legitimate reason to access it (e.g. out of hours and emergency services).

5. **Coordination of care** - mechanisms need to be established to ensure that each person approaching the end of life receives coordinated care, in accordance with the care plan, across sectors and at all times of day and night.

6. **Rapid access to care** - medical, nursing and personal care and carers' support services can be made available in the community 24/7, including in care homes, sheltered and extra care housing and can be accessed without delay.

7. **Delivery of high quality services in all locations** - Commissioners will wish to review the availability and quality of end of life care services in different settings. These will include services provided in hospitals, in the community, and in care homes, sheltered and extra care housing, hospices and ambulance services.

8. **Last days of life and care after death** – the use of the Liverpool Care Pathway, or an equivalent tool, is adopted by those providing end of life services.

9. **Involving and supporting carers** - The family, close friends and informal carers need to be closely involved in decision making, with the recognition that they also have their own needs. They need information about the likely progress of the person's condition and information about services which are available. Additionally they may need practical and emotional support both during the person's life and after bereavement. Carers already have the right to have their own needs assessed and reviewed and to have a carer's care plan.

10. **Education training and continuing professional development** - end of life care needs to be embedded in training curricula ensuring that health and social care staff at all levels have the necessary knowledge, skills and attitudes related to care for the dying.

11. **Measurement and research** - Good information on end of life care is needed by patients, carers, commissioners, clinicians, service providers, researchers and policy makers.

12. **Funding** - £88m in 2009/10 and £198m in 2010/11

End of Life Care in East Berkshire

In East Berkshire, End of Life Care is split into two constituent parts:

1. Specialist Palliative Care (SPC) and
2. General end of life care

Specialist palliative care is provided by a range of specialist providers i.e. the Specialist Palliative Care team in Heatherwood and Wexham Park Hospitals Foundation Trust (HWPH), the Macmillan Team in Berkshire East Community Health Service (BECHS) and Thames Hospicecare

General end of life care is provided by a much wider range of health and social care professionals such as GPs, community nurses, community matrons, domiciliary care workers and in a wide range of settings such as care homes, community hospitals and patient's home. Domiciliary care is provided by the three intermediate care services in each of the Unitary Authorities, supported by clinical staff from BECHS.

Annually approximately 3000 people die across east Berkshire of which only 19% actually died at home with the vast majority dying in hospital. National research suggests that most people do not want to die in hospital; the reality is around 60% of people do.

An east Berkshire End of Life Care Steering Group has been operating since 2008 and acts as a reference group to steer the direction and commissioning of end of life services and includes user and voluntary sector involvement.

In 2009 the PCT re-framed its Strategic Plan with four strategic programmes of work and End of Life Care has a firm place within one of these strategic programmes (Preventing Crisis, Providing Support). Additionally the PCT has made a commitment to invest approximately £4.7 million over the next 4 years to improve and enhance end of life care services, both general end of life care and specialist palliative care, in order to achieve the recommendations laid out in the Strategy. Whilst the commitment is there from the PCT the landscape in health and social care is rapidly changing and so future plans reflect the opportunities presented with the changing environment.

A lot of work has been done over the 18 month to improve the services that are available for people at the end of their lives, one of which is the joint development of an end of life care pathway (Appendix 1). Additionally the following work has been implemented or in implementation to enhance the services:

Identification of people entering the last stages of life: One of our aims is to embed high quality, consistent end of life care in primary care and so we have developed an enhanced service. This promotes development of an End of Life Register in each practice, the identification of patients in their last 12 months of life. It sets out certain requirements of GPs such as:

- regularly reviewing those patients
- resuscitation preferences discussed and recorded
- the development of care plans
- the allocation of a care coordinator
- discussion of preferred place of death
- planning bereavement support
- anticipatory prescribing - making sure that any drugs that are need for the last days of life are available
- training for staff on end of life care standards

Communication of information across all settings: People entering the last stage of their life are often supported by different professionals across a variety of different settings and communication is key to ensuring their care is optimised. In many cases the systems used are unable to "talk to one another", therefore we have commissioned the purchase of a piece of software developed by Adastra which is used by our primary care out of hours service. When this is completed by primary care the information is forwarded to the out of hours service and in the future will be accessible by professional and will achieve our locality registers.

Specialist Palliative Care provides complex symptom control, emotional, psychological and social support for adults (and their families) with advanced life limiting illness. From October this is an integrated service between the Hospital, Community Health Service and the hospice and will provide the following

- 7 day admission to Hospice
- 24/7 access to expert palliative care advice and guidance for professionals
- Provide face to face assessments by clinical nurse specialists 7 days a week, 9.00-5.00
- Consultant on-call rota
- Provide training and education on palliative care and end of life issues to health /social care professionals who are providing end of life care
- Utilise a holistic approach to enhance the quality of life for patients and their families ensuring dignity and respect.

Additional resources have been invested to ensure this is delivered in the way of:

- A Consultant in Palliative Care based in the Hospice
- 4 extra Clinical Nurse Specialists (Macmillan nurses)
- A GPwSI in Palliative care
- Nurse in Medical Assessment Unit

Bereavement services are vital for family members and carers before and after the loss of their loved one therefore extra investment into providing more bereavement and pre-bereavement support to families. The range of bereavement services available across east Berkshire is currently being mapped to ensure this is easy to access. This work will inform the development of information packs for patients/ carers in the future.

Marie Curie provides a night sitting service to support those that are looking after a person in the last stages of life. It gives carers a short break in order that they can rest and continue in their caring role. Additional investment has been in to the night sitting service (both in an emergency and planned) so more of this is available to support carers and ensure the individual remains within their home environment for as long as they can.

Education and training of staff is absolutely vital in making sure people have as good death as possible. An Education Practice Facilitator has been employed who is/ will:

- Mapping the training available on end of life care
- Identifying the training and educational needs of health and social care staff
- Develop a training and education strategy
- Implement an end of life training programme for staff

Intermediate Care teams which are jointly funded by health and social care across east Berkshire are currently developing more capacity within their service so that people can have intermediate domiciliary care at the end of life for up to 12 weeks rather than the current 6.

Summary

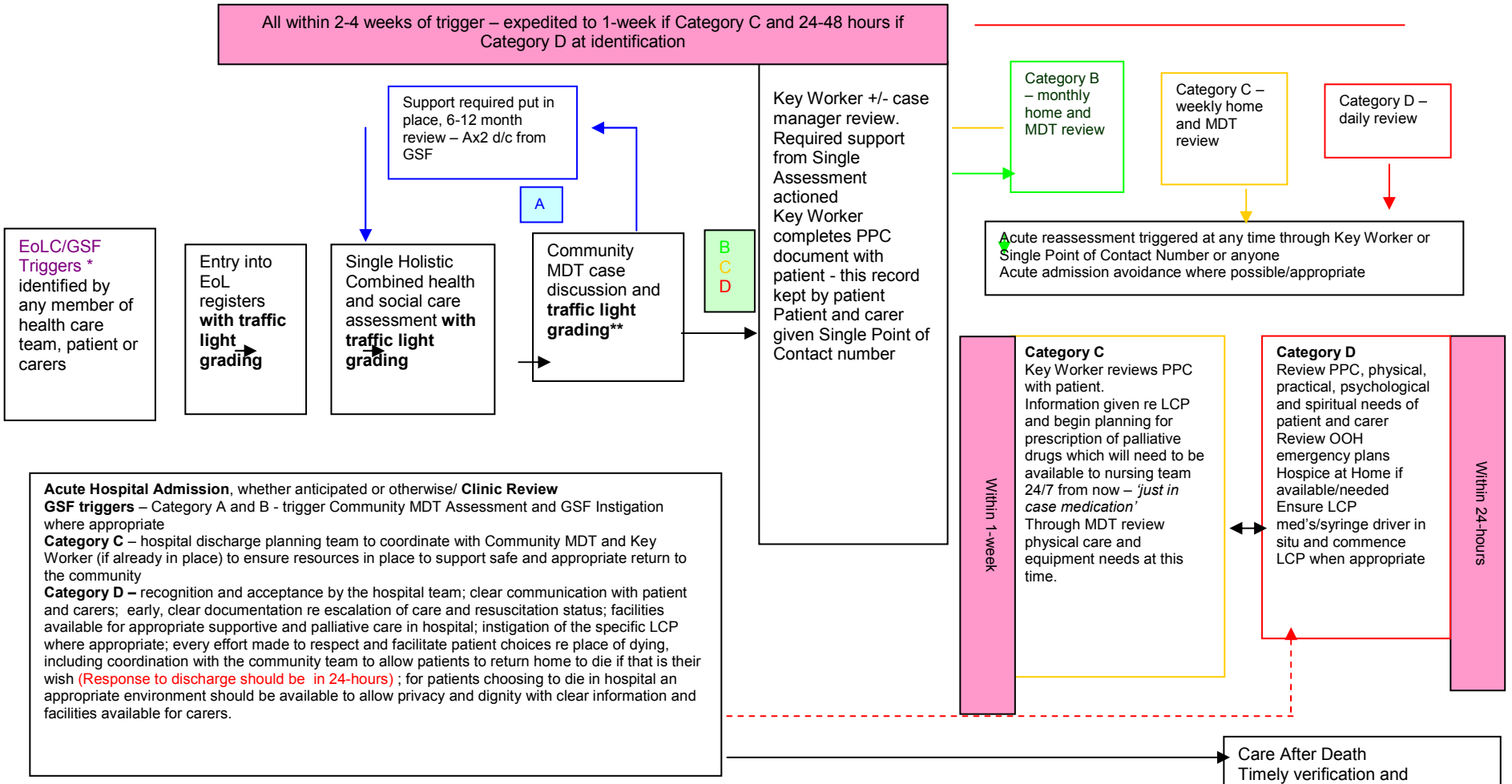
As outlined above it is clear to see a vast amount of work is being done and investment is being made to ensure that people get access to the range of services they need during this difficult stage of life. The plans that have been put in place and that are in the process of being implemented and will be regularly monitored and reviewed through the PCT End of Life Steering Group. The potential impact of the above on patients and their families should be felt as and when different elements of the end of life project are implemented, however the impact on the health and social care system is not likely to be seen until it is all implemented (January 2011).

The PCT has been working in collaboration with its partners across health, social care and the 3rd Sector to implement the recommendations laid out in the End of Life Care Strategy and are committed to delivering high quality services that absolutely meet the needs of the local people of east Berkshire.

Nadia Barakat
Project Lead, Planned Care
NHS Berkshire East
October 2010

Appendix 1 – East Berkshire End of Life Care Pathway

NHS Berkshire East



•EoLC/GSF Triggers – *any* of – 1. Need for supportive/palliative care; 2. clinical indicators of disease severity;
• 3. 'No' to 'would you be surprised if your patient died in the next 6-12 months?'
** A – Blue – Years Prognosis; B – Green – Months Prognosis; C – Yellow – Weeks Prognosis; D – Red – Days Prognosis
Abbreviations: MDT = Multidisciplinary Team; LCP – Liverpool Care Pathway;
GSF – Gold Standards Framework; OOH – Out of Hours Services;
EoLC – End of life Care; PPC – Preferred Place of Care