

## PROCESSES AND SYSTEMS

## Dying at home the Midhurst way

**Authors:** Catherine Waight<sup>A</sup> and Bill Noble<sup>B</sup>

## ABSTRACT

Ensuring high quality of care for dying patients and their families is a challenge for both primary and specialist palliative care services throughout the UK. A model of a consultant-led palliative care community team was set up following the closure of a specialist palliative care inpatient unit in Midhurst, with the aim of providing that same level of care to patients in their own homes, care homes and community hospitals. It works closely with primary care to enhance community services and with secondary care to enable rapid discharge from hospital to the community. Anticipatory prescribing, advanced care planning and education of social care and nursing home staff are also key aspects of the service. The Macmillan Midhurst Service costs an average of less than £3,000 per patient and enables 85% of referred patients to die in their preferred place. Evaluations of the service have highlighted benefits to patients and families as well as cost reductions to the NHS of around 20% when patients are referred early.

## Introduction

Although there remain questions about whether home is always the best place of death, meeting patients' preferences for place of care and place of death are commonly used as indicators of good care.<sup>1</sup> In Midhurst, as in most of the UK, the majority of patients state their preference is to be cared for and die at home. Achieving this and ensuring a high quality of care for patients and families is a challenge faced by both primary care and specialist palliative care services.

Over the past decade, initiatives such as the Gold Standards Framework, Preferred Place of Care and the Liverpool Care Pathway were disseminated throughout UK<sup>2</sup> and although these have had mixed success, a trend towards death at home rather than in hospital has emerged.<sup>3</sup> Many palliative care initiatives aim to save NHS resources, but the Marie Curie Nursing Service (MCNS) is a rare example of an intervention that supports home death and reduces costs of hospital care. In an independent review, costs for those who received MCNS care were £1,140 per person less than for the matched controls from the first contact with MCNS until death.<sup>4</sup>

Early intervention by palliative care services, soon after the diagnosis of advanced lung cancer, was demonstrated to improve both quality of life and survival, countering the commonly held

opinion that palliative care should be reserved for the time when oncological treatment has been abandoned.<sup>5</sup>

However, the projected 42% increase in demand for palliative care by 2040 will test any adjustment of the existing models of care.<sup>6</sup> It is possible that interventions to support family carers will have the impact to meet the coming demand. If they are to be successful, however, community palliative care services will be required to scale up. Although the hospice movement has set a standard of palliative care, delivery in the community at scale has proved difficult and the radical step of wholesale diversion of specialist palliative care resources away from an inpatient facility into the community is rare within the NHS or the voluntary sector.

## Background

The Midhurst Macmillan Service was set up in 2006, following the closure of King Edward VII Hospital. This hospital had a 12-bed specialist palliative care unit, so a new community team was formed with the aim of replicating the care given in the inpatient unit. The team was led by a consultant in palliative care who was supported by clinical nurse specialists and a team of nurses and healthcare assistants. The team was modelled on the Motala model in Sweden,<sup>7</sup> which provides community-based care at home to cancer patients. The Midhurst model differs from Motala, where some palliative care in patient beds were retained within the service. In Midhurst, when an inpatient bed is essential or is the preference of the patient, beds can be accessed in care homes, community hospitals or neighbouring hospices.

The aim was to work with the local primary health care team to support patients in the community, enabling patients to be cared for and die in their place of choice. Clinical interventions formerly offered in the inpatient unit, such as blood transfusions, intravenous infusions, paracentesis and subcutaneous infusion, became available to patients in the community. The team was funded jointly from the Macmillan Cancer Care and the three primary care trusts in Surrey, West Sussex and Hampshire. The area is approximately 400 square miles and has a population of 150,000. The team was hosted by the West Sussex primary care trust (PCT).

Macmillan commissioned an evaluation by the universities of Sheffield and Huddersfield in collaboration with a management consultancy.<sup>8</sup> The aim of the evaluation was to determine whether the service had met its original aims in the provision of palliative care, to gain evidence for clinical commissioning groups and Macmillan for commissioning and funding, and to see if this model of care could be replicated elsewhere.

The evaluation concluded that the team did provide services which supported and provided a good experience for patients

**Authors:** <sup>A</sup>consultant in palliative care, Cornwall Hospice Care, St Austell, UK; <sup>B</sup>vice president, Public Health Palliative Care International

and carers. It had good relationships with other services, and was willing to take early referrals before the terminal phase of illness. Of the Midhurst service study group, 71% (2008) of patients were facilitated to die at home or in a care home, similar to the 70% out-of-hospital deaths for the group referred to local hospice services, but higher than the contemporary nationwide estimate for out-of-hospital deaths in England, which is 52%.

Overall, including the voluntary sector contribution, the mean cost of care provided by the Macmillan Midhurst service was £3,000 per case. The service is funded jointly between the NHS and Macmillan charity. While each patient referred to the Midhurst service incurs cost to the commissioners of £1900, the cost savings relating to other secondary care activity were estimated to be of the order of £6000 per patient, about 20% of the total costs. This was achieved by early referral to the Macmillan Midhurst service, a special feature not apparent in surrounding hospice-based services. It was noted that the team had good clinical leadership and flexible working practices. Although local socioeconomic conditions supported significant volunteer capacity, general practice provision of end-of-life care was within national norms and there were no other local factors that might preclude replication.

The service was also selected to be part of a King's Fund project looking at coordinated care for people with complex chronic conditions.<sup>9</sup> They highlighted the single assessment, anticipatory prescribing, treatments given in the home, continuity of relationship between the team and patients and carers, the key roles played by the clinical nurse specialist and medical team, and role flexibility as factors which led to good outcomes for patients and their families. They identified challenges with respect to geography, a catchment area which straddles three clinical commissioning groups (CCGs), a rural area with poor public transport, and a local population comprising mainly elderly white middle class people but with areas of deprivation. They concluded that the service has developed to meet the needs of the population.

### Current service provision

Following reconfiguration and mergers in the local health care system, the team is currently hosted by the Sussex Community Foundation Trust, and is still jointly funded by the Macmillan Cancer Care and three CCGs: Coastal West Sussex, Guildford and Waverley, and South East Hampshire. The number of referrals has increased from 350 in 2006 to 650 in 2016 with 430 deaths. The percentage of non-cancer referrals has also increased from 15% in 2006 to 25% in 2016. The proportion of deaths at home was 85% and patients achieving their preferred place of death was 85% (2016).

Since its foundation the team has increased over the past 10 years, but remains relatively small. It now has 2.2 WTE (whole time equivalents) doctors (including two consultants and two specialty doctors) and 6 WTE clinical nurse specialists and registered nurses who provide hands-on care. Other members of the team include a part-time counsellor, physiotherapist and occupational therapist, as well as administrative support, including a volunteer coordinator. The team now operates 7 days a week.

The service maintains close working relationships with general practitioners and community nurses. The team attends meetings held in GP practices, where cancer and palliative patients are discussed. The medical team provide telephone support and joint visits with GPs and well as the clinical interventions.

A modified version of the National Voices Questionnaire<sup>10</sup> for bereaved relatives and carers is sent out after the death of patients; it has reported that 90% of patients died in the right place, as perceived by their carers, and that there were good working relationships between the team and the primary health care teams.

The team has just completed transition over to a new electronic patient record and is now using SystmOne as used by primary care in Coastal West Sussex, which will enable clinical records to be shared with some other healthcare providers

### Lessons from Midhurst on how to achieve a home death

So how do we achieve a home death?

- > **A flexible workforce**, so that whoever is in the home can carry out the care that is needed, regardless of their profession, provided that it is within their skill set.
- > **Rapid response to patients in distress**: this could be the response of a nurse or doctor to a crisis, rapid discharge home from hospital, or sourcing medication for patients who are discharged from hospital so they are not waiting for drugs to be supplied in the hospital.
- > **Good relationships and trust in the team**, built up from first referral, and enhanced by interventions in the home, so that when patients and carers need support they trust the community team to respond adequately. This was promoted by referral to the Macmillan Midhurst Service earlier in a patient's disease history, compared to referrals to other palliative care services.
- > **Good working relationships with primary care and hospitals**, aided by the sharing of electronic patient records where possible as well as good direct communication, including joint visits. These are essential to provide the seamless care which anticipates problems before they become a crisis of care.
- > **Correct documentation**, such as a 'Do not attempt resuscitation' (DNAR) form and prescriptions for injectable medications, in place within the home, pre-empting deterioration and loss of control of symptoms. Contingency plans for treatment, anticipatory care plans and advance care planning are all valuable tools for jointly planning and sharing with the out-of-hours services and ambulances services.

### What might the future hold?

The increased referral rate, without extra funding, has required a review of working practices. Patients are now being assessed and then supported at different levels depending on need, by a clinical nurse specialist or the clinical support team, or via phone contact by the triage nurse. Child or family therapists have been brought in to work with counsellors to provide increased support to children and their families in the most difficult cases.

The role of volunteers might be expanded to support families, for example to give assistance or respite to family carers, or when a patient has died and they need help registering the death. The team is based at the Midhurst Community Hospital, supporting inpatients, and may develop new services for frailty. Care home education programmes and ongoing support from the team should increase their competency and willingness to care for

patients at the end of life, reduce hospital admission, and improve the training of all the staff in the home.

Collaboration with other specialist palliative care providers will help the team to work on a number of educational initiatives such as communication skills training.

Ongoing assessment will be essential. The Voices questionnaire to bereaved relatives and carers was part of the evaluation of Midhurst and provided evidence of the nature of families' experiences of care. The Outcome Assessment Complexity Collaborative (OACC) has been designed by Kings College<sup>11</sup> as a suite of outcome measures to enable commissioners to understand effectiveness of palliative care services.

## Conclusion

The provision of a consultant-led specialist palliative care community service that accepts early referrals, provides 7-days-a-week support, has a close working relationship with primary and secondary care and is capable of reacting quickly to crises has enabled the majority of patients referred to them to die at home. Anticipatory prescribing, advance care planning and education of social care and nursing home staff are also key factors. Evaluations of the service have highlighted benefits to patients and families as well as a possible cost reduction in NHS services of the order of 20% when patients are referred early. ■

## Conflict of interest

Catherine Waight works for Macmillan and Bill Noble works for Marie Curie.

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**Address for correspondence: Dr Catherine Waight, Midhurst Macmillan Team, Pearson Unit, Midhurst Community Hospital, Dodsley Lane, Midhurst GU29 9AW, UK.**  
**Email: [catherine.waight@nhs.net](mailto:catherine.waight@nhs.net)**