



National Audit Office

A Review of the Provision of End of Life Care Services in Sheffield Primary Care Trust



National Audit Office

2008

Whole System Review

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Part 1: Introduction

The NAO is carrying out a value for money study on the delivery of end of life care services in England.

1. Over the course of two days, four staff members from the NAO health value for money team (the Review Team) conducted a qualitative review of end of life care services in Sheffield

2. The visit forms one strand of the study team's work on end of life care which will result in a full Value for Money report to Parliament in 2008. Our work involves a range of methodologies including:

- (a) Surveys of PCTs, Care Homes, Hospices and Clinicians;
- (b) Economic Modelling of the potential cost savings and days of acute care which can be avoided by delivering more services in the community;
- (c) Focus Groups of Patients and Carers and
- (d) System reviews of end of life care provision at Sheffield, Hereford and City & Hackney PCTs to identify the strengths and challenges of delivering end of life care in a range of settings.

3. Alongside these methodologies we are also working with the Balance of Care group on a retrospective review of the patient records of all patients who died of cancer, chronic disease, or frailty or who died unexpectedly in Sheffield in October 2007. This is a valuable piece of unique work which will provide demographic information on patients dying of these conditions, but will also examine how many hospital deaths might have been avoidable had alternatives been available and given due consideration: Headline findings from the work of the Balance of Care Group include:

- (a) 40 per cent of patients who died in hospital did not have medical needs which required them to be in an acute setting, and could have been cared for elsewhere;
- (b) Services for cancer patients are the best organised but gaps remain;
- (c) Care home patients are sometimes admitted avoidably at the end of life but the majority die in care homes
- (d) Specialist disease nurses have limited involvement in delivering care at the end of life.

4. Our study of end of life care services in England is currently in the analysis and drafting stage and its findings are due to be reported to Parliament's Public Accounts Committee in November 2008. The team would like to thank Sheffield PCT and all those involved for agreeing to participate in this work and for their support, knowledge, and advice. We hope the findings prove useful in developing future end of life care services for the people of Sheffield.

The Review team met with staff and stakeholders to analyse the current situation and look ahead.

5. To gain an understanding of the strengths and challenges of end of life care in Sheffield the Review Team interviewed over 40 members of staff involved in the commissioning and delivery of services as well as current patients and carers:

- (a) Senior directors and managers from Sheffield PCT;
- (b) Acute care staff;
- (c) GPs;
- (d) District Nurses;
- (e) Community Matrons;
- (f) Social Workers;
- (g) Hospice staff;
- (h) Managers and care staff from care homes; and
- (i) Carers and Patients

6. The feedback and findings from these meetings were collated and analysed in conjunction with facts and figures taken from both internal and external sources including the PCT baseline review, ONS mortality data for 2007 and a research report "The Standards We Expect – Choices for End of Life Care" based on work carried out in Sheffield by the Joseph Rowntree Foundation.

End of life services in Sheffield operate in a complex and changing environment.

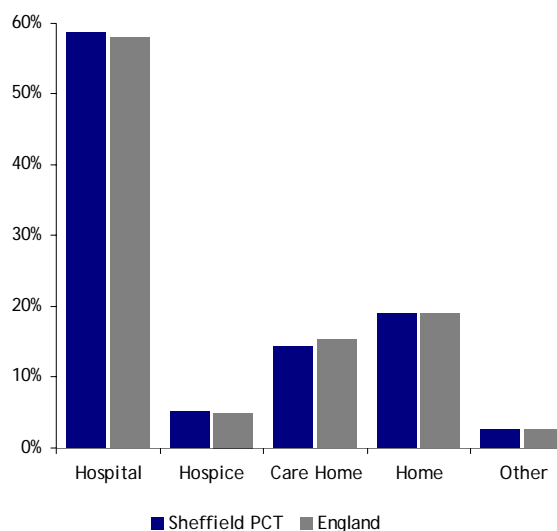
7. Advances in medical care and changes in lifestyles mean that the average age of the population is increasing and patients with significant complex illnesses are living longer. As a result there is an increasing need for palliative and end of life care services.

8. End of life care is likely to receive greater media and public attention in the near future. The Department of Health published a National End of Life Care Strategy led by Mike Richards, National

Director for Cancer in July of this year. End of life care is also one of the eight care pathways included in the review of the NHS led by Lord Darzi.

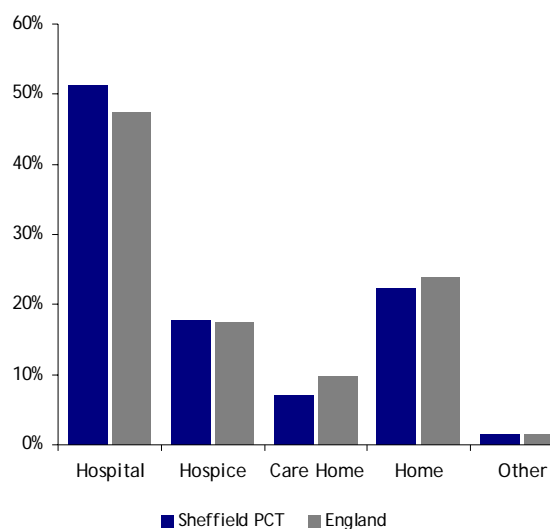
Sheffield Facts & Figures

Place of death for all patients in Sheffield PCT 2006



Data taken from 2006 Mortality Statistics

Place of death for cancer patients in Sheffield PCT 2006



Data taken from 2006 Mortality Statistics

- 39% of all deaths from all conditions occurred in Home, Care Home or Hospice and 59% in Hospital. 39% of deaths occurring outside acute care is typical of the national picture and if all PCTs were to be ranked on this measure Sheffield would be placed 74th out of 152.¹
- 26% of cancer deaths and 19% of all non-cancer deaths occurred at home as compared to the national averages of 24% and 19%
- The place of death for cancer patients is also typical of the national picture.
- Deprivation in the city is approximately average.²
- Sheffield was ranked 43rd out of the 152 PCTs in England in September 2006 in terms of comparative end of life care need (where the PCT ranked 1 has the highest comparative need). This is because although Sheffield has an average level of deprivation it has a comparatively high level of deaths per 100,000 of the population.³

¹ NAO analysis of 2006 mortality statistics

² Population-based Needs Assessment for End of Life Care, The National Council for Palliative care, September 2006

³ Population-based Needs Assessment for End of Life Care, The National Council for Palliative care, September 2006

Part 2: Strengths

This part of the review outlines the key strengths exhibited within end of life care provided in Sheffield, as identified during the course of the our interviews.

Sheffield has a history of addressing the issue of end of life care and has been proactive in developing services

9. There has been a long standing presence of palliative and end of life care in the community in Sheffield. St Luke's Hospice was founded in Sheffield in 1971 and was the first purpose built hospice outside London.

10. For the last 14 years, the PCT has provided an Intensive Home Nursing Service as part of the Variable Intensity Palliative Care Scheme which received 692 referrals in 2005/06 and provided care to 593 people.

11. In the acute care setting Sheffield Teaching Hospital NHS Foundation Trust has inpatient palliative care services which cover the Royal Hallamshire Hospital, The Northern General Hospital and Weston Park Cancer Centre which has been designated one of three specialist cancer centres in the UK since 1995. The Team includes a Professor of Palliative Medicine, Medical consultants, Specialist Registrars, Clinical Nurse Specialists, Pharmacists, and Physiologists input. The case load is varied; the majority of patients have a cancer diagnosis but also includes a significant number of people with other conditions. The team assessed 1,870 new patients over the course of 2007/08.

12. The University of Sheffield has a history of academic research into both the medical and social sciences and features a Palliative and End-of-Life Care Research Group. In addition to its close links with the Cancer Research Centre at Weston Park, the University offers a short period of palliative and end of life care training for 4th year medical students either in the hospitals or in the community.

13. The long standing provision of end of life care services means that they are well known and well respected within the Sheffield health and social care community.

It is clear that Sheffield's end of life care providers are dedicated to their work and committed to providing the highest quality of care possible.

14. Staff providing end of life care in Sheffield have energy and passion for the work they do. At every level within the community there is a commitment and desire to treat patients as individuals with dignity and respect and to enable them to have a good death in the absence of pain and other symptoms and in familiar surroundings. This commitment should be acknowledged as crucial to championing end of life care and driving future change.

15. This commitment has driven the establishment of the Sheffield Palliative Care Committee (SPCC). This informal group meets to discuss plans and issues around palliative care. Interviewees generally agreed that all of the appropriate services and organisations are represented on the committee and that it provides an invaluable forum for discussion, in particular between NHS and charitable services.

16. To aid them in their work, Sheffield's care providers have collaboratively developed a modified version of the Liverpool Care Pathway (LCP), a tool for improving care for dying patients in all places of care, known as the Sheffield Care Pathway.

There is a wide range of end of life care services available to the people of Sheffield

17. Sheffield provides a number of services to patients within the community:

- St Luke's Hospice offers a variety of services to the community which include 30 in-patient beds⁴ corresponding to 11,138 bed days available, a day care centre, a Community Specialist Palliative Care Nursing team, social and bereavement support and a 24-hour advice help-line. Approximately 40 percent⁴ of the Hospice's funding is provided by the PCT with the rest coming from fundraising activities.
- Since 2002 the Macmillan Palliative Care Unit has operated at the Northern General Hospital site offering both in-patient and outpatient care to cancer and non-cancer patients as well as physiotherapy, occupational therapy and an on-site social worker. In 2006/07 the unit had

⁴ Taken from St Luke's Hospice submission in our survey of hospices in England based on 2006/07 data.

6,519 bed days available to patients approaching the end of their lives⁵.

- The Evening and Night Nursing service has operated from the Michael Carlisle Centre on the Nether Edge Hospital site. This service builds on the daytime District Nursing Service and runs from 5pm to 8am 365 days a year city-wide allowing care to be delivered round the clock. Referrals come from St Luke's Hospice, GP out of hours services and from the hospital units. Patients and their carers are also encouraged to contact the service directly in the event of a crisis.
- The Cavendish Centre, a support charity, offers supportive care, assessment, counselling and a range of complementary therapies for patients with cancer and their carers. The Weston Park Cancer Information & Support Centre also offers some complementary therapy sessions.

18. End of life care services are also provided in the acute setting

- The Macmillan Palliative Care Unit at Northern General Hospital is a specialist unit with 18 in-patient beds. Care is provided to patients by a multi disciplinary team of consultants, clinical nurse specialists, social workers and occupational physiotherapists. The unit also offers 2 outpatient clinics per week and staff can carry out home visits when required, although this is not a large part of the unit's work. A similar service is provided by the palliative care team at Weston Park Hospital.
- There is generally good integration and communication between the primary and secondary care services, and jointly funded consultant posts appointed jointly by Sheffield Teaching Hospital and St Luke's Hospice help promote this integration.

Sheffield has introduced some innovative services designed to improve end of life care.

19. The PCT provides an Intensive Home Nursing Service. This service works with patients and carers in their own homes, providing nursing care and support. Originally the service provided 7 nights per week care to those thought to be in the last month of life and 24 hour care to those thought to be in the last week of life.

20. Since April 2004 the service has been extended to offer additional Variable Intensity Palliative (VIP) Care to provide a more flexible, responsive care to those with longer term palliative care needs.

21. This level of home nursing is not common outside of Sheffield and the services are considered to be invaluable by both care providers and service users as they support patients to remain at home as they approach the end of their lives and to die at home where appropriate. This can help avoid unnecessary admissions to an acute hospital which are costly and often not in the best interests of patients or their carers.

A number of noteworthy cases of good practice were brought to our attention.

22. Interviewees highlighted several examples of good practice in service delivery which they believed had been particularly successful. These included:

- (a) District Nurses in the city are each attached to a number of local GP surgeries which means that patients receive greater continuity of care and there is enhanced ongoing contact and liaison between District Nurses and GPs.
- (b) We were made aware of a GP practice where patients expected to die in the near future are provided with a direct contact number for the practice in case of an out of hours emergency. The system avoids patients relying on the out of hours services who often have access to little background information on a patient's case history. This system of improved continuity of care is likely to reduce unplanned admissions. By rotating the GP partner responsible for the practice each night the demand placed on individual GPs is seen by the practice to be acceptable, however, this remains uncommon
- (c) The Weston Park Cancer Information Centre has been set up in order to help cancer patients and carers access the information on end of life care services which they need. The centre offers a range of services for both patients and carers including information on specific conditions, practical courses, emotional support, complementary therapies and advice on benefits and financial matters.
- (d) St Luke's hospice has appointed a palliative care nurse as a care home co-ordinator. The main role of this position is to provide end of life care training in Sheffield care homes. If a patient is discharged to a care home the co-ordinator will ensure that this process runs smoothly by helping the home understand how the patient needs to be cared for and following up cases once they have moved back home.

⁵ Taken from the McMillan Unit's submission to our survey of NHS run in-patient palliative care services, based on 2006/07 data.

- (e) Sheffield Teaching Hospital is currently running a 10 month secondment for an End of Life Co-ordinator to provide training and supervise the roll out of the Liverpool Care Pathway. This has been adapted to suit local needs and staff at all levels are being trained on how to use it.

End of Life Care is moving up the Sheffield PCT agenda

23. In undertaking the Baseline Review of End of Life Care services set by the Department of Health as part of the development of their strategy. The high quality of Sheffield's Baseline Review compared to others we have seen indicates the significant effort which was put into the exercise.

24. The PCT recognises that there are a number of key drivers for changes in the existing provision of care and has approved a series of actions to ensure that the PCT will be ready to respond effectively to the National End of Life Care Strategy when published.

25. There is also ongoing work in Sheffield looking at provision of services for older people, one strand of which is looking at palliative and end of life care.

Part 3: Challenges

This part of the review outlines the key challenges and limitations of End of Life Care in Sheffield, as identified during the course of the Review Team's interviews.

Equity of access to end of life care services is not guaranteed for all who need them.

26. Whilst Sheffield's services are not exclusively geared towards cancer patients there are some which still have a heavy focus towards caring for patients with malignancies. This means that there is an inequity of access to some services for patients with a condition other than cancer.

27. One area where this is particularly evident is in the provision of information and advocacy services. Whilst the Weston Park Cancer Information & Support Centre offers a very valuable service as detailed in paragraph 22(c), a similar service to support non cancer patients as they approach the end of their lives is not on offer.

28. There is variability in the provision of services across the city. Examples which were highlighted to us were the availability of carers and the variability in the services and expertise of GPs and District Nurses.

Secondary and primary care are not as well integrated as they could be.

29. Patients who have experienced a sudden deterioration in their condition are often admitted to hospitals or hospices for a period of acute care. In some cases their condition may improve such that the level of treatment they require can be provided in the community. In other cases patients close to death may wish to spend their remaining time in the more familiar surroundings of their normal place of residence. In both instances there is a need to transfer their care from a secondary to a primary setting where possible. When this transition does not occur smoothly it can impede the delivery of high quality end of life care. The availability of equipment and inconsistency in care across primary and secondary care were highlighted as two barriers to the delivery of effective end of life care.

30. Many end of life patients require essential equipment such as hospital beds pressure control equipment and syringe drivers to be put in place before they can be discharged into the community. For such patients there is often a very short window of opportunity in which they can be transferred from hospital to enable them to die in familiar surroundings.

31. Equipment can be provided to patients in Sheffield to support them to remain at home at the end of their lives. However, interviewees felt that this service had very limited resources in terms of both staff and volume of equipment. In addition the service only operates Monday to Friday during normal working hours. This can lead to delays in getting equipment to where it is needed with the consequence that some patients die as an in-patient whilst waiting to be discharged.

32. In order to mitigate delays in discharge and meet the demand for its services, the Intensive Home Nursing Service has recently entered into its own lease arrangements for a hospital bed from a private provider. The lease arrangement means that the provider will deliver and assemble the bed anywhere in the city within 2 hours at a relatively minimal cost.

33. Care plans are often not designed to be effective in acute and community settings which can lead to disparate and uncoordinated provision. On admission to hospital patients undergo an assessment of their care needs and an appropriate care plan is put in place. Once discharged back into the community a new assessment must be made and will often cover similar information. Delays in carrying out this reassessment can lead to unnecessary readmission or treatment which is not consistent with patients' original wishes.

34. One example of this lack of consistency relates to Do Not Attempt Resuscitation (DNAR) decisions made by patients and/or carers. A DNAR decision made whilst in secondary care ceases to become extant when a patient leaves the ambulance in which they are discharged. Until a separate DNAR is made and documented in their normal place of residence, care and emergency services are obliged to attempt resuscitation and re-admit the patient to hospital where necessary even if this is against a patient's wishes. This has led to at least one situation where a patient was discharged from acute care in the morning only to subsequently die in an ambulance on the way back to hospital that afternoon.

Effective prescribing relies on good communication.

35. In some cases GPs may not be informed of the full basis on which a prescription by another clinician is made and may as a result decide to change a regime which has been agreed, for example, by palliative care consultants in hospital. This can lead to confusion and many patients and carers lack the knowledge and confidence to question such a decision.

36. The lack of summary patient records and agreement on how they should be held is not unique to Sheffield. However, sufficient access to

such information would provide care professionals with a more complete and current picture and enable them to deliver better continuity and quality of care and help ensure patients are not adversely affected by their transfer between care settings.

37. There are additional challenges relating to the discharge of patients with medication regimes, particularly if those regimes involve administering controlled substances. In order for nursing staff in the community to be able to administer controlled medication a GP must attend the place of care after the discharge and sign documentation authorising them to do so. This can disrupt the continuity of care particularly if patients are discharged overnight when GP out of hours services have limited resources.

38. A further issue arises when patients are discharged to care homes. Many care homes now administer medication only if it is received in blister packs specially prepared by pharmacists with all medication for a patient grouped together. This system is not the norm in hospitals where medicines are dispensed in different containers. As a result hospitals may discharge patients with a supply of the drugs but care home staff will not administer them. This inconsistency not only results in interruptions to patient care but also considerable cost when care home approved medication has to be dispensed.

There is a lack of 24 hour provision of some key services.

39. The nature of end of life care means that it needs to be available 24 hours a day. If services are not integrated or are reactive only then this can adversely affect patient care and may cause unplanned admissions.

40. The service which provides specialist equipment to enable patients to be treated at home is only able to operate during office hours Monday to Friday and often makes it difficult for the services which do operate out of hours to access equipment when it is most needed.

41. Sheffield currently does not provide a 24 hour pharmacy service. Medication required by patients at the end of life such as controlled pain relief is not carried by GPs. An on-call pharmacist is available to the GP Out of Hours Collaborative at the Royal Hallamshire Hospital however this facility is rarely used and patients may be forced to wait until the following day to obtain medication.

42. One method for avoiding out of hours prescribing issues is for GPs to pre-emptively prescribe medication in anticipation of likely symptoms such as severe pain. Pre-emptive

prescribing ensures medication is on hand in advance of need and can be administered by nurses under a set of conditions expressly set out by the GP. Interviewees raised concerns that whilst this method is generally accepted to be beneficial for patients, it is not as widely used as it could be in Sheffield.

43. GPs providing out of hours services face problems as the nature of these services means that doctors often do not have detailed knowledge of the individual patients they are called to. It was felt by interviewees that lack of patient knowledge and suitable notes often drives unplanned admissions out of hours.

44. Whilst there are palliative care doctors on call 24 hours a day to provide specialist care and advice covering Weston Park Hospital, St Luke's hospice, the Northern General Hospital Macmillan Unit and the hospice in Chesterfield, interviewees expressed some concern that face to face contact recommended by the 2005 NICE palliative care guidance is not always possible because they are so busy.

A number of issues are not currently addressed at a strategic level.

45. The PCT does not provide senior management representation to the SPCC. This means that whilst participants feel that the committee is a valuable forum for discussing palliative and end of life care issues, it is essentially informal with limited power to influence or direct the PCT's commissioning of services.

46. A small number of the city's GP practices have experienced success in providing higher quality care through use of the Gold Standards Framework (GSF), which aims to develop a locally-based system to improve and optimise the organisation of quality of care for people in the last year of life. Some interviewees felt that the lack of a champion for GSF implementation in Sheffield at the PCT level has led to both the limited use of the tool and variability in its effectiveness when it has been used.

There is currently a lack of management information in respect of end of life care.

47. In the absence of sufficient information it is difficult to evaluate both the demand for, and cost effectiveness of, the services the PCT provides. Such evaluations might include analyses of:

- (a) the amount of savings to the health economy the Intensive Home Nursing Service has produced by supporting people to remain in the community rather than acute care, and the number of patients which would be eligible for this service if it were expanded;

- (b) the number of patients who die in acute care whilst waiting for care packages to be put in place to allow their discharge;
- (c) the proportion of acute palliative care admissions made out of hours;
- (d) the cultural, ethnic or social diversity of those accessing or not accessing the services; and
- (e) any need currently not met by the city's services.

48. There is also no analysis of any unmet need from specific groups such as those with mental health needs or minority cultural and ethnic groups.

There is a lack of planned, bookable respite and long term care offered in Sheffield

49. We were made aware of the fact that Sheffield does not currently provide planned, bookable respite care and also long term inpatient nursing care for those patients and carers whose specialist palliative care needs have been met but who still require regular respite or long term complex nursing care (often unavailable in care homes).

There is a need for further education around the issue of end of life care.

50. The quality of end of life care delivered is highly dependent on the skills of those providing it. It was brought to our attention that there are a number of areas in which education around the area of end of life care would be beneficial.

51. Staff working in nursing and residential institutions come from a range of cultural backgrounds and have varied experience of working in such a setting. This can lead to very different abilities and attitudes in respect to end of life care, which may not meet with patients or families' wishes or expectations.

52. The expertise and experience of GPs and hospital specialists in the principles and practice of end of life care varies widely as a function of their different exposures to end of life and palliative care work.

Part 4: Recommendations

53. This part of the report outlines our high-level suggestions for improving the provision of end of life care services in Sheffield.

54. We realise that the limited duration of our visit and lack of knowledge of the unique challenges facing the health economy means that we are not going to address all of the issues facing the city nor completely solve what are complex problems. Our aim is for our ideas and suggestions to generate discussion and drive

change by contributing to Sheffield PCT's own internal work on improving care services. We hope they are valuable.

55. The Review Team is happy to discuss further any of the recommendations it has put forward. These recommendations should be considered alongside those which will be made in our full study of end of life care services when it is published in November. We will also be producing individual feedback reports for each PCT to enable them to assess their data against other PCTs and prioritise areas for improvement.

1. The PCT should gain an understanding of the costs and benefits of its various end of life care services in order to better evaluate potential savings, identify groups either not accessing service or with unmet need and to inform the direction of future care services. For example the potential costs and benefits of expanding and improving access to the Intensive Home Nursing, Variable Intensity Palliative Care and Evening and Night Nursing Services should be examined.
2. A senior representative from the PCT should attend SPCC meetings so that the Committee's expertise can be used to inform the PCT's commissioning plans for end of life care services.
3. The PCT should explore what services need to be provided on a 24 hour basis in order to ensure high quality end of life care is provided for all
4. The commissioning of a support and information centre designed to aid non-cancer patients in better understanding and accessing the care available should be given due consideration.
5. Health and social care should work together to examine the provision of education for nursing and care home staff in the areas of palliative and end of life care.

ANNEX 1: Review Team Membership

The NAO Review team consisted of the following members:

- Shamail Ahmad
- Tom McBride
- Hannah Payne
- Duncan Richmond