

Authors

Veronika Thiel
Lara Sonola
Nick Goodwin
Dennis L Kodner

Midhurst Macmillan Community Specialist Palliative Care Service

Delivering end-of-life
care in the community

The King's Fund
11-13 Cavendish Square
London W1G 0AN
Tel 020 7307 2400

Registered charity: 1126980

www.kingsfund.org.uk

TheKingsFund>

Co-ordinated care for people with complex chronic conditions

**Midhurst Macmillan
Community Specialist
Palliative Care Service**
Delivering end-of-life
care in the community

Veronika Thiel

Lara Sonola

Nick Goodwin

Dennis L Kodner

Supported by The Aetna Foundation, a national foundation based in Hartford, Connecticut that supports projects to promote wellness, health and access to high-quality health care for everyone; and Aetna Inc, one of the nation's leaders in health care, dental, pharmacy, group life, and disability insurance, and employee benefits. The views presented here are those of the author and not necessarily those of The Aetna Foundation, its directors, officers, or staff; or Aetna, its directors, officers, or staff

Contents

About this research	4
Acknowledgements	5
1. Introduction	6
2. The Midhurst Macmillan Service	9
3. The process of care co-ordination	16
4. Impact	21
5. Challenges and facilitators	25
6. Key lessons	28
References	30
Appendix 1 – Methodology	31
Appendix 2 – Staffing establishment	32

About this research

Age-related chronic and complex medical conditions account for the largest and growing share of health care budgets in all industrialised nations. However, people living with multiple health and social care needs often experience a highly fragmented service leading to sub-optimal care experiences, outcomes and costs. To address this, strategies of care co-ordination have been developed to promote more cost-effective care through integrated services.

For older people in need of both health and social care support, the divisions in the organisation, funding and delivery of care in the United Kingdom (UK) can result in poor user experiences and outcomes. There have been many innovative projects to promote better care co-ordination for older people, but these have often not met their objectives and the failure rate has been high because of poorly designed interventions, difficulties in targeting those most likely to benefit from care co-ordination and the unmet patient needs that improved follow-up can uncover. There is a lack of knowledge about how best to apply care co-ordination tools in practice.

This case study is part of a research project undertaken by The King's Fund and funded by Aetna and the Aetna Foundation in the USA to compare five successful UK-based models of care co-ordination (see Appendix 1 for methods used to collect the study data). The aim of each case study has been to understand the strategies used to deliver care co-ordination effectively; examine barriers and facilitators to successful care co-ordination; isolate key markers for success for the practical application of the tools and techniques of care co-ordination; and to identify lessons in how care co-ordination can best be supported in terms of planning, organisation and leadership.

Further details about this project can be found at: www.kingsfund.org.uk/coordinatedcare

Acknowledgements

The King's Fund would like to thank everyone at the Midhurst Macmillan Community Specialist Palliative Care Service for their kind co-operation in supporting this research. We would like to give special thanks to Sue Dewar and Jo Stuttaford for their pro-active involvement in the work, helping our research team with administrative arrangements and fielding the many questions that we posed about the service. The authors would also like to thank our colleagues at The King's Fund who have supported the production of this case study report, with special appreciation to Clare Bawden for her excellence in supporting the administration of the case study visits.

1 Introduction

The health and social care system in England

The National Health Service (NHS) is responsible for providing health care to the public in the UK. It is publicly funded, mainly through taxation, and services are provided free of charge at the point of delivery to all patients in the UK, with certain exceptions permitted by parliament. Since its establishment in 1948, the overarching principle of the NHS has been to ensure that health care is available to all on the basis of need, not ability to pay and these responsibilities are formally enshrined in the NHS Constitution (NHS Choices 2013).

Responsibility for health care is devolved to the governments of each of the four constituent countries (England, Scotland, Wales and Northern Ireland). In England, community, mental health and general hospital services are provided by a number of bodies, from statutory NHS organisations to charities, social enterprises and private organisations that provide NHS-funded services.

Primary care providers act as the first point of contact for physical and mental health care services. General practitioners (GPs) are local primary care physicians based in general practices alongside nurses and support staff. They operate as independent businesses paid through a national contract administered in England by NHS England. Dentists, opticians and pharmacists also provide primary care services.

General practice accounts for around 90 per cent of all patient contacts in the NHS and the majority of people are registered with a GP practice (The King's Fund 2011). When specialist treatment is required, patients are referred to hospital or other specialist providers. In this way, general practice acts as the gatekeeper to specialist care. Urgent and emergency care services are available direct through out-of-hours services and hospitals.

Planning and purchasing of NHS services is referred to as commissioning. In England, general hospital services, urgent and emergency care, mental health and community services are commissioned at population level by 211 clinical commissioning groups (CCGs), who hold the majority of the NHS budget (£65 billion in 2012/13). Each CCG is formed from the GP practices in that locality who come together to assess the needs of their population and commission services from NHS or other provider organisations that meet those needs.

NHS England

NHS England is a statutory body that commissions primary care health services (including GPs), public health and prescribed specialist services, such as trauma care, on a national basis.

In contrast, responsibility for funding (and some provision) of social care services, for example, for assisted living at home and long-term care, is held by local government (through local authorities), with users having to pay for services direct and/or gain access through means-testing based on levels of need and ability to pay. Residential and domiciliary care are predominantly privately provided, and there is substantial self-payment. There is also a wide range of voluntary sector providers that deliver a range of health and social

care services. While there are national rules for residential care costs, home care is subject only to guidelines and there is considerably more variation in the organisation and delivery of domiciliary services at the local level. Direct payments are increasingly being made available to eligible recipients of local authority-funded social care, allowing individuals to control and purchase services direct to meet their own needs.

Alongside the introduction of CCGs in April 2013, responsibility for public health has shifted to the local authorities. Health and wellbeing boards have been established to support dialogue and the development of joint service strategies between the health and social care system. This is underpinned by a statutory duty to work in partnership. Significant emphasis has been placed on encouraging jointly funded and delivered services that promote person-centred care co-ordination as a means to improve the experience of patients and service users and ensure they receive high-quality care.

End-of-life care in England

End-of-life care supports people and their family or carers as they approach the terminal phase of their condition, usually considered to be the last 12 months of life. It seeks to help them to live as comfortably as possible, and ensure they are able to die with dignity.

Over the past decade, strategies and initiatives have been developed to improve quality of care, promote care co-ordination, and enable patients and their families to choose their preferred place of death, accompanied by the acknowledgment that older people often deteriorate in hospital settings (Cornwell *et al* 2012). As steps to improve end-of-life care gained momentum, the drive to transfer health services into the community has gathered pace, with community care thought to be more cost-effective than hospital provision, reducing unnecessary emergency admissions and readmissions in some contexts.

End-of-life care services in England are funded and delivered by a mix of providers from the NHS, local authorities, and the voluntary and independent sector. Funding levels vary according to the priority local commissioners place on end-of-life care, resulting in differing provision across the country. This plurality poses an additional challenge as patients' needs can either be medical (NHS funded) or social (local authority funded). Complex patients tend to span both health and social care requiring detailed assessment of their needs to determine the appropriate source of funding, which often changes as their condition deteriorates.

All hospice care in England is provided by charities, with many small and local hospices bidding for NHS contracts supplemented by charitable donations. Within primary care, GP practices are incentivised to maintain a palliative care register of patients in the last 12 months of their lives, but management of end-of-life care remains variable. As a result of these and other factors, most people still die in hospital despite surveys indicating that between 60 and 67 per cent would prefer to die at home (Gomes *et al* 2011).

A's story by B and D

We lost our son A just after Christmas, following a nine-year battle with cancer. He was a builder by trade and returned to England in 2001, having lived and worked in Canada for many years.

Shortly after A returned he was diagnosed with bowel cancer. He had treatments and surgery over the years but about two years ago, the doctors found that the cancer had spread, first to one lung and then to the other. Fortunately, it was slow growing, so he had another year-and-a-half with his family. Adrian's son had moved to England to live with his dad and us six years earlier.

Our GP put us in touch with the Midhurst Macmillan Specialist Palliative Care Service. A was able to drive to its base at Midhurst Community Hospital for his daily checks until the last three months, when the drive became too much for him so the team started visiting at home. Adrian had a pump fitted, which fed painkilling drugs direct into the base of his spine. The nurses visited every day to change the dressing and check on him. If anything cropped up, they could administer the appropriate treatment, including injections or drips. It was so much better than having to go into hospital or a hospice. He could be with us, a part of the family, right to the end. When he took a final turn for the worse, a nurse stayed with A and us all day.

Source: Patient stories taken from *Transforming palliative care for the better* with permission from Midhurst Macmillan Service.

2 The Midhurst Macmillan Service

The Midhurst Macmillan Service – summary

Background

The Midhurst Macmillan Service is a community-based, consultant-led, specialist palliative care service in a rural community in the south of England. The service covers approximately 150,000 people across three counties – Surrey, Hampshire and West Sussex – with a geographic coverage of 400 square miles. The service was set up in 2006 in response to the sudden closure of a local hospital with a Macmillan Cancer Support palliative care unit. It has since evolved to offer an innovative solution that provides end-of-life services to local people at home. The service is jointly funded by the NHS and Macmillan Cancer Support to the total value of approximately £1.2 million per year.

Aims and objectives

The service seeks to prevent avoidable admissions into hospital, to enable patients with complex needs to be cared for at home, and to allow them to die in the place of their choosing. As a flagship end-of-life care model supported by Macmillan Cancer Support, the service acts as an exemplar for successful home-based specialist palliative care services and an innovative model of co-operation between the NHS, the voluntary sector and the local community.

Target population

The Midhurst service caters for approximately one-quarter of all patients needing end-of-life care in the area. The majority of patients supported by the service have a diagnosis of cancer, but the service supports a growing number of patients with other conditions including dementia, heart failure and neurological disorders. In 2010/11, 409 patients benefited from the service.

Approach to care co-ordination

The consultant-led service is run by a dedicated and multidisciplinary team of nurses and palliative care consultants, occupational therapists, physiotherapists, and a large group of volunteers. This core team works in close co-operation with other care providers in the local area to provide care in people's own homes. This includes general practitioners (GPs), district nurses, social services and continuing care teams.

Results

The Midhurst Macmillan Service, as with the other case studies examined in this research, was selected on the basis that it was able to demonstrate benefits to service users enabling them to die in a place of their choosing and to operate cost-effectively. An independent evaluation of the programme, looking at both the impact on patients and carers and cost-effectiveness, is in the process of academic peer review.

The Midhurst Macmillan Service covers an ageing population with increased rates of long-term conditions and co-morbidities. In addition, breast cancer rates are higher than the national average in all age groups (National Cancer Intelligence Network 2013).

The catchment area covers a large and mostly affluent rural area with a dispersed population, necessitating long driving hours by care providers. Many patients do not live near a hospital. There are also areas of deprivation, characterised by social housing.

The geographic coverage of the service cuts across three clinical commissioning groups (CCGs) and three local authority areas (see Table 1 below), hence the funding for the service is derived from more than one commissioning body.

Table 1: Commissioning health geographies by Midhurst Macmillan Service

Commissioning primary care trusts (until April 2013)	Clinical commissioning groups (from April 2013)	Population covered by Midhurst Macmillan Service
NHS West Sussex	Coastal West Sussex	50,500
NHS Hampshire	East Hampshire	51,500
NHS Surrey	Guildford and Waverley	45,500

The patient group

The population is mostly elderly and white middle class. The patients in the service reflect these demographics, with the majority of patients aged over 65. Most live in rural areas.

Most patients suffer from a terminal form of cancer, but growing numbers of patients with non-malignant diseases receive care from the service. The cancer/non-cancer split is approximately 80:20. In 2010/11, there were 409 referrals into the programme, 365 of whom had cancer. Other diseases include motor neurone disease, chronic obstructive pulmonary disease (COPD), heart failure, multiple sclerosis and other neurological disorders. Most patients have complex problems and co-morbidities. Other than an increase in the non-cancer proportion, there has been little change of socio-economic indicators in the patient group over the years. In line with the wide variety of diseases encountered in the programme, there are varying degrees of disability and mobility, and some patients receive palliative care while having curative treatment or continuing to work.

The service focuses on specialist or complex cases, which amount to about 25 per cent of deaths in the area in a given year. Most of the remaining 75 per cent of patients at the end of their lives are cared for by district nurses and GPs. As will be discussed later, there may be unmet demand, but so far all patients referred to Midhurst have been assessed and, where appropriate, accepted into the service.

Programme history

The Midhurst Macmillan Service was established in 2006 following the sudden closure of the local hospital – King Edward VII – where an in-house palliative

care unit (part-funded by the NHS and by Macmillan Cancer Support) had run for many years. The closure of the hospital prompted a consultation exercise among local stakeholders to find an alternative solution. The resulting choice of a community-based service was strongly influenced by the Motala model in Sweden (Beck-Friis and Strang 1993). The transition from a hospital to community-based service has since developed incrementally over time (see Table 2, below).

Table 2: Timeline of key service developments

1970s–2003	Midhurst Macmillan Unit established in King Edward VII hospital in Midhurst
2003	King Edward VII hospital bought by a private company
March 2006	King Edward Hospital closes; one week later services transfer to community Agreement on funding for six months to explore service delivery options Service runs with one consultant and the clinical specialist nurses, one staff nurse and one health care support worker
April 2007	Two clinical leads are recruited to manage the service
October 2007	Occupational therapist starts
October 2008	Physiotherapist starts
October 2009	Original consultant retires; replaced by an associate specialist in palliative medicine and one part-time consultant
September 2011	Service is transferred into Surrey Community Trust
October 2011	Second part-time consultant joins the service.
2012	Opening hours expanded to between 8.30am and 8.30pm, with an out-of-hours on-call medical rota.

In the initial period, funding for the first six months only was secured with an emphasis placed by Macmillan Cancer Support on supporting and researching what was seen as an innovative community-based palliative care alternative. For the staff, all of whom had to have their contracts transferred to a new employer (the local commissioner – West Sussex PCT), the transition was regarded as a difficult and uncertain time with a degree of ‘mourning’ for the previously well-regarded hospital-based service. Some consultants also mistrusted the idea that a palliative care service could operate at home.

A key to overcoming the challenges of the transition phase was the leadership, vision, commitment and enthusiasm of the lead palliative care consultant. An extensive process of engagement with key stakeholders within the community took place – including staff, hospices, commissioners and (crucially for funding) Macmillan Cancer Support – and the service was quickly and successfully established in just six weeks.

Seven years on, the model of a consultant-led specialist palliative care service delivering interventions in the community has become an accepted and integral part of the local health landscape. By focusing on evaluation to demonstrate tangible benefits to patients and their families, as well as financial benefits, the service continues to gain support from local commissioners.

Funding

The service receives a mix of NHS and charitable funding. Three CCGs provide NHS funding each year at the levels detailed in Table 3, below, with any underspend retained by the CCGs at the end of the financial year. Macmillan Cancer Support matches the funding from the NHS through an annual grant of up to £600,000.

Table 3: Funding of Midhurst Macmillan Service

Coastal West Sussex CCG	£303,898
East Hampshire CCG	£132,136
Guildford and Waverley CCG	£145,000
Macmillan Cancer Support*	£600,000

*Macmillan Cancer Support will match up to £600,000 of CCG funding

For 2013/14, the service has a maximum budget of £1.16 million (around US\$1.8 million). One interviewee felt that while this prevented the service from 'growing under its own steam', at the same time it ensured they used their funds efficiently.

Organisational structure

There are three types of staff in the Midhurst team: medical, clinical support, and non-clinical. The medical professionals focus on care management and care co-ordination, liaising with GPs, district and community nurses, specialists and other relevant medical staff to arrange or change treatment for patients.

This role largely falls to the consultants, who take on the formal case manager role with patients, other team members and external providers. Consultants visit about 30 per cent of patients cared for by the service; of these patients, one-third require a single visit; the rest are reviewed more frequently. Outside the visits consultants are updated through weekly multidisciplinary team meetings and occasionally provide specialist medical procedures, such as paracentesis. A full list of procedures administered by the team in a patient's home is listed in the box below.

There are seven clinical nurse specialists (CNS) on the team who hold a caseload based on allocated GP practices. One CNS does not carry a caseload, but covers the cases of the other nurses if they are overstretched, ill or on leave.

The clinical support staff consists of trained nurses and health care support workers who carry out the majority of the hands-on clinical care, with consultants and CNSs conducting more specialist procedures or providing care in emergencies. Although the CNSs do not usually provide hands-on care, they maintain their clinical skills to ensure that they are able to respond when urgent care is needed.

The service also employs a physiotherapist and an occupational therapist, roles that are not typically involved in community-based palliative care. The two members of staff work interchangeably, conducting an assessment for both disciplines that often takes place during joint visits with the allocated CNS or a consultant. A counsellor works with patients and families pre- and post-bereavement. A full staffing establishment for the service is detailed in Appendix 2.

Procedures administered by the team in a patient's home

- Blood product transfusions – managed by a CNS/clinical support staff.
- Bisphosphonate infusions – a CNS/clinical support staff.
- Paracentesis – undertaken by a consultant or associate specialist, then managed by a CNS/clinical support staff.
- Intravenous infusions – cannulation and infusion set up by a Midhurst CNS/clinical support staff, can be taken down by community teams (district and community nurses).
- Sub-cut fluids – usually set up by CNS/clinical support staff, management can be shared with community teams.
- Management of specialist lines – shared with community teams.
- Ultrasounds – consultant or associate specialist.
- Intrathecal infusions – CNS/clinical support staff.
- Set-up and change of syringe drivers – consultants/CNSs.

A key lesson of the Midhurst model of care co-ordination arises from the team structure and skill mix, with a fully integrated mix of consultants, senior nurses, health care support workers, allied health professionals and volunteers. Clinical staff are allocated to specific patients, enhancing continuity, and the floating CNS is able to pick up cases and respond quickly to urgent situations. Professionals have the time and freedom to conduct joint visits assessing medical, social and holistic needs at the same time, reducing the need for multiple visits. Volunteers are integrated into the service, supporting patients and carers as and when needed. Finally, knowledge about the patient and their circumstances is shared within the team through meetings and logged on the internal IT system.

The Midhurst Macmillan Service organisational model

The Midhurst Macmillan Service is hosted in Sussex Community Trust, an NHS provider organisation that delivers community NHS services across Brighton and Hove and West Sussex. It uses the Trust's administrative, human resources and finance systems.

The service and its staff are located at Midhurst Community Hospital, which acts as a base for the team. There are no palliative care beds at the hospital, but they have access to a treatment room for outpatient appointments. The service operates seven days a week between 8.30am and 8.30pm. Out of hours, there is an answering machine which can be accessed remotely.

The organisational model for end-of-life care in Midhurst can effectively be split into the Midhurst 'core' team and a wider network of care providers (see Figure 1, p 15).

[The CNS] has been able to provide a level of continuity of care, which, actually, has been at times, easier for her to achieve than, say, GPs whose role has... changed slightly into being more supportive of the requirement for medical interventions into the journey, rather than being involved in the baseline care.

Local GP

Volunteer service

The service has around 70 volunteers who take on a host of roles, from practical tasks, eg, helping with the shopping or gardening, to complementary treatments, such as Reiki or aromatherapy. Volunteers are matched to the needs of the patients rather than providing a fixed set of services. Some volunteers have been trained in bereavement counselling and visit the family and/or carers after a patient has died. Others with legal expertise support patients and families with wills and related matters, and Macmillan Cancer Support provides access to a financial adviser from Citizens Advice Bureau, a charitable advice service. The volunteers within the Midhurst service fulfil the holistic component of this care co-ordination model, supporting patients and carers with everyday tasks to enable them to live well, and contributing to the skill mix of the core team.

Primary care and other external care providers

In addition to the care provided by the Midhurst team, care is co-ordinated across the range of other partners including GPs, district and community nurses, social workers and others who are involved in the care of patients. Inpatient beds in local hospices and hospitals are used for short-term stays or outpatient procedures that cannot be carried out in the patient's home (the service 'buys' the care directly). The Midhurst team also works with different care agencies employed by the families to support the patient at home. Such care is incorporated into the patient's care plan, although the service does not subcontract out any care.

The involvement of external providers can vary. For example, some but not all patients will benefit from a social worker. Similarly, GPs' level of involvement varies, with some very actively engaged in patient management and care co-ordination in partnership with the Midhurst service, while others take a more passive role. On the other hand, the team works very closely with community staff (district and community nurses who typically have extensive experience of end-of-life care). They regularly update each other on a patient's status, arrange visits and discuss care plans in regular meetings at GP practices.

...if we are concerned or anything we just phone Macmillan [the Midhurst service] direct... we've got this real direct link to them, which is great, to ask advice... It's so important to get that right and to have that kind of communication with the doctors, with Macmillan, with ourselves...all singing from the same hymn sheet and all going in the right direction.

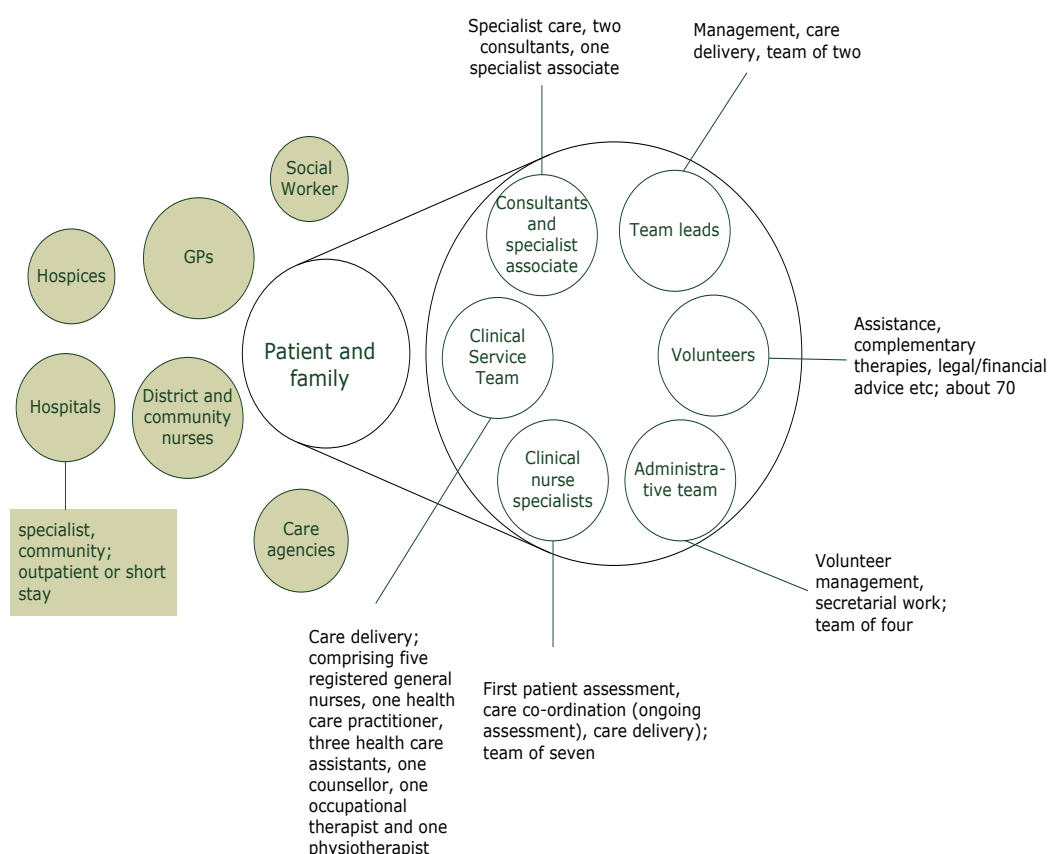
Community nurse

The Midhurst team works with social care teams in their catchment area, but they do not directly employ a social worker. Personal care is mostly delivered by care agencies and/or social services – the Midhurst team helps to organise and

fast-track referrals to these services, navigating through differing procedures for assessing eligibility across three local authorities within the catchment area.

The Midhurst service illustrates the lesson that building strong, mutually supportive relationships with external providers is vital to co-ordinate care successfully. Key to this is the local context and history of partnership working, particularly with GPs. In Midhurst, working closely with GPs and community teams reduces duplication and the service can 'fill in' when community staff are stretched, or step back if the community team is the most appropriate team to provide care. This helps to build trust and respect between professionals. Although social care has not been integrated into the team, the team is well versed in the procedures and shortcuts needed to secure personal care quickly, and uses this knowledge to liaise with the relevant social care departments and navigate the system for patients.

Figure 1: The Midhurst Macmillan Service organisational model



3 The process of care co-ordination

Referrals

Referral criteria for the service are based on World Health Organization (WHO) and National Institute for Health and Care Excellence (NICE) guidelines for palliative patients. The NICE guidelines are statutory for specialist palliative services in the United Kingdom. Referrals often come from GPs and hospitals, but also from specialist nurses and community hospitals. Referral criteria are:

- severe, intractable complex symptoms that have persisted after palliative care by generalist
- patients and their carers having difficulties in adjusting to/coping with their disease, psychologically, spiritually or emotionally
- information and explanation is required relating to the illness, treatment, care options and allied support services
- patients and carers experiencing difficulties in bereavement, who would benefit from specialist support/further psychological intervention
- to assess the need for further specialist unit services, ie, day care or inpatient care
- health care professionals require specialist advice and support with case management.

(Source: Midhurst Macmillan Service Referral and Discharge leaflet)

Referral is made to one of the clinical nurse specialists who act as the single point of contact for the patient and families. The CNS then assesses patients at their home, taking their wishes and needs on board.

Clinical governance

GPs remain accountable for their patients' care. Consultants from the Midhurst team carry out specialist procedures, as described on p 13, without sign-off from the GP, but they have to inform the GP. Consultants also have oversight of the specialist input provided by the clinical support team, approving interventions such as inserting a syringe driver.

Care planning

A key feature of the service is its vision to provide personalised care responding to the changing needs of patients with multiple morbidities or complex needs. As a consequence, there is little standardised guidance on how patients should receive care. Care plans are the result of a mix of formal assessment and informal discussions with patients, carers, nurses and GPs who are involved in the patient's care. The team uses the Gold Standards Framework and the Liverpool Care Pathway (see box below) as appropriate and in line with national guidelines for end-of-life care provision. This is an interesting lesson as it suggests that lack of a defined care package does not appear to hinder care co-ordination, although this finding may not be transferable to other settings.

Gold Standards Framework

The Gold Standards Framework (GSF) provides best practice guidance to GPs and care homes to optimise the care of patients towards the end of their life. More information is available at: www.goldstandardsframework.org.uk/

Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway (LCP) is a recognised care pathway for managing the treatment of patients in the last days of their life when death is imminent. From about 2014 onwards, it will be replaced by individual care plans for the dying, reflecting new best practice recommendations.

Care co-ordination

Once a patient is admitted to the Midhurst Macmillan Service, care co-ordination proceeds according to the care plan. Continuity of care is delivered through the relationship between the allocated CNS and the patient. The CNS holds overall responsibility for organising and co-ordinating care, while other team members retain responsibility for their aspect of the service and can arrange additional services without initial sign-off from the CNS. For example, the volunteer co-ordinator can arrange for help independently of the CNS. Information is shared face-to-face or by telephone, and all team members update their actions on the internal IT system, Crosscare.

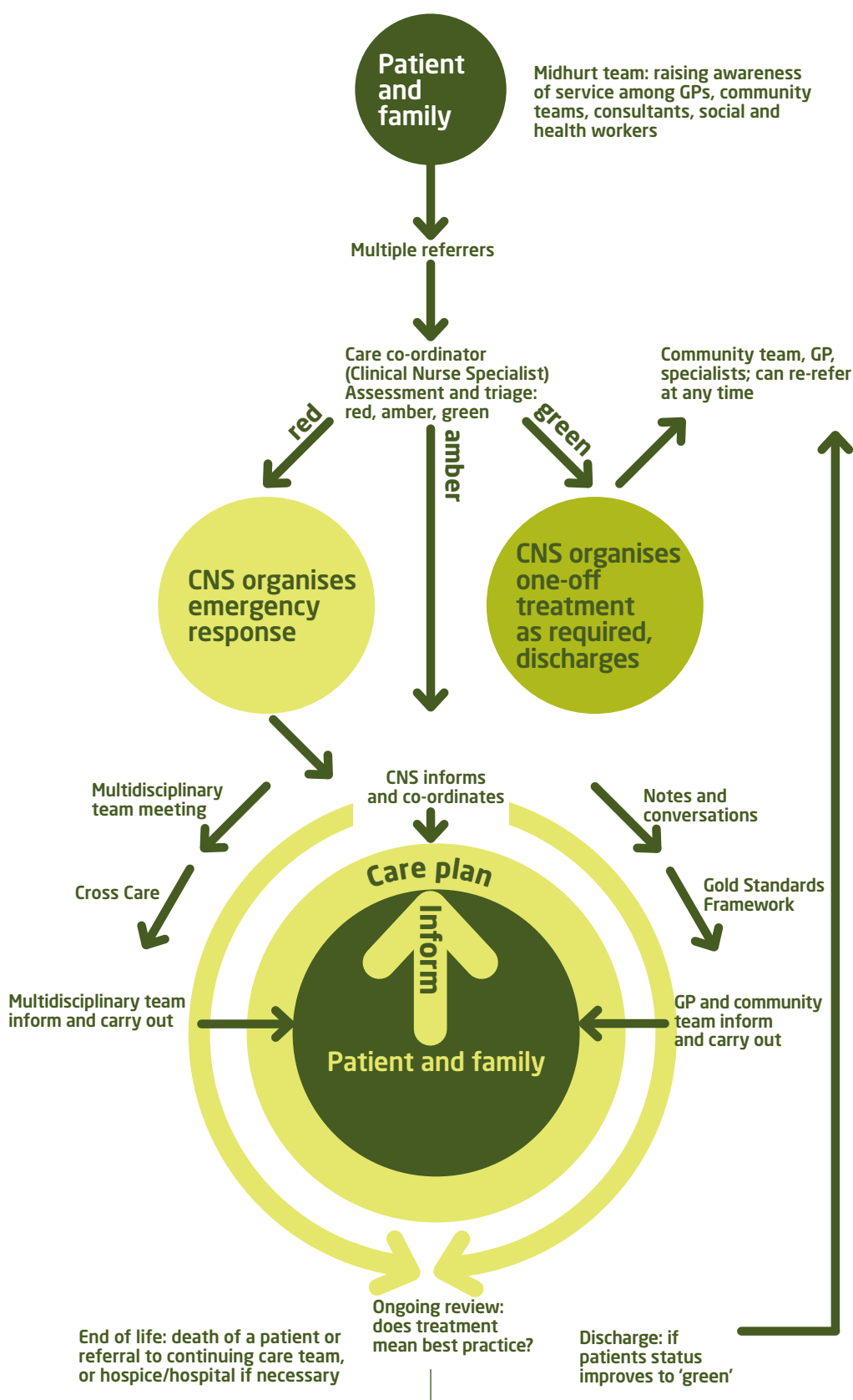
Following assessment and treatment, patients can be discharged and readmitted at a later stage if they need further specialist intervention; however, most patients are very near the end of their lives and die within a few weeks of being admitted.

As mentioned earlier, the flexibility of the service derived from its structure facilitates decision-making, enabling professionals to act quickly to fill gaps in care and adapt the care plan when circumstances change without going through the CNS. It relies on mutual respect and trust between staff within the Midhurst team.

Mapping the care process

A patient is typically referred by a GP or a consultant. A CNS will carry out the assessment at the patient's home. If the patient is in a crisis, the CNS will see the patient on the same day and do what is necessary to alleviate the crisis before carrying out a full assessment, including an assessment of the carers. The patient is then assigned a status of zero, green, amber or red. Zero indicates no admittance to the service at this stage. Green indicates that there is a need for some low-level input that can be provided over the telephone. The CNS will visit occasionally to check on the patient's status. Amber indicates higher-level problems needing more complex interventions. A CNS will visit weekly and the clinical support team will be involved in providing care. A red status prompts several visits a week from the CNS and strong involvement of the clinical support team. New cases are presented to the team at a daily meeting, and all patients are discussed at a weekly meeting. The CNS will assign the clinical support team to carry out agreed procedures and ensure the

Figure 2: The care process for patients in the Midhurst Macmillan Service



GP is informed. All team members interacting with the patient note their contact on the Crosscare system. In the last days of life, the NHS continuing care team takes over (see box below), with the CNS remaining the co-ordinator and point of contact for the patient.

Continuing care

Continuing care is a free service providing NHS-funded care outside the hospital setting for people with a complex medical condition which results in substantial and ongoing care needs. More information is available at: www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/NHSContinuingCare.aspx

Functional integration

In order to support the co-ordination of care between GPs, community teams and the Midhurst team, effective communication is crucial. Since there is little integration outside the Midhurst team in the use of shared or electronic health records, staff rely on face-to-face communication, telephone or email to ensure relevant professionals are informed about patients and their care. After an initial assessment, the care plan is sent to the GP, community teams and other specialist consultants involved in the patient's care.

In addition, a patient notebook is kept at the patient's home by the community nurses, which Midhurst staff update, providing an overview of the notes for other external professionals visiting the patient.

Within the Midhurst team itself integration is supported by *Crosscare* which is used to record detailed patient information for use by the team. These records contain a rich narrative about the patient, including details of their family situation and their personal wishes – for example, giving the name that they prefer to be called by.

This system is the backbone of the service, although external providers do not have access to it. The Midhurst approach can be described as 'high touch/low tech', relying on frequent communication through other channels to maintain continuity outside the service. This element of the service is a key lesson of the care co-ordination model as it suggests that integrated care is possible without up-front investment in ICT, particularly where the population is small and defined. At the same time, a huge effort has to go into communication to support information exchange, promote awareness, and ensure a more co-ordinated response which would be impractical on a larger scale.

Team culture

The Midhurst Macmillan Service emerged from a need to provide high-quality, co-ordinated care for people at the end of their lives based in the community. This shared vision clearly permeates throughout the team, in their interactions both with each other and with other care providers. There is a high level of dedication and co-operation, and respect for the skills of a wide range of professionals.

Team members work well across traditional silos such as physiotherapy and occupational therapy in a positive environment with a flat hierarchical

structure. Consultants play a supporting, rather than leading, role and staff are supported by the clinical leads through regular supervision and have access to external counselling services if needed.

Continuous improvement and learning are viewed as a core activity and this is reinforced through monthly team education sessions, which external care providers are invited to attend. The team attend a weekly multidisciplinary meeting to review the caseload and managerial/administrative issues are discussed once a month to update staff on policy issues and new guidance.

A final key lesson from this model is the value placed on staff experience. Fostering a positive, supportive team culture creates an environment where staff can deliver high-quality holistic care to their patients. Positive staff experience is associated with good patient experience and it is likely that this aspect of the model significantly contributes to the overall effectiveness of the team.

Overall, the service culture is marked by the team ethos that puts the patient first, has a holistic approach to patient care and a flat hierarchical structure. Staff listen to feedback and advice from all members of the team, respecting each other's field of expertise while not being proprietary about who can do what. This vision has been translated into a 'can-do' attitude: if a team member encounters a situation they are not equipped to deal with they will find a solution, either by finding the right person to carry out a procedure or by referring the patient to the appropriate service. In time-critical situations staff take action immediately to resolve situations as quickly as possible.

4 Impact

Outcomes

The overall goal of the service is to enable terminally ill patients to die in the place of their choosing and to prevent emergency admissions to hospital at the end of life. The contract between Macmillan Cancer Support and the Midhurst Macmillan Service specifies a set of high-level outcomes that need to be reached. These are:

- 70 per cent of patients should die in their preferred place
- 80 per cent of patients should have an agreed care plan; they must indicate why there is no care plan for the remaining 20 per cent
- a quarterly review of care for 10 per cent of patients and comparison against agreed care plan
- reduction of inappropriate admissions to hospital
- identification of areas of improvement through service plan review
- development of a sustainable and affordable community-based service.

Data from the Midhurst Macmillan Service for 2011/12 shows that the service achieves its target of enabling people to die in their place of choice: 185 of the 348 patients treated in that year died at home, and for 183 (99 per cent), this was the place of their choice (see Table 4).

Table 4: Percentages for preferred place of death and place of death

Place of death	Total	Preferred place of death	Preference not known	Not preferred place of death	% rate
Home	185	183	2		98.9%
Nursing Home	49	46	3		93.9%
Hospice	20	17	3		85.0%
Community hosp	37	28	7	2	75.7%
Hospital	57	7	25	25	12.3%
Total	348	281	40	27	

Source: Activity Tables for Midhurst Macmillan Service for 2011/2012

Evidence from interviews with staff, commissioners and external care providers detail the positive impact of the service on patient care in several ways.

- Although the dedicated case manager, in the form of the allocated CNS, acts as a single point of contact for patients, other team members can step in when needed.

[We've] worked on having a much more flexible approach so that one person can go in and do tasks that perhaps they might be a little bit over-qualified to do but it's much better; they're qualified to do those tasks and they're there in the patient's house.

Commissioner

-
- Conducting a single assessment to develop a comprehensive overview of the patient's medical, psychological and social needs reducing stress and accelerating care planning.

One thing we do in the assessment is draw a very simple family tree... [to] see who is attached to whom, who is important, who doesn't talk to who, which is very important.

Midhurst nurse

- Medicines management ensuring continuous symptom control, and immediate access to medication.

[A key benefit is] access to immediate medication... I've had problems at weekends when we needed medication and then we've had to get the on call doctors and then the relatives have had to go to get the medication at the nearest place, and that can sometimes be very frustrating, especially if somebody is in pain.

Community nurse

- Stability of relationships with the CNS and the team anchoring care around the patient. Care workers delivering personal care can change from day to day and the team provides continuity and familiarity for the patient and their family.
- A focus on delivering care in the community wherever possible. Enabling patients to receive treatment at home avoids travel time, and treatment takes place in a familiar environment, shortening recovery time.

[A]ttending hospital for some procedures is extremely exhausting for patients, and if you can actually deliver that care in the home you're removing all of that stress and exhaustion, because it might take days to recover from a trip to hospital.

Commissioner

Patient and carer experiences

Positive patient experiences describe how the service has worked flexibly to provide patient centred care co-ordination (see also A's story above).

Patient stories

D's story *by C and V*

D, our son, had been training at the British School of Osteopathic Medicine for two years when he was diagnosed with a gastro-intestinal stromal tumour (GIST). He was only 27. Initially, it was very difficult for him to accept because he was a fit, active young man, passionate about anatomy and physiology and he took a keen interest in his own health and nutrition.

Following discharge from hospital in May 2005, D came to live with us. The Midhurst Macmillan Specialist Palliative Care Service was alerted and consultant Peter Hargreaves referred D to GIST specialists at the Royal Marsden Hospital. In the meantime, the service arranged blood transfusions and pain relief.

The Marsden prescribed a new drug, Glivec, which reduced the size of the tumour. D grew stronger and in 2006 he felt he could live independently again. The Midhurst Macmillan Specialist Palliative Care Service helped him to apply for the benefits to which he was entitled and he moved into a house about a mile from us. By February 2008 the Glivec stopped working. We were told D probably had about six months but he was determined to fight. He exercised whenever he felt well enough, which gave him both physical and mental strength.

When all other approved drugs had been tried, D took part in trials for the Royal Marsden. They did not help, but D felt he was contributing to research that might help others. In April 2009, D's condition was worsening. We visited a hospice with him, but he wanted to remain as independent as possible. We re-established contact with the Midhurst Macmillan Specialist Palliative Care Service, which provided all the care and support needed not only by D, but also by us, as parents, brother and sisters.

It meant that during the final weeks of D's life we were able to be with him every day. The nurses visited several times a day to administer pain relief and provide practical and emotional support; they also provided night-time care. They were like a beacon of light in our lives.

As D saw it, the Midhurst Macmillan Specialist Palliative Care Service enabled him to retain his dignity and independence throughout, by living – and dying – in his own home.

Mr E's story *A service perspective*

Mr E, 92, was referred to the Midhurst Macmillan Service towards the end of January 2013 by his local acute hospital, where he had been an inpatient for 12 weeks with repeated chest infections and end-stage cardiac disease. Mr E's wife had been cared for by our service about four years before, when we supported her to die at home. Mr and Mrs E had no children – their next of kin were a niece and her son, their great-nephew.

Mr E had expressed a wish to die at home and following a case conference at the hospital it was decided that he would be offered no further courses of intravenous antibiotics and would be transferred home with a continuing care package. Because Mr E lived on his own, his family contracted with a care agency for a 24-hour live-in carer. A hospital bed and other equipment were delivered to his home before his discharge.

Mr E was eligible for continuing care funding for additional care. This took the form of two carers four times a day. Other services involved in his care included the community nursing service, the GP and the Midhurst Macmillan Service. Because Mr E was not able to co-ordinate all the care himself it was important that all the services communicated effectively between themselves and with Mr E's great-nephew. The district nurses left notes in the home of Mr E after each visit and we wrote into these notes to help facilitate effective communication.

On the first visit following his discharge home his clinical nurse specialist found him in bed awake and obviously able to respond to questions though he became easily tired. He had no pain at rest but did have pain when he was moved and he was moved by the carers every time they visited to help prevent pressure injuries. His main carer reported that he was drinking a small amount of fluids but was finding solid food difficult to swallow. Our role in monitoring and advising on pain and symptom control was explained to his live-in carer and our contact numbers left with her. A telephone call was made to his great-nephew to let him know we had visited.

We made regular visits to Mr E during the next three weeks, during which time he required changes to his pain control, which was mainly via a dermal patch. We spoke to the district nurses regularly and provided a night sit so that his carer could rest.

Mr E became increasingly unable to tolerate large amounts of fluid but he was able to drink small amounts. He gradually declined over a period of three weeks and received medication via a syringe driver for the last 48 hours of his life. He died as he wanted, in his own home with his remaining family present.

The main points of care from the service were communication between all services involved, assessment of need for pain and symptom control, advising on the most effective methods of drug delivery, and to support non-medical carers and Mr E's family with an explanation of the importance of their role.

Source: Patient stories taken from *Transforming palliative care for the better* with permission from Midhurst Macmillan Service. Available at: www.institute.nhs.uk/resources/nhslive/4563/4287%20Factsheet%20FINAL.pdf

5 Challenges and facilitators

Challenges

The service has had to overcome a series of challenges to achieve its current success, some of which remain. These challenges can be categorised either as challenges related to the wider context (that the service has little or no influence over) or challenges relating direct to the organisation and delivery of a community-based service.

Contextual challenges

Within the wider context, three key challenges have influenced the ability of the service to make progress:

- NHS reforms
- funding
- geography.

The Midhurst Macmillan Service has grown within a national context of major **NHS reform**. In its early years, the service benefited from a degree of autonomy by operating on behalf of local commissioners as a directly managed service. In 2009, however, directly managed community-based services were contracted out to new provider units (in this case, to a large provider of community-based services called Sussex Community Trust). This resulted in a loss of managerial and financial autonomy (eg, in hiring staff) and required the service to meet new and more stringent corporate rules and strategies.

The most pressing concern among interviewees in Midhurst, however, was about **funding**. While Macmillan Cancer Support and the three local clinical commissioning groups remained committed to shared funding for the service in 2013/14, there was no certainty on this financial commitment in the longer term. A key challenge to the managers of the team, therefore, has been to raise awareness and support for the service – a process helped by an evaluation providing positive evidence on patient and user experiences as well as cost-effectiveness.

A third key challenge to the service has been presented by **geography**. The catchment area covered by the service straddles three counties, which poses logistical challenges, not only in terms of gaining commitments from a number of different agencies, but also in meeting the different governance and accountability rules of each one (for example, in terms of reporting requirements and, in some cases, clinical practice). The rurality of the local area (400 square miles) and poor public transport has also posed limitations on what can be provided and has defined how the service operates. Nonetheless, it should be recognised that the home-based approach to palliative care has added legitimacy in such a context given the lack of access to alternatives (though a network of hospices exists).

Organisational challenges

One of the key organisational challenges faced by the service has been to develop and maintain positive relationships between the various partners in

care. This has been important in developing trust and legitimacy (and therefore more referrals) to the service as well as to improve care co-ordination for patients. The managers in the core team described the importance of 'walking the patch' to engage and educate GPs, nurses and the wider community and the significant challenges they have faced in changing people's views on the provision of specialist palliative care at home.

Linked to this challenge is the lack of ability to share information on patients electronically between partners in care. As a result, significant time and effort is taken to update GPs and community staff through letters, emails, telephone calls and face-to-face communication. The team and its external partners have developed other ways of sharing information (for example, using a case notebook at the patient's home) but the lack of an integrated IT support system remains an underlying problem.

The service has also had its challenges in ensuring an adequate numbers of staff are available with the right skill mix to support its goals. Since 2006, managers have reported a gradual growth in staff numbers to the point where a more comprehensive service is being delivered, but it was also stressed that more staff were needed to improve the service and to increase patient numbers. Though the service is highly responsive to urgent patient needs, the goal of providing a 24/7 service has not yet been fully realised.

Facilitators

Contextual facilitators

Despite developing within a backdrop of significant NHS reforms, the service has benefited from a general shift in health policy towards delivering care closer to people's homes, increasing patient choice, and delivering more person-centred and integrated care. The profile of end-of-life care also increased with the publication of an End of Life Care Strategy (Department of Health 2008). These policies, combined with the support of local commissioners and Macmillan Cancer Support, have created an environment in which the service has thrived.

The service was also established in a local context where community support for the previous hospital-based palliative care unit was high, linked to the high profile of Macmillan Cancer Support. The commitment of key leaders, and especially the palliative care consultant, together with staff and volunteers, to drive forward the new community-based service can be seen as the legacy and strength of historical relationships.

Organisational facilitators

The relationship with Macmillan Cancer Support as co-funder has been especially important to the success of the service. In addition to funding, co-operation with the charity has enabled the service to benefit from free legal and financial advice, grants for building adaptation works, and the active involvement of 70 volunteers.

The service has a flexible structure that allows each individual to work in partnership and respond to patient needs rapidly and effectively. The culture of 'the team' appears to be a vital component in the success of the service as like-minded people are attracted to work in a flexible and dedicated way to meet

the holistic needs of patients at the end of life. Positive team dynamics have undoubtedly created a context within which commitment to each other and also to patients is high, thus enabling the service to overcome some of the stresses associated with high-demand periods (eg, in the winter months).

6 Key lessons

A key aim of the research was to tease out lessons and markers for success that can be transferred to other settings and countries. In terms of the Midhurst Macmillan Service it is important to recognise the unique nature of its geography, history, governance and funding arrangements, and how these have impacted on the success of the programme. For example, interviewees were divided on the potential transferability of the programme to other localities, stressing the unique set of circumstances that came together to create the service and implying that without the rush of the hospital closure and the previously existing service, there may have been too much resistance to develop the service.

The role of Macmillan Cancer Support is also seen as a critical and unique component, not only in terms of money but in terms of the quality of the staff and gaining access to volunteers. Few other charitable organisations would have the same resources to provide this help and following an evaluation Macmillan Cancer Support plans to replicate this service in other parts of the country. It is uncertain whether commissioners would be willing to find the necessary resources to meet the funding gap if Macmillan Cancer Support stopped funding the service. However, the wider political commitment to support and invest in end-of-life care suggests that support for the aims and objectives of the service will continue to be prioritised.

The other key and more intangible element to the success in Midhurst has been the vision, commitment and drive of a small number of key leaders, often working 'against the system' and despite wider reorganisations, to make things work. While such leadership is often seen as a necessity for integrated care to flourish, a key lesson from Midhurst is how this commitment and energy have also been present within the core team, providing a highly positive team culture which appears to have been crucial to success. The nature of the way the team operates to distribute responsibilities and leadership has undoubtedly contributed in a key way to the outcomes that have been achieved.

Despite these factors, respondents felt that the approach to care co-ordination in Midhurst would work well in other areas as it contained a number of key elements about the care process that could be replicated. These include:

- *Awareness-raising and relationship-building*
The service has built relationships with a wide range of key partners in care (GPs, community staff, social services, hospital consultants, volunteers and local people) that have ensured legitimacy and trust in the service, so ensuring its ability to 'capture' people nearing the end of life before, or very soon after, a hospital admission.
- *Multiple referrals to a single-entry point*
Rather than rely on referrals from specific health care professionals, such as GPs, the service has encouraged referrals from all partners in care (including family and friends). This direct access to the service goes through a single point of entry, supporting effective decision-making and care co-ordination.
- *Holistic care assessment and personalised care plan*
A single assessment process examines both the health and social care needs of the patient *and* their family and also takes into account their

life situation and choices about future care and treatment options, and a personal care plan that uses clear criteria on patient need to initiate appropriate packages of care.

- *Dedicated care co-ordination*
The care co-ordinator (usually a clinical nurse specialist) plays a crucial part of the care process by acting in a number of roles: being the principal point of contact with the patient and their family and effectively co-ordinating care from the multidisciplinary team and the wider network of care providers.
- *Rapid access to care from a multidisciplinary team*
The rapid deployment of care professionals working flexibly and with the appropriate skill mix (including volunteers and non-clinical care) allows care and support to be initiated to meet the needs of people at home.
- *Assigned accountability*
Decision-making at the team level is made with clear role demarcation and an understanding of professional boundaries.
- *Responsive provider network*
Partnership working with GPs and community services outside of the core team is promoted to ensure services are co-ordinated and provided effectively. Significant effort is placed on effective communication of patient and family-sensitive information in the absence of linked care records

The lessons drawn from the process of care co-ordination in Midhurst have been reflected in other review studies, for example, on case management in Ross *et al* 2010. What appears most important to the success of the approach, however, has been its ability to detect and provide a personalised and rapid response to meet people's needs at an earlier phase than other models as well as to have a community-based team with the mix of skills to maintain most people effectively at home.

In addition to the care process, other markers for success in the service include a passion and dedication among staff manifest in a positive team culture and a commitment to improving the patient's experience of care. This has been underpinned by a readiness to learn and reflect on quality of care and outcomes in a team structure with a flat hierarchy supporting devolved responsibility. Finally, commitment to fund a robust evaluation of the impact of the service to demonstrate its positive benefits to users and carers and the wider system has further allowed the model of care to gain legitimacy.

The multiple components that make the Midhurst Macmillan Service a success contain both tangible and intangible factors. It is important to recognise that it is unlikely that Midhurst's model of care can be, or indeed should be, fully replicated in other contexts. While the case reveals a number of key lessons and markers for success, these have been the result of a seven-year process of development, influenced by a variety of national and local events and shaped by specific funding and organisational arrangements. Personalities have also played a key part. A key lesson from Midhurst, therefore, is that as much can be learned from the process of how care co-ordination was developed as from the eventual structures and processes that have been created.

References

- Beck-Friis B, Strang P (1993). 'The organization of hospital-based home care for terminally ill cancer patients: the Motala model'. *Palliative Medicine*, vol 7, no 2, pp 93–100.
- Cornwell J, Levenson R, Sonola L, Poteliakhoff E (2012). *Continuity of Care for Older Hospital Patients: A call for action*. London: The King's Fund.
- Department of Health (2008). *End of Life Care Strategy – Promoting high quality care for all adults at the end of life*. London: Department of Health. Available at: www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life (accessed on 12 April 2013).
- Gomes B, Calanzani BN, Higginson IJ (2011). *Local Preferences and Place of Death in Regions within England 2010*. London: Cicely Saunders International.
- The King's Fund (2001). *Improving the Quality of Care in General Practice: Report of an independent inquiry commissioned by The King's Fund*. London: The King's Fund.
- National Cancer Intelligence Network (2013). 'UK Cancer e-Atlas by NHS health boundaries'. National Cancer Intelligence Network website; Available at: www.ncin.org.uk/cancer_information_tools/eatlas/pct/atlas.html?select=Eav&indicator=i0 (accessed on 12 April 2013).
- NHS Choices (2013). 'The NHS in England'. NHS Choices website. Available at: www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx (accessed on 20 May 2013).
- Ross S, Curry N, Goodwin N (2011). *Case Management. What it is and how it can best be implemented*. London: The King's Fund.

Appendix 1 Methodology

The research team used a mixed-methods approach which involved:

- 20 semi-structured qualitative interviews with staff within the Midhurst service, local GPs, community nurses and commissioners and at Macmillan Cancer Support
- observational analysis of a weekly multidisciplinary team meeting, caseload meeting and palliative care (Gold Standard Framework) meeting at a local GP practice
- content analysis of key documents and impact data provided by the Midhurst service and an evaluation of the service conducted by the University of Sheffield and the University of Huddersfield for Macmillan Cancer Support.

Appendix 2 Staffing establishment

Staff group	Hours whole-time equivalent establishment	Comments
2 team leads	1.0	Two team leads share the job
2 consultants	0.6 and 1.0	Six sessions over three days usually Tuesday, Thursday and Friday (one session is done for the Trust); full-time consultant works 10 sessions a week
1 associate specialist	0.5	Works five sessions over three days, usually Monday, Tuesday and Wednesday
7 clinical nurse specialists	4.0	
5 community registered general nurses	5.0	
1 health care practitioner	30.00	
3 health care support workers	3.0	
Other clinical staff:		The counsellor works 15 hours and the occupational therapist and physiotherapist 7.5 hours per week.
1 counsellor	0.5	
1 bank nurse	0.30	
1 physiotherapist	0.30	
1 occupational therapist		
4 admin staff	1.0 1.0 2 bank	Two admin staff, of which one is the volunteer co-ordinator, work full-time, and there are two bank workers who can be drafted in for 2.5 days a week (0.5 full-time equivalent)