

“To allow people the deaths they want, end of life care must be radically transformed...”

DYING FOR CHANGE

Charles Leadbeater
Jake Garber

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As ever, all errors and omissions are our own.

Charles Leadbeater

Jake Garber

October 2010

Preface

Bill died at 4am on 18 August 2010, the morning of his 86th birthday, in Ward 3 of Airedale General Hospital in north Yorkshire. His final view in life would have been the stained polystyrene tiles above his bed. The drab room in which he died provided a measure of privacy but little else. The walls were covered with a fading washable wallpaper of indeterminate colour. The room was a workplace for nurses and doctors rather than somewhere someone would choose to reflect on their life and be close to his family in his final days. Bill's wife Olive would struggle past chairs, push away stands and tubes, and stretch across the metal guards surrounding his bed to kiss him. The room was designed for medical procedures, not for kissing. The ward's 'lounge' was barely worthy of the name. Lit with fluorescent strip lights, its comforts were a jumble of old armchairs, an ageing television and a public payphone.

It was not just the room that made Bill's dying so impersonal but the ward's procedures. His relatives struggled to find a telephone number for the senior medics serving on the ward, let alone to talk to them. When Bill's family met his consultant for the first time it was after his death and she revealed that she talked to patients' families only when they pestered her. The nurses on Ward 3 were caring and hard working. Yet establishing a relationship with them was impossible: with every shift came a different nurse. Often it seemed as if no one knew what was wrong with Bill. But that might be because no one was comfortable talking about the fact he was dying.

As his family acknowledge, it would be too easy to blame everything on an unfeeling system. His family could not have cared for Bill at home. His wife was 92 and frail. His sons, married with families, were not local. None of them were well

prepared for a direct discussion with Bill about the fact that he seemed to be dying. Everyone had an interest in skirting around the subject. When Bill was asked directly whether he wanted to carry on living, he said he did not see any other option: he did not want to give up on life. The medical profession took its cue from that desire to eke out the last moments of life.

Seemingly fairly fit and well, although anxious and at times depressed, Bill had been admitted to hospital in February with an enlarged prostate. An attempt to insert a catheter was successful and he was discharged but just before a weekend, in a rush. When he arrived, home support from social services and district nurses took days to come. Lying in his bed he quickly developed a pressure sore. After another visit to hospital for a procedure to open his urinary tract, the pressure sores grew. In common with many people his age, Bill had other conditions, among them a weak heart. By the time he was admitted to hospital for the final time, in July, the combination of these conditions and the infection caused by pressure sores were killing him. The district nurses decided they could not cope with him at home. So he was despatched to hospital, even though it was unable to do much for him.

Most of us will die as Bill did, in old age, with a combination of conditions, in hospital. Some hospitals may provide sensitive, high quality care. Others will resemble impersonal waiting rooms, inhabited by people poised uncertainly between life and death. It was not that the staff on Ward 3 did not want to do a good job. They were part of a system that seemed designed by and for the doctors rather than the patients and their families. Too often hospitals neglect the social, psychological and spiritual aspects of dying, which are vital to dying a good death. That social shortfall is why hospitals are rarely the best places in which to die. Bill's doctors had an ethical commitment to try to mend and heal him. Yet he could not be healed and no one could bring themselves to open a conversation about the fact that he was going to die.

Bill's death was not a tragedy. He lived a long, happy and healthy life. Some of that life he owed to interventions by the medical profession: operations to fix his knees and sight.

Without modern medicine he would not have been alive at the age of 86. Yet the medical profession that had extended his life was unable to provide him with a good way to die.

Once Bill had died it did not take his wife long to work out she wanted to die as well because life without him would hold little for her. Olive did not want to sit alone at home or be parked in a nursing home. She was 92; she'd had enough. Yet before Bill's funeral could be organised Olive had a thrombosis and ended up in Bradford Royal Infirmary. She went on hunger strike. For weeks she lived on a diet of Ribena. She kept asking the nurses for 'one big pill' to see her off. The nursing staff cared for her professionally but also sensitively. Gently they tried to talk her round. Finally her original condition was cured and they let her go to a nursing home a stone's throw from her home – heavy chintz and pine furniture, with lovely views down the Yorkshire Dales.

Olive realised that if she stopped taking the anti-blood-clotting drugs that were keeping her alive, she could bring her life to a close. She did not commit suicide but she knew that she was ending her life. The last time her youngest son saw her she ushered him out of the room with a wave and a knowing nod. She had things to do.

In the last weeks of her life Olive was on a mission to find her way around a system that was determined to keep her alive when she was equally determined to die. Somehow, at the age of 92, despite being frail, weak and losing her memory, she managed to orchestrate her own death, which came with a sense of completion and achievement, dignity and grace, agency and control. Hers was a good death. Yet it felt like an act of civil disobedience. Olive and Bill were cremated together, their ashes mixed and scattered across their favourite beaches on the Isle of Arran.

This pamphlet was inspired by these two experiences, eight weeks apart, in the autumn of 2010: my parents' deaths. My mother's was a good death: she lived a long life; she was not in pain; she was surrounded by friends and family; she was in control and so she died with dignity. My father's death felt like a bad death. He was not in pain but nor was he in control; his

death lacked dignity and there was limited scope for relationships with friends and family in the final weeks. The hospital and its systems were not solely responsible for this but they played a big part.

Far too many of us, perhaps hundreds of thousands each year, will die deaths like Bill's, in places like Ward 3. Far too few will die deaths like Olive's, supported, dignified and in control, close to home and family. This report is about why and how we should change that to give more people a chance of dying a modern, good death.

Charles Leadbeater
November 2010

Executive summary

As a society we are ill-prepared for how we will die in the next two decades.

About 500,000 people die each year in Britain. From 2012 the number of deaths will start to rise as baby boomer generations die. By 2030 about 590,000 people will die each year.

Many people say they want to die without warning, in their sleep. The reality is that most people will die drawn out deaths and they will need support over many months because they will be frail and suffering from multiple chronic conditions.

That is largely because most of us will die in old age. By 2030, people over the age of 65 will account for 86 per cent of deaths. Those over 85 will account for 44 per cent of deaths.

As things stand most people will not die where and how they would wish.

In our poll conducted with YouGov, two-thirds (66 per cent) of people said they would prefer to die at home. On current trends by 2030 only one in ten people will die at home. Only 1 per cent said they wanted to die in a care home. Yet by 2030 more than 20 per cent of deaths will be in care homes. Only 7 per cent said they wanted to die in hospital. Yet about 58 per cent of deaths take place in hospital and the figure will rise to close to 65 per cent by 2030.

The way we die has improved markedly in the last century. Medical advances mean many fewer people die in pain. Most people do not die young. Britain recently came top of an international league table for end of life care.

Yet the institutionalised ways we cope with dying are out of kilter with how most people aspire to live at the end of life. Most people want to die with family and friends nearby, cared for, free from pain, with medical support available when it is needed.

Instead, most people will die in hospitals and care homes, often feeling cut off from friends and family, dependent on systems and procedures that feel impersonal, over which they have little control and which offer them scant sense of dignity. As things stand, many of us will die unnecessarily distressing deaths.

Our conservative estimate is that at least a fifth of NHS spending goes on end of life care and the cost of that care will rise from about £20 billion today to £25 billion in 2030. Yet 40 per cent of people who die in hospital do not have medical conditions that medics can fight. About half of all complaints to the NHS involve criticism of the circumstances in which someone died.

Dying at home, in contrast, conjures feelings of warmth, intimacy and control. However, the burdens of caring for someone dying at home, possibly over many months, are huge. It will only be possible for more people to die at home if the people who care for them can rely on much better personal support and medical care. People want to die with their families, without being a burden to them. Many elderly people will die while they are on their own; to die at home they will need special support.

We should be able to provide people with better ways to die wherever they die. One priority is to improve the way hospitals and care homes look after people who are dying. Four developments should be at the core of this:

- Unless we can devise ways to get people to talk about how they want to live while they are dying, our efforts to improve services will be like groping in the dark. It should become standard for people reaching the end of life to create advanced care plans with the help of friends, family members, trained peers or professionals. Evidence from the USA suggests this can dramatically reduce unnecessary admissions to hospital and improve care.
- Training in palliative care needs to be much more widespread among doctors, nurses and care home staff at large. Too few doctors, nurses and care home staff are ready to have open conversations with people about the prospect of death and how they want to die.

- We should draw on the models of federated schools to link hospices to groups of care homes, so that hospice skills and values can migrate into care homes.
- Services should be commissioned by end of life trusts in an integrated way that bring together public, private and voluntary providers within a community.

Improving the services we have, however, will not meet people's aspirations not to die in a hospital or care home. As well as better hospitals and care homes we need effective community alternatives to them.

We estimate that an investment of £500 million a year, about 2.5 per cent of NHS spending on end of life care services, would create the backbone for community services that would allow perhaps 50 per cent of people to die at or close to home. This investment would more than pay for itself in the course of a decade through fewer and shorter hospital admissions.

This investment would enable the NHS to carry out the following:

- Create new places for people to die close to home where they could be with friends and family, have their personal care looked after and their pain relieved, while calling in medical support when it is needed. These places may emerge from several roots: the re-creation of community hospitals; ultra-local home hospices with a handful of beds; and shared housing schemes, which provide people with on site nursing support. These should be social places which can call on medical services when they are needed.
- Strengthen family capacity to care by providing a dedicated compassionate care benefit or care leave entitlement, modelled on a mixture of the Canadian and Swedish schemes, to provide financial support for someone looking after a dying relative.
- Create a properly trained volunteer support network modelled on Kerala's Neighbourhood Network for Palliative Care. Using the Kerala ratio of one volunteer mentor for every 2.5 patients a UK-wide system would cost £74 million to coordinate volunteers to provide 40,000 hours of support a week.

- Set up a dedicated 24/7 nursing support service to help people cope with medical crises that hit families, especially overnight and over weekends. We estimate this would cost an additional £33 million.
- Establish dedicated end of life telephone help lines with a friendly, familiar and knowledgeable person at the end of the line. Pilots in the USA and the UK show these telephone services are highly effective in supporting carers.
- Set up a national hospice at home service to come to people dying at home. An effective national hospice at home service serving about 90,000 people a year would cost about £150 million.
- Provide people with a key relationship, such as Age UK's end of life advisers, who work with clients over a prolonged period to help them understand what is most important to them in the final months of life, navigate them to appropriate services and accompany them when they visit formal services.
- Spread the use of personal budgets at the end of life, which will allow people and their families greater scope to commission the kinds of care they want.

Our challenge is to help people to achieve what is most important to them at the end of life. That will require the creation of a network of health and social supports so that people can die at and closer to home, with the support of their family and friends, as well as professionals.

If we do not create this social network, then in the decades to come many hundreds of thousands of people will experience unnecessarily distressing deaths. We will die badly in places not of our choosing, with services that are often impersonal, in systems that are unyielding, struggling to find meaning in death because we are cut off from the relationships which count most to us.

This is a litmus test for the coalition government's idea of a big society in which civic, mutual, self-help solutions play a much larger role. Communities and families have coped cooperatively with death for centuries. Only very recently have we become heavily reliant on institutional, professional

solutions. There is mounting evidence that a lot of money is spent on public services that people do not want as they are currently delivered, and which are poorly designed to meet their needs.

People want solutions that allow them to die at home. Yet big society-style community solutions will not emerge from thin air. Volunteers can at best carry a small share of the burden. Most families cannot be expected to cope on their own with dying relatives. We need a serious and properly funded government strategy to support the creation of the local, social and cooperative solutions people want. The big society will not come into being without a supportive and creative state.

1 Introduction

Britain needs to create ways for people to live well even as they are dying, otherwise in the decades to come many hundreds of thousands of people will experience unnecessarily distressing deaths. We will die badly in places not of our choosing, with services that are often impersonal, in systems that are unyielding, struggling to discover meaning in death because we are not in surroundings that provide for intimacy and care and find ourselves cut off from the relationships which count most to us. Our challenge is to help people to achieve what is most important to them at the end of life. That will require the creation of a network of health and social supports so that people can die at and closer to home, with the support of their family and friends, as well as pain relief and medical services as they need them.

The way we die in Britain is a litmus test for the arguments that swirl around David Cameron's idea of the big society in which civic, mutual self-help solutions play a much larger role in meeting shared needs. The case for a big society approach to death and dying is both powerful and deep rooted. Communities and families have coped cooperatively with death for centuries. Only very recently have we become heavily reliant on institutional, professional solutions – care homes and hospitals. There is mounting evidence that the services these institutions offer are costly and inappropriate. A lot of money is spent on public services that people do not want as they are currently delivered, and which are poorly designed to meet their needs.

Many of the most impressive alternatives have their roots in community self-help. Independent hospices, for example, raise most of their funds from their local communities and involve volunteers heavily in their work. Half the population of the Isle of Wight took part in a sponsored walk for the island's hospice.

Yet new community solutions will not emerge from thin air. Volunteers at best can carry only a share of the burden. Families that are often already stretched to breaking point between their commitments to work and their children cannot be expected to cope on their own with dying relatives. So the test is whether the government can respond to the demand for more local, social and cooperative solutions with a properly funded strategy to support the alternatives people want. As far as death and dying is concerned the big society that people want will only come into being with a supportive and creative state.

The case for innovation in how we cope with the dying is made by the findings of our poll with YouGov.¹ Two-thirds of people (66 per cent) said they would prefer to die at home, a figure in line with other polls on the subject. Yet on current trends by 2030 only one in ten people will die at home.²

Only 1 per cent of people said they would prefer to die in a care home. Yet by 2030 almost 25 per cent of deaths will take place in care homes and many people will spend much of their final year in a residential home. Only about 7 per cent of people said they would want to die in hospital. Yet in 2010 about 60 per cent of deaths will be in hospitals and the figure will rise to close to 65 per cent by 2030.³

Our estimate is that by 2030 the direct NHS costs of providing beds for people at the end of life will be £25 billion, up from £20 billion today. We spend very large sums of money providing people with solutions that do not reflect their aspirations nor even their needs: the National Audit Office (NAO) estimates that 40 per cent of people dying in hospital are not receiving medical treatment that requires them to be in hospital.

Hospitals and care homes are unable to provide vital parts of what matters to most people at the end of life: 36 per cent of respondents said access to friends and family would be the most important feature of a good place to die, 20 per cent mentioned good personal care, about 22 per cent mentioned accessible pain relief and 12 per cent access to good medical services. Social and personal factors are more important than religious or medical services in making somewhere a good place to die.

That is what makes dying at home seem so attractive. About a third of people mentioned having friends and family close by as the main reason for wanting to die at home. A fifth said they wanted to be surrounded by possessions that had meaning for them; 18 per cent said it was because home was a place with memories. In contrast, hospitals are often regarded as poor at meeting people's social and psychological needs in the approach to death.⁴

Another indication of the appetite for different approaches is that people are prepared to trade money for greater control. We asked people to imagine that they were elderly, in the last three months of their lives and they were offered a personal budget to organise their own care. Even though we said this budget would be worth 15 per cent less than the amount that would be spent on them in hospital, six in ten people said they would take such a budget.

Yet as things stand there is fundamental mismatch between what people want from home and what it can provide. Two-thirds of people want to die at home. Yet only a quarter of people (25 per cent) said they thought they would be able, on their own, to look after someone dying at home. Half of people (50 per cent) said they thought they would feel stressed, 44 per cent would feel exhausted and 40 per cent would be fatigued by caring for someone dying at home. People dying do not want to be a burden to their family. That is why many people accept going into a hospital or a care home: to relieve the burden on their family.⁵

However, if the burdens of home care were eased by the provision of proper medical and social support, then 50 per cent of people said they would be able to cope. Six in ten people (62 per cent) said they thought they would be able to cope if they had both medical and personal care support.⁶

Our poll shows we have two priorities. We need to improve hospitals and care homes, so they make room for relationships and draw people into shaping how they want to live in the last weeks of life. In tandem, we need to find ways to support many more people to die at and close to home, without becoming an unbearable burden for their families.

We need to improve the services we have *and* create alternatives to them. This pamphlet explains why such innovation is so needed and how it can happen.

2 Dying the modern way

As a society we are ill-prepared for the way we will die in the two decades to come. More people will die drawn out, complex deaths, in their old age, deaths that will require support over many months if not years.

One dimension of the challenge is the numbers of people involved. About 500,000 people die each year in England and Wales.⁷ From 2012 the number of deaths will start to rise as baby boomer generations die. By 2030 about 590,000 people will die each year.⁸

The number of deaths will start to increase just as public spending is cut back to tackle the deficit. Funding end of life services will become more difficult if other calls of health spending – treating younger people, who are more economically productive, whose life span might be significantly expanded by medical intervention – take precedence.

Most people who die in the next two decades will be old. A century ago, before the advent of mass medical systems, antibiotics and public health programmes, few people lived past the age of 65.⁹ Over the last 25 years the population over 65 years old has risen by 1.5 million, and the number of people over the age of 85 has doubled to 1.3 million.¹⁰ In 2006, life expectancy was up to 77 years for men and 82 for women.¹¹ The Government Actuary Department predicts that by 2074 there will be 1 million people over 100 years old, a 100-fold increase.¹²

As a result, far fewer people are likely to die ‘before their time’. Most people will die after living a long life. Of the half a million people who die in England each year, two-thirds are more than 75 years old and one-third are more than 85 years old.¹³ By 2030 people over the age of 65 will account for 86 per cent of deaths. Those over 85 will account for 44 per cent of deaths.¹⁴ Death will overwhelmingly affect the old and dying

will be accompanied by the health conditions associated with ageing.

As Joanne Lynn, the leading US researcher into end of life puts it, people used to experience life-threatening illnesses the way they experienced bad weather – something that struck with little warning. People either weathered the storm, with the help of medicine, or they succumbed. Modern dying, for the old, is very different.¹⁵

Many of the extra years we live are spent in good health. Yet our healthy life expectancy has not risen fully in line with our life span. In the UK in 2004–06, healthy life expectancy at birth was estimated as 68.2 years for men and 70.4 years for women; disability free life expectancy at birth was 62.4 years for men and 63.9 years for women.¹⁶ Most people can expect approximately six years of ill health, mostly at the end of life.¹⁷

Modern death, concentrated among the old, is not usually caused by an accident, nor by a sudden single infection, but by a combination of chronic conditions, which slowly rob someone of their physical, social and mental capabilities. Around three-quarters of deaths in the UK are ‘predictable’ and follow a period of chronic illness.¹⁸ Dying has become protracted, complex and painful. The most common causes of death are cardio-vascular disease (31.6 per cent), cancer (27.4 per cent) and respiratory causes (13.9 per cent).¹⁹ The charity Marie Curie Cancer Care estimates that one-third of us will die with a form of dementia, such as Alzheimer’s.²⁰ At least a quarter of 85-year-olds are thought to have the disease.²¹ Those chronic conditions are still on the rise. In 1972, a fifth of people in the UK reported having a long standing illness; by 1998 this figure was 34 per cent.²² This kind of dying can take months and even years.²³

As Dr Guy Brown, senior lecturer in the Department of Biochemistry at the University of Cambridge, puts it:

The convenient fiction of attributing death to a single cause in order to fill out a death certificate can lead to other fallacious conclusions from death statistics. Older people appear to die from vascular disease, cancer or pneumonia; yet the incidence of these diseases rises dramatically with age, suggesting that the diseases themselves are caused by aging. Many doctors

*would now accept that it is more honest to say that old people die from old age, rather than a particular disease, but 'old age' is not acceptable as a cause of death on a death certificate.*²⁴

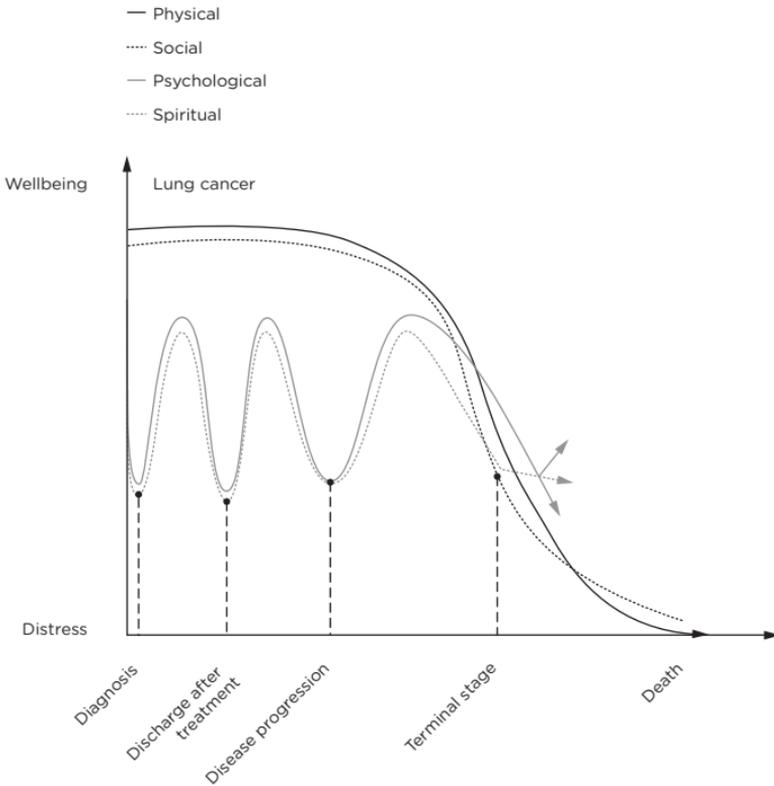
The conditions that cause our deaths attract very different medical and social responses. Cancer, which causes just over 27 per cent of deaths, takes the lion's share of specialist palliative care services including hospice beds.²⁵ However, many more people die of a mixture of long term conditions, such as diabetes and arthritis, combined with advanced old age and complicated by lung and heart conditions. While cancer has attracted huge investment in fundamental research science, medical treatments, services and a burgeoning self-help movement, deaths from other diseases and non-specific causes garner far less attention and support.²⁶ The people who are most likely to die in a care home or in a general acute hospital suffer from these more neglected multiple conditions.

The differences are highlighted by this comment from one of our interviewees, the daughter of a man who died of heart failure, aged 82, but who was diagnosed with lung cancer shortly before he died. She told us:

It seems like you can have everything if you have cancer. Because he was diagnosed with lung cancer, he could have everything, night sitter, Macmillan nurses. It seems so unfair. He couldn't walk before and we had to manage with him at home.

Many people say they would like to die without warning and in their sleep.²⁷ The reality is that most deaths will be lingering and long foretold. With some conditions the decline to death might be fairly predictable. For those dying from a mixture of long term conditions the decline is likely to be marked by sudden peaks and troughs, physically, socially and emotionally.²⁸ Dying has multiple dimensions: someone's physical state may bear little relation to how they are feeling psychologically and the health of their relationships. Scott Murray, St Columba's Hospice Chair of Primary Palliative Care Research Group at the University of Edinburgh, has mapped the connections between

Figure 1 **Mapping the physical, social, psychological and spiritual decline to death from lung cancer**

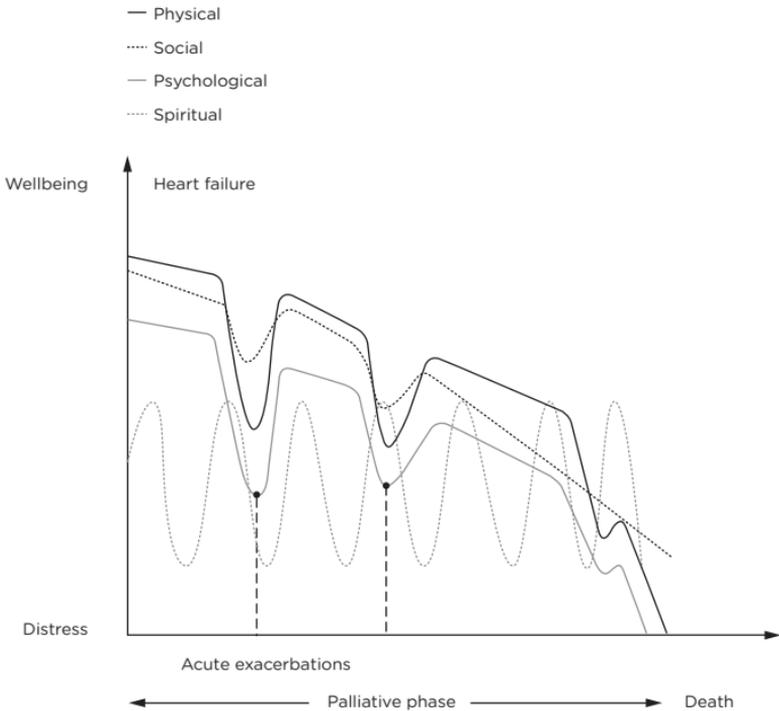


Lung cancer: physical, social, psychological, and spiritual well-being in the last year of life.

Source: Murray et al, 'Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure'²⁹

people's physical decline while dying and their social and psychological well-being. In some cancers the trajectory of physical decline follows a fairly predictable arc. Yet someone's psychological needs may vary considerably, from an initial depression after diagnosis to relative optimism during periods of

Figure 2 **Mapping the physical, social, psychological and spiritual decline to death from heart failure**



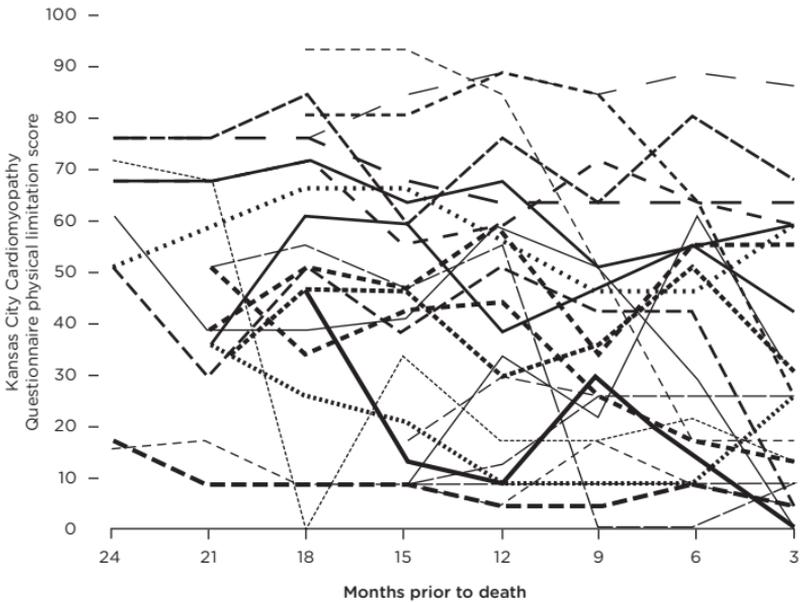
Heart failure: physical, social, psychological, and spiritual well-being in the last year of life.

Source: Murray et al, 'Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure'³⁰

treatment and remission. With lung and heart disease both the physical decline and the psychological aspects of dying are likely to be far more uneven, with marked ups and downs punctuating overall decline, as figures 1 and 2 show.

Even if it is fairly clear someone is dying it is often difficult to predict when death will come and so when the person will need medical services, still less psychological and social

Figure 3 Dying trajectories in heart failure (27 patients)



Source: Gott et al, 'Dying trajectories in heart failure'³⁴

supports. Modern, protracted ways of dying burden everyone involved with a deep uncertainty: how to know and when to accept that the battle to prolong life is lost. Few people are confident about making that call.

All this means that a good death cannot be delivered to someone in the way we deliver parcels, pizzas or even babies. An overly rigid approach, which mandated a detailed pathway, is bound to failure. Once we depart from fairly mechanical procedures, such as inserting a catheter, and impose a 'best practice' method on a malady made up of multiple conditions, with complex social and psychological ingredients, then services are almost bound to be inadequate.³¹

Dying is very complex. The typical disease trajectories that are often used show a route that is easily comprehensible, and

claim to represent an average of actual trajectories. Professor Merryn Gott plotted the trajectories of 27 actual heart failure patients, showing a very different picture (figure 3).³² One US study found that medical best practices are so often found to be wanting that within a year 15 per cent must be changed, within two years 23 per cent are reversed and after five and half years almost 50 per cent are incorrect.³³

Dying involves people coming together: the person themselves, their family and friends, often working with a range of health and social care professionals, usually amid great uncertainty, in conditions not of their choosing, with inadequate resources, making the best of it as they can. In some respects the best we should hope for is to muddle through an unavoidably distressing experience of loss and fracture, marked by sadness and anger.³⁵

People are likely to die in old age, after a prolonged decline, beset by multiple conditions: what makes for a good death under these conditions?

3 Living well while dying

Efforts to personalise services depend on professionals talking to consumers to understand what they want.³⁶ Expectant mothers are happy to talk at length about their birth plans. In contrast many people do not like talking about dying. Indeed for some people, a good death depends on *not* talking about it. The playwright Simon Gray and his wife instructed their doctors not to give them a detailed prognosis for his cancer because they preferred not to know when he was likely to die. A significant minority of people want to die ‘disregarding’ death, to carry on living normally. In *Keeper*, a thoughtful account of caring for elderly in-laws with chronic conditions, Andrea Gillies explains why she felt unable to talk to her father-in-law about dying: ‘Once the darkness is self consciously admitted into our situation, all hope of lightness is lost.’³⁷ In one interview with a recently bereaved wife and carer from south-west England we were told that before the death they did not talk about it, ‘because you don’t want to lose them, you don’t want to discuss it because it brings that fact nearer’. For some people acknowledging they are dying is a precondition for having a good death. For many people, it’s the other way around: dying well depends on not talking about it.

Instead many people prefer to talk obliquely about dying, using euphemisms: giving up the ghost, passing away, letting go, pushing up daisies, kicking the bucket, passing over, taking our final bow. Many people are able to talk about the kind of funeral they would like, where they would like to be buried, how they would like their possessions distributed. Very few people are able to talk directly about what dying would be like. As a contributor to Mumsnet put it: ‘For a lot of people it isn’t actually being dead that’s the scary bit. It’s doing the dying.’³⁸

A further complication is that for these conversations to shape services they often have to involve the person dying, two generations of their family and an assortment of professionals. Medical staff are often ill-prepared openly to raise the fact that someone is dying. When they do so they can be clumsy. A contributor to the Patient Opinion website left this comment about his mother's death in hospital: 'Some of the junior doctors seemed inexperienced in dealing with a terminal diagnosis.'³⁹

It is difficult for someone to die well without a shared recognition that they are dying. Unless we can find ways to get people to talk about how they want to live while they are dying our efforts to improve services will be like groping in the dark.⁴⁰ All too often dying is accompanied by a dour hush.

Having those conversations is vital to tease out the very different views people have on what counts as a good death. To prescribe one version of the good death would be a mistake.⁴¹ Elisabeth Kübler-Ross's famous model of the five stages of death in which people initially disbelieve they are dying, then fight it and eventually accept it will not work for some people.⁴²

For some a good death comes from a degree of acceptance. For others, such as the evolutionary biologist Stephen Jay Gould, fighting death is essential to dying well. As Gould put it:

It has become, in my view, a bit too trendy to regard the acceptance of death as something tantamount to intrinsic dignity. Of course I agree with the preacher of Ecclesiastes that there is a time to love and a time to die – and when my skein runs out I hope to face the end calmly and in my own way. For most situations, however, I prefer the more martial view that death is the ultimate enemy – and I find nothing reproachable about those who rage mightily against the dying of the light.⁴³

Most people want to be with members of their family while they die. Yet for some people families bring emotional baggage that is too heavy to bear. Dying can bring families together and drive them apart. Some people like the bustle of having people around them, neighbours popping in and out; others like peace and quiet. For some, religious rituals are essential; for others they would be an unwanted imposition. For some, euthanasia or

physician assisted suicide would count as a good death if it meant they could avoid weeks clinging to a miserably poor quality of life with the help of a suite of life support machines. For many devout Christians euthanasia would count as a bad death because life is God's gift.

As Britain has become more diverse in most aspects of its cultural life so this has coloured approaches to death. St Joseph's, a busy hospice in London's East End, has white working-class patients who survived the Blitz, devout West African Christians, and recent Muslim immigrants. Each day St Joseph's responds to scores of people from cultures with very different accounts of what makes death bearable. We need services that are capable of understanding and then responding to the very different views people have about what counts as a good death.

Our workshops with patients, however, showed that there is a degree of consensus over what counts as a bad death. These factors include: being in severe pain, or other uncontrolled symptoms such as nausea and breathlessness; being lonely; a feeling of powerlessness; the shame brought on by stigma associated with a condition; and a lack of dignity and privacy. Someone dying lonely and in pain, with a socially stigmatised condition, such as Aids, in a large open ward, in a medical system they barely understand, is unlikely to have a good death.

The flip side of that consensus is a degree of agreement about what makes a good death more likely. These ingredients include: dying at the right time in life; dying not taking too long; being able to exercise a degree of control; having the right people around you; having the space and support to reflect on life and to find meaning in death in an appropriate way; not dying in pain; and dying with a degree of dignity.⁴⁴

When we asked people in our poll what features would make somewhere a good place to die, 36 per cent said being able to be with friends and family; 20 per cent said good personal care; 22 per cent mentioned access to pain relief. The balance of these factors changes with age. Almost 60 per cent of 18–24-year-olds said having friends around would be vital to dying well, compared with 25 per cent of those over the age of 55. Older people put much greater emphasis on pain relief: only 7 per cent

of those aged 18–24 said pain relief would be important, compared with 25 per cent of those over 55 years old.

Being able to exert a degree of control while you are dying is vital for people to feel not only a sense of agency but also a degree of dignity. The most controversial expression of this desire for control is the growing clamour for the law governing voluntary euthanasia and physician assisted suicide to be liberalised. Only a small minority of people chose unprompted to talk about these issues during our research. In the Netherlands and Oregon, the US state, where assisted suicide or euthanasia has been legalised, only a very small number of people have availed themselves of these services.⁴⁵

Yet the debate over euthanasia is symptomatic of a widespread desire people have for greater control over how they die. Timing is not the only issue people want control over. Many more people want control over who they have around them and levels of pain control. Yet the time it takes to die is a critical factor in making death distressing. Most people say they do not want to be trapped in limbo, somewhere between life and death, supported only by tubes and machines, unable to do much more than lie in bed. The issues that patients, doctors and families face in such situations are more about managing omissions, choosing not to intervene and even slowly withdrawing support, rather than deciding to end a life. The General Medical Council's End of Life Care guidelines say that doctors should favour prolonging life, but that 'there is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views, if they are known or can be found out'.⁴⁶

Even if there is legislation to allow voluntary euthanasia and physician assisted suicide under specific circumstances, patients, families and doctors will be navigating their way through a moral grey zone. The duties of doctors may conflict with the perceived rights of patients to determine their own death. A utilitarian cost benefit analysis of treatment programmes would be considered by most people to be too cold. Measuring someone's quality of life is fraught with difficulty when there may only be a matter of days left. Rigid interpretations of abstract ethical principles and legal theories are unlikely

to help in situations that require a sensitive, informed, compassionate pragmatism, focused on care and dignity, rather than rights and duties.⁴⁷

Conclusion

For most people dying well means having the people who matter around you; being cared for attentively, so you are clean, fed and well looked after, and not in pain. Relationships are key to this. Dying well means being supported by the right relationships with family, friends, carers *and* professionals. People often find solace, support, humour and meaning in death through the support of relationships.⁴⁸

To cope with modern aspirations for dying well and modern forms of death, we need services that can support people over many months, which are flexible enough to respond to people's changing needs and adapt to people's different views of a good death.

Putting in place appropriate supports will be impossible unless we encourage people to have conversations that they feel comfortable with in which they can explore with friends, relatives and professionals what they want to achieve and set care priorities accordingly.⁴⁹ Not everyone will want to talk about how they want to die. But everyone should be offered the opportunity to do so. Those conversations should not be one off events, reduced to a simple checklist. Most people do not want grand planning sessions. They should be friendly and low key, teasing out what people feel and most of all what they value most. The more people are encouraged to talk about what matters to them about life the more likely they are to get it even while they are dying.

How do current services perform against these yardsticks?

4 How well do we do?

Until the second half of the last century most deaths happened in homes, with the support of family and neighbours, perhaps with a priest and a local doctor in attendance. Home deaths fell from 31 per cent of deaths in 1974 to 18 per cent in 2003. By 2030, on current trends, one in ten people will die at home. Nowadays death is contained in institutions supported by professional services.⁵⁰ About 60 per cent of people in Britain die in hospital, 17 per cent in care homes, and 5 per cent in hospices.⁵¹ By 2030 about 90,000 more people a year will die in hospitals and nursing homes, rising from 440,000 in 2008 to 530,000 a year in 2030. Institutional deaths will increase by 20 per cent and home deaths will fall by 42 per cent.

Should we be satisfied with how these institutions cope with the protracted modern way of dying? How well do they meet people's aspirations for living well at the end of life?⁵²

Hospitals

The one patient in our workshops who wanted to die in hospital thought it would be the best place to fight death to the end. For those who see medicine as the main means in that fight, hospital is the best place to be, especially if they are young and battling a specific illness. Hospital is the most appropriate place to die for some people. Intensive care units often provide exemplary care for people, for example after an accident, at the end of life. This is the kind of acute care that NHS hospitals were designed for.

Hospitals have other strengths. They provide forms of intravenous pain relief – morphine – that are often difficult to arrange at home. Once someone is on a ward they should be fed, warm and clean. People often speak highly of the care they receive in hospitals.

This is how one of our interviewees described his wife's death in a London hospital:

She had as far as anyone can, a good death. She was looked after by a wonderful consultant and she died in hospital; unfortunately she wanted to die at the hospice but it all went too rapidly. She died in hospital with the Macmillan nurses around her. She died so peacefully and as far as it can be it was a good death. What really helped was that the consultant that dealt with us was completely frank and so were the junior doctors working under him. My wife was the kind of person who wanted to know what was happening, how long she had got to live.⁵³

These were among some of the compliments paid to hospitals by relatives posting on the Patient Opinion website:

My grandfather was admitted in the early hours of Thursday morning, and from the outset we were informed that his condition was terminal. Unfortunately he passed away on Monday evening, but the care received by my grandfather was excellent, and the concern, compassion and professionalism shown by all the staff was just outstanding, especially given how busy the ward was.⁵⁴

I would like to praise all the staff at the Intensive Care unit. My father passed away on May 18th but he was made as comfortable as could be and my sister and I and our adult children were made to feel welcome at his bedside. We were given space and time when we needed it but always with the knowledge that experts were the other side of the curtains if we needed them. We are so grateful for this. Also, because we were not ushered away at any time and all our questions were answered, we felt we were able to do as much as possible to support our father at the very end of his life. Thank you all, including the reception staff who were sensitive and tolerant of us in the waiting room. I've seen West Mid change over the years and I am heartened that the level of care for my father and for us was excellent.⁵⁵

When he was first admitted it is safe to say that he was extremely ill and the nurses on the ward nursed him back from the brink. The care he received from the staff on both occasions was second to none. He was treated with the utmost respect at all times and his every need and more were catered for.

*Every effort was made at all times to maintain the patients' dignity. He was always clean shaven, nicely dressed with his own clothes and clearly had his personal hygiene needs addressed. The staff were also an excellent source of support for me in that they were always available to listen to any concerns I may have had etc.*⁵⁶

Hospitals are improving the support they give to people dying. The End of Life Care Strategy launched by the Labour government in 2008 is starting to have an impact especially through more extensive staff training in palliative care,⁵⁷ and the Liverpool Care Pathway, which focuses on how people should be cared for in the very last hours of life (box 1). Developments set in train by the strategy will continue to deliver results in years to come.

Box 1 Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway for the Dying Patient (LCP) is a tool designed to improve communication and coordination of care for people who are predicted to die within 48 hours. It consists of assessment leading to a plan that all healthcare professionals can contribute to and a system for recording and sharing the information in this plan. It covers the following aspects of care:

- *symptom control*
- *anticipatory prescribing of certain drugs to prevent symptoms before they start*
- *when to discontinue some treatments or aspects of care*
- *psychological and spiritual support*
- *support for the family*

The LCP began as an attempt to export and formalise good practice in the hospice sector to improve care for the dying in other settings. Developed in the late 1990s, it is now in its 12th iteration.

Significant media attention has focused on the LCP, often reporting that it is dangerous and hastens death in some

cases. Yet the LCP has been recognised as good practice on several occasions by the Department of Health. Studies have shown that use of the LCP lessens the symptom burden on patients and improves the way staff deal with documentation. One study found that 84 per cent of 25 bereaved carers surveyed at one hospital were highly satisfied with the use of the LCP for their loved one.

Hospitals are getting better. However, our growing reliance on hospitals also creates a range of problems, for families and staff alike. Dissatisfaction with how hospitals care for those dying is widespread: about 50 per cent of the most serious complaints about acute hospitals relate to the conditions in which someone dies.⁵⁸

First, hospital is not the appropriate place for many people to die. The NAO estimates that 40 per cent of people who die in hospital do not need to be there for the treatment of a medical condition.⁵⁹ One in ten people who die in hospital have been there for at least a month before death and about 20 per cent of hospital bed days are taken up by end of life care.⁶⁰ At Salisbury General Hospital senior staff estimated that as many as 50 per cent of the 1,000 people who die in the hospital each year did not need to be there on medical grounds. As one medic put it:

We have eight people on our ward this morning and we knew there was nothing we could do for four of them when they were admitted. They are there to die, not to be treated.

Hospitals are designed, and doctors trained, to diagnose, cure and heal people, to prolong their life. Yet perhaps half the people that hospitals deal with at the end of their life have chronic conditions that will not respond to medical intervention. Beyond providing pain relief, what is the role of medicine and doctors when there is nothing more they can do to extend someone's life?⁶¹

The lack of a clear answer to that question leaves people feeling frustrated. This is how one contributor to Patient

Opinion we spoke to described his wife's final treatment of chemotherapy for an incurable cancer:

My view is that every time she's in hospital, or anyone's in hospital unnecessarily, there's a cost to that. There's a cost to the patient, there's a cost to the carers and the cost to the hospital. There's a physical and emotional cost to all this, the whole bloomin' lot. She was actually in that hospital 26 days unnecessarily.

Second, hospitals are often not the best place in which to have a conversation about dying and not just because the most intimate conversations have to be conducted within earshot of complete strangers.

This is how one of our interviews from north-west England described his efforts to open a conversation with medical staff about his 90-year-old father-in-law:

We never spoke to any consultant. There was no opportunity to do that. There was no compassion at all. It was just 'get you in, get you out' because of the pressure that are on the staff. There was no relaxed atmosphere; you couldn't sit down for five minutes and talk to a nurse. The consultants, the nurses you can't talk to them. The system's basically designed so that you cannot really talk to any of them...

Even when doctors have the time to talk they are often not the best people to have that conversation with. It is not a routine part of a doctor's training to learn how to talk to people about dying. Doctors are trained to search every last avenue to keep someone alive, to offer them hope, however slim. Doctors are loth to disappoint patients and so find it difficult to tread a line between providing the truth and maintaining hope. That is why more than 40 per cent of US oncologists report offering treatments they believe are unlikely to work.⁶²

The same interviewee from the north west described how staff talked around the fact that his father-in-law was dying:

It's all very well a doctor saying to you 'it's ok he's getting well' when you know realistically in your own mind what is happening, or that you feel that

you know, but you're not told the truth. For example, you say to a nurse, how's he doing? And she says 'oh he's eating well, he's going to the toilet' when you know in your own mind he cannot do it. They are not being truthful.

Doctors recognise that they often err on the side of hope rather than truth. The US brain surgeon Atul Gawande, one of the most reflective medical practitioners in the field, reported this conversation with someone in the last stages of an incurable cancer:

After one of the chemotherapies seemed to shrink the thyroid cancer slightly, I even raised with her the possibility that an experimental therapy could work against both her cancers, which was sheer fantasy. Discussing a fantasy was easier, less emotional, less explosive, less prone to misunderstanding than discussing what was happening before my eyes.⁶³

As one study of how people talk about death put it: 'We consistently deflect debate around death and transform it into the vocabulary of saving lives.'⁶⁴

Third, hospitals are often impersonal and can provide a hostile environment for the social relationships that count for so much at the end of life.⁶⁵ Patients often feel processed by systems they have scant knowledge of, little voice in and no control over.

Part of the problem is that doctors tend to focus on the medical conditions they are presented with rather than the person with the condition.⁶⁶ More deaths will involve multiple conditions. That means families will see a range of specialists. Establishing relationships with a cast of consultants is very difficult. Nursing staff working on varying shifts rarely have time to form relationships with patients. Among the main reasons people dislike hospitals is the lack of privacy and dignity that general wards provide. In hospital people can die in public and yet feel alone.⁶⁷

A contributor to Patient Opinion told us about his experience caring for his wife in hospital:

I actually think that a lot of people would not be able to cope. We had the wherewithal to do it, her and I. And I think we were very exceptional.

Which means that those who don't have anybody to support them would just get rolled over by the system. They're not used to people standing up for themselves and they're basically always in the right.

Many studies comparing care across many settings find general acute hospitals are among the least satisfactory places to die.⁶⁸ These other comments taken from Patient Opinion about people's experience of end of life care reinforce that point:

Some of the night staff were unbelievably noisy. I accept that jobs need to be done but they discussed their social lives and laughed and shouted from one end of the ward to the other with no consideration for patients.⁶⁹

The consultant was very unhelpful – wouldn't meet with us or speak on the telephone and the nurses on the ward would not give a proper report of his condition on the telephone even though I live 40 miles away and could not visit every day.⁷⁰

They said a prayer for him with screens around him, but the relatives of other patients were present in the (six bed) bay.⁷¹

They call it the caring profession – what an absolute joke – they could not care less – there is no empathy with elderly, frail and sick people, no compassion and certainly no caring. I hope to God I die before I end up in a hospital as grim as this – it feels like a workhouse!⁷²

I've gone up to the ward and she is ill, really ill. The fluorescent lights are on, there's somebody incontinent next to her, there's sick, it's absolutely appalling. She's delirious, she's in a hell of a state and nobody's come anywhere near her. They just left her like that.⁷³

We had five meetings with the doctors. It would have been nine but on four occasions the doctors never turned up... After her death I got a call from a doctor I had never heard of (or spoke to) telling me that they did not know what to put on her certificate. I informed him neglect or malnutrition would be good choices...⁷⁴

As one patient told us about her hospital experiences in a workshop, 'We have lots of meetings with doctors but by now

I've switched off. They talk on about what matters to them, about this test and that procedure, but I cannot follow it.' Another said: 'Doctors see me, that's it. They see me. But nothing they do does much for me. I just get seen.'

Fourth, hospitals are among the most expensive places in which to die. Doctors do not want to let down people who want to fight for life. Relatives often press for the most aggressive treatment possible, to do everything they can for their loved one. This twin pressure often justifies repeated medical intervention to prolong life to the very last breath (box 2). This creates intense dilemmas for everyone involved. Some people complain because too much was done to keep an elderly relative alive, others complain because too little was done. A forthcoming US study found that networks of specialist doctors in large hospitals sanctioned many more interventions in the last year of life than primary practitioners, the equivalents of GPs, with 16 per cent higher costs, 14.5 per cent more hospital days and 23 per cent more physician visits.⁷⁵ In the USA a quarter of the Medicaid budget is spent on the 5 per cent of patients who are in the last year of life and much of that is spent in the last couple of months, often to little apparent benefit in terms of extending life.⁷⁶

As Atul Gawande sums it up in his essay 'Letting go':

People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in more than hard dollars.⁷⁷

Hospitals are becoming the main way we cope with death when they should only be part of the solution.

Box 2 Medical intervention at the end of life: cardiopulmonary resuscitation

One of the most contentious issues surrounding end of life care in hospitals is the use of cardiopulmonary resuscitation (CPR),

*an emergency procedure for people in cardiac arrest or respiratory arrest.*⁷⁸

CPR is widely seen as a life saving intervention, perhaps because of its frequent use in TV dramas such as Casualty and ER. Many studies show undue optimism among medical staff in CPR success rates. In one, the 269 doctors responding reported a mean expected survival rate after CPR of 65 per cent.⁷⁹ Yet CPR is overwhelming associated with death.⁸⁰ Its success rate among older people is very low. Only 9.6 per cent of people aged over 80 leave hospital alive after undergoing CPR.⁸¹ One-third to one-half of hospital survivors of CPR will have new, moderate to severe functional or neurological impairment.⁸²

One study found the use of CPR at the end of life had a ritual component to it, to show that everything possible had been done before someone dies.

The performance serves as a marker by drawing attention to the significance of what is occurring and, in actually undertaking the actions, attention is diverted away from the proximity and finality of death. The performance itself appeases quasi-legal concerns by showing committed intervention, it offers a degree of solace to the family that everything was tried and it reinforces for the staff their role in these circumstances.⁸³

Home

People prefer the idea of dying at home because it should provide them with relationships, social support, intimacy and a degree of autonomy.⁸⁴ People are more likely to be able to be themselves in their own home, with their family and friends (mentioned by 31 per cent in our poll) and their own things (mentioned by 20 per cent as a reason to die at home) around them. People value the memories that home evokes (18 per cent) and the comfort (12 per cent) of being in familiar surroundings (13 per cent). When people are at home they have more control. Professionals have to come to them.

Yet dying at home can be over-idealised. Most people – 62 per cent in our poll – expect a spouse or partner to look after

them if they die at home. Many women, however, outlive their husbands. About 44 per cent of women die without a partner;⁸⁵ 51 per cent of over 75-year-olds lived alone in 2007, up from 40 per cent in 1973.⁸⁶ People who are widowed have to turn to children and friends for support; 58 per cent of the widowed said they expected their children would look after them at the end of life. This may be problematic for many families.

Family composition has changed with the rise in rates of divorce and separation. Only 19 per cent of divorced people expect their partner to care for them; 43 per cent said they too would turn to their adult children to carry the burden. Most caring work at home is still done by women. The rise in female employment means that women have less time to devote to family care.

Dying can change a home permanently. Medical equipment – oxygen cylinders, blood pressure gauges, wheelchairs – fill living rooms and bedrooms, which also become places of work for professionals. Being with someone dying while normal life continues around them can create jarring juxtapositions. An interviewee told Scottish researchers, ‘It’s odd watching a soap opera on television knowing your wife is on a bed behind you dying.’ After someone’s death relatives have to try to recover domestic life.⁸⁷ As one participant in our workshops put it, ‘It would be great to go to sleep and not wake up, not know anything about it, but not so great for the person you sleep next to.’

The full costs of caring at home are difficult to calculate. MacBride-King found that 48 per cent of family caregivers have difficulty balancing caregiving and workplace responsibilities while 42 per cent experienced a great deal of stress trying to meet these two demands.⁸⁸ One estimate is that earnings foregone by people caring for family members at the end of life amount to £2.9 billion a year.⁸⁹ As family income goes down, so costs often go up, as people have to acquire special equipment – hydraulic beds, stair lifts, shower supports – and buy in personal care services.

The economic costs are outweighed by the emotional toll: 50 per cent of people responding to our poll said it would be stressful to care for someone dying and 44 per cent said they

would be exhausted. Hospital can leave people feeling powerless but caring alone for someone dying can leave people feeling drained and depressed. In 2005 the Office of Fair Trading found that ‘carer stress’ was cited as a reason for someone going into a care home in 38 per cent of cases.⁹⁰ Caring motivated by love and generosity can often turn into what feels like hard labour, accompanied by a sense of guilt at feeling trapped and resentful.⁹¹

The dilemmas of caring for someone at home are revealed in discussion threads on the website Mumsnet (www.mumsnet.com). In a thread entitled ‘Those of us with elderly relatives who won’t accept outside help’ one participant remarked:

*My mother was dreadful regarding having help. She would be very bloody minded about the whole thing and would insist on doing stuff on her own and then would normally fall, injuring herself and creating masses more trouble... The feeling of helplessness is the worst... if they are in hospital at least they are being taken care of. However she will be very upset if that has to happen.*⁹²

On caring at home for an elderly father with dementia another contributor said:

There is really only myself and my sister that are his main carers and I feel terribly guilty about this but now he has got to the stage where he is wetting the bed but won’t let us clean up.

In reply another Mumsnet participant suggested family carers are being exploited: ‘The system is designed to make the carer do everything until they reach a point where they break down.’⁹³

As people get closer to death they are more likely to see the downsides of dying at home. In our workshops most patients near the end of their life said they did not want to die at home because they did not want to be a burden on their family. Coping with someone dying is more than most families can bear. We will meet people’s aspirations to die at home only if people are provided with proper support.

Care homes

There are 18,000 care homes in England alone, of which the majority are residential homes, providing just personal care. The remainder are nursing homes providing a mix of personal and nursing care.⁹⁴ Care homes provide places for about 420,000 older people.⁹⁵ In 2006 there were about 72,500 deaths in care homes. Over the next two decades many more people are likely to die in care homes that specialise in serving very old people who will be frail and often suffering from dementia.⁹⁶ By 2030 about 43 per cent of deaths will be among people over the age of 85. Most deaths in care homes follow a long slow decline, punctuated by periods of acute illness.⁹⁷ Only 9 per cent of those who die in care homes do so with a recognisable terminal illness.⁹⁸

In our research we heard as many praising care homes as damning them. At their best, care and nursing homes provide what people want – a warm, friendly, safe, local place in which people can still see their friends and family. This resident was typical of many we spoke to in care homes during our research: ‘I am comfortable here, this is my home now, so yes, this is where I’d want to end my days, not at the hospital.’

Yet the quality of care in many homes still leaves much to be desired, according to a mix of official, academic and anecdotal reports.⁹⁹ Care homes provide people with long term support but often at the cost of giving them only low levels of attention and stimulation. They are widely regarded as warehousing people before death.

These contrasting experiences are captured by these comments by a Patient Opinion contributor we spoke to describing his 90-year-old father-in-law’s treatment in two different homes:

The first home he was in was absolutely brilliant. I cannot fault it in any which way. It was a home for people who feel they need to go somewhere for company, to be protected and want to be in a family unit, and it was a family unit, beautiful.

After a spell in hospital his father-in-law was discharged to a different home:

The following week we went round, went up to his room, and he was literally strapped in a wheelchair. Ninety three years old who didn't know what day it was, had been got up out of bed, strapped in a wheelchair, like a prisoner, gazing into nowhere because he just didn't want to be there. Didn't recognise anybody. We said to the person who was supervising:

'Why is he in a wheelchair?'

'Oh we always get our patients up.'

I said, 'Look this guy's dying.'

'No he's not dying,' she said. We got them to unstrap him, put him back to bed and he actually died that day.

That account is reinforced by other comments on the Patient Opinion website:

I visited Mum on the 7th May and found the nursing home to be filthy; I saw sticky carpets, half eaten eggs and food lying on the floor, bed linen filthy etc. She had fallen on a number of occasions during her stay there causing severe bruising and swelling of her arms and knuckles.¹⁰⁰

Care home staff are often ill equipped for conversations about how people want to die partly because they have limited training in end of life issues. To complicate matters a high proportion of the care home workforce has English as a second language. Many of the people they work with may have forms of dementia and so find it hard to express themselves. Staff turnover is high, so it is difficult for staff to form lasting relationships with clients.

Care and nursing homes are often unable to provide people with the medical and pain relief they need at the end of life. That helps to explain why a quarter of those dying in hospital are former care home residents who are transferred to hospital at the very end of their life. Care homes use hospitals as a backstop when staff do not know how to cope.¹⁰¹ Application of the Gold Standards Framework for better care (box 3) has raised staff confidence and training in many homes, but uptake is patchy. There is huge potential for improving the care homes as places in which to live and die.

Box 3

The Gold Standards Framework

The Gold Standards Framework (GSF) aims to improve the quality of care for people in the last years of their lives. Originally developed in 2000 for use in primary care, the framework is now used in a wide variety of settings including care homes. Like the Liverpool Care Pathway for the Dying Patient, GSF is an attempt to formalise and export hospice practice and philosophy to other settings.

The GSF is recommended as best practice by the Department of Health End of Life Care Strategy, NICE, the Royal College of General Practitioners, the Royal College of Nurses and other major policy groups.

GSF is described on the website as:

a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last years of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together. GSF can help coordinate better care provided by generalists across different settings.¹⁰²

GSF aims to provide:

- consistent high quality care*
- alignment with patients' preferences*
- pre-planning and anticipation of needs*
- improved staff confidence and teamwork*
- more home based, less hospital based care*

The framework covers communication, coordination, control of symptoms, continuity out of hours, continued learning, carer support and care in the dying phase.

GSF contains several tools that have helped to provide good end of life care. One which is often referred to as the 'surprise question' asks professionals to code patients based on if they would be surprised if a person died in different time

Figure 4 **Gold standard framework colour-coding for prognosis**



Source: K Thomas, 'The GSF Prognostic Indicator Guidance'¹⁰³

periods. This seems to be enabling professionals to communicate with one another more effectively.

The extra awareness this creates makes it possible for anticipatory prescribing of medicines and pain relief for 'just in case boxes' in homes and care homes. These drugs are then available if there is a need.

A system of needs-based (colour) coding is used for prognosis (figure 4).

A survey of GSF usage in care home found that crisis admissions to hospital in the last six months of life had reduced

*from 37.8 per cent before adopting GSF to 26.3 per cent shortly after adoption.*¹⁰⁴

Hospices

Hospices are the most recent and significant social innovation in approaches to death and dying. Born out of frustration with the cold, technical, medical deaths many people had in hospital, hospices embody a holistic philosophy that combines top quality medical services with social activities, spiritual and psychological care.¹⁰⁵

Yet only 7 per cent of people in our poll said they wanted to die in a hospice.¹⁰⁶ That is because many people with no experience of hospices regard them as dark, forbidding and depressing places, indelibly associated with death. In reality hospices are generally light, warm and friendly, at least compared with hospitals, and they provide much better quality medical support than care homes. Entering a hospice is widely seen as giving in to and so hastening death. In fact people rarely die more quickly in a hospice than in a hospital. A US study that followed 4,493 Medicare patients with terminal cancer or heart failure found no difference in survival times between hospice and non-hospice patients with breast cancer, prostate cancer and colon cancer.¹⁰⁷ For some patients hospice care seemed to extend life: those with pancreatic cancer gained an average of three weeks, those with lung cancer six weeks and those with heart failure three months. One workshop participant summed up the impact of regular visits to a hospice this way: 'It's saved my life. It's got me out of the house, made me more independent, given me people to see and lots to do. It's comforting and helpful. It's more for life than death.' Another remarked: 'I really look forward to coming to the hospice. You need a feeling that life is good even if it is coming to an end.'

Hospices reach well beyond the beds they provide. They serve about 44,000 patients per year including outpatients who visit the hospice or are cared for at home along with many family members.¹⁰⁸ Hospices embody social capital: they are among the best supported community institutions in the country, raising

close on £600 million a year. Their impact extends well beyond their own services. They have inspired much of the innovation which has eventually been taken up by hospitals and care homes, such as the Liverpool Care Pathway.

However, hospices too have limitations. They tend to specialise in cancer related deaths rather than the more uncertain deaths associated with frailty, advanced old age and organ failure. Hospices serve a disproportionately high number of younger people. Yet the biggest growth in deaths in the next two decades will be among those aged over 85.¹⁰⁹ Hospices started as disruptive innovators, challenging the medicalisation of death. Critics warn they are in danger of becoming incorporated as niche providers of specialist services within the system they set out to change.¹¹⁰ The holistic model hospices provide is more costly than nursing homes and home care.

Conclusions

Much has been done over a long period to improve the conditions in which people die. Medical advances mean many fewer people die in pain. Most people do not die young. End of life care has started to receive funding and attention. Britain recently came top of an international league table for end of life care.¹¹¹

Yet we have become heavily dependent on relatively costly medical and institutional approaches to dealing with dying and death. We need to innovate, to improve current services in hospitals and care homes *and* to create alternatives to them, by mobilising more support for people dying at home. That alternative will have to combine professional and family, formal and informal care, institution and community, in more creative and productive ways.

5 Four kinds of innovation

Innovation involves the generation and application of ideas that change how we organise ourselves to meet our needs in more effective ways. Sometimes innovation involves the application of brand new ideas; often it involves the creative application of old ideas. Frequently it comes from blending ideas together rather than inventing something from scratch. Innovation is never, however, just about the generation of ideas. Most innovation is about the iterative development of ideas in practice to create new products and services. The point of public service innovation is to generate better outcomes with the public money we spend.¹¹² Social innovation has a broader remit: to allow society to find better solutions to its challenges by combining public, private and voluntary resources in more effective ways.¹¹³ To create better ways for people to die we will need to combine public service and social innovation: big society solutions will not emerge unless the state invests intelligently to support them.

A simple way of thinking about the kinds of innovation we will need is to divide it into two main types. Sustaining innovations improve an existing service, product or process. Japanese companies are still regarded as the masters of incremental, sustaining innovations that continuously improve products and services. Disruptive innovations on the other hand meet needs in radically new ways or – even more radically – define needs in new ways so they can be met with completely different means. The Sony Walkman was a disruptive innovation because it allowed people to listen to music on the move. Low cost airlines have also been disruptive by making it affordable for many more people to fly.

Innovation can take place inside familiar and institutional settings. In the public sector these are hospitals, schools and prisons. It can also take place outside institutions in communities, social networks and households.

These four categories create these four main types of public and social innovation strategy (table 1).

Table 1 The four main types of public and social innovation

	Inside	Outside
Sustaining innovation	Improve	Combine
Disruptive innovation	Reinvent	Transform

The first strategy is to *improve* existing institutions, especially hospitals and care homes, for example through better training, so they provide more reliable and higher standards of quality. The second is to *combine* existing institutions and services more effectively, especially to connect hospitals, care homes and hospices to social, community and voluntary services. The third approach is to *reinvent* institutions so that they can do a radically different job. We still need institutions to cope with dying but very different kinds of institution. The most radical approach is to *transform* how we deal with death and dying in homes and the community. We need effective alternatives to hospitals, hospices and care homes so that people can create their own solutions where they live. Each of these strategies has strengths: it's likely we need elements of all four.

Improve

Most people die in hospitals and care homes. That will not change soon. We should be able to guarantee people good quality care wherever they die and serious efforts are being made to improve the quality of care in hospitals.¹¹⁴ The General Medical Council recently issued detailed guidelines to help doctors cope with the dilemmas they face while treating people with a terminal illness.¹¹⁵ These guidelines emphasise that patients should be given time and information to be able to

reach their own informed decisions about their care, if they are capable. Medical decisions, the guidance says, should be based on an explicit balance of the likely benefits, burdens and risks of any treatment. Patients should be supported to participate in these decisions.

Yet as these guidelines tacitly acknowledge there are still significant gaps in professional guidance and medical practice, as Sheila Payne and her colleagues note:

There is currently no National Service Framework (NSF) or NICE guidelines with specific advice on methods for prognostication or assessment of palliative care requirements of heart failure patients. Many healthcare professionals in palliative care have primarily trained and worked in cancer care and may rightly feel concerned about whether they have the skills to care for other patient groups.¹¹⁶

Hospitals' main weaknesses, however, are their lack of privacy and personalisation; they are designed around professional, medical procedures and hierarchies rather than to accommodate social relationships; they deliver services for and to people but are less adept at working with them. Patients and families often complain that staff have not got the time, knowledge or skills to communicate effectively.¹¹⁷

What innovation there has been in hospitals, such as the Liverpool Care Pathway, has been directed at the very end of life, when death is imminent. Hospitals need to provide rounded support to people earlier, when it becomes clear they are dying but the timing of their death remains uncertain.

That means doctors need better training from before they register and regularly thereafter, to equip them to deal with the complex medical, social and psychological issues at the end of life, and indeed all health and social care workers may need some specific end of life care training. Doctors need to be able to talk in a better way to patients when there is little more they can do to extend life. Swedish doctors call these 'breakpoint conversations', when doctors and families need to switch from fighting to give someone extra time to live, to making sure whatever time they have left is enjoyed to the full. These conversations are

difficult, painful, unpredictable and often tumultuous. They need time and care. Handled well they can release people.

As the End of Life Care Strategy argues, this will require more than training:

*A cultural shift in attitude and behaviour related to end of life care must be achieved within the health and social care workforce. Death is inevitable and does not necessarily constitute a failure of care. Indeed, one of the key roles of health and social care staff is to help patients, as far as possible, to come to terms with the transition from life to death.*¹¹⁸

Specialist palliative care professionals can play a vital role in this but mainly as a resource to train other staff who come into contact with death and dying. There are approximately 2.5 million health and social care staff in Britain, of whom just 5,500 are specialist palliative care staff. Most health and social care workers will at some point be involved in end of life care, if only in passing. Better training and awareness for all staff, particularly in care homes, is more important than creating more dedicated, specialist palliative care staff to deal with critical cases. In NHS South West, hospice staff provide training for generalist health and social care staff. In NHS South Central, end of life care has been emphasised in junior doctors' training. In NHS East of England, 'advanced level communication skills training' has been targeted at senior generalist health and social care professionals working with adult patients and their families in end of life care.¹¹⁹ An end of life skills framework and qualifications are being developed by Skills for Health and Skills for Care to provide a framework for developing staff skills in care homes where quality of care is inconsistent.

Doctors, nurses and care workers would find their work much easier, however, if more patients adopted advanced care plans before they got into hospital. A NatCen survey for Dying Matters in 2009 found that while 29 per cent of people had talked about their wishes around dying, only 4 per cent have written advance care plans.¹²⁰ These plans are often limited in scope and they can become outmoded as someone's condition deteriorates. However, evidence from the USA, where advanced

care planning is much more widespread, suggests that people who have these plans have had to think about how they want to be treated as they die. What matters is the conversation that takes place around the creation of the plan, as much as the plan itself.

An indication of how difficult these conversations are and how badly they can be handled came from an interviewee who told us about what happened when her frail, elderly father moved into a care home in the Midlands:

Part of a list of questions on a form that staff had to go through when he first got there – what time do you want your lunch, what do you like to eat and what do you think about dying? It didn't feel appropriate in the context of that conversation. It would have been better as part of a general, non-structured chat and worked their way round to it.

Research by Peter Singer's Joint Centre for Bioethics at the University of Toronto shows that one of the main merits of living wills or advanced care plans is that they encourage families to discuss the values and beliefs that shape their view of death.¹²¹ Several studies have found advance care planning can help people achieve what they want at the end of life. Starting in 2003, staff at West Essex PCT audited their first 100 patients who died with a preferred priorities for care plan; 88 per cent of the group died in their preferred place of care, including 67 per cent at home.¹²² Care planning has been shown to increase patients' hope for the future, improve patients' quality of life and reduce risk of depression in bereaved carers.¹²³ On the other hand, some studies find too much is expected of these documents, and that they can be hard to access and rely on in the heat of the moment.¹²⁴

A US study found that patients who have substantive discussions with their families and doctors about their preferences are far more likely to die outside hospital, with a degree of control and to spare their family anguish.¹²⁵ The town of La Crosse, Wisconsin, provides further evidence that patients who are given the opportunity to explore and then express their preferences have better deaths. Elderly residents of La Crosse

spend half as many days in hospital in the last six months of life as the US national average and yet their life expectancy is a year longer than the average.¹²⁶ Part of the explanation is that local medical leaders have been campaigning since 1991 to get physicians and patients to discuss their end of life wishes. About 90 per cent of La Crosse residents who die have a written advanced directive based on answers to four main questions:¹²⁷

- Do you want to be resuscitated if your heart stops?
- Do you want aggressive treatments such as mechanical ventilation?
- Do you want antibiotics?
- Do you want intravenous feeding if you cannot eat on your own?

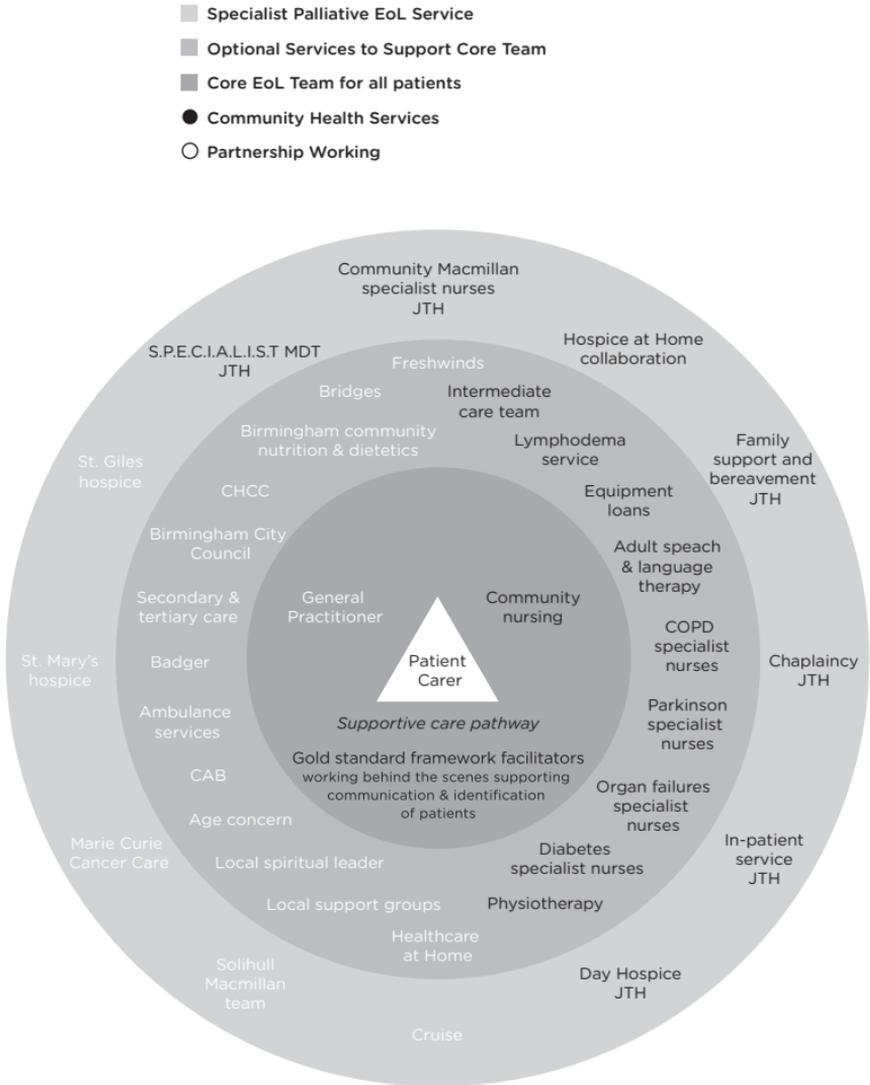
In La Crosse it is routine for elderly patients to answer these questions and to talk with their doctors and families about the issues they raise. That means that when crisis comes they have already had the conversation. Thoughtful, intelligent, early discussions means that La Crosse has much lower end of life costs than the rest of the USA and yet gives many more people a better death. The Department of Health should identify a handful of British towns where similar programmes could act as exemplars of advanced care planning. These conversations would be made easier if hospitals made sure that people had a peer or a trained counsellor as their ally, advocate and adviser.

The key to improving hospital and care home services for those at the end of life is conversation: to devise plans and approaches with people.

Combine

We have many of the ingredients we need for better services at the end of life – from hospitals and hospices to community nurses and social care services. Yet these services are fragmented and disconnected, operated by different agencies, with different funding regimes and professional disciplines, as figure 5, outlining services in Birmingham, makes clear. In the course of the last year of life people often need support at home, access to

Figure 5 End of life services diagram

Source: John Taylor Hospice at Birmingham East and North PCT¹²⁸

primary care, to make visits to hospital and perhaps the support of a hospice or a care home. People need help to navigate their way through these services to ensure continuity of care.

Some of the innovations needed in this area are apparently simple but difficult to organise, for example transport for patients at the end of life who may need to leave hospital quickly to be able to spend their last days at home. We should focus on four potential innovations.

First, many people would benefit from having navigators to help them find the best mix of services and support available. Age UK Tower Hamlets, for example, has nine full time paid workers that each look after between two and five isolated and elderly clients for up to 14 hours a week. They offer practical support, give advice about other services and accompany people on visits in hospital.

A scheme run by Aetna, the US health insurance company, illustrates the potential. In 2004 Aetna decided to allow patients to choose to have palliative care, provided by a hospice, as well as acute care in a hospital. Previously patients had to choose one or the other and most chose hospital. More patients chose palliative care, far fewer used intensive care in hospital, patient and carer satisfaction greatly increased and costs were reduced. The key to the scheme's success were health plan nurse case managers, trained in palliative care, who helped patients navigate the options available to them.¹²⁹ Informed and supported patient choice is a powerful way to generate improved outcomes measured in costs and well-being.

Second, far more attention should to be paid to active discharge planning in hospitals, which was central to the success of Marie Curie's Delivering Choice Programme trials. About 42 per cent of people on Marie Curie's programme in Lincolnshire died at home, compared with a countywide average of 19 per cent of people who die at home. Dedicated discharge teams sought patients who wanted to die at home and made sure all the elements were in place to make that possible, including coordinating packages of home care, providing support and advice to patients and their care givers, communicating patient

needs to community healthcare teams and, in some cases, accompanying patients home to help them get settled.¹³⁰

Third, the fragments of the system need to be brought together. One approach would be to borrow the federation models used in education to team up a high performing school with a small group of other schools in difficult circumstances. A hard federation creates a single management team for all schools. A soft federation allows separate schools to share teachers and resources. Federations of end of life service providers could, for example, allow a hospice to provide end of life care expertise and training for a group of local care homes.

Fourth, it is difficult to combine services without integrated commissioning around outcomes. End of life services cut across health and social care, public, private and voluntary. Each locality really needs an integrated platform, which can develop these complementary services together. We should pilot end of life care trusts to bring together all the services in a locality, possibly by the planned GP consortia banding together to commission end of life care services in new ways, to relieve pressure on primary care practitioners and to avoid high cost stays in hospital.

Reinvent

We need a new hybrid institution to support people who are dying, one which mixes elements of hospital, hospice and care home. Our workshops with people dying suggested there is a yawning unmet need for a local, social, informal place, with a few beds and a large social area, which has proper medical support and pain relief on hand, and is easy for relatives to visit, cook in and stay in if necessary.

One possibility would be for hospices to develop small, ultra local places for people to die, ‘home hospices’, which could be satellites of large hospices. Another variant might come from hospices and care homes creating a new mix of the two. Social landlords could provide another version, for example through the extra care housing models, which provide sheltered, shared

housing developments with dedicated 24/7 care support as well as shared facilities like restaurants or hairdressers (box 4).¹³¹ People have much warmer feelings about local, community hospitals than acute, general hospitals.¹³²

Box 4 Extra care housing at the end of life

Extra care housing comes in many forms, but it is always designed to promote independence and facilitate social interaction. One leading provider, Housing 21, has been part of an NHS pilot to bring end of life capabilities into social, extra care housing facilities. Housing 21's facilities are wheelchair accessible and offer flexible accommodation to suit a range of disabilities and family circumstances. They also provide 24-hour on-site care – providing support to individuals according to their care plans – and they are able to respond flexibly if an unforeseen situation arises. The aim of this care is to enable and support independent living within the scheme.¹³³

As part of their pilot, they report improved staff confidence in identifying and dealing with end of life issues, including better links to other services.¹³⁴

In one study, two-thirds of new residents reported they had a good social life after moving to the scheme, compared with half who said that they felt lonely and socially isolated in their previous homes. Participants in the same study also reported increased feelings of control over their daily lives. Schemes like this have been shown to reduce hospital admissions and prevent delays to hospital discharge.¹³⁵

Transform

To meet people's desire to die at home, with their families, in ways that do not impose huge burdens and unbearable anguish, we need to go beyond improving, combining or even reinventing the services we have. Alternatives are needed that will support more people to cope at home and in their communities. No matter how much we seek to improve, personalise and soften the care provided in hospitals, the fact remains that hospital will not

be the appropriate, nor preferred, place to die for many people.

Our poll showed that although most people want to die at home, most people feel unable to cope on their own with someone dying.

Support families' capacity to cope with dying

First, families need more capacity to cope with dying. One of the main determinants of whether someone will die at home is whether there is someone to care for them.¹³⁶ Increasing the capability of families to cope is thus vital. The following measures should be explored: giving training, giving financial support, introducing a dedicated compassionate care benefit, using technology to provide remote monitoring and giving care givers access to flexible respite care.

There should be short forms of training, including peer-to-peer support, for family care givers embarking on a prolonged period of caring for a relative. One model is the peer-to-peer training programme pioneered by Nottingham University to develop community-based activists to train members of the public to deliver end of life education. The initial findings show some success for those who were already well connected into a well-established community group.¹³⁷

Financial support will also be critical. One of our interviewees who had a terminal illness described the impact on their finances:

I think one of the most difficult things is finance. I was lucky in being advised to go to Age Concern. They were a huge help in getting me the attendance allowance. One of the snags of this is that nearly everyone is turned down on first application, so you have to appeal, which Age Concern helped me with too and of course we won... It was very useful, and helped me really to have more enjoyment towards the end of my life.¹³⁸

We should introduce a dedicated compassionate care benefit to help working care givers cope with the loss of income involved in caring. A quarter of care givers lose a significant portion of their income when they take up full-time care.¹³⁹ The

UK policy approach has been to support people caring for a dying relative through the general framework for carer support.¹⁴⁰ The Swedish Care Leave Act, introduced in 1989, has provided targeted support for people caring for terminally ill relatives. Partly as a result, approximately 50 per cent of Swedish cancer patients die at home.¹⁴¹ See box 5.

Box 5 **Benefits for family care givers**

In the UK there are no benefits explicitly aimed to support carers of terminally ill people. Carer's Allowance of £53.90 per week is available for those providing over 35 hours of care per week. Statutory sick pay and attendance allowance can also ease the financial burden of end of life care for families. However, because end of life can be a particularly demanding and unpredictable time to be providing care, several other countries have developed specific benefits aimed at end of life care givers.

Canada's Compassionate Care Benefit (CCB) enables family members and other loved ones who are in full-time employment to take a temporary secured leave to care for a terminally ill individual at end of life. CCB entitles recipients to up to 55 per cent of their average earnings, with a maximum of C\$435 (£267) per week, over a six-week period to provide care for a gravely ill family member at risk of death within a six-month period, as evidenced by a medical certificate. Although this scheme is seen as a step in the right direction, it is criticised for excluding part-time workers, excluding those who have already taken time off work to provide care, having too rigid time constraints and creating burdens on small businesses.¹⁴²

Sweden's Care Leave Act (1989) entitles care givers to up to 60 days from work at 80 per cent salary. This has been found to broaden the pool of family carers available. One particular issue with this scheme is that because it is administered locally, it can be complicated for family members who live away from their dying relatives to access.¹⁴³

Technology is evolving to make support at home more practicable, including through the internet and digital television to provide remote monitoring, support and advice so that people do not feel alone.

Care givers need access to flexible respite care, to give them a break. This is one potential role for trained palliative care volunteers. Marie Curie's helper programme is training 40 volunteers in Somerset to provide support for 3 hours per week to people caring for someone dying at home.¹⁴⁴ Many hospices have also provided this kind of service in their local areas.¹⁴⁵

Give home carers access to support services

Second, home carers need support services to help with personal care and to cope with medical crises. Often it is one of these crises that leads to someone being admitted to hospital, especially when they hit at night or over a weekend, when out of hours support from GPs is harder to access.

This is how one person with terminal prostate cancer living in London described the need for access to round the clock support:

One of the problems in chemotherapy is that the side effects are never entirely predictable. I had intense pain, for example, neuropathic pain, which occurs obviously in the middle of the night and having lost my partner and having a completely empty house and nobody to scream to. And because this happened at the weekend it was some time before I could make contact with anybody. You really need a 24/7 contact person who can help in that kind of situation. There will be a number of events over the course of terminal care that would require that kind of contact.

Marie Curie's Delivering Choice programme pilots found that when people caring at home have a dedicated telephone support line and rapid response teams the rates of admission to hospital can fall significantly.¹⁴⁶ The fact people knew they could call if necessary gave them the security they needed. Aetna, the US health insurance company, ran a dedicated, palliative care, phone service in which specialists regularly called patients and

care givers and offered to call in if needed. Among those patients using the service, enrolments in home hospices rose to close to 70 per cent, while use of intensive care units fell by more than 85 per cent and satisfaction scores with Aetna's services rose.¹⁴⁷

When reassurance is not enough, however, people need to be able to call on services that will come to them, at speed, to sort out a crisis. Marie Curie's pilots with rapid response teams show they too can reduce unplanned admissions to hospital.¹⁴⁸ Hospice at home services have also proved highly effective in allowing people to return to home to die.¹⁴⁹ The hospice at home services run by Queenscourt Hospice in Liverpool, for example, increased home deaths to 74 per cent compared with national average for cancer of 28 per cent and at lower direct cost. St Luke's Hospice at Home in Essex provides 24/7 on call support from nurses including crisis support, planned respite for both day and night, volunteer befrienders for some of the more isolated patients, signposting and access to services from local providers. In the first half of 2010, more than 47 per cent of deaths of terminally ill people that the St Luke's staff worked with were at home.¹⁵⁰ Even widowers more than 80 years old, with terminal cancer, were able to die in their own homes with the help of these services.¹⁵¹ Hospice at home services in Australia have reported similar results.¹⁵²

The need for a stable relationship with someone who can help

Third, people need a stable relationship with someone who can help them. Often people can get a blizzard of disconnected services, from community nurses, the GP, personal social care, social workers and others. What they want is a continuous, supportive relationship with one person to whom they can turn for support and advice. Specially trained volunteers might be able to provide aspects of this role, perhaps especially if they themselves have experience of caring for someone with a particular condition. But it may be that we need to create a new role, akin to a midwife for the end of life, a skilled professional who can work with a family over the course of nine months, including support after death.

Systemic change

Taken together these measures could create the basis for a social and community-based alternative to institutions that would allow many more people to die at or close to home. It is only comparatively recently that dying has become institutionalised and professionalised in the developed world. For most of history people coped with death through social and religious rituals at home and in communities. These measures would enable a modern recreation of these social and communal traditions, a mixture of the very old and the very new.

Systemic change on this scale, to improve dramatically a community's capacity for coping, is possible. One example is the Indian state of Kerala, which has developed the Neighbourhood Network for Palliative Care (NNPC), in which 10,000 specially trained volunteers provide most frontline palliative care services to over 2,500 patients per week. The central premise of NNPC is that:

*chronic and incurable diseases require a different model of care compared to acute illnesses, and it appreciates their enormous social cost. It states that chronic and incurable illnesses are social problems with medical components rather than the commonly held converse view.*¹⁵³

The NNPC volunteers, who come from all walks of life and age ranges, help organise and provide personal care services, deliver medication, provide links to further social and spiritual support, and act as the sensory system for medical services, which are called in as needed. Volunteers are encouraged to form local groups, identify end of life care needs and design appropriate supports, in contrast to the traditional top-down, doctor organised model. Almost no one dying in Kerala does so alone and without support. Yet formal, hospital-based palliative care services are minimal.¹⁵⁴

In Germany there are more than 60,000 voluntary hospice workers who provide psychological support to terminally ill patients and their families. Since 2001 these volunteers have been supported by qualified staff paid by the state.¹⁵⁵

Another example of systemic change is the way that Aetna has innovated alternatives to hospital in the USA. A two-year

study of Aetna's 'concurrent-care' programme, which allowed people to receive hospital services and to have palliative care from a hospital, found that the proportion of patients using hospice care leapt from 26 per cent when the programme started to 70 per cent. Patients' use of hospital services dropped by two-thirds, and overall costs fell by almost a quarter.

It is possible to support people to die at home, without pain, at significantly lower cost than in hospital and without the distress that hospitals can cause patients and relatives alike. Properly supported dying at home is not only different, but cheaper and better.¹⁵⁶

Shifting our focus so we provide more support in communities will be far from straightforward. Funds to invest in creating an alternative social system have to be levered out of acute hospitals. Local vested interests will need to be brought along with the change, especially GPs. The GP consortia due to be established in 2011/12 to take over commissioning primary and acute care services may be the springboard for innovation as GPs search for ways to make their budgets go further. Yet one of the reasons that caring for someone at home has become so hard is that GPs have cut back on home visits and out of hours services.¹⁵⁷ Inequalities in social capital and family resources may affect people's capacity to cope, although there is no evidence that areas of deprivation have lower rates of home deaths.¹⁵⁸ Most importantly, home and community services will not emerge purely voluntarily. They will require sustained and intelligent investment in these new services, and it is the investment case to which we now turn.

6 Investing in a new approach¹⁵⁹

The NHS spends about £20 billion a year on care for people at the end of life, equivalent to 19.6 per cent of the NHS budget or 1.4 per cent of GDP. By 2030, all else being equal, that cost will rise to close to £25 billion, mainly as a result of a larger number of people spending more time in hospital. Yet for many families hospital provides a distressing way to die and many of those who die in hospital are not receiving medical treatment that requires them to be in hospital. An investment of £500 million a year over ten years, just 2.5 per cent of the amount we currently spend on NHS end of life services, could create the backbone for a system to allow many more people to die at or close to their homes with the support of their families and friends. Not only would this enable many more people to achieve something like a ‘good death’ but it would do so at lower direct cost to the taxpayer.

In this chapter we first estimate the current costs to the taxpayer of end of life care. We also look at estimates of the social costs of informal care. Then we estimate how public spending on end of life care is likely to change over the next two decades. Finally, we examine the case for investing £500 million a year in the creation of an alternative system to support people at home.

We offer these findings with a significant caveat. We have drawn on a wide range of studies in the UK and elsewhere. Yet data on costs of end of life care are patchy and imprecise. As a result we have had to make estimates based on the hard numbers we can find. Our costings are indicative. Nevertheless, the story they tell makes a strong case for innovation.

Costing current approaches

It is difficult to make the case for innovation unless the costs and benefits of current approaches are properly audited. There are no

comprehensive estimates of the total costs of end of life care in the UK, to the taxpayer and individuals, now or projected into the future. A survey conducted by the National Council for Palliative Care in March 2010 showed that 35 per cent of responding PCTs were unable to identify how much they spent on end of life care in 2009/10.¹⁶⁰

The NHS does not routinely provide information broken down in this way. End of life care is not separated out from care provided for people with particular conditions. Often care is provided without it being clear at the time when or that someone might die. Many services are provided by other public agencies, such as social services, voluntary groups and informal carers. Gathering better information about the costs of care at the end of life is an essential precondition for devising different approaches.

In the absence of that data the most fruitful route is to look at publicly available information by institution – hospitals, hospices and specialist palliative care, nursing and care homes and community nursing – for care given in the last year of life.

The costs of different institutions

Hospitals

The 2008 End of Life Care Strategy put the total cost of consultant episodes ending in death at about around £750 million per year. These are cases in which consultants were involved in treating a patient that died.¹⁶¹

However, this is just a small portion of the costs of end of life care. People with heart or lung failure, for example, often have a number of hospital visits in the year before their death. Others may have a spell in hospital before being referred to palliative care. The NAO found that many patients dying with chronic conditions were in hospital for at least a month before their death.¹⁶² People with multiple conditions are likely to see more than one specialist.

A more realistic estimate of hospital costs is the number of bed days that are taken up with end of life care. A study in the *Journal of Pain and Symptom Management* found that about

20 per cent of hospital bed days are taken by end of life care.¹⁶³ There are about 46 million bed days annually in the NHS, at a cost of between £250 and £300 each.¹⁶⁴ That means roughly £11.5–13.8 billion is spent on hospital bed based services at the end of life care.

Even this is likely to be an underestimate. A working group for the Scottish government, for example, estimated that 30 per cent of acute bed days are used by patients in their last year of life.¹⁶⁵ A study in *Critical Quarterly* cites a UK figure of 29 per cent of NHS hospital expenditures being incurred by patients in their last year of life, equivalent to £29.6 billion.¹⁶⁶ The average cost of a bed day is likely to underestimate the costs of care at the end of life. Taking these factors into account we estimate conservatively that hospital bed based services at the end of life amount to about £15 billion a year.

Hospices and specialist palliative care services

Based on operating expenditure data from Help the Hospices, Sue Ryder Care and Marie Curie Care, we estimate that the cost of hospices is £812 million¹⁶⁷ of which the direct costs to the taxpayer is about £260 million – based on NHS and other government grants and contributions. Hospices raise in excess of £650 million a year mainly from within their local communities.

Community nursing services

The Audit Commission estimates that end of life care takes up 40 per cent of district nurses' time.¹⁶⁸ The cost of district and community nursing in 2005/6 was about £1 billion.¹⁶⁹ End of life care provided by community nurses costs about £400 million.

Care homes

There are no government figures for the cost of end of life care in care homes. Some costs are met through NHS Continuing Care funds.¹⁷⁰ Most fees are paid by individuals and their families.¹⁷¹ Data from the Personal Social Services Research Unit and other

studies suggests that the average weekly cost to the taxpayer of keeping someone in a nursing or residential home is about £290, equivalent to £15,063 a year.¹⁷² About 77,000 people die in care homes each year,¹⁷³ usually after a long stay. Using these figures we estimate the annual cost to the taxpayer of end of life care in care homes to be about £1.2 billion.

In addition the government pledged to increase expenditure on end of life care by a further £150 million of revenue funding by 2010/11. Given the commitment by the coalition government to ring-fence NHS spending, it is reasonable to include this in the calculations. About £8.8 billion of adult social services spending in England goes on people over the age of 65¹⁷⁴ and especially on those with chronic conditions which seriously limit their lives. A significant portion of this spending could be counted as end of life care. Taking all these figures together, we believe a conservative estimate of the annual direct costs to the taxpayer of end of life care is about £20 billion.¹⁷⁵

Wider public and social costs

The £20 billion we estimate is spent on direct, public end of life care services is an underestimate of the total costs to economy and society. Substantial costs are borne by informal carers such as family and friends. Carers UK estimate that informal carers of those aged over 65 save taxpayers £61 billion per year.¹⁷⁶ Indeed, of the 6.8 million informal carers in the UK, approximately 75 per cent are looking after people aged 65 and over. One study estimated that informal care for coronary heart disease patients costs approximately £2.42 billion per year, with an additional £2.91 billion in productivity losses¹⁷⁷ corresponding to £518 million loss in taxes. Dementia UK estimates that informal and unpaid carers of those with dementia provide services worth £5.4 billion.¹⁷⁸ The same report estimated that the wider economic costs of dementia, such as loss of output due to absence at work was valued at £690 million and lost tax revenues at £123 million.¹⁷⁹ The value of informal care for cancer patients has been estimated at £1.2 billion¹⁸⁰ although only a proportion of these costs would be attributable to end of life care.

Future costs

The cost of end of life services are likely to rise faster than the growth rate of GDP for a combination of reasons. From 2012, as baby boomer generations die, the annual number of deaths will rise to nearly 590,000 by 2030.¹⁸¹ This alone will increase end of life costs from about £20 billion to about £23 billion in today's money. More of these people will die in older age and will likely require more support for longer.

The medical conditions these people suffer are likely to be more complex and so more costly. For example, the NAO estimates there will be a 20 per cent increase in cancer diagnoses by 2020.¹⁸² The annual direct costs to the NHS and social care of dementia will rise to more than £18.1 billion per year by 2026. On current trends about 89,500 more will die in hospitals and care homes in 2030 compared with 2003.¹⁸³ Our estimates for the relative costs of different places in which people die indicates that a 10 per cent increase in hospitalisation in the last year of life could raise costs by £1.5 billion; a 10 per cent increase in care homes will raise costs by £300 million and an increase of 10 per cent in the numbers of people treated in hospices could raise costs by a further £50 million. The predicted shifts in where people die are likely to increase costs by a further £2 billion by 2030.

Overall, we estimate that the direct NHS and taxpayer costs of end of life care can be expected to rise by 25 per cent to around £25 billion in today's money by 2030, all else being equal.

Potential to improve end of life care

Much will change in the next 20 years. The economy will grow, probably by close to 60 per cent over the period.¹⁸⁴ Significant advances in medicine may increase demand for more costly treatments that may keep people alive for longer. Changes to the way the health service is organised and the level of funding it receives would also make a significant difference, for example to the costs of an average bed day. Some of these factors may be beyond our control. However, if we can reorganise how we support people at the end of life we could limit the rise in costs while also providing people with better services.

Studies have found there is considerable potential to reduce dependence on costly hospital treatment and shift to more effective, community-based solutions. Sampson et al found that 43 per cent of hospital admissions of people with dementia were caused by pneumonia and urinary tract infection, ‘ambulatory care sensitive conditions’, which could have been prevented or treated in the community.¹⁸⁵ This is consistent with the Marie Curie study which found that ‘in the majority of cases people with dementia were admitted to hospital for ambulatory conditions that could have been treated at home’.¹⁸⁶

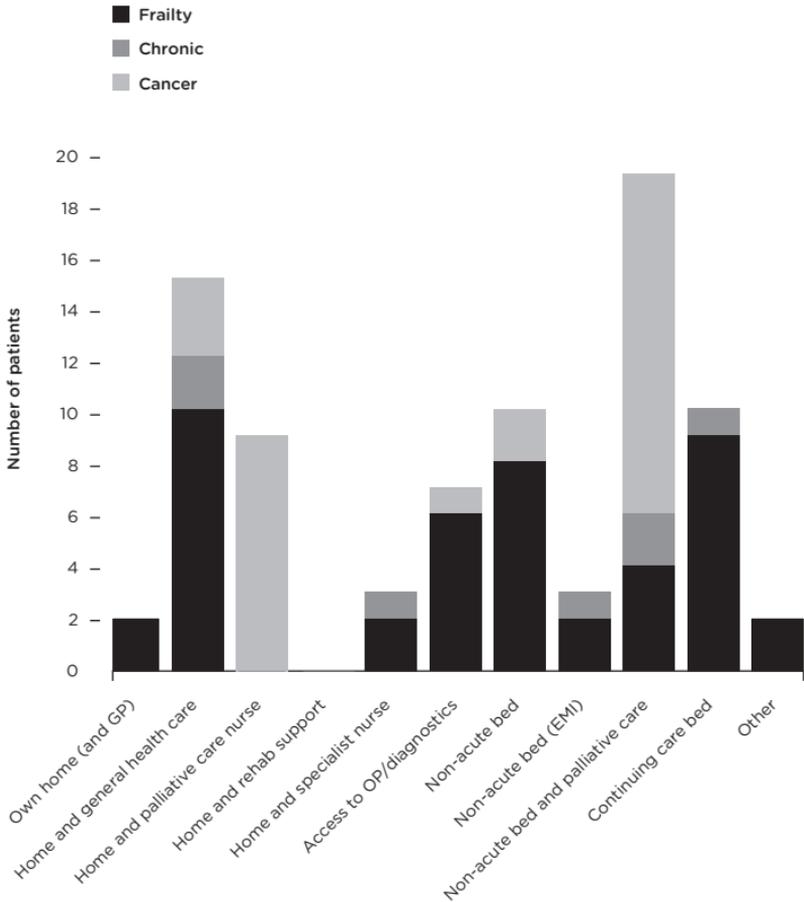
A NAO survey conducted in Lincolnshire found that 68 per cent of patients in acute hospital beds were no longer in need of acute care and alternative kinds of care could be identified for most of them.¹⁸⁷

The NAO looked in detail at the cases of 200 hospital patients at the end of life in Sheffield in October 2007 and concluded alternatives could have been arranged for 80 of them (figure 6).

The NAO also estimated the savings that would come from reduced hospital admissions and shorter stays at the end of life.¹⁸⁹ A 10 per cent decrease in the number of emergency admissions for cancer patients and a reduction of three days in length of stay per admission would release £104 million annually from NHS budgets. For organ failure, £67 million in annual savings could be achieved if the mean length of stay was reduced by three days with a corresponding 10 per cent decrease in admissions.

A Department of Health impact assessment argued that £130 million a year could be saved by delaying entry of people with dementia into care homes.¹⁹⁰ The Alzheimer’s Society estimates that reducing the length of stay of dementia patients in hospital by one week could produce savings of over £80 million.¹⁹¹ At a more local level, South Gloucestershire PCT estimated that savings of £937,000 could be achieved with a 10 per cent reduction in admissions for deaths to 624 deaths in 2012/13.¹⁹² We estimate that if savings were to be realised for cancer, organ failure and dementia concurrently, savings in year one could be in the region of £300 million.¹⁹³

Figure 6 Alternatives for 80 patients who died in hospital



Source: Balance of Care Group and National Audit Office, *Identifying Alternatives to Hospital for People at the End of Life*¹⁸⁸

That is a lower limit. The full potential for savings is very much larger. About 40 per cent of people who die in hospital have medical conditions that hospitals cannot treat or cure. If we could find alternatives for these people at the end of life then it could save up to £10 billion by 2030.

However, these savings could not be achieved without extra support for people dying at home and in the community. We have estimated what could be achieved with a relatively modest investment: a £500 million a year programme over ten years to develop effective alternatives to hospital that would both save money and meet people's needs more effectively.

One priority would be 24-hour community nursing to help people cope with caring at home. A survey conducted by the Audit Commission found that 32 per cent of PCTs provided no overnight service or no service after midnight.¹⁹⁴ NICE estimated the cost of establishing a 24-hour community nursing service across England and Wales would be £280,920 per PCT or £89.8 million in total. Based on Audit Commission data on existing provision, about £33.2 million extra would be required to create a national 24/7 support service.¹⁹⁵

Hospice at home is an established free home nursing and support service for those at the end stage of life.¹⁹⁶ In Carlisle, a hospice at home service cares for 300 patients a year, covering an area of 1,500 square miles and a population of 188,000. In 2009, the cost of the programme was £650,817, of which £520,653.60 went directly to patient care, about £1,735.51 per patient. Another hospice at home based service in St Albans cares for nearly 1,000 patients per year in a population area of 750,000 and at an annual cost of around £2.2 million. This amounts to approximately £2,250 per patient. Since hospice at home services and costs vary depending on location and population density, we have constructed a model for the UK based on different examples from across the country. We estimate that a UK-wide hospice at home service caring for roughly 90,000 patients every year would cost approximately £152 million.

Another option would be to create a volunteer support programme to augment professional services. In the Kerala, the Neighbourhood Network in Palliative Care (NNPC) runs 150 palliative care clinics, with 10,000 active trained volunteers, 85 doctors, and 270 nurses who look after around 25,000 patients. All services including doctors, consultations and medicines are free of charge. The total expenditure on NNPC programmes in

2003 was approximately 12 million rupees or roughly £153,000,¹⁹⁷ of which 77 per cent came from small donations.¹⁹⁸

It is difficult to estimate the costs of creating a similar volunteering programme in the UK, which has a much higher level of deaths and very different social structure. We estimate that approximately 83,000 patients would use the support of a volunteer mentoring scheme.¹⁹⁹ Using the Kerala ratio of one volunteer mentor for every 2.5 patients, and with one lead training roughly 18 mentors, a fully established UK-wide system would cost £74 million. This would create and sustain 1,850 leads at a cost of £40,000 (including salary and costs of training material);²⁰⁰ they could train 33,300 volunteers, capable of providing 40,000 hours of support a week to people dying.

Conclusions

The amount we spend on dying is going to rise dramatically in the next 20 years, more people will die, more expensively and often in an unsatisfactory way, in places not of their choosing. We estimate the taxpayer costs will rise from about £20 billion now to £25 billion by 2030, all else being equal. The wider social and economic costs of coping with dying will be even larger. A fairly modest £500 million investment programme over ten years to create an alternative system to support more people to die at home would more than pay for itself while also providing people with ways to die that meet their aspirations.

7 From living longer to living well

The institutionalised ways we cope with dying are out of kilter with how most people aspire to die. Most people want to die with family and friends nearby, cared for, free from pain, with medical support available when needed. Yet most people will die in hospitals and care homes, often cut off from friends and family, dependent on systems and procedures that feel impersonal, over which they have little control and which too often offer them scant sense of dignity. We spend large sums of taxpayer's money – at least £20 billion a year – on services that leave too many people feeling confused, frustrated and distressed too much of the time.

We should be able to provide people with better ways to die wherever they die. That means one priority must be to improve hospitals and care homes. Four innovations should be at the core of this:

- It should become standard for people reaching the end of life to create advanced care plans with the help of friends, family members, trained peers or professionals. Creating such a plan encourages people to have difficult but vital conversations about how they want to die before they are caught up in the tumultuous crises that mark the last weeks of life. If people have these conversations ahead of time they are more likely to be able to shape what happens to them when they are in the midst of crisis.
- For staff to be able to respond, training in palliative care needs to be much more widespread among doctors, nurses and care home staff. Palliative care should not become another specialism. The skills of palliative care need to be spread broadly through the nursing and care workforce.

- We should draw on the federation models being developed in schooling to link hospices and groups of care homes, so that hospice skills and values can migrate into care homes.
- End of life services should be commissioned in an integrated way that crosses public, private and voluntary services within a community.

However, improving the services we have will not meet people's aspirations to die with the support of their families yet without being a burden to them. We need not only better hospitals and care homes but also effective community alternatives to them. To create them we need an interconnected set of innovations to:

- create new places – home hospices – for people to die close to home where people could be with friends and family, have their personal care looked after and their pain relieved, while calling in medical support when needed
- strengthen family capacity to care by providing a dedicated compassionate care benefit or care leave entitlement, modelled on a mixture of the Canadian and Swedish schemes, to provide financial support for someone looking after a dying relative
- establish a properly trained volunteer support network modelled on Kerala's Neighbourhood Network for Palliative Care;²⁰¹ a UK-wide system would cost £74 million to train and support volunteers to provide 40,000 hours of support
- set up a dedicated 24/7 phone line and nursing support service to help people cope with medical crises that hit families, especially overnight and at weekends
- provide people with a key relationship, such as Age UK's end of life advisers, who work with clients over a prolonged period to help them understand what is most important to them in the final months of life, navigate them to appropriate services and accompany them when they visit formal services
- spread the use of personal budgets at the end of life which will allow people and their families greater scope to commission the kinds of care they want.²⁰²

We should not seek to guarantee a good death to everyone nor to promise to make the loss involved less painful. We can do a much better job of allowing more people to negotiate their own deaths, to write their own script for how they want to die. Dying should not be reduced to an orderly progression along a well-designed service conveyor belt. People die well when they are supported by relationships with people who care for them and provide their lives with a sense of meaning. Most of what we most value in life – love, friendship, respect, recognition, care – comes from relationships.²⁰³ We are recommending a mixture of going back to a pre-modern emphasis on family and community but combined with the best support that modern professions and technologies can provide.

Creating this alternative system will not just raise challenges for service design and public finance. It will involve challenging entrenched interests and viewpoints. We do not just need new services but a different culture and public discussion around death and dying. We will need to question the faith we put in medical expertise and unpick the taboos that prevent us from talking about dying, so we will need to rework our ethical and legal frameworks. An ethics based on formal rights and duties, on the one hand, and utilitarian cost benefit calculations, on the other, may be too inflexible and cold to help us navigate our way through the intensely personal dilemmas we face. More promising may be a care ethic, a compassionate pragmatism, guided by the values of respect, decency and dignity.²⁰⁴ This kind of approach may be more fruitful in allowing people to find what really matters to people at the end of life, which for most people centres on relationships.

Tackling these questions will pose a persistent challenge to our political systems, which are much more at home dealing with issues of space and territory than time and ageing. Perhaps the chief political drama of the last two decades has been the nation state's response to the twin challenges of globalisation and citizens' desire for greater local control. Politicians are thus at home offering remedies to our problems, which revolve around where political decision making takes place through devolution, localism, regional governance, subsidiarity, federalism, trans-

national institutions or global governance. Yet increasingly our dilemmas will be about time as much as space, as society ages and faces intergenerational challenges, from pensions to climate change. Dying in old age is a central part of that politics: how long should people live; when is it worth investing in extending life; how does quality of life change as we get older? For the last two decades politics has been obsessed with space and the challenge posed by globalisation. In the two decades to come it will have to think much more about time and the challenges posed by ageing.

That means we will need to debate our priorities as a society. One of the main successes of the twentieth century was to provide people with longer, healthier lives. Some scientists argue we should continue to invest in extending the life span by developing genetic and regenerative techniques that would make it commonplace for humans to live until they are 125 years old.²⁰⁵ Yet that would mean giving more power over life and death to people who already have huge control, as the archaeologist Timothy Taylor points out:

*The people who... in our increasingly complex societies end up controlling birth and death – surgeons and doctors – may easily come to feel that, through it, they somehow control life. More significantly, the majority of us who do not feel part of the medical colossus may easily come to feel we do not.*²⁰⁶

Our research suggests that further extending the lifespan would be a mistake unless we can provide people with much better quality of life at the end of life. The goal for the twenty-first century should be to improve quality of life, learning to live well, including at the very end of life: quality should become more important than further quantity; better years rather than more years. Death is not a failure. Far from it – the prospect of death, the point beyond which our reputations are irrevocable and personal reparations are impossible, helps us understand what makes life worth living, what we owe to others and hope for them.

For thousands of years people have honoured the dead with special rituals and in special zones, from burial mounds to humanist funerals. These rites of passage first developed when life was usually nasty, brutish and short and death was sudden. The modern, long lives that we lead have created both an opportunity and responsibility for us to do more than that: we are the first society in human history that can plan to honour people *while* they are dying not just after they are dead. That is why we need to find better ways to die.

Annex Research methodology

Aims of the project

The original stated aims of the project were to:

- audit how and where people die in Britain and to project how this will change in the future
- investigate experiences of and attitudes to death and dying from a range of stakeholders including people near the end of their lives, family carers, bereaved relatives and professionals working with people at the end of their lives
- identify national and international examples of innovation that have been successful in improving experiences of end of life
- investigate the costs of end of life care in Britain and project how these might change under several possible scenarios

Data collection

We collected a great deal of data from many different areas. For simplicity, we have categorised our data as coming from three broad sources: archival research, polling and field research.

Archival data

The archival data were obtained through an in-depth literature review of academic publications, government publications, third sector research, books and various media publications, such as websites and newspapers. This included both quantitative and qualitative sources.

Polling

This survey has been conducted using an online interview administered by members of the YouGov Plc GB panel of more than 280,000 individuals who have agreed to take part in surveys. An email was sent to panellists selected at random from the base sample according to the sample definition, inviting them to take part in the survey and providing a link to it. YouGov Plc normally achieves a response rate of between 35 per cent and 50 per cent to surveys, depending on the subject matter, complexity and length of the questionnaire. The responding sample is weighted to the profile of the sample definition to provide a representative reporting sample. The profile is normally derived from census data or, if not available from the census, from industry accepted data.

YouGov plc makes every effort to provide representative information. All results are based on a sample and are therefore subject to statistical errors normally associated with sample-based information.

All figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2,127 adults. Fieldwork was undertaken on 3–6 September 2010. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).

Field research

The data gathered through field research were obtained through focus groups, ethnographic-type observations, websites and interviews. We undertook 131 interviews between April and October 2010, and conducted five focus groups, with hospital and hospice professionals, members of the public and dying people. We held six in-depth, face-to-face interviews with care home and nursing home residents, and 15 in-depth telephone interviews with bereaved carers who had posted opinions on the website www.patientopinion.org.uk. We conducted separate interviews with 50 academics, policy experts, government officials and medical and ancillary staff. We undertook ethnographic visits to three hospices and four care homes.

Methodology

Recruiting and interviewing dying people

Recruiting and interviewing dying people was a crucial element of the project and yet one that was difficult to achieve. Our strategy was to partner gatekeeper organisations that work with people who are terminally ill and then to recruit through those organisations via a trusted member of staff. We found that staff in a significant number of organisations (much higher than for projects on other topics) decided they could not be involved in the research. This is understandable given the deeply sensitive nature of the subject area and this type of reaction has been documented elsewhere.²⁰⁷

As a result, we worked with different institutions in different ways to collect data on dying people. Hospital, hospice and care home staff identified potential participants to ensure a mix representative of their services, and those who were less likely to be upset by discussing the subject. Then someone in the institution whom they trusted approached these potential participants and gave them a short written statement about the aims of the project and what involvement would entail. Those who were interested to take part were then introduced to the researcher who conducted the semi-structured interviews. At this point, the researcher repeated information about the project and asked the participant to confirm verbally that he or she was prepared to take part before beginning the interview.

Recruiting and interviewing bereaved relatives

We worked with Patient Opinion to make contact with bereaved relatives of people who had died in hospital. Patient Opinion (www.patientopinion.org.uk) is a website that allows users to post comments on NHS care anonymously. Approximately half of the comments on the site are compliments about care received, so it is unlikely that the material is particularly biased against NHS services.

We sent an email explaining the project and the process of being involved in a telephone interview to all Patient Opinion users who had posted comments about death and dying between 1 January 2008 and 8 June 2010 and had agreed at the time of

posting to be contacted in the future by Patient Opinion regarding their comments. The email invited people to contact the researcher by email if they wanted to be involved or wanted more information. We conducted in-depth, semi-structured interviews with all 15 respondents who decided to take part.

Data analysis

We analysed data gathered during the interviews and web comments qualitatively using coding techniques similar to those of grounded theory. However, our methodology was unlike that of grounded theory in that we began with certain concepts derived from conducting the interviews and desk research that we wanted to test. We coded each of the texts according to these concepts, which included themes around place of death, communication at end of life and visions of good deaths. Other themes that we had not expected also emerged from the data.

In grounded theory, 'theoretical saturation' is the point at which any new data just confirm what has already been found. This is considered to be the moment at which a sufficient sample has been reached. We began to reach this level after analysing over 350 web comments and the 15 interview transcripts.

Data protection and ethics

We knew there would be a number of difficult ethical concerns to overcome in this project so we convened a steering group to act as an ethics panel, whose members advised on all matters of ethical concern. We also drew advice from academic researchers working in the field, hospice management staff and local NHS research ethics committees.

The project required us to work with sensitive issues of a personal and cultural nature. For this reason, we drew extensively on the expertise, advice and experience of those working in the area. We complemented the advice from the committee by carefully designing the research process to take into account potential sensitivities and to provide structures to enable participants to feel supported in their involvement.

We made it clear to each person before they were involved what our research was about and who was funding it, while stressing the independence of our work. We ensured that all research participants understood how far they would be afforded confidentiality and were able to reject the use of data-gathering devices such as digital recorders. All conditions relating to freedom from coercion, confidentiality, secure data storage and anonymity were followed. Data were stored securely in case they included sensitive and private information. Access was restricted to researchers working on the project.

Estimating end of life care costs

One way to estimate the NHS costs of end of life care is to look at the costs of treating people with specific conditions in the last year of their life. A study undertaken by RAND Europe in 2008 for the NAO looked at the costs of end of life care for people with cancer and organ failure. We have supplemented that with an analysis of dementia (table 2). Although cancer and organ failure account for a significant portion of annual deaths (approximately 70–75 per cent), it must be remembered that a summation would not indicate a global cost.

Table 2 **Costs of caring for people with cancer, organ failure or dementia in the last year of their life**

Cost of care by type of illness	Cohort health cost to taxpayer (bn)	Unit cost per patient (cost to taxpayer)	Informal care (not specific to end of life) (bn)
Cancer	£1.8 ²⁰⁸	£14,236 ²⁰⁹	£1.2 ²¹⁰
Organ failure	£0.553 ²¹¹	£18,771 ²¹²	£2.24 ²¹³
Dementia	£0.8 ²¹⁴	£14,000 ²¹⁵	£5.4 ²¹⁶

Cancer

Based on the average cancer patient spending 17 days in hospital at a cost of £238.61 per day, 4 days in a hospice at a cost of £132.57 per day, and 344 days at home during their last year on life at a cost of £28.01 per day to the NHS, the unit cost of services per patient in the final year of life is about £14,236. Approximately 126,779 people die from cancer each year. These figures suggest that the NHS services for cancer patients in their last year of life cost about £1.8 billion (2005/6 prices).

Organ failure

The cost of care for organ failure patients in their last year of life was £553 million. This figure is based on the estimate that 29,450 die annually as a result of organ failure, with the average stay in hospital being 40 days at a cost of £238.61 per day, 2.5 hours in a hospice at a cost of £132.57 a day, and the remaining 325 days at home at an average cost of £28.01 per day.

Dementia

An examination of the cost of caring for dementia exemplifies why it is so difficult to estimate costs for services at the end of life. An estimated 820,000 in the UK are affected by dementia.²¹⁷ The direct health and social care costs of dementia in England is £8.2 billion per year according to the NAO.²¹⁸ It is difficult to determine when a patient with advanced dementia is entering the dying phase. Patients can live with dementia for more than seven years and although thousands die with dementia annually, only a small proportion dies as a direct result of the disease.

To calculate the annual end of life costs of dementia we assumed the costs on the final year of life to be the same as in other years. Dementia patients decline gradually compared with other conditions, so we assume that there is no sudden increase in costs in the last year of life.²¹⁹ The annual cost to the taxpayer of dementia services is about £14,000 per person in England. As there are about 54,000 dementia related deaths in the UK each year, the end of life costs from dementia alone are about £800 million.²²⁰

Notes

- 1 Throughout this document, references to ‘our poll’ relate to a survey carried out by YouGov on behalf of Demos. Total sample size was 2,127 adults. Fieldwork was undertaken on 3–6 September 2010. The survey was carried out online. The figures have been weighted and are representative of all GB adults (aged 18+).
- 2 Projections for 2030 are from B Gomes and IJ Higginson, ‘Where people die (1974–2030): past trends, future projections and implications for care’, *Palliative Medicine* 22 (2008). Figures are for England and Wales. This situation was a key factor prompting the End of Life Care Strategy, 2008.
- 3 NEoLCIN, *Variations in Place of Death in England: Inequalities or appropriate consequences of gender and cause of death?*, Bristol: National End of Life Care Intelligence Network, 2010.
- 4 National Audit Office, *Patient and Carer Experiences Regarding End of Life Care in England*, London: Ove Arup & Partners Ltd, 2008.
- 5 C McPherson, K Wilson and M Murray, ‘Feeling like a burden to others: a systematic review focusing on the end of life’, *Palliative Medicine* 21, no 2 (2007).
- 6 K Steinhauser et al, ‘In search of a good death: observations of patients, families and providers’, *Annals of Internal Medicine* 132, no 10 (2000). It is worth noting that we use the term ‘good death’ somewhat loosely. The notion of a good death has changed historically (see A Kellehear, *A Social History of Dying*, Cambridge: Cambridge University Press, 2007, and T Walter,

The Revival of Death, London: Routledge, 1994). Equally, the components of a good death are dependent on culture and individual preferences. As we will outline, we do not prescribe a particular vision of the good death, but look for common contemporary themes. See K Kehl, 'Moving toward peace: an analysis of the concept of a good death', *American Journal of Hospice & Palliative Medicine* 23, no 4, 2006.

- 7 In 2009 there were 491,348 deaths registered in England and Wales; see Office for National Statistics, www.statistics.gov.uk/cci/nugget.asp?id=952 (accessed 27 Sep 2010).
- 8 Gomes and Higginson, 'Where people die (1974–2030)'.
- 9 G Brown, *The Living End: The future of death, aging, and immortality*, London: Macmillan, 2008.
- 10 Office for National Statistics, 'Older people's day 2009', *Statistical Bulletin*, www.statistics.gov.uk/pdfdir/age0909.pdf (accessed 18 Oct 2010).
- 11 Office for National Statistics, 'Health expectancy: Living longer, more years in poor health', www.statistics.gov.uk/cci/nugget.asp?id=934 (accessed 26 Oct 2010)
- 12 Brown, *The Living End*.
- 13 National Audit Office, *End of Life Care*.
- 14 Gomes and Higginson, 'Where people die (1974–2030)'.
- 15 Quoted in A Gawande, 'Letting go', *New Yorker*, 2 Aug 2010.
- 16 Office for National Statistics, 'Older people's day 2009'.
- 17 There is a certain amount of controversy about the interpretation of healthy life expectancy (HLE) and disability free life expectancy (DFLE). In particular, Raymond Tallis,

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 - 20 Marie Curie Cancer Care, *End of Life Care for People with Dementia*, London: Marie Curie Cancer Care, 2009.
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 - 26 H Anderson et al, 'The concerns of patients under palliative care and a heart failure clinic are not being met', *Palliative Medicine* 15, no 4 (2001); P Edmonds et al, 'A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer', *Palliative Medicine* 15, no 4 (2001).

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- 31 J Groopman, 'Health care: who knows best', *New York Review*, 11 Feb 2010.
- 32 See M Gott et al, 'Dying trajectories in heart failure', *Palliative Medicine* 21, no 2 (2007).
- 33 KG Shojania et al, 'How quickly do systematic reviews go out of date? A survival analysis', *Annals of Internal Medicine* 147, no 4 (2007).
- 34 Gott et al, 'Dying trajectories in heart failure'.
- 35 See J Kay, *Obliquity: Why our goals are best achieved indirectly*, London: Profile, 2010; C Lindblom, 'The science of "muddling through"', *Public Administration Review* 19, no 2 (1959).
- 36 The Dying Matters Coalition, set up as a result of the End of Life Care Strategy (2008) and hosted by the National Council for Palliative Care, exists to encourage people to talk more openly about death and dying. See www.dyingmatters.org.
- 37 A Gillies, *Keeper: Living with Nancy. A journey into Alzheimer's*, London: Short Books Ltd, 2009.

- 38 See www.mumsnet.com/Talk/bereavement/981660-Dad-expecting-cancer-diagnosis (accessed 28 Sep 2010).
- 39 See www.patientopinion.org.uk, comment 28,965 (2010).
- 40 Dying Matters is a coalition of almost 12,000 organisations in the UK that aims to promote awareness of and conversation around death and dying. It was set up in 2009 by the National Council for Palliative Care and hopes that by ending the taboo around end of life, more people will be able to 'die well'.
- 41 New pathway approaches including the Liverpool Care Pathway and the Gold Standards Framework are undoubtedly producing improvements in end of life care. Proponents argue that these systems are a framework for making decisions with patients rather than a detailed pathway prescribing particular treatments.
- 42 E Kübler-Ross, *On Death and Dying*, London: Routledge, 1973.
- 43 SJ Gould, 'The median isn't the message', http://cancerguide.org/median_not_msg.html (accessed 18 Oct 2010).
- 44 These themes emerged clearly from our interviews and focus groups. Similar findings were obtained in Steinhauser et al, 'In search of a good death'; Kehl, 'Moving toward peace'; J Seymour et al, *End of Life Care*, Bristol: Policy Press, 2005.
- 45 In 2005 euthanasia accounted for 1.7 per cent of all deaths in the Netherlands; see J Rietjens et al, 'Two decades of research on euthanasia from the Netherlands: what have we learnt and what questions remain?', *Bioethical Inquiry* 6, no 3 (2009). In Oregon, in 2008 less than 0.2 per cent of deaths were recorded as the result of assisted suicide; see 2009 Summary of Oregon's Death with Dignity Act, www.oregon.gov/DHS/ph/pas/ (accessed 18 Oct 2010)

- 46 General Medical Council, 'Treatment and care towards the end of life: good practice in decision making', www.gmc-uk.org/guidance/ethical_guidance/6858.asp (accessed 18 Oct 2010).
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- 48 D Miller and F Parrot, 'Loss and material culture in south London', *Journal of the Royal Anthropological Institute* 15, no 3 (2009).
- 49 This is currently the aim of the Dying Matters Coalition.
- 50 See Kellehear, *A Social History of Dying*, and Walter, *The Revival of Death*.
- 51 Figures in this paragraph are based on Gomes and Higginson, 'Where people die (1974–2030)'. The hospice figure relates to inpatient hospice only. Help the Hospice figures show that in 2008 8.72 per cent of all deaths had hospice involvement.
- 52 In this section we look at the institutions where most people currently die: hospitals, care homes, hospices and homes. Other settings include sheltered, supported and extra care housing. It is also worth noting that many care home residents consider their care home to be their home, so the boundaries are not as clear as they might appear.
- 53 Interview with bereaved carer who posted a comment on www.patientopinion.org.uk.
- 54 See www.patientopinion.org.uk, comment 15934 (2009).
- 55 See www.patientopinion.org.uk, comment 33232 (2010).

- 56 See www.patientopinion.org.uk, comment 11955 (2008).
- 57 National Council for Palliative Care, *Specialist Palliative Care Workforce Survey 2008/2009*, National Council for Palliative Care, 2010.
- 58 Almost half of complaints about NHS services related to acute hospitals. Of these 54 per cent related to care given at the end of life. See Department of Health, *End of Life Care Strategy*, 2008; I Higginson, *Priorities for End of Life Care in England, Wales and Scotland*, London: National Council for Palliative Care, 2003; YouGov survey, 'Patients wanting home death fear they won't get care they need', 2008, www.campaign.mariecurie.org.uk/Scotland/press_centre/yougov_survey.htm (accessed 20 Mar 2008). See also National Audit Office, *Patient and Carer Experiences Regarding End of Life Care in England*.
- 59 Based on a study of 348 records of patients who died in Sheffield PCT during October 2007 in National Audit Office, *End of Life Care*.
- 60 I Higginson et al, 'Is there evidence that palliative care teams alter end of life experiences of patients and their caregivers?', *Journal of Pain and Symptom Management* 25 (2003).
- 61 Gawande, 'Letting go'.
- 62 Ibid.
- 63 Ibid.
- 64 M Lock, 'Death in technological time: locating the end of meaningful life', *Medical Anthropological Quarterly* 10 (1996).
- 65 'In most cities, if you look for the most lumpen, ungainly, charmless building, hospitals from the 1960s and 1970s will be near the top of the list. Gartnavel in Glasgow, the Royal Liverpool, Addenbrooke's in Cambridge, the Royal Free and

Guys in London, to name a random few, all follow the same type. They are silos for the sick; multi-level garages for parking the unwell. Inside they are more like the interiors of aircraft carriers, vast unwindowed complexes linked by bewildering networks of corridors. You might have thought some decency and dignity would be suited to places where people are born and die, but the makers of these hospitals didn't seem to agree' (R Moore, 'Circle hospital/ Foster and Partners', *Observer*, 21 Mar 2010).

- 66 'Both my wife and I felt that consultants need to have a better understanding of patients and to treat them as people not just as a patient. Although no doubt they are highly skilled and knowledgeable they need to talk to people not down to them. Especially when a patient has a terminal illness!' (comment 18268 posted in 2009 on www.patientopinion.org.uk); see also Brown, *The Living End*.
- 67 N Elias, *The Loneliness of Dying*, Oxford: Blackwell, 1985.
- 68 Higginson, *Priorities for End of Life Care in England, Wales and Scotland*; YouGov survey, 'Patients wanting home death fear they won't get care they need'. See also National Audit Office, *Patient and Carer Experiences Regarding End of Life Care in England*.
- 69 See www.patientopinion.org.uk, comment 18615 (2009).
- 70 See www.patientopinion.org.uk, comment 17136 (2009).
- 71 See www.patientopinion.org.uk, comment 7826 (2008).
- 72 See www.patientopinion.org.uk, comment 27646 (2010).
- 73 In conversation with a Patient Opinion contributor.
- 74 See www.patientopinion.org.uk, comment 21572 (2009).

- 75 ML Barnett et al, 'Physician Networks are Associated with the Cost and Intensity of Care in US Hospitals', forthcoming. Available from BE Landon, Department of Health Care Policy, Harvard Medical School.
- 76 Gawande, 'Letting go'.
- 77 Ibid.
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- 79 D Sokol, 'The death of DNR', *British Medical Journal* 338 (2009).
- 80 S Page, 'Never say die: CPR in hospital space' in J Hockey et al (eds), *The Matter of Death: Space, place and materiality*, Basingstoke: Palgrave Macmillan, 2010.
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- 86 General Household Survey 2007.
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- 89 In society as a whole, In Control, the social care charity, states that 'most care and support is provided unpaid by families and friends' equivalent to support of more than 50 hours per week to more than 6 million people; see R Brewis and J Fitzgerald, *Citizenship in Health*, London: In Control, 2010.
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- 91 Exley and Allen, 'A critical examination of home care'; Gillies, *Keeper*.
- 92 See www.mumsnet.com/Talk/carers/527431-those-of-us-with-elderly-relatives-who-won-t-accept, posted 2008.
- 93 See www.mumsnet.com/Talk/carers/368487-here-we-go-again, posted 2007.
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- 113 G Mulgan et al, *Social Innovation: What it is, why it matters, how it can be accelerated*, London: Young Foundation, 2007.
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- 116 S Payne, J Seymour and C Ingleton, 'Independent evaluation of the Marie Curie Cancer Care "Delivering Choice Programme"', International Observatory on End of Life Care, 2010.
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- 146 Payne, Seymour and Ingleton, Independent Evaluation of the Marie Curie Cancer Care 'Delivering Choice Programme'.

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The institutionalised ways we cope with dying do not align with how most people aspire to die. Most people want to die with family and friends nearby, cared for, free from pain, with medical support available when needed. Yet most people will die in hospitals and care homes, often cut off from friends and family, dependent on systems and procedures that feel impersonal, over which they have little control and which too often offer them little dignity. We spend large sums of taxpayer's money – at least £20 billion a year – on services that leave too many people feeling confused, frustrated and distressed too much of the time.

The UK should be able to provide people with better ways to die. This pamphlet argues for improvements to existing services: making end of life advance care plans the norm; training more in the medical profession in palliative care; and more greatly integrating the care services provided by the public, private and voluntary sectors. It also suggests radical innovations: a new infrastructure of home hospices, the creation of a compassionate care benefit and a properly trained volunteer support network providing palliative care – a perfect opportunity for the Big Society.

The challenge is to help people to achieve what is most important to them at the end of life. Dying for Change describes how that challenge can be overcome.

Charles Leadbeater and Jake Garber are associates of Demos.

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