

# A different ending

## Addressing inequalities in end of life care

Good practice case studies



The Care Quality Commission is the independent regulator of health and adult social care in England.

### Our purpose

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

### Our role

We **register** care providers.

We **monitor, inspect and rate** services.

We **take action to protect people** who use services.

We **speak with our independent voice**, publishing regional and national views of the major quality issues in health and social care.

### Our values

**Excellence** – being a high-performing organisation

**Caring** – treating everyone with dignity and respect

**Integrity** – doing the right thing

**Teamwork** – learning from each other to be the best we can



# Contents

<b>HOW TO USE THIS REPORT .....</b>	<b>2</b>
<b>WHAT IS GOOD END OF LIFE CARE? .....</b>	<b>3</b>
<b>PROVIDERS GETTING IT RIGHT .....</b>	<b>4</b>
<b>A STRATEGIC APPROACH TO EQUALITY-LED COMMISSIONING .....</b>	<b>7</b>
<b>IMPROVEMENT APPROACHES TO END OF LIFE CARE FOR SPECIFIC GROUPS .....</b>	<b>9</b>
<b>COORDINATION OF CARE AND INFORMATION SHARING .....</b>	<b>11</b>
<b>COMMUNITY DEVELOPMENT .....</b>	<b>12</b>



# How to use this report

This report is one of a suite of documents reporting on our end of life care thematic review, and is designed to be read in conjunction with the other documents. The suite of documents includes:

- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained settings
- Gypsies and Travellers.

## **A different ending: addressing inequalities in end of life care** Overview report

This report provides the background to the review, an overview of the key findings and recommendations for providers, commissioners and local health and care system leaders, as well as information about what CQC will do going forward.

## **A different ending: addressing inequalities in end of life care** Good practice case studies

This document brings together examples of good practice in end of life care that we found through our review for different groups, including our visits to local areas, which others can learn from.

Visit [www.cqc.org.uk/differentending](http://www.cqc.org.uk/differentending) to read the other documents in the suite of products.

## **A different ending: addressing inequalities in end of life care** People's experience briefings

These documents provide more detail on people's experiences of end of life care. There are 10 briefings in the series:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and minority ethnic (BME) groups
- lesbian, gay, bisexual or transgender people



# What is good end of life care?

As highlighted in our overview report, the organisations National Voices and the National Council for Palliative Care describe good, personalised end of life care in the following way:

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”<sup>1</sup>

This emphasises that good care at the end of life places the individual at the centre of their care. The wishes and choices of the person who is dying are paramount, because what is important to each individual in the last phase of their life will be different.

The Care Quality Commission (CQC) recognises the importance of end of life care as an integral part of the good health and care that everyone should receive throughout their life. Good end of life care is consistently described in national standards and guidance, and the National Palliative and End of Life Care Partnership, of which CQC is a member, sets out the action needed to achieve high quality

care for everyone in *Ambitions for Palliative and End of Life Care*.<sup>2</sup>

We are committed to encouraging the improvements in quality that are needed to make sure that everyone receives the good, personalised care they should be able to expect at the end of their life.

This document brings together some examples of good practice in end of life care for different groups. We have identified these examples from our inspections and through our review, including our visits to local areas. They represent only a small proportion of the good care being delivered by committed and compassionate staff to people who are in the last phase of their life.

Furthermore, these examples demonstrate what can be done when commissioners and services themselves understand the needs of everyone in their community and ensure that end of life care is personalised and responsive to people’s individual needs. We hope that others will be able to learn from them.

<sup>1</sup> National Voices and the National Council for Palliative Care, **Every moment counts: a narrative for person-centred coordinated care for people near the end of life**, 2015

<sup>2</sup> National Palliative and End of Life Care Partnership, **Ambitions for palliative and end of life care**, 2015



# Providers getting it right



## Frimley Park Hospital

In September 2014, we rated Frimley Park Hospital in Surrey as outstanding for its end of life care services overall, and for the key question “are services responsive?”. When we inspected, we found a trust-wide commitment to providing caring and compassionate support that was tailored to people’s individual needs.

Many specialties and staff, at all levels, were involved in the end of life care strategy and its governance and delivery. The trust had systems in place to identify people who were approaching the end of their life at an early stage, including people with conditions other than cancer, which involved specialist palliative care staff in conversations. Over half (51%) of people seen by the specialist palliative care team in 2013/14 had conditions other than cancer.

The trust ensured that people’s social, cultural, religious and language needs were met. It did

this, for example, by providing family rooms that accommodate same sex partners or large Traveller families, and trained interpreters from the local Nepali community. The end of life care needs of people with dementia were specifically considered in the Dementia Strategy, and people with dementia and their families were supported by the dementia lead nurse and link nurses.

Equality and diversity was embedded in practice. As well as considering the demographics of the local population to inform service development, the trust was also monitoring quality of care for different groups.

In addition, the hospital worked with other local services, including hospice at home and community teams, to reduce the number of people dying in hospital. Between 2008 and 2013, it had reduced deaths in hospital by 28%.



## Salford Royal NHS Foundation Trust

We rated Salford Royal’s community end of life care services as outstanding overall and for the key question “are services responsive?” in March 2015.

The way in which the trust responded to people’s individual and group needs, in particular through the work of the Care Homes Medical Practice,

was outstanding. The specialised focus of the practice meant that GPs and other staff were experts in the care of frail older people and, consequently, in end of life care. The practice was set up to respond to the needs of individuals who were in their last year of life.

Community end of life services were highly accessible, timely and person-centred. The trust's board and governors prioritised engagement with seldom-heard community groups, and were improving their provision of end of life care to different groups within their local community.



## Nazareth Lodge

We rated Nazareth Lodge care home in Dorset as outstanding. We found that compassionate, high-quality end of life care was a central principle of the service, and all staff were trained in end of life care. One senior member of staff had qualified as a trainer and also trained other staff in the area to help build confidence and understanding.

Staff worked closely with the local hospice and community health professionals to make sure that people who were approaching the end of life received good care. The care home put people and those who are important to them at the centre of their care, ensuring that when a person

As a result, there were good links with the local Jewish community, and regular meetings with the Rabbi to ensure that the service could respond positively to traditional Jewish end of life care cultural practices and timings.

died, they looked after their family as well as the other people who lived at the care home who had been bereaved.

The care home is accredited by the Gold Standards Framework, an organisation that recognises good practice in end of life care.<sup>1</sup> As an accredited care home, Nazareth Lodge held advance discussions with everyone in the home and avoided inappropriate hospital admissions. Staff also provided good care in the final days of life, which were in line with the Five Priorities of Care for the Dying Person.

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<sup>1</sup> Gold Standards Framework:  
[www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)



## Inclusion Healthcare Social Enterprise

Inclusion Healthcare provides primary medical services for homeless people in Leicester. We rated it outstanding following our inspection in November 2014. Our inspectors found strong leadership at its heart and a positive culture, which ensures that patient safety is paramount.

The practice was committed to reducing health inequalities and improving the health and wellbeing of vulnerable population groups, including people who are homeless, in prison, live in a hostel or have a learning disability. It worked with many organisations around Leicester to support patients, and held and actively used a register of people who may be vulnerable because of their circumstances.

The practice had an identified lead for end of life care and used the local clinical commissioning group model, 'Deciding Right – Planning your care in advance' to support advance care planning. In addition, each patient had

an 'emergency health care plan' (EHCP). This informs healthcare professionals of the patient's wishes and any treatment they should receive. Patients, and any relatives or carers where appropriate, were involved in developing the EHCP with the clinician.

The practice has created a charity, 'INCH foundation', to support homeless people. Recently the foundation funded a day trip to the beach for a homeless person before they died, and members of the nursing team supported the patient. The practice also contributed to funeral costs and memorials for patients who were homeless. They have created a memory wall at a local day centre and a project for homeless people.

You can hear more about the experiences of the staff and patients at Inclusion Healthcare in our online video: [www.cqc.org.uk/soc-outstanding](http://www.cqc.org.uk/soc-outstanding)



## Rosebank Surgery, Lancaster

We rated Rosebank Surgery in Lancaster as good overall and outstanding for its care for older people. The practice was caring and strived to give people a dignified death. This was actively supported by practice staff and local community initiatives. It also had systems that reflected best practice in end of life care.

Patients were offered conversations around end of life planning, including advance care plans, preferred priorities for care and resuscitation wishes. Ninety-eight per cent of patients who should be on the palliative care register were on the register, and 85% of patients had their preferred place of care documented. Eighty-one per cent of patients were not in hospital when they died.

The practice had taken a supportive approach to end of life care. This included changing the palliative care register to a supportive care register to help identify frail older people and people with dementia at an earlier stage. Multidisciplinary supportive care meetings were held on a monthly basis to discuss the needs of people approaching the end of life. In addition, clinical staff received in-house training in end of life care, including how to hold difficult conversations.



# A strategic approach to equality-led commissioning



## Needs assessment and prioritisation in North West Surrey

North West Surrey Clinical Commissioning Group (CCG) has prioritised the needs of its local population in developing its end of life care services. As well as conducting a needs assessment to inform its strategic commissioning plan, the CCG is updating the Joint Strategic Needs Assessment to focus on the needs of different equality groups.

In particular, the CCG has focused on the needs of older people and people with dementia. It is supporting professionals to identify people earlier so that there is a proactive and planned approach to care. The needs of other groups, including people with a learning disability, people who are homeless, and Gypsies and Travellers, have also been identified.

There is an End of Life Care Steering Group for the area and members include the CCG and representatives from key providers across the acute, community, hospice and wider voluntary sector. This feeds in to the CCG's clinical and executive decision-making forums, as well as

North West Surrey Palliative Care Forum, which includes representatives of people with dementia and Gypsies and Travellers. The steering group has agreed a single approach and has standard documents for advance care planning that are to be used across all care settings.

The CCG has commissioned the Coordinated, Safe, Integrated (CoSI) team to improve care in the last six to eight weeks of life for people with chronic progressive illness. The team, which is a collaboration between local hospices, acute and community services and Marie Curie, coordinates services across community care providers. It helps people to choose their preferred place of care, as well as help to prevent inappropriate admission to hospital. The service also supports carers with heightened anxiety, fear, or fatigue, who need additional care and respite day or night. The service supports over 90% of people to die in their preferred setting, and recently won the Kent, Surrey & Sussex Academic Health Science Network award for End of Life Care.



## An equality-led approach in Central Manchester

Central Manchester Clinical Commissioning Group (CCG) has made equality a central part of its end of life care approach and focuses on inclusive service delivery to ensure it is delivering the Equality Duty.

As well as embedding equality analysis into its decision-making processes, the CCG looks at the impact on people from socially excluded groups, such as people who are homeless, Gypsies and Travellers and migrant workers, as well as those with protected equality characteristics.

One action taken as a result of equality analysis in commissioning end of life care is assessing whether gender identity differed at birth for each person. While this was initially omitted from the development of the Electronic Palliative Care Coordination System, it has subsequently been added in to the system.

As part of its approach, the CCG works closely with MACC, Manchester's voluntary and community sector support organisation, to gain

feedback from patients and advocates. As a result of this engagement, a care home project was commissioned to ensure that frail, older people with non-cancer diagnoses have access to the right services. The project has delivered training to staff in care homes, to enable them to be more confident in discussing people's preferred place of death and advance care planning, and to deal with a crisis more effectively. As a result, admissions to hospital have reduced by 68%.

The CCG has also commissioned the Manchester Pathway (MPath) service to reduce A&E attendances and hospital readmission for homeless people. This has led to people who are likely to be approaching the end of life being identified earlier (see case study 'MPath: improving end of life care for homeless people' on page 10).

The CCG undertakes ongoing monitoring and reporting through yearly equality performance monitoring, provider monitoring and strategic overview.



## Taking a strategic approach to end of life care

Havering Clinical Commissioning Group (CCG) prioritises the needs of vulnerable adults and older people through its Joint Strategic Needs Assessment. As a result, the CCG commissioned training from the Gold Standards Framework (GSF) for all 48 GP practices, as well as care and nursing homes in Havering. GSF training encourages organisations to take a systematic approach to improving care for people approaching the end of life. To date, 90% of GP practices and 44% of care homes have undertaken the training.

The majority of care and nursing homes in Havering have also been aligned to a GP practice. GPs told us that weekly reviews in care homes, as well as receiving discharge summaries from hospital admissions, were helping them to identify the end of life phase for people over

75 and people with dementia in a timely way. This is supported by figures that show hospital admissions for people who live in care homes reduced by 24% in 2013/14.

In addition, the CCG has established an End of Life Steering Group to coordinate end of life care initiatives within the borough. Members include the CCG, local authority, the local acute hospital, the community and mental health trust, hospices, and voluntary sector providers. The CCG also collaborates with two neighbouring CCGs on a number of joint strategic priorities, including GP end of life training; strengthening coordination of end of life services across health and social care through community services development; investment in community nursing; electronic end of life care planning; and implementing the Five Priorities for Care of the Dying Person.



# Improvement approaches to end of life care for specific groups



## Improving quality of care in South Sefton

South Sefton Clinical Commissioning Group (CCG) identifies care for older and vulnerable people, including end of life care, as a priority. Frail older people make up a large proportion of the deaths in the local area, with around 1,200 people living in care homes across South Sefton. However, in many cases people were frequently being transferred to hospital, sometimes unnecessarily, or were not being identified as approaching end of life until their very final days.

The Care Home Innovation Programme (CHIP) aims to improve the quality of care for people who live in a care home and to reduce unnecessary interventions. The ultimate goal is to enable the number of people dying in their preferred place of care to increase. CHIP also aims to help the person and their next of kin to make decisions about their care, and encourages advance care planning through the support of a community multidisciplinary team (MDT).

In order to facilitate change and take a proactive approach to end of life care, it was critical to

provide care homes with an alternative to calling 999, as well as the support of a community-based team. CHIP provides a multifaceted approach, including a focus on quality improvement, locally-based care home community matrons, community geriatricians, and training for healthcare staff in care of the dying through the Six Steps programme (see the following case study on page 10). A telemedicine service provides MDT support for the care homes 24/7 and is available for emergency and less urgent clinical matters.

Feedback from care homes is that staff have increased confidence in caring for people at the end of life. There is good support from other services, including out-of-hours, resulting in fewer transfers to hospital and quicker access to services when needed. The 'CHIP collaborative' meets bimonthly. This has enabled networking and learning to be shared between care homes. End of life care systems are more integrated and new protocols, such as a syringe driver protocol, are bringing consistency across different healthcare professionals across the community.



## Six steps to good care in Oldham

The Six Steps Programme in Oldham and Central Manchester Clinical Commissioning Group (CCG) areas aims to develop the skills of care home staff providing end of life care to prevent unnecessary hospital admissions, including care in the last days of life.

The programme was originally developed in the North West and is based on the good practice guidance *Route to success in end of life care: achieving quality in care homes*. It follows the six steps of the end of life journey, from discussions as end of life approaches to care after death.<sup>1</sup>

In Oldham, 20 nursing and residential care homes and some dementia care homes have completed the programme. Anecdotally, hospital staff reported fewer admissions and care staff reported feeling more confident in looking after people at the end of life. This meant that more people were able to go back home for the last days of their life. The programme was being rolled out further because of this positive feedback.

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<sup>1</sup> National End of Life Care Programme, **Route to Success: achieving quality in care homes**, 2010



## MPath: improving end of life care for homeless people

The Manchester Pathway (MPath) service aims to reduce A&E attendances for homeless people who have attended A&E 12 times or more in the previous 12 months and reduce re-admissions. The service works with people who are currently homeless, including people who are sleeping rough, in temporary accommodation such as a hostel or B&B or who are 'sofa surfing'.

MPath provides hospital in-reach, with staff from the practice visiting the acute hospital to assess homeless patients. They make sure that patients are discharged with a package of care, housing, and engagement with primary care services to help prevent unnecessary re-attendance at A&E. The project has helped to identify a number of people at the end of life, and approximately 700 homeless people are now registered with a GP as a result of the MPath project.



## Better end of life care for people with dementia

Developed jointly by local commissioners, health and care services and the community and voluntary sector, Greenwich Advanced Dementia Service aims to improve the quality of life for people with dementia by enabling them to live in their own home. The service also minimises unnecessary emergency admissions to hospital, and provides a comprehensive package of community-based support for people with dementia and their families.

To date, the service has supported over 100 people to live and die in their own homes and is saving up to £265,000 a year on reduced care home costs and hospital admissions. A recent audit of 48 consecutive deaths of people with dementia under the care of the team showed that 77% died at home and the remaining 23% needed only a brief hospital admission at the very end of life. Members of the team have made urgent visits to 75% of patients as an alternative to A&E and prevented admission to acute hospitals.



# Coordination of care and information sharing



## Coordinating care in Erewash

The care coordinator role in Erewash, near Nottingham, demonstrates how coordinated care at the end of life can make a difference. The care coordinator looks at admissions and discharges from hospital to identify those patients who may be approaching the end of life. Together with the GP, they also manage and lead regular community delivery team meetings, and review admissions and discharges for 'high risk' people, including older people and those with conditions other than cancer.

Details of people in the last 12 months of life are entered on GP palliative care registers and they have a named GP to support continuity of care. Specific GP practices are responsible for each care home, and there are regular multidisciplinary palliative care meetings to talk about people on the register.

GPs reported good communication with other health and care staff, which supported people to receive good care.



## The Gold Line in Airedale

Airedale NHS Foundation Trust introduced the Gold Line to support people who are approaching the end of life and their families in the local area. It provides a single point of contact through a dedicated 24/7 telephone service staffed by nurses who provide advice and support and can contact other services including a doctor, district nurse, or hospice. Nurses can also see people face-to-face using a secure video link if needed.

The Gold Line is part of a wider initiative where the Gold Standards Framework (GSF) is being used across all health and care settings to

improve integrated, coordinated care and reduce avoidable hospital admissions. GSF is being used in all wards within the trust, as well as a large number of GP practices and care homes.

There have been significant improvements, including fewer hospital deaths (14% compared with 49% nationally) and almost double the national average of deaths at home (41% compared with 22%).



# Community development



## Community advocates for people with long-term conditions

Great Yarmouth and Waveney Clinical Commissioning Group (CCG) worked with the national charity Turning Point to address the high levels of emergency admissions for people with long-term conditions living in the Gorleston area.

A team of 15 local people with experience of long-term conditions was recruited and then trained as Community Advocates to research the experiences, needs and priorities of people living with long-term conditions. Following this they were able to recommend how services could be improved to be more cost-effective,

better support self-management and improve experiences and outcomes of care, including at the end of life.

Health and social care partners are now working together with members of the community through seven Community Advocates. The CCG better understands the pathways of care and experiences of people with long-term conditions, and is developing services with input from people who use them. The project has specifically supported people at the end of their lives by connecting them with appropriate services.



## Through our eyes: minority perspectives on end of life care

The Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network produced a film to raise awareness of the end of life care issues and needs of Black and minority ethnic (BME) communities. The aim of the film is to start conversations and increase understanding of what might be important to people and why.

In the film, people from different cultural and religious backgrounds share their own experiences and reflections on end of life care. The film includes messages for care staff,

communities and commissioners of care, and is designed to promote discussion about people's individual end of life care needs.

The film was launched at a stakeholder summit, where participants reflected on the film and how to use it to improve the quality of end of life care for people from BME communities. One participant said, "It's a very different experience hearing it from a person's perspective. I love the honesty from the storyteller's perspective. The film reinforces 'one chance to get it right'".



## Supporting people to talk about end of life in Hackney

St Joseph's Hospice in Hackney works with local spiritual leaders and community organisations to try to support people in their local communities to talk about end of life care.

The imam attached to the hospice has liaised with local mosques so that discussions about death and dying have been introduced at prayer sessions and meetings at mosques. There have been broadcasts about end of life care on the local Ramadan radio network. The hospice has also introduced a neighbourhood befriending scheme.

Volunteers have been recruited to represent the different Black and minority ethnic communities in the local area, and given training to act as 'compassionate friends' to support neighbours with end of life care needs. These volunteers also speak with members of their community at established meetings, for example, women's groups and carers' groups, to raise awareness of end of life care.



## Engaging with BME communities in Basildon and Brentwood

St Luke's Hospice has prioritised promoting awareness of end of life issues and the services available through engaging with the Black and minority ethnic (BME) community. This includes offering a meeting room to the local community for the Asian women's group meetings, and running a six-week programme focused on BME groups to educate people about the hospice and its work, to increase awareness before a person reaches the end of life phase.

The hospice runs a group called VERVE – Valuing Local Diversity and Enhancing Patient Experience Raising Public Awareness and Visible Equity in End of Life Care. This working group is formed of faith leaders, local police, people from different ethnic backgrounds and people with a learning disability. The group raises awareness of end of life care within the community and they attend local festivals and community events.



## Engaging with Oldham's Bangladeshi and Pakistani communities

Oldham Community Services (Pennine Care NHS Foundation Trust) and Voluntary Action Oldham have started a project to give Oldham's Bangladeshi and Pakistani communities better access to community health services at the end of life. The trust aimed to learn about end of life preferences for Bangladeshi and Pakistani residents of Oldham, and to help them support more people to die in their preferred place. They also wanted to improve their communication with members of the communities, and inform their commissioning for 2016/17.

Using community development funding, the trust commissioned local community organisations to undertake research with the communities using questionnaires, focus groups and interviews, as well as informal outreach and engagement

activities, including making announcements after prayers in local mosques. The research identified issues around timely diagnosis, and a lack of knowledge and information about end of life care, particularly about hospices and care homes. This meant that people were not able to make informed choices about end of life care. There were also gaps in services, particularly in support for carers, and poor communication and engagement with the communities.

Based on these findings, a number of recommendations are being taken forward through the local End of Life Strategy group and service development. Representatives from these communities now also attend local area end of life care task and finish group meetings.

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## See our other reports on the thematic review:

### OVERVIEW REPORT

### PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BME) groups
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers

