

6.3.01 End of Life Care

Context

End of life care has been defined as care which:

“helps all those with advanced, progressive and 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”¹

People are generally regarded as approaching the end of life when they are likely to die within the coming 12 months. This includes people for whom death may be imminent and also those facing an uncertain future due to progressive, incurable illness, life-threatening acute conditions or increasing frailty and/or life-limiting co-existing conditions². A palliative care approach supports those nearing the end of their lives to live as well as possible until they die by preventing or relieving suffering through early identification and treatment of pain and other physical, psychosocial and spiritual problems³. As such, palliative care falls within the remit of all health and social care professionals. Some, but not all, people approaching the end of life also need the services of a specialist palliative care team to ensure that they receive the best possible care.

The needs of people approaching the end of life may be complex as well as highly individual, and are likely to span both health and social care. Movement between care settings occurs more frequently in the final year of life than at any other stage. Successful end of life care therefore requires effective multidisciplinary working within, and between, health and social care services across hospitals, hospices, care homes and the community.

A large part of end of life care is provided not by health care professionals but by family members, that may include children, and by friends, carers and volunteers. The role of these supporters is essential to the provision of good quality care at the end of life, but caring for someone who is dying is both physically and mentally demanding and carers frequently have needs of their own before, during and after the person's death that must be also addressed. End of life care must therefore include bereavement care and support.

The Government made improving the quality of care at the end of life a priority with the publication of the National Strategy for End of Life Care in 2008⁴. In 2012, the Government formally required the NHS to provide the highest standards of care to older people and those at the end of people's lives⁵. Responsibility for planning how to provide end of life care services became the remit of the NHS England in April 2013.

A new approach to end of life care has been introduced following a review⁶ of the Liverpool Care Pathway. This focused on the needs and wishes of the dying person and those close to them, moving end of life care away from the previous pathway based approach to one focused on the following priorities for care⁷:

- Priority 1:** The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- Priority 2:** Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- Priority 3:** The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- Priority 4:** The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- Priority 5:** An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

It is recognised that, wherever possible, enabling individuals to plan for death should start well before a person reaches the end of their life and should be integral to personalised care. The End of Life Care Strategy 2008⁴ highlighted the importance of the place of death, and choice in this, to dying people and their families. A key aim of the Strategy is to enable more people to be cared for and die where they choose, with dignity and respect.

Research has shown that home is the preferred place of death for the majority of people^{8,9} and meeting the expectations of individuals in relation to this is an important measure of quality in end of life care. Responding to this priority, an independent review with the aim of expanding choice and improving the quality of end of life care was commissioned in 2014; the panel are due to present their findings and recommendations to Government in February 2015.

National and local targets

- Proportion of all deaths that occur in own home / hospice / care home/ hospital
- Proportion of people identified as approaching the end of life
- Proportion of non-cancer patients identified as approaching the end of life
- Proportion of people with advance care plans available to all relevant professionals
- Proportion of people on end of life care register considered by a multidisciplinary team

Relevant strategies and local documents

- One chance to get it right: Improving people's experience of care in the last few days and hours of life 2014, Leadership Alliance for the Care of Dying People
- Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values, A mandate from the Government to Health Education England: April 2013 to March 2015, Department of Health 2013.
- More Care, Less Pathway: A Review of the Liverpool Care Pathway 2013
- National Survey of Bereaved People (VOICES) 2013, Office of National Statistics
- Rapid Evidence Review: Pathways Focused on the Dying Phase in End of Life Care and their Key Components 2013, University of Nottingham
- Delivering Dignity: Securing dignity in care for older people in hospitals and care homes, Commission on Dignity in Care, June 2012
- NICE QS13: Quality standard for end of life care 2011, National Institute for Health and Care Excellence (amended October 2013; to be reviewed following the outcome of the work of the Leadership Alliance for the Care of Dying People)
- Implementing the End of Life Care Strategy: Lessons for good practice 2010
- National Strategy for End of Life Care, 2008. Department of Health.
- Gold Standards Framework www.goldstandardsframework.org.uk

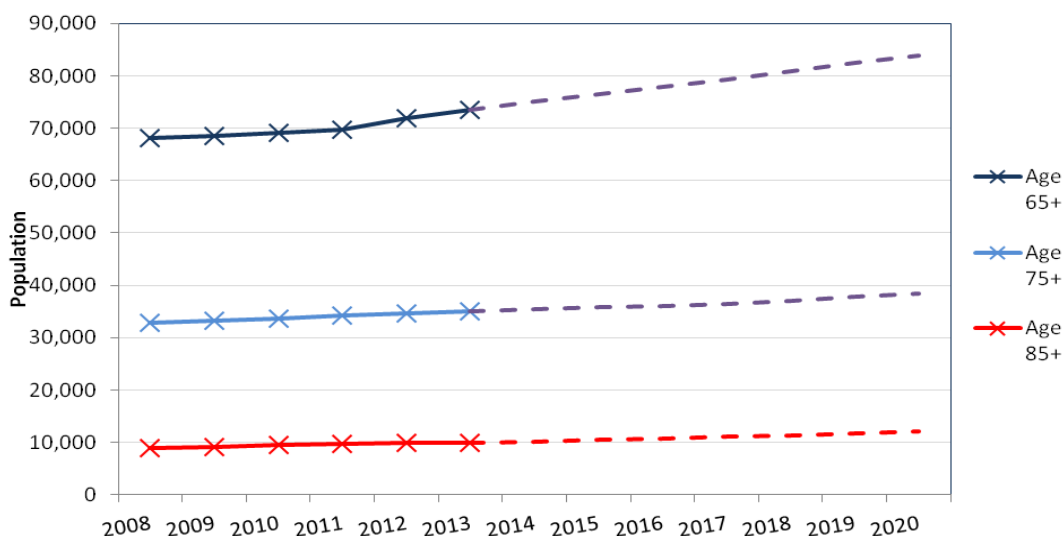
What do the data tell us?

People are living longer and proportionally, there are larger numbers of older adults now than in previous generations. Although the number of people dying each year has been declining over the last 30 years, this trend is predicted to change with the number of deaths rising over the coming twenty years from about 503,000 deaths a year in England and Wales in 2006 to around 586,000 in 2030¹⁰. The incidence of frailty and co-morbidity in the district are therefore set to increase as the population ages.

The table below compares Bradford's older population to the national:

| | Bradford District | | England | |
|---------------------------|-------------------|------|------------|------|
| | No. | % | No. | % |
| Total population | 526,369 | | 53,865,817 | |
| Older people aged: | | | | |
| 65 yrs and over | 73,572 | 14.0 | 9,305,179 | 17.3 |
| 75 yrs and over | 34,958 | 6.6 | 4,281,606 | 7.9 |
| 85 yrs and over | 9,855 | 1.9 | 1,237,867 | 2.3 |

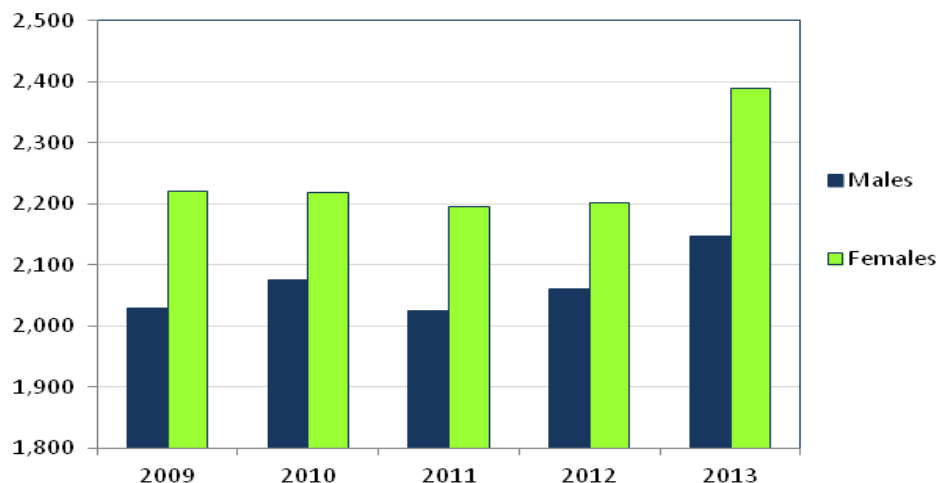
Source: Annual Mid-Year Population Estimates 2013, Office for National Statistics



Source: Population Estimates by single year of age mid-2008 to mid-2013 and 2012-Based Sub National Population Projections Office for National Statistics

Over 450,000 people die each year in England, and almost two thirds of these are aged 75 or over¹¹. The table below gives the total deaths registered in Bradford District over the last three years; the graph shows the pattern of deaths registered in the District over the last five years.

| Deaths registered in Bradford District | 2011 | 2012 | 2013 |
|--|-------|-------|-------|
| Total: | 4,222 | 4,261 | 4,537 |
| Male | 2,026 | 2,060 | 2,148 |
| Female | 2,196 | 2,201 | 2,389 |



Source: Deaths by Local Authority of usual residence 2009 - 2013, Office for National Statistics

Death occurs in a wide variety of settings, including the community, hospitals, care homes and hospices. The PRISMA survey¹² reported that the preferred place of death was their normal place of residence for 64% of people surveyed. Hospices and palliative care units were the second most common preference, with 29% of respondents choosing this option.

In Bradford a higher proportion of people die in their usual place of residence, which may be their own home or a care home, than is the case either regionally or nationally. This continues the trend observed in Bradford over recent years. However, despite the trend towards increasing numbers of deaths at home, hospital remains the most common place of death overall, despite there being no clinical need in an estimated 40% of these deaths^{8,13}.

The involvement of specialist palliative care services has a significant impact on outcomes for patients. In Bradford, their involvement results in significantly more people dying in their usual place of residence, with a concomitant reduction in the number of people that die in hospital. The table below provides data for place of death in Bradford District, where specialist palliative care services have been involved.

| Place of death: | 2013/14 |
|-----------------|---------|
| Home | 33% |
| Care Home | 8% |
| Hospital | 27% |
| Hospice | 30% |
| Unknown | 2% |

Source: MCNS and Data Quality EPaCCS Report 2013/14

There is some evidence that around a fifth of people who expressed a preference for their place of death to be their home may change their preference as their illness progresses^{14,15}. The reasons for this are not yet well understood but may include a range of issues such as increasing dependency, concerns about burdening their family and uncertainty about the adequacy of support available to manage worsening pain and other symptoms at home^{16,17}. There is evidence that the availability of dependable and effective support from family or other care providers increases the number of people who fulfil their wish to remain in their own home until death¹⁷.

Cause of death has a bearing on place of death. Research has shown that cancer is the most common cause amongst those who died at home or in a hospice, whereas deaths due to causes other than cancer occurred more often in hospitals or care homes¹⁸.

The table below shows the most common causes of death in Bradford for which end of life care was required, by place of death. The data are annual averages for 2008-10.

| Place of death | All causes | Causes of death recorded on death certificates | | | | |
|----------------|-------------|--|------------------------|---------------------|-----------------------------------|---------------------|
| | | Main causes | | | Contributory causes | |
| | | Cancer | Cardiovascular disease | Respiratory disease | Alzheimer's / Dementia / Senility | Respiratory disease |
| Hospice | 327 | 286 | 12 | 13 | 2 | 37 |
| Home | 874 | 274 | 315 | 94 | 73 | 195 |
| Care home | 941 | 145 | 249 | 152 | 519 | 307 |
| Hospital | 2101 | 376 | 723 | 379 | 191 | 924 |
| Total | 4358 | 1097 | 1338 | 642 | 789 | 1476 |

Source: National End of Life Care Profile for Bradford 2012, National End of Life Intelligence Network

In Bradford, cancer is by far the most common cause of death amongst those that occur in hospices; in care homes Alzheimer's disease and other forms of dementia predominate. Where the cause of death is respiratory or cardiovascular disease, the place of death is more likely to be a hospital.

Historically, only a small number of deaths other than those caused by cancer occur in hospice settings. However, hospices place no restriction on admissions by diagnosis and the low numbers seen are due to a number of external factors including a lack of advance care planning and the expectations of patients, carers and professionals. In 2013/14, referrals for non-malignant conditions made up 26% of all referrals to Specialist Palliative Care Services.

The proportions of deaths in which the Specialist Palliative Care Services (SPC) have been involved over the last three years are shown below for the three local CCGs; note that this includes Craven area data.

| % of deaths with SPC involvement | BDCCG, BCCCG & AWCCCG |
|----------------------------------|-----------------------|
| 2011 / 12 | 23% |
| 2012 / 13 | 24% |
| 2013 / 14 | 29% |

Source: MCNS and Data Quality EPaCCS Report 2013/14

More people are also living with cancer and are surviving for longer. It is likely that these people will need support for longer periods and later in their lives than was previously the case. It is important to note however, that the two hospices in the District have a bed occupancy rate of 85-90%. This means that there is no capacity to expand the provision of inpatient care within the current system.

Socioeconomic deprivation is also a determinant, not only of when and how people die but also of where. On a national level, people living in the most deprived quintile of the population are more likely to die in hospital and less likely to die in residential or nursing care homes than those in any other quintile¹⁹. Those in the most deprived quintile also experience the least choice over their place of death, as illustrated below²⁰.

| Deprivation Quintile | Number of responses | Proportion who had enough choice about their place of death |
|----------------------|---------------------|---|
| 1 (Most deprived) | 2,157 | 43.8 % |
| 2 | 2,403 | 50.9 % |
| 3 | 2,888 | 51.9 % |
| 4 | 2,923 | 53.0 % |
| 5 (Least deprived) | 2,867 | 53.6 % |
| Total | 13,238 | |

Source: Adapted from the National Bereavement Survey, 2011 release, Office for National Statistics

The correlation between deprivation and outcomes at end of life care is significant for Bradford, since around one third of the District's population live in the most deprived 10% of areas nationally²⁰.

The End of Life Care Strategy 2008⁴ highlighted the inequalities that exist between the care received by different groups of people the end of life. There is a growing body of evidence that unmet needs in relation to end of life and palliative care services are persisting, and in fact increasing, amongst older people from black, Asian and minority ethnic (BAME) communities for whom poor access to, and poor uptake of, end of life services is common²¹. A range of factors underlie these problems, including non-referral, lack of awareness about the service, poor communication about what is available and how to access the services and expectations that family will step in to provide the care. Problems stemming from cultural insensitivity and failures to provide information in appropriate formats or languages are also persisting^{21,22}.

These problems are significant as the numbers of older people of black, Asian and ethnic minority origins are increasing²³ and are expected to continue increasing into the future²⁴. The population of Bradford is currently estimated to be 526,369²⁵, 21.7% of which are of BAME origin. These issues will impact on not only the over 65 year olds in this group, but also on their families, friends and the wider community.

Locally in Bradford, people of South Asian heritage account for 27% population but make up only 8% of deaths because of their younger age profile²⁶. This group make up 7% of referrals to specialist palliative care, showing that a broadly equitable service exists. Non-cancer deaths account for 26% of referrals to specialist palliative care in the overall population; this rises to 30% amongst people of South Asian background.

A final minority group that deserves consideration is the single elderly. The number of people who live alone is increasing and a growing proportion of these have never had children²⁷. Therefore, as the population ages, a growing number of people will enter their third age without the benefit of family support. These individuals will face end of life decisions, and death itself, without the kind of support that has existed for previous generations and that we currently regard as the norm²⁸.

Research has shown that the preferred place of death for the majority of single older people is still their home, single status notwithstanding²⁹. There will therefore be an increasing need to consider the particular health and the social care needs of this group in the provision of end of life and palliative care services in coming decades³⁰.

Locally, 27% of referrals to specialist palliative care are for people who live alone and despite the challenges of providing care for the terminally ill under such circumstances, around 30% are cared for at home until death. However, outside specialist palliative care services both service users and staff describe services that are patchy and of variable quality.

What do our stakeholders tell us?

Nationally End of life care is often poorly coordinated, leading to duplication and gaps across health and social care service, and inappropriate hospital admissions, investigations and treatments.

A major review of end of life service provision across Bradford and Airedale for patients in their last year of life was carried out in 2007/8. Work carried out as part of this review showed that overall, the teams and services available in the District were well set up and could be expected to deliver end of life care of a good standard.

Future needs and gaps in provision

As a result of the 2007/8 review of End of Life Services in Bradford, the eight work streams shown were formed, each led by members of the Bradford and Airedale End of Life Programme Board and Managed Clinical Network for Palliative Care.

1. Electronic Palliative Care Co-ordination System
2. Last Weeks of Life
3. Integrated Care for Last Year of Life
4. Workforce Development
5. Easy to Ignore Groups
6. Carers
7. Bereavement
8. Transport

To address the need to improve and integrate end of life services, the Gold Standards Framework (GSF) has been rolled out across the District. The GSF meets all national standards for quality of care and is designed to enable staff to deliver coordinated and integrated cross boundary care between providers. Outcomes for patients include earlier recognition, proactive planning and care, better coordination of care in accordance with their wishes, less hospitalisation, more living and dying where they choose.

The GSF has now been introduced into clinical practice across Bradford with all District Nurse teams trained in GSF, around 30 nursing homes undertaking similar training and a dozen GP practices taking part in "Going for Gold", GSF for Primary Care. In acute settings Airedale General Hospital use GSF and Bradford Teaching Hospitals use the Amber care bundle, a similar framework designed specifically for acute settings.

Summary of priorities

Further to the work already undertaken to deliver on the eight priorities identified in 2008, there remained areas that needed to be taken forward as part of new commissioning arrangements.

An End of Life Summit was held in 2012 with representation from all three local Clinical Commissioning Groups (CCGs) and Social Care Services. This produced the following ten key recommendations to address the problems identified by service users and professionals:

- Improve the identification of patients at end of life and their entry onto the end of life register and increase the use of the SystemOne end of life template across all settings.
- Agree the role of the Lead Clinician and Coordinator of Care for patient thus identified.
- Embed the Gold Standard Framework in clinical practice and support the existing project to implement this within Care Homes.
- Agree solutions to effective integration of services, including social care, health (primary and secondary), out of hours services and voluntary services.
- Improve end of life care in hospital settings.
- Improve access to rehabilitation or patients in the final year of life.
- Ensure education to underpin the provision of high quality care.
- Consider measurement of user experience locally.
- Address inequities in bereavement care.
- Address the need for carer support.

The 2012 Summit also emphasised the need for, and secured agreement from stakeholders to adopt a collaborative approach for taking forward the work to implement these recommendations across all three of the Districts' CCGs, with a local focus where appropriate.

People entering the last stage of their life are often supported by many different professionals across a variety of specialties, and across a diversity of settings including, home, acute hospital, ambulance, residential / nursing home, hospice, community hospital and prison. A well integrated end of life care service is fundamental to enabling individuals and their families to exercise choices, both in their end of life care and in their choice of place to die.

The single, most important overarching priority for end of life care locally is that service planning and provision should continue to be undertaken collaboratively across all statutory and voluntary organisations together.

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