



Care home survey results



# 2008 **END OF LIFE CARE**

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# Care home survey results

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# Context for the survey

1. With assistance from the English Community Care Association and the Commission for Social Care Inspection (CSCI), we surveyed a purposive sample of 1,410 residential and nursing care homes in England with more than ten beds to find out about:

- occupancy levels and the age of residents;
- place of death for care home residents that died in 2006-07;
- levels of staffing and training;
- use of end of life care tools;
- policies and procedures for when people are at the end of life; and
- interactions with external services.
- 2. The survey was carried out between February and March 2008 and final responses were received from 134 care homes (a response rate of 9.5 per cent). Based on their CSCI classification, 65 per cent of those care homes responding were classified as 'care home only', 34 per cent were classified as 'care home with nursing' and, for one per cent, no classification was available.
- 3. The survey forms one strand of our work on end of life care which resulted in a full value for money report to Parliament in November 2008 (**End of Life Care**, HC 1043, 2007-2008), where the overall findings from the survey are presented.

# Background

- 4. In 2006, 15.4 per cent of all deaths in England (72,429) occurred in care homes. As a result, it is essential to recognise care homes as the normal place of residence for many people and to ensure that good quality end of life care can be delivered in this setting. As at March 2007, over 18,500 registered care homes, run by private and voluntary organisations and councils, provided almost 442,000 care home places to adults of all ages.<sup>1</sup>
- 5. A summary of the quantitative results from the survey is presented here. All percentages shown are the "valid percentages" i.e. they exclude blank and not applicable responses.<sup>2</sup>

<sup>&</sup>lt;sup>1</sup> Commission for Social Care Inspection. The state of social care in England 2006-07 (January 2008)

<sup>&</sup>lt;sup>2</sup> The data from the survey have not been subject to audit, and therefore some of the variations in the information provided by care homes may be due to different interpretation by individual organisations.

# Occupancy and age of residents

6. As at 31 March 2007, the mean occupancy level amongst care homes responding to our survey was 92 per cent (CI 95% [87, 97]).<sup>3</sup> The mean number of residents per care home was 26, ranging from 5 to 127 (n=122).<sup>4</sup> The mean number of vacant places per home was 5 (n=65). Thirty-one per cent (CI 95% [21, 41]) of care home residents were aged 74 or under; 28 per cent (CI 95% [18, 38]) were between 75 and 84; and the majority, 41 per cent, were aged 85 and over (CI 95% [30, 52]).

# Place of death

- 7. We asked care homes to indicate how many of their residents died in 2006-07 in the care home; a hospital; hospice; or other setting. On average, 70 per cent of care home resident deaths occurred in a care home (Cl 95% [61, 79]). A significant proportion, however, occurred in a hospital. Using ONS mortality data (72,429 deaths occurred in care homes in 2006) and data provided in response to our survey, we estimate that between 91,700 and 118, 700 care home residents die each year, representing between 19 and 25 per cent of all deaths in England.
- 8. When we used the CSCI classifications of 'care home only' and 'care home with nursing' to examine place of death, we found a significantly higher proportion of residents were able to die in care homes with nursing (Table 1). For 26 care homes, all resident deaths occurred in the home. In five cases, all resident deaths in occurred in a hospital. The majority of those residents who died (86 per cent) had been resident in the care home for over three months (CI 95% [79, 93]).

Table 1: Place of death for care home residents (2006-07)					
Place of death	% - all care homes (n=100)	% - care home only (n=100)	% - care home with nursing (n=100)		
Care home	70	63	83		
Hospital	27	32	15		
Hospice	0	0	2		
Other setting	3	5	0		

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# Funding, staffing and training

9. As at 31 March 2007, half of the places in the care homes responding to our survey were entirely state funded (Figure 1). The average number of care staff working in the homes responding to our survey was 21 (n=122), whilst the average number of registered nurses per home was 7 (n=68). There was a high

<sup>&</sup>lt;sup>3</sup> The respondents to this survey are only a sample of the total 'population' of care homes. This means that we cannot be certain that the figures obtained are exactly those we would have if every care home had responded (the 'true' values). We can, however, predict the expected variation between the sample results and the 'true' values from a knowledge of the size of the sample on which the results are based and the number of times that a particular answer is given. The confidence with which we have chosen to make this prediction is 95% (i.e. the chances are 95 in 100 that the 'true' value will fall within the specified range). In this case, we are 95 per cent confident that the 'true' level of occupancy in care homes lies between 87 per cent and 97 per cent.

<sup>&</sup>lt;sup>4</sup> The term n= refers to the number of care homes responding to a given question. In this case, 122 care homes responded.

level of correlation between the number of filled places in care homes and staffing levels for both care home workers ( $R^2 = 0.63$ ) and registered nurses ( $R^2 = 0.63$ ).<sup>5</sup>

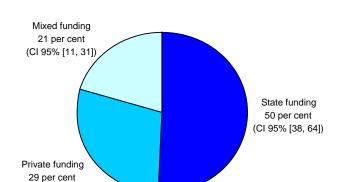


Figure 1: Funding of care home places as at 31 March 2007

(CI 95% [18, 40])

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- 10. Specific training on end of life care was provided to care staff in 74 per cent of homes (CI 95% [66, 82]) and to registered nurses in 80 per cent (CI 95% [70, 90]) of homes. Training was not, however, always compulsory or part of a formal qualification. Where training was provided for care staff it was compulsory in 49 per cent of homes (CI 95% [38, 60]) and part of a formal qualification in 44 per cent of homes (CI 95% [33, 55]). Where training was provided for registered nurses it was compulsory in 30 per cent of homes (CI 95% [17, 43]) and part of a formal qualification in 16 per cent of homes (CI 95% [4, 28]).
- 11. We also asked care homes to rate the skills and training of their staff in terms of their ability to avoid unnecessary admissions for residents at the end of their life. Ratings were requested on a scale of 1 to 10 where 1 is 'poor or well below the standard required by residents and their families' and 10 is 'well exceeds the standard required by residents and families'. The mean rating given was 7.7 (n=114).

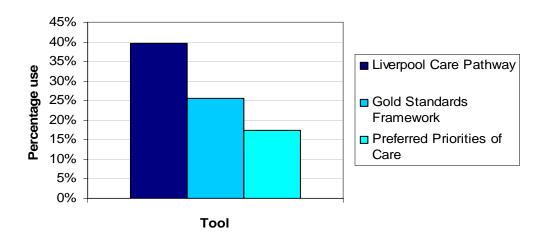
# Use of end of life care tools

12. We asked care homes whether they had used the Liverpool Care Pathway (LCP), Gold Standards Framework (GSF), or Preferred Priorities for Care (PPC) tools when planning and coordinating care for residents at the end of life. Forty per cent stated that they had used the LCP (CI 95% [31, 49]); 25 per cent had used the GSF (CI 95% [17, 33]); and 17 per cent had used PPC (CI 95% [10, 24]) (Figure 2). Nine care homes stated that they had used all three tools.

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<sup>&</sup>lt;sup>5</sup> The R<sup>2</sup> value measures the degree of correlation between 2 variables where -1 is perfect negative correlation, 0 is no correlation and 1 is perfect positive correlation.

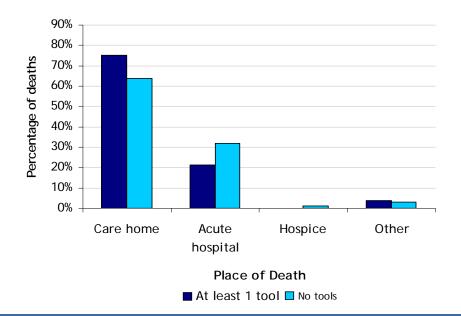
Figure 2: Use of end of life care tools in care homes



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13. When asked to rate the improvement to end of life care services as a result of using the tools, those care homes using the tools rated the LCP highest with a mean improvement rating of 8.1 out of 10 (n=42). Views on the GSF (3.5/10, n=25) and PPC (1.4/10, n=17) were less favourable. When we compared use of the tools against place of death (n=100) we found that use of at least one of the tools was associated with an 11 per cent increase in the number of residents able to die in the home, rather than in a hospital (Figure 3). However, given the small size of the sample, there is some uncertainty about the statistical significance of this increase.

Figure 3: Effect of using at least one end of life care tool in a care homes



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14. When we compared use of the LCP, GSF, and PPC against care homes' CSCI performance ratings we found that those assessed as 'Good' or 'Excellent' were more likely to be using these tools (Table 2). However, there was no association between the CSCI performance ratings and the proportion of residents able to die in the home.

Table 2: Use of end of life care tools v CSCI performance rating					
CSCI performance rating	% - use of LCP	% - use of GSF	% - use of PPC		
Excellent (n=16)	38	31	31		
Good (n=52)	35	21	13		
Adequate (n=22)	14	9	14		
Poor (n=2)	0	0	0		

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# Policies for caring for people at the end of their life

15. We asked care homes whether they had policies in place for a range of issues related to planning and coordinating care for people approaching the end of their life. Amongst those homes responding to the question, 100 per cent had a policy in place for dealing with the death of a resident, but only 30 per cent had a policy for anticipatory prescribing (Cl 95% [22, 38]). A policy for talking to residents and their carers about where they would like to die was in place in 64 per cent of homes (Cl 95% [56, 72]), and policies for advance care planning were in place in 61 per cent of homes (Cl 95% [52, 70]). Fifty seven per cent of homes had a joint arrangement with GPs to support continuing care for people as they are dying (Cl 95% [48, 66]).

# Interaction with external services

16. We asked care homes to rate a range of external services according to the extent to which they meet resident and carer requirements for care at the end of life. Ratings were requested on a scale of 1 to 10 where 1 is 'well below resident and carer requirements' and 10 is 'well exceeds resident and carer requirements'. The most highly rated services were integration with residents' GP surgeries, support from specialist palliative care services and access to 24 hour emergency assistance, which all had a mean rating above 7. All other services had a mean rating above 5, with the exception of out of hours services for equipment (Figure 4).

Figure 4: Care homes' mean ratings of external services Integration with residents' GP surgeries Support from specialist palliative care services Access to 24 hour emergency assistance **External service** Services received from the Ambulance Service Out of hours services for medication Commissioning of end-of-life care by PCTs Integration with social services Out of hours services for equipment 0 1 2 5 6 8 9 10

Average rating out of 10

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# Glossary

### **Care home**

A residential home which provides either short or long term accommodation with meals and personal care (e.g. help with washing and eating). Some care homes, known as nursing homes, also have registered nurses who provide nursing care for more complex health needs.

# **End of life care**

Services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This support is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

# **Gold Standards Framework**

A primary care based approach for identifying end of life care patients, assessing their needs, and coordinating their care. It provides prompts to a healthcare professional that discussions about the end of life should be initiated, if they have not already taken place, and enables GPs to identify patients for inclusion on a palliative care register.

# **Hospice**

Hospices provide care and support to people at the end of their life and their carers, through a range of services such as in patient care, day care, community services, out patient appointments, sitting services, respite care and bereavement counselling. The first modern hospice was opened in south London in 1967 and, since then, hospice care has developed into a movement to change the way in which end of life care is delivered. Most hospices in England are independent local charities which are part funded by the NHS, although some hospices operate nationally and a small number are provided by the NHS. For the purposes of this report, the term 'hospice' covers both independent and NHS run facilities.

# **Liverpool Care Pathway**

Developed for use in hospitals, but can be used in primary care, care homes, or hospices. It empowers generalist clinicians to care for the dying and manage pain and other symptoms in the last days and hours of life by providing guidance on comfort measures; anticipatory prescribing of medicines; discontinuation of inappropriate interventions; psychological and spiritual care; and care of the family (both before and after death).

# **Nursing home**

See care home. In the report we use the term 'care home with nursing'.

### **Palliative care**

The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. Most palliative care is provided non-specialist staff such as GPs, hospital doctors, ward nurses, and staff in care homes.

# **Preferred Priorities for Care**

A patient held record documenting care on an ongoing basis which helps staff follow patient's expressed wishes. This record enables patients and carers to express preferences over the care they wish to receive, including where they wish to be cared for as they approach the end of life.

# Specialist palliative care

See palliative care. Specialist palliative is provided by multi-disciplinary teams that might include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. Such staff are specifically trained to advise on symptom control and pain relief.