We know about end of life care

Marie Curie Cancer Care
Understanding the cost of end of life care in different settings

www.mariecurie.org.uk
Overview

This briefing draws on Marie Curie’s experience as the leading organisation in end of life care to consider the economic impact of providing care to patients in the community, rather than in the acute setting.

At a time when commissioners are being asked to demonstrate QIPP savings by delivering transformational change through clinical service redesign rather than efficiency savings\(^1\), it shows one way in which they can improve on traditional service models.

As with any innovative approach, the evidence is not yet exhaustive. But a strong business case can be made for developing high-quality community-based care, and an ever-increasing number of trusts are substantially increasing their investment in their local Marie Curie Nursing Service.

Marie Curie Cancer Care is also working closely with many trusts to develop new ways of delivering services and on innovative approaches to caring for patients at the end of life.

\(^1\) NHS Operating Framework, 2012/2013
Key points

- Around 53 per cent of deaths in England take place in hospital despite the fact that this is the location least preferred by patients.
- Between 92,000 and 142,500 people in England each year have an unmet need for palliative care.
- The estimated cost for a day of community care at the end of life is £145 compared with the cost of £425 for a specialist palliative in-patient bed day in hospital. Changing the setting of care for a patient at the end of life has the potential to reduce the daily cost of care by £280.
- Between 355,000 and 457,000 patients need palliative care every year. If additional community services were developed to enable even 30,000 patients to reduce their hospital stay by just four days, there would be a potential saving of £34 million.

Background

There have been improvements in end of life care services in the UK in recent years but there remains a significant need for further development.

Despite the majority of people expressing a preference to die at home, in 2010 only 39.3% of people in England died in their usual place of residence \(^2\) (20.8% at home and 18.5% in care homes). Although hospital is the least preferred place of death \(^3\), 53.3% of deaths occurred in hospital, and just 5.3% in an in-patient hospice bed.

There remains a large unmet need for palliative care. The Palliative Care Funding Review commissioned research by King’s College London and partners. It estimates that between 92,000 and 142,500 people each year have an unmet need for palliative care.\(^4\)

Improving access to palliative care services presents a considerable challenge for commissioners in the current economic environment.

Marie Curie believes that much of the unmet need for palliative care services could be provided by community services. This briefing looks at existing evidence on the relative costs of providing end of life care at home and in hospital.

The evidence is divided into three sections:
1. How the per-day costs of providing care to terminally ill patients at home differs from the costs of providing it in hospital.
2. Cost modelling studies of the financial impact of caring for more patients in the community rather than in hospital.
3. Developing the evidence base to support more end of life care in the community.

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\(^3\) Local preferences and place of death in regions within England 2010, Barbara Gomes, Natalia Calanzani, Irene J Higginson. August 2011
\(^4\) Palliative Care Funding Review, Thomas Hughes-Hallett and Professor Alan Craft 2011
1. Per day costs

Hospital in-patient services
The latest estimate of the cost of specialist in-patient palliative care for adults is £425 per bed day. This is based on submissions from both NHS trusts and Primary Care Trusts in England on the cost of care in hospital, uplifted to 2009/10 prices.

Community palliative care services
For palliative care, there are challenges to establishing the costs of the multidisciplinary (and multi-agency) packages of community care that patients receive at the end of life.

The findings of the Palliative Care Funding Pilots being commissioned by the Department of Health will greatly improve our understanding of the per patient costs of providing palliative care in the community.

There are five main elements to a community palliative care service:
1. The NHS District Nursing service, which coordinates the provision of end of life home nursing and delivers some hands-on care
2. Community nursing providing hands-on care as needed on a 24/7 basis
3. Social care for people at home
4. Community specialist palliative care – specialist advice alongside the patient’s own doctor and district nurse to enable them to stay in their own home
5. Hospital or hospice palliative care outpatient services

Other community services which patients may use at the end of life include:
- GP contacts (including home visits and out of hours)
- Hospice day services
The patient may also require specialist equipment such as a hospital bed.

NHS District Nursing service
The local District Nursing service normally supervises the clinical care of patients at home. The University of Kent study estimates the cost of the District Nurses’ supervision of supporting end of life care patients at £39 per patient contact. For the purpose of this analysis, we have estimated that on average a patient will receive one District Nurse contact every third day, giving a weekly cost of £91.

Community nursing
Marie Curie Cancer Care operates a community nursing service for patients at end of life across most of the UK. The Marie Curie Nursing Service supported 23,400 patients at end of life care in the community in 2010/11.

While the Marie Curie Nursing Service is a major provider of community nursing to patients at the end of life, there are other organisations which provide similar services. We have used Marie Curie data because we do not have access to information from other providers.

The number of hours of care we provided to these patients in 2010/11 was 1.25 million. The average amount of care provided to each patient was 53 hours at an average cost of £1,626 per patient, an average of £465 per patient per week.

Social care costs
In addition to the health costs there are social care costs of supporting a person at home. These costs may be met by the authority or the person (depending on their financial means), or by the NHS if they are in receipt of continuing healthcare funding.

A report by the Nuffield Trust found that the average cost per user of providing social care (including equipment and adaptations) to individuals in the last year of life was £9,972. This equates to £27 per day, although the amount of social care that individuals...
use per month increases slightly in the last three months of life. This may be an overestimate of the average cost per day of social care for patients at the end of life, as it assumes that all patients will require social care – the Nuffield Trust study found that only around 30 per cent of people used local authority funded social care in the last year of life.

**Community specialist palliative care**

Patients with complex needs may need support from a specialist community nurse who can provide specialist advice, assessment and help with care planning. The University of Kent study estimates the cost of a community nurse specialist at £77 per hour of patient contact. For the purpose of this analysis Marie Curie estimates that on average a patient will have one hour with a specialist nurse per week.

**Outpatient attendance**

NHS reference costs estimate the cost of a medical outpatient specialist palliative care attendance at £194\[^8\] which is in line with the average cost of an outpatient appointment at Marie Curie's Hospices. For the purposes of this analysis we have assumed that each patient will attend one outpatient visit per week.

**Comparing the weekly costs of community palliative care with specialist in-patient palliative care.**

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost per contact</th>
<th>Contacts per week</th>
<th>Cost per week</th>
<th>Cost per day</th>
</tr>
</thead>
<tbody>
<tr>
<td>District nursing *</td>
<td>£39</td>
<td>2.3</td>
<td>£91</td>
<td>£13</td>
</tr>
<tr>
<td>Community nursing (8 hours per contact) *</td>
<td>£246</td>
<td>1.9</td>
<td>£465</td>
<td>£66</td>
</tr>
<tr>
<td>Social care ^</td>
<td>£191</td>
<td>1</td>
<td>£191</td>
<td>£27</td>
</tr>
<tr>
<td>Community Nurse Specialist (1 hour)</td>
<td>£77</td>
<td>1</td>
<td>£77</td>
<td>£11</td>
</tr>
<tr>
<td>Outpatient attendance</td>
<td>£194</td>
<td>1</td>
<td>£194</td>
<td>£28</td>
</tr>
<tr>
<td><strong>Total community</strong></td>
<td><strong>£1,019</strong></td>
<td></td>
<td><strong>£145</strong></td>
<td></td>
</tr>
<tr>
<td>**Hospital in-patient specialist palliative care ***</td>
<td><strong>£2,975</strong></td>
<td></td>
<td><strong>£425</strong></td>
<td></td>
</tr>
</tbody>
</table>

Figures are shown to the nearest £, but calculations based on unrounded figures.

* = Unit Costs of Health and Social Care, University of Kent, 2010
^ = Marie Curie Nursing Service data
˜ = Social Care and Hospital Use at the End of Life, Nuffield Trust, 2010

The table shows that the estimated cost of a day of community care at the end of life is £145 compared the cost of £425 for a specialist palliative care bed day in hospital. This indicates that changing the setting of care of a patient at the end of life has the potential to reduce the daily cost by £280.

The Palliative Care Funding Review estimated that there are 355,000 to 457,000 patients in need of palliative care every year. If additional community services were developed to enable even 30,000 patients to reduce their hospital stay by just four days there would be a potential saving of £34 million.

The cost of community nursing above represents the full cost of the service. Marie Curie contributes approximately half of its cost from charitable funds, leaving the NHS to pay the balance, so if community nursing were provided by Marie Curie then the cost to the NHS would be lower.

\[^8\] Unit costs of Health and Social Care (2010)
University of Kent
Other community services
A number of other community services will be used (to varying extents) by people at the end of life. These include GP contacts – £36 per surgery consultation, £120 per home visit (Unit Costs of Health and Social Care, 2010).

There is little data available on the number of contacts patients at the end of life have with GPs. However the cost of a GP visit is unlikely to have a material effect on the balance of cost.

2. Cost modelling studies
A number of studies have built on the unit costs data to produce models about how shifting care from one setting to another might affect the costs of providing care to patients at the end of life.

Rand Europe
The most important modelling in recent times was a collaboration between the National Audit Office (NAO) and Rand Europe to construct a model to estimate the economic impact of changing the setting in which care was provided.10 Part of the analysis examined the potential for a redistribution of resources that could be made possible by providing care at the end of life at home rather than in a hospital setting.

The study found that patients who died in 2005/06 spent on average 17 days in hospital and two in a hospice in the year prior to death. Researchers estimated that the cost to the NHS and social services of caring for cancer patients in the last year of their lives amounted to £1.8 billion.

If a 10 per cent reduction in the number of emergency admissions and a reduction of three days in the length of stay per admission could be achieved through greater use of community care, then a total of £104 million could have been made available for redistribution in community services.

Balance of Care Group
In its analysis the NAO also engaged the Balance of Care Group to undertake a study in Sheffield.11 The survey found that 40 per cent of the 200 patients who died in hospital in the month of October 2007 were not found to have medical needs which required them to be in hospital at the point of admission and could have been cared for elsewhere. The alternatives identified were equally split between home-based alternatives (for example, in a patient’s own home or a care home) and bed-based care in a hospice or palliative care ward.

These patients used 1,500 bed days in acute hospitals, the equivalent of 48 beds being occupied for an entire month. The survey authors estimated that £4.5 million in Sheffield PCT alone could be made available for investment in end of life care services in the community if all those who were in hospital unnecessarily when they died, had been cared for in the community.

School of Pharmacy, University of London
A study by the School of Pharmacy, University of London in 2004 involved a comparison of homecare and hospital costs.12

The study estimated the cost of hospital care in 2003/04 at £300 per day based on the cost per bed day from the Sheffield School of Health and Related Research (ScHARR) study findings and recent evidence to the Department of Health to the Health Select Committee. For comparison the cost of an in-patient day at a Marie Curie Hospice at that time was £374. Accordingly a patient spending the last 14 days of their life in hospital would represent a cost of £4,200.

10 The potential cost savings of greater use of home- and hospice based end of life care in England, prepared for the National Audit Office, Published by the Rand Corporation, 2008
11 Identifying Alternatives to Hospital for People at the End of Life, The Balance of Care Group in association with the National Audit Office, 2008
12 David Taylor and Sarah Carter (2004) – School of Pharmacy, University of London, Valuing Choice – Dying at Home. A care for the more equitable provision of high quality support for people who wish to die at home. An economic and social policy opinion commissioned by Marie Curie Cancer Care.
They estimated the cost of an intensive community support package for the same period of 14 days at £2,500. This represents a saving of £1,700 per patient. If the place of care of 23,500 patients could be changed the potential saving would be £40 million.

As Marie Curie meets part of the cost of the community nursing we estimate the cost to the NHS at £2,000.

This was made up as follows:

<table>
<thead>
<tr>
<th>Weekly cost</th>
<th>Cost over 14 days</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>£</td>
<td>£</td>
<td></td>
</tr>
<tr>
<td>GP visits</td>
<td>210</td>
<td>420</td>
</tr>
<tr>
<td>Other health and social care professionals</td>
<td>420</td>
<td>840</td>
</tr>
<tr>
<td>Marie Curie Nurse</td>
<td>500</td>
<td>1,000</td>
</tr>
<tr>
<td>Drugs and equipment loans</td>
<td>120</td>
<td>240</td>
</tr>
<tr>
<td><strong>Total cost</strong></td>
<td><strong>1,250</strong></td>
<td><strong>2,500</strong></td>
</tr>
</tbody>
</table>

Other studies
A review by Bosanquet (2002) concluded that there is a considerable amount of intermediate quality evidence from countries such as Italy, Spain and the US showing that home-based palliative care intervention leads to cost savings.

Note on data
The evidence presented in this review is of mixed quality. To date, there are no ‘gold standard’ randomised controlled trials comparing the costs and outcomes of ‘usual care’ with the costs and outcomes of enhanced community services. Most studies are theoretical in nature (e.g. RAND study). This places considerable limitations on the strength of the conclusions that can be drawn from these studies about the economic evidence around the cost and impact of different approaches to end of life care in different settings.

3. Developing the evidence base

A number of pieces of work are underway which will strengthen the evidence base on the cost and impact of community palliative care services.

Palliative Care Funding Review pilots
The Palliative Care Funding Review pilots will involve a large element of data collection to inform palliative care provision in England.

The review recommends that the pilots are made up of networks of providers rather than single organisations so that the full pathway of acute and community interventions for patients can be captured.

The aim of the pilots will be to link clinical episodes of care with cost information providing new insight into resource use in palliative care.

Minimum Data Set pilots
The existing Minimum Data Set for specialist palliative care managed by the National Council for Palliative Care (NCPC) collects comprehensive data about hospice and specialist palliative care services at a service level.

The NCPC is currently working with the National End of Life Care Programme (NEoLCP) and the National End of Life Care Intelligence Network (NEoLCIN) to pilot the development of this data to allow for the collection of patient level data in five pilot sites in England. The pilot work should

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provide insight into service use at a patient level in hospices including specialist community palliative care.

**Potential savings for commissioners**

NICE guidance for commissioners on end of life care for adults¹⁴ highlights the potential for service redesign to produce savings in hospital costs. The NICE online benchmarking tool, based on data from the Hospital Episodes Statistics (HES) database, provides PCT-level estimates on the scale of financial savings that could be delivered by reducing the number of hospital admissions ending in death, and by increasing the number of discharges from hospital before death for patients at the end of life. The tool can be found at:

http://www.nice.org.uk/media/607/E7/EndOfLifeCareCABtool.xls

This briefing reviews a number of studies which have examined the relative costs of providing end of life care at home and in hospital. They have shown that providing additional care at home can be cost neutral or can produce net savings for health services.

Given the small number of studies evaluating the economic impact of changing services and the lack of community service usage data, most of the forecast savings are estimates. This, together with differences in the interventions studied, may help to explain the wide range of per day savings estimates between studies.

Estimates of per day savings should be treated as indicative. The work in progress will generate more precise estimates and build on existing data to strengthen the economic evidence to support increased spending on Marie Curie's community services.