

End of Life Care Hospice at Home Services – Overview



Hospice at Home Services – Overview

Background

The following summary paper has been prepared to help inform the discussions planned by the Oxfordshire CCG Locality group. The Locality group decided to review the potential benefit of Hospice at home services and set up a Working group, the first meeting will take place on 5th November 2015.

The purpose of this paper is to provide an overview of some of the evidence available about Hospice at Home services. It includes links to specific papers which are of relevance. It covers information from the National Association of Hospice at Home (1). This is a national group representing the views of providers, which sets standards and communicates information about good practice. Relevant information is included from a population based study (2) which identifies factors which are associated with and facilitate dying at home. The views of stakeholders are considered in a further research paper (3) which can enable the Working group to be aware of key aspects of service which are considered essential.

A model used to set up a new Hospice at Home service is highlighted (4) which allowed these key aspects to be incorporated. This service provides information about outcomes which give information about benefit and explores the economic aspects. A paper is included (5) which demonstrate the challenges of evaluating the impact of a new service. The Cochrane review paper (6) provides information collected from published research and draws conclusions about service benefit based on a wide range of evidence.

1. The choice to die at home: a reality or an aspiration? Does hospice at home hold the key?

Kay Greene, Chair & Trustee, National Association for Hospice at Home 16 October 2015

<http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/17108/language/en-GB/View.aspx#.ViFL1q4j9ds.mailto>

The National Association of Hospice at Home identifies seven core elements of a hospice at home service:

- Ability to provide all services on a 24/7 basis, 365 days per year
- Hands on practical nursing and social support.
- Crisis response to patient need regardless of diagnosis.
- Planned response to patient need regardless of diagnosis.
- Single point of access, working in partnership with other organisations.
- Respite for carers.
- Team includes clinical nurse specialist i.e. has specialist palliative care qualification.

It offers guidance on a service specification:

<http://www.nahh.org.uk/about-hospice-care/service-specifications>

2. Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study

Barbara Gomes Natalia Calanzani Jonathan Koffman and Irene J. Higginson

<http://www.biomedcentral.com/1741-7015/13/235>

Findings are based on the results of questionnaires completed by bereaved relatives of cancer patients in London. Of the 352 patients included in the study, 177 died in hospital and 175 died at home.

Factors associated with dying at home

We found several modifiable factors associated with place of death that are amenable to intervention and are rarely measured. Namely, we identified four conditions that are almost essential for patients to die at home rather than in hospital: patient's preference, relative's preference, receipt of home palliative care, and of district nursing/community nursing. The study also shows that, if patients get intensive nursing care specific to the end of life (provided by Marie Curie nurses), they very rarely die in hospital. However, 96 % of those who died in hospital did not get such help. The study observes dose-response relationships for two factors from a previous model: hospital days and GP home visits. It challenges current thinking about the influence of patient's functional status, social conditions, and living arrangements, showing no association once other factors are considered. Importantly, we identified three factors previously overlooked – length of relative's awareness of incurability, discussion of patient's preference with family, and relative's work arrangements in the 3 months before death. Our final model explained well why some patients died at home whilst others died in hospital. Subject to testing, this may be effective for clinical decision-making.

3. Service evaluation of community based palliative care and a hospice-at-home service Wilson J, et al.

<http://eolj.bmj.com/content/5/1/eoljnl-2015-000004.full.pdf+html?sid=a2476220-c66e-4548-833a-1b29376c883b>

Method A qualitative methodology was used to explore stakeholder views about an expanded hospice-at-home service. Focus groups were conducted with four stakeholder groups: patients/carers; community nursing staff; palliative care nurse specialists; and GPs/senior managers. Data analysis used a framework approach to categorise the stakeholder responses.

Findings Participants perceived that important aspects of end-of-life care needs were being met including quick access to hospice-at-home services and the prevention of admission to hospital for patients who received visits and treatment at home from this service. Issues that needed improvement included communication between hospital and community services, education and training needs regarding the use of technology and the limitations of the current service in relation to home visits from the hospice-at-home service.

Conclusions Recommendations included 24-hour access to home visits over 7 days each week, the provision of training and education for staff in the use of technology, talking to

families about advance care planning, and improved communication between and timely transfer of information from hospital to community services when patients are discharged.

4. Hospice to home: a patient-centric multi-professional community approach

Lesley Spencer

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http://nahh.org.uk/component/docman/cat_view/33-news?Itemid=

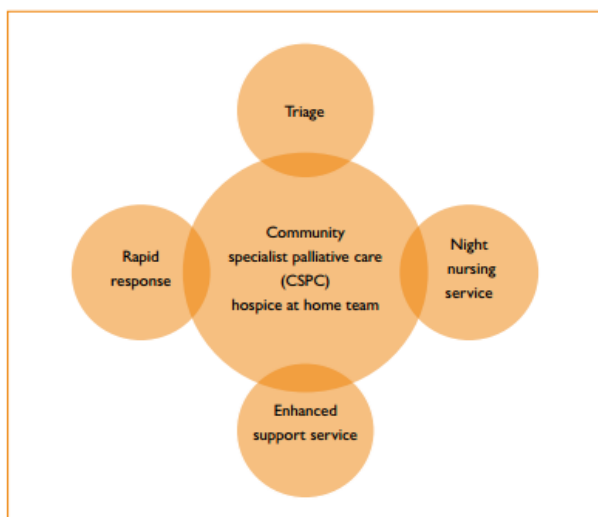


Figure 1: Integrated model of community specialist palliative care

This article describes how one hospice developed a model of care working in partnership with statutory services that provided patient centred care, achieved preferences and prevented unnecessary admissions into hospital. It describes each element of the model and how they work seamlessly together. The evaluation of the model suggests that maximum impact can be gained by focusing service development on expanding and improving care at home. The referral form was designed to collect key data and metrics. This data was analysed on a 6-monthly basis and the service was reviewed in-line with results.

Details of the 4 key Service Components:

Triage

Triage was designed to be a command base. Two CNSs from the CSPC team rotated into Triage on a daily basis. All new referrals were processed with increased efficiency. Depending on need, all referrals were forwarded seamlessly to other disciplines where the other elements of the model were activated, in order to support patients and their carers. There was easy access to specialist advice for health professionals and generic advice for patients/carers not necessarily under the auspices of the hospice. The CNSs, between the hours of ten and four, Monday to Thursday and ten and five on Fridays, were mainly office-based, but were able to support the rapid response element of the model should an urgent home visit be required.

Night sitting service

The prime aim of providing the night nursing service was to optimise the opportunity for patients to remain at home under the care of the hospice when the patient was assessed to be terminally ill or the patient had been discharged from the hospice inpatient unit and required additional nursing support. In addition to this, night nursing would support patients with complex symptom-control problems or those undergoing a psychosocial crisis requiring management that would have otherwise required admission to the acute trust. The night-sitting service started gradually but is now supported by permanent registered nurses and senior health-care assistants working with hospice trained bank staff to deliver around 40 night supports per month.

Rapid response role

The CSPC team removed a CNS from their caseload to support a rapid response role. The CNS worked under the auspices of the CSPC team and worked flexible hours within the working week in order to be able to respond to urgent calls, make urgent visits, support hospital discharge, support Triage and undertake CNS urgent caseload requests. The rapid response CNS role was designed to meet the following primary aim: to enable palliative care patients in the community to access prompt specialist palliative care services and to increase the number of patients achieving their preferred place of care and death. In addition to this primary aim, the team sought to enhance collaborative working with existing service providers, have a positive impact on carers' quality of life and prevent unnecessary admissions to hospital.

Enhanced support service

The enhanced support service (ESS) team was a multi-professional team (MPT) coordinated by a CNS. The team includes practical care nurses, a specialist social worker, physiotherapist, occupational therapist and a speciality doctor

Results

Key results after 1 year:

- 81% of patients supported were new to the Hospice and required EoLC assessment and or symptom control management, with nearly 60% of visits lasting 1–2 hours
- 93% of patients wanted to be cared for in their usual place of residence. For 34% this was a nursing home
- With regard to preferred place of death, 84% wanted to remain at home and 16% preferred to die in a hospice. No patients wanted to be transferred to hospital. However, 1.5% of patients were admitted to hospital as a result of the rapid response assessment, which suggested transfer into the acute sector
- 96% achieved their preferred place of death with 71% seen on the day of referral. During the visit 83% had an advance care plan discussed in order to help prevent further crisis. 71% of patients died within 10 days of the visit.

Conclusions: The evidence supports our clinical opinion that the vast majority of patients requiring a rapid response visit were at high risk of being admitted unnecessarily to hospital, acknowledging that patients and their carers 'struggle on' regardless of a potentially poorer quality experience. Rapid response visits, by their very nature, are crisis visits with some nursing homes in particular appearing to struggle and when challenged would either not have accepted a patient from hospital or would have admitted the patient to the local Accident and Emergency unit.

The service has demonstrated benefits to patient experience and efficiency savings amounting to thousands of pounds. This is crucial when considering the wider economy. It is estimated that in the last 90 days of life, the cost of the care required to support an individual will average £4500, with the bulk of this cost being attributed to emergency hospital admissions which increase rapidly during the last few weeks. The prevention of inappropriate hospital admissions and achievement of preferred place of care and death must therefore remain fundamental to service delivery.

5. A quasi-experimental controlled evaluation of the impact of a hospice Rapid Response community service for end-of-life care on achievement of preferred place of death.

[Holdsworth LM](#), [Gage H](#), [Coulton S](#), [King A](#), [Butler C](#).

[Palliat Med](#). 2015 Oct; 29(9):817-25. doi: 10.1177/0269216315582124. Epub 2015 Apr 16.

AIM:

To assess the impact of a rapid response hospice at home service (intervention) on people dying in their preferred place, and carer quality of life, compared to usual care (control).

DESIGN:

Quasi-experimental multi-centred controlled evaluation. Patient data were collected from hospice records; carers completed postal questionnaires to report quality of life, anxiety and depression.

SETTING AND PARTICIPANTS:

Community served by one hospice (three contiguous sites) in South East England; 953 patients who died with a preferred place of death recorded and 64 carers who completed questionnaires.

RESULTS:

There was no significant difference between control and intervention groups in proportions achieving preferred place of death (61.9% vs 63.0% (odds ratio: 0.949; 95% confidence interval: 0.788-1.142)). People living at home alone were less likely to die where they wanted (0.541; 95% confidence interval: 0.438-0.667). Carers in the intervention group reported worse mental health component summary scores (short form-12, $p = 0.03$) than those in the control group; there were no differences in other carer outcomes.

6. Cochrane Review 2013 Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers

Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ

http://www.cochrane.org/CD007760/SYMPT_effectiveness-and-cost-effectiveness-of-home-based-palliative-care-services-for-adults-with-advanced-illness-and-their-caregivers

We identified 23 studies (16 RCTs, 6 of high quality), including 37,561 participants and 4042 family caregivers, largely with advanced cancer but also congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), HIV/AIDS and multiple sclerosis (MS), among other conditions.

We found that when someone with an advanced illness gets home palliative care, their chances of dying at home more than double.

Meta-analysis showed increased odds of dying at home (odds ratio (OR) 2.21, 95% CI 1.31 to 3.71; $Z = 2.98$, P value = 0.003; $\text{Chi}^2 = 20.57$, degrees of freedom (df) = 6, P value = 0.002; $I^2 = 71\%$; NNTB 5, 95% CI 3 to 14 (seven trials with 1222 participants, three of high quality)).

In addition, narrative synthesis showed evidence of small but statistically significant beneficial effects of home palliative care services compared to usual care on reducing symptom burden for patients (three trials, two of high quality, and one CBA with 2107 participants) and of no effect on caregiver grief (three RCTs, two of high quality, and one CBA with 2113 caregivers). Evidence on cost-effectiveness (six studies) is inconclusive.

Conclusion

There are clear benefits from Hospice at Home services, which include a rapid response alongside a night sitting element. The rapid response element can alter outcomes by enabling patients to be cared for and die in their place of choice. Results available for analysis from the Cochrane review provided clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief. These authors concluded that this benefit justifies providing home palliative care for patients who wish to die at home.

Further work from a single study has not demonstrated that same benefit in an area already well served by community palliative care. The difficulty of recording preferences with changes in preference over time presented particular challenges in this study when evaluating outcomes. This reinforces that moving towards measuring 'experience of care' rather than 'preferred place of care' will be a more informative and better outcome measure.

It is possible to modify existing palliative care services to incorporate the key aspects of Hospice at home and show benefit, as was achieved by one service. Their model of service has much to consider and recommend itself with the combination of triage, rapid response, night sitting and enhanced support service (i.e. access to multidisciplinary team).

The economic benefit has to date been hard to clearly demonstrate and Cochrane stated that more work is needed to study cost-effectiveness especially for people with non-malignant conditions.

The need to address some of these questions is on the agenda for the National Association of Hospice at Home who are in the process of collating national data from teams across the UK. It is anticipated that this will be one of the areas of focus at their national conference next year.