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



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2008

WHOLE SYSTEM REVIEW

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

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Part 1: Introduction

The NAO is carrying out a value for money study looking at the delivery of end of life care

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 Herefordshire.

2. The visit forms one strand of the study team's work on end of life care which will result in and 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 Herefordshire, Sheffield, 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.

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 Herefordshire PCT and all those involved for agreeing to participate in this work for their support, knowledge, and advice. We hope the findings prove useful in developing future end of life care services for the people of Herefordshire.

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 Herefordshire the Review Team interviewed 18 members of staff involved in the commissioning and delivery of services:

- (a) Senior directors and managers from Herefordshire PCT;
- (b) Acute care staff;
- (c) GPs;
- (d) Head of District Nursing;
- (e) Well being co-ordinators;
- (f) Representatives from Herefordshire Council;
- (g) Hospice staff;
- (h) Herefordshire Alliance, representing the Third Sector Bodies; and
- (i) the Involving People Team, representing the views of 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 information presented during the visit.

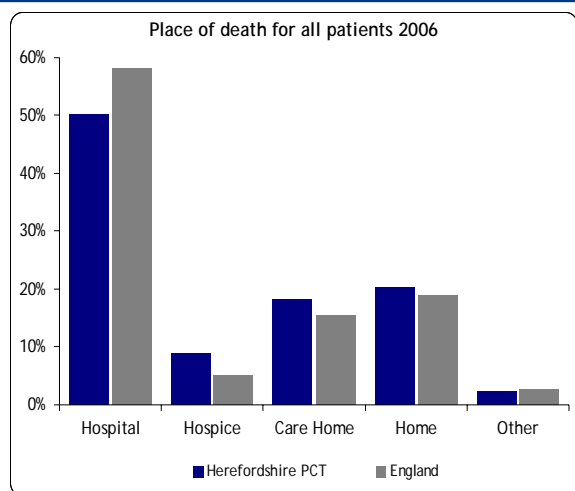
The Review Team recognises that end of life services operate in a complex and changing environment.

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 being led by Lord Darzi.

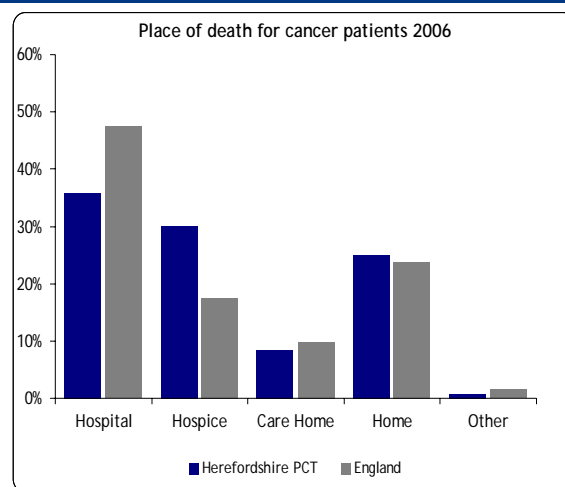
Herefordshire Facts & Figures

Place of death for all patients in Herefordshire PCT 2006



Data taken from 2006 Mortality Statistics

Place of death for cancer patients in Herefordshire PCT 2006



Data taken from 2006 Mortality Statistics

- 48% of all deaths from all conditions occurred in Home, Care Home or Hospice and 50% in Hospital which is significantly better than the national average. If all PCTs were to be ranked on this measure Herefordshire would be placed 6th out of 152.¹
- The city is just outside the 25% least deprived PCT areas in England.²
- The region has a comparatively high number of deaths per 100,000 residents, ranking 36th out of 152 nationwide.
- Herefordshire was ranked 84th 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).³ This is because although Herefordshire has a low level of deprivation it has a comparatively high level of deaths per 100,000 of the population.

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 Herefordshire, as identified during the course of our interviews.

Herefordshire's end of life care providers are dedicated to their work and committed to providing the highest quality of care possible.

9. Staff providing end of life care in Herefordshire have both energy and passion for the work they do. At every level within the end of life 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.

10. This commitment has driven the establishment of the Herefordshire Palliative Care Directorate which is a committee responsible for the planning and commissioning of palliative care within the region. The Directorate is a well established, multi-disciplinary team with representatives including those from the acute setting, Marie Curie, St Michael's hospice, PCT commissioning and provider services. The Directorate meets quarterly to discuss strategy and current issues around palliative care. The Directorate provides an invaluable forum for discussion, in particular between NHS and charitable services and has senior level buy in.

11. In 2007 the Palliative Care Directorate made a successful bid to the Strategic Health Authority for funding for a one year dedicated Palliative Care Clinical Facilitator post to coordinate the introduction of the Gold Standards Framework, Preferred Priorities of Care and the Care Pathway for the Dying (Liverpool Care Pathway) into care homes across the region.

12. There has been a long standing presence of palliative and end of life care in the community in Herefordshire. St Michael's Hospice was founded in Herefordshire in 1985 and is extremely well regarded both within the community and from staff involved in the delivery of end of life care. Interviewees spoke of the professionalism of the staff at the hospice, of their desire to share their knowledge with others, and of their commitment to ensuring people die with the utmost dignity in their preferred place of care whatever setting this may be.

There is a wide range of end of life care services available to the people of Herefordshire and services are well integrated.

13. There are a range of services for people with end of life needs:

- There are 24 GP practices within the region and GPs are highly regarded as being focused on family centred issues including end of life care. A number of GPs make use of anticipatory prescribing which mitigates against the risk of patients running out of drugs such as pain relief in their last days of life.
- 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.
- There is a 24 hour pharmacy service and out of hours doctors have an approved list of medication such as controlled pain relief which they carry.

14. Herefordshire provides a number of services to patients within the community:

- St Michael's Hospice offers a variety of services in the community which include 16 in-patient beds, a day care centre, a Macmillan Community Specialist Palliative Care Nursing team, social and bereavement support and a 24-hour advice help-line. St Michael's offers both in-patient and outpatient care to both cancer and non-cancer patients as well as physiotherapy, occupational therapy and two on-site social workers.
- Five Community hospitals within the region act as a bridge between acute and primary care and enable people in rural areas to receive palliative care in a community hospital closer to their home and loved ones, rather than be admitted to the general hospital.

15. End of life care services are also provided in the acute setting. Whilst there is no palliative care ward at the Hereford County Hospital there exists a specialist palliative care team which consists of a consultant in palliative medicine and a clinical nurse specialist. Both roles are funded by the acute trust.

- The role of the clinical nurse specialist is to provide clinical advice to medical staff in order to support all inpatients that require specific palliative care input. A large element of the role is to raise the standard of generalist doctors and nursing staff by providing

education, advice and guidance about palliative care within the acute setting.

- The role of the consultant spans both the acute and community setting. The consultant is responsible for the medical care of half of the 16 specialist palliative care beds within St Michael's hospice. Input in the hospital is largely as a tertiary consultant for patients under the care of other consultants. The Consultant also provides monthly outpatient clinics both in Hereford and Powys (There is no DGH in Powys) to support the community Macmillan nurses in the area.

A number of noteworthy cases of good practice were brought to the attention of the Review Team.

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

- (a) The District Nursing service offered to patients being cared for in the community has recently been highlighted as an example of good practice on the Department of Health Website. The new standardised service, implemented in December 2006, involves shift working between 8am and 10pm, with district nursing sisters providing an overnight on-call service. As a result those who are dying have access to qualified district nurses 24 hours a day. A review of the service after three months – including feedback from district nurses, patients and GPs showed the service to be efficient, equitable and cost-effective.
- (b) The PCT have recently funded a dedicated GP post to work specifically in nursing and residential homes within the region. This is a relatively new post and it is too early to make any assessment of the success, but it is hoped that the post will help considerably in terms of timely access to a GP, continuity of care for patients in care homes and improving the links between care homes and primary care providers.
- (c) Herefordshire PCT has appointed two well-being co-ordinators on a one year pilot scheme. The well being co-ordinators are responsible for liaising with clinicians and organising care packages for people at the end of their life. The organisation and co-ordination of care packages can be especially time consuming for people in the last days of life who may require 24 hour care. This co-ordination role was previously performed by District Nurses and social services staff as part of their overall role and the introduction of the well being co-ordinators has freed up valuable

time for both services. The well-being co-ordinator role has now been made permanent which will alleviate concerns as neither District Nurses nor Social Services felt that they had sufficient resources to take back this responsibility.

- (d) A standardised Do Not Attempt Resuscitation (DNAR) document has been introduced across the care homes and community hospitals within the borough and in the acute hospital. Having a standardised form means care staff, ambulance crews and hospital staff find it easier to recognise, are familiar with the content, and as such are prepared with how to treat DNAR patients in order to respect their wishes.
- (e) At the PCT level there is integrated commissioning between social services and healthcare and a joint commissioning board supported by stakeholder groups who provide feedback to the commissioning board including that from a clinical viewpoint.

There is good sharing of skills on end of life care.

17. The quality of end of life care delivery is highly dependent on the skills of those providing it. Poor communication between service providers can drastically affect the quality of care received by end of life patients. It was brought to the Review Team's attention that there are a number of examples highlighting good communication between stakeholders at the delivery level, and there are good examples of skill sharing and education.

- Since 1990 St Michael's hospice has offered an increasing number of courses focusing on end of life care. As well as delivering between 15 and 20 different training courses and workshops each year, the hospice undertakes outreach training in nursing homes, doctor's surgeries, community hospitals and other care giving organisations.
- The Macmillan Community Palliative Care service (based at the hospice) has just recently rolled out the Gold Standards Framework, Preferred Priorities of care and Liverpool Care Pathway to 90 per cent of nursing homes in Herefordshire; helping raise the confidence of staff involved in the delivery of end of life care within the community setting.
- There is heightened recognition of mental health issues and the difficulties this can cause in terms of equity of access for people at the end of their lives. The Psychiatric liaison team work across both the general hospital and community nursing and residential homes to run training courses to raise the profile of

mental health issues. The liaison team have close links with the palliative care team at the hospice who provide training courses to nursing and residential homes on how to deal with people with challenging behaviour/mental health problems.

- The PCT has plans to fund a post for a palliative care nurse within mental health services for older people to raise the profile of mental health needs along with palliative care needs. The job description is currently with the Trust headquarters but it is hoped that this role will be established in the near future.

Part 3: Challenges

This part of the review outlines the key challenges and limitations of End of Life Care in Herefordshire, 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.

18. The largely rural geographical area was highlighted as a major factor in determining the level of access patients had to the various care services.

19. There are a growing number of people who choose to retire in Herefordshire and as such the area has an expanding number of elderly people who are likely to require some type of care before the end of their life.

20. A combination of relatively high employment and low wages offered to care staff, and the fact that young people tend to leave the area to find work makes recruitment of quality care staff a real issue. There is therefore wide variability in the quality and expertise of residential and nursing home staff across the region. The recruitment and availability of care staff is particularly difficult in rural areas such as the Golden Valley. Not only are there few care homes in these areas, care staff can be unwilling to travel the long distances to provide home visits to patients living in rural areas.

21. Whilst Herefordshire's services are not exclusively geared towards cancer patients there are some which still have a heavy focus towards caring for this group, and there appears to be more information and advice for those suffering from cancer. This means that there is inequity of access to some services for non cancer patients.

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

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

23. 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.

24. 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. Whilst there have been some improvements recently in equipment provision, the service is not 24 hours which causes difficulties for some end of life patients requiring specialist equipment who are discharged out of office hours and often have a very short window of opportunity in which they can be transferred from hospital to enable them to die in familiar surroundings.

25. In Herefordshire, the Out of Hours GP service is provided by Primecare. Out of Hours GPs often do not have the detailed knowledge of the patients they are called to attend to and have to rely solely on patient records being kept up to date. A number of interviewees raised concerns about the lack of continuity of care for patients who require GP services out of hours and felt that there may be increased numbers of hospital admissions during out of hours. Further investigation of out of hours admissions to analyse whether they could have been avoidable would be beneficial.

26. End of Life patients often require regular medication to be administered throughout the day and during the night. There can be problems associated with out of hours prescribing given that patients may have to rely on the out of hours GP service. 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. In this way the medication can be in situ in advance of need and 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.

27. Out of hours service provision could be improved with better planning and integration of services. If decisions about when a person is classified as end of life were made earlier, then it would be possible to better plan care packages; therefore reducing the number of people who are discharged out of hours and requiring these services.

There are limited financial resources for end of life care in Herefordshire.

28. St Michael's hospice is highly regarded in Herefordshire and the hospice raises approximately £3.2m in fundraising activities from within a community of only 104,000 people. Fundraising activities account for over 85 per cent of the hospice's total funding- the remainder being received from the PCT. This level of funding from the PCT is much lower than the national average (which currently stands at 32%⁴) and raises issues

⁴ Information taken from Help the Hospices- 24 July 2007. Adult hospices. England only.

about how far the hospice should be accountable to the PCT. The limited amount of PCT funding also means that the hospice is very heavily reliant on its future fundraising activities being successful.

29. Herefordshire has seen the introduction of a number of short term pilot schemes. One example is the Integrated Cancer Care Programme; an 18 month pilot scheme which established two band 6 nurses to track the care packages of a number of cancer patients and identify barriers in terms of delivery of care. Interviewees talked about this pilot as a success story and expressed their surprise that the pilot scheme has not been given permanent funding.

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

30. A piece of work is currently being carried out looking at unscheduled admissions. The project, whilst not specifically looking at end of life patients has highlighted more general issues which impact on end of life service delivery.

- There are issues with out of hours triage (the process of prioritising patients based on the severity of their condition) and there is a tendency to divert people to the emergency services when it is not always necessary.
- There may be fewer unplanned admissions if advice was consistent regardless of whether people choose to phone Primecare, NHS direct, the ambulance service or their GP.
- The study found only small numbers of patients who had died within 72 hours of being admitted to hospital, however this measurement will mask end of life patients who survive longer than 72 hours post admission.
- Anecdotally, the ambulance service and doctors within the hospital stated that a significant proportion of their time is spent dealing with end of life patients which suggests that unscheduled admissions are a problem for end of life patients.
- The study found that there was a need to educate carers in nursing and residential homes in order that staff did not immediately ring the emergency services for end of life patients.

31. The project is due to run until November 2008 at which time the results of the study will be fed back to the project board for health and social care, as well as the palliative care directorate.

32. In the absence of sufficient information 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 well being co-ordinator service has produced by supporting people to remain in the community rather than acute care, the amount of time this has freed up for District Nursing and social services teams, 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 unnecessary acute palliative care admissions made out of hours;
- (d) the number of unnecessary acute admissions that could be avoided through expansion of community services;
- (e) any need currently not met by the city's services; and
- (f) unmet need from specific groups such as those with mental health needs or minority cultural and ethnic groups.

33. The Review Team were made aware that the well being co-ordinators had collated evidence on which areas were not referring patients to them and some limited cost information.

There are a number of valuable services offered which might benefit from expansion.

34. Interviewees highlighted several examples of good practice in service delivery which they believed could be expanded. These included:

- Community services (District nurses and Macmillan staff) were highly regarded by interviewees and many felt that more people could die at home if these services were to be expanded.
- The well being co-ordinator role is viewed as essential by many interviewees but could be expanded to include patients with long term critical illnesses rather than just those at the end of life.
- The role of the two hospice social workers is concentrated largely on bereavement services and supporting families. This role could be

extended to include the co-ordination of care packages for people moving from the hospice to their home.

Communication at Strategic level between stakeholders could be improved

35. It was brought to the Review Team's attention that there are a number of areas in which increased communication regarding end of life care would be beneficial.

36. Some interviewees expressed that whilst there was good communication between service providers at the delivery level, there were occasions when communication at the strategic level could be improved. There was a view from some interviewees that there was a need for strong evidence based commissioning and a need for the PCT to ensure that they are compliant with the guidance set out in the framework agreement for how the government and the voluntary sector should work together, 'The Compact on Relations between Government and the Voluntary and Community Sector in England' (Compact).

37. It is encouraging that end of life care is moving up the PCT agenda, and the PCT recently organised an end of life care workshop to raise the profile of end of life care. Some key stakeholders expressed concern that they were not fully consulted about the workshop.

38. Patient choice as to preferred place of care is key to the successful delivery of end of life care. A number of interviewees expressed that there needed to be increased provision of information to carers and patients as to what choices they had and what entitlements they should receive.

The PCT may wish to explore the possibility of commissioning additional services which it does not currently offer.

39. Herefordshire does not have a specialist palliative care unit in the hospital and as such patients who die in hospital do so in general wards. The hospital may wish to review whether current in patient services are sufficient for ongoing need, especially in an area with an ageing population. The PCT may also wish to consider if specialist palliative care services are equitably distributed within Herefordshire and whether there is a need to expand services to reach those in rural locations.

40. Interviewees spoke highly of the bereavement services offered to the families of patients at the hospice and expressed a need for better co-ordination of bereavement services for the families of in acute care and within the community.

Part 4: Recommendations

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

42. 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 region nor completely solve what are complex problems. Our aim is for our ideas and suggestions to generate discussion and drive change by contributing to Herefordshire PCT's

own internal work on improving care services. We hope they are valuable.

43. 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 to enable it both to better evaluate potential savings and to 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 the well being co-ordinators role, and improving access to Community Services should be examined.
2. The PCT should explore the possibility of providing access to key items of care equipment on a 24 hour, seven days per week basis.
3. The PCT should decide at the earliest opportunity whether the role of the well being co-ordinators is to be made permanent and communicate the decision to those affected, especially the district nursing teams and social services to understand what additional pressure this extra responsibility would put upon the services should responsibility be transferred back to them.
4. The PCT should investigate the possibility of opening a support and information centre to patients and carers to aid them in better understanding and accessing the care available. The PCT should ensure that information and advice is not specifically cancer focussed and provides information on the many other diseases and illnesses associated with end of life patients.
5. The PCT should continue in its' provision of education for nursing home staff in the areas of palliative and end of life care and should consider rolling this out to care homes within the area

ANNEX 1: Review Team Membership

The NAO Review team consisted of the following members:

- Tom McBride
- Kirsten Payne
- Duncan Richmond
- Colin Ross