



House of Commons
Health Committee

Palliative Care

Fourth Report of Session 2003–04

Volume I



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Report, together with formal minutes

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The Health Committee

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Footnotes

In the footnotes of this Report, references to oral evidence are indicated by 'Q' followed by the question number. Written evidence is cited by reference to Volume II of this Report, in the form 'Ev' followed by the page number.

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Summary

Currently, around 56% of people die in hospital, 20% at home, 20% in nursing or residential homes and 4% in hospices. Yet surveys suggest that the majority of people would prefer to be supported to die in their own homes. We note the recent economic analysis which Marie Curie has produced of the potential cost benefits arising from a shift towards more patients dying at home and recommend that the Department assesses this carefully. We welcome the fact that the Government is considering legislation to grant extra rights to carers and recommend that it provides for a period of paid leave for them. We recommend that the Department reviews the place of domestic support within the spectrum of social care services and ensures that people's needs for domestic help are adequately met. We were concerned to note the variation in the criteria for continuing healthcare between Strategic Health Authorities and recommend that national criteria for continuing care should be developed. Many of our witnesses drew our attention to disputes between health services and those providing personal social care for the terminally ill. Unseemly arguments about who should pay for different elements of a care package are especially abhorrent in palliative care, and we call for an integrated structure in the delivery of care. We also seek the inclusion of hospices or specialist care units in the ambit of the Community Care (Delayed Discharges etc.) Act to ensure that higher priority is not attached to other patients in dealing with delayed discharges.

We note a wide range of inequities in the current provision of services. There exists inequity by geographical area, where need and provision are not well matched; inequity by patient group, with particular problems in services dealing with patients in transition from children's to adult services, older people, patients with complex needs, and patients from black and minority ethnic communities; and most fundamentally, inequity by disease group, with cancer being by far the commonest disease for which patients receive palliative care. We call on the Government to consider what more can be done to inform Primary Care Trust commissioning of palliative care by issuing clearer guidance on preferred models of care, and to obtain better data on where services are provided and where they are needed. We hope that the forthcoming National Service Framework (NSF) for Children will acknowledge the particular difficulties of the transition from adolescent to adult services. In order to make palliative care services available to a broader range of users we believe it is important that attention is paid to the need for palliative care services in the community. To try to remove some of the 'disease bias' towards cancer we recommend that the forthcoming NSF for Long-Term Conditions should assume responsibility for palliative care in non-cancer conditions and take full account of the recent National Institute for Clinical Excellence (NICE) guidance. It should incorporate the key principles of the NICE guidance as far as possible in order to remove the distinction that is made in the palliative care of cancer patients and of those patients dying from other diseases.

There are significant challenges in raising the skills of healthcare staff, and we urge the Royal Colleges to ensure that training in palliative care becomes part of continuing professional development and to consider making such modules a requirement for revalidation. We recommend that the Department encourages local champions to develop the uptake of proven tools for addressing the needs of those receiving palliative care, which would also promote better communication between health professionals, carers and

patients. We also recommend that the Government urgently reviews the regulatory inconsistencies in palliative care services.

Turning to resources, we applaud the ambitious goal the Government has set to double the number of palliative care consultants by 2015; shortfalls in other relevant staff will also need to be addressed. We welcome the additional £50 million the Government has directed to the development of specialist palliative care services. The Treasury's cross-cutting review has set a deadline of 2006 by when statutory agencies will be obliged to meet the full costs incurred by the voluntary sector in providing public service. We hope that the fact that the state will bear more of the cost of provision can be used as an opportunity to ensure greater equity of provision.

Finally we believe that the right to a good death should be fundamental and that social attitudes contribute to problems in helping people achieve this. We hope that the Department for Education and Skills will address this area by examining the place of death education within the curriculum and within teacher training.

1 Introduction

1. As one of our witnesses observed, “we all die ... 100% mortality is an immutable fact and it is not actually a sign of failure”.¹ However, death remains the last taboo. Every year about 520,000 people die in England, around a quarter of whom access some form of palliative care. Many patients experience “severe symptoms” and “psychosocial problems” in their last months of life.²

2. Palliative care has much to offer in terms of addressing these problems, with its goal of achieving the best quality of life for the patient with advanced progressive illness, and for their families, friends and carers. Sir Nigel Crisp, Chief Executive of the NHS, has described better care of the dying as “a touchstone for success in modernising the NHS” and “one of the really big issues” which must be addressed.³

3. We announced our inquiry into palliative care on 23 January 2004 with the following terms of reference:

The Committee will inquire into the provision of hospice and palliative care by the NHS and by independent services, including the related support services of local authorities and other agencies for both adults and children. The inquiry will examine the extent to which the needs and wishes of patients of different ages are taken into account, including their care choices, ethnicity, cultural and spiritual beliefs. It will address the financing, governance, staffing, location and quality of palliative care.

In particular the Committee will examine:

- Issues of choice in the provision, location and timeliness of palliative care services, including support to people in their own homes.
- Equity in the distribution of provision, both geographical and between different age groups.
- Communication between clinicians and patients; the balance between people’s wishes and those of carers, families and friends; the extent to which service provision meets the needs of different cultures and beliefs.
- Support services, including domiciliary support and personal care.
- Quality of services and quality assurance.
- The extent to which services meet the needs of different age groups and different service users.
- Governance of charitable providers, standards of organisation, links to the NHS and specialist services.

1 Q162 (Dr Keri Thomas)

2 Ev 6

3 The Nuffield Trust for Research and Policy Studies in Health Services, Press Release 17 March 2003

- Workforce issues, including the supply and retention of staff and the quality and adequacy of training programmes.
- Financing, including the adequacy of NHS and charitable funding and their respective contributions and boundaries.
- The impact and effectiveness of Government policy including the National Service Frameworks, the Cancer Plan and NICE recommendations.

4. We took oral evidence on four occasions between 15 March and 26 May 2004, hearing from a range of charities, service providers, health professionals, patient groups, and Melanie Johnson MP, Parliamentary Under-Secretary of State, Dr Stephen Ladyman MP, Parliamentary Under-Secretary of State, and officials, Department of Health. We also received around 70 memoranda which informed our inquiry. We are most grateful to all those who submitted oral and written evidence.

5. We are also extremely grateful to our three specialist advisers: Melanie Henwood, an independent health and social care analyst; Dr Anne Naysmith, Consultant in Palliative Medicine, Kensington and Chelsea Primary Care Trust; and Chris Vellenoweth, an independent health policy adviser, for their most helpful advice and support during this inquiry.

6. We visited a specialist palliative care unit/hospice attached to a hospital in Malmö, Sweden, in the course of a visit relating to three separate inquiries we undertook in February 2004. We noted the model used there of having a hospice annexed to the hospital, and were impressed by the extent of freedom of movement between home and hospice we witnessed, with patients having a large degree of autonomy and choice. In May 2004 we visited Milestone House, Edinburgh, which offers respite care for those with HIV/AIDS, and the Marie Curie Care Hospice in Edinburgh. We met staff, patients and representatives of charities. We were extremely impressed by the quality of services we witnessed in both establishments. We also noted that staff pressures were less in the Lothian area than they were in England and that this yielded great benefits in terms of the quality of patient care. We saw that there were six palliative care consultants in the Lothian area alone, a far more favourable ratio than currently exists in England. We are extremely grateful to those who gave up their time to accommodate these visits and made them such helpful and informative occasions.

7. Palliative care is an area of the health service which places particular stress on health professionals and other carers. We have been greatly struck by the dedication, professionalism and personal commitment of many of those we have encountered working in this field, and wish to pay tribute to their efforts in this Report.

Defining palliative care

8. The most widely used definitions of palliative care are those adopted by the World Health Organisation:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable

assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁴

9. Within palliative care it is important to distinguish between *general* and *specialist* care. General palliative care is provided by the usual professional carers of the patient and family, such as GPs, district nurses, hospital doctors, ward nurses, allied health professionals and staff in care homes.⁵ Most palliative care is provided by non-specialist staff such as these.

10. Specialist palliative care is provided by multi-disciplinary teams that might include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. Such staff are specifically trained to advise on symptom control and pain relief and “to give emotional, psychosocial and spiritual support to patients, their families, friends and carers, both during the patient's illness and into bereavement”.⁶

11. In addition, supportive care constitutes an important part of patient care. This is defined by the National Council for Hospice and Specialist Palliative Care Services as:

That which helps the patient and their family to cope with cancer [and other diseases] and treatment of it—from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.⁷

12. In its recent guidance on Supportive and Palliative Care,⁸ the National Institute for Clinical Excellence (NICE) suggests that supportive care is not a distinct speciality but the responsibility of all health and social care professionals delivering care. It ranges from self-help to user involvement, spiritual and social support.

4 See www.who.int

5 Ev 8 (Department of Health)

6 Ev 8 (Department of Health)

7 Ev 273

8 Supportive and Palliative Care for Adults with Cancer, March 2004

The provision of palliative care

13. Palliative care is provided in England by NHS services, independent hospices and other voluntary services. There are currently:

- 130 voluntary hospices for adults providing 2,147 beds, offering a range of services which might include day care units, community support (sometimes extending to full hospice at home services⁹), support therapies (which may extend to support for carers and relatives) and bereavement counselling.¹⁰
- 27 children’s inpatient units providing 201 beds.
- 42 NHS palliative care units providing 490 beds supported by a range of community services.
- 264 home care services offering community support evenly divided between the NHS and voluntary sector.¹¹

2 Choice in palliative care

14. Commenting in December 2003 on the release of additional funding to support the terminally ill, Dr John Reid, the Secretary of State for Health, remarked:

People with incurable illnesses should be able to choose appropriate services that can offer them relief. They also want to make choices relating to the end of their life, such as where to die. We are working towards an NHS where every patient has a choice of when, where and how they are treated.¹²

15. At present, England is lagging behind many countries of similar socio-economic status. Preliminary data on place of death and hospital death rates for England and Wales, Germany, Netherlands, Switzerland, France and Ireland, compiled for the World Health Organization and cited in its recent report *Solid Facts: Palliative Care*, suggest that England and Wales have the highest hospital death rates of all.¹³

16. In evidence to us the Department accepted that “many more patients would choose to die at home if they could be adequately supported in the home environment”.¹⁴ Improving patient choice is a key goal of Government health policy, set out in the response to a consultation on the subject issued in December 2003, *Building on the Best: Choice, Responsiveness and Equity in the NHS*. This allocated a further £12 million to end of life programmes. It also expressed a desire “to offer all adult patients nearing the end

9 There are at present around 81 hospice at home services in England— See Ev 24 (Department of Health)

10 Ev 9 (Department of Health)

11 Ev 275 (National Council for Hospice and Specialist Palliative Care Services)

12 DoH Press Notice 26/12/03

13 World Health Organization, *The Solid Facts: Palliative Care*, ed Elizabeth Davies and Irene Higginson, 2004, p17

14 Ev 7

of life, regardless of their diagnosis, the same access to high quality palliative care so that they can choose if they wish to die at home”.¹⁵

17. Judging by the evidence submitted to our inquiry, this aspiration is a long way from being realised. For Dr Keri Thomas, a GP with specialist knowledge of palliative care, patients at present had little real choice: “Though most of the final year of life is spent at home, most patients still die in hospital, under generalists’ care, despite most wishing to die elsewhere.”¹⁶ The gap between where patients wish to die, and where they actually die, is well demonstrated in a table drawn up by Irene Higginson, Professor of Palliative Care and Policy, at Guy’s, King’s and St Thomas’ School of Medicine, King’s College London:

	Preference for place of death, %	Where people with cancer die, %	Where people die – all causes, %
Home	56	25	20
Hospice	24	17	4
Hospital	11	47	56
Nursing/Residential Home	4	12	20
Other/don’t know	5	–	–

Source: Higginson, I. (2003) *Priorities and Preferences for End of Life Care in England, Wales and Scotland*. National Council for Hospice and Specialist Palliative Care Services.

18. Marie Curie Cancer Care, who have recently conducted a survey of choice issues, concluded that there were many reasons why so many patients died in hospital rather than at home, including:

- family/carer fatigue
- lack of information and support
- ignorance on the part of health professionals
- unco-ordinated care with out-of-hours cover being a particular problem; it was also difficult to co-ordinate so many health professionals across so many boundaries
- patient ignorance of how the system worked
- patients changing their mind as their health deteriorated
- patients developing symptoms which become unmanageable at home.¹⁷

15 *Building on the Best*, para 69

16 Ev 214

17 Ev 67

19. The National Council for Hospice and Specialist Palliative Care Services additionally identified the lack of specialist support staff as a key factor underlying the inability of so many cancer patients who wish to do so to die at home.¹⁸

20. While we strongly support measures to improve patient choice and empowerment, and find it disheartening that people wishing to die at home often fail to realise that wish, we recognise that some caution is required in interpreting surveys such as that conducted by Marie Curie. Their analysis was based on a random survey of people, many of whom would have been healthy, with an unfocused view of the desirable place of death. It is not clear whether the same questions put to those suffering from life-threatening illnesses would produce similar results. A number of submissions emphasised that choice in palliative care was a complex matter, easily over-simplified. Dr Ann Morris, from North Lincolnshire Primary Care Trust (PCT), pointed to recent Macmillan research which showed that “patients and relatives were subject to changing their minds as situations changed”.¹⁹ Hospice in the Weald cautioned that “the belief that most patients can be treated at home is overstated”, noting their experience that many patients’ initial preference for dying at home changed as their situation deteriorated. Marie Curie itself cited a survey where most respondents said they would be likely to support the choice of someone they knew to die at home but “when asked to say realistically whether they feel capable of supporting a dying friend or relative, less than half say they do”.²⁰ St Christopher’s Hospice, the pioneer of the modern hospice movement, drawing on experience of almost 40 years of patient care, remarked that: “Choices [are] made throughout the patient’s journey, not only by the patient but also by their carers, families and others around them.”²¹

21. Choice in services cannot be divorced from some of the other areas of our inquiry. If the provision of services is not equitable, patients will sometimes be denied any choice at all. If communication of the available options is poor, patients and carers will not be able to exercise informed choice. Choice is also linked to issues of quality and training. Many health professionals are poorly informed of the options open to their patients. According to Sam Ahmedzai, Professor of Palliative Care Medicine, Clinical Sciences Division at the Royal Hallamshire Hospital in Sheffield, health professionals have “differing and incomplete awareness of the benefits of palliative care” and often fail to provide the early referral that can alleviate or prevent later problems.²²

22. Non-specialists in palliative care looking after patients with severely disabling or potentially terminal illnesses must appreciate the value of early referral to palliative care consultants.

23. While we sympathise with, and support, the aspiration to allow all patients to die at home if they choose, we question how realistic this objective really is at the present time. The option to die at home will only be realisable if there is a guarantee of 24-hour care and support, with back-up from appropriate specialists. In the absence of

18 Ev 280

19 Ev 231

20 Ev 259

21 Ev 254

22 Ev 180

such back-up, relatives and other carers will, understandably, be reluctant to take care of a patient at home.

24. A possible means of securing additional support has been suggested by Marie Curie Cancer Care. The charity commissioned a study from Professor David Taylor and Sarah Carter of the School of Pharmacy, University of London, to examine how people's preferences to die at home might be realised.²³ This analysis suggested that 14 days of home care, comprising seven GP visits, 28 hours of other health and social care, and 50 hours of Marie Curie nursing would cost around **£2,500**, while the last 14 days in hospital cost **£4,200**.²⁴ Marie Curie invited us to consider their analysis. We think some caution has to be exercised in interpreting these figures. There are relatively few beds in hospitals which are used exclusively for dying patients. Any increase in available beds as the result of such a move would be small on a hospital-by-hospital basis. There would be little, if any, prospect of closing beds and overheads would largely remain the same. However, we believe there may well be merit and appeal in what Marie Curie suggest, even if there is a real cost to be met. Tom Hughes-Hallett, Chief Executive of Marie Curie, frankly admitted that there would be no "direct saving" but that an investment of slightly less than £100 million to meet the annual costs of dying at home would release £200 million of resources in hospitals for other acute services.²⁵ This economic benefit was not what Marie Curie had expected when commissioning the report.²⁶

25. Department of Health officials and Ministers told us that they thought the Marie Curie analysis was indeed worthy of further study. The National Cancer Director, Mike Richards, made reference to this research and suggested that work was needed to see whether the amount of money that could be saved by transferring patients into the community might mean that no additional funding was required.²⁷ Melanie Johnson, the minister with direct responsibility for palliative care as part of her remit for cancer, similarly described the Marie Curie analysis as "very interesting and powerful".²⁸ Dr Stephen Ladyman, our other ministerial witness speaking in respect of his responsibilities for children and older people, went so far as to suggest that there were potentially "massive savings to be made by our being more proactive about, first of all, stopping people getting into hospital in the first place and also delivering far more care at home—both healthcare and social care", and that such a shift would be a "major theme in the vision for adult social care".²⁹

26. We recommend that the Department of Health should consider the recent economic analysis produced by Marie Curie Cancer Care of the potential cost benefits arising from a shift towards more patients dying in their homes. If indeed there are "massive savings" to be made from such a shift, as one health Minister predicted, we hope that urgent measures will be taken to develop this strategy.

23 *Valuing Choice—Dying at Home: A case for the more equitable provision of high quality support for people who wish to die at home*, 2004

24 Q95-96

25 Qq95-96, 101

26 Q95

27 Q37

28 Q283

29 Q285

Support services including domiciliary support and personal care

27. In the delivery of palliative care in the home, a crucial burden falls on support services, whether from the statutory sector, the voluntary realm or from friends and relatives.

28. The Health Service Commissioner for England described how carers sometimes felt disempowered by being denied the opportunity of caring for their loved ones at home. Carers were subject to enormous burdens, however, and needed considerable support if they were to be able to help care for patients at home.³⁰ As the Royal College of General Practitioners put it, “being an informal carer is a full time job, 24 hours a day, and often without a break”.³¹ The representative organisation of the hospice movement, Help the Hospices, suggested that there were difficulties in securing continuing care funding, with some Strategic Health Authorities (SHAs) applying rigid criteria for life expectancy, such as the patient having fewer than eight weeks to live, as a condition of funding such care.

29. The Association of Hospice and Specialist Palliative Care Social Workers pointed to serious shortfalls in out-of-hours cover. Night care was seldom available except for Marie Curie Nurses who were provided on a strictly time-limited basis. Day care support was normally provided by agencies and not specialist staff: some patients had different carers every day. Some local authorities would not provide help with cleaning and housework.

30. Several submissions pointed to the model of palliative care being created through legislation in Canada. Under the new Canadian National Strategy, family members are entitled to take six weeks compassionate leave during which their job and income are protected; and patients have access to a ‘virtual hospice’ online, which includes a chat room, an online nurse practitioner and online consultants. Describing the Canadian model, Christine Shaw for Help the Hospices emphasised its flexibility. The six weeks paid leave, for example, could be shared between a range of relatives or friends.³² Tom Hughes-Hallett for Marie Curie pointed to the inequities of the current system within England for supporting carers, noting that one of his organisation’s own staff had had to report himself off on long-term sick leave to “support his mother in death”, a situation Mr Hughes-Hallett described as “a scandal”.³³

31. In articulating why it was difficult for patients to achieve their wishes in dying at home, Dr Ladyman argued that the role of the family in providing care for elderly and frail members of society was diminishing, such that “it seems that we no longer want to care for each other *in extremis*”.³⁴ While we acknowledge that the extended family living within the same household is generally less prevalent now than it was fifty years ago, there are nonetheless still almost six million carers in Britain. Even now, one in six households contains a carer, and one in eight adults (13%) is a carer. Some 1.7 million people are heavily involved in care, giving at least 20 hours of care per week.³⁵ There are,

30 Ev 179

31 Ev 193

32 Q103

33 Q102

34 Q280

35 Q109

of course, significant challenges to the caring role of the family, such as the geographical dispersal of family members; the greater mobility of modern households that reduces the likelihood of people living in close proximity to relatives; and the complexity of relationships in partnerships, through the breakdown of marriages and remarriages.

32. We questioned ministers on whether they would contemplate introducing into England some of the measures being taken in Canada. We specifically asked Melanie Johnson whether she would examine the Canadian policy of six weeks paid leave for carers. She told us that this was not under consideration at the present time.³⁶ However, Dr Ladyman explained that the Department was about to engage in a series of consultations with employers and carers' groups, with a view to the possibility that the Government "may wish ... to legislate on extra rights for carers in the workplace".³⁷ Dr Ladyman noted that many of the biggest companies, such as BT or British Gas, were "very focused on the need to involve carers in their workforce" so as to allow them to achieve the balance between the roles of carer and worker.³⁸

33. We welcome the suggestion from Dr Ladyman that the Government, following consultation, is considering legislation relating to extra rights for carers in the workplace. The Canadian model of care is itself only at an early stage of development but it seems to offer an imaginative and sensible solution. We recommend that the Department seeks feedback from the Canadian authorities on their experiences of additional support to carers to establish the impact the scheme is having on choice in place of death, the quality of care and on the ensuing costs.

34. We recommend that the Government legislates to provide for a period of paid leave for carers, taking account of the flexibilities provided by the Canadian model. We believe that such a step would empower many more people to achieve their wish to die at home. We also believe that at least some of the cost to public funds of such a measure would be offset by savings accruing from reduced hospital care.

35. We strongly encourage the Department to support Marie Curie in its efforts to develop pilot schemes, in conjunction with a range of partners, to explore the best ways of supporting carers when someone is dying at home.

Personal care

36. A familiar theme of Health Committee inquiries has been problems arising from the demarcation between health and personal social care. In a report of the predecessor Committee in 1998 it was noted that barriers between the two services "frustrate the goal of seamless service provision and often appear confusing to the users of services".³⁹

37. The Association of Hospice and Specialist Palliative Care Social Workers noted that the boundaries between health and social care in palliative care were often "blurred" and

36 Q290

37 Q292

38 Q300

39 Health Committee, First Report of Session 1998-99, *The Relationship between Health and Social Services*, HC74, para 1

“contested”.⁴⁰ The Association of Directors of Social Services gave the example of those with progressive neurological conditions who were not entitled to NHS continuing care and instead had to undertake means-testing to qualify for social services care.⁴¹

38. A number of witnesses commented on problems caused by the health/social services divide. This was well articulated by Tom Hughes-Hallett for Marie Curie:

We would like to see much closer working between Social Services and Health Services. We do think there is a gap between those two at the moment and we are hopeful that the Select Committee will recommend that work is done in this area to bring these services closer together ... However good the quality and support provided by Marie Curie, Macmillan, Help the Hospices and others, if at the end of the day the patient is in the home being looked after healthwise but the food is rotting in the fridge and the cigarette ash is piling up on the carpet, they will go into hospital.⁴²

39. Dr John Wiles, for the Association of Palliative Medicine noted the particular problem with delays in assessment, where the “process of supporting” patients wishing to die at home was often the weakest link. Suzy Croft of the Association of Hospice and Specialist Palliative Care Social Workers explained that, in the very limited number of cases where a housing transfer was needed, it was “almost impossible” for this to be arranged in time, and that sometimes people “get an offer after they die”.⁴³ In its written evidence the Association noted that some patients were offered different carers every day and that some carers would not provide help with cleaning and other housework.⁴⁴

40. Dame Gill Oliver for Macmillan, suggested that things needed to go further than just having people sitting round a table together. In her view what was required was “a single point of entry”:

Somebody affected by cancer, someone requiring palliative care does not need to think ‘Do I have to go to a health person or to a social care person?’. They go to their contact and the rest will happen. It is going through one door, and that is the ideal that we will be working towards.

41. Dr Michael Cushen, medical director of an independent hospice, noted “a serious crisis in the provision of social care”, with patients in homes and hospices “waiting for unacceptable periods both for Social Services assessments and for a placement of carers within their homes”.⁴⁵ Tricia Holmes for the Motor Neurone Disease Association described how her organisation had funded co-ordinators, employed by the NHS, to take on some of the duties of a specialist nurse in order to try to overcome the “chasm”

40 Ev 111

41 Ev 287

42 Q97

43 Q168

44 Ev 110

45 Ev 309

between health and social care. She, too, thought there should be “a single point of contact”.⁴⁶

42. Most of the witnesses we questioned were firm in their support for much greater integration of health and social services. While Professor Mike Richards, the National Cancer Director, favoured pooled budgets, others went further. Sue Hawkett, Team Leader for Supportive and Palliative Care at the Department of Health, described the current situation as “not always very helpful at all” and called for a system that was “totally integrated”.⁴⁷ Christine Shaw for Help the Hospices agreed that integrating health and social care commissioning would be “a very valuable way forward”⁴⁸ and Tricia Holmes felt that such a step would “make a lot of difference”.⁴⁹ Phillip Hurst from Age Concern cautioned that such a fundamental structural reform would be very “distracting” but agreed that abolishing means-testing for personal social care would be a very positive measure.⁵⁰

43. The health and social care needs of people receiving palliative care are often complex and closely interwoven. However, we are struck by the absence of social care partners from many local cancer and palliative care networks. Moreover, there are still too many accounts of people trying to find their way through the health and social care maze and finding a chasm opening up between the two services.

44. When people wish to spend their final days at home, there are particular challenges to health and social care services, and it is vital that they are properly integrated. We are concerned that the emphasis on personal care within social services has been to the detriment of equally important domestic support. We do not believe that it is acceptable for people who choose to die at home to find that they are doing so in increasingly squalid surroundings. Indeed, it is likely that it is poor domestic conditions that often precipitate admission to hospital for people who should be supported so as to be able to remain in their own homes. We recommend that the Department of Health should review the place of domestic support within the overall spectrum of social care services, and ensure that people’s needs for domestic help are adequately addressed. We also recommend that particular attention is given to providing aids and adaptations to allow people to stay in their own homes.

45. One area in which the boundary between health and social care is especially blurred and contested is that of continuing care. We are aware that the Department has required the 28 SHAs to review and develop eligibility criteria for NHS continuing healthcare that will operate on an SHA-wide basis incorporating all their constituent PCTs. In addition, following a report from the Health Service Commissioner in 2003, SHAs and their partners have also been required to review whether the application of earlier criteria has resulted in patients being wrongly denied continuing care, and where this is the case, to make appropriate recompense. This work should have been completed by 31 March 2004. The Minister told us that the results of the reviews were still being examined, and

46 Q229

47 Q89

48 Q138

49 Q240

50 Q245

that work was taking place to compare the criteria developed by the SHAs and to see whether they were diverging in their approach to palliative care. However, Dr Ladyman observed that “they ought not to be diverging too greatly”.⁵¹ He assured us that the results of the reviews would be published as quickly as possible.⁵²

46. We note that the 2001 guidance on continuing health care made it clear that patients who require palliative care, and whose prognosis is that they are likely to die in the near future, qualify for NHS continuing care. The Department has emphasised that eligibility should be based on need, and not on an anticipated time to death (which is notoriously hard to predict). Other witnesses, however, painted a worrying picture, and drew attention to the different time limits employed across SHAs in their specification of eligibility for continuing care on palliative care grounds. As Christine Shaw for Help the Hospices commented, while national guidance says that time limits should not be applied:

in practice it does still seem to happen. This process cannot be activated unless you are within the last six weeks of life or eight weeks or 11 weeks, or whatever it might be ... therefore, that is a barrier to some effective discharges.⁵³

47. We are concerned that there is still considerable variation in the criteria for continuing healthcare between SHAs, and that people who meet the criteria in one SHA for continuing healthcare because of their palliative care needs, fail to satisfy the criteria in another authority. This is unfair, and is incompatible with the principle of a national health service. We look forward to the publication by the Department of the reviews of eligibility criteria and any associated guidance. We are convinced that the only way to ensure that there is equity in access to NHS continuing care is to introduce national eligibility criteria. We recommend that the Department develop national criteria for continuing care, including criteria for palliative care, to remove the inequitable anomalies that arise between criteria operated by different SHAs. Guidance and support will also be needed to ensure that a single national set of criteria is consistently interpreted and applied.

48. Witnesses supported the case for closer integration of health and social care, not only at the level of local commissioning, but also in terms of national structures and removing the distinction between ‘free’ NHS services and means-tested social care. We explored this issue with the Minister, who told us that the question of “seamless services” would be a key theme in his forthcoming “new vision for adult social care”.⁵⁴ We welcome this renewed focus. However, Dr Ladyman also indicated that he was dubious about the importance of structural change in bringing about seamless care.

49. We look forward to the publication of the Department’s vision for adult social care, and hope that it will provide the basis for some wide-ranging and innovative developments and the promotion of new models of care. We wish to underline the importance of removing the distortions created by the boundary between the parallel

51 Q358

52 Q371

53 Q137

54 Q352

health and social care systems. While we recognise that structure is not everything (and that partnerships and joint working are of great importance, as the Health Committee has made clear in previous reports), we are convinced that an integrated structure is a necessary pre-condition for tackling the anomalies that arise in trying to distinguish between health and social care needs. These issues, and the associated disputes, are especially abhorrent in respect of palliative care, where unseemly arguments about who should pay for different elements of a care package can lead to inexcusable delays and poor practice that is anything but patient-centred.

Delayed discharges

50. A previous Health Committee inquiry into *Delayed Discharges* opposed the principles behind the reimbursement proposals relating to delayed discharges (as they were at the time), and highlighted the potential for “buck passing and mutual blame between health and social care”.⁵⁵ However, the Community Care (Delayed Discharges etc.) Act received Royal Assent on 8 April 2003, and the reimbursement arrangements were introduced in shadow form from 1 October 2003, becoming fully operational on 5 January 2004. The legislation applies, in the first instance, only to patients in acute hospital beds. Various witnesses drew our attention to the knock-on effects of this discrepancy for hospice patients. The National Care Standards Commission gave a case study as an example of the sort of problems this could create:

An individual was admitted to a hospice for pain and symptom management. Their explicit wish was that they remain in the hospice for as short a time as was necessary to address their symptoms. Their express wish was that they would then return home following this treatment. The individual’s symptoms were controlled within five to six days. There was a delay in the care planning meeting, which only took place 17 days following admission, due to the problems with the availability of participants. At this stage it was identified that a special bed would be required—this took a further six days. After this, the hospice were advised that carers (provided by the local authority) would not be available for a further nine days. The individual died eight days later—one day before the planned discharge home.⁵⁶

51. Christine Shaw, for Help the Hospices, remarked:

There is the fear and the worry that that means for hospice patients, for whom time is definitely not on their side and who want to go home and be cared for at home and die at home, that has to be arranged in very short order quite often ... as long as hospice patients are excluded from that piece of legislation, that discrepancy will continue and the possibility of hospice patients being disadvantaged in the discharge process will continue.⁵⁷

52. The Department acknowledged that patients receiving palliative care in hospices or specialist palliative care units are excluded from the definition of acute care within the

55 Health Committee, Third Report of Session 2001–2, *Delayed Discharges*, HC 617

56 Ev 251

57 Q137

Act, but stressed that their discharge should still be in accordance with good practice it disseminated in January 2003.⁵⁸

53. There is a danger that where the reimbursement system relating to delayed discharges is applied selectively there may be damaging and unintended consequences emerging elsewhere in the system. There are real risks that this will lead to different classes of patients—those for whom discharge planning is prioritised because of the financial penalties that might otherwise be incurred by social services, and those for whom timely discharge becomes a lower priority, even where objectively timeliness is of the essence. We understand that Help the Hospices is undertaking a survey of the scale of the problems this is causing in the hospice sector. We urge the Government to examine these findings as a matter of urgency and to consider whether the delayed discharges legislation is having deleterious effects on the care and well-being of patients in hospices, for whom any delay in discharge arrangements can be catastrophic, meaning the difference between someone ending their days in the place of their choice, or having that wish denied.

3 Equity in palliative care

54. A key area of our inquiry, referred to in almost all the submissions we received and frankly acknowledged as a major concern by the Department,⁵⁹ is the lack of equity in the provision of palliative care. Health inequalities are compounded in that services are disproportionately *needed* in areas of social deprivation and disproportionately *present* in areas of social affluence; services deal predominantly with cancer patients and seem not to be geared to the palliative needs of other disease groups; services are underused by those in black and minority ethnic communities; services favour some age groups over others; and they seem hard to access by those with complex needs.

Inequity by geographical area

55. The National Council for Hospice and Specialist Palliative Care Services acknowledged that the Cancer Networks were beginning to undertake network-wide assessments of needs. Preliminary findings already indicated the inequity of distribution: “the Network with the highest estimated need has one of the lowest ratios of beds to population ... two of the Networks with the least need have two of the highest ratios of beds to population”.⁶⁰ A lack of evenness of distribution is not confined to adult services. Lizzie Chambers, for the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT), suggested that there was a concern that children’s hospices “are not being strategically planned”.⁶¹

56. The local initiative to establish or support a hospice is often the outcome of individual charitable initiatives and this results in an inverse relationship of provision to need. Once

58 Ev 30

59 Ev 5

60 Ev 278

61 Q219

palliative care was recognised as an important component of healthcare resulting, for example, in a WHO definition at a global level and a Department of Health policy position at a national level with the publication of the NHS Cancer Plan, the issue of achieving equity of access became more prominent. Much of our evidence suggests that there is need for more equitable distribution of both hospices and of care at home through an assessment of the needs of the population, greater planning of services and the introduction of detailed contracting arrangements.

57. Tom Hughes-Hallett for Marie Curie described the “extraordinary inequities” that exist in service provision. He cited the example of Yorkshire, telling us that Marie Curie was asked to provide 20,500 nursing hours to North Yorkshire, which has a population of 886,000, but only 11,000 nursing hours to West Yorkshire, which has a population of 2.3 million.⁶² To support the argument that there is a severe mis-match between service provision and need, Peter Tebbit for the National Council for Hospice and Specialist Palliative Care Services told us that his organisation had developed a methodology to undertake comprehensive, population-based needs assessments. Using this Comparative Index of Need, the Northern Cancer Network, comprising Newcastle and Northumbria, was found to have a need for palliative care 30% above the average but to have only half the average number of beds; Surrey had a need 20% below the average but had one of the highest complements of beds to population in the country.⁶³

58. According to evidence submitted by the Cicely Saunders Foundation:

There are great geographical variations in the percentage of cancer deaths occurring at home with variations between some electoral wards of between 11 and 70% of cancer deaths occurring at home. Only 30% of this variation can be explained by demographic and social factors, such as age and deprivation.⁶⁴

59. The geographical inequities that have developed in the provision of palliative care in general, and hospice provision in particular, are a direct result of the charitable history of this sector. The development by happenstance that has characterised the availability of facilities is increasingly recognised as unacceptable. The Department acknowledged to us in its memorandum that “the government recognises that provision of palliative care services has not been equitable” and “is firmly committed to tackling inequalities in palliative care provision”. We welcome this position but we remain concerned about the laissez-faire approach to achieving this objective, and do not altogether share the confidence of Christine Shaw, for Help the Hospices, that “the historic pattern is not the pattern we will see in the future”.⁶⁵ The risk is that the historic pattern will become entrenched. However, we agree with Ms Shaw that a national strategy is required to address needs and funding together. The fact that there are within the NHS some 42 palliative care units, whilst the majority of hospices are in the voluntary sector, indicates a basis for a further study as to the relationship between the NHS and the voluntary sector in relation to the provision of palliative care.

62 Q107

63 Q110

64 Ev 311

65 Q115

60. The Minister for Public Health, Melanie Johnson, implied it would be a mistake to focus too narrowly on hospice provision in assessing the equity of distribution of specialist palliative care. She told us that it was preferable “to accept that we already have a diverse pattern of provision in palliative care, and that diversity and richness is likely to continue—the exact configurations varying from area to area”.⁶⁶ She suggested that the funding formula for PCTs already recognised the needs of a local population in health terms and that the historic “imbalances” that had emerged would “be addressed fairly rapidly by the future arrangements”.⁶⁷ She also maintained that the move to PCT commissioning of services would help ensure that “provision meets the need”.⁶⁸

61. We recommend that the Department analyses the Comparative Index of Need drawn up by the National Council for Hospice and Specialist Palliative Care Services to assess whether a better match between need and provision can be agreed.

62. We accept that palliative care goes well beyond hospice provision; however, the role of a hospice within the spectrum of provision is an important one. We are uncertain how the Government plans to ensure greater equity in service provision in the context of devolved responsibilities to PCTs, and without clear guidance on the preferred models of care. An acceptance of the current diversity of provision could also entail tolerance of continued inequity. We urge the Department to consider what more can be done to inform PCT commissioning of palliative care services by the issuing of clearer guidance on preferred models of care. We deal below with the possible impact on equity of provision of additional Treasury funding for hospices.

Inequity by patient group

Inequity by age group

63. Palliative care services for children, adolescents and young people raise a number of distinctive issues. Children with terminal conditions (such as cystic fibrosis) are surviving for much longer than was the case in the past, with a corresponding shift in emphasis in services. Care can be needed over a period of many years, involving different combinations of general care, respite care, palliative care and terminal care. Increasingly, the focus is on quality of life and enabling the young person to participate in education and social activities, to maintain as normal a life as possible “and to be young people first and foremost”.⁶⁹ In fact, the hospice is only one element of a child’s care, and we were told that it is often in school that a child or young person will receive the majority of their healthcare.

64. Thankfully, the number of children diagnosed with a life-limiting illness is relatively small. According to Professor Stuart Tanner, Adviser on Paediatrics and Child Health to the Department, approximately one in a thousand children have such an illness and

66 Q321

67 Q305

68 Q315

69 Q91 (Jane Scott, Team Leader Children’s Health Services, Department of Health)

around 10% of these die each year.⁷⁰ These children typically have a different pattern of illness from adults with terminal conditions. Children with life-limiting conditions are less likely to have cancer, and more likely to have congenital heart disease, neurological or developmental conditions.

65. Evidence from Dr Lynda Brook, one of only three consultants in paediatric palliative care in England and Wales, suggested that an important difference between children's and adult palliative care was that children and their families prefer to be supported as much as possible by those professionals known to them and who have cared for them from the point of diagnosis, through the child's illness to end of life care. There are no dedicated NHS inpatient beds for children's palliative care and it was suggested by Dr Brooke that end of life care in hospital for children is often of a poor standard. Given the comparative rarity of death in childhood, she considered that there was a specific need for palliative care expertise to support other healthcare professionals involved with the care of children with life-limiting conditions.

66. Provision of palliative care for children is closely bound up with support for carers. Lizzie Chambers, for ACT, told us that parents were usually the "chief carer" for children.⁷¹ But although the majority of families would want to care for their child in the home it was important for there to be a proper range of options. For example, the presence of a children's hospice might offer the prospect of respite care, offering a break both for the family and for the child with friends in a hospice. Thus, in her view, hospices were an "essential" component of palliative care for children.⁷² We asked her if the current provision of 34 operational children's hospices, with another eight planned, was an appropriate response to demand. She told us of her concern that these were not necessarily being "strategically planned", yielding the same sort of inequities discussed above.

67. ACT drew particular attention to a gap in services for adolescents and young adults bridging children's and adults' services, noting that the transition between the two was often "badly managed".⁷³ Currently children's hospices are not able to treat anyone aged over 18, leading to problems of continuity. The Association of Children's Hospices, the national umbrella organisation working on behalf of all UK children's hospice services, described the availability of services for young people aged 13–24 years as "very patchy". They noted that the requirements of the Care Standards Act 2000, and their local interpretation, was "restricting the ability of children's hospices to accept referrals of young people aged 16 and over".⁷⁴

68. A possible catalyst for improvement in children's palliative care services lies in the forthcoming National Service Framework for Children, which Dr Ladyman told us would have a chapter on this subject. He felt that this document would assist PCTs in their strategic planning to work towards the appropriate range and level of provision.

70 Q4; around 4,500 children aged under 16 years die in England each year (National Statistics, *Mortality Statistics*, 2001)

71 Q218; see also Ev 264 (Association of Children's Hospices)

72 Q220

73 Ev 129

74 Ev 264

69. We hope that the forthcoming National Service Framework for Children will acknowledge the particular difficulties of the transition from adolescent to adult services. We also believe that boosting the role of carer and giving proper support in care are vital components of palliative care for children.

70. Age Concern described problems at the other end of the age spectrum, with some older people being less likely to receive specialist services. This they attributed to some providers placing more emphasis on younger cancer sufferers than on older ones; to the beliefs and attitudes of some health professionals to older people and death; and to the expectations of some older people themselves.⁷⁵ Philip Hurst, Health Policy Officer for Age Concern, suggested that typically the referral route to specialist palliative care was through specialist cancer services, which older cancer sufferers tended to access less than younger ones. Moreover, the disease bias towards cancer in palliative care, which we discuss below, discriminated against the increasingly prevalent age-related conditions such as respiratory failure. In Mr Hurst's view, the key need was to shift attitudes. He felt it was particularly important to ensure that health professionals' training, education and development confronted these issues.⁷⁶

Inequity by ethnicity

71. Patient discrimination is not restricted to age. A number of studies have suggested lower utilisation of palliative care services by black and minority ethnic users. A 1999 analysis in Derby found that only 1.5% of patients referred to palliative care were from black and minority ethnic communities, even though these groups formed 9.7% of the city's population. Help the Hospices similarly noted that only 3.9% of the adult hospice population was non-white, while black and minority ethnic groups formed 8.7% of the total population. However, it needed to be borne in mind that such groups formed only 2.6% of the population aged over 65 years.⁷⁷ Gurch Randhawa and Alastair Owens, who have carried out research into this issue, suggested a number of factors underlying the under-representation of black and minority ethnic communities in palliative care:

- certain types of cancer are less prevalent in these populations, though evidence here is lacking
- services are culturally insensitive
- there is a perception that palliative care services are available only for white middle class patients
- there is a lack of information provided to minority ethnic groups, and a lack of translation facilities.⁷⁸

72. Another issue raised in evidence is the fact that the hospice movement grew out of a Christian, charitable movement which is not always receptive—or at least is not

75 Ev 142; Q243

76 Q244

77 Ev 80

78 Ev 133

perceived to be receptive—to other faiths and cultures. Rashid Gatrad, in an article in the *British Medical Journal*, illustrated some of the cultural barriers in this area:

No effective national provisions are in place for training of healthcare professionals in transcultural medicine, and few professionals will therefore have had any real opportunity to learn about death rites in different cultures. Why is it that a middle-aged Muslim daughter insists on maintaining a day and night hospital vigil of her dying mother? Or why is it that Hindu parents wish their terminally ill child to die as close to the floor as possible? The importance of these and other rites of passage needs to be understood by caregivers.⁷⁹

73. Dr Wiles, for the Association of Palliative Medicine, suggested that the problem lay not so much in the attitudes of hospices themselves but in the way they were perceived:

Having worked in St Joseph's, St Catharine's and St Christopher's, there are connotations with religion and hospice work. To be fair I do not think it has impacted on what the patients received. I worked in St Joseph's, which is a highly Catholic founded organisation, and I think the patients were offered the same [treatment] regardless of their faith, but I am sure that their perception is that it is different and you have to comply or conform, and we have not reached out to the non-religious, the atheists or other religions ... you only have to look in the hospice directory at the names of saints ...⁸⁰

74. Tom Hughes-Hallett for Marie Curie Cancer Care was, however, anxious to dispel the idea that hospices were merely “a collection of bodies full of very well-meaning and excellent nuns”.⁸¹ None of their hospices was named after a saint, and their newest was in Bradford. The family room in that hospice, normally used by a few friends and relatives, had recently accommodated 250 people who came to grieve for an Asian woman who had died.

75. The Department is currently funding a study in Warwickshire to address how inequalities relating to ethnicity in palliative care services can be addressed.⁸² Melanie Johnson also told us that the Department was issuing grants to organisations such as the Policy Research Institute, Cancer Equality and Cancer Black Care to look at ways of overcoming some of the social barriers in place.⁸³ While there were some very good examples of specialist palliative care in respect of black and minority ethnic users, the difficulty was in mainstreaming best practice.⁸⁴

76. We received evidence from the New Opportunities Fund (which distributes money from the National Lottery to those at the greatest disadvantage in society) that demonstrated that its Community Fund has given substantial awards of money to a

79 “Palliative care needs of minorities: understanding their needs is key”, *British Medical Journal*, 26 July 2003, vol 327 pp 176–77

80 Q117

81 Q118

82 See www.dh.gov.uk

83 Q304

84 Q304

number of projects concerned with palliative care, especially hospices.⁸⁵ Both the adult and the child programmes have been aimed at disadvantaged regions and groups with particular regard to black and minority ethnic communities' access to cancer services and children's access to palliative care services. We were pleased to learn that some programmes have led to new ways of working, innovative approaches and the delivery of services to marginalised groups.

Patients with complex needs

77. A final group suffering discrimination is patients with complex needs. The Association of Hospice and Specialist Palliative Care Social Workers observed that its members had raised the issue of the lack of attention to the needs of people with learning difficulties in palliative care. This point was supported by the National Network for the Palliative Care of People with Learning Disabilities, which noted that "those with more substantial disabilities tend to have characteristics that make them less likely to have awareness of and secure access to palliative care services when they need them".⁸⁶ Such individuals were more likely to have more limited social networks, to have greater communication deficits and to be living with aged parents.

78. We welcome the fact that the Department recognises the problems of inequitable provision of palliative care services relating to age, ethnicity and complex needs. We also welcome the research they have commissioned in this area to improve services and to bring into the mainstream the good practice that exists patchily. We believe it is important that work on improving the accessibility of palliative care services does not focus solely on that provided within hospice buildings. It is at least as important that community palliative care services are available (and acceptable) to members of black and minority ethnic communities, to older people and to those with complex needs. These may well be provided by hospices, as is already often the case. The need to ensure that all services are culturally sensitive should form an important dimension of the training of both generalist and specialist palliative care staff.

Inequity by disease

79. The lack of palliative care for non-cancer sufferers constituted a major and recurrent theme of our evidence. The Department itself admitted that this was the greatest inequity of all in palliative services. Over 95% of those in hospices have cancer. Cancer dominates the structure through which palliative care is mapped and distributed. Cancer underlies the NICE guidelines that will apply to palliative care. One submission even noted that palliative care was not separately indexed in the Department of Health website but appeared as a sub-heading under "cancer".⁸⁷ Yet cancer is actually the cause of death in about a quarter of the population.

80. Help the Hospices noted one estimate that suggested that "there may be as many as 300,000 people dying from progressive diseases other than cancer each year who need

85 Ev 208–10

86 Ev 258

87 Ev 194 (Cotswold Care Hospice)

palliative care”.⁸⁸ Professor Irene Higginson has estimated that as few as 1% of those who might benefit from some palliative care have access to specialist palliative care services.⁸⁹

81. A number of other charities speaking on behalf of ‘under-represented’ diseases criticised the inequity of provision. The British Lung Foundation described the “bias” towards cancer patients compared with long-term chronic conditions such as chronic obstructive pulmonary disease.⁹⁰ The Motor Neurone Disease Association suggested that many hospices gave preferential access to those suffering from cancer, with some imposing a limit of one motor neurone disease (MND) patient at any one time. They noted that, while MND was a devastating disease, with a typical trajectory such that half of all patients died within 14 months of diagnosis, many hospices would only provide respite care, or care in the later, terminal stage of the disease.⁹¹ The Alzheimer’s Society argued that most forms of dementia were terminal conditions but that few patients with dementia accessed palliative care. The problem was partly the uncertain trajectory of the disease. One estimate suggested that the end of life stage could last two to three years, this in a disease which could last in all 10 to 20 years. The Society suggested that this, together with ageism and stigma, underlay the lack of palliative care facilities for patients. An additional concern was that pain was not well palliated for those with dementia.⁹²

82. Dr Keri Thomas pointed out that some hospital palliative care teams had up to 30% non-cancer referrals but that fewer than 10% of hospice beds were devoted to non-cancer patients. This she ascribed to:

- limited capacity
- different expectations from patients and carers
- different trajectories of diseases other than cancer
- a lack of appropriate expertise in specialist units.

83. Dr Thomas noted that in America around 15–20% of hospice inpatients had heart failure, whereas in England around 98% of patients had cancer. She felt that the Government’s strategy towards end of life care was too disease-focused, dependent on “specific NSFs, where these exist” and failed to acknowledge the potential of the voluntary sector to contribute more effectively. Help the Hospices agreed that there was a risk that a disease-specific approach, as advanced by NICE, was likely to lead to fragmented care.

84. Professor Mike Richards for the Department suggested that “one of the key differences” was the likely course of non-cancer diseases compared to cancer. While cancer patients were usually relatively well for a long time and only required special care for a short period, for other patients there could be a slow, and far from steady, decline.⁹³

88 Ev 75

89 Cited in the memorandum from The National Council for Hospices and Specialist Palliative Care Services, Ev 277

90 Ev 188

91 Ev 135–36

92 Ev 200

93 Q35

He suggested that one way in which this problem could be addressed would be by ‘skilling up’ those providing general palliative care, for example by encouraging specialists in palliative care to work more alongside generalists from other disciplines. Such a process would have the additional benefit of educating palliative specialists in other disciplines, given that they normally had a background in cancer medicine. Professor Richards told us that many patients who are dying from heart failure, chronic lung disease and other conditions have many symptoms which “are broadly quite similar to those experienced by cancer patients”. This suggests that the key skills developed in specialist cancer services are transferable to other diagnostic groups.

85. The Department itself cited research to suggest some of the contiguities between other life threatening conditions and cancer, highlighted in research from Professor Irene Higginson.⁹⁴

Prevalence of problems (per 1,000,000 population)

Symptom	% with symptom in last year of life	
	Cancer patients	Progressive non-malignant disease
Pain	84	67
Trouble with breathing	47	49
Vomiting or nausea	51	27
Sleeplessness	51	36
Mental confusion	33	38
Depression	38	36
Loss of appetite	71	38
Constipation	47	32
Bedsore	28	14
Loss of bladder control	37	33
Loss of bowel control	25	22
Unpleasant smell	19	13

I. Higginson. Palliative and Terminal Care in Health Care Needs Assessment (1997) Ed A Stevens and J Raftery. Radcliffe Medical Press.

86. Some of our witnesses were sceptical about the impact of the recent NICE guidance. While the clear exposition of the core services that should be provided in palliative care for adults with cancer was welcomed, some questioned the way in which such guidance was interpreted locally. Moreover, because the guidance does *not* address the needs of patients with a non-cancer diagnosis, witnesses emphasised the need both to ‘translate’ the messages of the guidance for other patient groups, but also to match this with central funding as has been the case with stimulating the development of cancer services.

87. A separate but related issue is the extent to which long-term chronic conditions, which cannot be cured but are not immediately life-threatening, should be included in mainstream palliative care. The Stroke Association, for example, noted that little palliative care was given to non-cancer patients. Yet stroke patients might benefit from expert treatment in pain relief which was a feature of good palliation.⁹⁵ Professor Richards told us that the Department was “definitely” thinking about the application of

94 Study based on random sample of deaths and using the reports of bereaved carers (Cartwright A, “Changes in life and care in the year before death 1969–1987”, *Journal of Public Health Medicine* 1991; 13 (2): 81–7 and Seale C, “A comparison of hospice and conventional care”, *Soc Sci Med* 1991; 32(2): 147–52). The study looked at 2,805 patients who died from cancer and 6,864 patients who died from progressive non-malignant disease.

palliative care to such conditions. He argued that the NICE guidelines on Supportive and Palliative Care were relevant here, in that they recognised that people had physical, psychological, social and spiritual needs throughout their care pathway. However, the Department needed to “define the service models which are going to be the best for diseases other than cancer”.⁹⁶ Work was ongoing with the Chronic Care management programme and the End of Life care initiative.

88. We note the suggestion of Rowena Dean of Hospice at Home of the desirability of a national needs analysis of non-cancer diagnosis requiring palliative care.⁹⁷ We recommend that the Department undertakes such an analysis.

89. While we welcome the guidelines on supportive and palliative care for adults with cancer published by the National Institute for Clinical Excellence (NICE), we are concerned that an opportunity has been missed to extend the range of palliative services. The guidance relates solely to cancer services, even though cancer accounts for only one quarter of all deaths in the population. The principles and recommendations would be broadly applicable to the general and specialist palliative care for patients with conditions other than cancer. We recommend that the forthcoming National Service Framework for Long-Term Conditions assumes responsibility for palliative care in non-cancer conditions and takes full account of the recent NICE guidance. It should incorporate the key principles of the NICE guidance as far as possible in order to remove the distinction that is made in the palliative care for cancer patients and for patients dying from other diseases.

90. The transition towards more central Government funding of hospices should afford an opportunity to introduce greater equity in the caseload than hospices manage currently. We develop this point below.

4 Quality of services

91. The majority of dying patients receive no care from specialists in palliative care medicine; they are looked after by generalists. Dr Keri Thomas stressed to us the crucial importance of ‘skilling up’ non-specialist doctors, district nurses, ward staff and care home staff. She went so far as to imply that the growth of the hospice movement had to some extent resulted in GPs feeling deskilled. She believed that that the best practice in the voluntary sector needed to become part of the mainstream NHS. As Professor Mike Richards, National Cancer Director, acknowledged:

Most patients spend a lot of their life at home, particularly in the last year of life, or in a care home. The problem there is, very often, that the staff who are looking after them may not have received any training in palliative care.

He went on to suggest that the “particular challenges” were therefore to ‘skill up’ staff working in all sectors and to co-ordinate care between them.⁹⁸

96 Q37

97 Q186

98 Q3

92. Recent improvements are coming about as a result of the development of two particular protocols which have been widely disseminated for palliative care. The Gold Standards Framework (GSF) developed by Dr Thomas in conjunction with Macmillan, sets general criteria for palliative care of patients in their homes; the Liverpool Care Pathway for the Dying Patient (LCP), developed by Dr John Ellershaw, focuses on care in the last days of life.

93. The GSF is now being used by 1,000 GP practice teams in England. It is targeted at GPs and District Nurses and its main underlying principles are that health professionals should:

- **Identify** patients in need of palliative/supportive care on a register;
- **Assess** them according to their needs and preferences (preferred place of care/death); and
- **Plan** ahead with anticipatory measures such as drugs in the home, handover for the out-of-hours provider etc and at all levels to communicate this to the patient, the carer and other teams involved, including specialists.⁹⁹

94. The five goals are to enable patients to die: as symptom-free as possible; in their place of choice; feeling safe and supported, with fewer crises; with carers feeling supported, involved, empowered and satisfied with care; and with staff feeling confident, satisfied, with good communication and team-working with specialists. This is to be achieved by seven key tasks or standards, the seven Cs: Communication; Co-ordination; Control of Symptoms; Continuity Out-of-Hours; Continued Learning; Carer Support; Care in the Dying Phase.¹⁰⁰

95. Keri Thomas suggested that the introduction of the GSF could double the number of terminally ill patients able to die at home.¹⁰¹ The GSF is currently being evaluated by the University of Warwick and early indications are that its use leads to more patients dying in a place of their choice, better communication and symptoms assessment, and fewer crises.

96. The LCP has been developed to transfer the hospice model of care into other care settings. It focuses on the last three days of life.¹⁰² It is a multi-professional document which provides an evidence-based framework for end of life care. The LCP provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included. The LCP replaces all other documentation in this phase of care and is

99 Ev 215 (Dr Keri Thomas)

100 Ev 215

101 Q172

102 See www.lcp-mariecurie.org.uk

applicable in hospital, hospice, nursing home and community settings. It also provides an ongoing record of care that can be audited and analysed.¹⁰³

97. In December 2003 the Department announced that £12 million of funding would be provided over the next three years under the End of Life Care Initiative to support the improved training of staff working in the community, general practices, care homes and hospitals using validated tools such as the GSF and LCP.¹⁰⁴

98. We agree with the evidence received from Professor Richards and other witnesses that there are significant challenges in raising the skills and awareness of all health care staff in palliative care, whether they work in hospitals, care homes or the community. We recognise that steps towards this objective are already in progress in respect of the End of Life Care Initiative, but we recommend that these should be accelerated. We would urge the appropriate Royal Colleges to ensure that training in palliative care becomes part of continuing professional development, and to consider making such modules a mandatory requirement for revalidation.

99. We also recommend that in supporting the take-up of tools such as the Gold Standards Framework and the Liverpool Care Pathway for the Dying, the Department should particularly encourage local champions working in care homes, in general practice and in the community, since these have been identified as priorities for palliative care knowledge-development.

Communication issues

100. Poor communication, according to the evidence we received, constitutes a major problem in palliative care. This is a critical issue, identified as a key goal in the GSF. At every stage of care, good communication can radically affect patients' and carers' attitude to the patient's condition. One particular problem, which the NICE guidance seeks to address, is the multiplicity of different people patients and carers currently see. A Marie Curie hospice in Edinburgh found that the average cancer patient coming to a palliative care service had met 32 doctors in the course of a two and a half year illness.¹⁰⁵

101. A good feel for some of the problems that arise came in the memorandum from the Health Service Commissioner for England. She suggested that the lack of effective communication constituted "the most common cause of concern among patients" and noted that this could have "a devastating effect". She listed three anonymised cases which indicated the range of problems:

A recent investigation of a complaint about palliative care provided in an acute Trust identified the failure to integrate the patient's palliative care, which was provided by Macmillan nurses, with her ward-based care on a surgical ward. As a result, the palliative care team had no input to the patient's care plan and the ward nurses had no access to the clinical notes maintained by the palliative care nurses, which were not

103 For further information see the memorandum from John Ellershaw and Deborah Murphy, National Clinical Leads—Specialist Care, Ev 233–35.

104 DoH Press Notice 26/12/03; Q3 (Professor Mike Richards)

105 Ev 69

part of the ward nursing notes. As a result, neither team took responsibility for overall management and the patient remained on a general surgical ward for much longer than was appropriate, because neither her family nor the ward staff were aware of the referral system to the Macmillan Unit within the Trust.

In another case, I found that there was considerable confusion between Trust staff and the patient's family as to what constituted palliative care. The patient was in the final stages of a terminal illness and his family agreed with staff that he would be kept comfortable but not actively resuscitated. There were then a number of interventions by medical staff which Trust staff maintained were congruent with this agreement but which were interpreted by the family as a direct contravention of it; as a result, the relationship between the family and Trust staff broke down. I found that the absence of documented policies on withdrawal of treatment and Do Not Resuscitate decisions led to confusion among staff, and this was exacerbated by the absence of a documented agreed plan of care for the patient. This led to the family receiving very mixed messages at what was already an extremely difficult and distressing time for them.

In a third investigation, I found that there was a lack of openness and transparency in the way in which decisions were taken about the care of a terminally ill man. The Consultant responsible for the man's care took a decision not to resuscitate him in the event of a cardiac arrest, and noted this decision in his clinical notes. However, neither the Consultant nor any other member of Trust staff told the patient or his family that the decision had been made, or involved them in discussion about it. Whilst I understand that such discussions are not easy and need to be handled with great sensitivity, it is clearly unacceptable to deny patients and, where appropriate, their families the opportunity to discuss such matters should they so wish.¹⁰⁶

102. Dr Keri Thomas pointed to a problem with communication between the day team caring for a patient and the out-of-hours team. She suggested that electronic handover forms would be beneficial (as already happens, for example, in parts of Canada).¹⁰⁷ She also recommended that medical revalidation should include a requirement to show satisfactory communication skills, perhaps by means of workshops.

103. Some specific communication issues were raised in evidence. For example, the Motor Neurone Disease Association described the need to establish good communication about the patient's wishes whilst the patient retained the faculty of speech.¹⁰⁸ ACT noted how in children's palliative care services health professionals were often more comfortable discussing cases with the parents and carers of children rather than with the children themselves.¹⁰⁹ Cancer BACUP identified a weakness in the frequent lack of explanation about community-based services once patients had been discharged from hospital.

104. We hope that the widespread dissemination of the Gold Standards Framework as a tool to ensure that information follows the patient will do something to address the

106 Ev 179

107 Ev 212; Q169

108 Ev 137

109 Ev 129

major issue of communication failure in some palliative care. We also believe that gaps between health and personal social care contribute to communication failures.

105. As we have noted in other inquiries, the delays in establishing electronic patient records consistently act as a barrier to good communication between health professionals and patients, families and carers. We believe that the introduction of electronic patient records in palliative care would be particularly beneficial to patients, given the need for so much support to patients out of normal working hours, and the need to involve a wide range of health professionals in care at the end of life.

Governance

106. Until recently, regulation of care homes was the responsibility of the National Care Standards Commission (NCSC). As a consequence of recent changes in the regulatory arrangements, responsibility for regulation of stand-alone hospices now falls to the Commission for Health Audit and Inspection (CHAI), whilst the Commission for Social Care Inspection (CSCI) has responsibility for adult services and outreach.

107. Several witnesses stressed that there were too many different regulatory bodies (though often they failed to distinguish between statutory organisations and peer review bodies). St Michael's Hospice in Harrogate suggested that the peer review inspection it was subject to lasted three days, was conducted to a high standard and was very useful, whereas that from the NCSC had lasted a few hours and was "superficial", mainly looking at compliance with legislation.¹¹⁰ The Cotswold Care Hospice felt that NCSC regulation had been cumbersome and was governed by a "ticking the box" mentality.¹¹¹ Help the Hospices contended that it would be better if standards were built around the patient's needs rather than the relevant provider organisation.¹¹²

108. Evidence we have taken demonstrates that the current regulation of palliative care services is unsatisfactory. For example, a hospice at home that is part of an in-patient service is regulated under a different framework from a stand-alone hospice at home team.¹¹³ This discrepancy is going to get wider with the establishment of CHAI and CSCI. Patients at transition from a children's to an adult hospice are denied continuity of care.¹¹⁴ As a consequence of anomalies in standards regulation: "There is a two tier system in place where 18 year olds with new diagnoses are not eligible for services available to other 18 year olds who have a long-standing diagnosis."¹¹⁵

109. We recommend that the Government review the regulatory inconsistencies that beset hospice and palliative care service providers, and ensure that these are removed in the interests of simplicity, fairness and ease of use. We do not believe that these inconsistencies have been adequately addressed in the latest restructuring of the

110 Ev 187

111 Ev 194

112 Ev 81

113 Q143

114 Ev 264 (Association of Children's Hospices)

115 Ev 270 (Dr Lynda Brook, RLC-NHS Trust and Merseyside and Cheshire Children's Palliative Care Clinical Director)

regulatory bodies (which came into effect only in April 2004), or by the Memorandum of Understanding that has been developed between CSCI and CHAI. This should be tackled as a matter of urgency if these new organisations are to have credibility.

5 Resources for palliative care

Staff

110. Workforce shortages, and the lack of appropriately qualified staff were major themes of the evidence we received. The Department itself acknowledged that there is currently a serious shortfall in staff but drew attention to the substantial investment being made in training more health professionals across the board.¹¹⁶ Melanie Johnson cited the figures collated by the Association of Palliative Medicine which showed a total head count of 237 palliative care consultants in England in 2002 with a whole-time equivalent of 169.¹¹⁷ The total head count figure projected for 2008 is 358, an increase of 51%, which translates to a whole-time equivalent of 255. Overall, Ms Johnson anticipated that the total number of consultants would double between 2002 and 2015.¹¹⁸ She felt that this would also help boost the degree of non-cancer work dealt with by specialists.

111. For the moment, however, numerous areas of staffing seem to be in shortage. Dr Keri Thomas pointed out that at least 100 posts for consultants in palliative medicine remain unfilled. As Help the Hospices put it: “it is clear that significant resources are being used to recruit non-existent consultants”.¹¹⁹ Some areas had so few consultants that they were unable to train specialist registrars. Adherence to the working time directive and the new consultant contract, in Dr Thomas’s view, were likely to exacerbate the problem.

112. Numerous memoranda attested to specific problems:

- St Barnabas Hospice in Lincoln noted “currently we have been unable to recruit any accredited consultants to work in Lincolnshire”.¹²⁰
- The Prince of Wales Hospice, Pontefract, described the supply of trained doctors in palliative medicine as “poor” and also drew attention to a shortage of nurses.¹²¹
- Shropshire Palliative Care at Home Service found it difficult to provide nurse cover and in particular noted the problem of getting genuine commitment from Bank nursing staff.¹²²

116 See Ev 3, 6 and 25

117 Q316

118 Q316

119 Ev 82

120 Ev 185

121 Ev 206

122 Ev 185

- Greenwich and Bexley Cottage Hospital referred to the serious lack of responsive overnight specialist care and support available in the Greenwich borough.¹²³
- Marie Curie suggested that a number of PCTs were asking for healthcare assistants rather than nurses purely for budgetary reasons.¹²⁴
- The Chartered Society of Physiotherapy told us there was a shortage of physiotherapists, a group of workers the Society felt was in any case marginalised within palliative care.¹²⁵

113. The impact of the new GP contract on palliative services was highlighted by some witnesses. The Royal College of General Practitioners suggested that the number of GPs opting out of out-of-hours cover would mean that continuity of care in relation to palliative care would be reduced. They felt that the impact of this could to some extent be mitigated if communication was improved and if protocols such as the GSF became used nationally.¹²⁶ Sue Ryder Care felt that this was particularly likely to be a problem with patients with “complex needs” where a lack of co-ordination between carers would be very injurious.¹²⁷

114. The voluntary sector providers who gave evidence to us welcomed *Agenda for Change*¹²⁸ for the opportunities it could bring. However, it is equally clear that there will be significant financial costs associated with implementation, not least because the NHS and hospices are essentially ‘fishing in the same pool’ to recruit nursing staff, and are therefore in competition with one another. Christine Shaw for Help the Hospices estimated that the consequences of implementing *Agenda for Change* might be in the region of a 10–15% increase in costs.¹²⁹

115. We applaud the ambitious goal the Government has set to double the number of palliative care consultants by 2015 based on the figures for 2002. Given the ageing of the population, and the current problems being faced by many providers submitting evidence to this inquiry, we believe that these additional resources will be sorely needed. We also welcome the fact that the Government is offering funding to address the current deficit. We still remain to be convinced that the ambitious targets being set will be realised. We also think it is essential that shortfalls in staff involving other health and social care professionals with relevant expertise—such as community nurses and social workers—are addressed at the same time. Palliative care is manifestly a branch of medicine requiring a team approach.

123 Ev 229

124 Q125

125 Ev 246

126 Ev 193

127 Ev 196

128 *Agenda for change* is the document setting out the new pay, grading, terms and conditions proposals for all NHS staff. Published in March 2003 it comes into effect from October 2004.

129 Q158

Funding issues

116. The months leading to an individual's death pose the highest cost burden of all on the NHS. One estimate suggests that 90% of all health expenditure occurs in the last months of life, and that almost a quarter of hospital bed days are used by patients in their last years of life.¹³⁰

117. The Department cited an estimate produced by the National Council for Hospice and Specialist Palliative Care Services that total expenditure on adult palliative care in 1999 was around £300 million per annum of which £170 million was provided by the voluntary sector. No figure for expenditure on children's palliative care has been provided to us. Janet Vickers, a nurse consultant in palliative care described this as a major problem:

Children's palliative care ... is not a high profile specialty with distinct separate funding, it has, in the majority of cases, been excluded from accessing recent Government funding for palliative care which was specifically designated for adult palliative care.¹³¹

118. ACT asserted that children's hospices received, on average, just over 5% of their funding from statutory sources.¹³²

119. The NHS Cancer Plan, which is a key policy framework document for palliative care, acknowledged that the voluntary sector had for too long shouldered the burden of funding palliative care.¹³³ It pledged to increase funding for specialist palliative care by £50 million per annum by 2004. In July 2002, Ministers reaffirmed their commitment to ensure that the full sum was devoted to specialist palliative care and the National Cancer Director was charged with developing a mechanism to achieve this. He set up the joint NHS/Voluntary Sector/Department of Health National Partnership Group for Palliative Care. In order to speed up progress an extra £10 million was devoted to specialist palliative care in 2002–3. This was allocated to PCTs “with clear instructions that it had to be spent on specialist palliative care”.¹³⁴

120. The National Partnership Group's recommendations included:

- Investment in specialist palliative care should be in line with local strategic plans and NICE guidance on supportive and palliative care.
- Inequalities in access to specialist palliative care services needed to be addressed.
- Local decision-making and accountability were essential.
- Voluntary sector organisations should be fully involved in planning services.

130 Ev 215 (Dr Keri Thomas); Seale C and Cartwright A, *The Year Before Death*, Aldershot 1994

131 Ev 268

132 Ev 131

133 The NHS Cancer Plan: A Plan for Investment A Plan for Reform, September 2000, ch 7

134 Ev 11

- The NHS should make a “realistic contribution” to services provided by hospices etc. but should not be the sole provider. Equally, voluntary sector bodies, while having the freedom to offer innovative services, should provide value for money.
- The voluntary sector should have more secure funding flows but should be able to offer clear projections of its future contribution.
- Local planning and funding should include, “over time”, non-cancer specialist palliative care services.

121. Primary Care Trusts are required to work together through cancer networks¹³⁵ (32 at present, set to rise to 34) to identify local spending and development priorities. The networks are also currently engaged in the process of correlating need for services against service availability. The £50 million is intended to:

- Fund an additional 66 whole-time equivalent palliative care consultants;
- Fund an additional 162 whole-time equivalent Cancer Nurse Specialists;
- Produce an extra 92 specialist palliative care in-patient beds;
- Give additional funding support to the voluntary sector, including hospices, Marie Curie and equivalent local services;
- Increase the availability of out-of-hours provision, support hospital and community services; and
- Contribute to meeting the specialist palliative care recommendations in the draft NICE guidance.¹³⁶

122. In addition to this funding, the New Opportunities Fund’s Community Fund has issued 119 grants totalling £29 million to hospices and related programmes; £22 million towards facilitating care at home; and £48 million to children’s hospices, home-based care teams and bereavement teams dealing with children.¹³⁷ This includes £25 million to children’s hospices to enable them to sustain or develop their provision. New Opportunities funding is for a fixed period and does not provide for ongoing funding of services. A particular challenge to recipients of such funds is to sustain the gains made by projects once their funding from the New Opportunities Fund is complete, and to develop continuation funding.

123. Some submissions complained that PCTs were creaming off part of the additional money awarded to palliative care and were not devoting it to specialist services. For example, St Michael’s Hospice in Harrogate noted that the Craven, Harrogate, and Rural District PCT had received £188,000 from the £50 million allocation but that only £39,000 of this had come through to the hospice.¹³⁸ Similarly, Greenwich and Bexley Cottage

135 Cancer networks were advocated in the Calman-Hine Report into the commissioning of cancer services published in 1995. They are intended to bring together commissioners and providers, the voluntary sector and local authorities. They serve populations of 1–2 million.

136 Ev 12

137 Ev 208

138 Ev 187

Hospital noted that they received none of the same funding, all of which was appropriated by Greenwich PCT.¹³⁹ A further problem, which was noted by Cotswold Care Hospice, was the last-minute nature of much statutory funding, consequential on the need for local NHS approval and the complexity of the relevant application forms.¹⁴⁰

124. A number of submissions commented on the possible impact of the Treasury's cross-cutting review which has set a deadline of 2006 by when statutory agencies will be obliged to meet the full costs incurred by the voluntary sector in providing public services. National tariffs will be drawn up to allow costs to be calculated.

125. Precisely how the Treasury funding will work remains unclear. Officials told us that agreed tariffs for services provided would need to be drawn up which would allow the Government to fund core services. Christine Shaw for Help the Hospices queried whether there needed first to be an interim tariff established.¹⁴¹ Peter Tebbit for the National Council for Hospice and Specialist Palliative Care Services suggested that the NHS would have to swallow the bitter pill of paying for services which at the moment they were receiving with a heavy subsidy from the voluntary sector. In his view this would yield a bill of an extra £100 million per year. He felt that this was not unreasonable, given that, according to his estimate, the Government had received between £1–2 billion worth of services at no cost over the last 10–15 years. Tom Hughes-Hallett for Marie Curie offered the analogy of cream and milk: if the Government paid for the 'milk' that the core services constituted, the charity would have more resources to devote to the cream, "new ways of delivering care and help".¹⁴² Peter Tebbit agreed that an end to the need to concentrate day to day on how to raise funds would "release an enormous amount of creative and innovative energy".¹⁴³

126. What is not clear is the extent to which the Treasury's obligations would be open-ended. For example, if there is a substantial short-fall of hospice provision in one area at the moment, would the Treasury be obliged to step in and fund in full a string of new hospices opening up? Even in areas with relatively generous provision, if the beds can be filled and care provided, should the Treasury still offer funding? To what extent will funding be related to the quality of provision?

127. How hospice services are to be funded in the future is an important matter that is still being considered by the National Partnership Group and the Department of Health. Peter Tebbit told us that it was likely there would be "a funding mechanism for governing NHS funding flows that is common to both NHS and voluntary providers. If we put both the voluntary and the NHS managed services on the same level playing field, I think we will get a nationally agreed range of prices for the supply of care services".¹⁴⁴

128. We welcome the additional resources that the Government has directed to the development of specialist palliative care services throughout the country. The

139 Ev 230

140 Ev 195

141 Q141

142 Q141

143 Q141

144 Q141

allocation of the additional £50 million has been facilitated by the establishment of the National Partnership Group for Palliative Care, bringing together the voluntary sector, the NHS and the Department.

129. We note the momentum achieved in Canada by an end of life/palliative care coalition. We recommend that the Department assesses the membership of the National Partnership Group and extends it to include representation from all relevant areas, including education; carers; charities dealing with illnesses other than cancer; those suffering inequity on the grounds of age; as well as black and minority ethnic groups.

130. It is now widely accepted that the NHS has relied heavily on the goodwill and charitable funding of the hospice movement. We welcome the Government's statement that it is committed to increasing the contribution made by the NHS to hospice costs. Witnesses repeatedly emphasised the need to ensure that when hospices provided services for NHS patients, they should receive an appropriate payment. Important questions arise about the basis for calculating such costs. We are aware of the perverse incentives which operate against hospices admitting patients with non-cancer diagnoses. Patients with conditions such as motor neurone disease, for example, may have complex care needs of a long-term nature. When hospices are paid on the basis of a care episode there will clearly be an incentive to admit patients with a relatively short life expectancy.

131. We welcome the transition that will take place to more sustainable funding mechanisms for hospices, and the benefits this will have for the voluntary sector by 2008. We are especially concerned that the funding mechanism (whereby money will follow the patient) should be sufficiently sophisticated to recognise the different requirements of parts of the service and the distinction between longer and shorter stays for different patients and diagnostic groups.

132. A fundamental shift in funding from the voluntary to the state sector also offers, in our view, a golden opportunity to address some of the issues relating to equity. We believe that need should be carefully mapped against resources, as is already happening, and that this process should inform the distribution of central funding. If necessary, tough decisions will need to be taken *not* to fund particular projects if they are in areas which are relatively over-supplied. Similarly, if particular centres are failing the needs of their population in terms of ethnicity and age relative to other providers serving populations with similar profiles, we believe commissioners should consider withholding funding.

6 Conclusion: changing attitudes

133. The taboo nature of the subject of death has been a recurrent theme of this inquiry. A general reluctance to discuss the topic informs much of society and perhaps accounts in part for the problems people encounter in negotiating choices in this area. Whereas in all eras up to the present, death was a very visible fact of everyday life, now it is something which tends not even to be discussed, and is rarely witnessed.

134. An important place to begin is in addressing end of life issues, the nature of dying and the rituals of death, within the education process in schools. In this respect we note the materials being developed by Help the Hospices for use within the National Curriculum and the recent guide to teaching young children about death and dying produced by the Child Bereavement Trust. The author of that guide, Gill Frances, director of children's development at the National Children's Bureau, has suggested that the issue of death is "currently sidelined in a lot of schools".¹⁴⁵ ACT also suggested that, although there is much reference material available on this issue, in the main children are not taught about death even though it is an aspect of everyone's life.

135. The right to 'a good death' should be fundamental. We believe that social attitudes are part of the problem, and that a willingness to be open about death will facilitate better communication and ultimately better provision. We hope that this is an area the Department for Education and Skills will address, both by examining the place of education about death within the curriculum and within teacher training.

136. We also believe that all health professionals will increasingly face the issues raised by this inquiry, given shifts in the population, with more people living longer with a range of progressive illnesses, as well as cancer, where cure cannot be achieved. The key message from our inquiry is that if palliative care is to achieve improvements in the quality of the last months of life across the population it will need to operate in a much more equitable way. It will also need to be delivered more strategically and to find a way of overcoming the divide between health and social care.

145 *The Times*, 4 May 2004

Conclusions and recommendations

1. Non-specialists in palliative care looking after patients with severely disabling or potentially terminal illnesses must appreciate the value of early referral to palliative care consultants. (Paragraph 22)
2. While we sympathise with, and support, the aspiration to allow all patients to die at home if they choose, we question how realistic this objective really is at the present time. The option to die at home will only be realisable if there is a guarantee of 24-hour care and support, with back-up from appropriate specialists. In the absence of such back-up, relatives and other carers will, understandably, be reluctant to take care of a patient at home. (Paragraph 23)
3. We recommend that the Department of Health should consider the recent economic analysis produced by Marie Curie Cancer Care of the potential cost benefits arising from a shift towards more patients dying in their homes. If indeed there are “massive savings” to be made from such a shift, as one health Minister predicted, we hope that urgent measures will be taken to develop this strategy. (Paragraph 26)
4. We welcome the suggestion from Dr Ladyman that the Government, following consultation, is considering legislation relating to extra rights for carers in the workplace. The Canadian model of care is itself only at an early stage of development but it seems to offer an imaginative and sensible solution. We recommend that the Department seeks feedback from the Canadian authorities on their experiences of additional support to carers to establish the impact the scheme is having on choice in place of death, the quality of care and on the ensuing costs. (Paragraph 33)
5. We recommend that the Government legislates to provide for a period of paid leave for carers, taking account of the flexibilities provided by the Canadian model. We believe that such a step would empower many more people to achieve their wish to die at home. We also believe that at least some of the cost to public funds of such a measure would be offset by savings accruing from reduced hospital care. (Paragraph 34)
6. We strongly encourage the Department to support Marie Curie in its efforts to develop pilot schemes, in conjunction with a range of partners, to explore the best ways of supporting carers when someone is dying at home. (Paragraph 35)
7. When people wish to spend their final days at home, there are particular challenges to health and social care services, and it is vital that they are properly integrated. We are concerned that the emphasis on personal care within social services has been to the detriment of equally important domestic support. We do not believe that it is acceptable for people who choose to die at home to find that they are doing so in increasingly squalid surroundings. Indeed, it is likely that it is poor domestic conditions that often precipitate admission to hospital for people who should be supported so as to be able to remain in their own homes. We recommend that the Department of Health should review the place of domestic support within the overall spectrum of social care services, and ensure that people’s needs for domestic help are

adequately addressed. We also recommend that particular attention is given to providing aids and adaptations to allow people to stay in their own homes. (Paragraph 44)

8. We are concerned that there is still considerable variation in the criteria for continuing healthcare between SHAs, and that people who meet the criteria in one SHA for continuing healthcare because of their palliative care needs, fail to satisfy the criteria in another authority. This is unfair, and is incompatible with the principle of a national health service. We look forward to the publication by the Department of the reviews of eligibility criteria and any associated guidance. We are convinced that the only way to ensure that there is equity in access to NHS continuing care is to introduce national eligibility criteria. We recommend that the Department develop national criteria for continuing care, including criteria for palliative care, to remove the inequitable anomalies that arise between criteria operated by different SHAs. Guidance and support will also be needed to ensure that a single national set of criteria is consistently interpreted and applied. (Paragraph 47)
9. We look forward to the publication of the Department's vision for adult social care, and hope that it will provide the basis for some wide-ranging and innovative developments and the promotion of new models of care. We wish to underline the importance of removing the distortions created by the boundary between the parallel health and social care systems. While we recognise that structure is not everything (and that partnerships and joint working are of great importance, as the Health Committee has made clear in previous reports), we are convinced that an integrated structure is a necessary pre-condition for tackling the anomalies that arise in trying to distinguish between health and social care needs. These issues, and the associated disputes, are especially abhorrent in respect of palliative care, where unseemly arguments about who should pay for different elements of a care package can lead to inexcusable delays and poor practice that is anything but patient-centred. (Paragraph 49)
10. There is a danger that where the reimbursement system relating to delayed discharges is applied selectively there may be damaging and unintended consequences emerging elsewhere in the system. There are real risks that this will lead to different classes of patients—those for whom discharge planning is prioritised because of the financial penalties that might otherwise be incurred by social services, and those for whom timely discharge becomes a lower priority, even where objectively timeliness is of the essence. We understand that Help the Hospices is undertaking a survey of the scale of the problems this is causing in the hospice sector. We urge the Government to examine these findings as a matter of urgency and to consider whether the delayed discharges legislation is having deleterious effects on the care and well-being of patients in hospices, for whom any delay in discharge arrangements can be catastrophic, meaning the difference between someone ending their days in the place of their choice, or having that wish denied. (Paragraph 53)
11. We recommend that the Department analyses the Comparative Index of Need drawn up by the National Council for Hospice and Specialist Palliative Care Services to assess whether a better match between need and provision can be agreed. (Paragraph 61)

12. We accept that palliative care goes well beyond hospice provision; however, the role of a hospice within the spectrum of provision is an important one. We are uncertain how the Government plans to ensure greater equity in service provision in the context of devolved responsibilities to PCTs, and without clear guidance on the preferred models of care. An acceptance of the current diversity of provision could also entail tolerance of continued inequity. We urge the Department to consider what more can be done to inform PCT commissioning of palliative care services by the issuing of clearer guidance on preferred models of care. We deal below with the possible impact on equity of provision of additional Treasury funding for hospices. (Paragraph 62)
13. We hope that the forthcoming National Service Framework for Children will acknowledge the particular difficulties of the transition from adolescent to adult services. We also believe that boosting the role of carer and giving proper support in care are vital components of palliative care for children. (Paragraph 69)
14. We welcome the fact that the Department recognises the problems of inequitable provision of palliative care services relating to age, ethnicity and complex needs. We also welcome the research they have commissioned in this area to improve services and to bring into the mainstream the good practice that exists patchily. We believe it is important that work on improving the accessibility of palliative care services does not focus solely on that provided within hospice buildings. It is at least as important that community palliative care services are available (and acceptable) to members of black and minority ethnic communities, to older people and to those with complex needs. These may well be provided by hospices, as is already often the case. The need to ensure that all services are culturally sensitive should form an important dimension of the training of both generalist and specialist palliative care staff. (Paragraph 78)
15. We note the suggestion of Rowena Dean of Hospice at Home of the desirability of a national needs analysis of non-cancer diagnosis requiring palliative care. We recommend that the Department undertakes such an analysis. (Paragraph 88)
16. While we welcome the guidelines on supportive and palliative care for adults with cancer published by the National Institute for Clinical Excellence (NICE), we are concerned that an opportunity has been missed to extend the range of palliative services. The guidance relates solely to cancer services, even though cancer accounts for only one quarter of all deaths in the population. The principles and recommendations would be broadly applicable to the general and specialist palliative care for patients with conditions other than cancer. We recommend that the forthcoming National Service Framework for Long-Term Conditions assumes responsibility for palliative care in non-cancer conditions and takes full account of the recent NICE guidance. It should incorporate the key principles of the NICE guidance as far as possible in order to remove the distinction that is made in the palliative care for cancer patients and for patients dying from other diseases. (Paragraph 89)

17. The transition towards more central Government funding of hospices should afford an opportunity to introduce greater equity in the caseload than hospices manage currently. (Paragraph 90)
18. We agree with the evidence received from Professor Richards and other witnesses that there are significant challenges in raising the skills and awareness of all health care staff in palliative care, whether they work in hospitals, care homes or the community. We recognise that steps towards this objective are already in progress in respect of the End of Life Care Initiative, but we recommend that these should be accelerated. We would urge the appropriate Royal Colleges to ensure that training in palliative care becomes part of continuing professional development, and to consider making such modules a mandatory requirement for revalidation. (Paragraph 98)
19. We also recommend that in supporting the take-up of tools such as the Gold Standards Framework and the Liverpool Care Pathway for the Dying, the Department should particularly encourage local champions working in care homes, in general practice and in the community, since these have been identified as priorities for palliative care knowledge-development. (Paragraph 99)
20. We hope that the widespread dissemination of the Gold Standards Framework as a tool to ensure that information follows the patient will do something to address the major issue of communication failure in some palliative care. We also believe that gaps between health and personal social care contribute to communication failures. (Paragraph 104)
21. As we have noted in other inquiries, the delays in establishing electronic patient records consistently act as a barrier to good communication between health professionals and patients, families and carers. We believe that the introduction of electronic patient records in palliative care would be particularly beneficial to patients, given the need for so much support to patients out of normal working hours, and the need to involve a wide range of health professionals in care at the end of life. (Paragraph 105)
22. We recommend that the Government review the regulatory inconsistencies that beset hospice and palliative care service providers, and ensure that these are removed in the interests of simplicity, fairness and ease of use. We do not believe that these inconsistencies have been adequately addressed in the latest restructuring of the regulatory bodies (which came into effect only in April 2004), or by the Memorandum of Understanding that has been developed between CSCI and CHAI. This should be tackled as a matter of urgency if these new organisations are to have credibility. (Paragraph 109)
23. We applaud the ambitious goal the Government has set to double the number of palliative care consultants by 2015 based on the figures for 2002. Given the ageing of the population, and the current problems being faced by many providers submitting evidence to this inquiry, we believe that these additional resources will be sorely needed. We also welcome the fact that the Government is offering funding to address the current deficit. We still remain to be convinced that the ambitious targets being set will be realised. We also think it is essential that shortfalls in staff involving other

health and social care professionals with relevant expertise—such as community nurses and social workers—are addressed at the same time. Palliative care is manifestly a branch of medicine requiring a team approach. (Paragraph 115)

24. We welcome the additional resources that the Government has directed to the development of specialist palliative care services throughout the country. The allocation of the additional £50 million has been facilitated by the establishment of the National Partnership Group for Palliative Care, bringing together the voluntary sector, the NHS and the Department. (Paragraph 128)
25. We note the momentum achieved in Canada by an end of life/palliative care coalition. We recommend that the Department assesses the membership of the National Partnership Group and extends it to include representation from all relevant areas, including education; carers; charities dealing with illnesses other than cancer; those suffering inequity on the grounds of age; as well as black and minority ethnic groups. (Paragraph 129)
26. It is now widely accepted that the NHS has relied heavily on the goodwill and charitable funding of the hospice movement. We welcome the Government's statement that it is committed to increasing the contribution made by the NHS to hospice costs. Witnesses repeatedly emphasised the need to ensure that when hospices provided services for NHS patients, they should receive an appropriate payment. Important questions arise about the basis for calculating such costs. We are aware of the perverse incentives which operate against hospices admitting patients with non-cancer diagnoses. Patients with conditions such as motor neurone disease, for example, may have complex care needs of a long-term nature. When hospices are paid on the basis of a care episode there will clearly be an incentive to admit patients with a relatively short life expectancy. (Paragraph 130)
27. We welcome the transition that will take place to more sustainable funding mechanisms for hospices, and the benefits this will have for the voluntary sector by 2008. We are especially concerned that the funding mechanism (whereby money will follow the patient) should be sufficiently sophisticated to recognise the different requirements of parts of the service and the distinction between longer and shorter stays for different patients and diagnostic groups. (Paragraph 131)
28. A fundamental shift in funding from the voluntary to the state sector also offers, in our view, a golden opportunity to address some of the issues relating to equity. We believe that need should be carefully mapped against resources, as is already happening, and that this process should inform the distribution of central funding. If necessary, tough decisions will need to be taken not to fund particular projects if they are in areas which are relatively over-supplied. Similarly, if particular centres are failing the needs of their population in terms of ethnicity and age relative to other providers serving populations with similar profiles, we believe commissioners should consider withholding funding. (Paragraph 132)
29. The right to 'a good death' should be fundamental. We believe that social attitudes are part of the problem, and that a willingness to be open about death will facilitate better communication and ultimately better provision. We hope that this is an area

the Department for Education and Skills will address, both by examining the place of education about death within the curriculum and within teacher training. (Paragraph 135)

30. We also believe that all health professionals will increasingly face the issues raised by this inquiry, given shifts in the population, with more people living longer with a range of progressive illnesses, as well as cancer, where cure cannot be achieved. The key message from our inquiry is that if palliative care is to achieve improvements in the quality of the last months of life across the population it will need to operate in a much more equitable way. It will also need to be delivered more strategically and to find a way of overcoming the divide between health and social care. (Paragraph 136)

Formal minutes

Thursday 14 July 2004

Members present:

John Austin
Mr Keith Bradley
Jim Dowd

Dr Doug Naysmith
Dr Richard Taylor
Mr Jon Owen Jones

In the absence of the Chairman, John Austin was called to the Chair.

Draft Report (Palliative Care), proposed by the Chairman, brought up and read.

Ordered, That the Chairman's draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 136 read and agreed to.

Resolved, That the Report be the Fourth Report of the Committee to the House.

Ordered, That the provisions of Standing Order No. 134 (select committees (reports)) be applied to the Report.

Ordered, That the Appendices to the Minutes of Evidence taken before the Committee be reported to the House.

[Adjourned till Monday 19 July at 4 pm]

Witnesses

Thursday 25 March 2004

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Professor Mike Richards, National Director, **Professor Stuart Tanner**, Medical Adviser, Child Health Services, **Mrs Jane Scott**, Team Leader, Child Health Services, and **Ms Sue Hawkett**, Team Leader, Supportive and Palliative Care, Department of Health.

Ev 33

Thursday 22 April 2004

Dame Gill Oliver, Director, Service Development, Macmillan Cancer Relief, **Ms Christine Shaw**, Acting Chief Executive, Help the Hospices, **Mr Peter Tebbit**, National Palliative Care Development Adviser, National Council for Hospice and Specialist Palliative Care, **Dr John Wiles**, Chairman, Association for Palliative Medicine and **Mr Tom Hughes-Hallett**, Chief Executive, Marie Curie Cancer Care.

Ev 85

Thursday 6 May 2004

Dr Keri Thomas, General Practitioner, National Clinical Lead, Palliative Care Cancer Services Collaborative, **Ms Corinne Lowe**, National Executive Committee Member, Community and District Nursing Association, **Mrs Rowena Dean**, Chair, National Forum, Hospice at Home and **Ms Suzy Croft**, Chair, Association of Hospice and Specialist Palliative Care Social Workers.

Ev 117

Ms Lizzie Chambers, Acting Chief Executive, Association for Children with Life-Threatening or Terminal Conditions and Their Families, **Mr Gurch Randhawa**, Principal Research Fellow, Institute for Health Service Research, University of Luton, **Ms Tricia Holmes**, Director, Care Development, Motor Neurone Disease Association, **Ms Joanne Rule**, Chief Executive, Cancer BACUP and **Mr Philip Hurst**, Health Policy Officer, Age Concern.

Ev 143

Wednesday 26 May 2004

Miss Melanie Johnson, a Member of the House, Minister of Public Health, and **Dr Stephen Ladyman**, a Member of the House, Parliamentary Under-Secretary of State for Health, Department of Health.

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3	Macmillan Cancer Relief (PC55)	Ev 60
4	Help the Hospices (PC45)	Ev 72
5	Marie Curie Cancer Care (PC35A)	Ev 102
6	Association of Hospice and Palliative Care Social Workers (PC21)	Ev 109
7	National Forum for Hospice at Home (PC33)	Ev 112
8	Community and District Nursing Association (PC60)	Ev 114
9	ACT (PC38)	Ev 128
10	Gurch Randhawa (PC20)	Ev 132
11	Motor Neurone Disease Association (PC32)	Ev 135
12	CancerBACUP (PC49)	Ev 138
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14	ACT (PC38A)	Ev 152
15	Health Services Commissioner (PC1)	Ev 179
16	Teenage Cancer Trust (PC2)	Ev 180
17	Professor Sam Ahmedzai (PC3)	Ev 180
18	Dr Mary Parkinson (PC4)	Ev 182
19	Community and Public Affairs Unit, Church of England (PC5)	Ev 183
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21	Shropshire Palliative Care at Home Scheme (PC7)	Ev 185
22	AHPCC (PC8)	Ev 186
23	Saint Michael's Hospice (PC9)	Ev 186
24	British Lung Foundation (PC10)	Ev 188
25	College of Occupational Therapists (PC11)	Ev 189
26	The Stroke Association (PC12)	Ev 191
27	Royal College of General Practitioners (PC14)	Ev 192
28	Cotswold Care Hospice (PC15)	Ev 194
29	Sue Ryder Care (PC16)	Ev 195
30	Alzheimer's Society (PC17)	Ev 199
31	Hull and East Yorkshire Hospitals NHS Trust (PC19)	Ev 201
32	The Prince of Wales Hospice, Pontefract (PC22)	Ev 204
33	New Opportunities Fund (PC23)	Ev 207
34	Dr Keri Thomas (PC24)	Ev 210
35	Voluntary Euthanasia Society (PC25)	Ev 220
36	The Royal College of Physicians and the Association for Palliative Medicine of Great Britain and Ireland (PC26)	Ev 223
37	Greenwich and Bexley Cottage Hospice (PC27)	Ev 228
38	Dr Ann Morris (PC28)	Ev 231
39	Dr John Ellershaw and Deborah Murphy (PC29)	Ev 233
40	Jan Morrison (PC30)	Ev 235
41	The Pharmaceutical Services Negotiating Committee (PC31)	Ev 238
42	Multiple Sclerosis Society (PC34)	Ev 239

43 Chartered Society of Physiotherapy (PC37)	Ev 244
44 National Care Standards Commission (PC40)	Ev 248
45 St Christopher's Hospice (PC41)	Ev 253
46 National Network for the Palliative Care of People with Learning Disabilities (PC44)	Ev 258
47 Hospice in the Weald (PC46)	Ev 259
48 AstraZeneca UK (PC47)	Ev260
49 Association of Children's Hospices (PC48)	Ev 262
50 Janet Vickers (PC51)	Ev 267
51 Dr Lynda Brook (PC58)	Ev 268
52 Gill Booth (PC54)	Ev 271
53 National Council for Hospice and Specialist Palliative Care Services (PC56)	Ev 272
54 Parkinson's Disease Centre of the United Kingdom (PC61)	Ev 289
55 Royal College of Nursing (PC62)	Ev 291
56 College of Health Care Chaplains (PC63)	Ev 293
57 Don Aston (PC66)	Ev 294
58 The Baroness Finlay of Llandaff (PC67)	Ev 295
59 Department of Health (PC18C)	Ev 299
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61 Marie Curie Cancer Care (PC35B)	Ev 303
62 Department of Health (PC18D)	Ev 307
63 Department of Health (PC18E)	Ev 307
64 Dr Michael Cushen (PC68)	Ev 308
65 The Cicely Saunders Foundation (PC69)	Ev 308

List of unprinted written evidence

Additional papers have been received from the following and have been reported to the House but to save printing costs they have not been printed and copies have been placed in the House of Commons library where they may be inspected by members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074) hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

Abbott Laboratories Ltd (PC13)

Breast Care Cancer (PC36)

Joint Palliative Care Planning Group, Mid Yorkshire Hospitals NHS Trust (PC42)

Sunderland Teaching Primary Care Trust (PC43)

National Network for the Palliative Care of People with Learning Disabilities (PC44)

Janet Vickers (PC51)

Roche Products (PC53)

International Myeloma Foundation, UK (PC59)

Reports from the Health Committee since 2001

The following reports have been produced by the Committee since the start of the 2001 Parliament. The reference number of the Government's response to the Report is printed in brackets after the HC printing number.

Session 2003–04

First Report	The Work of the Health Committee	HC 95
Second Report	Elder Abuse	HC 111 (Cm 6270)
Third Report	Obesity	HC 23

Session 2002–03

First Report	The Work of the Health Committee	HC 261
Second Report	Foundation Trusts	HC 395 (Cm 5876)
Third Report	Sexual Health	HC 69 (Cm 5959)
Fourth Report	Provision of Maternity Services	HC 464 (Cm 6140)
Fifth Report	The Control of Entry Regulations and Retail Pharmacy Services in the UK	HC 571 (Cm 5896)
Sixth Report	The Victoria Climbié Inquiry Report	HC 570 (Cm 5992)
Seventh Report	Patient and Public Involvement in the NHS	HC 697 (Cm 6005)
Eight Report	Inequalities in Access to Maternity Services	HC 696 (Cm 6140)
Ninth Report	Choice in Maternity Services	HC 796 (Cm 6140)

Session 2001–02

First Report	The Role of the Private Sector in the NHS	HC 308 (Cm 5567)
Second Report	National Institute for Clinical Excellence	HC 515 (Cm 5611)
Third Report	Delayed Discharges	HC 617 (Cm 5645)