The shape of the future for Palliative Care

"Addressing the future of palliative care could provide a paradigm for the knotty problems with which (we) must concern (ourselves); how to make proper provision for recognised need in a situation of rapid growth and social change."¹

Introduction

The National Council for Palliative Care has identified the need to develop a long-term vision for palliative care services over the next 20 years. This follows the Wanless Report, A Response to HM Treasury Interim Report on Securing our Future Health: Taking a Long Term View, ("the first Wanless Report") which examined the resource implications of future healthcare provision until 2022.

Our work in this area has already begun, under the heading 20:20 Vision. This document reports on our progress to date and what we would like to do next. It is set in the context of the many developments that are taking place in palliative care nationally. It also identifies some wider societal trends and examines their potential impact. It is intended to fuel the debate about what palliative care services should look like 20 years on, to meet the diverse needs of the population at that time. We hope that it will generate ideas and discussion, and we will welcome any comments that you wish to contribute.

Box 1

20:20 VISION TERMS OF REFERENCE

- To identify the palliative needs in 20 years’ time of people with advanced, progressive and life-threatening conditions
- To identify the implications for service delivery
- To identify the future pattern of service delivery and the required changes to meet it
- To undertake this work in partnership with key stakeholders and policy makers.
Palliative Care: A Time of Change

There is a current momentum behind palliative care, which is gathering pace as policy makers give increasing recognition to the importance of ensuring appropriate care for all people with life-threatening and life-limiting conditions. Examples of developments in the last few years include:

- The government’s decision to contribute an additional £50m per annum to specialist palliative care services from 2001 onwards
- The establishment of the National Partnership Group (NPG) for palliative care in England to oversee allocation of the additional £50m contributed by government, and to develop a long-term funding mechanism for voluntary and NHS services
- The NHS emphasis on patient choice: Building on the Best: Choice, Responsiveness and Equity in the NHS (December 2003)
- The NICE Guidance on Supportive and Palliative Care for Adults with Cancer (“the NICE Guidance”) published in March 2004
- The development of new tools such as the Gold Standards Framework, the Liverpool Care Pathway, and the Preferred Place of Care Plan
- The End of Life Care Initiative in 2004, which allocated £12m over 3 years to skilling-up health professionals in palliative care in England, specifically aimed at promoting the use of the above tools in relation to conditions other than cancer
- Marie Curie Cancer Care’s 2004 campaign for choice in relation to place of death
- The formation of a cross-sector consensus that palliative care services must be developed to meet the needs of people with diagnoses other than cancer
- The House of Commons Health Committee’s 2004 report into palliative care, which identified inequities by reason of diagnosis, geography, age and ethnicity, and which also called for greater integration between health and social care provision
- The National Service Frameworks for Coronary Heart Disease and for Older People, which promote the importance of good palliative care
- The Coronary Heart Disease Collaborative’s publication of Supportive and palliative care for advanced heart failure (December 2004), which made recommendations about ways in which the NICE Guidance could be developed to benefit patients with heart failure.

If palliative care services are to build positively on current and future developments, rather than simply respond reactively, a long-term strategic vision for palliative care is required, to provide a route-map towards the future that we would like to bring about.

Expert workshop

The first phase of our 20:20 Vision work culminated in an expert workshop held in conjunction with the King’s Fund in 2003. A range of key figures across health and social care attended this event, including chief executives of leading national charities, policy and public health directors, user representatives, professionals and academics. They worked together in round-table groups to consider a series of questions about the future.
Box 2

20:20 VISION WORKSHOP CONCLUSIONS

The initial questions that our expert workshop considered, with a summary of the preliminary conclusions reached, are set out below. More detailed work is now required in relation to all these issues.

1.) In what way will people’s experiences of the last years of life be different in 20 years, compared with now?

They will often live longer, some with longer periods of ill-health at the end of life. Some will live with more than one condition: medical advances will convert many acute life-threatening episodes into chronic life-limiting conditions.

2) What are likely to be the most important implications arising from the shape of the population and its culture, ethnicity and diversity in 20 years time?

There will be a higher proportion of older people in the population. Many will need support and care, but will have very different individual needs.

The current epidemiological variances between different ethnic groups are likely to change as original immigrant generations grow old, and the needs of the younger generations that follow them develop. At the same time, expansion of the European Union, with a large, fluid employment market, and an influx of people from Eastern Europe, will start to change the picture in a different direction.

Cultural diversity will be an important driver of increased choice and personalised care. The significant challenge for palliative care will be to develop a thorough understanding of the epidemiological impact, and of diverse cultural attitudes and needs.

3) What impact will life-threatening illnesses other than cancer have on the demand for palliative care services in 20 years?

The impact will be very significant. The importance of extending palliative care to non-malignant conditions is now universally acknowledged, and the demand for services will increase. One size will not fit all. Not all solutions and services will be provided by palliative care. New models of care and approaches to partnership will be needed.
The National Council for Palliative Care’s new policy unit will provide evidence and analysis to enable palliative care services to identify and meet the needs of people with conditions other than cancer.

4) Are there likely to be wider economic or policy changes which will impact on the supply and demand of health and social care professionals on the wider care economy, and more specifically on palliative care services in 20 years?

Yes. The reduced numbers of the working age population, and the increase in numbers of those past the current retirement age will reduce the number of available professionals and increase the demands on them. This will be addressed both externally to the existing population, by encouraging immigration or developing new employment and training partnerships both across the EU and beyond, and internally, by changing work and career patterns.

Increased life expectancy, the increase in the number of older people and the reduction in people of current working age, and under-funded pensions are all factors which will contribute to the lengthening of working lives. Similarly, more people will live in active retirement, continuing to do part-time voluntary and paid work long after they have formally retired from full-time paid employment.

5) To what extent will the adoption of palliative and supportive care into mainstream health and social care affect the demand for specialist palliative care services?

The publication of the NICE Guidance in 2004 was a vital first step towards mainstreaming palliative and supportive care. It now needs to be fully implemented, which is a significant challenge. As awareness of palliative care grows amongst professionals and members of the public, that will lead to a rise in demand for both specialist and generalist palliative care services.
The 2003 expert workshop identified a number of key drivers that will impact the ways in which palliative care needs and services will develop over the next 20 years. These include the following themes, many of which are inter-linked.

**Theme 1: Demographic Change – An Ageing Society**

The evidence is that whilst people in Great Britain may expect to live longer in the future, some can also expect to experience longer periods of ill-health at the end of life.

Current government projections are that the proportion of the population aged over 65 will have increased from 16% in 2004 to 21% by 2024. In 2024 10.7% of the population will be aged 75 or over (see Table A).

Yet, whilst we will be living longer, for some those extra years will not necessarily be lived in good health.

Life expectancy is increasing. However, healthy life expectancy (expected years of life in good or fairly good health) whilst rising, is not keeping track with that increase: life expectancy and healthy life expectancy both increased between 1981 and 2001, with life expectancy increasing at a faster rate than healthy life expectancy (see Table B).

When considering demographic change and life expectancy, it should be remembered that there is considerable inequality of life expectancy within the UK.

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<td>63832</td>
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*Table A: Demographic change over 20 years: table comparing projected UK populations in 2004 and 2024. (Source: Government Actuary’s Department, 2002)*
For example, figures by local authority area for 2001–3 show that Glasgow City has the lowest life expectancy in the UK: 69.1 years for men, and 76.4 years for women. Contrast the highest: for men, 80.1 years in East Dorset; for women, 84.8 years in Kensington & Chelsea.³

Whilst geography contributes to this, it is also a reflection of social and economic inequality. There are considerable variances even between communities in close geographical proximity. For example, there is a difference of almost 11 years in the mean age of death for women between individual wards within the Coventry local authority area⁴.

### Theme 2: Grey power and consumerism

The increasingly consumerist nature of society across all generations is now well-documented. People are used to exercising choice in every area of their lives, and expect to be able to do that in relation to their health and social care as well. And so as “baby boomers” approach retirement and old age, we can predict that they will be at least as forceful in asserting their interests as they have been thus far.⁵ This applies both collectively, as “pensioner power” grows as an electoral force⁶, and individually, as people demand more choice and control over the care they receive.

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### Table B: Ill-health expectancy

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<td>5</td>
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Table B: Ill-health expectancy: Table comparing total life expectancy with healthy life expectancy. Source: Government Actuary’s Department (life expectancy), 2002; ONS (healthy life expectancy)
Already different expectations are developing between generations. Those who have made lifelong payments into National Insurance have high expectations of a cradle to grave system of public services, pensions and benefits. Those currently moving beyond their working years expect the system they have always paid into now to pay out. At the same time they expect to be informed and involved in their treatment and care, and to have their choices met. In contrast “Thatcher’s children” have little expectation of the level at which the state will be able to meet their needs, and face having to make personal provision for their future, whilst funding the needs of older generations out of their taxes.

It is a mistake to lump any generation into a single category. Baby boomers have different life experiences, life styles, values and expectations, which will shape the services that they will require individually.7 In every generation, there is an increasing gap between people who are well-off and well-informed, and people living in poverty with poor access to information and services. A significant challenge will be to ensure that people of the latter description obtain the services that they need, and do not become lost in the system, or bewildered by an array of complex choices.

The impact of consumerism on service provision has already been recognised as the government emphasises the importance of choice and personalised care as drivers for change. Similarly, the NHS Expert Patient Programme marks a focus on self-management of health and social care. Following assessment, patients may soon be given a direct personalised budget for their health and social care needs, so that they can design their package of care around their own priorities.8

Increased choice means that communication will be of ever-increasing importance. Not only between patient and professional, although that is vital. The need to cut across existing professional boundaries is already with us, and is essential to the future of palliative care. Sharing of information, and the development of new knowledge and skills, will become of ever greater importance. Multi-disciplinary partnerships will increase. Professionals will need to be able to explain to patients how to access services that they themselves do not provide. To do so, they will need to understand the benefits of those services, and be able to discuss options with patients.

Palliative care services, which are already provided by multi-professional teams, may be better placed to respond to this than some others, where the multi-professional approach is less familiar.
Theme 3: Workforce Changes

The ageing population will also have an impact on the available workforce. On current retirement ages, fewer people of working age will be available to provide services to an increasing number of older people.

If this continues, there will be other resource implications beyond workforce availability: if there are fewer workers, tax revenues will fall. However, the likelihood is that working lives will lengthen. Under-funded pensions will drive that – people will need to work longer to fund their retirement, and will be increasingly less able to retire early. A growth in part-time working at the end of working life is also likely, as people support themselves partially through pensions and savings, and partially through work. This trend has been confirmed by the first Report of the Pensions Commission in October 2004. Policy targeted at ending age discrimination in the workplace will also assist.

Encouraging immigration is another solution to problems caused by a shrinking workforce. Yet it may prove a short-term fix, unless planned on a long-term and sustainable basis. Immigrants become part of the population, grow old, become ill, and need care.

There is already a reaction against encouraging professionals from poorer nations with younger populations to come to care for Britain’s sick and elderly, rather than tending to the urgent needs of their own people. Another view is that mutual benefit and sustainability can be derived through partnerships by which professionals coming from emerging economies gain skills and experience through practising in the UK that enable them subsequently to return and develop services in their country of origin. This is already evident in relation to countries beyond the EU, and the fluid employment market in the expanded EU will encourage it. Indeed EU employment patterns will be a significant influence on workforce issues for the future.

On a less skilled level, should basic social care be provided by poorly-paid ill-trained workers, often from poorer nations? Those who provide basic social care for our elderly people are currently amongst our most low-paid and poorly-trained workers. Will we continue to accept that state of affairs? As grey power increases, we are likely to place a higher value on older people, and accordingly on those who care for them.

Theme 4: Cultural and Ethnic Diversity

As a result of government employment and immigration policy over many years, the UK has a very diverse ethnic population, particularly in its cities. Understanding cultural and ethnic diversity of need is and will continue to be a key issue in planning service provision. This will remain the case, whatever employment or immigration policy governments adopt in the future.
Service commissioners and providers will need to develop a thorough understanding of different cultural attitudes to disease, care, dying, and death. Those different attitudes may give rise to different service needs. This must affect the way in which services are designed, and made accessible. Dialogue and communication are vital.

Understanding epidemiological trends is also an important key. For example, cancer was initially less prevalent as a cause of death amongst some first generation ethnic minority immigrants than it was amongst the existing white population. This may in part have been because they were generally younger than the existing population. However “over time cancer rates of migrants appear to converge with those of host countries, suggesting that as the populations age and adopt a Western lifestyle and diet, there are socio-economic and environmental links to the risk of the disease.”

It should though be noted that the extent to which migrants do adopt Western lifestyles or conversely retain their cultural and ethnic identity, may vary. For example, one trend amongst some young Muslims is to emphasise and embrace traditional Muslim culture rather than gradually integrate into a Western lifestyle.

We can expect that the impact of cultural and ethnic diversity will change as palliative care becomes increasingly available for people with life-threatening conditions other than cancer, and so begins to address the variance in the incidence of different diseases between ethnic groups, as well as similarities.

The relationship between epidemiology, ethnicity, migration, and aging is already complex. Diversity of cultural attitudes makes that more so. There will be continuing needs for dialogue, research, enhanced understanding and professional education for the foreseeable future.

**Theme 5: Epidemiological Change**

As people live longer, so we can expect epidemiological trends to change. Acute health conditions will be converted into chronic ones; as people survive acute life-threatening diseases, they will live longer with chronic life-limiting conditions. There will be longer survival rates after acute episodes. Technological change and improved management of conditions will also contribute to this.

Co-morbidity will increase; people will live with multiple pathologies, any one of which might be responsible for the final illness, but all of which might be contributory in some respect, and all of which will form part of the person’s overall symptom burden. Examples of this might include people living with different combinations of conditions such as...
as cancer, coronary heart disease, dementia, diabetes or arthritis.

A trend already with us, that will increase, is the number of children with life-limiting illnesses who survive into adulthood. This has significant implications for the delivery of services, and the management of transitions between service providers at different stages of life.

**Theme 6: A Society Engaged with its Health?**

One factor that will have a profound impact on the shape of services in the future is the extent to which people take care of themselves, become engaged with their health and develop expectations about what care should be available. Recent public debates about smoking and obesity are relevant in this context.\(^\text{12}\)

The Wanless Report identified 3 possible scenarios for the future. Policy makers will have to test and assess the Wanless scenarios in their planning for future service provision (see Box 3, on page 12).

**Theme 7: Living alone and in communities**

"If the demand for care continues to increase at present rates and if we are to meet the pressures of demographic change in the future – then we will never be able to meet demand entirely with professional carers.\(^\text{14}\)

Even if we had the money – which we never will – there just won't be enough people available to work in the sector. That means we have to find ways to increase the capacity of care, within families, within neighbourhoods and within communities. And volunteering and the voluntary sector will take on a new and even more pivotal role.\(^\text{13}\)

Social changes will affect more than our attitude to our health. Current trends indicate that people will be more likely to live alone. Rising divorce and family fragmentation have contributed to this. Many of those living alone are older people. Currently 14.4% of households are occupied by pensioners living alone. Over 50% of women aged over 75 live alone.\(^\text{14}\)

The rise in ill-health expectancy at the end of life, combined with a growth in self-management of health, means that more people are likely to be living with long term conditions in their home setting, possibly alone, and will require support from friends, family and their community. Much of their health care is likely to be provided in a primary setting. Their health and social care needs will become increasingly indivisible. Already there is a need for greater integration of health and social care. The Health Committee Report identified this as a key objective.\(^\text{15}\)

Integrated commissioning and pooled budgets must become the norm. If this comes with personalised direct budgets, it will empower patients...
and increase the choices available to them\textsuperscript{16}. A Green Paper on adult social care is imminent, and promises to start addressing this issue.

As more people live alone, so there will be fewer informal carers within the family home. Networks of friends, wider family, community and volunteers will have to arise to fill those gaps.

**Theme 8: Invigorating civil society**

The 2003 expert workshop identified the need to foster the conditions in which a stronger civil society can flourish. The Treasury’s cross-cutting review\textsuperscript{17}, which recognised that the voluntary sector should be properly remunerated for the services it provides to the state, is a welcome step in that direction\textsuperscript{18}. There is however a danger that, through providing services to the state, the voluntary sector will become over-bureaucratised and lose the organic creativity that enables it to flourish.

At the same time, we need to cultivate less formal areas of voluntary activity. This may involve the identification of communities where effective self-help and thriving civil society exists, or taking steps to reverse the fragmentation of society, for example looking at ways of encouraging families to care for elderly or sick dependents. This might take the form of tax incentives or compassionate leave\textsuperscript{19}.

This will influence the way in which communities develop. People will come together to share resources, companionship and care. This might be reflected in new forms of architecture, enabling people to live in a mutually supporting way whilst retaining some privacy of space. For example, how will care homes be constructed in 20 years time? Will new models of supported homes and extra care schemes evolve? Planning strategies and building design will need to evolve in ways that enable people and families to come together and reinvigorate their communities and support networks. Housing associations and local authorities will have a significant contribution to make.

One example of new forms of mutual community-based support is Time Banks and LETS (Local Exchange Trading Systems). These are schemes by which people exchange all kinds of goods and services by using community credit points rather than money. People earn credits by providing a service, and can then spend them on services offered by other members of the scheme. These are now operating in some locations in the UK.
Box 3

The Wanless Scenarios

The first Wanless Report used three scenarios for the future: slow uptake; solid progress; and fully engaged.

Slow uptake

No change in the level of public engagement in relation to their health. Life expectancy rises by the lowest amount in all 3 scenarios. Health status of the population is constant or deteriorates. Health service is relatively unresponsive with low rates of technology uptake and low productivity.

Solid Progress

People become more engaged in relation to their health. Life expectancy rises considerably. Health status improves. People have confidence in the primary care system and use it appropriately. Health service is responsive with high rates of technology uptake and a more efficient use of resources.

Fully engaged

Levels of public engagement in relation to their health are high. Life expectancy increases go beyond current forecasts. Health status improves dramatically. People are confident in the health system and demand high quality care. Health service is responsive with high rates of technology uptake, particularly in relation to disease prevention and a more efficient use of resources.

Comment

Current actuarial assumptions are based upon the solid progress scenario. However the government required Wanless in his second report, Securing Good Health for the Whole Population, to make recommendations consistent with the fully-engaged scenario being achieved.

Policy makers will need to consider the extent to which that is a realisable ambition, or whether other scenarios represent a more reliable forecast. What impact will initiatives such as the November 2004 Public Health White Paper Choosing Health: making healthier choices easier, have towards the fully-engaged scenario becoming a reality? Is it sensible or even possible to try and impose a single scenario on the entire population, or is it more likely that there will be large numbers of people within each of those 3 scenarios, and that the picture will be mixed – across social and ethnic groups, geographically, and economically?
**Next Steps**

"Better care of the dying should become a touchstone for success in modernising the NHS. This is one of the really big issues – we must make it happen".\(^{20}\)

The National Council for Palliative Care has recently established a national palliative care policy unit. Whilst this has been part-funded by the Big Lottery Fund and other organisations, further resources to support its work are required, particularly to develop the longer-term future for palliative care.

The policy unit’s brief is to produce policy for the development of palliative care for all who need it. This will involve the continuation of our work in relation to cancer, and, vitally, the extension of that work to address the palliative care needs of people with conditions other than cancer. This will require the formation of new partnerships and collaboration with organisations across the voluntary, public and independent sectors, not only in health and social care, but in education, and fields of wider public policy. Some of this work is now underway.

A key part of that work will be to look at many of the cross-cutting themes that have been identified above, including population and epidemiological change, co-morbidity, social exclusion, ethnic and cultural diversity, understanding patient needs through user involvement, and the needs of older people (themselves a very diverse group, defying easy categorisation).

Although the policy unit will focus on policy models and options for the short to medium term development of palliative care services, it has also been tasked to take a longer term view, and take up the 20:20 Vision project.

The policy unit’s long-term vision building will be based on available data, statistical projections, literature review, and solutions identified by stakeholders across palliative care. These will include service users and carers, service commissioners and providers, academics and palliative care professionals, across all sectors. Our hope is that, through widespread dialogue and consultation in our policy groups, a shared view of the future can be developed.

Part of this work must include bringing the philosophy that gives rise to palliative care into the mainstream of health and social care. There is still too much misunderstanding about what palliative care is, on the part of health and social care professionals as well as members of the public. This lack of understanding, particularly on the part of professionals, is a consistent barrier to the development of palliative care. If professionals do not understand what palliative care is, how can they explain and offer it to their patients, or signpost them to the range of available services?
Palliative care is not solely concerned with the end of life; it is relevant throughout the course of long-term conditions, as the NICE Guidance identified. Looking forward, palliative care needs to become a compulsory part of the training and continuing education of all health and social care professionals. The aim should be to ensure that palliative care principles become completely integrated throughout health and social care.

**Conclusion**

"Some see things as they are, and ask, Why?"

*I dream things that never were, and ask, Why not?*

It is a measure of the success of palliative care services that policy makers are now recognising the relevance of palliative care across a far wider spectrum. There is an increasing readiness to bring the principles that underpin palliative care into the planning and provision of health and social care, although we are still at the beginning of that process. This brings with it the challenge of ensuring that future services are developed in a consistent and coherent manner, without either compromising the diversity that enables patients to be treated in a holistic way or losing sight of their individual needs and the choices they wish to make. A shared vision for future development will provide a framework within which that can take place.

The key message from the 2003 expert workshop was that we should not be content simply to think in terms of managing to cope with the future. Instead, we should have the confidence both to imagine what palliative care might one day be like, and to identify the drivers, forces and strategies that will make that happen. If we can combine clarity of mind to identify the ideal vision for the future with boldness to be radical in identifying ways to make it the reality, great achievements can be accomplished, and the quality of life and care of many people will be improved. This will require policy makers to think in new and different ways about the infrastructure of our society, and to explore the relationships between things that at first sight might seem unrelated, such as primary care provision, architecture, and civil renewal.

It is too easy to paint a gloomy scenario when thinking about the future. It need not be like that. In 20 years time we may be living longer, be more engaged with our health, have realistic choices to make about our care, be better informed about those choices, and living in communities with vibrant and innovative volunteer networks. The policy choices that are made now will determine whether that becomes the reality.

It is essential that all those involved, not just in palliative care, but in developing policy across health and social care take part in the debate about the future. At the same time,
society as a whole needs to become engaged. How do we want to look after our older people? What quality of care do we want those who are living with long-term progressive conditions to receive? When our time comes, how do we want to die?

We at The National Council will play our part in that by encouraging discussion and seeking to develop a long-term strategic vision. However, we encourage anybody with an interest in palliative care to contribute to this debate and our future work in this area. We would in particular welcome support and resources to enable us to progress the work set out in the 20:20 Vision Terms of Reference (see Box 1).

If you wish to respond to the issues raised in this document, please e-mail Simon Chapman at; s.chapman@ncpc.org.uk or write to him at our London office.

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The King’s Fund, for hosting the June 2003 expert workshop.
References

1 Peter Cardy, Chief Executive, Macmillan Cancer Relief, January 2003

2 See Box 2 for a summary of the initial responses to these questions


4 Coventry PCT figures for 1999–2001 show that the highest mean death for women is in the Earlsdon ward at 82.6 years, and the lowest, in nearby St. Michael’s, is 71.7 years

5 Looking beyond the grey, Age Concern, 2004

6 70% of people aged over 65 voted in the 2001 general election, compared with a national average of 59%: MORI

7 Age Concern’s 2004 research, published as Looking beyond the grey identified 6 distinct segments of older people, with markedly different outlooks and expectations

8 Stephen Ladyman MP, Parliamentary Under Secretary of State for Community, speech 17/11/04

9 www.pensionscommission.org.uk

10 For further information and discussion on this theme, see our publication Wider Horizons, Shirley Firth, 2001

11 Shirley Firth, Wider Horizons, ibid

12 See (for example) the Public Health White Paper Choosing Health: making healthier choices easier, November 2004

13 Stephen Ladyman MP, Parliamentary Under Secretary of State for Community, speech 17/11/04

14 Source: ONS – 2001 Census

15 Palliative Care, 4th report of session 2003–4, para. 4949

16 See further the discussion under theme 2 above

17 The Role Of The Voluntary And Community Sector In Service Delivery – A Cross Cutting Review, H M Treasury, September 2002

18 The Treasury has said that voluntary adult hospices will receive full cost recovery for the services they provide to the NHS by 2006/7

19 The Health Select Committee recommended that the government follow the recent example of Canada, and legislate to provide carers with paid statutory leave. That might enable more people to die at home. Marie Curie’s research suggests that the cost to the public purse of such compassionate leave would be offset by the reduced costs of home deaths

20 Sir Nigel Crisp, Chief Executive of the NHS, March 2003

21 NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer, March 2004, para. 114

22 Robert F. Kennedy

23 See themes 7 and 8 above.