

# The state of hospice services in England 2014 to 2017

Findings from CQC's initial programme of comprehensive inspections of hospice services





#### **Our purpose**

The Care Quality Commission is the independent regulator of health and adult social care in England. We make sure that 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 health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

#### **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

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# Foreword

We have now completed the initial programme of comprehensive inspections of hospice services registered with CQC in October 2014, and this report is one of a series produced by CQC to share our findings.

It is striking that hospices have an extremely high standard of care – 70% are rated as good and, outstripping the performance of any other sector, 25% are rated as outstanding. This is a remarkable achievement, which the staff and leaders in hospices can be proud of and can celebrate.

This report sets out our key findings and some of the factors that have led to this performance. Across many of the services we regulate we see that good and outstanding services have strong leaders who inspire a positive culture that is focused on providing person-centred care – treating people as people and not just as recipients of care. These leaders motivate, develop and value their staff who are dedicated and committed to providing the best possible care.

These characteristics are exemplified in the hospices we highlight in this report, and are typified in so many of the hospices that we have inspected. The leaders, staff and volunteers in hospices across England work with passion and enthusiasm to transform people's lives, and make sure that people in their final days and their families experience compassionate, respectful care. There is much for other care providers to learn from.

Now that we have completed the first round of inspections under our current model, hospice services are switching from being under the responsibility of the Chief Inspector of Adult Social Care to being under the responsibility of the Chief Inspector of Hospitals.

My team and I have enjoyed the experience of witnessing and reporting on the great care that hospices so often provide and wish them every success in the future.

#### Andrea Sutcliffe

Chief Inspector of Adult Social Care

# 1. Introduction

In 2013, CQC set out its plans to radically transform the regulation of adult social care services, including hospices. A year later, we began our new programme of comprehensive inspections, with ratings to make it easy for people to understand the quality of care and to help them choose care; a focus on identifying, highlighting and celebrating good practice; and a determination to drive improvement and hold providers to account for poor care.

We have now completed this initial programme of comprehensive inspections and ratings. This report focuses on hospices. CQC regulates, inspects and rates in-patient hospices, day hospices and community-based hospice services, including those for children.

Hospices represent a very small proportion of the services we regulate – around 200 out of a total of 24,000 adult social care locations inspected between October 2014 and January 2017.

In our next phase of inspections, CQC moves from 11 inspection frameworks to two – one for health services and one for adult social care. In recognition of the varying nature and complexity of hospice services, the care pathways involved and the extent of clinical knowledge and experience required to inspect them, hospices will now be regulated within the healthcare framework and move from the responsibility of the Chief Inspector of Adult Social Care to the Chief Inspector of Hospitals.

#### How we work

We register providers that apply to CQC when they are able to satisfy us that they meet the requirements.

We make intelligent use of data, evidence and information, including information shared with us by staff and people using services, their families and carers to decide when, where and what to inspect.

Our inspectors use their professional judgement, supported by objective measures and evidence, to assess services against our five key questions. Supported by people who have experience of using care services (Experts by Experience) in the majority of inspections, our inspectors use feedback from people who use services, their carers and families to inform their judgements.

We always ask the following five questions of services.

- Are they safe?
- Are they effective?
- Are they caring?
- Are they responsive to people's needs?
- Are they well-led?

We rate services to highlight where care is outstanding, good, requires improvement or inadequate. We rate hospice services at two levels:

1. We rate each one of the five questions.

2. We aggregate these separate ratings to give an overall rating for the location.

Our enforcement policy sets out what action we take to require services to improve and, where necessary, the action we take to make sure those responsible for poor care are held accountable for it.

#### About hospice care

Hospice care seeks to improve the experience of people living with terminal or life-shortening conditions, and helps them to live as well as they can, to the end of their lives. There is no charge to the people who use hospice care. Adults' hospices in the UK receive around a third of their costs from the NHS and children's hospices receive 17 per cent. The majority of costs are paid for through fundraising.<sup>1</sup>

Hospices have been recognised by the Commission into the Future of Hospice Care for the characteristics that contribute to a positive experience for people (Box A). These characteristics align with the features of high-quality care that we have found in our inspections of hospice services (section 3).

#### BOX A: Characteristics of hospice care that contribute to a positive experience

#### Hospice care is led by people's needs

The care of the individuals receiving hospice care is led by their needs. To that end it is highly personalised and reviewed on a regular basis to ensure an approach that acknowledges changing needs.

#### Hospice care embraces family carers

Hospices recognise family carers' vital and indispensable role in caring for someone affected by lifeshortening conditions. It seeks to support them and works in partnership with them, recognising their important and often expert contribution.

#### Hospice care is expert in nature

All those who work in hospices have expert skills and knowledge. Each person also plays a part in teaching others – using, reflecting upon and sharing their extensive experience in delivering palliative and end of life care day in and day out. The expertise of hospices allows them to address the most complex of needs in their patients or their families. Importantly, this complexity extends beyond clinical symptoms to include much else that is vital to living well, including social, emotional, spiritual, and financial needs.

#### Hospice care is innovative

Hospices are part of a movement that has produced radical innovations in institutions, services and beliefs.

#### Hospice care is integrated

Being integrated means combining efforts with the NHS, local authorities, care homes and other providers in order to work together to improve care for all who have life-shortening conditions wherever they are.

Adapted from: Future ambitions for hospice care: our mission and our opportunity: The final report of the Commission into the Future of Hospice Care, Commission into the Future of Hospice Care, October 2013<sup>2</sup>

# 2. What have we found in our inspections?

#### Overall ratings

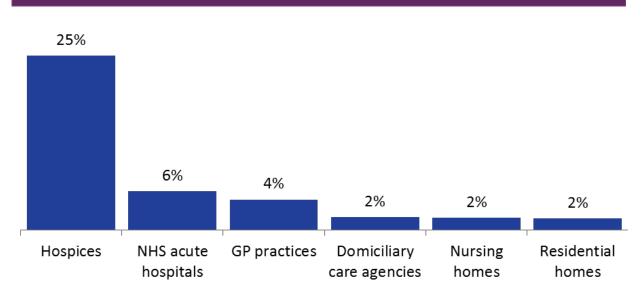
Hospices have a great deal to be proud of; a quarter of hospices were rated as outstanding, and 70% were rated as good. Only 4% were rated as requires improvement and only one hospice was rated as inadequate.



Source: CQC ratings data, 8 September 2017.

Hospices achieve considerably higher levels of performance when compared to all of the sectors we regulate. By comparison, 6% of NHS acute hospitals' core services and 4% of GP practices were rated as outstanding and, within adult social care, 2% of domiciliary care agencies, nursing homes and residential care homes were rated as outstanding (figure 2).

Our report, *A different ending: Addressing inequalities in end of life care*, <sup>3</sup> which reported on our end of life care thematic review in 2016, identified that hospices tend to provide much higher quality care than end of life care services in acute hospitals. The report also found that local approaches to organising and delivering end of life care to different groups were variable, and the end of life care needs of people from some groups were not always considered and understood. We encouraged hospices to champion an equality-led approach and to play a key role in engaging local communities and supporting them to deliver end of life care based on individual need.



#### Figure 2: Overall outstanding ratings by type of service

Source: CQC ratings data, 8 September 2017. The percentage for NHS acute hospitals is based on the core service ratings for non-specialist and specialist hospitals.

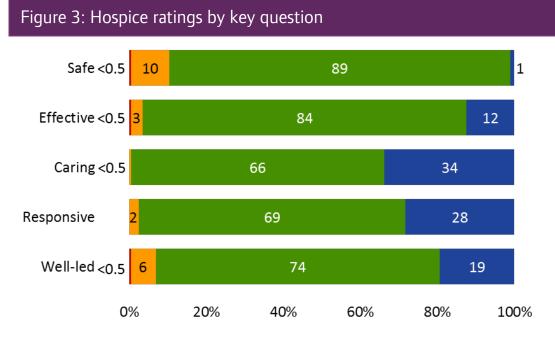
#### Ratings by key question

As well as the overall rating, we give a rating for each of the five questions we ask of all care services. These allow us to look in greater detail at the issues that matter to people: are services safe, effective, caring, responsive to people's needs and well-led?

When we look at key question ratings for hospices, they follow a similar pattern to most services, with caring and responsive being stronger than safe and well-led. In line with other types of service, hospices mainly received poorer ratings for safe because there were issues with the way medicines were stored or administered, and issues with well-led included failings in quality monitoring systems and the support given to staff.

But generally, hospices perform to a much higher degree than other types of care service. For example, across all of adult social care, 16% of services were rated as requires improvement and 1% as inadequate when we asked whether they are effective. For NHS acute hospitals' core services, 23% of services were rated as requires improvement and 1% as inadequate for effective. When we asked the same question in hospices, we found that only 3% were rated as requires improvement and less than 0.5% were rated as inadequate. This reflects the outstanding person-centred care that we saw and heard about in our inspections (discussed in the next section), with staff taking time to really get to know and understand people, so that they can support and treat them as effectively as possible.

It is also clear that staff involve and treat people with compassion, kindness, dignity and respect, given that almost all hospices are either good or outstanding when we ask whether their service is caring (only one hospice was rated as requires improvement). By comparison, 5% of adult social care services and 3% of GP practices and NHS hospitals' core services are rated as requires improvement for caring.



Source: CQC ratings data, 8 September 2017.

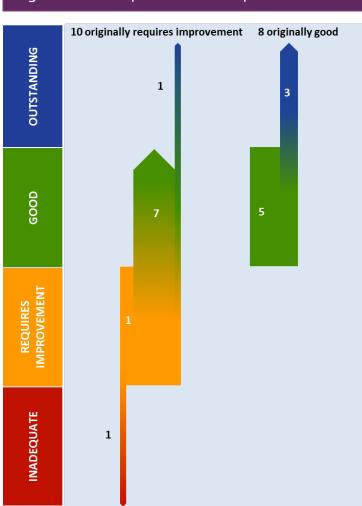
#### Improvement

Where we see any aspects of care that are not good or outstanding, we expect all providers to use our findings and reports as an opportunity to tackle any issues and put things right for the benefit of people using services. We ask them to evidence what they plan to do to improve quality and we go back to inspect to find our whether they have kept to their commitments and if these have had the desired effect.

As discussed at the beginning of this section, poor quality among hospices is much less common than in other types of service. However, where we have seen problems, these have been:

- Issues with the culture or leadership within a service that had an impact on the quality of care.
- Lack of cohesion across departments, or failing to manage competing pressures from different areas of hospice activity.
- Poor medicines management.
- Lack of focus on meeting the needs of the whole community, for example people with dementia, or people from Black and minority ethnic communities.

Up to 8 September 2017, CQC has re-inspected and re-rated 18 hospices. Ten of these were originally rated as requires improvement; one deteriorated to inadequate, one remained requires improvement, seven improved to good and one to outstanding. The other eight were originally good; of these, three improved to outstanding.



#### Figure 4: Re-inspections of hospice services

Source: CQC ratings data, 8 September 2017.

Although two services still need to make improvements after re-inspections, this generally shows a positive picture of improvement – both from requires improvement and from good. As highlighted in *The state of adult social care services*<sup>4</sup>, managers' and providers' acceptance and ownership of the issues raised by CQC during inspections is key to improvement. It is clear that hospices have been effective at improvement planning and turning around the quality of their services between inspections.

# 3. What can care providers learn from our inspections of hospices?

In this section, we focus on the main features of high-quality care that we have seen during our initial comprehensive programme of inspections, illustrated by two examples from our inspections of high-performing providers of hospice care. We think that, although there are differences between hospices and other types of care provision, there are aspects of our findings that all services could learn from. Good and outstanding providers, and hospices themselves, can also learn from the high-quality care seen here. Findings from our initial programme of inspections in other services have shown that even the highest rated services can decline, so a focus on continuous improvement is vital to maintain quality care for people.

The two examples of hospice care share certain characteristics of high quality, and show the remarkable support for people using services that is characteristic of the hospice sector (figure 5).



Figure 5: Characteristics of high-quality, person-centred care in hospice services

- The examples both feature strong leadership with clear vision and values. These leaders prioritised continuous improvement and innovation, which is informed by good practice and shared with others. In one case, CQC's *A different ending* had been used to inform service improvement. Often, good practice is backed up by appropriate endorsement and qualifications, such as The Queens Award for Voluntary Service and the Level 2 certificate in the Palliative Care Program mentioned in the first example. Hospices are also being innovative in moving away from paper-based records to store and share information electronically, such as care records, staffing information and incident reporting.
- People who use services spoke positively, and inspectors highlighted how caring, compassionate and person-centred the care was. Staff took time to have, sometimes difficult, conversations in order to really get to know and understand people. This meant that care and support not only covered people's basic physical needs, but also emotional, social and financial needs, setting achievable goals with a focus on maintaining independence. All of this was done with privacy, dignity and the person using the service and their family as the central consideration. Typically, effective workforce planning and monitoring enable hospices to provide exceptionally personalised care to meet people's needs and have an impact on their daily lives.
- The inclusive nature of the care was seen in the support provided to carers and families and the way this extended beyond the life of the person. Counselling and therapeutic sessions, visits to the hospice and memorial services were still available long after the person had died.
- In line with these findings, staff also spoke positively about the culture of the services within which they work. Inspectors highlighted that hospice staff are required to have a high level of professional skills, which they use alongside a compassionate approach to care and a 'can do' attitude. Leaders supported staff to continually develop their skills in all areas of care provision, for example through training in clinical skills as well in keeping people informed and helping them to make meaningful choices. They also had mechanisms to promote best practice and ensure expertise in their staff for example, through the use of link champions to lead on specific areas, such as falls prevention or pressure sores. Hospices have also been adopting an integrated approach to training. For example, Springhill Hospice in Rochdale developed the Palliative Care Education Passport in collaboration with Age UK Rochdale and Rochdale Borough Council to provide training to care providers specifically on end of life care.
- The hospices strived to overcome inequalities in end of life care, for example by forging links with minority groups and homeless people to better understand their needs, and by communicating well with people through training in deaf awareness and access to interpreters and translation services. The links between outstanding care and equality work have been particularly strong across the hospice sector. Seventy-five per cent of hospices rated as outstanding in 2016/17 had carried out some work on equality for disabled people, but only 55% of hospices rated as good had done so. Eighty-eight per cent of hospices rated as outstanding had carried out some work around equality for people of different religions and beliefs, compared with 63% of hospices rated as good.<sup>5</sup>

Partnership working was also a key factor in terms of delivering excellent care – particularly having strong links with professionals, services and the local community. Also, a focus on reaching out to those in the local community and understanding their needs was seen in both cases. This enabled them to provide services outside of the residential setting of the hospice. In one case, the hospice had become central to the community and health economy, tendering for and operating most of the end of life services in the area. Forming links with local hospitals and clinical commissioning groups and support services meant they could provide a joined-up, responsive service.

## EXAMPLE OF PERSON-CENTRED CARE AND PARTNERSHIPS IN A HIGH-PERFORMING HOSPICE

#### Introduction

St Ann's Hospice in Salford, Greater Manchester is a hospice providing palliative and supportive care services to people with life-limiting illnesses. It is registered as a charity, and services include hospice at home, day therapy, inpatient care and a community specialist palliative care team. When we inspected in October 2016, there were 12 people being cared for on the inpatient unit and about 250 people receiving care and support in the community. We rated the service as outstanding overall, with three out of the five key questions rated as outstanding.

#### Feedback

People who used the service said:

"They are constantly encouraging me to get up and out of bed as I haven't walked in a long while. As a result, I walked for the first time today due to staff not giving up on me."

*"I've been bedbound for a long time now and I didn't ever think I would be able to sit in this chair, but as a result of the care I have received here I am able to do it each day."* 

"The prospect of being able to go back home is a reality now, even if it's just for a short period. I'd made it clear to staff that was what I wanted to do and with regular physio, I'm nearly ready."

One relative said:

"I would definitely describe the care here as outstanding. They really make an effort to get to know people and find out what is important to them."

#### Making a special effort to have an impact on people

- The hospice had a system where a white board was placed in each person's room which recorded what each person wanted to achieve that day. Staff took the time to find out and helped them achieve those goals. When we talked to the people involved, they said that, although these may have only seemed like small milestones, they were huge accomplishments and achievements for them.
- The daughter of a person using the service was getting married, but they had been unable to attend the hen party due to their illness. Staff therefore hosted a hen party at the hospice. Staff

brought a rail of clothing in for the person to choose from so they could get dressed up and feel part of the occasion.

• A person's granddaughter was due to get married at the weekend after our inspection. The person was looking forward to it very much, since staff were supporting them to watch it over the internet via Skype. This person's relative said "The hospice staff have definitely gone above and beyond with this one. The bed is going to be brought into the main lounge so it will be more comfortable. It will make all the difference to mum as she was extremely disappointed at the thought of missing out on it due to coming here."

#### Forging links with the community to promote equalities

- The practice development manager chaired a meeting with a local transgender group. They learned of some of the concerns and anxieties people had, which included end of life medication, hormone replacement, body image, family complexities and documentation. In response, the registered manager had provided people with advice and guidance in these areas. The group asked to look around the hospice and were interested in volunteering opportunities. This led to training about transgender people at the end of their life and also transgender people living with dementia.
- The hospice had links with the Myriad Foundation a local Islamic charity, which provided volunteers to spend time with patients of all faiths or no faith, providing emotional and moral support through simple gestures like having a chat, going for a walk in the gardens, playing games or simply sitting and keeping them company. The project aimed to bring greater social inclusion and provide companionship to people at difficult times in their lives. Another aim of this project was to break down barriers and open up pathways for more Muslim people to access the services provided by St Ann's. This initiative helped to raise awareness and ensure that people were getting the care they needed.

#### Supporting staff excellence

- The hospice had achieved The Queens Award for Voluntary Service and the Level 2 (highest award) certificate in the Palliative Care Program. The directors were also presenting research papers to Hospice UK.
- The hospice had implemented an 'Exchange Programme' in partnership with Central Manchester University Hospitals NHS Foundation Trust, offering nurses a five-day placement on haematology, gastroenterology, respiratory or cardiac wards. Nurses from the Trust had also been invited to take up a placement at St Ann's, which enabled both sets of staff to learn new skills and experience what it is like to work in the different care settings. One nurse said "It has been a huge benefit to me and my personal development. I've really enjoyed it and it is really good to see the journeys people have been on and the care they receive. It has really helped with referrals and I've learnt things I had never encountered here which can only be a good thing."

Read the full report on our website

# EXAMPLE OF PERSON-CENTRED CARE AND LEADERSHIP IN A HIGH-PERFORMING HOSPICE

#### Introduction

Dorothy House Hospice near Bath is registered for 10 beds and provides specialist palliative and end of life care for adults with life limiting illness or complex symptom management needs. It is run by a registered charity.

After our inspection in September 2016, we rated the service as outstanding overall, with four out of the five key questions rated as outstanding.

#### Feedback

A person who used the service said:

"The nurses are attentive, and doctors are good at symptom control; there is time to talk and everyone is very very kind."

One relative said:

"The care given to my dear husband was filled with love, respect, dignity, and empathy."

#### Person-centred care and treatment

- The homeless project nurse was very dedicated. She assisted a man with terminal liver disease to access hospice services. He was living in his car, often resisting and refusing support and could not access services through the normal routes as he was not registered with a GP. The nurse worked with different services to make them aware of his situation. There were improved outcomes for this man as he went on to live in a hostel with district nurse support after a short stay at the hospice. The nurse also worked in all aspects of the community, making links with Christian organisations and the YMCA. This promoted her role and what the hospice could offer, all with a view to identifying other people who could be referred.
- The hospice had an artist in residence who supported people to make 'creative keepsakes' such as casting a hand in plaster or creating memory boxes. Sometimes people using the service did this with their loved ones, and at other times it was after the person had died that relatives came in. People found it very therapeutic, with people holding difficult conversations while they were being creative.
- When our inspector was on the ward, they saw a dying mother supporting their child. The young person was coming to terms with the situation and wanted to spend more time with their mother. She was, however, surrounded by other family and friends and the child lost their temper. A member of staff immediately intervened and supported the child to talk through their feelings and find time alone to spend with their mother.

#### **Continuous improvement and leadership**

• Staff had 'link roles' that included skin care and prevention of pressure sores, falls prevention, nutrition and hydration and infection control. One of these told us about their tissue viability link role and said they attended a conference and visited other units to look at skin care. They had

introduced a bespoke end of life pressure ulcer risk assessment tool, which helped staff identify factors that might make people more at risk of skin breakdown. They were involved in updating their local policy, and in purchasing moving and handling and pressure relieving equipment. They provided educational resources for other staff to read, shared information at staff meetings and supported and monitored skin care in the unit.

- Dorothy House continually sought external good practice for example, reviewing CQC's report into equalities in end of life care, *A different ending*, and taking part in a mock inspection by another hospice.
- A training needs analysis looked at the future training needs of hospice staff and identified additional skills needed, so that staff could take on extra roles for example, clinical skills to support people to have more treatments in day services, such as blood transfusion, and prescribing for nurse specialists.
- Dorothy House worked with Royal United Hospital on projects to support people to leave hospital more quickly. People with ongoing care needs could be discharged into the care of the hospice, which provided palliative treatments for certain blood and breast cancers with their trained staff and specialist nurses. This meant people would not need to attend hospital outpatient departments but could receive their care in a more relaxed environment, as well as having access to all the additional support and services the hospice could offer.
- The provider was good at identifying where services were not efficient and therefore redirected resources. For example, the in-house respite service they were offering was demanding too much resource from the main inpatient unit. Since their aim is to invest in what will benefit the greatest number of people, they redirected their resources into other services, such as hospice at home and the palliative cancer treatments and outpatient services.

Read the full report on our website

# Conclusion

We have seen through our ratings that hospices perform well, including when compared to other types of service.

This report highlights the inclusive, caring, compassionate and person-centred approach that CQC has seen many hospices take to improve the quality of life and wellbeing of people with a life-limiting or terminal illness. It also highlights the partnership work and the strong links with professionals, services and their communities that enable hospices to understand the needs of people in their area.

As we wrote in *A different ending*, we continue to encourage hospices to engage in their communities and for health and adult social care services to use the learning from them to meet the needs of local people.

### References

<sup>4</sup> Care Quality Commission, *The state of adult social care services 2014 to 2017*, 2017

<sup>&</sup>lt;sup>1</sup> Hospice UK, *Hospice care in the UK 2016*, 2016

<sup>&</sup>lt;sup>2</sup> Commission into the Future of Hospice Care, <u>Future ambitions for hospice care: our mission</u> and our opportunity The final report of the Commission into the Future of Hospice Care, October 2013

<sup>&</sup>lt;sup>3</sup> Care Quality Commission, <u>A different ending: Addressing inequalities in end of life care</u>, 2016

<sup>&</sup>lt;sup>5</sup> Care Quality Commission, *The state of health care and adult social care in England 2016/17*, 2017



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