HILLINGDON
LONDON

Policy Overview & Scrutiny Committee Review Scoping Report 2011/2012

OBJECTIVE

Short title of review

REVIEW OF END OF LIFE CARE IN THE BOROUGH

Aim of review

To review the services and support available for end of life care in the Borough.

Terms of Reference

1. **To consider existing internal and external arrangements in the Borough with regard to end of life care and any improvements that could be made;**
2. **To review the guidance and support that is currently available from the Council and partners to these individuals and their carers;**
3. **To consider how working arrangements between the different services and service providers contribute to meeting national standards, best practice and related national policy;**
4. **To seek out the views on this subject from residents and partner organisations using a variety of existing and contemporary consultation mechanisms;**
5. **To examine best practice elsewhere through case studies, policy ideas, witness sessions and visits; and**
6. **After due consideration of the above, to bring forward cost conscious, innovative and practical recommendations to the Cabinet in relation to end of life care arrangements in the Borough.**

PART 1 – MEMBERS, PUBLIC AND PRESS

Reasons for the review

In the health sector, end-of-life care refers to medical care not only of patients in the final hours or days of their lives, but more broadly, the medical care of all those with a terminal illness or terminal condition that has become advanced, progressive and incurable. End of life care has been identified by the Department of Health as an area where quality of care has previously been "very variable", and which has not had a high profile in the NHS and social care. To address this, a national end of life care programme was established in 2004 to identify and propagate best practice and a national strategy document was published in 2008.

Approximately 500,000 people die each year in England, about 99% of which are adults over the age of 18 and almost two thirds of which are adults over the age of 75. Most deaths follow a period of chronic illness. The common causes of chronic illnesses and death are those resulting from: circulatory disease, cancer, respiratory disease, neurological disease and dementia. Most deaths occur in hospital (58%), the remainder occurring at home (18%), in care homes (17%) and in hospices (4%). There is some evidence that indicates that most people would prefer to die in their own homes.

'End of life care' aims to help all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

A "good death" is described as one that would involve:

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

In Hillingdon, there are around 2,000 deaths a year; approximately 35% deaths are due to circulatory diseases (strokes, heart attacks etc), 25% to cancer, 17% to respiratory diseases, 3% to neurological disease and the remaining 20% to a variety of other diagnoses. The causes, as well as the place of death, are comparable to those in London and reflect national trends.

Taking the above into consideration, the following areas are suggested for Committee's review and are in line with the care pathway recommended by the National End of Life Strategy:

1. Identification of people approaching the end of life and initiating discussions about preferences for end of life care: enhancing the skills of health and social care staff to equip them to identify patients approaching the end of life and initiate discussions around preferences for care.

2. Care planning: assessing needs and preferences, agreeing a care plan to reflect these, reviewing these regularly and documenting them in a care plan accessible to relevant health and social care staff.
3. Co-ordination of care: with particular emphasis on coordination across sectors and out of hours providers; a central coordinating facility and single point of access may be the most efficient way to deliver this.
4. Delivery of appropriate high quality services in all locations: including community, hospitals, hospices, care homes, extra care housing, ambulance service etc.
5. Management of the last days of life: adopting a care of the dying pathway which can be used in all care settings.
6. Care after death and access to bereavement services.

Supporting the Cabinet & Council's policies and objectives

To be confirmed.

INFORMATION AND ANALYSIS

Key Issues

- Access to advice and support and crisis management.
- Patient pathways for accessing palliative care.
- Staff training.
- Joint working arrangements.
- Choice of place to die.
- Information and communications for patients and their families.
- Access to respite.
- Care planning and support.

Remit - who / what is this review covering?

It is proposed that this review will look at:

1. establishing what skills currently exist amongst health and social care staff with regard to identifying individuals that are approaching the end of life and identify any skills gaps;
2. reviewing the care planning process and make suggestions for improvements;
3. reviewing the current coordination of care across sectors and make suggestions for improvement;
4. establishing whether appropriate high quality services are delivered in all locations;
5. ensuring that a care of the dying pathway, which can be used in all care settings, is available; and
6. the availability and access to bereavement services.

Connected work (recently completed, planned or ongoing)

The NHSs National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy.

Improving end of life care involves primary care trusts and local authorities working in partnership and engaging with their local communities to raise the profile of end of life care. At a national level, the Department of Health and the National Council for Palliative Care have set up *Dying Matters*, a coalition that aims to raise the profile of end of life care and to change attitudes to death and dying in society.

Major scrutiny reviews have been undertaken by Warwickshire County Council and Hampshire County Council.

EVIDENCE & ENQUIRY

Witnesses

Possible witnesses include:

1. Individuals living in Hillingdon that are nearing the end of their life and their carers.
2. Older People's Services, Public Health Team.
3. External partners, e.g., care homes, hospices (Michael Sobell House Hospice, etc), Clinical Commissioning Group (formerly referred to as GP Consortium), National Council for Palliative Care, NHS Hillingdon/Hillingdon PCT, Central & North West London NHS Foundation Trust and The Hillingdon Hospital NHS Foundation Trust.
4. Cabinet Member for Social Services, Health and Housing.

There may need to be some further prioritisation within this list in order to make the review manageable and ensure that it is completed within the prescribed timescale.

Information & Intelligence

To be determined.

Consultation and Communications

Consultation could be undertaken with individuals that are nearing the end of their life and their families, relevant charities, service departments and outside organisations.

Lines of enquiry

1. How can the quality of care across the Borough and across all individuals who are nearing the end of their live be made more consistent?
2. Are residents' expectations and concerns about end of life care reflected in the Council's services?
3. How well developed are local strategies and partnerships with regard to end of life care?
4. How have other areas/councils successfully dealt with the issue of end of life care?
5. What training is available to staff to properly address end of life care?
6. How can education and training in relation to end of life care for health and social care professionals, care home staff, individuals and their carers/families be improved?
7. How big a problem is the inappropriate admission of end of life patients to hospitals and how can this be addressed?
8. What support would be advantageous to individuals nearing the end of their life and their carers/families? How could this be best delivered?
9. How can unscheduled care costs (on the health side) and care home admissions (on the Local Authority side) be reduced? What impact would this have on individuals nearing the end of their life and their carers/families?
10. What information and advice is available locally? What treatment and support services are available?
11. How good is care for people nearing the end of their life in hospital? How are people nearing end of life supported in living at home? What is the quality of life for people nearing end of life in care homes/hospices?
12. What support is available for the family of those that are nearing the end of their life? Is this support sufficient/how could this be improved?

PROPOSALS

To be developed as the review progresses.

LOGISTICS

Proposed timeframe & milestones

Meeting	Action	Purpose / Outcome
ESSC – 20 July 2011	Agree Scoping Report	Information and analysis
Date TBA	Introductory Report / Witness Session	Background and Evidence gathering
Date TBA	Witness session	Evidence & enquiry
Date TBA	Witness session	Evidence & enquiry
Date TBA	Draft Final Report	Proposals – agree recommendations and final draft report

Equalities

The Council needs to ensure that procedures for dealing with individuals that are nearing the end of their lives and their families are applied equitably to all community groups, races and ethnicities, enhance community cohesion and adequately meet the needs of a diverse borough.

Risk assessment

The review needs to be resourced and to stay focused on its terms of reference in order to meet this deadline. The impact of the review may be reduced if the scope of the review is too broad.