Care during the last years of life

Introduction
End of life (EOL) care provides support for people identified as being in their last year of life. Palliative care offers a holistic approach to care to support people to live as well as possible and to die with dignity in their preferred place of care. End of life care is specific to the individual and the associated advanced care plan supports the provision of a care package and plan to identify and deliver patients preferences and wishes. In Luton, too many people approaching death are admitted to hospital when they could have received more appropriate care in the community. This could result in a poorer end of life experience for the patient and their family or carer compared to if they had died in their usual place of residence. In Luton, more people have been enabled to die at home since 2007 (as shown in the local picture below) and this trend needs to continue.

Local picture
The number of people dying in their usual place of residence, that is, at home or in care homes, has increased from 34.8% (95% CI: 31.6%-38.1%) in 2010/11 to 45.8% (42.0%-49.4%) in 2013/14 Q2-2014/15 Q1. The target for 2013/14 was to increase the number of people who were able to die at home, if they choose to do so, to 43%. This was exceeded with 45% of people dying in their usual place of residence. Figure 106, shows the rolling average over the preceding four quarters for the percentage dying at usual place of residence; Luton is now comparable to the England average.

Figure 106: Percentage dying at usual place of residence for Luton and England.

Each quarter represents a rolling annual average, for example Q1 2014/15 represents Q2 2013-14 to Q1 2014-15.

What is the evidence base?
The recently published document on the choice of end of life care identifies seven statements outlining what patients and families wanted at the end of life. A national equality impact assessment on the End of Life Care Strategy found that older people and those with a learning disability or severe mental illness would need further information and support to make the right
choices for themselves.iii Services would need to be aware of potential language barriers and religious and cultural beliefs in some communities to ensure assumptions are not made about sexuality. The report also highlights that consideration should be made for homeless people about the place of death, also that carers should be recognised for their role and to consider flexible access to make the death of a loved one easier.

There is a lower uptake of palliative and end of life care services in BME groups compared with White groups, and there is evidence of poorer outcomes, such as symptom burden or dying in their preferred place.iv People with learning disabilities are less likely to have access to specialist palliative care and are more likely to have their deaths described as not being planned.v Approximately one third of people aged over 60 years will die with dementia, many with complex physical and psychological needs and yet many receive poor quality care towards the end of life.

What is being done locally?
There is a range of actions locally to support people to make the right care choices for themselves at the end of their life. This starts with identifying people approaching end of life through practice-based registers and working with them to identify their wishes and needs, which are then supported by regular reviews to coordinate care.

Within Luton, specialist services work collaboratively to provide multidisciplinary, multi-agency, health and social care education programmes. These enable staff to increase their confidence and help demonstrate the knowledge, skills and behaviours that are needed to promote high quality, individualised, palliative and end of life care, to patients, their families and carers, wherever they are supported. This is achieved through a variety of blended learning (e-learning, workshops and structured programmes of study) across acute and primary care (including nursing homes and domiciliary agencies, based upon the principles and practices of end of life care including; communication, symptom management, holistic assessments of a patient’s needs, advance care planning, identifying dying and caring for the patient and their families within the last days of life, through to identifying and supporting those individuals who are at risk within their bereavement.

The avoiding unnecessary admissions (AUA) scheme was launched in 2014, in which practices identify the top 2% of patients that are likely to access A&Em in the next 12 months. Being at end of life was one of the factors associated with A&Em admission and therefore patients that are identified as being end of life should be on the scheme. Community services are being developed to support integration of care.

There has been an increase in coordination of care through care plans, with the person’s consent, readily accessible to all professionals who may be involved in their care through a secure, electronic palliative care co-ordination systems developed on SystmOne, a data system used by GPs. This allows rapid access across care boundaries to key information about an individual approaching the end of life, including their expressed preferences for care. An improved gold standard template is being finalised and will be introduced onto SystmOne which will further improve the co-ordinated care to patients identified as being end of life.

My Care Coordination Team and Palliative Support Workers, based at Keech Hospice, provide coordinated 24/7 care to patients with end of life care needs. Patients identified as being at end of
life, and who consent, are added to the register and the My Care Coordination Team becomes the first point of contact for patients, carers and those who co-ordinate the multi-disciplinary care with patients. The My Care Co-ordination Team ensures medical, nursing and personal care and carers’ support services can be made available in the community to help more people live and die in the place of their choice.

The Luton End of Life and Palliative Care group provides a strategic approach to partnership working in the provision, planning and commissioning of local palliative/end of life care. The LIG will facilitate ensuring services meet local health and social needs in line with local and national priorities/intentions and contribute to the CCG priorities to reduce hospital admissions and improve communication across all areas delivering end of life services. There are two Macmillan GPs who lead on palliative care, improving cancer services and increasing the uptake of screening programmes.

There are well established monthly multi-disciplinary meetings at Keech Hospice for palliative patients with a non-malignant diagnosis. This ensures all palliative patients may access services and receive equitable care.

**Perspective of public/service users**

The National Bereavement Survey collects information on bereaved people’s views on the quality of care provided to a friend or relative in the last three months of life, for England. The survey identified:

- Quality of care was rated significantly lower for people who died in a hospital, compared with people dying at home, in a hospice or care home.
- For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012.
- The dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013.
- Pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%).
- Only half of people (50%) who express a preference to die at home actually die at home.

**Priorities**

1. Ensure everyone at the end of life is identified and offered palliative care by reviewing end of life end of life services and pathways to ensure there is adequate provision to increase community-based care and increase patient and carer involvement in reviewing and designing services including integrating work from My Care Coordination Team and Avoiding Unnecessary Admissions caseloads.

2. Refresh the End of Life Care Strategy to join up end of life care services across Luton Increase through the LIG to increase patient opportunities to die in their preferred place.

3. Increase end of life training for staff across services including primary and secondary care, Luton Community Services, staff within care homes (especially helping staff to identify those nearing end of life) and how to have conversations with patients and relatives.
References


