

# Health: End of Life

## *Motion to Take Note*

11.38 am

*Moved by Lord Dubs*

That this House takes note of the case for patient choice at end of life.

**Lord Dubs (Lab):** My Lords, my aim in this debate is to consider, in its widest sense, end-of-life care, to note what progress has been made in recent years and to look into the future. I accept that while some of the

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issues will command broad support in this House and in the country, others are controversial. But there is one thread running through all this: how we can best achieve informed patient choice. We are better able to discuss death today than ever in the past and it is becoming less of a taboo subject. This is in large part down to the work of the hospice movement, other stakeholders such as the Dying Matters coalition, successive Governments who have implemented the end-of-life care strategy, and the ongoing public and parliamentary debate on assisted dying led by Dignity in Dying, to which I owe my thanks for some of the help that it has given me in this debate, and indeed in the past.

I would like to say a little about what has influenced my own views. I remember, as vividly as if it were yesterday, the debate on my noble friend Lord Joffe's Bill in this House some years ago. I listened hard to that debate; at the beginning of it, I was not even certain where I stood, but by the time I had heard the arguments I realised that I could not vote to deny other people something that I would want for myself. So of course I supported the Bill, and have been a supporter of that cause ever since.

It was at about that time that a friend of mine with motor neurone disease was dying. I went to see him, his wife and children around him, and he tapped out a message to me on a keyboard, the only way in which he could communicate because he was no longer able to speak. His message was that I should support the change in the law to permit assisted dying—a very passionate plea from a person who could not actually speak with passion. That was almost the last time I saw him because he died at home shortly afterwards. It moved me enormously in my attitude to this whole issue.

It is worth noting that palliative care, an area of healthcare that focuses on alleviating the suffering of patients, is, by comparison with other established forms of healthcare, a fairly modern development. I believe that palliative care merged with the hospice movement in the late 1960s, and since then it has made great progress to ensure that patients at the end of life can die comfortably and peacefully. Of course there is still some way to go in making this a reality for all people at the end of life, but I believe that this House will be united in its admiration for how far we have come in such a short space of time and would like to join with me in expressing my admiration for the healthcare professionals, in both the NHS and the wider hospice movement, who have dedicated their lives to alleviating the suffering of their patients.

However, we know that the journey to date has not been without difficulties and areas of controversy. The House will be aware of the recent concerns raised in the media about the Liverpool care pathway for the dying. These concerns resulted in an independent review by the noble Baroness, Lady Neuberger, in July, which recommended the phasing out of the pathway, a recommendation that the Government accepted. There are other documented cases where standards of care at the end of life have fallen well short of what we expect, some of them highlighted by the Patients Association.

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I understand that in the near future the Government will make proposals to replace the Liverpool care pathway, and I wonder if the Minister can give us some idea of when this might be expected.

This debate comes at a critical time for the development argument of end-of-life care. The Government have asked NHS England to lead an alliance of stakeholders in creating and delivering,

“the knowledge base, the education, training and skills and the long-term commitment needed to make high quality care for dying patients a reality, not just an ambition”.

Separate to the review, and as a matter of profound conscience, my noble and learned friend Lord Falconer has tabled an Assisted Dying Bill that awaits its Second Reading in, I believe, the next Session of Parliament. I hope

that with the combination of the NHS England review and my noble and learned friend's Bill we will be able to develop a broader approach to end-of-life decision-making in the next two years, an approach that puts patients first.

I turn to what I understand by patient choice. Some people are uncomfortable about that concept. There is a concern that the patient may not make a free choice but may somehow feel under pressure from those close to him or her, possibly not always from worthy motives—I have had that point put to me. However, it is only right to point out that there are no safeguards at all in going to Switzerland to have an assisted death provided that one can afford the air fare, so my noble and learned friend's Bill would actually improve the situation significantly by having safeguards in the process. The issue is whether there can be satisfactory safeguards for an ill patient who may also be in considerable pain. I believe firmly that this can be done otherwise I would not support changes in the law, because I believe that these safeguards are essential.

I should add that there are those who oppose people's choices at the end of life because they are based on sincerely held—although, I believe, faulty—religious beliefs. To me, though, and I suspect to most people, the desire not to suffer or to see others suffer against their wishes is a worthy sentiment, and I see greater patient choice as ensuring that people do not suffer against their wishes at the end of life.

Of course, suffering is subjective. To some, the inability to spend their final days in familiar surroundings may cause distress; to others it may not. Some may have a higher threshold of pain than others or a stronger desire to live. Within reason, though, and with sufficient resources, informed choice can surely accommodate individual wishes and preferences that would enable the patient to have what they themselves consider to be a good death.

The *End of Life Care Strategy* published by the previous Government in 2008, and taken forward by the present Government, has led to increased investment in end-of-life care and more people dying at home. The strategy recognises the importance of treating people,

“as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings and being in the company of close family and/or friends”.

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The right,

“to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this”,

is now also reflected in the NHS constitution.

Furthermore, I understand that the Government are giving active consideration to the merits of the Macmillan campaign, championed by my noble friend Lord Warner in this House, to provide free social care at the end of life so that people can stay in their own home with adequate support.

I do not believe that choice is simply matter of saying, “I want to be at home”. Choice is wider than that, but I do not want to diminish the importance, for those who want to do it, of dying at home. I believe that there are other people who would also like greater choice over their care and treatment at the end of life regardless of where that care is delivered. We need a broader approach to patient-centred care at the end of life. On this I wish to commend the work of Sue Ryder and its excellent report *A Time and a Place: What People Want at the End of Life*. It states:

“End of life care policy and practice has, for some years, focused on ensuring people die in their preferred place of death and usually at home. But this focus on where people die—rather than what they want at the end of life—has inhibited personalisation and informed choice for patients and their families. It has led to a lack of proper scrutiny of the experience of dying at home and left other settings neglected when it comes to developing them as good places to die”.

The report goes on:

“People's first priority at the end of life is to be free from pain and discomfort (78% of respondents said this would be important to them), followed by being surrounded by their loved ones (71%) having privacy and dignity (53%), and being in familiar surroundings and being in a calm and peaceful atmosphere (both 45%)”.

It concludes:

“No care setting is perfect—home, hospices, hospital and care home all have their weaknesses—but all can do more to ensure that no matter where a person dies, the experience will deliver as much as possible on the outcomes people value at the end of life”.

Turning to what sort of care people wish to receive at the end of life, a poll commissioned by Compassion in Dying, the partner charity of the campaign organisation Dignity in Dying, recently found that a majority would want little or no medical intervention at the end of life. Specifically, it found that more than half of adults—57%—would want only comfort care, 13% would want limited intervention, and just over one in 10—12%—would prefer all available treatment, so people have a range of views about what they want, which is why I believe that choice is such an important factor. Relevant recommendations have been made by Sue Ryder, Compassion in Dying and other stakeholders which I would urge the Government to consider.

Let me draw attention to one specific recommendation by Compassion in Dying, which is that there should be a positive duty on healthcare professionals to inform patients of all their rights at the end of life, including the ability to make an advance decision, or a health and welfare lasting power of attorney, if there is a reason to believe that patients may lose capacity.

The wider issue of assisted dying is surely one of conscience, and it is a matter for Parliament to resolve rather than the Government. I welcome the Assisted Dying Bill that has been tabled by my noble and

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learned friend Lord Falconer. It seems inevitable, as an issue of conscience, that this choice must be enacted and safeguarded separately from other initiatives to promote patient choice at the end of life. I recognise there is opposition from some quarters to this approach—I have heard it before in this House and in Grand Committee—but I sincerely believe that at the end of life people have the right to choose to be free from intolerable pain and discomfort, provided it is their free choice.

Of course palliative care can alleviate much pain and discomfort, but not in all cases for all people, so assisted dying, with safeguards, is but one of many legitimate choices dying patients should have.

I return to the experience in Oregon, which of course introduced assisted dying about 15 years ago. All the assessments conclude that the law worked safely. Eligibility has never been extended beyond terminal illness, nor has there been pressure for it to be extended. Numbers are very low. Assisted deaths have remained stable since 2008 at around 0.2% of all deaths per year. There is no evidence that potentially vulnerable groups are negatively affected. Around 40% of dying people who meet the strict safeguards to obtain life-ending medication never use it, simply taking comfort in having the option. That is a crucial point. It means in practice that people in Oregon who are terminally ill and in great pain can be in hospice care, knowing that if things become intolerable for them, they can opt to take the medication that will end their lives. Because people in Oregon feel that they are in full control, they seldom exercise that choice. That, to me, is one of the particular arguments in favour of a change in the law.

Compare that with the position here, where people have to agonise over whether to make the journey to Switzerland before they are really ready in their own mind to end their life. Yet they worry that they may be too ill to make that journey. This seems to be an intolerable dilemma which we impose upon people. Assisted dying and palliative care are not, and should not be, alternatives. As was stated by the noble Earl, Lord Arran, in a debate last week, the former chief executive of the Oregon Hospice Association, Ann Jackson, told the Select Committee on my noble friend Lord Joffe's Assisted Dying Bill that the Oregon Act had not adversely affected the hospice movement. In fact, hospice provision had improved in Oregon since the passage of the Act. Last year, 97% of those who had an assisted death in Oregon had been enrolled in hospice care.

Assisted dying and palliative care are therefore complementary. Choice at the end of life does not begin and end with where you die. Within safeguards, and in line with public opinion, dying people should not have to suffer against their wishes. It is time for change. If we entrust dying patients to refuse potentially life-prolonging treatment, we should also entrust them to choose whether they want an assisted death.

We had a debate in Grand Committee last week. I was not very happy with some of the comments made from the government Front Bench, particularly using words such as “killing” and so on. It limited the argument and was not very helpful. Present law and practice allow doctors to administer sufficient doses of

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pain relief to end a patient's life, so long as they can argue that it is not their direct intention to end life but to minimise suffering: the principle known as “double effect”. These things occur, so there is not that steep threshold over which we should go, as has been suggested.

The beauty and nature of choice is that it accommodates different views. Within reason, it accommodates the views of those who wish to prolong life as much as it accommodates the views of those who wish to hasten death at the end of life. While it is the job of Parliament, the Government and healthcare professionals to ensure that people's choices are informed at the end of life, where necessary through upfront safeguards, we must also

find it within ourselves to respect people's choices even when they differ from ours. That is the message I want to leave with your Lordships today.

**11.53 am**

**Baroness Morris of Bolton (Con):** My Lords, we will all of us die one day, and how we die is as important as how we live. This is about the best possible care at the end of life, and the choices which that affords. I am grateful to the noble Lord, Lord Dubs, for giving us the opportunity to debate this important issue.

As a society, we are becoming personally less familiar with death. At one time, death was an integral part of life. Most deaths took place at home, with family present or nearby. My husband and I both come from large Irish Catholic families and it was the usual practice for your loved ones to be laid out at home for family and friends to pay their last respects before burial. However, with advances in medical science—advances for which we are all enormously grateful—death has increasingly become a clinical act that takes place in hospital, often after an emergency admission to an acute ward and, sadly, all too often in isolation. We have come to believe that medicine has the answer for everything.

We cannot recreate a society from another age, and each age must shape its own way. However, it is a fact, as the noble Lord, Lord Dubs, said, that when questioned, most people say that they would wish to die at home. We should strive to make that possible, wherever possible. That means greater investment in community care. It also means building on the investment which successive Governments have made in the development of specialist palliative care—an investment that has made this country a world leader in end-of-life care.

Those are the choices that I want to see embraced at the end of life. What I do not wish to see is the right to choose when to die, with assisted suicide enshrined in law as one of those choices for some people.

There is nothing more distressing than witnessing someone you love in pain and with little hope of recovery. I completely understand the honourable intentions of those who support a change in the law to license “assisted dying”. However, in reality that means licensing doctors to involve themselves in deliberately bringing about the deaths of some of their patients.

In the Bill of the noble and learned Lord, Lord Falconer, now before your Lordships' House, responsibility for assisting suicide is placed on the shoulders of

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doctors. However, most doctors do not want that responsibility, and nor do their professional bodies. The Royal College of Physicians has stated explicitly that a doctor's duty of care for patients,

“does not include being, in any way, part of their suicide”.

We need to remember that the law exists to protect us all—especially the more vulnerable among us. It is hard to imagine anyone more vulnerable than someone who is struggling to come to terms with their mortality and who is worried about the impact of their illness on those they love. The last thing they need is an invitation to take their own life. Instead they need and deserve our unflinching care and protection.

**11.56 am**

**Lord Taverne (LD):** My Lords, I strongly support the Motion so eloquently and persuasively moved by the noble Lord, Lord Dubs.

The official position at the moment puts the law in a state that is indefensible. The Director of Public Prosecutions decides whether to prosecute those who help people suffering from an incurable disease who want to die but cannot travel on their own to Dignitas in Switzerland. She decides on a case-by-case basis, at her own discretion.

Take a case of bank robbery. The driver who drives a bank robber to the bank and helps him escape after the robbery is clearly guilty of aiding and abetting. The Director of Public Prosecutions does not say, “I will exercise my discretion whether to prosecute, and I won't prosecute if, say, the driver intended to share the proceeds of the robbery with his poor old grandmother”. Aiding and abetting a bank robbery is a crime, whatever the driver's motives.

The law about assisted suicide, as it stands, is equally clear. To help someone die is a serious crime, punishable by up to 14 years of imprisonment. But what is the difference between taking someone to Switzerland to help them to die and driving a bank robber to a bank? Both are equally guilty of a crime. However, when it comes to assisting someone to die, the Director of Public Prosecutions says, “Sometimes I will decide it is a crime and sometimes not. It is entirely for me to decide”. She would never say that in a case of assisting a bank robbery.

This practice brings the whole system of justice into disrepute. It makes the law, to quote Mr Bumble, “a ass”. Indeed, that most eminent judge, the late Lord Bingham, said that the law was a mess and needed revision.

In the past, when some laws came to be regarded as intolerable, juries would ignore the law and acquit. At one time it was a capital offence to steal goods worth more than 40 shillings. Juries were required to make two findings: did the defendant steal, and what were the stolen goods worth? If someone stole £10, juries would often find that, yes, he had stolen the goods, and decide that the goods were worth 39 shillings and sixpence, since 40 shillings was the level at which the capital offence became due. Time after time, juries made a nonsense of the law, and the law was changed.

A vast majority of the public consistently tell pollsters that they support assisted suicide and favour a change in the law. I believe the reason is obvious. They want a

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change because so many have personal experience of the suffering undergone by a dying family member or friend. There is a mass of anecdotal evidence that, because the law is unjust, it is often disregarded by many doctors, who deliberately give some patients an overdose of morphine to end their suffering. But the law says that mercy killing is murder, for which the mandatory penalty is life, even if the act is a compassionate response to a dying person’s request for help to die. I regard that law as monstrous and intolerable.

Perhaps one day, in cases of mercy killing or assisted dying in the most compassionate circumstances, defending counsel may remind juries of their absolute right to acquit. Not long ago, Clive Ponting, acting on principle, broke the Official Secrets Act; his jury cocked a snook at the law and acquitted him. Juries should be reminded that their absolute right to acquit is one of the great virtues of the jury system.

### **12.01 pm**

**Baroness Hayman (CB):** My Lords, it is nearly 10 years ago that I was appointed a member of the Select Committee of your Lordships’ House on the assisted dying Bill proposed by the noble Lord, Lord Joffe, under the as ever brilliant chairmanship of the noble and learned Lord, Lord Mackay of Clashfern. It is on the question of assisted dying and legislation to implement it that I shall concentrate today. I put on record my passionate support for the hospice movement, which has come both from personal experience and from my time as a Minister with responsibility for hospices in the Department of Health. That commitment extends, as the noble Lord, Lord Dubs, said in his excellent opening speech, to all settings in which people die.

When my own father was dying, I was deputed as the member of the family who should go and put the question to him—we thought that this was the only question—as to whether he wanted to die at home. It was a difficult conversation to have, more so because he thought that I was absolutely mad to be having this conversation. He turned to me in his way and said, “Well, dear, we’ll just have to see how it goes and what’s best at the time”. As it happened, he did die at home, but he would not have wanted to do so if that was a terribly distressing situation for my mother and it was more appropriate for him to be in another setting. That element of individuality in these choices is tremendously important.

Like the noble Lord, Lord Dubs, I came to the Select Committee as someone without objection in principle, understanding about the hard cases and moved by them but as an ex-law student who had had it drummed into me that hard cases made bad law. Therefore, I was concerned as to whether adequate safeguards could be incorporated to make sure that there was no pressure on individuals to avail themselves of this option. My experience of taking evidence, visiting Oregon and going to other jurisdictions, persuaded me that it was possible to provide those safeguards, and I think that the Bill proposed by the noble and learned Lord, Lord Falconer of Thoroton, is particularly robust in that respect.

There were two other things that I learnt in the course of the past 10 years. One was that no one can speak for their demographic on this issue. Different

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people take different opinions from the same sort of background. I cannot speak for 64 year-old female Jewish parliamentarians in good health. There are probably quite a few of them around. I cannot speak for that group. There are differences of opinion among doctors—I am a member of the General Medical Council—nurses, people with disabilities, people of faith and, indeed, ministers of religion. However, overall, there is consistent general public support for a change in the law on this issue.

The second thing I have learnt concerns the insurance cover value of assisted dying legislation, to which the noble Lord, Lord Dubs, referred. In Oregon, the latest figures for 2007 show that 9,800 people considered a prescription for assisted death out of 30,000 who died. Just over 1,000 talked to a doctor about the prescription.

Of these, 85 received the prescription and only 49 used it. However, other people gained great confidence and strength from knowing that if life was intolerable at the end, something could be done. I gain confidence from the fact that I have in place an advance directive about what should happen to me. I think that that confidence should be extended to others through legislation.

**12.06 pm**

**Lord Bishop of Sheffield:** My Lords, I must begin by thanking your Lordships for the warmth of welcome extended to me here. Thank you also to the staff for their guidance and help. I look forward very much to serving with you in this House and count it an immense privilege to be here.

It is particularly poignant for me to contribute to this debate on patient choice at the end of life as my own father is very seriously ill. Over the last few days I have been involved in a number of conversations with medical staff and my close family about the questions before us today. I am sure that these conversations are familiar to many noble Lords. The matters we debate are of profound importance to those who are near the end of their life, and to their wider families.

The diocese of Sheffield, where I now serve, covers most of south Yorkshire and parts of east Yorkshire. Its communities are vibrant, coherent, friendly and welcoming. Its manufacturing is alive and growing. There are vigorous partnerships between industry, civic life and the universities, including in the area of healthcare. Its people are deeply committed to their local institutions, including their National Health Service.

The city of Sheffield has this year embraced a new commitment to fairness and equality through its Fairness Commission and aims to become the fairest city in Britain in the coming years, including in equality of access to all forms of healthcare.

Like many others, I am grateful to those who have produced the independent review of the Liverpool care pathway. There is much in their report to be welcomed: the valuing of end-of-life care as a specific discipline, the move away from the language of pathway to a personal care plan, the greater shift to patient choice, and greater clarity in decision-making. Like others, I welcome particularly the continued valuing of the hospice movement. The greater shift to patient choice commended in the review does not, of course,

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include extending patient choice to physician-assisted suicide, something to which I remain opposed and which seems a very different kind of conversation.

I also welcome the work of the Leadership Alliance for the Care of Dying People, and in particular the collaborative partnership and way of working it has established between the medical profession, patients and their families. I note the sense of urgency among those involved in end-of-life care with whom I have spoken that proper provision should be in place soon in every place to replace the Liverpool care pathway, lest an imperfect system be made even worse by a period of uncertainty and confusion.

*More Care, Less Pathway* calls for a proper national conversation about death, which the Leadership Alliance is taking forward. This takes us to the heart of the issue. The death of someone we love, our own death, is far more than the cessation of life for medical reasons. Death is an existential event which raises and asks significant questions. Those questions are often suppressed, masked by humour or denied, but surface in times of vulnerability throughout our lives. What is it of the human person which endures? What light does death cast on the way in which we live? What is a good death? What does it mean to come to terms with our mortality and, from the Christian perspective, our vocation to eternity?

For all these reasons and more, the ministry of chaplains in our hospitals and hospices remains a vital part of end-of-life care. Chaplains are present to minister to those of all faiths and of none. They are drawn, of course, from every faith. They are present to offer spiritual support to the dying and to the bereaved, to patients and staff. They are a vital part of the team in end-of-life care as a specialist resource, as experts able to offer training to colleagues and as a point of referral in moments of crisis. I invite the Minister in the response to this debate both to affirm the key role of chaplains in this context and to ensure that the part they play is written clearly into the documents which will shape end-of-life care into the future.

I look forward very much to playing my part in the business of your Lordships' House.

**12.11 pm**

**Lord Alton of Liverpool (CB):** My Lords, it is a particular pleasure for me both to thank the right reverend Prelate the Bishop of Sheffield for his thoughtful and poignant maiden speech, and to welcome him to your Lordships' House. I see that, like Moses, he chose to read from a tablet.

I am married to an Anglican whose father and grandfather were, for more than 60 and 50 years, Anglican priests, and there are eight ordained Anglican clergy crossing the generations on my wife's side of the family. As an outsider, I have seen something of the extraordinary selflessness that characterises the men and women from whom the right reverend Prelate has been drawn.

Steven Croft is a Yorkshireman who, after graduating from the University of Oxford, studied for the priesthood and obtained his doctorate at Durham. After serving in parishes and as a diocesan adviser in Wakefield, he

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returned to Durham with his family as warden of the university's Cranmer Hall, St John's College. This required him to lead the training of men and women for Church of England ministry. He thrived in his new responsibilities, wrote widely about his experiences as a parish priest and began to express increasing concern about the urgent need for the church to engage with a society that has been drifting spiritually but where the Christian faith is needed like never before.

Shortly after Rowan Williams—now the noble and right reverend Lord, Lord Williams of Oystermouth—was appointed as the Archbishop of Canterbury, the right reverend Prelate became Archbishops' Missioner and Fresh Expressions Team Leader. For four years he oversaw the emergence of Fresh Expressions, an initiative of the most reverend Primates of Canterbury and York, in conjunction with the Methodist Church. Fresh Expressions encourages and resources new ways for the church to engage with the world. The movement has resulted in thousands of new congregations being formed alongside more traditional churches. The right reverend Prelate is known as a very shrewd and strategic thinker. The energy and determination that he has brought to his work thus far will prepare him perfectly for his duties in your Lordships' House. Sheffield is lucky to have him. I have no doubt that, as the years pass, we will hear many more thoughtful and challenging contributions to our proceedings, and I know that I speak for all sides of your Lordships' House when I thank him again for making such an excellent start with his maiden speech.

It was an illustrious English woman, a devout Anglican, Dame Cicely Saunders, whom I was fortunate to meet, who was the founder of the modern hospice movement in England. Dame Cicely trained as a nurse, a medical social worker and finally as a physician. Involved from 1948 onwards with the care of patients with terminal illness, she founded St Christopher's Hospice in 1967 as the first hospice linking expert pain and symptom control, compassionate care, teaching and clinical research. St Christopher's has been a pioneer in the field of palliative medicine, which is now established world wide. Like the late Lady Ryder of Warsaw, Sue Ryder, whose charity the noble Lord, Lord Dubs, referred to earlier, Dame Cicely was resolutely opposed to assisted suicide and euthanasia. She once said:

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die”.

In declaring a non-pecuniary interest as a patron of two hospices, I stand with the hospice movement, the disability rights groups and the British Medical Association in believing that we should never confuse the importance of providing end-of-life care with the legalisation of euthanasia. Were the law to change, we would see the emasculation of the hospice movement but we would also see a fundamental change in the relationship between doctors and their patients, especially the vulnerable.

Nor does experience overseas, which has been referred to, encourage me to change my mind. We are told that in the US state of Oregon, one of the handful of places where these practices have been legalised, everything is fine and the law is working well. That is a highly questionable assertion. There is no audit system in

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place for Oregon's law. It is totally dependent on the honest reporting of doctors. What we do know, from the annual statistical reports, is that the number of legal assisted deaths is rising year on year. In 2012, the number was nearly five times that in 1998, and the latest figure is the equivalent of between 1,100 and 1,200 such suicides per annum in England and Wales. It is claimed that the rising trend has levelled off. It has not. The official data show that the death rate from assisted suicide has increased by over 20% in the past five years.

There is another reason for being cautious about Oregon. The latest report states that nearly half of those in Oregon who asked for lethal drugs with which to end their lives listed as a reason that they feared being or becoming a burden on their families. In today's society, where we are living longer and where younger generations are often burdened with debt and other responsibilities, such fears are all too natural, and I fear that they will become even more so. For those reasons, I hope that we will resist the temptation to legalise something which on two occasions your Lordships have voted against.

**12.16 pm**

**The Earl of Arran (Con):** My Lords, last week I spoke of my experience as yet another member of your Lordships' Select Committee on the Assisted Dying for the Terminally Ill Bill. I travelled to Oregon, as did the noble Baroness, Lady Hayman, and the noble Lord, Lord Taverne, in 2004 to see how the Death with Dignity Act works in practice, it having been enacted there 10 years before. I wish to talk further briefly on Oregon simply because we think that the Act works well.

We often hear from opponents that there has been a meteoric, inexorable rise in the number of people who have an assisted death in Oregon. Quite aside from the fact that a modest rise should be expected in a new system such as this—proving, surely, that the system is working well—we are still looking at a very small number of cases each year. There have been fewer than 80 cases each year, representing less than a quarter of 1% of all deaths in that state. In this country, as has already been said, that would amount to approximately 1,000 to 1,200 people.

What better proof can there be of the law's effectiveness than the continued support of Oregonians themselves? They voted to retain the Act by 60% to 40%, and polling consistently confirms that between 75% and 80% of Oregonians continue to support the Death with Dignity Act.

I can suggest several reasons why that support remains so high. First, as I have already said, assisted dying is not running rampant across Oregon. It is used by a small number of people who suffer from intractable distress. However, while assisted dying is not used widely in Oregon, it offers reassurance—again, as has already been said—to a great many people. Forty per cent of those who request medication that would allow them to have an assisted death and meet the safeguards to access the medication do not use it and die naturally. Only around 1% or 2% of those who begin the discussion with their doctor about assisted dying actually go on to take life-ending medication.

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The Act offers reassurance to dying people that they may avoid unnecessary suffering; it offers reassurance to healthcare professionals that they may discuss openly and frankly with their patients the whole range of choices at the end of life; and it offers reassurance to family members that they need not face the impossible moral dilemma of breaking the law and helping a loved one to die, as is the case in this country. The fears raised by those who are opposed to a change in the law have simply not materialised. There are no documented cases of abuse in Oregon. Vulnerable people are not disproportionately affected by the Death with Dignity Act. There have been no public calls to extend the Act to cover those who are not terminally ill or do not have mental capacity, proving that the alleged slippery slope does not exist. Indeed, assisted dying is now law in the states of Washington, Denver and Montana.

As I said last week, palliative care continues to play a vital role alongside assisted dying in Oregon, showing that they are not mutually exclusive. Of course, we must offer excellent palliative care for all, but we must also acknowledge that some people who are dying, even with the very best palliative care, will suffer at the end of life. For this small but significant minority of people, our current law is not working. As so often happens, it tends to be society as a whole that eventually brings about the great humanitarian reforms. Witness, first, the Sexual Offences Act 1967 on homosexual reform, which incidentally was introduced by my father in your Lordships' House; and, secondly, the Abortion Act 1967 and further such legislation in 1990. Ultimately, it is the will of the people that pushes open the barriers and Parliament has to act. Both of those reforms involved the possibility of death. This Act deals directly with death and it is critical therefore that we get it right. Against a background of a growing majority of public support, I believe that we have got it right.

We have been arguing among ourselves for a long time—too long—about this reform. Now, dithering is done and Parliament must act soon—and very soon. Finally, none of us here today asked to come into this world. Should we therefore not have a choice to say how we might wish to depart from it?

**12.22 pm**

**Lord Joffe (Lab):** My Lords, I, too, join the welcome of the noble Lord, Lord Alton, to the right reverend Prelate the Bishop of Sheffield, and I look forward to his contribution to the important issues that this House considers.

The starting point for the debate must surely be the law on personal choice in England and Wales. The law has been considered in a large number of cases and was admirably summarised by the noble and learned Baroness, Lady Butler-Sloss, in her judgment in 2002 in the case of *Ms B v an NHS Hospital*. In it she endorsed the 1993 judgment of Lord Donaldson of Lynton in *Re T (Adult)* when he held that,

“the patient's right of choice exists whether the reasons for making that choice are rational, irrational, unknown or even non-existent”.

Likewise, Robins, Judge of Appeal, in the case of *Malette v Shulman*, held that:

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“The right to determine what shall be done with one’s own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based”.

It is against this law that we should be considering the various options for patient choice at the end of life. These include the following options. Option 1, palliative care: where it is available it is the preferred option for the overwhelming majority of patients. However, despite the excellence of UK palliative care it is not the solution for a small but significant minority of patients—a point accepted with a measure of reluctance even by palliative care professionals.

Option 2, refusal of further life-saving medical treatment: all patients have this right to bring their suffering to an end.

Option 3: patients have the right to starve themselves to death by refusing either food or water. This takes great courage, self-determination and suffering because weeks can pass before the patient withers away.

Option 4, terminal sedation: the patient is so heavily sedated that he or she remains unconscious for all or most of the time until they die. However, it is not certain that patients can insist upon this option.

Option 5, a request by patient for removal of life-saving equipment: based on the case of Ms B, doctors are obliged in law to accept an instruction from mentally competent patients to remove them from the equipment so that they can end their suffering.

Option 6, the double effect option: the doctor at the request of a patient can prescribe potentially lethal medication to control the patient’s pain which could end the patient’s life.

Option 7, the Director of Public Prosecutions option: provided that the patient has mental capacity he or she can be assisted to die by any person except a doctor if the assistance was given on the grounds of compassion.

Option 8, assisted dying: this is not yet an option but one wonders why not in the light of all the options open which are dependent on choice. This should be a compassionate option but it is currently not available because our law prohibits it. This is why the noble and learned Lord, Lord Falconer, has introduced the Assisted Dying Bill to change the law so that mentally competent patients who choose that option can end their suffering through ending their lives.

The only limitations upon patients making choices on their own lives is that they should have mental capacity and should not, when selecting their option, put vulnerable members of society at risk. In the case of assisted dying, this risk would be prevented by an array of safeguards introduced in the Bill of the noble and learned Lord, Lord Falconer.

In congratulating the noble Lord, Lord Dubs, on introducing this debate and agreeing with his unqualified support for the Bill of the noble and learned Lord, Lord Falconer, I ask the opponents of that Bill one question, which so far they have never answered: what option do they propose for the suffering of terminally ill patients for whom palliative care is not the solution and who make an informed decision to end their

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suffering by ending their lives? Surely that option cannot be that they continue to suffer terribly until they eventually die.

**Lord Ahmad of Wimbledon (Con):** My Lords, before the next noble Lord rises to his feet, I remind all noble Lords that this is a time-limited debate. That means that when the clock shows “4”, they should look to conclude their remarks.

**12.27 pm**

**Lord Purvis of Tweed (LD):** My Lords, I am new to your Lordships’ House but not new to this issue. It is a privilege to follow the noble Lord, Lord Joffe, as it was the fact that his Bill did not cover Scotland that was, in part, the reason for me lodging a Private Member’s Bill in the Scottish Parliament in 2005.

My Bill did not propose euthanasia, and nor did it concern all adults. It did not concern the elderly, the infirm or the depressed. It concerned mentally competent adults coming to the end of a terminal illness who were seeking to be able to choose the precise timing of their death. Many of those who opposed my Bill did so by opposing

things that it did not stand for. The issue is now being carried forward ably in the Scottish Parliament by the independent MSP Margo MacDonald.

It is a personal sadness to me that in the eight years since my proposal people have continued to come to the end of their life without the legal protection for them to choose how to spend their final days. The law gives some protections, but they are primarily not for the patient.

After a landmark case in Scotland in 1996, the then Lord Advocate, the noble and learned Lord, Lord Mackay of Drumadoon, issued a statement that he would not authorise the prosecution of a doctor if the doctor, acting in good faith and with the authority of the Court of Session, withdrew life-sustaining treatment from a patient with the result that the patient died. Commenting on the case, Professor Sheila McLean of Glasgow University's Institute of Law and Ethics in Medicine said:

“What our law does, therefore, is to endorse decisions which will result in the deaths of certain patients (most notably those who cannot express a preference) but not those who are competent to ask for aid in dying”.

There are further protections for the medical professions if they stop medical treatment that is keeping a patient alive but not making them better. Such futile treatment, as so defined, can be withdrawn, as they describe, without legal repercussion. Indeed, mention has been made in the debate of the double effect. However, if a mentally competent patient who is coming to the end of their life wishes to choose the precise timing of their death, no protection is allowed for—unless, of course, they wish to starve without hydration and to have their treatment withdrawn.

What is also indefensible is the current state of affairs in Scotland, where people do not even know if they may be prosecuted for supporting the choice of a patient to travel somewhere that does afford them that protection. As noble Lords will be aware, the DPP guidance does not apply to Scotland. The previous guidance had been provided for the medical professions,

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but successive Lord Advocates have repeatedly refused my calls for greater clarity for those who are coming to the end of their lives. This is quite simply a horrendous status quo, and the Scottish authorities need to act to remedy it.

I led a debate in the Scottish Parliament in similar terms to those of the noble Lord, Lord Dubs, to whom I pay sincere tribute for bringing this issue before us today. The debate was held in the Scottish Parliament on Wednesday, 26 March 2008. The preceding Saturday I had been with a lifelong friend and mentor of mine who was in palliative care in Berwick-upon-Tweed. In the debate I said:

“He is a man of strong faith. He told me that he knows that he is leaving this world for a better one, and that his time to do that is now upon him. He has asked for treatment to be withdrawn and is now receiving only increasing amounts of palliative medicines ... He told me that he is not afraid to die, and he has made the arrangements for his funeral. He has instructed that it will be forbidden for anyone to cry at his thanksgiving ... My friend has celebrated life all his life and has helped others ... he has asked us, if we remember his life when he is no longer with us, to ensure that other people's wishes can be respected as they approach the end of their lives, if his wishes cannot be respected”.

in asking for assistance at the end of his. His refusing medication and then food and water finally took its toll and, three days after my debate, he died.

Let us in this place recognise that we enhance society, we strengthen life and the love of our loved ones, and we cherish life more, if those who request it are given the protection in their final days that is currently denied them.

**12.32 pm**

**Lord Brown of Eaton-under-Heywood (Non-Affl):** My Lords, one day we will look back on our present law on assisted dying with the same wry surprise as we now look back on our past laws on homosexuality, capital and corporal punishment, abortion and, indeed, attempted suicide. Let it be remembered that we used to prosecute people who attempted but failed to take their own lives. I believe that the present law is not merciful, but merciless.

Of course there are profound difficulties in devising the right legislation, with real dangers to be avoided and real concerns to be met, and of course it is imperative that nothing is done to imperil the continuing availability of the very best palliative care for those whose lives are drawing to a close. We must recognise the vulnerability of the terminally ill and ensure that they are not subject to the least pressure to end their lives a day earlier than needs be. Obviously, assistance must be given only to those of sound mind with a clear and settled intention of ending their lives early. All these safeguards seem to me to be fully enshrined in the draft Bill of the noble and

learned Lord, Lord Falconer. If I have any reservations about that Bill, they are that it is too restrictive rather than too extensive in its application.

Let us take someone like the late Mr Tony Nicklinson, whose posthumous appeal has been heard this very week by the Supreme Court, although not yet decided. Mr Nicklinson would have been unable to invoke the Bill of the noble and learned Lord, Lord Falconer, for two distinct reasons. First, his condition, insupportable

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though he found it after suffering for so long, was not terminal in the sense of dictating that he was likely to die within six months. Secondly, his case was argued on the basis that he could not himself do whatever was required actually to end his life. He needed more than assistance to commit suicide, and in fact he needed what under the present law can only be described as mercy killing. One might have thought, with his position being even more helpless than that of someone who can at least self-administer the final medication, that the law should be, if anything, the readier to allow him the choice of death.

I am, for my part, no less interested in how voluntary euthanasia is working out in Holland and Belgium, where it applies, than in how assisted dying is working out in Oregon and the various other American states where it is practised. As far as it goes, I shall certainly support the Bill of the noble and learned Lord, Lord Falconer. Surely the underlying principle must be to promote human dignity and autonomy and to allow—always when consistent with the rights of others—the individual his choice as to how he should end his life, no less than as to how he should live it.

My final point is one that has been made, and rightly made, by a number of other noble Lords. The great advantage of the Bill would be to give the terminally ill the knowledge that they have a safety net available if things get too terrible. In some cases, that confidence and assurance—that the time and manner of their ending is ultimately in their own hands—will not only give them peace of mind but actually prolong their lives, by deciding them against committing suicide early, while they are still able to do so unaided. That, I recollect, was very much part of Mrs Purdy's thinking in the very last case that we heard in the House of Lords as Law Lords—the subject of that picture in Committee Room 1, "The Last Judgment". I wish the Bill of the noble and learned Lord, Lord Falconer, the greatest of fortune.

### **12.36 pm**

**The Lord Bishop of Chester:** My Lords, I join other Members of the House in welcoming the reinforcements to the Bishops' Benches. I will make three brief points in my contribution, the first of which does not have a direct connection with assisted suicide. We typically have long waiting lists today for transplantation surgery in this country, due to an absence of an adequate supply of donated organs. I hope that we will do as much as we can, and more, to encourage people to carry organ donation consent cards and to engender a culture in society in which transplantation and donation of organs are encouraged, especially for those whose death comes in an untimely and unchosen way. This is a matter of choice at the point of death, as are the things that we are discussing in the main part of this debate.

Some religious communities exhibit a particular reluctance to support organ donation, which often works to the disadvantage of the members of that community who are waiting for transplantation. For some time, efforts have been made to overcome this reluctance. Earlier this week, a new interfaith organ donation action plan was launched, backed by the

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NHS and with the active involvement of a number of churches including the Church of England. I mention this simply to underline that there are various issues connected with choice at the point of death beyond the main issue of today's debate.

Turning to issues of choice in relation to assisted suicide, I acknowledge the strength of the momentum for legalising assisted suicide, which has been well illustrated in the contributions to the debate so far. I must acknowledge the state of public opinion on the matter, which I believe is likely to get stronger. For a society that has now embraced abortion by choice, the move to assisted suicide by choice might seem, in moral terms, rather a modest step. I am surprised that this connection is not made more often, although two noble Lords in today's debate have acknowledged it and, in last week's rat-a-tat-tat debate, the noble Baroness, Lady Hayter, made quite a lot of it, saying that the parallel between abortion and assisted suicide was connected by issues, as she put it, of common humanity. Whether one accepts that parallel or not, and whatever one makes of the parallel, I believe that the wider social context is crucial to our debates on this subject. Choice always has a context, and the context of our society has changed and is changing. I need to acknowledge that.

I remain personally opposed to the change in the law that is in the Bill of the noble and learned Lord, Lord Falconer. But the question with which I wrestle is: on what basis can I prevent others who take a different view from making their choices on the basis of a change in the law? It is a somewhat open question but I think I am still persuaded that in order to sustain justice for the vulnerable in our competitive and individualistic society—the context in which we are discussing this matter—there would have to be very powerful bulwarks in the law to prevent the exploitation of the weak and vulnerable.

Even with the safeguards in the draft Bill, changes in the law tend to create their own momentum, as has been well illustrated with what has happened with abortion. For me, that is where the problem will lie if a change in the law is based too much on the notions of choice and autonomy to which a number of noble Lords have referred very centrally. If you accept assisted suicide fundamentally on the basis of autonomous choice, how can you simply leave it to a very restricted group who are believed to be terminally ill? Logically, one day or another, sooner or later, it would have to be extended.

That leads me to my current conclusion: that the risks inherent in legalising assisted suicide still outweigh the benefits that might accrue.

**12.41 pm**

**Lord Davies of Stamford (Lab):** My Lords, the whole House ought to be very grateful to the noble Lord, Lord Dubs, for giving us this important and necessary opportunity to discuss this matter, although of course we do not have long enough to do it real justice.

At the heart of the debate there is, unfortunately, an illusion or a self-deception: the suggestion that under the present regime the medical profession does not get

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involved in determining the timing or circumstances of the death of its patients. In fact, as we all know, for a number of generations it has been pretty widespread practice for doctors who have a patient who is in distress right at the end of life to accelerate the process. One doctor put it to me as, “helping the patient on his way”, generally by administering a lethal dose of an opiate or perhaps a barbiturate. This is not talked about because of course it is against the law, so there is a great deal of hypocrisy here, but we should not have any illusion about the truth.

More frequently in recent years, the patient has been referred to a hospice and there a clinical decision is taken steadily to withdraw the necessary means of life support: resuscitation, ventilation, antibiotics and dialysis will be denied or withheld. In the case of someone who was very close to me, liquids were denied. The only thing that was administered was a sufficient amount of opiate to keep the poor patient comatose, presumably on the grounds that if she was killed by an overdose of the opiate that would be against the law, but if she was killed by dehydration that would not be against the law. She actually took two weeks to die. I cannot think of a more cruel fate.

I support the Bill of the noble and learned Lord, Lord Falconer, for three reasons. First, it would liberate the patient and give the patient a choice; it would give the patient a vote in the important matter of his or her demise. Secondly, it would liberate the medical profession from these agonising dilemmas—the conflict between the law and the duty to do the best for the patient. The third reason goes to the heart of the responsibilities of this House. The law in this country—in any country worthy of the name of a country living under the rule of law—ought to be clear, unambiguous, respected and upheld. The law in this area is none of those things in this country. The law is cruel, anomalous and nobody takes it seriously. The previous Director of Public Prosecutions said that he would not prosecute in certain cases under this law, as has already been referred to.

In another area, jurisprudence has changed the law in respect of establishing the double-effect rule. No doubt the GMC will be producing guidance on what doctors can and cannot do, particularly as new pathways are brought in, and perhaps that guidance will be prayed in aid before the courts. The whole situation is completely unclear, unsatisfactory and, frankly, hypocritical. Nobody takes it seriously.

The law should not be made by the back door by the Director of Public Prosecutions. On a matter of fundamental principle it should not even be made by judges under jurisprudence. It certainly should not be made by professional associations producing guidance for their members. That is a completely disreputable way of producing the law. We in Parliament have abdicated our responsibility to ensure that we have a law that is clear, can be respected and can therefore be upheld. We must no longer abdicate this vital responsibility.

**12.45 pm**

**Baroness Nicholson of Winterbourne (LD):** My Lords, I serve as a Member of this Chamber in the Parliamentary Assembly of the Council of Europe. It is in that

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context that I wish to draw noble Lords' attention to the Council of Europe's banning of euthanasia on 25 January 2012. As your Lordships of course know, Britain was one of the founder members of the Council of Europe and, in May 1990, we assisted through the treaty of London in forming the European Convention on Human Rights. Although that convention was misinterpreted when it was put into law by the previous Labour Government, with Articles 6 and 8 distorted, we are none the less committed to it and continue to support it fully as a nation.

Nearly two years ago, on 25 January 2012, the Parliamentary Assembly of the Council of Europe adopted a resolution stating:

“Euthanasia ... must always be prohibited”.

This articulates a strong principle for life and against euthanasia, given that, for the very first time, euthanasia was so clearly rejected by a major European political institution.

This was a third major victory for life and dignity of the weakest after the 2010 resolution of the Parliamentary Assembly that strengthened freedom of conscience for doctors and medical staff, and after the European Court of Human Rights asserted in 2011 that there was no right to euthanasia or assisted suicide under the European convention. The Council of Europe resolution, passed in January 2012, states in Article 5:

“Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, must always be prohibited”.

The resolution is entitled:

“Protecting human rights and dignity by taking into account previously expressed wishes of patients”,

and aims for a clarification of the principles that should govern the practice of “living wills” or “advance directives” in Europe. Patients should be permitted and encouraged to express in advance their wishes with regards to medical intervention and treatment in case a situation occurs in which they are no longer capable of doing so.

Given that divergent regulation in European countries and the abuse of so-called “living wills” or “advance directives” can provide a gateway for euthanasia or assisted suicide, there are growing concerns about the effective protection of human dignity at the end of life. Therefore, the Parliamentary Assembly judged it necessary to present clear guidelines to close the door to euthanasia, to the abuse of “living wills” and to surrogate decisions by recalling principles elaborated in previous documents such as the Oviedo Convention on Human Rights and Biomedicine. First and foremost, the Assembly sets the principle that,

“intentional killing ... must always be prohibited”.

Secondly, an important amendment introduced by an Italian Member of the European Parliament, Luca Volontè, was adopted, so that Paragraph 7.8 states that,

“surrogate decisions that rely on general value judgements present in society should not be admissible and, in case of doubt, the decision must always be pro-life and the prolongation of life”.

With the adoption of this resolution, the Council of Europe placed the ball in the court of countries that permit euthanasia, such as the Netherlands and Belgium.

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Even if this resolution is not legally binding, these member states are expected to be aware of the standard set forth by the Parliamentary Assembly and to review their own legislation.

That draws my attention to the words of the noble Lord, Lord Joffe, in 2004, who said that his Assisted Dying for the Terminally Ill Bill was just a “first stage”. The slippery slope opens up there. In the Netherlands, euthanasia is permitted for children who are 12 years old; in Belgium the age is coming down to 12. Let us think of the burden that this would place on National Health Service, with at least 11,500 to 12,000 deaths being assisted, the mass of prohibitions that would surround that, the amount of debates and the enormity of transforming our National Health Service perhaps into a national death service. I strongly oppose.

**12.49 pm**

**Baroness Meacher (CB):** My Lords, I, too, applaud the noble Lord, Lord Dubs, for moving today's Motion. I strongly support his position that every individual should have the right to decide how much suffering they must bear. Of course, we acknowledge that right for those who want to continue until the end point and take any suffering that life throws at them. We just ask for the same right for those of us who wish to take advantage of it. Patient autonomy is a well established principle in medical ethics, enshrined in professional guidance. How can we justify removing the right of choice—the autonomy—at the end of life when people most need it? I simply do not understand that. To respond to the noble Baroness, Lady Nicholson, we are not here talking about euthanasia, yet most of her contribution was devoted to that.

I shall not repeat the very eloquent points made by many noble Lords but will instead focus my comments on two other end-of-life issues, particularly the right of choice. One is the right not to be resuscitated when life has become unbearable and the second is the right to decide where we die. When a person has capacity, there is no excuse at all for not doing what they wish. Yet, routinely, patients are resuscitated against their wishes and do not die in the place of their choice. The Mental Capacity Act 2005 created advance directives that should ensure that patients' wishes are known and followed should they lose capacity. However, even when a patient completes an advance directive and a copy is included in their medical records, too often it proves useless because we do not have in place procedures that ensure as far as possible that emergency services and hospital staff know that an advance directive exists, let alone what it says. We need a national policy that governs exactly how and where advance directives are documented. It sounds a trivial point, yet there is really no use in having a document hidden away in some GP's surgery when the ambulance men turn up and have to make decisions.

One suggestion is a register of advance directives similar to the organ donor register. Of course, it should be electronic for easy access. That would greatly increase the likelihood that emergency services have the information they need when they need it. Will the Minister consider whether NICE should publish guidance

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on the detail of these advance directive procedures, such as how they should be recorded and stored, and what procedures the emergency services should follow to make sure that they access that crucial information? I understand that, shortly, electronic medical records should include advance directives. Again, these must be user-friendly and accessible quickly. Will ambulance men have access quickly to that information? Also, will the Minister propose to the CQC that it gives priority to inspecting these procedures? In mental health services, the CQC gives terrific focus and priority to how documentation is preserved, kept and stored in relation to detentions in hospital. If the CQC gave anything like that priority to advance directives, the care of elderly people towards the end of life could be radically enhanced.

Now I turn to the issue of where patients die—I will do this rather quickly. The issues are raised very clearly in the Macmillan Cancer Support briefing. The fact is that 73% of cancer patients want to die at home but only 29% are able to do so. There are all sorts of reasons for this, such as a lack of free social care at the end of life. Can the Minister say a little about that? There is also the lack of 24/7 care, most particularly nursing care. Again, what does NHS England plan to do about that? Thirdly, there is the need for the early identification of people at the end of life. Is the Minister able to provide some statistics about the projected numbers of domiciliary nurses available over the next five years relative to last year? I hope that the Minister can provide some reassurance to this House.

#### **12.54 pm**

**Lord Rowe-Beddoe (CB):** My Lords, I, too, thank the noble Lord, Lord Dubs, for providing us with the opportunity to debate this topic. It is being proposed that the law should be changed to allow assisted suicide. This presupposes that there is agreement that the law as it stands is not adequate. What is being referred to by some noble Lords today would represent a major change to the criminal law. Parliament is being asked to agree that some people, namely doctors, should be licensed by law to involve themselves in deliberately bringing about the death of some others, namely people who are terminally ill. This, I propose, is no small adjustment; it is a major change of the law.

I suggest that if your Lordships' House is to consider such a proposal seriously, it needs hard evidence that currently the law is not fit for purpose and if that is so, that which would be put in its place would be better and, above all, safer for us all. I do not believe that such evidence has been produced. All we hear are some honeyed words about the need to reduce suffering and some ill informed claims of what the law says and how it works.

For example, we are told that the law does not provide certainty as to whether a person who assists a suicide would be prosecuted. As citizens, we most certainly have the right to know what the law is. I submit that we do know. The law is clear: encouraging or assisting another person's suicide is a criminal offence. Discretion is provided to the Director of Public Prosecutions to decide whether a prosecution is

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needed in the individual circumstances of any case. There is a published prosecution policy setting out how such decisions are reached and providing some of the circumstances which might incline the DPP to prosecute, or not to prosecute. This, however, is not sufficient for those who wish to see assisted suicide licensed by law.

A major complaint is that someone who breaks the law and assists a suicide does not have certainty as to whether the offence will be prosecuted. Certainty cannot be given as the outcome of a breach of the law will depend on the circumstances in which it was committed. To give assurance that a prosecution for assisted suicide would be in this or that circumstance would clearly amount to changing the law. Further, we are encouraged to believe that the law is cruel because of the maximum penalty that it holds in reserve—some 14 years. But no sooner do we work ourselves up on this issue than we are told that the law is not working properly because those who break it are not being prosecuted.

The reality, when the spin and fog is cleared away, is that we see a law with a stern face and an understanding heart. The penalties which the law holds in reserve are, I suggest, sufficient to make anyone minded to assist another person's suicide think very carefully before proceeding. As a result, the offence is rare and the few cases that reach the DPP tend to be those where there has been serious soul-searching and genuinely compassionate assistance, perhaps somewhat reluctantly given. In such cases, the DPP is able to exercise the discretion that the law provides. I suggest that before there can be serious discussion of how the law should be changed by Parliament, we need clear and convincing evidence that it should be changed and that what would be put in its place would be better and safer—safer, that is, for us all. Until that evidence is submitted, we should return these proposals to the drawing board.

### 12.58 pm

**Lord Blair of Boughton (CB):** My Lords, I should declare an interest in that, along with the noble Baroness, Lady Murphy, I served on the commission of the noble and learned Lord, Lord Falconer. My contribution to today's debate will be to consider some of the practicalities of the current situation and their appalling effect on individuals.

One of the main aspects of the Bill introduced by the noble and learned Lord, Lord Falconer, as the noble Lord, Lord Rowe-Beddoe, has just described, would be to seek to alter the legal framework concerning assisted dying, which it found to be unfit for purpose. As has just been said, while 14 years' imprisonment is the penalty, no one has been prosecuted for many years. Furthermore, the previous DPP issued guidance that makes it unlikely that any non-medical person assisting another to die with no malicious reason would be prosecuted. So what is the problem and why is it unfit for purpose?

I suppose I was asked to be on the commission so that I could help it with investigative and prosecutorial experience. Actually, I did not need to because the witnesses did that. As the law sees assisted dying as a criminal act, and because such an act has no regulation, then when such a process takes place the police inevitably

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have to be involved. I do not think that anyone quite understands what that means. If an assisted death has taken place and the police arrive, they will deal with that as a potential homicide scene. They will photograph it, isolate it and seize notes left for relatives, gifts and computers. Those involved are under the threat of arrest, are interviewed under criminal caution and will face months of waiting for a prosecutorial decision, and it may not be possible even to have a funeral very quickly. However kind and professional the police are, how much more pain do we want to inflict on people who have done what they believe to be right, out of compassion?

I shall tell noble Lords just how much more pain. One witness spoke of his wife, who had been diagnosed with motor neurone disease. She was a nurse so she knew what the disease would do. She was determined to die before she was unable to take her own life. She told her family that but she would not ever tell them when and where she would do so, which meant, as the witness said, that the love of his life died alone with no one, particularly him, to hold her hand while she was dying. If that was not enough, it did not work, of course, because the police came in and investigated her death anyway since that is what they have to do.

That is the practicality of a law that is wrong, which is protected only by prosecutorial guidance that can be changed, and which leaves the police inevitably to have to perform an immensely distasteful process for people who are already suffering enough. We should remember the wise advice of the friends of the noble Lord, Lord Dubs.

### 1.02 pm

**The Earl of Glasgow (LD):** My Lords, I made a speech a week ago in support of the legalisation of assisted dying, and I do not wish to bore your Lordships by repeating the same arguments all over again—many of which, by the way, have been made very well by noble Lords today.

However, I want to emphasise a point that is misunderstood by many of those who oppose assisted dying: the change in the law that we are proposing would apply to only a very small number of people in very specific circumstances. It has nothing to do with euthanasia or helping or encouraging people to die prematurely unless they have specifically and unambiguously requested it. It certainly would not apply to elderly people suffering from some form of dementia. Yet some of our opponents appear convinced that assisting dying is just the thin end of the wedge, the slippery slope that will eventually lead to helpless old people being quietly put to sleep. No; as many noble Lords have already said, this is first and foremost about individual choice, a choice that we may all have to make when we learn that we are dying and have only a short time to live.

In the vast majority of cases, nature will take its course and we will be fortunate enough to die peacefully in our sleep with the minimum of pain near our end. However, a minority of us will contract a terminal disease or illness where we will face the inevitable prospect of several months of severe pain and indignity, even with the best medical treatment. Some of us will

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seek palliative care while some will choose to fight through to the end, but others would like the option of being able to die in their own homes on their own terms at some time before the scheduled time of their death. To achieve that, though, they will almost certainly need assistance, particularly from a doctor or medical practitioner. As the law stands now, they are denied that help. Consequently, they are denied that choice and sometimes feel desperate enough to travel at considerable cost so that they can spend their last hours in an impersonal clinic in Switzerland.

Why should the law in this country deny them that choice, to die in their own home with their family around them, because of fears of slippery slopes or the second coming of Dr Shipman? This choice would be taken up by only a small but significant minority of people. Surely the law should allow terminally ill patients who are in their right mind to die in the way that they choose. Anything else is nothing less than unnecessary cruelty and a denial of human rights. The choice—I repeat that it is only the individual's personal choice that I am talking about—of being able to avail oneself of assisted dying should surely be a great comfort to all of us, and certainly not a threat.

#### **1.05 pm**

**Lord Hylton (CB):** My Lords, today's debate seems to be a dress rehearsal for the Second Reading of the Bill of the noble and learned Lord, Lord Falconer. However, I start from antiquity, where suicide was normal if someone suffered disgrace or their honour was seriously impugned. The Japanese samurai had a somewhat similar view. For the Jews, suicide largely fell under the command, "Thou shalt not kill". For the western world, the Christian faith changed the earlier ways of thought. Shakespeare summed it up and gave a strong pro-life view in Act I of "Hamlet":

"Or that the Everlasting had not fixed His canon 'gainst self-slaughter".

Islam is clearly opposed to euthanasia. Buddhists are doubtful about the rightness of suicide, emphasising the principle of not doing harm. Hinduism stresses Ahimsa, which is similar, and believes in Dharma, the accepting of moral duties. All faiths seek to minimise unnecessary suffering. Given the views of the great world religions, I conclude that humanists would be unwise to impose their genuine convictions on everyone else.

My second point comes from the old saying, "Hard cases make bad law". We may be harrowed by individual cases of people suffering great pain, longing to die but perhaps too weak to kill themselves. Appeals to our compassion or to the principle of utility, however, should not be allowed to outweigh our duty to the common good of the great majority.

Changing the existing law would impose unnecessary burdens on a range of people. The handicapped or depressed will ask, "Am I a charge on society? Am I using resources that should be devoted to others? When will I reach the six-month point?". Carers will wonder, "Should I speak to the declining person while they are still capable of deciding?" Temptations will face the beneficiaries of wills. Young people, perhaps aged 19 or 20, could make valid decisions, thus robbing

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their parents of precious time still together. Doctors and nurses also believe in preserving life rather than ending it. They have, and still seek, to provide a health service, not a death service. We should not add to their burdens but remember their Hippocratic oath.

I respect the deeply held convictions of those proposing change. Neither side will probably convince the other. Can we at least agree to work for a more co-operative and caring society where more people are enabled to die at home and fewer in the institutional surroundings of hospital wards? I believe that we should aim for all to be accompanied to a natural death in a familiar setting, with loved ones close at hand.

**1.10 pm**

**Baroness Murphy (CB):** My Lords, there are policy priorities for the end of life and there are legislative priorities. They are very far apart, but intimately connected. I have no doubt that the policy priority must be to improve the experience of dying in hospital, as that is, at the moment, where most people die.

End-of-life care requires honest conversations between doctors, nurses, patients and families. The antecedents of a bad death are exactly the same as those that engender generally poor care in hospital wards. I admire the report published by the noble Baroness, Lady Neuberger, and her colleagues which looked at how to replace the Liverpool Care Pathway with individual care plans, but I fear it will not make a jot of difference until the culture of medicine and nursing is transformed.

However, this policy priority is not the legislative priority, and compassion dictates that we find a safer way in legislation to help all dying people, just as in Oregon state the death with dignity law stimulated the public's understanding of death and dying and increased the provision of good palliative care. I believe that focusing our legislation on the tiny few who want to make their own choice of time of death will not only help the few but will help to create an understanding of the broader needs of dying people.

Let us imagine for a minute that the Falconer Bill has already been enacted. In the average clinical commissioning group area, we are talking about five or fewer people a year who would make the request and fit the criteria. That figure is derived directly from Oregon state. The noble Lord, Lord Alton, is right in saying that the numbers have gone up slightly in Oregon, but there is no statistically significant increase. It has remained at that tiny figure over the past 15 years, and it looks as if in Washington state, which is double the size of Oregon, it will be the same. There are four years of experience there. Five people annually are enough for a small team of expert doctors to administer a code of practice that would be devised by the professions and laid before Parliament.

I want to concentrate on just one safeguard because the others are fairly easy to address. It is about what the noble Lord, Lord Tebbit, in a debate in Grand Committee so memorably referred to recently as “the vultures”—relatives who cannot wait to get their hands on an inheritance—and those who might exert subtle pressures on people to kill themselves. This has already been mentioned by the noble Lord, Lord Hylton, and

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has been mentioned in the past by the noble Lord, Lord Tombs, and the noble Baronesses, Lady O'Neill, Lady Campbell and Lady Grey-Thompson. I spent many years as an academic psychiatrist doing much testamentary capacity expert witness work and, believe me, I know that the vultures are circling overhead. It is crucial that we can spot where there are profound or subtle pressures on individuals. But given that all those seeking an assisted death will have full mental capacity, how susceptible are they really? We do not need to guess or to create false scares. A research review has recently been published by the American Bar Association Commission on Law and Ageing. Almost all those who are subject to undue influence or subtle pressures are indeed suffering from lack of mental capacity, as you would expect. They are very aged, frail and have dementia. They are habitually exploited. The very few who are subject to undue influence when they have full capacity are in those very curious situations, which are fairly easy to detect, where one individual is very dependent on another. We saw that recently in the case where a group of people were subject to imprisonment. I would refer to it as emotional imprisonment. They are very rare cases indeed. We can take account of them. A humane society that really cares for individuals should be able to meet the wishes of that tiny few who want to say where and how they die, with whom they die and also when.

**1.14 pm**

**Lord McColl of Dulwich (Con):** My Lords, if it was possible to choose the occasion of one's death by electing to be killed, it would create an escape route at the onset of an illness which, given time, would take away one's

independence and one's mind. It would be an escape route from the fear of indignity and suffering. I understand that fear only too well. My wife, Jean, died last year having had dementia.

I have drawn two conclusions from my experience. First, it is imperative that we care for those who are suffering in this way and that we treat them with dignity. We need to create a society in which such care and treatment is the norm. I am so grateful to those of your Lordships and, especially, the doorkeepers and security officers who treated Jean with dignity and extended many kindnesses to her. It is so important to invest our time and resources to ensure that dementia patients receive proper care. Secondly, dependence is natural at certain stages in life. All of us were dependent on others at birth and for a considerable time thereafter. Dying is part of living and during that time we may be dependent on others. Why should that be a fearful thing? It is probably because our society prizes independence and schools us into it at an early age. We need to revisit this and to be educated to appreciate that dependence is no cause for shame.

The choice that I would like people to be able to make at the end of life is a choice to go on living in the assurance that they will be cared for with compassion and not ignored or regarded as a burden. All sides of this debate recognise that if assisted suicide is to be legal, there must be safeguards. Many of us believe that it is not possible to legislate for adequate safeguards.

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That aside, it is pertinent to ask whom the safeguards are intended to protect. It is sometimes assumed that it is only the would-be suicide who needs protection. Indeed, he or she does need protection, but society as a whole is also in need of protection from changes in the law which may have a deleterious effect.

There is a danger of confusing the role of the health professional and undermining the trust which exists between doctor and patient. At present, the health carer's mandate is crystal clear. It is always to care and never to kill or assist in killing. One cures by treating the patient and eliminating the disease. Eliminating the patient is not treatment, no matter what the patient may request. Where one cannot cure, society should provide care. At present, the provision of adequate care is patchy and uncertain, and this needs to be addressed urgently.

If one was to legalise assisted suicide, one would be setting up independence as a quality whose worth is greater than life itself. What would such a society be saying to disabled people and the mentally ill? As the New York State Task Force on Life and the Law reported:

“The legalization of assisted suicide would itself send a message that suicide is a socially acceptable response to terminal or incurable disease. Some patients are likely to feel pressured to take this option, particularly those who feel obligated to relieve their loved ones of the burden of care. Those patients who do not want to commit suicide may feel obligated to justify their decision to continue living”.

While those who champion the legalisation of assisted suicide do so, I am sure, with the best of motives, I believe it to be a profound mistake. For these reasons and others, which time does not permit me to address, I believe that our energies and resources are best spent on improving the care that is available so that people can choose to go on living with confidence that they will not be neglected.

**1.19 pm**

**Baroness Hollins (CB):** My Lords, as the immediate past president of the BMA and chair of the BMA Board of Science, I remind your Lordships' House that the BMA opposes all forms of assisted dying and believes that ongoing improvements in palliative care allow patients to die with dignity. The BMA respects the concept of individual autonomy and encourages patient choice about clinically appropriate treatments, but it believes there are limits to what people should be allowed to choose when their choice impacts on other people.

The Department of Health end-of-life care strategy says that more people are making choices about their care and treatment, but that too few health professionals yet know how to talk about death and dying. Can the Minister say what is being done about this? There is clearly still plenty of room for improvement.

Despite that, we can be rightly proud of our pioneering work to create and develop the specialty of palliative care. We are ahead of the curve, leading the global race. Dame Cecily Saunders, the founder of palliative medicine, left us an extraordinary legacy. As suggested by my noble friend Lord Alton, I agree that her legacy could be undone by the introduction of assisted suicide

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as a choice. Without strong advocacy, constraints on NHS funding could lead to more cuts being made to end-of-life care. Assisted suicide, instead of being an option, would be the cheaper alternative. We would be offered either/or—rather as in Oregon, where patients have to sign out of active treatment to access hospice support and where palliative care is not a clinical specialty. Since our healthcare system is more similar to that of the

Netherlands than that of the USA, we should be studying practice there, with one in 34 deaths now being through euthanasia.

It could be argued that it would make economic sense both for families and for the nation. However, this is a policy change that would replace our traditional commitment and compassion to each other—“in sickness and in health”—with a greater value being placed on high-achieving, fit and healthy members of our communities. Instead, we could invest more in our pioneering palliative care services and sell them abroad. We could train overseas doctors and nurses. We could accelerate our search for a cure for dementia and other long-term conditions. Now that we have legally recognised parity between physical and mental health, we could become the most psychologically aware nation in the world, and bring our new learning about their interrelatedness to our understanding of death and dying, rather than continuing to deny it. Let us use our emotional intelligence here.

In response to the question of the noble Lord, Lord Joffe, it is usually unfinished business with family and friends that causes someone’s unbearable suffering, both mental and physical. People who have expressed a wish to die are now being publicly encouraged to commit to such a view to support the campaign by Dignity in Dying—which of course formerly had “euthanasia” in its title.

Certainty is difficult to commit to until you have the experience. Deciding is a process that unfolds and human beings have an extraordinary capacity to adapt. Help the Hospices told the Select Committee that informed choice means experience of palliative care, not just information about it. Let us show the world that our palliative care services put us ahead, not behind, those—only seven—jurisdictions which have chosen a cheap and unwise solution to the problem of death and dying and dependency.

The focus in the debate today has been more on a timetable for dying rather than coming to terms with leaving this life and what that will mean for the dying person and those left behind. Healthy adults are emotionally interdependent upon one another, and if we had time I would draw on psychoanalytic literature. Suffice it to say, the real issues at the end of life are the care and compassion that comes from being in a relationship with other people, including receiving more than giving, including becoming more dependent. I am talking about the love that endures rather than any physical inconvenience.

Emotional angst about unfinished business is better worked through than avoided through the mistakenly perceived control that comes with suicide. Dealing with unfinished business allows someone to let go of life and let go of suffering. Dealing with unfinished

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business is also better for those left behind, who will then live more peaceably when their loved one has gone.

**1.24 pm**

**Baroness Flather (CB):** My Lords, I have spoken on this issue on every possible occasion. The first time I spoke, I mentioned that if my husband, who is very disabled, were in great pain and did not want to go on living, I would help him regardless of what the law would do to me, because I love him. A lot of us who love people—those who are close to us and suffering—cannot bear it; as much as the person cannot bear it, we cannot. I think the DPP will now say that that is all right. That is a move forward. Fortunately, however, my husband is not in pain and is doing everything, so that is all right. However, he got two e-mails saying, “Watch out for that woman” on that occasion.

I remind noble Lords that, when the noble Lord, Lord Joffe, first brought his Bill forward, one noble Lord likened it to Nazi practices. I have never forgotten that, and I hope that nobody will ever think of it like that.

It is a matter of choice. It is about us being given a choice, not compulsion. Nobody is going to be compelled to take their life in their own hands. The noble and learned Lord, Lord Brown, put it so well when he said that we have moved on in all sorts of ways, legally. We do not have capital punishment, and many other changes have come about. Everybody talks about the slippery slope—thank goodness for the slippery slope, otherwise we would still be sitting in caves. We always need to move forward. Perhaps we should not have invented the wheel. It is important for us to look to the future.

Abortion has been mentioned as if we suddenly discovered it and therefore introduced a law. No, we did not suddenly discover abortion; it has been with us since the dawn of time. Women have suffered since the dawn of time. What we did was to save their lives. Many women cannot manage to bring up a child. Many women do not want that child. Well, it is not worth that child who is not wanted coming into this world.

We have to think about things which have been and are going on, and provide for them. It is no use saying that we have discovered this or that and are therefore doing it. These things have been with us for a long time.

Medical science has practically made it impossible for us to die quietly and peacefully. We get taken into hospital. We are treated and given antibiotics. The case of Bland led to a commission on euthanasia. It is important for us now to think about our choice. It is extremely selfish of those who are against assisted dying to deprive the rest of us. The right reverend Prelate the Bishop of Chester mentioned that and said that he thought of it as a matter of conscience: if he was against it, should he tell other people that they should be against it? It should and is meant to be a personal choice, and applies only when people have the mental capacity to make it.

That brings me to another point. I feel very sad that the disability lobby feels that they are vulnerable. They, too, will be able to ask for it only if they have the

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mental capacity to do so. Not only that, they can appoint an LPA to help them make the end-of-life decisions if they need someone they trust. We have a lot of choices in the Bill. I hope that we will think about it carefully, for the sake of those who want it. Care at the end of life will never be sufficient. The Bill would actually make end-of-life care more valuable and give it impetus.

**1.29 pm**

**Lord Harries of Pentregarth (CB):** My Lords, patient choice is a very great good and we ought to do all we can to encourage and enhance it. There are various ways in which we can do that. First, we can make it much more widely known that there is no moral obligation to go on receiving burdensome treatment when it is doing no good. There is no moral obligation to prolong life at all costs. That has always been the fundamental teaching of both the Roman Catholic Church and the Anglican Church. It is part of our culture and is quite properly reflected in all medical ethical codes.

I was very glad that the right reverend Prelate the Bishop of Sheffield, whom we congratulate on his maiden speech, spoke about the Liverpool care pathway. I myself was very privileged to be on the commission chaired by the noble Baroness, Lady Neuberger, and I examined very carefully the principles on which the Liverpool care pathway was set up, coming to the conclusion that they were fundamentally sound. The Liverpool care pathway was set up with good intentions, but it became bureaucratic and was not always administered well. I very much hope that our recommendations for the future, from pathway to personal care, will set good palliative care firmly in place in all our hospitals, not just in hospices.

There is another way in which personal choice can be enhanced and encouraged: by encouraging more people to sign up for advance directives. I know of somebody who is developing an interactive website to help people do that.

Patient choice is, therefore, a very great good. However, sometimes other goods override the good of patient choice. I will put before your Lordships three very simple and straightforward examples. First, a teenager in great despair pleads with you to help them end their life. Quite properly you override their choice because there is a greater good: the long-term well-being of that teenager. Somebody who is deeply depressed, who should be in a psychiatric hospital, resists going. They have to be sectioned, and sometimes drugs have to be administered to them so that they can be forcibly put into their hospital. Their choice is, quite properly, overridden. If a prisoner is in danger of suicide, they are put under “suicide watch”—a very careful watch has to be kept on them so that they do not commit suicide. Finally, the Samaritans organisation has saved hundreds of thousands of people.

I suggest by those examples that although patient choice is a good, it is not the only good, and that sometimes there is an overriding good. Those examples indicate that our society values human life at all times and in all circumstances. The noble Lord, Lord Taverne, said that the present law and DPP guidance are a mess

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and have been brought into disrepute. However, I suggest that where you have a very difficult situation, between lives that are unbearable and society’s desire to convey the message that lives at all times—even at the end of life—are of value, you are bound to get some kind of compromise like that. The DPP compromise is workable. It expresses society’s view that everybody’s life, even in extremis, is of value. The noble Lord, Lord Alton, quoted the words of Dame Cicely Saunders:

“You matter because you are you, and you matter to the end of your life”.

By having the law—which does express moral values—in place, that conveys society’s high estimate of every single human life.

**1.33 pm**

**Lord Judd (Lab):** My Lords, I thank my noble friend Lord Dubs, not only for giving us the opportunity to debate this subject, but for the very sensitive and objective way in which he introduced the debate this afternoon.

Surely it is important, wherever possible, to encourage people to consider their choices of treatment in good time, and for them to have the fullest possible information on which to make well considered choices. If possible, there should always be the opportunity for them to change course.

To believe in human rights must mean the right to control one's own life for as long as that is possible. That must include the right to seek release from intolerable suffering—not only for yourself but for those around you. Sometimes, sadly, it is just not possible for a person to communicate their wishes, which places a huge responsibility on others who are involved.

Some people of my own faith take an inflexible and absolutist position on this, but there will never be an escape from the responsibility of applying love, understanding and compassion in all that is decided. It is never a matter of just clinically managing a decision on the end of life: there are the real issues of direct, indirect or supposed pressure, and it is always a matter of profound consideration of the individual as an individual. The input, if possible, of those who have known the patient for a long time will be a crucial part of this. The physicians should include, wherever possible, a doctor who has cared for the person concerned for a long time.

Meanwhile, how much of a priority is invariably being given in all training—not least of doctors—to end-of-life care? With increasing longevity and ever-growing survival prospects, dealing with the terminally ill and dying leads to a constantly greater demand on medical professionals and takes up an increasingly important part of their professional lives.

It is absolutely clear that the majority of people do not want to die in hospital, and seek the psychological or emotional security of home or a hospice. What I have experienced from my own involvement as the president of Hospice at Home West Cumbria is that that concept of a hospice at home can be a very valuable available choice. It brings together a community of professionals and volunteers. While the volunteers seek to achieve professional standards in all that they contribute, the professionals are really volunteers

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themselves in bringing a quality of commitment which is way beyond what could be expected from a contract. At its best, there is a culture of teamwork and mutual support. Volunteers can have a sensitive and effective part to play in family support and bereavement counselling. Strengthening all this is the accessibility of what the hospice offers, very much on a socially inclusive basis, and the widespread feeling in west Cumbria that it is “their” hospice to which they have a responsibility, not least in fundraising. I am convinced that this broad base contributes to a reassuring sense of belonging among patients and families alike.

What is essential is a close, flexible and imaginative working relationship between the hospice and the NHS—a context of mutual support, recognised interdependence. While the hospice can ease the pressures on the NHS, the latter is indispensable to ensuring, for example, support for specialist services, particularly palliative care and pain relief.

It is very significant, when we are looking at the future of health services in our countries, to see the relevance of that kind of initiative. I hope that the Government take it seriously, and that they can play their part in making sure that the necessary resources are available.

#### **1.38 pm**

**Lord Singh of Wimbledon (CB):** My Lords, this debate takes us into new ethical territory with complex medical, legal and emotional implications. Rational discussion is made more difficult by a polarisation of attitudes and opinions. I saw something of this about 12 months ago when I attended a meeting of the All-Party Parliamentary Group on Assisted Dying. I raised some concerns and was made to feel that there was something wrong with my thinking if I could not immediately see the open-and-shut case for changing the existing law. I am also too aware of the opposite arguments, couched in religious terms, that life is a gift from God and we should never, ever, even think of curtailing it.

I served for some years as a member of the BMA Medical Ethics Committee and am well aware of major changes in society and bewildering advances in science and medicine that require us to constantly look anew at previously accepted views and attitudes. Sikhs accept that life is a gift of God to be cherished and preserved wherever possible, but we are also required to bear in mind the important Sikh teaching of compassion, dignity and care for the suffering. These two considerations are not necessarily incompatible. However, I am unhappy about a narrow focusing on individual autonomy to justify attitudes that clearly affect others. We have seen some of this today. We constantly hear the argument that we are all individuals and that our happiness and needs

are all-important to the exclusion of our responsibility to others. I believe that this over-focusing on self, on me and my, is responsible for many of the ills in society today. For example, we are all aware that religious teachings suggest that marriage is a committed partnership for mutual care and support and for ensuring that children grow up as responsible adults. What I believe to be a short-sighted contemporary social attitude encourages

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us to believe that it is okay to look exclusively at our rights, without consideration of the effect on others. This focusing on individual needs rather than on the family as a whole is, at least in part, responsible for the growing increase in dysfunctional families, with children frequently ending up in what we euphemistically call care, or with them mirroring the narrow thinking of their parents. A person's decision to end their own life has an effect on friends and, importantly, on the message it can give to wider society of trivialising life. We all have wider responsibilities in all that we do.

I shall pull together these different threads in rational and compassionate decision-making to arrive at the way forward. First, we should always respect the gift of life and question the concept of autonomy. Secondly, there are times when those in ill health feel that life is not really worth living but, within a short time, they often feel that it is not really that bad. It is worse for those who find themselves with severe disabilities but, as the Paralympics showed, despite such disabilities, it is often possible to live a meaningful life. Relatives and carers sometimes find looking after someone onerous, and they can inadvertently make their feelings known to those they are caring for, making them feel an unnecessary burden. Sadly, there are others who may have more mercenary motives. A seemingly hopeless situation today may not always remain so. Huge strides are constantly being made in combating previously incurable diseases, as well as in palliative care.

In summary, while we should always be on our guard against the notion of individual autonomy trivialising life, we need to recognise that, from an individual's perspective, life can become pretty intolerable and there is an argument for helping to end it in strictly controlled circumstances. The danger is that, if we go down this path, it could itself be a slippery slope to trivialising life, altering the very ethos on which medical care is provided. I feel, on balance, that we should leave the law as it is.

### **1.43 pm**

**Baroness Warnock (CB):** My Lords, I congratulate the noble Lord, Lord Dubs, on introducing this debate, which is timely on two counts. First, we have a chance to think about the demise of the Liverpool care pathway, which was obviously well intentioned but had flaws. We have not yet had a chance to consider in detail what should be put in its place, if anything. Secondly, as this debate has shown, it is a kind of run-up to the debate that will take place later next year on the Bill proposed by the noble and learned Lord, Lord Falconer. I do not want to say anything more about that Bill except that I agree very strongly with the view that the present state of the law is unsafe and intolerable and cannot be supported.

I go on to one issue that seems something of a scandal—the case of patients who are dying who may actually be, or may be perceived to be, incompetent to make decisions about their treatment. I cannot think of anything more humiliating than to say that I wanted to die and that my life was no longer worth living only to be told that I was suffering from depression. Well, I would be suffering from depression in the ordinary

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sense of the word—but I could be told that I was suffering from clinical depression and could be cured by medication. My lawful refusal of medication might even be disregarded in those circumstances, because I should be deemed not competent to make it.

I regard it as a scandal that so very few people draw up advance directives or put in place a lasting power of attorney. Since the passing of the Mental Capacity Act 2005, this is something that is worth doing and which preserves choice, even in the case of the person being incompetent. One difficulty that has already been mentioned is the difficulty of access to an advance directive, even if it has been made. This is very serious. I have a friend who was involved in trying to devise a bracelet that people could wear to say that they had made an advance directive and how it could be accessed by people in the ambulance service. She was refused hospital help in devising this bracelet because the authorities said that they would be liable to prosecution as assisting suicide if they were known to have helped to devise this bracelet. That seems bizarre, because it would be a help if, as one can carry a donor card, one could also carry some kind of indication that an advance directive existed.

A worse difficulty is that so few people know about what their rights actually are under mental capacity law, and that many even do not know that there are such things as advance directives or that a power of attorney can be given. The culprits here are general practitioners, who should have a duty to have in their surgery accessible

information about advance directives, in the way that they have dozens of leaflets about diabetes, asthma and other kinds of ills that people may suffer. This seems to be something that would be very easy to do—and then people, whatever their age or state of health, who came to the surgery, would have access to the means of making an advance directive. The means could be made simpler; the doctor could sign the pro forma that could be supplied in the surgery. People could, almost as a matter of routine, ensure that they had such a thing in place if they feared that their treatment at the end of life would be not what they would want and not what would be best for their own interests and the interests of society.

This is a very important change that ought to be made, and which could be made, if only the medical profession was not so very much afraid of death. This is a terrible indictment, really. Even at my age, I frequently talk to my GP, who I know well, about death—and he to me. But that is very rare. On the whole, doctors need, most of all, to change their attitude to death, because their professional and compassionate duty is not always to save life but to relieve the suffering of their patients. I think that this is a change that we can make.

**1.49 pm**

**Baroness Masham of Ilton (CB):** My Lords, I thank the noble Lord, Lord Dubs, for giving us the chance to discuss the final moments of life. End of life comes in so many ways; very often there is not the opportunity to have a choice. I was so pleased that Nelson Mandela, a remarkable person who had been ill with a chest infection and treated in hospital, went home, with

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medical help, and was able to die with his family around him. Seventy-three per cent of cancer patients would prefer to die in their own homes. However, only 29% of people with cancer are able to do so. Macmillan estimates that, in 2012, 36,000 cancer patients died in hospital who would have preferred to die at home.

My husband, who would have liked to die at home, died in an A&E department on a Sunday because the out-of-hours doctors would not come out on the Saturday and Sunday. On the Friday evening, when he became ill with a chest infection, which was serious as he had many medical conditions, the out-of-hours doctor came and prescribed a liquid antibiotic as my husband had a swallowing problem. However, I think that she wrote in the notes that he was not too bad. We had to drive for miles to find a supermarket with a pharmacy with the liquid antibiotic. This is the problem with rural healthcare; pharmacies and out-of-hours doctors are miles away. It is much easier to get an out-of-hours vet. With so many medical conditions it would be so much better if the people suffering from them had a copy of their own medical records. My husband died in a hospital 24 miles from home. The doctor could not get any records and had only the information that I could give him. My husband died in the presence of myself, a doctor and a very helpful and kind charge nurse. As it was classed as a sudden death, one had to wait for the police. The chaplain was late. So many people have a real fear that if a loved one goes into hospital they will be neglected.

During this year a young cousin of mine, aged seven, died of neuroblastoma after a two-year amazing battle with this aggressive childhood cancer. His parents did everything possible, including having him treated in America. He had a lovely thanksgiving service at York Minster, with all the children from his class and his headmistress attending. It is good for children to understand that death happens, and so much research is needed to make things better, but there needs to be ongoing support for those who are left behind.

We need mindfulness and compassion from those who have the responsibility of looking after patients at the end. Care for the dying must get better. Life and death are precious and sacred. Many vulnerable disabled people fear that they will be at risk of other people making decisions about their life and death if there is new legislation. It is dangerous as it could be a very slippery slope.

**1.53 pm**

**Lord Low of Dalston (CB):** My Lords, I thank the noble Lord, Lord Dubs, for securing this debate, which may aptly serve as something of a curtain-raiser for the debates we will have on the Bill of the noble and learned Lord, Lord Falconer, when it comes to the Floor of the House next year. I particularly commend the measured and dispassionate way in which the noble Lord, Lord Dubs, introduced the debate, and, indeed, the generally restrained temper of the debate as a whole.

We do not have long, so I will make just a couple of points. The first, picking up on a point that the noble Lord, Lord Dubs, himself made, is that assisted dying and palliative care are often portrayed as antithetical

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to one another; indeed, we have heard echoes of this today. The supporters of assisted dying are depicted as heartless monsters who simply want to bump their relatives off for their money or because they have become a

burden, but this is a travesty. Most people would want to see the alleviation of suffering that palliative care can bring exploited to the maximum. It is only when palliative care is inadequate or can do no more that they say an assisted death should not be ruled out as an option. Pace my noble friend Lord Hylton, nothing is being imposed on anybody.

I certainly do not accept the argument that the desire for an assisted death simply shows that the palliative care is not good enough, and that it would not be necessary if it was. That is one of those arguments that cannot be disproved because, by definition, the care could always be better. The fact is that in practice that is not always the case. In fact, assisted dying goes hand in hand with palliative care. Evidence from Oregon, where assisted dying for terminally ill adults was legalised in 1997, demonstrates that the vast majority of people who are assisted receive palliative care and support. The use of assisted dying legislation is very low and researchers suggest that the reason for this may be the high quality of care provided by Oregon's hospices. Hospice provision in Oregon now ranks among the best in the country, but its growth has actually gone hand in hand with the legalisation for assisted dying rather than the reverse. Fears of assisted dying impacting negatively on palliative care have not been borne out; in fact, the opposite seems to be true, and assisted dying can act as a catalyst for the improvement of palliative care. But though palliative care may be excellent, there will still be some people who at the end of life seek assistance to die, and they should be allowed to do so.

My second point is that the views of disabled people are much more diverse than is represented by disability activists. No, that is too mealy-mouthed in an effort to avoid polemic; they are actually the opposite of how they are commonly represented. In a YouGov survey of 1,000 disabled people reported in the *Times* yesterday, almost 80% said that someone who helps a friend or family member who is terminally ill to die should not face prosecution. Asked what position they thought disability rights groups should take on assisted dying for the terminally ill, just under half said they should remain neutral, and a third that they should support a change in the law. Only 8% said that they should oppose a change in the law.

I align myself with Tom Shakespeare, himself a disability activist but not at one with the disability movement on this issue, when he says that,

“calm and evidence-based deliberation is usually more useful to disabled people than extreme rhetoric”.

He goes on:

“It seems to me to be inconsistent to support autonomy for disabled people in all matters except the moment and manner of their death”.

I agree with my noble and right reverend friend Lord Harries that there are occasions when it is right to override a person's choice, but the decision must depend

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on all the circumstances. In my judgment, a case where a person is terminally ill, in great pain and wants to die is not one of them.

**1.58 pm**

**Lord Tombs (CB):** My Lords, I begin by apologising for my late arrival by a few minutes. I came rather a long way and the transport was not quite up to scratch.

I start by saying that I am opposed to assisted dying—as I think is well known—which has monopolised the discussion today, although the debate is rather wider than that and covers other aspects, which I would classify as assisted suicide. I do not think that we should place too much credence on reports of what happens in Oregon. There are good things about the system there and there are bad. One of the more worrying things is the number of fatal doses lying around that country in medicine cabinets, for which there seem to be no clear plans. That is a time bomb waiting to happen.

I think that the objections to assisted dying in particular, but also to assisted suicide, concern the vulnerability of ill people, old people, disabled people, and all sorts of people who require help—help which selfish people can consider a nuisance. My own experience, which is getting quite long now, is that the law is a very blunt instrument. It is designed as such because it has to be for the majority of people, quite rightly, because it is a societal invention and exists because of society. In doing so, it incorporates, because of pressure groups, so many exceptions or variations that it becomes almost impossible to administer.

**2 pm**

**Baroness Finlay of Llandaff (CB):** My Lords, this has been a double-sided debate. On the one hand, it is about improving services for people in their last months, weeks and days so they have real choices in care—to be

home or in a hospice with their symptoms controlled at the medication level they wish, offered any helpful intervention without waiting, with personal care given with respect, time and as they want, and knowing that their family are properly supported.

On the other hand, some propose a licensing system for doctors to supply lethal drugs to patients to deliberately shorten the lives of those who are thought to be dying. That is totally different to providing pain relief while a person dies of their disease. Seale's research showed that illegal action by doctors in Britain is rare or non-existent. This is not just about the complexities of an individual choosing to end his or her life. There are ramifications for others. It is a matter of both conscience and public safety. Others are directly involved in the suicide, and by normalising assisting suicide an attitudinal change occurs across society. Currently, doctors have a key role in preventing suicide; now they are being asked to go into reverse and facilitate it.

I am afraid that Oregon's figures do not confirm safety but show an almost fivefold increase in the incidence of reported physician-assisted suicide. That would translate, as has been said, to about 1,200 assisted suicides each year in England and Wales. That means that in Oregon since 2008 there has been a 21%

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increase in physician-assisted suicide, from 19 to 24 cases per 10,000 deaths. Compare that with the UK, where currently fewer than 20 cases cross the DPP's desk. Oregon has no audit system to shed light on what is happening there. The dynamic seems to have changed. The Bill of the noble and learned Lord, Lord Falconer, gives eligibility criteria, not safeguards. It seems to be looser than the Bill proposed by the noble Lord, Lord Joffe. The current proposal has no reporting and audit system to detect abuse. Indeed, in Oregon, it was only research that showed that one in six patients who ended their life by physician-assisted suicide had clinical depression that was undiagnosed and untreated. There are also reports of patients being offered not oncology treatment but physician-assisted suicide.

The inquiry by the noble Baroness, Lady Neuberger, into the Liverpool care pathway called for research to improve prognostic tools for the last weeks and days of life. We are very bad at prognosis. The Royal College of General Practitioners has said that we can,

“make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years”.

People are particularly vulnerable when very ill. On call last weekend, I was acutely aware how each patient hung on my every word and gesture, reading into it how I thought things were going. Behind each question was another. The GMC guidelines are absolutely clear—they enable in-depth discussions with patients about their dying or their fluctuating wish for death, and doctors are not frightened today of talking about death and dying. People fear being a burden on family, society or state, or being disempowered by the scandalous care that hits the headlines. The message that proponents portray is that for some the only way in which you have dignity when dying is by assisted suicide, that suffering is inevitable and pain often uncontrollable. That is deeply misleading and creates a great deal of anxiety.

Futile treatment is stopped because it is a burden not a benefit, not to bring about death. However, when a patient asks for help to end it all, the doctor can respond by processing the request at face value, which risks sending a subliminal message that the person would be better off dead; but when I ask, “What is making today so difficult?”, and, “What can I do, however small, to improve today?”, I give the message that, “You are worth me working hard for”. I have to redouble efforts, and rethink and reharne resources to meet the patient's need to give true choice in care to the person.

A clinician cannot go in two directions at once by striving to improve quality of life and revise and review, while simultaneously booking an appointment for death. Physician-assisted suicide is being placed in the comfort zone of medicine, suggesting to society that it is some kind of therapy. We have heard euphemisms—assisted dying is not really assisted suicide or will not be extended to euthanasia, we have heard. Let us be clear: what is proposed is that Parliament should license an act that is otherwise regarded as criminal. As the Royal College of Physicians has said, a doctor's duty of care to a patient,

“does not include being in any way part of their suicide”.

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**2.05 pm**

**Lord Beecham (Lab):** My Lords, as the noble Baroness has just reminded us, this debate encompasses two issues. The first is one that has clearly attracted unanimous approval throughout the House: the need to provide

care and support for the dying at the end of life and to honour their choice, particularly in relation, for example, to whether they die at home, in hospital or in hospice—matters referred to by the noble Baroness, Lady Murphy. There is clearly agreement that this objective should be fulfilled, and there are ways in which matters can be taken forward from the current position. Compassion in Dying, for example, has recommended that progress be made in dealing with advance decisions, and simplifying the procedure for living wills and lasting powers of attorney. The noble Baroness, Lady Meacher, referred to establishing a register that, again, Compassion in Dying has referred to. There is the issue of training for professionals and much else. I hope that the Government will look at these matters.

One matter came to my attention yesterday by virtue of an article by Jackie Ashley in the *Guardian* pointing out that whereas people can get leave from work for various reasons, there is no provision in law for leave for carers of those who are terminally ill. Perhaps the Government could look at that. I am of course not asking the Minister for a response today but it is something that I invite her and colleagues in other relevant departments—BIS and so on—to look at. It could well make a significant contribution.

The second area with which we are concerned is assisted dying. On this we have had a very balanced debate. I have been keeping a scorecard of those who have spoken in favour and against, and it roughly balances out across your Lordships' House. I must also say that the debate has been in the highest traditions of this House in terms of thoughtfulness and sensitivity. There are clear issues here—ethical, moral, religious and practical—that need to be addressed. It is not a party issue. There is no official opposition line, and I suspect that there is no official government line. I speak from a personal standpoint.

However, it is perhaps necessary briefly to rebut three points that have been made by some speakers. The noble Baroness, Lady Morris, said that under the proposals of my noble and learned friend's Bill doctors would be required to take the life of patients. That is not the case. The Bill specifically deals with self-administered drugs that could end life. The noble Lord, Lord Alton, spoke of the "emasculatation" of the hospice system. I see no evidence of that at all. As I shall say later, I have knowledge of the working of the hospice system and I do not think that anyone who might support my noble and learned friend Lord Falconer's Bill or some version of it would for a moment wish to diminish the effective role of an important part of our health provision. There was a suggestion by the noble Lord, Lord Hylton, that among the major religions Buddhism was clear in its maxim that one should do no harm. That, of course, is also the substance of the Hippocratic oath. However, the question is: what constitutes harm? Is it confined only to causing death? Can it not also be allowing or facilitating the prolongation of suffering? Therefore, the situation is perhaps more nuanced.

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My own position is informed by my personal experience. My wife died five weeks after I was introduced into your Lordships' House, having suffered from bowel cancer for two years, with secondaries in the liver and lung. It was always a treatable but not curable condition. She was the daughter and sister of doctors. She nursed her mother, who died of cancer, in our home. She was a health visitor, a nurse and a Relate counsellor. From the outset of her illness, she was very clear that, should she suffer considerable pain, she would wish to be helped to end her life. She received wonderful treatment from the National Health Service in Newcastle and from the hospice in which she spent her last few days. Fortunately, she never experienced quite the degree of pain that would have led her to invoke the remedy, which in any event would not have been available to her.

She lived very fully in those two years. She made a television programme about bowel cancer; she made a DVD about stoma, having undergone a cystostomy; and, with friends, she produced a book about living with cancer. Therefore, she was very conscious of the condition and anxious that people should learn from her experience. However, I know that she would have wished me to express support for the choice that in the end she did not have to make. I suppose that I had the dubious privilege—nevertheless, I felt it to be a privilege—of being with her when she died in the hospice. She had been sedated and was out of pain for those last few days. Of course, not everybody has that opportunity, and there are those who would clearly wish to have the chance to end what can be a very painful experience.

I have friends who are undergoing precisely these difficulties now. I have a particular friend who has also suffered from cancer, and it is a recurrent condition. Having, again, been treated very well in hospital and in a hospice, she is now having home care and there is great gratitude for that but, frankly, it is a very painful condition—more painful than my wife endured. It is one which my friend wishes could end swiftly, rather than see her pain prolonged, even though she is having wonderful care, with full medical back-up, at home with her family. I have other friends who have undergone very difficult experiences, and there will be many in your Lordships' House who can testify to that.

So we have some difficult choices to make. We are not asked to make choices today; we are debating and discussing how policy might evolve in both the areas that have been the subject of this debate. I take the point

made earlier that, if you have the means, it is possible to avoid that debate. You can go to Switzerland, as some people have done, and leave the stage, as it were, there under the system that currently prevails. However, a minority of people can take that course and there will not be many, although there will be some, who would prefer the alternative, which my noble and learned friend's Bill would secure. Of course there are issues of safeguarding and of avoiding people being persuaded to take that course of action, and it would be essential to embody that in any legislation, should we reach that position.

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There are clearly many who would adopt the approach that Dylan Thomas advised in a memorable poem:

“Do not go gentle into that good night ...

Rage, rage against the dying of the light”.

For those who do not want to go gentle, whether they want to rage or not, of course we must offer every conceivable support to allow them to do that. However, others would take a different line of poetry. They might take the line from Keats and wish:

“To cease upon the midnight with no pain”.

In my view and the view of some of your Lordships, that is a decision which should also be respected, supported and facilitated, but with the very clear proviso that there must be proper safeguards and that nobody should be required to go against their conscience—for example, as a medical practitioner—to administer what would be required to produce that ceasing upon the midnight with no pain.

### **2.15 pm**

**Baroness Jolly (LD):** My Lords, I thank the noble Lord, Lord Dubs, for securing this debate. I fully appreciate his position on this issue, which is clearly personally heart and head-felt. I know that, as a member of the All Party Parliamentary Group on Choice at the End of Life, this is a subject in which he takes a great deal of interest.

I echo the words of the noble Lord, Lord Beecham. This is a well informed debate, and at times it has been very moving to hear personal stories from Members of your Lordships' House. With a four-minute time constraint on speeches, noble Lords have focused their thoughts, and that has led to many powerful points being well made. Here, I should like to make special mention of the maiden speech of the right reverend Prelate the Bishop of Sheffield, which was sensitive, thoughtful and thought-provoking. I am sure that he will make a huge contribution to the work of your Lordships' House.

This is an important debate on a highly emotive and complex issue. Death affects us all. First, I assure noble Lords that, as a Government, we are committed to improving quality and choice in end-of-life care. Today, many noble Lords have focused on assisted dying. As was highlighted by the noble Lord, Lord Dubs, and others, the Government believe that any change to the law in this emotive and contentious area is an issue of individual conscience and a matter for Parliament to decide rather than one for government policy.

The Assisted Dying Bill, introduced by the noble and learned Lord, Lord Falconer of Thoroton, seeks to legalise, in England and Wales, assisted suicide for terminally ill, mentally competent adults who are reasonably expected to die within six months and who have been ordinarily resident in England and Wales for at least 12 months. The Government will take a collective view on the noble and learned Lord's Bill in order to respond to the debate on its specific provisions at, but not before, Second Reading. As things stand, however, no date has been set for the Second Reading of his Bill and today's debate does not address it.

My noble friend Lord Taverne raised the question of the DPP's role in prosecuting offences. Prosecutors must apply the two-stage test set out in the Code for

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Crown Prosecutors in cases of encouraging or assisting suicide and all other offences. The full code test has two stages: the evidential stage and the public interest stage. A case which does not pass the evidential stage must not proceed, no matter how serious or sensitive. Where there is sufficient evidence, prosecutors must then consider whether a prosecution is in the public interest.

The noble Lord, Lord Davies of Stamford, stated that the DPP has said that he will not prosecute those who encourage or assist suicide. The DPP's policy is clear that it,

“does not in any way ‘decriminalise’ the offence of encouraging or assisting suicide”.

Indeed, it specifically says:

“Nothing in this policy can be taken to amount to an assurance that a person will be immune from prosecution if he or she does an act that encourages or assists the suicide or the attempted suicide of another person”.

**Lord Davies of Stamford:** I am grateful to the noble Baroness for giving way. Of course, in a four-minute speech I had to use some shorthand, but my essential point was that it was extremely undesirable in the interests of both the clarity of the law and in how our democracy works to have the law on such an important subject made by the back door—by DPP decisions or even by jurisprudence. Would the Minister like to comment on that remark?

**Baroness Jolly:** I take the noble Lord’s point. I am not a lawyer but I will certainly write to him to ensure that his point is answered. In a letter to all Members of this House I will make sure that they, too, hear the same response.

Noble Lords may be aware of the different ways in which to document decisions on end-of-life care. Many of the general public are not. One option is a health and welfare lasting power of attorney. It allows someone to give authorisation to the attorney to make decisions about health and care, including decisions on life-sustaining treatments. Another option is making an advance decision. This enables anyone aged 18 or older who has capacity to make a decision about their future care. They may wish to refuse a particular treatment or intervention in the future when they no longer have the capacity to make their wishes known. It is a way of making plans for the future. It is a legally binding way of being able to refuse a treatment or intervention. An advance decision can be made not to be resuscitated under certain conditions. An advance decision can be made to refuse all life-sustaining care, provided that certain conditions are met. The decision must be witnessed and made in writing. These advance decisions are legal mechanisms to help a person plan their care. Both advance decisions and lasting power of attorney exist in addition to the systems that clinicians use to record patients’ wishes for end-of-life care.

The noble Lord, Lord Dubs, said that there should be a positive duty to inform a patient of their rights. Healthcare professionals should proactively seek to communicate with their patients and where appropriate, the patients’ families to find out their needs and preferences, and to capture these in an advance care

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plan if the patient so wishes. Healthcare professionals should understand the Mental Capacity Act so that they can inform patients about these rights if the patient is willing. It would be inappropriate to compel healthcare professionals to force such information on people who do not want it.

The noble Baroness, Lady Meacher, suggested that it would make a lot of sense to ensure that advance decisions are stored so that they could be accessed at the right time. It is important that those making an advance decision should decide how best to record their decision to suit their individual circumstances. There are also practical issues in trying to rely on a central register to record wishes, such as ensuring that it is up to date and accurately reflects current issues and wishes. Even if a register was established and showed that an advance decision was in place, healthcare professionals would still be required to satisfy themselves that it was valid and applicable, and would have to seek information from other healthcare staff and close family to ensure wishes, so a register would not be solely relied on. The noble Baroness, Lady Meacher, also raised the point of whether NICE should issue guidance on the use of advance decisions. NICE is an independent body and anyone can suggest a topic to it through the topic selection procedure. These are then evaluated to decide the topics on which guidance will be developed.

The noble Baroness, Lady Hollins, asked what is being done about ensuring that we have the right palliative care services. She raised various points, and when I get to the body of my text I will address that subject. All patients should receive high quality and compassionate care in the last days and hours of their lives, and we know that choice is at the heart of this. The noble Baroness, Lady Murphy, highlighted two issues: legislative decisions and policy decisions. I will direct the rest of this speech to policy-related actions and decisions.

The mandate to the NHS was refreshed in November this year. We highlighted the importance of improving standards of care at the end of people’s lives as a priority for the NHS and an area in which we expect particular progress to be made. In response to a recommendation made by the NHS Future Forum, the Government updated the NHS constitution in March 2013 to make it clear that patients should be fully involved in all discussions and decisions about their health and healthcare, including end-of-life care.

I now want to set out further details on the work that we have planned for extending choice in end-of-life care. We recognise that dying well means people being able to exercise more choice in where they receive their care, and to have quality services delivered where and when they need them. We know that most people would prefer

to be cared for and to die at home, in familiar surroundings, surrounded by friends and family. We know that currently more than 50% of people die in hospital, the place where they would least prefer to be. We want to make sure that services are set up to help people to die at home, with high quality end-of-life care for all those who need it. However, increasing choice is not an easy task that can be done overnight.

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In *Liberating the NHS: Greater Choice and Control*, we set out our commitment to move towards offering more choice nationally to support preferences on how to have a good death. In light of this, we have been working with the National Council for Palliative Care to undertake a review, of when and how choice could be offered in end-of-life care. Noble Lords will be interested to know that a workshop involving all the key individuals and organisations in end-of-life care will take place early in the new year. It will discuss the key issues and barriers that the review will need to consider. In particular, a review will consider when such choices could feasibly be introduced, with the right services and support in place to deliver this. Our intention is that the review should be as comprehensive as possible, looking at all the issues in depth and involving all key stakeholders. We would therefore encourage and greatly appreciate your Lordships' input. Any changes requiring legislation would be introduced using existing legislative powers. The outcome of the review will inform NHS England's future approach to choice in end-of-life care.

The noble Lord, Lord Dubs, asked when we could expect proposals to replace the Liverpool care pathway. The work on a response to the independent review of the Liverpool care pathway is being led by the Leadership Alliance for the Care of Dying People. The alliance is currently engaging on draft outcomes and guiding principles that would underlie the care of people at the end of life in all settings. The system-wide responses will be published in the first part of 2014 after the engagement concludes. The right reverend Prelate the Bishop of Sheffield asked about the role of chaplaincy services. The College of Health Care Chaplains is represented on the alliance and will be part of the process of developing the final version of the outcomes and guiding principles. I endorse the comments made by the right reverend Prelate on the key role that chaplaincy services can play in end-of-life care.

Recent survey findings indicate that there is an increasing trend that people wish to die at home, and we cannot ignore that. The *End of Life Care Strategy*, published by the Department of Health in 2008, set out the ongoing ambition to support more people to die in their preferred location. Work is ongoing from NHS England—the leadership alliance—to refresh the strategy. This refresh will look at the strategy's recommendations, including on patient choice, and build on them for the future direction of end-of-life care. NHS England is looking to complete this work early in 2014, which will inform its future approach. Following on from this, we know that one of the main barriers to people receiving the care they deserve is a lack of open discussion between health and social care staff. The noble Lord, Lord Dubs, spoke of the death taboo slowly receding, but in some cultures death is still considered part of life itself.

We know that after speaking to their loved ones about plans for end-of-life care, GPs are next on the list of people that patients most want to talk to. We also know that where GPs initiate conversation, nine out of 10 people are happy to continue with it. However, we recognise that some people would not wish to enter into conversations, either with their family or with

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health and social care staff. If this is their choice, we would expect healthcare staff to respect that.

All this is the background to the Find Your One Percent campaign. One per cent of people on a GP list will die each year. The purpose of the Find Your One Percent campaign is to help GPs make sure that people who may be approaching the end of their life have the chance to discuss and plan for their end-of-life care. The campaign is hosted by the Dying Matters coalition, working with Macmillan Cancer Support, the Royal College of General Practitioners and others to ensure that clinicians are provided with the information and, more importantly, the resources they need to support a good death.

The focus is on helping. We believe that GPs play an important role in helping patients to make choices that are right for them and to make sure that this happens. Guidance has been produced for GPs to help patients make informed choices. It is not compulsory for them to follow, nor is it about hitting government targets: it is about improving the quality of people's experience at the end of life and ensuring that they receive the care they need, when they need it. GPs can help make sure that that happens by offering people the opportunity to prepare an end-of-life care plan. Care planning of this type is not a single event. Plans evolve as people's conditions change or their preferences alter. This mechanism allows GPs to ensure that people get the treatment they want at the end of their lives, and have a chance to discuss this difficult topic and express their preferences.

Further, the quality and outcomes framework, a voluntary reward and incentive scheme for GP practices in England, currently has two dedicated indicators for palliative care. The framework encourages GPs to establish and maintain a register of all patients in need of palliative care and to have regular, multi-disciplinary case review meetings where all patients on the palliative care register are discussed. These indicators are being retained in the quality and outcomes framework for 2014-15.

In October 2013, NICE, the National Institute for Health and Care Excellence, announced that it is shortly to review its quality standard for end-of-life care for adults and the support guide for commissioners. This will provide further help to develop end-of-life care services and provide incentives for better conditions.

Many noble Lords have recognised the valuable role that hospices play in delivering end-of-life care services. The noble Lord, Lord Judd, spoke powerfully about a community's sense of identity and ownership in their local hospice. Building on the success of the £40 million capital budget for hospices in 2010-11, which funded 123 projects in 116 hospices, the Government have provided a further capital budget for hospices of up to £60 million.

The independent Palliative Care Funding Review panel, set up by the Secretary of State for Health, was asked to recommend how a new per-patient funding system for adults and children should be developed. It reported in July 2011 and was recommended by the Government. As noble Lords will know, pilots were set up as a result of this and are currently gathering

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evidence. This evidence gathering will finish in March 2014. We have already stated our position: we see merit in removing the means test at the end of life, and this is being considered as part of the review. Noble Lords will be pleased to note that we have committed to introducing the new funding system by 2015-16, which is a year earlier than recommended by the review.

Before concluding, I thank those charities and hospices that do such wonderful work with patients at the end of their life, and with their friends and families after death to come to terms with their bereavement. In particular, Marie Curie, Sue Ryder and Macmillan Cancer Support have all been mentioned in today's debate, but there are other smaller organisations.

I hope that I have been able to offer some reassurance that the Government are making progress on these complex and sensitive issues. If there are any questions that remain unanswered, I will write to all noble Lords who have taken part in this debate.

### **2.35 pm**

**Lord Dubs:** My Lords, it was a privilege for me to secure this debate, in which there were some outstanding contributions. It was also very humbling to hear matters of conscience discussed so openly and with such obvious honesty and sincerity. I pay tribute to the right reverend Prelate the Bishop of Sheffield. I hope we will hear from him many times in the future, but perhaps on issues where he and I are in agreement. I am grateful to the Minister for the way she has dealt with this and to my noble friend on the Front Bench. All I can say is that we are going to debate these issues again and again.

*Motion agreed.*