Summary of the Midhurst Macmillan Community Specialist Palliative Care Service

June 2012

Executive Summary

- This paper outlines the results of an economic and qualitative evaluation commissioned by Macmillan Cancer Support into the Midhurst Macmillan Community Specialist Palliative Care Service.

- The Midhurst Macmillan Community Specialist Palliative Care Service (Midhurst Service) is an innovative community based specialist palliative care model that enables many more people to die in their preferred place of care.

- Our findings suggest that if the Midhurst Service was replicated elsewhere, the total cost of care in the last year of life could be reduced by 20 per cent, because it is associated with more proactive use of community based palliative care.

- Patients are referred to Midhurst earlier than to other models of specialist palliative care, which is associated with patients spending fewer nights in a hospital setting and having fewer A&E attendances than those not referred to a specialist palliative care service. It is also associated with fewer deaths occurring in a hospital setting.

- The Midhurst Service is able to maximise patient choice by providing as much treatment and support in the home or community as possible, through a multidisciplinary community based team.

- Providers of specialist palliative care should investigate ways to implement service models like Midhurst: key components are early referral to active specialist palliative care, delivered by multi-disciplinary and flexible community based teams, therefore allowing more people to die in their place of choice while reducing NHS costs.

- Given the likely increased demand for specialist palliative care as indicated in the Palliative Care Funding Review, the Midhurst Service may represent an efficient way of expanding specialist palliative care capacity. We want the Government to ensure that key funding levers, such as the proposed Palliative Care tariff, support a shift to community based specialist palliative care.

Macmillan Cancer Support

There are currently two million people living with or beyond cancer in the UK. On the basis of current trends, this will have risen to four million by 2030.[1] Macmillan is striving to improve the care given to patients at all points on their cancer journey, including the management of advanced and metastatic cancer and end of life care.

In 2010 Macmillan spent over £25 million on initiatives for people needing palliative care or end of life adult services. There are also over 1600 Macmillan professionals working in the field of palliative and end of life care. Macmillan believes that if someone is nearing the end of their life, they should have a choice over where to spend that time.

For the majority of people, home is the place of choice to receive care and to die. 73 per cent[2] of people with cancer would choose to spend their last weeks and days of life at home if all their concerns about dying at home (such as access to pain relief, round the clock care, and support for their family and carers) were addressed, yet only 27 per cent[3] do.

We have been campaigning for all people with cancer near the end of their life to have access to 24/7 community nursing to enable more people to die in their place of choice.

Background

The Midhurst Service was set up in 2006 when the King Edward VII Hospital's inpatient palliative care unit closed. The Midhurst Service adopted a modified version of the Swedish Motala Model for advanced home care, which comprises of a consultant led multi-disciplinary team that aims to provide 24/7 'hands on' care and advice at home, in community hospitals and in nursing or residential homes. The service is currently part funded by Macmillan (50 per cent) and part funded by the NHS (50 per cent).

The Midhurst Service was set up in order to:

- Maximise patient choice by providing as much treatment and support in the home/community setting as possible
- Reduce acute hospital interventions and inpatient hospice stays
- Ensure close working between the NHS, voluntary, charitable and private sectors in order to deliver high quality patient care, in line with recommendations that specialist palliative care is provided as early as possible, and
- Be a sustainable and affordable service for the population within Midhurst and the surrounding areas.

The Midhurst Service accepts referrals for any patient, living within the specified area, over the age of 18 with cancer or any life limiting chronic progressive disease

[1] Macmillan Cancer Support, www.macmillan.org.uk/
[2] Statistic taken from Macmillan February 2010 online survey of 1,019 UK adults living with cancer.
[3] Office for National Statistics. Mortality statistics: deaths registered in 2009 in England and Wales.

experiencing complex problems that are not responding to routine treatment and therapeutic intervention.

The Midhurst Service is managed by the Sussex Community NHS Trust and is commissioned by three local PCTs. It consists of specialist professionals as well as a large team of volunteers providing active specialist palliative care and support following early referral from either the hospital or GP. It also works with members of primary healthcare teams, community services, social services, care agencies and voluntary organisations within the area.

The Midhurst Service provides active specialist palliative care through a range of interventions undertaken either at home or in the community. It offers access to care at all times as well as bereavement support. Palliative interventions include blood/blood product transfusions, parenteral treatments, IV antibiotics, IV biphosphates, fluids, paracentesis and intrathecal analgesia.

Who are users of the Midhurst Service?

The Midhurst Service covers a rural area of about 25 miles radius including Midhurst, Pulborough and Billingshurst in West Sussex, Haslemere and Hindhead in Surrey, Petersfield and Bordon in Hampshire. The service serves patients of approximately 19 GP practices.

The population is an aging one with pockets of rural deprivation. The area also has higher than national average rates of breast and prostate cancer in all age groups.[4] The total size of the population is about 155,000 and 409 referrals were received in 2010 - 2011, of which about 85 per cent were patients with cancer. It is likely, given a current national death rate of 1 per cent, the Midhurst Service supported 25 per cent of all dying patients in the area.[5]

What makes the Midhurst Service an innovative model of specialist palliative care?

There are a number of characteristics of the Midhurst Service team that enable it to function very effectively. It is distinctive in having a consultant-led multidisciplinary community based team. Whilst with a patient, all members of the team will attend to whatever the patient's needs are as long as they are within their capabilities. The Community Nurse Specialists operate within a certain patch which enables them to develop very strong relationships with other professionals within that area. The service also has a large community based volunteer service and is able to signpost people to financial support and advice as well as other services as appropriate. Volunteers also provide a range of other support such as bereavement support and complementary therapies.

[4] Taken from the National Update, National End of Life Care Programme January 2012 Newsletter.

[5] Final Integration Report - Evaluation of the Midhurst Real Choice Project: A joint report of findings and conclusions arising from studies by Monitor, the University of Sheffield and the University of Huddersfield, February 2012.

Flexibility is a key offering of the Midhurst Service. This includes being flexible about role definitions, working hours and working across PCT boundaries. There is a lack of emphasis on hierarchy in relationships within the team that helps make people feel valued. It offers significant benefits for patients and carers as a result of the breadth of services delivered in the patient's home and the way the team works together to deliver them.

Leadership within the team is clear and effective and the structure that combines patch-based Community Nurse Specialists and a pool of nurses and nursing assistants in the Community Support Team works effectively. Relationships with other services in and around Midhurst are functional and supportive. The Community Support Team can be deployed flexibly to respond to fluctuating demands across the Midhurst area as a whole. The comprehensive nature of the team, which includes doctors, therapy professions, and counselling as well as nursing also means they can respond to a wide range of patient and carer needs in the community.

Formal evaluation findings

Macmillan Cancer Support commissioned an evaluation of the Midhurst Service, designed to assess whether the service is meeting its operating principles, its replicability as a model of care, and to gather evidence to inform future commissioning and funding intentions.

The evaluation included two distinct elements:

- An economic evaluation of the service, undertaken by Monitor Group[6]. The analysis focused on all patients who died from cancer[7] within the 12 month period between August 2008 and August 2009.
- A services review of the organisational context and the patient and carer experience, undertaken by the University of Sheffield and the University of Huddersfield.

An overview of the methodology is available at Appendix 1.

[6] Monitor Group, http://www.monitor.com/
[7] As defined by the Public Health Mortality File

Economic Review Findings

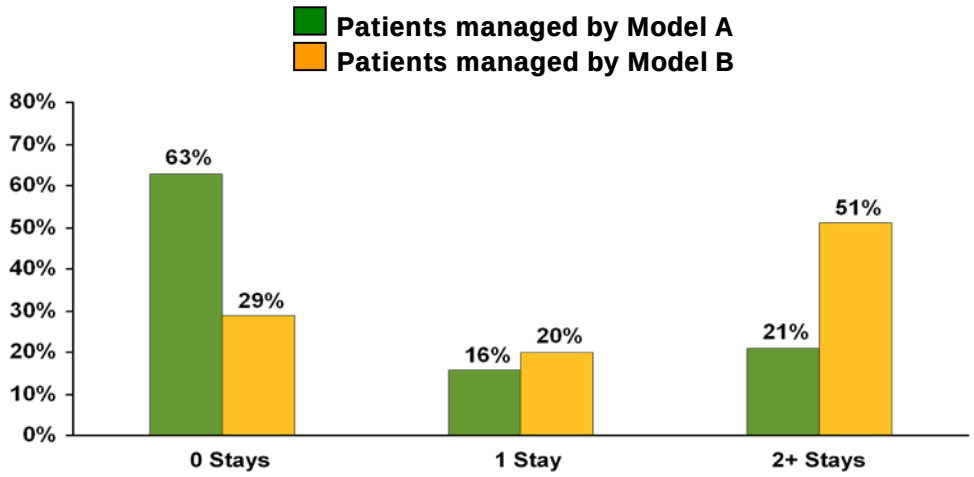
Does the Midhurst Service provide good value for money?

The economic review found that the Midhurst Service extends choice for patients, clinicians, families and carers facilitating, as part of an integrated specialist community palliative care service, 71 per cent of patients to be able to die at home[8].

The key finding of the economic review was that the presence of the Midhurst Service is associated with early referral to specialist palliative care. The majority of referrals to the Midhurst Service took place before one inpatient admission. Most patients referred to a hospice will have had at least two admissions prior to referral. Figure 1 demonstrates the relative likelihood of patients referred, either to Midhurst or to the local hospices, after different numbers of inpatient admissions.

Figure 1: The pattern of referral for patients for the two care models.

*Please note in the graph below, Model A refers to the Midhurst Service; Model B refers to a sample of local hospices operating broadly traditional models within neighbouring towns to the Midhurst Service.



Referral to a specialist palliative care service is associated with patients spending fewer nights in a hospital setting and having fewer A&E attendances than those not referred. The Midhurst Service is also associated with fewer deaths occurring in a hospital setting.

The economic review found contact with both the Midhurst Service and hospices reduce the use of NHS services (inpatient, outpatient and A&E activities) for patients under their care. However, it is the variation in the timing of referral which could influence the wider economic impact of the service.

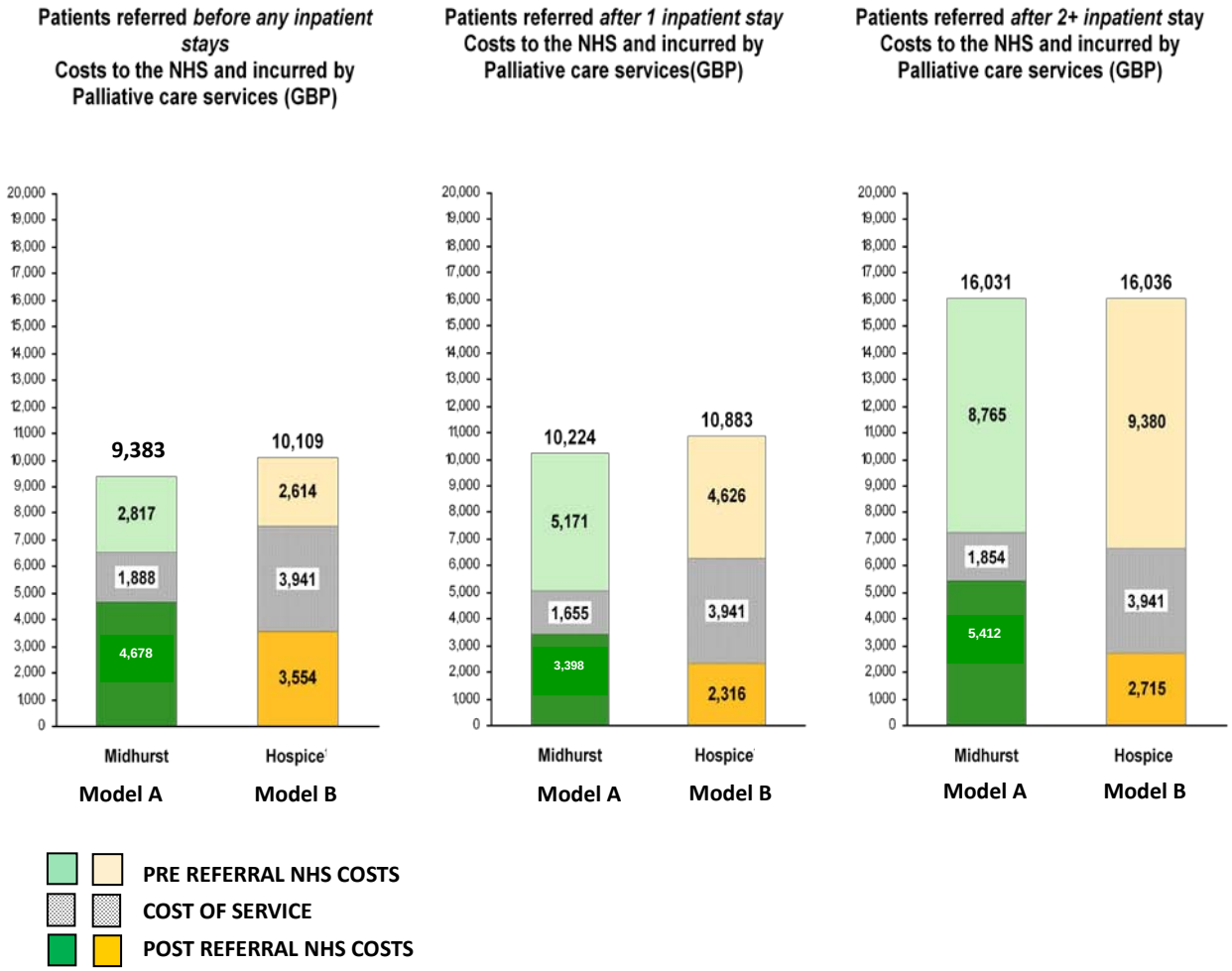
In the Midhurst Service, the service total cost of care in the last year of life could be reduced by 20 per cent. This saving is attributed to the Midhurst Service having more patients referred to the service before the second inpatient stay has occurred.

[8] Home is defined as usual place of residence, care homes or nursing home.

The total costs of care for cancer patients in the last year of life are higher when referral to community based specialist palliative care is made according to more typical patterns of referral. Facilitating more proactive use of community based specialist palliative care, as observed in Midhurst, is associated with lower total care costs and enables many more people to die at home than the national average, which studies show would be the majority of cancer patients' place of choice, and many fewer to die in hospital.

Both specialist palliative care services, Model A and Model B, reduce the use of secondary NHS services for patients under their care, and there is little difference in cost between the two specialist palliative care models for each inpatient stay category, as shown below in Figure 2. Each column consists of the three elements of cost, the pre referral cost, the Model A and B service cost and the post referral NHS cost.

Figure 2: Cost parity of Models A and B at an individual patient level i.e. per patient. *Please note in the graph below, Model A refers to the Midhurst Service; Model B refers to a sample of local hospices operating broadly traditional models within neighbouring towns to the Midhurst Service.



The distribution of these costs differs between the two models of care as can be seen in the relative breakdown of each bar in Figure 2; Model B substitutes more NHS costs however, the provision of the Model A service is itself less costly (based on the assumption of costs for Model B).

With the traditional hospice model (Model B), as shown in Figure 1, the pattern of referral is markedly different. This is associated with higher costs being incurred prior to referral. These costs appear to be avoidable with Model A, with its pattern of early referral and proactive use community based specialist palliative care.

Figure 3: Variation in timing of referral and influence the total cost and economic impact of each care model. *Please note in the graph below, Model A refers to the Midhurst Service; Model B refers to a sample of local hospices operating broadly traditional models within neighbouring towns to the Midhurst Service.

Fig. 3a Average cost of patient by inpatient stay category (£)

Average cost of patient by inpatient stay category

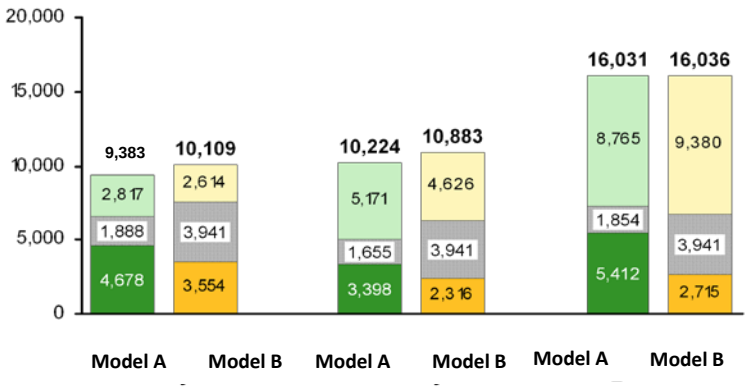


Figure 3a shows that the mean total cost of care rises substantially after the first inpatient stay prior to referral in each care model

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Fig. 3b Distribution of patients by inpatient stay category (%)

Distribution of patients by inpatients stay category

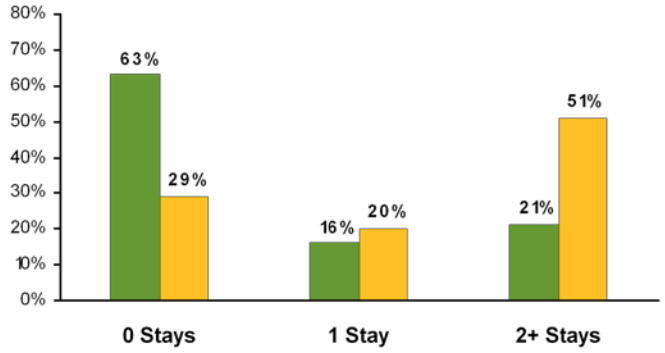

Figure 3b shows that a high percentage of Model A patients are those who have 0 or 1 inpatient stays (the least costly of the groups) and conversely a high percentage of patients to Model B are those who have had two plus inpatient stays (the most costly of the groups)

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Fig. 3c Cost of a modelled group of 1000 patients by inpatient stay category (000's GBP)

Cost of a modelled group of assumed 1000 patients by inpatient stay category

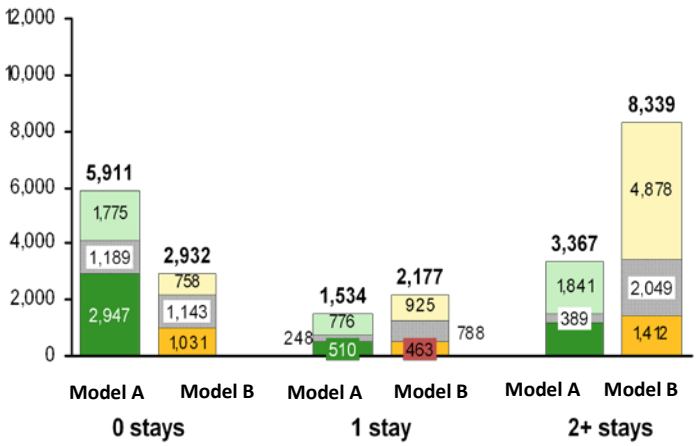

Figure 3c shows the cost implication of timing of referral for an extrapolated group of 1000 patients

If we multiply the mean total cost of care (Figure 3a), by the percentage distribution of patients by inpatient stay category (Figure 3b), we can see that cost distribution across the two care models differs

This results in more costs for Model A in the least expensive category (0 inpatient stays) and more costs for Model B in the most expensive category (2+ inpatient stays)

Fig 3d Total cost of a 1000 patient under each care model

Total cost of assumed 1000 patients in each Model

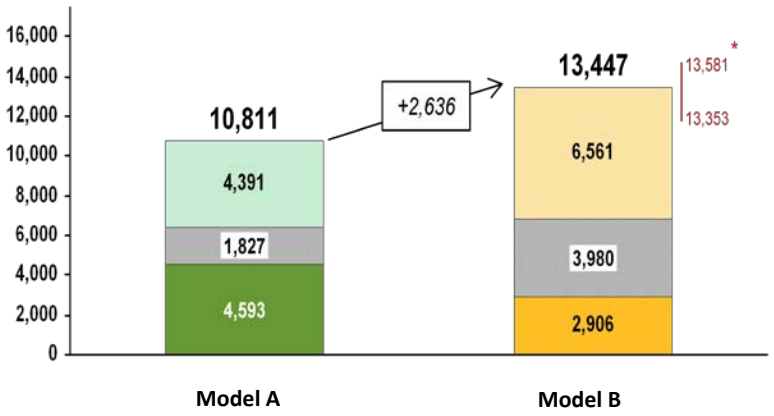

Figure 3d shows the cost of 1000 patients expressed as a total for each model

The study indicates that Model A incurs approximately 20% less cost than the Model B

The cost saving is attributed to the model having more patients referred before any inpatients stays rather than an identifiable clinical feature of the service

Service review findings

What is the patient and carers experience of Midhurst?

The service review supports the findings of the economic review in showing that the Midhurst Service does extend choice at end of life for patients, clinicians, families and carers and enables more people to be able to die at home.

The good clinical outcomes of the service can be seen in less frequent A&E attendances, decreased hospital stays and a majority of patients dying in their preferred place, which is consistent with patient and family wishes, as indicated in the survey of bereaved carers.

Observation and interviews confirmed the ability of Midhurst to give flexible and truly holistic care. The range of clinical interventions on offer, some of which avoid the need for travel or admission to hospital or hospice, are instrumental in promoting confidence in home care as disease progresses.

A substantial number of bereaved carers reported services provided in the home to be excellent or good and good experiences predominated in the comments on care quality. A majority reported that they received as much support as they wanted.

How is care provided by Midhurst?

Current patients and carers were very positive about the supportive and personal nature of the care they experienced from the Midhurst team. Often, the Midhurst team were presented as playing a key role in enabling patients and carers to cope with the very difficult situation in which they found themselves.

The breadth of services delivered into patients' homes and the earlier referral to Midhurst provides the opportunity to develop a relationship of trust between the patient, carers, family members and the team.

Patients, carers and staff themselves report that a key aspect of the Midhurst Service is the flexibility of roles of the team members. A broad range of different team members will undertake a span of different activities. Volunteers fulfil many important roles and are well integrated within the service.

Data from the service evaluation gave an account of good, functional relationships between the Midhurst professionals and community nursing services, general practitioners and NHS outpatient services. Patients, on the whole, appeared to regard their professional attendants as working together. The Community Nurse Specialists are able to build relationships with other health and social care professionals local to their patch, facilitating collaboration, while the Community Support Team can be deployed flexibly to respond to fluctuating demands across the Midhurst area as a whole.

There was no evidence from service evaluation that the Midhurst Service was reliant on high quality primary care, or that it deskilled local GPs or district nurses in the geographical boundaries. In this sense, it was truly integrated, operating at a secondary care level and filling gaps in existing community service provision. In fact, a significant proportion (74 per cent) of bereaved care givers reported the GP care to be excellent, quoting 'understanding GP's and 'good access to visits'.

The quality, flexibility and holistic nature of the care provided by Midhurst appear to be a factor that allows GPs and hospital consultants to refer patients more proactively in the course of illness. Finally, the comprehensive nature of the team, with doctors, therapy professions, and access to counselling as well as nursing, means they can respond to a wide range of patient and carer needs in the community.

Is the Midhurst Service a credible option for future systems change or service development?

The evidence from the evaluation suggests there could be a key role for a community based model of specialist palliative care, such as Midhurst, as an integrated service option for patients to choose, alongside high quality hospice and hospital palliative care services.

It demonstrates there is real value in a service that supports patient choice by providing as much treatment and support in the home or community as much as possible through the multidisciplinary community based team. Also cost savings could be made if patients are referred at an early stage before the second inpatient stay has occurred.

In those local areas outside the catchment area of Midhurst, the pattern of referral is markedly different. This is associated with higher costs being incurred prior to referral. These costs appear to be avoidable with more proactive use of community based specialist palliative care.

There does not appear to be any special feature of the Midhurst catchment area that is particularly advantageous to the operation of the service. It is estimated that a similar service could be established in other areas and that it has the potential to serve 25 per cent of a population at the end of life. As the Midhurst Service operates in an area that spans three PCTs, this suggests that the Midhurst Service could be applied to diverse areas.

Evidence from a comparable service, Hospice at Home service in West Cumbria[9] implies that the Midhurst Service model is sustainable and capable of serving more patients with a diagnosis other than cancer. It is estimated that from 2016 there will be a steady rise in the annual number of deaths in England. Forecasts also suggest that an additional 90,000 hospital or other beds will be required by 2030, unless alternatives are provided through an increase in community services.[10] Based on this likely increase in demand for specialist palliative care, the Midhurst Service model may represent an efficient way of expanding capacity without incurring significant capital costs.

[9] Hospice at Home West Cumbria, www.hospiceathomewestcumbria.org.uk
[10] Gomes and Higginson, 2008

Conclusions

The Midhurst Service is an effective integrated service option for patients to choose, which can operate alongside high quality hospice and hospital palliative care services. The Midhurst Service enables many more people to die in their preferred place than the national average, and many fewer to die in hospital.

The Midhurst Service demonstrates that significant economic savings could be made, through earlier access to community based specialist palliative care before one or less inpatient stays have occurred. The findings of the economic review suggests that if a service such as Midhurst was replicated elsewhere, the total cost of care in the last year of life could be reduced by 20 per cent, because it is associated with more proactive use of community based palliative care.

The presence of a service such as the Midhurst Specialist Community Palliative Care Service would encourage clinicians and secondary care providers to systematically assess the potential palliative care needs of patients with advanced disease, or metastatic cancer, at the point of inpatient admission. Moving away from a more traditional model of later referral to one of early referral could be applied in all specialist palliative care settings. This would ensure that both the economic benefits and the clear benefits for patients and their families are experienced more widely.

Given the likely increased demand for both generalist and specialist palliative care services, the Midhurst Service may represent an efficient way of expanding capacity without incurring significant capital costs. Macmillan believes there is a case for expanding the role of existing hospital-based palliative care consultants into the leadership of community based services that deliver care in patients' homes.

Recommendations

1. Commissioners and providers of specialist palliative care should consider adopting the principles of the service offered at Midhurst: early referral to active specialist palliative care, delivered by multi-disciplinary and flexible community based teams, therefore allowing more people to die in their place of choice while reducing NHS costs.

2. Funding levers such as those being developed through the palliative care funding review pilots, including an end of life tariff, should incentivise early referral and the development of multidisciplinary, community based services, providing active specialist palliative care.

3. Quality levers, such as the Commissioning Outcomes Framework, should ensure any end of life indicators record whether people die in their preferred place of death to incentivise providers and commissioners to meet these preferences.

Appendix 1

Methodology behind the economic evaluation and service review

Economic review

The study by Monitor Group of the economic and clinical activity was largely quantitative, based on a retrospective analysis of 11 different sources of data[11] supplied by the three commissioning PCTs: West Sussex PCT, Surrey PCT and Hampshire PCT. All sources of data removed any identifiable information. The analysis focused on all patients who died from cancer[12] within the 12 month period between August 2008 and August 2009.

Central to the analysis was the comparison of healthcare usage for patients using Midhurst, patients using local hospices and those known not to have used Midhurst or a local hospice. Patients' use of healthcare services across inpatient, outpatient and A&E was contrasted across the three groups. This allowed a full economic overview of service use in the last year of life.

In order to provide clinically meaningful analysis, the evaluation looked at when a patient was referred to the Midhurst Service or another specialist palliative care provider (hospice). This represented an identifiable choice that a referring physician needs to make i.e. 'when do I need to refer to specialist palliative care?' The analysis groups were based on the number of hospital inpatient stays before referral to a specialist palliative care service i.e. Model (A) before any inpatient stay, (B) after one inpatient stay, or (C) after two or more inpatient stays. These categories were a proxy for how early in an illness a patient is identified and referred for specialist palliative or supportive care as well as a proxy for the complexity of cases.

Service review

The University of Sheffield was commissioned to conduct a documentary analysis of annual reports and key informant interviews from the Midhurst Service. A postal survey of GPs in the three Primary Care Trusts serving the Midhurst area collected data on reported clinical practice, views on specialist palliative care services, participation in national initiatives and organisation of palliative care.

Researchers also used the VOICES questionnaire (a survey asking informal carers about care received in the last year of life) in a further postal survey of bereaved carers of patients who died following referral to the Midhurst Service over the period of one year.

The University of Huddersfield focussed on the role of the Midhurst team and the nature of its relationship with patients, carers and other health and social care professionals. It examined the practices from the perspective of all the groups of professionals through semi-structured interviews.

[11] This included activity cost data from the anonymised commissioning data set, data from the Midhurst Cross Care system and hospice activity data.
[12] As defined by the Public Health Mortality File