

# Chapter 15

## End of life care

### 15.1 Key audiences

Primary care trusts:

- commissioners of services for end of life care and for community and hospital services for older people
- directors of public health
- GPs
- community based palliative care teams
- community services providers
- frontline staff e.g. district nurses.

NHS foundation trusts and NHS trusts:

- medical directors
- palliative care teams
- care of the elderly physicians
- clinical directorate management teams
- nurse managers
- managers of allied health professionals (e.g. physiotherapy, occupational therapy, dietetics).

NHS ambulance trusts

- medical directors
- service development managers.

Third sector and independent providers of end of life services

- chief executives
- management committee members/trustees.

## 15.2 Key issues and concerns

### End of life – an issue for old age equality

It is an obvious but often overlooked fact that for most people the end of life occurs in old age.

- Of the 500,000 people in England and Wales who die every year, over 80 per cent are aged 65 or over.<sup>429</sup>
- The ratio of women to men of those aged 65 and over is falling. In 1983 there were 155 women aged 65 and over for every 100 men of the same age, compared to the current sex ratio of 130 women for every 100 men for this age group. By 2033 it is projected that the 65 and over sex ratio will have fallen still further to 117 women for every 100 men.<sup>430</sup>

Primary care trusts and healthcare providers will need to ensure that their end of life services meet the requirements of equality legislation. Any differences in access to end of life services would need to be able to be “*objectively justified*” i.e. would need to be a proportionate means of achieving a legitimate aim.

### Ageism and age discrimination at the end of life

- Ageism and age discrimination are thought by older people to be prevalent at the end of life.
- There are particular concerns about older people who are unable to speak for themselves and have no-one to speak up for them.
- Older people are not always enabled to make a choice about end of life care and where they die, perhaps not even to the limited extent that younger people can do so. The reasons for this are complex.

### ***Discrimination and disadvantage***

In 2005 Help the Aged published a report from the University of Sheffield<sup>431</sup> which reviewed the available evidence of the circumstances, experiences and preferences of older people in relation to end of life care. The report concluded that many older people and their carers experience systematic disadvantage and discrimination at the end of their lives, although that is not to say that individual staff held ageist attitudes.

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<sup>429</sup> *Mortality Statistics: Deaths registered in 2007*, Office for National Statistics, 2008

<sup>430</sup> [www.statistics.gov.uk/cci/nugget.asp?ID=949](http://www.statistics.gov.uk/cci/nugget.asp?ID=949)

<sup>431</sup> *End-of-life-care – Promoting comfort, choice and well-being for older people*, Seymour J, Witherspoon R, Gott M, Ross H, Payne S with Owen T, Policy Press, 2005

To supplement the University of Sheffield report, Help the Aged also published a further report<sup>432</sup> which included articles by seven older people about their experiences of dying, together with an overview of research evidence.

A further report from Help the Aged in 2006 found that some older people felt that ageism was responsible for the disrespectful and sometimes patronising way older people in need of care are treated. Particular concern was voiced about the care of vulnerable older people who had no family to speak up for them and people with dementia.<sup>433</sup>

### ***Inequalities in relation to choice about appropriate end of life care and preferred place of death***

It has been reported that of those who were aged 65 and over when they died, 59 per cent died in a hospital, 19 per cent died in a care home, 16 per cent died at home, and 4 per cent died in a hospice.<sup>434</sup> However, these figures do not indicate the proportion of older people who die in their preferred place, nor how the figures differ for over 65s compared to other age groups.

While it cannot be assumed that all older people wish to die at home (and for some, care homes are their homes at the end of life), it seems that older people may not always be able to choose where they would prefer to die, nor are they always enabled to receive the specialist palliative care services they may need at the end of life. These difficulties are not uniquely experienced by older people but there are various historical factors about the development of specialist palliative care which may result in older people having less choice about the kind of care they get at the end of life, and where it is delivered. [See section on palliative care, below.](#)

The higher proportion of older people dying in care homes and the lack of development of palliative care in these settings is another reason why older people may be less likely to receive good quality end of life services.<sup>435</sup>

### **Decision-making at the end of life**

- There are particular concerns about the impact of ageism and age discrimination on decision-making at the end of life – particularly in relation to decisions about resuscitation and clinically-assisted nutrition and hydration.
- Age should never be the determining factor in deciding when to withdraw or withhold potentially life-saving or life-extending treatments or procedures.

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<sup>432</sup> *Dying in Older Age – reflections and experiences from an older person's perspective*, edited by Owen T, Help the Aged, 2005

<sup>433</sup> *Listening to older people - Opening the door for older people to explore end-of-life issues*, Help the Aged, 2006

<sup>434</sup> *Dying and death, Age Concern Policy Position Paper*, 2008

<sup>435</sup> *Dying and death, Age Concern Policy Position Paper*, 2008

Older people often express concerns about decision-making at the end of life, particularly on life-and-death decisions on whether resuscitation should be attempted, and on whether clinically-assisted nutrition should be commenced or continued. These concerns are wide-ranging, with some older people fearing that they will be denied treatment from which they feel they may benefit, while others fear that they may be given certain treatments beyond the point when they might benefit.<sup>436</sup>

Honest and open communication with patients and their carers at the end of life is extremely important. Patients should be encouraged to think about and record their wishes for end of life care, where appropriate, and where they have capacity to do so.

Detailed guidance on end of life care is available from the General Medical Council, other regulators and professional bodies, and should be referred to as appropriate.

## Older people and palliative care

- Older people do not always have access to specialist palliative care that other age groups have.
- Most people receiving specialist palliative care have a diagnosis of cancer – but older people often die of other causes and may have co-morbidities and need more complex care.
- Older people with a diagnosis of cancer are less likely to be referred to or use specialist palliative care services than other adults with cancer.

Older people do not always have the same access to specialist palliative care services that are available to other age groups. Age Concern points out that since 33 per cent of all deaths are of people aged 85 and over, it could be expected that a similar percentage of people over 85 would gain access to specialist palliative care services.<sup>437</sup> In fact the percentage ranges from 9 per cent to 15 per cent.<sup>438</sup>

This may be partly because the development of specialist palliative care as a discipline was rooted in the modern hospice movement, and the care that they provided for cancer patients. It is only fairly recently that there has been a real push to make such care available to people with conditions other than cancer. Even recently, 90 per cent of people who receive specialist palliative care have a diagnosis of cancer, but cancer is the principal cause of death in only 25 per cent of cases.<sup>439</sup>

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<sup>436</sup> *Listening to older people - Opening the door for older people to explore end-of-life issues*, Help the Aged, 2006

<sup>437</sup> *Dying and death, Age Concern Policy Position Paper*, 2008

<sup>438</sup> *Minimum data sets for specialist palliative care*, National Council for Palliative Care, 2007

<sup>439</sup> *Dying and death, Age Concern Policy Position Paper*, 2008

There may be other explanations for why older people have used a relatively low level of specialist palliative care services. It is sometimes suggested that one reason for older people not receiving specialist palliative care is that they more often develop chronic illnesses which have not traditionally been the focus for specialist palliative care. But even older people with cancer may not have been referred to or may not use specialist palliative care.<sup>440</sup>

A further issue is older people are more commonly affected by multiple medical problems of varying severity. The cumulative effect of these may be much greater than any individual disease, and typically lead to greater impairment and needs for care.<sup>441</sup>

Age Concern notes that it has also been suggested that the lower levels of palliative care for older people may be due to a greater acceptance of death and more time to plan with a resulting reduced need for support. However, Age Concern has suggested that the lack of development of palliative care services for conditions more prevalent in older people or in settings where they are more likely to die, together with more limited access when they have the same diagnosis as younger people, is the result of underlying ageist attitudes and of the lives of older people being undervalued.<sup>442</sup>

Although there has been some change, older people remain under-represented in inpatient hospices, and with increasing age they are less likely to receive care for their final illness in a hospice. This may well signify discrimination which needs to be addressed, but it should be borne in mind that many older people (as well as people of other ages) would wish to access specialist palliative care in their own homes or other community settings, rather than in hospital.

## **End of life care and people with dementia**

[Also see Chapter 14 Mental health \(including dementia\).](#)

There is strong evidence to suggest that people with dementia receive poorer end of life care than those who are cognitively intact, in terms of provision of palliative care. For example, few people with dementia have access to hospice care.<sup>443</sup>

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<sup>440</sup> *The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review*, Burt J, Raine R, *Age and Ageing* 2006 35(5):469-476; doi:10.1093/ageing/af1001

<sup>441</sup> *Better Palliative Care for Older People*, edited by Davies E and Higginson I J, The World Health Organization Europe, 2004

<sup>442</sup> *Dying and death, Age Concern Policy Position Paper*, 2008

<sup>443</sup> *Living Well with Dementia: A National Dementia Strategy*, Department of Health, 2009

## Pain control at the end of life

Pain control can be a particular issue at the end of life, particularly if people are in residential settings.<sup>444</sup> There is evidence that older people tend to under-report their symptoms and doctors tend to under-treat pain in older people for both patients with cancer and those with other diagnoses.<sup>445</sup>

There are also particular issues for controlling pain in older people with dementia, whose condition makes it harder to communicate about their experience of pain, as a result of which clinicians may have difficulty in making an assessment of their pain.

## Dual/multiple discrimination

*“Variations in the quality of end of life care exist across the country and there is concern that among certain groups of dying patients, such as the old, those with non-cancer diagnoses, people from black and minority ethnic (BME) backgrounds and those in rural areas, there is an unacceptable level of variance.”<sup>446</sup>*

In the context of end of life care, it will be important to be aware of the possibility of discrimination resulting from age in combination with other factors that are associated with “*protected characteristics*”. Effective monitoring of access to and uptake of services (e.g. by BME groups) will be useful.

There is relatively little evidence in respect of inequalities in end of life care and age and race. However, a number of studies have looked at the needs of both BME patients and carers in end of life care and have found that there are factors associated with faith, culture and language which mean that closer attention needs to be paid in order to fully meet their needs. Even now, there are relatively few people from BME communities using care homes or hospices and this could be due to a range of factors including language, cultural and religious issues. However, as an article on the NHS Evidence website explains, it may be that BME patients are still choosing not to access these services, whether through the voluntary sector or the NHS, or it may be that primary and secondary care providers are failing to refer them to these services.<sup>447</sup>

These issues need to be explored more fully at a local level.

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<sup>444</sup> *Pain In Older People - A Hidden Problem. A qualitative study*, Picker Europe, commissioned by the Patients Association, 2007

<sup>445</sup> *Better Palliative Care for Older People*, edited by Davies E and Higginson I J, The World Health Organization Europe, 2004

<sup>446</sup> *End of Life Care Strategy – Equality Impact Assessment*, Department of Health, 2008

<sup>447</sup> *Palliative care and ethnic minorities in Britain*

[www.library.nhs.uk/Ethnicity/ViewResource.aspx?resID=284112&tabID=290](http://www.library.nhs.uk/Ethnicity/ViewResource.aspx?resID=284112&tabID=290)

Achieving age equality in health and social care – NHS practice guide | May 2010

Chapter 15 End of life care | [www.southwest.nhs.uk/age-equality.html](http://www.southwest.nhs.uk/age-equality.html)

Lesbians, gay men, bisexuals and transgender (LBGT) people may also experience multiple discrimination at the end of life. There needs to be attention paid to how advocacy services and bereavement counselling can be developed and tailored to meet the specific needs of older lesbians and gay men.<sup>448</sup>

Transgender people and those close to them can experience particular problems at the end of life, particularly in relation to gender recognition and the status of the deceased person.<sup>449</sup>

## 15.3 Drivers and policy imperatives

### End of Life Care Strategy - promoting high quality care for all adults at the end of life

In 2008 the Government published its *End of Life Care Strategy - promoting high quality care for all adults at the end of life*.<sup>450</sup> Its aim is to provide people approaching the end of life with more choice about where they would like to live and die, and it is also about improving the care that all adults at the end of life and their family and carers receive. It encompasses all adults with advanced, progressive illness and care given in all settings. It is explicit about the need to address inequalities in the provision of end of life care and it states:

*“In the past, the profile of end of life care within the NHS and social care services has been relatively low. Reflecting this, the quality of care delivered has been very variable. Implementation of this strategy will make a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.”*

A useful resource that sets out ten actions for implementing the National End of Life Care Strategy has been published by the King's Fund.<sup>451</sup>

→ [www.kingsfund.org.uk/publications/leeds\\_castle\\_eolc.html](http://www.kingsfund.org.uk/publications/leeds_castle_eolc.html)

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<sup>448</sup> *Lifting the Lid on Sexuality and Ageing*, Gay and Grey in Dorset, Help and Care Development Ltd, 2007

<sup>449</sup> *End of Life Care Strategy – Equality Impact Assessment*, Department of Health, 2008

<sup>450</sup> *End of Life Care Strategy - promoting high quality care for all adults at the end of life*, Department of Health, 2008

<sup>451</sup> *Delivering better care at end of life. The next steps. Report from the Sir Roger Bannister Health Summit*, Leeds Castle, 19–20 November 2009, Eds. Addicott R, Ashton R, King's Fund, 2010

## Mental Capacity Act 2005

The Mental Capacity Act (MCA) came into force in 2007 and is supported by the Mental Capacity Act Code of Practice. It protects people who cannot make decisions for themselves due to a learning disability or a mental health condition, or for any other reason. It provides clear guidelines for carers and professionals about who can take decisions in which situations. The Act states that everyone should be treated as able to make their own decisions until it is shown that they are not. It also aims to enable people to make their own decisions for as long as they are capable of doing so. Those who are working with people who are coming towards the end of their lives will need to be particularly aware of the provisions of the Mental Capacity Act and the Code of Practice. See:

→ [www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf](http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf)

## National Service Framework for Older People<sup>452</sup>

Although the *National Service Framework (NSF) for Older People* has run its course and the dates for the milestones have passed, it is mentioned here as it was an early key document that set standards that are relevant to end of life care, notably:

Standard One, rooting out age discrimination  
Standard Two, person-centred care  
Standard Four, general hospital care.

The *NSF for Older People* included a checklist for ensuring dignity in end of life care within Standard Two (person-centred care). This list highlighted the importance of information and communication, control of painful and other distressing symptoms, rehabilitation and support as health declines, social care, spiritual care, complementary therapies, psychological care and bereavement support.

The NSF also acknowledged that access to palliative care was limited for older people and that this can be age discriminatory.

## NHS Next Stage Review – High Quality Care for All

Lord Darzi's Review<sup>453</sup> introduced no new targets, but made it clear that the emphasis on personalisation must be seen to apply equally at the end of life. The report noted:

*“The necessity for greater dignity and respect at the end of life was movingly described by the end of life groups, as well as the desire to have round the clock access to palliative services.”*

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<sup>452</sup> *National Service Framework for Older People*, Department of Health, 2001

<sup>453</sup> *NHS Next Stage Review – High Quality Care for All*, Department of Health, 2008

## Living Well with Dementia: A National Dementia Strategy

Part of the vision of the National Dementia Strategy<sup>454</sup> is to:

*“enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.”* (page 21)

Objective 12 of the National Dementia Strategy specifically relates to improved end of life care for people with dementia.

**Objective 12: Improved end of life care for people with dementia.**  
*“People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.”*

Paragraph 14 of the National Dementia Strategy states:

*“Those involved in developing the Strategy worked closely with other emerging policy initiatives such as the NHS Next Stage Review, the Carers’ Strategy, End of Life Care Strategy and Putting People First. For example, the Next Stage Review local clinical pathway groups and the SHA vision process were informed by the evidence that was collected for the National Dementia Strategy. The objectives of this Strategy are complementary to such programmes of work and delivering the National Dementia Strategy will help to deliver these other goals.”*

## 15.4 What good age-equal practice might look like

### Treating people as individuals

Good practice for older people (and others) at the end of life depends to a great extent on treating people as individuals, which accords closely with the current emphasis on personalisation in health and social care. Research shows that people want to be treated as individuals, not primarily as patients or as *older* people; they wanted to be treated with respect and to be involved in decisions relating to their treatment and care; they want health and social care professionals to talk to each other, so that care might be planned appropriately; and they want decisions relating to treatment and care at the end of life to be equitable, rather than based on postcode, ability to pay or the ability of the individual, or the individual’s family, to articulate need.<sup>455</sup>

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<sup>454</sup> *Living Well with Dementia: A National Dementia Strategy*, Department of Health, 2009

<sup>455</sup> *Listening to older people - Opening the door for older people to explore*

## Identifying people who are approaching the end of life

Clinicians and those delivering care will wish to provide opportunities for having sensitive discussions about preferences for end of life care. When individuals are identified as approaching the end of life, it is important to have ways of ensuring that their needs and preferences are respected and met as fully as possible. Increasingly, GP practices have in place registers to support the identification of all people who are approaching the end of their lives. If they do so, many of the people who will be identified will be older people, and they will therefore be better placed to receive an age-equal service that meets their needs. To ensure that everyone gets access to end of life care who requires it, these registers should be in place across the country. These registers should also be accessible to other service providers, to ensure that they are alerted to, and can cater for the specific needs of people at the end of their lives.<sup>456</sup>

## Enabling people to choose their preferred place of death

Whilst a majority of people at the end of life express a wish to die at home, nearly 60 per cent die in hospital. A significant reason for this is the lack of service provision in the community. With limited access to appropriately skilled care, many people at the end of life are admitted to hospital for relatively routine treatment. Frequently, there is then a lack of sufficient support in place in the community, as well as problems gaining prompt access to an ambulance, to enable them to be discharged. Putting in place comprehensive 24/7 community medical and nursing cover, which can also provide a rapid response to emergencies, would enable the handling of many crisis episodes within the community setting, and would provide the necessary support to allow people to die at home.<sup>457</sup>

In 2007 the National Audit Office (NAO) concluded that services in the community, care homes and at the end of life were not delivering consistently or cost effectively against the objective of supporting people to live independently as long as possible in the place of their choosing. The NAO advocated a 'spend to save' approach, with upfront investment in services for early diagnosis and intervention, and improved specialist services, community services and care in general hospitals resulting in long-term cost savings from prevention of transition into care homes and decreased hospital stay length.<sup>458</sup>

One of the ways in which this might be best achieved is for NHS commissioners to work with local authorities and with providers of residential

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*end-of-life issues*, Help the Aged, 2006

<sup>456</sup> *Impact assessment of the end of life care strategy*, Department of Health, 2008

<sup>457</sup> *End of Life Care Strategy – Equality Impact Assessment*, Department of Health, 2008

<sup>458</sup> *Improving services and support for people with dementia*, NAO, 2007

care in order to improve end of life care in residential care homes, and avoid unnecessary hospital admissions. Older people and their organisations would be valuable partners in this work.

Since services have tended to engage with younger people on issues of choice and have tended to be less aware of age-equality in this context, it is important to ensure that older people are enabled and supported to make choices to the same extent as younger people.

## **Improving ambulance services for people at the end of life**

Ambulance services, and patient transport providers, play a key role in enabling people at the end of life to access health care and to die in the place of their choice. However, people at the end of life who are waiting for booked transport to take them back to their home (including care homes) after a hospital admission can experience substantial waits for an appropriately equipped and staffed vehicle, which could potentially be diverted to emergencies. This can result in some older people dying in hospital who could otherwise die at home. This issue could be addressed by reviewing the number of vehicles and staff so that an adequate service can be provided to people at the end of life, which will, in itself benefit many older people.

There are also concerns that information on a person's preferences for care are not always disseminated to ambulance crews, leading to medical interventions that are not consistent with the person's wishes. This issue requires ambulance trusts to have procedures in place to ensure that crews have access to details on the particular care needs and preferences of people who are at the end of life.<sup>459</sup>

## **Improving the environment**

The environment in which care is delivered has a substantial impact on people's perceptions of the overall quality of care provided at the end of life, both for those who are dying and their relatives and carers. However, in hospitals (where most people die) the environment is often poorly designed, and does not enable care to be delivered with appropriate dignity and respect. Putting in place a programme of improvements to hospital environments, such as the development of palliative care suites and areas for relatives and carers, will provide substantial improvements in the quality, and experience, of care.<sup>460</sup>

Some environmental issues are particularly important to older people, such as their experience of mixed sex wards. The Centre for Policy on Ageing (CPA) notes that while it might generally be assumed that older patients would be

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<sup>459</sup> *Impact assessment of the end of life care strategy*, Department of Health, 2008

<sup>460</sup> *Impact assessment of the end of life care strategy*, Department of Health, 2008  
[Achieving age equality in health and social care – NHS practice guide | May 2010](#)  
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those least happy with mixed sex wards, older patients are more likely than younger patients to be placed in a mixed sex environment.<sup>461</sup>

See also Chapter 5 High quality care for all.

More recently, the Department of Health has noted:

*“Women, older people and some minority ethnic groups are more likely to worry about being in mixed-sex accommodation. Older people represent the largest users of NHS services and account for two thirds of NHS hospital admissions. They are most likely to find mixing ‘not at all acceptable’.”*<sup>462</sup>

## Support for carers, including bereavement support

The time up to and after the death of a loved one is very difficult and can have long-term effects on the health of carers and relatives. Comprehensive support should therefore be available to carers and relatives to enable them to cope. This is particularly important since the carers of older people at the end of life are often in the older age groups themselves.

Ensuring that organisations dealing with people at the end of life have comprehensive information available on how to access bereavement support services will also improve the care that the bereaved receive.<sup>463</sup>

## Ensuring a whole system approach

The end of life care strategy notes the importance of a whole-system approach and appropriate care pathways. This approach encompasses many of the components of good practice identified above, from identifying those who are nearing the end of their lives to care for bereaved people, and all the stages in between. There is much documented good practice to draw on, and this is available on the website of the National End of Life Care Programme:

→ [www.endoflifecareforadults.nhs.uk/eolc](http://www.endoflifecareforadults.nhs.uk/eolc)

Essentially, many of the features of appropriate whole-system approaches to end of life care are similar for people of all ages. However, an age-equal approach will require commissioners and providers to consider whether older people and their carers have any particular needs in addition to those that are common across age groups.

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<sup>461</sup> *Ageism and age discrimination in secondary health care in the United Kingdom. A review from the literature*, CPA, 2009

<sup>462</sup> [www.dh.gov.uk/en/Healthcare/Samesexaccommodation/Whysame-sexaccommodationmatters/DH\\_110635](http://www.dh.gov.uk/en/Healthcare/Samesexaccommodation/Whysame-sexaccommodationmatters/DH_110635)

<sup>463</sup> *Impact assessment of the end of life care strategy*, 2008

## 15.5 Case studies of illustrative / good practice

### **Marie Curie Cancer Care/British Heart Foundation palliative care, heart failure nurses**

#### ***The Delivering Choice Programme, Marie Curie Cancer Care.***

The Marie Curie Delivering Choice Programme helps local providers and commissioners of care to develop the best possible local services for palliative care patients, regardless of diagnosis, so that they are cared for in the place of their choice. This has highlighted the benefits of taking a whole-systems approach to the delivery of end of life care. The programme has funded and managed seven projects across the UK - in Lincolnshire, Leeds, Tayside (Scotland), Barnet (north London), south-east London, Somerset and Northumberland, Tyne and Wear.

#### **Further information**

[nicky.agelopoulos@mariecurie.org.uk](mailto:nicky.agelopoulos@mariecurie.org.uk)

### **Bereavement Centre at St Thomas' Hospital**

St Thomas' Hospital - part of Guy's and St Thomas' NHS Foundation Trust - has, with the support of Guy's and St Thomas' Charity, set up a dedicated bereavement centre. Specially commissioned artwork has created a calm and peaceful environment and the centre enables bereaved people to access a range of help and support in a single location following the death of a loved one. The centre's staff work closely with the local authority to offer a service that enables families to deal with the notification of death, registration process and informing different government services all from one place. This is a significantly improved service, saving users distress and time.

#### **Further information**

James Lowell,  
[james.lowell@gstt.nhs.uk](mailto:james.lowell@gstt.nhs.uk)

## 15.6 Suggestions for quick wins / what you can do now

- **Work with local partners to understand the needs and experiences of older people regarding end of life care**  
While a huge amount is known about the needs and preferences of older people in relation to end of life care, less may be known about the specific needs and experiences of older people in particular areas, taking into account local demographic factors such as ethnicity and rurality. Joint work between NHS organisations, local authorities, the third sector and older people and their organisations should enable better joint work and joint planning on end of life issues.

- In particular (and as suggested by the equality impact assessment of the end of life care strategy), care homes, hospices, extra care housing, etc, should consider collecting information about each resident's ethnicity, religion, language and culture to ensure that they are able to meet the needs of people from BME communities. Information on other equality standards will be similarly valuable. (Appropriate consents to record, store and share this information must be obtained in compliance with the Data Protection Act ).
- **Review the provision of specialist end of life care and palliative care**  
Using the JSNA process, review, with the involvement of older people and their organisations, the extent to which local need for specialist and palliative care is adequate to meet the end of life care needs of people of all ages and with all terminal conditions, and in ways that are appropriate to people of diverse cultures and faiths.
- In particular, those involved in such reviews may wish to refer to the definitions of supportive care, palliative care and specialist palliative care services, as set out by the National Council for Palliative Care.  
→ [www.ncpc.org.uk/download/PalliativeCareExplained.doc](http://www.ncpc.org.uk/download/PalliativeCareExplained.doc)
- It may also be useful at a local level to compare the pathway of older people and younger people with similar conditions at the end of life, to assess whether there is evidence of age discrimination.

## 15.7 Useful resources

National Council for Palliative Care:

*Creative Partnerships: Improving Quality of Life at the End of Life for People with Dementia*, January 2008

*Progress with Dementia – Moving Forward: Addressing Palliative Care for People with Dementia*, August 2007