

Liverpool Care Pathway

[Mr Mike Weir *in the Chair*]

2.30 pm

Glyn Davies (Montgomeryshire) (Con): Mr Weir, I would like to say how much of a pleasure it is to serve under the chairmanship of a fellow Celt. I declare an interest as a board member of Living and Dying Well, which specialises in research into and opposition to the legalisation of assisted suicide.

I shall begin with a summary of the current position. The “Liverpool Care Pathway for the Dying Patient” was developed by the Marie Curie Palliative Care Institute Liverpool as a framework for health professionals to use to ensure that people who are dying have as comfortable and dignified a death as possible. The pathway was developed and has been in use since the 1990s. Today, about 130,000 of the 450,000 patients who die in hospital care every year die while being cared for on the pathway. It has also been exported and is now in use in more than 20 other countries.

However, during the past few months, the Liverpool care pathway has been the subject of some very serious criticisms and allegations in the media, which has led to questions about whether it is indeed a worthy process. I shall explain why I sought this debate and the outcomes that I would like to achieve before considering in greater detail the criticisms that have been made of the pathway.

By any measure, the Liverpool care pathway plays a very significant role in how the end of life is managed in our country. Its role is much greater than most of us realise: 30% of patients who die in hospital care die while on the pathway. The sheer scale of this is why I believe that debate about it is too important to be led by national newspapers, although I certainly do not criticise those newspapers for reporting stories in the way they have done. Indeed, they have served a valuable purpose by raising public awareness of such an important issue. However, there is, almost inevitably, a tendency for newspapers to couch the debate in sensationalist terms. It is up to us as parliamentarians to ensure that this complex and potentially controversial issue is subject to balanced and thorough debate in the House of Commons.

The outcome that I seek today is calm reflection by parliamentarians, including those on the Front Benches, on this most sensitive of issues—calm reflection on the issues without encouraging the spread of alarm and despondency among those entering care, which can result from sensationalist allegations. I also seek a response from Government—from the Minister—that they will ensure that the review on which they have already embarked includes careful and thorough investigation of the allegations that have been made of bad practice. It is important to know whether the allegations are accurate and, if they are, where the weaknesses lie and what needs to be done to put those matters right.

I am a supporter of the Liverpool care pathway, but my aim today is not to defend or to attack the pathway, those who have made allegations of shocking bad practice, or the media, which have given the allegations such great publicity. It is to promote open and genuine debate in Parliament. In any case, I am not in a position to judge how much substance there is to the various

8 Jan 2013 : Column 36WH

criticisms that have been made, but I do know that we cannot avoid death and I also believe that most people do not fear death so much as they fear the process of death. The aim of the Liverpool care pathway is to ensure that the process is as compassionate, dignified and free from pain and discomfort as possible and, importantly, consistent with public safety. Our aim should be that the pathway is used in a way that retains public confidence—that it is being used in accordance with the principles on which the Marie Curie Palliative Care Institute developed it.

I hope that the Minister will agree that we must ensure that the pathway is subject to the very highest levels of scrutiny and that the framework can be allowed to be implemented only against a background of total transparency. There must be discussion with patients or with patients' families or carers and there must be clearly available avenues through which complaints and concerns can be channelled. I hope that the Minister will assure us that the very serious allegations reported in the media will be thoroughly investigated and that, if any examples of bad practice are found, action will be taken to expose those responsible, to hold them to account and to do everything possible to prevent it from happening again. The experiences at Winterbourne View and hospitals in Worcestershire and the appalling and chilling events that took place in Stafford are too raw in the memory to allow anything else. It is only through audit and disciplinary measures, if and when appropriate, that the Liverpool care pathway will retain the integrity needed for it to be acceptable and the confidence of those who might use it.

Two years ago, I had never heard of the Liverpool care pathway. I first took an interest in it as a consequence of my concerns about and opposition to the legalisation of assisted dying. I was hugely surprised by how widely the pathway was in use. I had no idea that 130,000 patients in hospital care died while on the pathway every year and I do not think that many people realise that today.

Jonathan Evans (Cardiff North) (Con): I am grateful to my hon. Friend for giving way to a fellow Celt. I congratulate him not just on securing the debate, but on the tone in which he has introduced it. He referred to the number of people who are on the Liverpool care pathway, but to help the debate has he done any work on the expansion in numbers since the 1990s? Did we swiftly move to 130,000? Is that a consistent number, or has there been a gradual increase over time? I ask that because of course it is the rolling out of the pathway that may lead to some people having less expertise—less skill—and then, as a result of that, some of the instances that my hon. Friend refers to some poor reporting of?

Glyn Davies: My hon. Friend makes a very important point about the need for training and expertise for all those who are responsible for putting people on the pathway and for looking after them when they are on it. I want to come to that later in my comments.

The negative coverage in our national media has probably increased awareness of the Liverpool care pathway. To that extent, I think that it has been a very good thing, but because I do not believe that the scale of the pathway is widely known, I think that it is right to say something about what the Liverpool care pathway is and what it is not in order to set out the context of the

8 Jan 2013 : Column 37WH

debate,. It is certainly not and must never be any form of “euthanasia by the back door”—a phrase that I have heard—nor is it a form of clinical treatment or even any specific type of care. It does not instruct doctors or nurses to provide this or that treatment. What it does is prompt them to consider whether certain treatments are appropriate in individual circumstances. It supports—it does not replace—clinical care. It is no more than a framework of good practice, backed up by training and education, to guide doctors, nurses and other health professionals towards delivering the high levels of palliative care that have been available in hospices for many years. It enables them to be transferred to hospitals, care homes and patients’ homes. It is about the appropriate way to look after a patient who is clearly dying through the last few days and hours of life.

Some other points should be made in this debate. The Liverpool care pathway does not recommend, as some have suggested, that dying patients should be deprived of food and water, although food and water may be withdrawn in individual cases if clinicians believe that that is the right step to take. The Liverpool care pathway does recommend to doctors and nurses that they explain to dying patients, or more often their next of kin, exactly what is happening and why. Secrecy forms no part of the Liverpool care pathway whatever.

It is also important to emphasise that there is nothing irreversible about being placed on the Liverpool care pathway.

Andrew Bridgen (North West Leicestershire) (Con): Will my hon. Friend give way on that point?

Glyn Davies: On that point, I will, yes.

Andrew Bridgen: I thank my hon. Friend for calling this very important debate. I, too, share some of his concerns about the consistency with which the Liverpool care pathway is implemented across the country. I made some inquiries in the hospitals that serve my constituents, but information seemed to be lacking on the implementation of the care pathway. I am particularly concerned that patients placed on the pathway may have no opportunity to be taken off it if they improve. There are no figures on the number of patients for whom care has been reintroduced after being placed on the pathway. One of the hospitals told me, anecdotally, that no one there could remember anyone being taken off the pathway. I find that worrying.

Glyn Davies: My hon. Friend makes a very good point. Patients on the pathway should be monitored regularly, and if the patient shows signs of rallying, as does happen in a minority of cases, the treatment should be modified to support recovery. If that is not happening, the pathway is not being implemented properly. The Liverpool care pathway is not a pathway to death—a phrase I have seen used often, but which I think is unbelievably awful. It is a travesty of the truth to describe it as a form of euthanasia.

Why have we reached the point of huge public controversy, which has caused so much angst and fear? It has arisen from allegations—serious allegations, some of them from doctors and nurses—that the pattern of end-of-life care I have described has not been followed in some cases. There have been stories of dying patients

8 Jan 2013 : Column 38WH

being deprived of the food and water they needed and others being kept continuously sedated until they died; and of patients being placed on the pathway without consultation with them or their families, or to meet targets. The fear of that is especially shocking, and I hope the Minister will comment specifically on the issue of targets.

Let me look at some of the allegations in more detail. According to the *Daily Mail* in June last year,

“NHS doctors are prematurely ending the lives of thousands of elderly hospital patients because they are difficult to manage or to free up beds”.

The report is based on a presentation to the Royal Society of Medicine by Professor Patrick Pullicino, a consultant neurologist. He stated:

“The lack of evidence for initiating the Liverpool Care Pathway makes it an assisted death pathway rather than a care pathway.”

That is the debate being led by the *Daily Mail*. Professor Pullicino continued:

“Very likely many elderly patients who could live substantially longer are being killed by the LCP.”

Imagine how a frail elderly person entering hospital a few weeks after reading that would feel. Professor Pullicino added:

“Patients are frequently put on the pathway without a proper analysis of their condition.”

According to the *Daily Telegraph*, in September, a group of experts stated in a letter that

“dying patients...can...have fluid and drugs withdrawn and many are put on continuous sedation until they pass away.”

The letter—again according to the *Daily Telegraph*—spoke of a “national crisis” in patient care, and

“a national wave of discontent...building up, as family and friends witness the denial of fluids and food to patients.”

According to the newspaper, some patients were wrongly being put on the pathway, which created a “self-fulfilling prophecy” that they would die. The report continued:

“Patients who are allowed to become dehydrated and then become confused can be wrongly put on this pathway”,

and,

“many doctors were not checking the progress of patients enough to notice improvement in their condition.”

Those are shockingly serious allegations. If they are true, urgent corrective action is needed.

There is another side to the equation, however. More than 20 respected organisations, including the Department of Health, Age UK, the Alzheimer's Society, Macmillan Cancer Support, and the Royal Colleges of Physicians, General Practitioners and Nursing, have signed a declaration that:

“Since the late 1990s, the Liverpool Care Pathway has been helping to spread elements of the hospice model of care into other healthcare settings”.

It mentions:

“Published misconceptions and often inaccurate information”—

referring, I think, to the stories in national newspapers I have quoted. Our task and the Minister's is to reconcile the support of all those organisations for the Liverpool care pathway with the allegations made—in good faith, I am sure—by people who believe that the pathway is what they call a pathway to death.

Any tool is only as good as the workman who uses it. The declaration states clearly that the Liverpool care pathway:

8 Jan 2013 : Column 39WH

“Relies on staff being trained to have a thorough understanding of how to care for people who are in their last days or hours of life.”

We have to face the fact that, in most professions, there are instances of excellence and malpractice, and health care is no exception. It would be surprising if, when 130,000 people a year are dying on the Liverpool care pathway, there were no cases in which the pathway had been misapplied. That applies to every branch of medicine and, indeed, every occupation. There are good and less good doctors and nurses; there are well run and less well run hospitals; but to lay the blame at the door of the Liverpool care pathway is like tearing up “The Highway Code” because there are some bad drivers. Where there is bad practice and poor care, it should be rooted out and replaced with good care.

It seems to me that the review the Government recently launched provides an excellent opportunity to consider thoroughly all those issues. It is urgently needed. The review should call for any evidence of poor end-of-life care. We need the Minister to assure us this afternoon that the stories I have quoted will not simply be taken at face value, but will be investigated in detail, so that we can establish the scale of poor end-of-life care, and understand the causes and correct them.

Lilian Greenwood (Nottingham South) (Lab): I am listening carefully to the important points the hon. Gentleman is making. My constituents John and Mary Roche lost their mother five years ago. They came to see me because, having seen the media reports, they were concerned about her care toward the end of her life—she had been admitted to hospital and subsequently had her food and nutrition withdrawn. Does he think my constituents and others like them should be encouraged to share their stories, so that they can be taken into account in the Government's review of the Liverpool care pathway and its appropriate use?

Glyn Davies: I thank the hon. Lady for making that point, because I most certainly do agree. I hope that, as a result of today's debate, more people will come forward to put their experiences, especially of bad practice, in front of the Minister and the review.

We must not forget that it is necessary not to allow the shortcomings of some end-of-life care providers to undermine the outstanding work that the majority of doctors and nurses perform. It is easy to forget that, for those caring for people in the last days and hours of their life, alarmist stories cause real problems, misleading vulnerable people and their relatives into thinking that the unhappy experiences reported so prominently are typical of end-of-life care as a whole, making them reluctant to accept care that is genuinely beneficial, and generating fear of going into any sort of care setting. My sense is that the high profile given to these serious allegations, unaccompanied by supporting evidence, is analogous to shouting "Fire!" in a crowded theatre. We need to know that the Minister will consider all the allegations that are made, including those that have been reported, look at the evidence, and institute whatever changes are needed to ensure safety and thereby confidence in the integrity of the Liverpool care pathway.

8 Jan 2013 : Column 40WH

I end with a general observation. I was appalled, as I am sure everyone in the Chamber was, by the recent revelations of poor care in a Worcestershire hospital, in Winterbourne View and in Stafford hospital. I was moved, as many of us will have been, by the observations made in the main Chamber before the Christmas recess by the right hon. Member for Cynon Valley (Ann Clwyd) regarding the inadequate and cruel care given to her late husband. We are reading about too many such cases. Considerable advances have been made in medical science, but we must ensure that, at the same time, we do not lose commitment in the NHS to basic care. I cannot help wondering whether the examples of poor end-of-life care that some relatives believe was given to their loved ones stem from the wider malaise of forgetting how to care for the sick, rather than from any specific clinical protocols such as the Liverpool care pathway.

Several hon. Members*rose*—

Mr Mike Weir (in the Chair): Order. Several Members wish to speak. I want to call the first of the Front Benchers no later than 3.40 pm. A quick calculation suggests that, if Members keep their speeches to about seven minutes—and interventions are brief—I will be able to call everyone.

2.49 pm

Rosie Cooper (West Lancashire) (Lab): It is a pleasure to serve under your chairmanship, Mr Weir. I congratulate the hon. Member for Montgomeryshire (Glyn Davies) on securing this essential and timely debate.

As hon. Members and the Minister will know, opinions on this end-of-life care framework tend to be polarised, but I believe that fundamental questions need to be answered about how the Liverpool care pathway has fallen into such disrepute, when it was developed to help doctors and nurses provide quality end-of-life care for the dying. That involves palliative care options for patients in the final hours or days of life, not a procedure that some members of the public now regard as a way prematurely to kill off the terminally ill or senior citizens.

The hon. Member for Montgomeryshire has outlined the process in which the Liverpool care pathway should work, involving significant communication if possible with the patient, but certainly with their next of kin and family. I share his support for the framework when it operates properly and allows the dying to die with dignity and free of pain. Why are there so many stories in the press of distressed families complaining that they did not know that a relative had been put on the pathway? The huge problem lies in the human application of the rules, not necessarily in the rules themselves. One in three families of those dying say that they never received the leaflet explaining the LCP process that they should have been given. Why is it not mandatory to evidence in the notes discussions with the patient or the family about the Liverpool care pathway?

Some would say that the difference between a multidisciplinary team decision, taken with the family's knowledge and consent, and a decision taken in isolation could be seen as murder or at least manslaughter. The stark reality of the Liverpool care pathway is that 57,000 patients a year are dying without being told that efforts to keep them alive have been stopped. In some respects, there are parallels with the cases of Mid

8 Jan 2013 : Column 41WH

Staffordshire NHS Foundation Trust and University Hospitals of Morecambe Bay NHS Foundation Trust, which were supposed to be operating the same system as that in every other NHS trust in the country and yet somehow ended up abjectly failing their patients, so that people died unnecessarily. The sheer scale of the failure to inform people, or their relatives, that they are on the pathway opens up the practice to attack.

People talk about back-door euthanasia and some say that it is tantamount to assisted death, except that in 57,000 cases people were not aware that they were being assisted. That has to be added to the cocktail of the timing and the context of where we are now. The NHS is saving £20 billion over four years. There are service pressures—the lack of available beds and severe cuts in social services budgets that result in bed blocking, together with the demands of an aging society—but, frighteningly, as we have become aware via the press, at the same time hospital trusts receive financial incentives for achieving certain performance targets in putting people on the Liverpool care pathway.

Let me be clear—not for one second am I suggesting that those factors are part of the decision-making process; I use them merely to highlight the fundamental problem of the pathway and the perception that exists in the wider public, especially among the elderly.

Why do hospital trusts require any financial incentive to follow the Liverpool care pathway? For me, that question goes to the very heart of our national health service and our absolute understanding of what the medical profession stands for in people's eyes. We believe that it is the role of the NHS and medical professionals to take every conceivable step to preserve life until the options are exhausted. The Department of Health has proposed to enshrine in the NHS constitution, as a patient right, an entitlement to be informed of any consideration about placing a patient on the Liverpool care pathway. Why can that not be made a legal requirement, so that everybody knows—and we are sure that everybody knows—and can be assured that taking such a decision is right?

Robert Flello (Stoke-on-Trent South) (Lab): I add my congratulations to the hon. Member for Montgomeryshire (Glyn Davies) on securing this important debate. To go back to the hon.

Lady's point about the financial incentives for hospitals, it appals me, too. Surely, if patients or their families are not consulted, the Liverpool care pathway is not being followed, so any payment by the Department of Health to a hospital for having supposedly had someone supported by the pathway is money paid wrongfully, deceitfully and possibly unlawfully. Does she therefore agree that the Department should tell hospitals that have failed to consult family and friends or the patients themselves that the Department wants back some of that money?

Rosie Cooper: That takes me back to my earlier point that we should document the conversations with families, so that that would be the tick box for payments. I am running out of time, so I shall move on quickly.

Will the Minister elucidate how the NHS constitution requirement will make a difference? Procedures are already in place, yet 50% of patients on the pathway were not informed, or their families were not consulted. It is time that the soundbite, "No decision about me

8 Jan 2013 : Column 42WH

without me" became a principle and a value, rather than the vacuous phrase that it currently is. There is no politics in that—it is really important; it is the core of everything.

Through Lord Alton of Liverpool, I am aware that Liverpool medical school requires all its students to undertake one month's training in the care pathway, working in a hospice during their fourth year. Such good practice should surely be a core component nationwide, and in the light of a recent study, there is perhaps an argument for making it mandatory across the country. That kind of training needs to be given to those already qualified and working on our wards—not just doctors, but nurses and all members of the multidisciplinary team who are called on to make decisions. If there have to be financial incentives, they should follow the training to ensure that all those who care for the terminally ill and dying are properly equipped with the skills that they need, in what for all concerned are traumatic and often complex situations. Good training costs money and must be externally validated, and I invite the Minister to respond specifically about that need.

I see merits in a system that manages end-of-life care effectively—it is a measure of our humanity that we seek ways to ease suffering—but my concerns about the application of the Liverpool care pathway remain. There is far too little reassurance in the system, which has allowed the pathway to move from an end-of-life care system to one that is held up as hastening death. We can talk about the theory of how the LCP should be followed, but the fact remains that, in practice, it is not always implemented as intended. It should never be seen as a conveyor belt to the cemetery. Some 80,000 patients are supported by—not put on—the Liverpool care pathway, and many receive the finest care, but many is not good enough. It is said that about 1% of cases go badly wrong, but just one case—never mind 1% of cases—is one too many. Those who founded the pathway did so because of their respect for the dignity of patients; those who implement it need to understand and share that view or face the legal consequences and their own consciences.

2.59 pm

Sir Tony Baldry (Banbury) (Con): When I first entered the House of Commons some 30 years ago, I became the founder secretary of the all-party hospice support group, and Jack

Ashley was the founder chairman. I am glad to say that that group has now become the all-party parliamentary group on hospice and palliative care. During those 30 years, an enormous amount of work has been done on enhancing palliative care in hospitals. We are fortunate in this country in having an outstanding hospice movement. Part of the purpose of the Liverpool care pathway was to ensure that the good practice of palliative care, which had been developed in hospices, could be spread to other health care settings, such as hospitals and care homes. Extending it to people's own homes was also important because if people are asked where they would like to die, most say at home. The reality for each one of us is that we will die.

The Liverpool care pathway requires staff to ensure that all decisions to continue or to stop treatment are taken in the best interests of each patient, and emphasises that patients should be involved in decisions about their

8 Jan 2013 : Column 43WH

care and that carers and families should always be included in the decision-making process. An evaluation in 2011 showed that in 94% of cases, there had been such involvement. The idea of documenting conversations, which the hon. Member for West Lancashire (Rosie Cooper) mentioned, is sensible. In our own professional lives, and, indeed, as Members of Parliament, we all know that people, especially family members, do not always take on board news that may be distressing. Often it is quite a shock to be told that a loved one is near to death. Very often, the instinctive reaction is to want to ensure that life can be preserved for as long as possible, but we also have a duty of care to ensure that in people's last days and hours they die well and painlessly and with as much dignity as possible.

I was very struck by two contributions in the Library briefing. One was a brave article by a specialist registrar who herself is a terminally ill cancer patient. Of the Liverpool care pathway, she said:

“It prompts us to have open discussions with relatives, and, if possible, patients, to stop unnecessary medication, to discontinue futile medical interventions, and to shift our focus of care to symptom-control, comfort and dignity... Most patients on the LCP, in my experience, are too poorly to eat or drink, but where a patient is alert enough to swallow we certainly continue to offer them food and fluids in my hospital. They are not ‘starved to death’. The problem with intravenous fluids is that cannulae need to be inserted to administer them. This is painful, often very difficult and sometimes near impossible in patients who have been in hospital for a number of weeks.”

Jim Shannon (Strangford) (DUP): Although the hon. Gentleman makes a pertinent point, surely the issue must also be about those people who are not convinced about the system and who are suspicious and worried about what they have been told. There are people who have been denied fluids, and also drink and food. Does the hon. Gentleman think that there should be some protection in the system for such families so that they can feel assured that there is care? The point I am trying to make is that this should be about care and not killing, but many of us suspect that there is more emphasis on the killing than on the care.

Sir Tony Baldry: Very few of us can have the confidence of Cardinal Basil Hume who, in his book “The Mystery of the Cross”, observed:

“Death is a formidable foe until we learn to make it a friend. Death is to be feared if we do not learn to welcome it. Death is the ultimate absurdity if we do not see it as fulfilment. Death haunts us when viewed as a journey into nothingness rather than a pilgrimage to a place where true happiness is found . . . Death is not the end of the road, but a gateway to a better place.”

Few of us, irrespective of our faith, have that clear courage and confidence, but we all recognise that we will die. There is nothing about 21st century medicine that is going to keep the hon. Member for Strangford (Jim Shannon) or myself, or any of us, alive for ever. Death, and the process of death, can be extremely painful, and it is our collective duty and responsibility to try to ensure that people die as painlessly as possible and with as much dignity as possible.

I can assure the hon. Gentleman that people do not go into the medical profession to kill. My father became a doctor and my mother a nurse to ensure that they could give people the best quality of care. Although the

8 Jan 2013 : Column 44WH

press have published a number of stories about relatives who have expressed concern about how the local care pathway has been used, there is no systemic evidence to suggest that the policy is being abused. A consensus statement was published last year by several non-governmental organisations and charities, all of which are much respected in this House, supporting the Liverpool care pathway. They include Age UK, the Alzheimer’s Society, the British Heart Foundation, Help the Hospices, Macmillan Cancer Support, Marie Curie Cancer Care, the Royal College of General Practitioners, the Royal College of Nursing, the Multiple Sclerosis Society and the Royal College of Physicians.

Jim Shannon*rose*—

Sir Tony Baldry: No, I will not give way because others want to speak. This is an important issue, but we must ensure that we put it in perspective. If we are not careful, all the work that has been done over the past 30 years by a whole number of organisations, including those that I have just mentioned, to enhance and improve palliative care could be undone. Sadly, people die every day; that is the reality. It is not a failure of the NHS that people die. It is only a failure of the NHS if people do not die well. We need to ensure that all improvements, whether they be to records or to communication with patients and their families, are undertaken, but nothing should deter us from trying to ensure that everyone in this country gets the best possible end of life and the best possible palliative care.

3.7 pm

Meg Hillier (Hackney South and Shoreditch) (Lab/Co-op): I am pleased to serve under your chairmanship, Mr Weir. I congratulate the hon. Member for Montgomeryshire (Glyn Davies) on securing this debate on such an important issue.

I represent St Joseph’s hospice on Mare street in Hackney, which is a beacon of good practice in end-of-life care. Under the expert leadership of its chief executive, Michael Kerin, its medical director, Dr Anjali Mullick, and the Sisters of Charity, who founded it more than 100

years ago, the hospice ensures that people in their last stages of life receive care and die with the respect and dignity that they deserve, and that is what we are talking about today.

It is worth reiterating here what end-of-life care should offer. It is about treating someone who is dying as a person, and not as a number or a patient, and about looking at that individual's needs in the round. It is not about giving a mechanistic response. As my hon. Friend the Member for West Lancashire (Rosie Cooper) said, surely once a clinical decision has been made about someone's life chances, we, as a compassionate society, should try to ease suffering and support them to die well. The Liverpool care pathway, which is used only when someone is in the last hours or, in some circumstances, the last days of their life, aims to provide the tools to enable rest and care rather than making active interventions that would cause a person to die less well.

Those fine principles are great, although they may not always be adhered to fully. Good leadership and training of staff are vital, and that is one of the issues I want to address in the short time I have to speak.

8 Jan 2013 : Column 45WH

We face an important challenge as a society as we consider the end-of-life care we aspire to. Most of us want a choice of where we die. If we had a free choice, most of us would choose to die at home, supported by organisations such as Marie Curie or hospices such as St Joseph's, whose nurses go out and care for people in the community. Where individual practitioners are out and about and are not being overseen, that will create greater challenges in the future for regimes such as the Liverpool care pathway, but that is no reason to dismiss it or not to see it as an important way of helping and supporting people as they die.

That raises an important issue for us as a society. If we agree that dying well is important, we need to recognise that practical and policy issues need to be addressed. Patient and family choice about where to die works only if proper 24/7 care is provided, whether in the home, the hospice, the hospital or another setting, and we need to make sure that proper resources and support are available. Often, that is about training practitioners in general so that they know what best practice is. If we look to our inner humanity, we all know what we would want, leaving aside all the medical trappings, if we were dying: we would not want to be poked and prodded in the last hours of our lives; we would want to have a good, well-supported death.

Training and development are vital, and I welcome the work done by trainee doctors in Liverpool, which my hon. Friend the Member for West Lancashire mentioned. When the hospice movement started, it was rare for doctors to get proper training; indeed, I think they spent about a day on the bedside manner for dealing with a dying patient and speaking to their family. Things have moved on a lot since then, and it is vital that, in the debate about the Liverpool care pathway, we do not throw out the baby with the bathwater. The LCP has done good things, although improvements could probably be made at any point to any such approach. None the less, it is vital that we maintain the approach that dying well is important and should be available to all in every setting.

3.12 pm

Fiona Bruce (Congleton) (Con): I congratulate my hon. Friend the Member for Montgomeryshire (Glyn Davies) not only on securing the debate but on the calm and measured way in which he introduced it—his was exactly the constructive tone in which we should discuss this concerning issue.

Last year, an 83-year-old widower was taken into hospital feeling very unwell. His eldest daughter visited him every day. No particular illness was diagnosed, but he was certainly weak and frail. After a few days, the daughter asked a nurse in the corridor, “How is he today?” Almost casually, the nurse said, “Oh, he’s not very well at all. He has not long to live. We are putting him on the Liverpool care pathway.” There was no discussion, no explanation, no consultation—just an announcement, a statement of fact, almost in passing. The daughter was shocked. As his eldest child, she thought, “Surely there should be more formality, more dignity, more of a clear process.” What gave her particular cause for concern was that her mother had become frail just two or so years earlier—admittedly after a brain tumour operation—and had been put on a regime of limited food and fluids. It had taken her weeks to pass

8 Jan 2013 : Column 46WH

away, which was agonising for her and heart-rending for the members of her family, as they waited and waited for their wife and mother to die. Again, there was no discussion or consultation with the daughter, although perhaps there was with the father. He was an elderly man in his 80s, and he was now lying in bed himself, about to be put on a similar regime.

After her mother died, the daughter felt a terrible guilt. Perhaps it had taken too long for her mother to die. Perhaps the daughter should have asked more questions. Perhaps she should not have let her mother suffer so much. With no medical background, however, she was left rather sad and confused. When the nurse announced that the hospital was putting her father on the Liverpool care pathway, the daughter, knowing a little more about it by this time, immediately contacted her sister, and the next day their father was moved to a nursing home. There, his needs were attended to in a positive and caring way. There, he did not die; in fact, he got better.

Now, well over six months later, that elderly man is very much alive. He is still being cared for. He is eating well, getting up when he wants to and resting when he does not want to get up. He enjoys visits from his family, although he does not enjoy it when his favourite football team loses in the last minute or so of a match, as happened last Saturday. He is listening to tapes of Sadler’s Wells opera company singing Gilbert and Sullivan, and he is joining in with “Songs of Praise”. He is having intelligent and considered discussions about his finances and looking forward to his 85th birthday. It is not a fantastic quality of life, but it is a life, and as he told his doctor in the nursing home, “I want to live.”

Minister, Mr Weir, concerned Members, I know all that is true, because the lady who passed away so distressingly was my mother, and the elderly man I have described is my father. I, their daughter, witnessed all those events first hand. In one sense, I am not sure I need to say much else to support the points that have been made, but the application of the LCP needs to be looked into.

John Glen (Salisbury) (Con): My hon. Friend is making a powerful case, and it is obviously painful for her. Does she agree that there is a distinction between accepting the notion that a

life must end and accepting that there is an inevitable time frame in which that life must end? We must not make premature assumptions about that period, so it is critical that there is a clear understanding of what the Liverpool pathway means and how it can affect the timings of an event we do not know the actual trajectory of.

Fiona Bruce: I thank my hon. Friend for that intelligent comment, and I will talk further about that.

I want to speak now as a vice-chair of the all-party group on dying well and the all-party pro-life group. Despite my personal experiences, I believe the main intent of the Liverpool care pathway is compassionate and good. It is fundamentally aimed at what is increasingly called a good death. When correctly administered, the principles behind it are those of good palliative care, and they are fully in accordance with the view, which I hold, that all life is God-given and should be allowed to run its course, without death being hastened through unnatural intervention.

8 Jan 2013 : Column 47WH

Jim Shannon: I congratulate the hon. Lady on the passionate way in which she has dealt with this issue. Does she agree that it is important that those who work in the Liverpool pathway are highly skilled? If such care is left in the hands of those who are less skilled, there is a possibility that what could be termed voluntary euthanasia will take place. Does she agree that only highly skilled people should be involved in the Liverpool care pathway?

Fiona Bruce: I do, and this is where training is so important. Without the proper application of the Liverpool care pathway, death can be hastened, and that is not the intent of the pathway. Occasionally, even with correct application, it can be the unintended consequence—for example, through the use of narcotics to alleviate severe discomfort and facilitate a more peaceful passing.

I wholeheartedly welcome the Minister's decision to hold an independent public inquiry into the LCP. I have met him, and I thank him for his open-minded, calm and reasoned approach and for the fact that he has had ears to hear concerns about the LCP. Without wishing to prejudge the terms of the inquiry, may I make the following suggestions for it to consider?

First, a number of pressures might subvert the proper implementation of the LCP, and I am grateful to Professor David Albert Jones of Oxford, who is an authority on this topic, for highlighting them. He says they are:

“the subjective character of judgments about how soon someone is going to die...the fact that the LCP may be initiated by people who are not senior clinicians familiar with the individual patient's case and have not consulted with palliative care physicians... the influence of managerial pressures to reduce bed occupancy ...reluctance to face the difficulties of continuing care of certain difficult patients...the euthanasia outlook of some clinicians...the possibility of doctors or nurses regarding the LCP as a set of ‘tick boxes’...rather than assessing the needs of the patient...Other NHS organizational/staffing procedures or constraints”.

He adds:

“Research shows that care of the dying is poorest in the hospital setting”

in contrast to care in hospices, which I believe we all admire.

I also urge that the inquiry consider the following measures: that no patient should be placed on the LCP unless they are imminently, irreversibly and inevitably dying, which I understand to mean perhaps within 36 hours; no one should be placed on the LCP without its being discussed with a designated relative or carer; every patient placed on the LCP must be continuously monitored and reviewed by a multi-disciplinary team; documentation must be simplified and standardised, so that those implementing the LCP can easily follow the guidelines; training and supervision should be mandatory, as well as standardised and improved; non-clinical priorities in the use of the pathway must be eradicated and every patient must be treated solely according to their needs; payment for such care must be reconsidered; and the communication to relatives should be substantially improved.

I believe that, if it is well used, the LCP can improve standards of end-of-life care, especially in hospitals. It should promote better palliative care and support the kind of good death that we would all wish for ourselves and our loved ones. I sincerely hope that the independent inquiry will be a major step in facilitating that.

8 Jan 2013 : Column 48WH

3.20 pm

John Pugh (Southport) (LD): I also congratulate the hon. Member for Montgomeryshire (Glyn Davies) on introducing this important debate in such a measured and sympathetic way. It was effective indeed.

I do not like the term “Liverpool care pathway”; I prefer talking about guidelines for palliative care. That is probably a less contentious way of discussing it. The Liverpool care pathway was developed in Broadgreen, and I was born in Broadgreen. More importantly, my grandmother died there, having been readmitted several times. The last time she was admitted she had declined somewhat at home and I can remember the expression of horror on her face indicating that that was not the right way to treat her. She knew that she was going to die and she wanted to die at home, and she was being admitted unnecessarily to hospital. I regret that we arranged for that to happen. It is very important to get the last years, months and weeks of people’s lives correct and we certainly did not; hence there is a need for things such as the Liverpool care pathway and a more understanding, measured and sensible approach to affairs.

There is a need for the hospice movement, but the reality is that most people do not die in hospices; they die in the NHS and there is a need for the NHS to have some clinical guidelines to follow. That is particularly the case for those in their last hours, day, weeks and months, whose death is imminent and who cannot have that death prevented or, realistically, postponed. That is quite a high threshold to be met, and finance should in no way come into meeting that threshold. When finance does come into it, it can only corrupt the process. The Liverpool care pathway guidelines imply constant review and no one wants that coloured by financial incentives. After all, there is always the remote possibility of people getting the diagnosis wrong.

That is not a case against having guidelines at all or against thinking that we sometimes need to opt for a palliative choice rather than a remedial one, if there is no realistic remedial choice available. If that choice has to be made, there is no in-principle case for involving relatives and the patient in it, with the important caveat that what is done should be in the patient's interest. I am not always sure there is an obligation to clarify the situation for the patient or their relatives, if they prefer to die in hope or expectation of recovery and find the thought of their inevitable demise insupportable, particularly if it will not change clinical behaviour and the only option is palliative care for that person. That is a difficult issue, which every clinician needs to face and be guided on in facing it.

There is certainly a need to inform the patient and/or relatives if expectations about care are starting to differ, or if the nature of the palliative care offered is unclear. That might be the case if a patient is wrongly categorised, or if there is a debate about the palliative care itself, and it is seen as substandard. Some of the episodes of dehydration that have been described in the national newspapers have seemed to me to be substandard palliative care. The bottom line is that palliative care should not worsen the condition or augment the suffering of somebody who inevitably will die, unless the patient chooses it. In certain circumstances, I can imagine somebody trading pain for more life.

8 Jan 2013 : Column 49WH

Care can be worsened in two quite different ways: it can be worsened by disruptive, painful, pointless, futile interventions, and it can equally be worsened by neglect, and indifference to people's symptoms and the manner of their decline. My aunt recently died in the Royal Liverpool, which has taken over Broadgreen. I remember going to her bedside and seeing the signs that said, "Nil by mouth", and wondering whether we should offer her a drink while we sat there and talked. We never managed to get round to having a sensible conversation about that with the medical staff. I was never sure what I was confronted with. It might have been wise care; there may have been a genuine risk of choking, which I believe is one of the reasons why people are not given liquids at that stage. It might just have been neglect or absence of thought. What did not happen—and should have—was a discussion about treatment: a sort of negotiation.

If palliative care is the path chosen—it should only be chosen when it is, in a sense, the only path—there needs to be a negotiation. It is the trick of getting that negotiation right that is the difficult thing. We need to respect the rights of all people concerned, and the patient's rights sometimes differ slightly from the family's rights. The family fearing bereavement can only wish the patient to live at all costs. That may not always be the patient's aspiration in that circumstance. The hon. Member for Montgomeryshire has started us along the path of having a measured discussion and review of these matters and I hope it continues.

Mr David Burrowes (Enfield, Southgate) (Con): I respect what my hon. Friend says on communication with the patient, but I would like to clarify something. A survey by the Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians said that half of those on the LCP are never told that they are on such a pathway. Also, the LCP is not just a framework of good practice but a pathway, taking the patient towards the presumed outcome of death. Surely, therefore, it is important to make it clear that there should be communication with the patient; it should not be only the best half who know.

John Pugh: That in part is the dilemma. I know that the saying is “No treatment about me, without me”, but there are certain circumstances that we will all be aware of where the patient is dying and the clinician is in an acute moral dilemma over whether to inform them that that is the case—that there is no hope and that they will be given purely palliative treatment. I am fairly confident that a good number of people will die in our hospitals for years to come, despite the Liverpool care pathway or any other guidelines that we put in place, who will, until the moment of their decease, expect recovery.

Mr Mike Weir (in the Chair): We have just under 12 minutes left and two speakers to go. I ask that they bear that in mind.

3.28 pm

Mr Edward Leigh (Gainsborough) (Con): I am glad to have this opportunity and I thank my hon. Friend the Member for Montgomeryshire (Glyn Davies) for raising this important subject. We all know that the Liverpool care pathway was devised with the best of intentions. I assure my hon. Friend the Member for Banbury (Sir Tony Baldry) that none of us wants to end

8 Jan 2013 : Column 50WH

or take away palliative care. We all want to relieve pain and we all want people to die with dignity, but there are serious concerns about the Liverpool care pathway and that is why this debate is so important. Those concerns have been expressed by physicians. It was physicians—ethicists—who started this debate, not the newspapers. The newspapers did not start the ball rolling and we should be aware of that. Professor Peter Millard, emeritus professor of geriatrics at the university of London, and Dr Peter Hargreaves, palliative care consultant at St Luke’s cancer centre in Guildford, have warned of the risk of “backdoor euthanasia”—their words—and that economic factors are being included when treatment is considered. We must be aware of these concerns, which were originally expressed by clinicians. However, I believe that it is one of the chief duties of those of us in this House who are not clinicians to speak up in defence of the vulnerable, the voiceless and those who are sometimes forgotten.

It is simply unacceptable that vulnerable people, including the poor, the elderly and those who do not have close friends and family to look after them, come to a premature death—an unnecessarily early death. As my hon. Friend the Member for Congleton (Fiona Bruce) and others have said, in numerous cases, even friends and family caring for a loved one have not been informed that they have been put on the LCP. May I say that my hon. Friend’s speech was a wonderful speech? It drew on her personal experience and was one of the most moving speeches that I have heard in this place over many years.

I sat with my best friend, Piers Merchant, as he was dying; he was a former MP and my hon. Friend the Member for Banbury (Sir Tony Baldry) will remember him well. I saw the morphine being pumped through his body. I am sure that he died early—perhaps a few hours or even a few days early, I do not know—from the morphine. Those of us who loved him wanted him to be cared for properly, but we also did not want him, or any of our loved ones, to be put on an irreversible path to death where that was avoidable.

I welcome the statement by the Department of Health that it

“has consistently made clear that care provision, including for people at the end of life, should be based on need.”

But the question that we need to ask in this debate is this: how are the Department’s intentions implemented on the front line of medicine and hospital care? No doubt there is wonderful care being given in many hospices, but is that gold standard being replicated in all our hospitals?

It is undoubtedly true that the LCP has led to the premature death—it may not be premature by much, but it is still a premature death—of as many as 130,000 hospital patients each year. This is a vital issue that we must address in this House; with 450,000 hospital deaths in Britain each year, that figure of 130,000 is about 29% of the total number of hospital deaths. In fact, this is a frightfully serious issue.

Robert Flello: Will the hon. Gentleman give way?

Mr Leigh: Does the hon. Gentleman mind if I do not give way? I just want to make my speech and give my hon. Friend the Member for Plymouth, Sutton and Devonport (Oliver Colvile) a chance to speak too.

8 Jan 2013 : Column 51WH

Professor Pullicino, who was quoted earlier, has himself personally intervened to have a patient taken off the LCP who went on to be successfully treated. So, despite the fact that we must listen to clinicians, it is simply impossible to determine satisfactorily that a patient has hours or days left to live, which is one of the worrying flaws of the LCP.

In November, an independent inquiry into the LCP was announced, and I welcome that announcement. My hon. Friend the Minister is doing his job extremely well in this regard, and we respect him as somebody who will genuinely try to get to the truth. He himself has said that there have been too many cases of patients dying on the pathway while their families were not informed, so he is quite right to zero in on that issue. He has said, “This is simply unacceptable.” I echo those words and I hope that he will repeat them when he winds up the debate.

Of course there are people who speak on both sides of this issue, but I believe that any inquiry must be conducted by a suitable variety of individuals and not just by supporters of the LCP. It is not good enough to state, as the Department of Health sometimes does, that the LCP is not euthanasia. It might not be euthanasia and, of course, if it is implemented properly it is not euthanasia. However, it has become obvious to many people that the LCP can be employed, and indeed has been employed, in cases that are highly questionable.

I say to those who have spoken today that what worries me is this: why is it that the average time to death on the LCP is 33 hours? An identical figure for average time to death was found in two consecutive national audits that were conducted two years apart. In the view of many people, that shows that the LCP has a machine-like efficiency in producing death within 33 hours, and that is why some people say that the LCP is in effect a “lethal care pathway”. Statistics suggest that fewer than 5% of patients put on the LCP are taken off it. Why only 5%? There is something wrong here, and the inquiry needs to get to the bottom of it.

I believe that we should appoint a member of the judiciary rather than a medical expert, to carry out the inquiry. Of course, they will have medical advisers, but we should appoint a member of the judiciary rather than just a medical expert to lead the inquiry, so that they can look at this complicated issue with a fresh perspective and a judicial mind.

Thank you for calling me to speak, Mr Weir. In conclusion, I believe that we have a duty to instil confidence in each of the citizens and residents of this country that they live in a society that believes in their inviolable dignity as human beings, and that takes the necessary steps to ensure that they are cared for and looked after when they are ill, especially in the closing moments of their life.

3.35 pm

Oliver Colvile (Plymouth, Sutton and Devonport) (Con): Thank you very much indeed, Mr Weir, for calling me to speak. It is a pleasure to serve under you.

I congratulate my hon. Friend the Member for Montgomeryshire (Glyn Davies) on securing this important debate. I suspect that I am not particularly well qualified

8 Jan 2013 : Column 52WH

to speak about the Liverpool care pathway, but neither are an awful lot of my constituents. Therefore, it is very important that what we talk about today is how we can look after their interests, and the interests of others, in this regard.

I am very aware of what kind of death I want to end up having. Some six years ago, my father died while driving his car. He came out of his office, at the age of 89, to go and have lunch with the Archdeacon of Canterbury. My father had a massive heart attack, pulled over to the side of the road—thank goodness he did not take anyone with him—and duly died. It was just yards away from the church and I know very well that God decided, probably in his infinite wisdom, that the one thing that he was not going to do was allow my father, a former naval commander, to give the archdeacon a difficult time. However, I am very aware that—frankly—an awful lot of us do not have that kind of option about how we end up dying, if we have an option at all. Many people find themselves having to go into hospital, and dying there.

Many of us have a great deal of notice about dying. So, in the next few minutes, I want to talk about an individual constituency case that I had—an appalling story about the death of the father of one of my constituents in the Derriford hospital in Plymouth. In doing so, I want to ensure that the public are aware of the controversial approach to ending life and that we have a discussion about it.

My constituent's father went to Derriford hospital from Mount Gould hospital, which is also in Plymouth, in April 2011 because he had become bedridden. He was put on the Liverpool care pathway without any food and water. That was supposed to last for up to two days, but he lived for 12 more days, finally dying on 8 May 2011. My constituent claims that during the time that her father was on the LCP, he perked up and was even watching television. Despite that, he remained on the LCP.

My constituent's family feel, and I rather agree with them, that giving someone 12 days to die is not what this system should be about. Although Derriford hospital claims that staff spoke to the family on the ward, my constituent and her siblings dispute that. They claim that they did not know that their father was on the LCP until the car park attendant told them.

To give Derriford hospital its due, the chief executive—who is new to the job and was not at the hospital when this case happened—has dealt with the case subsequently, recognising that the clinical teams may not have explained fully to my constituent's family what was going to happen and what was actually involved in the LCP. The family feel that they were forced to watch their father die under very distressing circumstances. Despite having his food, water and medication withdrawn, the family were horrified to see him biting the sponge that was being used to wipe his lips, because he was so hungry and thirsty.

Unfortunately, my constituent has also had a subsequent —and completely different— experience of the LCP when her brother-in-law died at a hospice. It must be remembered that hospice staff are specialists in helping patients at the end of their lives, and the more that we can encourage people who are suffering in that situation to be dealt with by hospices, the better. Certainly a lot

8 Jan 2013 : Column 53WH

of hospitals are very busy indeed and their staff do not necessarily have the time to carry out the kind of checking that we feel they should do.

I am very aware that the death of a close relative is a traumatic time. One should remember that patients' relatives do not always take in the full story that they are being told and that they can become confused about what they are being told. However, we must ensure that a system is in place that avoids those kind of complications.

I am very aware that the Government are taking this whole matter very seriously and I am grateful to them for that. I thank my hon. Friend the Minister and his colleagues for the review, about which he wrote to me just today, and their proposal to produce a new pledge on care planning. To help my constituent, and many other people like her, we need to ensure that we have a timetable for that.

I pay tribute to bereavement charities, such as Cruse Bereavement Care. They do an enormously good job in helping families through the whole grieving process. I ask for more training, and for more information for families so that they can be assured that their relatives will get the best care possible. By giving detail to the Government's proposals, the Minister would be giving certainty to Benjamin Franklin. Members might remember that he wrote, in a letter to Jean-Baptiste Le Roy in 1789, that the only things we can be certain of are birth, death and taxes.

3.40 pm

Liz Kendall (Leicester West) (Lab): It is a pleasure to serve under your chairmanship, Mr Weir. I congratulate the hon. Member for Montgomeryshire (Glyn Davies) on securing this extremely important debate and on his heartfelt but calm and thoughtful opening speech, which set exactly the right tone. How we care for the dying is a measure of how we care for

all sick and vulnerable people. It is a litmus test not only for the NHS and the wider care system but for society as whole.

This debate comes at an important time because, as the hon. Member for Montgomeryshire said, in recent months growing media attention has been paid to the Liverpool care pathway. Several Members have talked about the misconceptions and the inaccurate information that has been published about it. I have read the recent consensus statement from 22 patient and professional organisations and also the full care pathway documentation, and it is clear to me that the Liverpool care pathway is not in any way about ending someone's life but about supporting the delivery of excellent end-of-life care.

The pathway does not seek to replace clinical judgment; it is not a treatment but a framework for good practice. It does not seek to hasten or indeed delay death, but to ensure that the right type of care is available for people in the last days or hours of life, when all the reversible possibilities for their condition have been considered. I do not believe that it is a deadly or lethal one-way street. Precisely because it is not always easy to tell whether someone is very close to death, the pathway emphasises the need for constant and regular review, and if a patient's prognosis changes, their care needs should be reassessed and, if appropriate, the use of the pathway stopped.

The pathway does not preclude the use of clinically assisted nutrition or hydration; in fact, it explicitly states that patients will be supported to eat and drink

8 Jan 2013 : Column 54WH

for as long as possible. It absolutely emphasises that wherever possible patients must be involved in decisions about their care, and that carers and families should always be included in decision making. Such involvement of patients and families is enshrined at the very heart of the Liverpool care pathway.

Robert Flello: Does my hon. Friend agree that if there is no consultation, and there is denial of care and of treatment that eases pain, it is not the Liverpool care pathway?

Liz Kendall: I absolutely agree. The issue we face is less about the pathway itself and absolutely about how it is implemented in practice. The pathway document states on its very first page that the pathway is only as good as the teams who use it.

There has clearly been an issue about taking a pathway that was developed by experts in one part of the country over several years, with regular training and audit, and trying to implement it across the wider NHS. Individual patients and families—as we have heard—and also the national audit of the Liverpool care pathway, suggest that there are genuine problems with communication. Too many patients and families are not properly informed about what the pathway is and how it works, and they are not effectively involved and their consent not sought at every stage and on all the necessary decisions. One incident in which patients and families are not fully and sensitively involved is one too many. It is not acceptable, and it directly contradicts the very essence of the Liverpool care pathway and its key principles and values.

Rosie Cooper: Will my hon. Friend give way?

Liz Kendall: If my hon. Friend does not mind, I will not give way as I do not have much time.

I welcome the fact that the issues are now being looked into. I understand that three separate reviews are being undertaken. The national end-of-life care programme is doing a short, snapshot review of complaints about the use of the Liverpool care pathway, the Dying Matters coalition is working with families whose loved ones have been on the pathway, to see what worked well and what did not, and the Association for Palliative Medicine and a range of other national organisations are talking to clinicians, to get their opinions regarding integrated care pathways in the last days of life, of which the Liverpool care pathway is one.

In November, the Minister said he would appoint an independent chair to co-ordinate the work of the different reviews, so I ask him: has a chair now been appointed? Will the chair, the Department of Health or any other organisations consider any additional issues, alongside the work that is under way? For example, will the way in which the Liverpool care pathway is paid for be reviewed? It is important that hospitals receive proper payment for the care they give and for any associated training, but any evidence that patients are being put on a pathway for financial reasons is a serious matter and is totally unacceptable.

Will there also be a review of the education and training in end-of-life care for new and existing staff, in particular training in how to discuss difficult, complex and emotional issues with patients and their families? One of the real challenges is that the process of death

8 Jan 2013 : Column 55WH

and dying is so uncertain. A patient's prognosis is not always clear; the situation changes. Doctors are used to treating and curing, giving clear evidence, treatment and advice—or they are trained to do so—but it is not always possible.

I want to finish on a broader point, which is important for us in this House. The difficulty that NHS and care staff, the media, families and the public have in discussing end-of-life care reflects wider society's lack of familiarity with death and dying, which was not the case 100 years ago. Age, cause and place of death are generally very different now from what they were at the beginning of the last century, when a far greater proportion of deaths occurred in childhood or early adult life, often from acute infections, with most people dying at home. Now, more than two thirds of the 500,000 deaths a year are among people aged over 75, most of them following a long-term illness such as heart disease, cancer, stroke, chronic respiratory disease or dementia, and most are in hospitals and care homes.

Many people do not, therefore, experience the death of a loved one until they are well into mid-life. We do not see dying people and dead bodies—not for real. We see them on television and in computer games but not in real life, and we do not talk openly in society about death. I know that in all our families it is difficult to discuss death, but in the century of the ageing society, with chronic conditions as the major cause of death and disease, that must change.

As the hon. Member for Banbury (Sir Tony Baldry) said, death comes to us all, and we should strive for as good a death as possible. That will, of course, mean different things to different people—I would like to go quickly, and I hope that the people I love go quickly, too, and do not have a long, slow death.

Rosie Cooper: We will not be bumped off.

Liz Kendall: Indeed, or have a premature death. For many of us, a good death means being treated as an individual with dignity and respect, without pain and suffering wherever possible, and in a familiar environment surrounded by the people we love. We need a full and frank debate about these difficult issues, handled calmly and sensitively and based on evidence and fact rather than on myths and misconceptions. Dying matters, not just to the NHS and the wider care system but to us all, and for that reason I am grateful to the hon. Member for Montgomeryshire for securing the debate.

3.48 pm

The Minister of State, Department of Health (Norman Lamb): I do not have a Parliamentary Private Secretary sitting behind me, and I am most grateful therefore to you, Mr Weir, for your assistance with some Members' constituencies.

I congratulate the hon. Member for Montgomeryshire (Glyn Davies) on securing the debate, and on the sober, serious and rational tone he deployed in his contribution. The whole debate, in fact, has been exemplary in that regard. I suspect that all of us in this room are after the same thing; it is how we secure it that matters so much. I have just over 11 minutes, which is not really enough to

8 Jan 2013 : Column 56WH

do justice to every contribution, so as soon as I possibly can, I will write to all the Members who have taken part, to update them.

I take the Liverpool care pathway extremely seriously. It has been much discussed recently: many hon. Members and members of the public have written to the Department of Health expressing their concerns, and there have been numerous parliamentary questions, too, all of which stems from a lot of media interest over the past few months. Several stories have appeared discussing the ways in which the LCP is used and what it is for. In particular, there have been a number of reports in the media alleging that patients are being placed on the LCP secretly, with no consultation with them or their relatives. It has been suggested that the LCP routinely involves medical staff withdrawing treatment, including food and fluids, from patients. Perhaps most seriously, the LCP has been accused of being a way to kill patients to save the NHS money. There have been suggestions that the Department of Health bribes hospitals with extra money for every patient placed on the pathway.

Those accusations paint a misleading picture of the purpose of the Liverpool care pathway, yet I take seriously the concerns raised by the families of patients who have experienced extremely poor end-of-life care. I am horrified by some of the stories that people have told me about the withdrawal of food and fluids from sick relatives in hospital and about the failure to inform loved ones that the patient has been placed on the pathway.

The hon. Member for Congleton (Fiona Bruce) spoke movingly of her experience, and I am pleased that she came to the round table that I held to discuss those concerns. As the hon. Member for Gainsborough (Mr Leigh) made clear, the concerns are legitimate and should be taken seriously, not dismissed because of exaggerated reporting. What happens on the front line and how we translate theory into practice are so important.

I agree with my hon. Friend the Member for Southport (John Pugh). I dislike the jargon: what on earth does “Liverpool care pathway” mean to patients and their families? We must use language that ordinary people understand, particularly at a most traumatic time for all involved. That is one thing we need to address.

One aspect of care that receives almost universal praise, as the hon. Members for Banbury (Sir Tony Baldry) and for Hackney South and Shoreditch (Meg Hillier) have made clear, is the hospice movement, which grew from Dame Cicely Saunders’s belief that, however ill, people matter at the end of their life and should never be abandoned. That is why the Marie Curie Palliative Care Institute Liverpool, led by Professor John Ellershaw, developed the Liverpool care pathway in the late 1990s. The pathway was designed to transfer the principles of hospice care—the shadow Minister, the hon. Member for Leicester West (Liz Kendall), made this point—so that terminally ill patients always get the best treatment, even if they do not receive specialist palliative care.

The Liverpool care pathway is not a treatment but a framework for managing treatments, which is important to understand. As the hon. Member for Montgomeryshire made clear, the LCP, when used correctly, is one way to ensure that the last hours or days of a patient’s life are as comfortable as possible. The guidance for using the LCP makes it clear that the aim is to support, not

8 Jan 2013 : Column 57WH

replace, clinical judgment. Sometimes there are questions about clinical judgment, but not about the pathway itself.

The Liverpool care pathway guidance sets out the following objectives and considerations for taking care of patients: determining whether any further medications and tests would be helpful; ensuring that the patient is as comfortable as possible—surely we all agree with that; helping the patient to take on food and drink for as long as possible, which means not denying them food and drink, as we sometimes hear; and taking care of the patient’s spiritual and religious needs, which is of acute importance to many people. The guidance reminds clinicians that unnecessary treatment or tests may cause harm rather than good.

The guidance states that regular review is acutely important. If their condition improves, the patient should be taken off the pathway. The 5% figure to which the hon. Member for Gainsborough referred is of concern and should be considered; it is essential that the medical team discusses the pathway with the patient, their family or their carers. Those people need to be fully involved in decisions about end-of-life care, even though those discussions may be very difficult. Obviously, those conversations need to happen as quickly as possible.

The Liverpool care pathway can work as intended only if each patient is fully consulted, unless that is not possible. Even then, the family must be fully involved. Through his interventions, the hon. Member for Stoke-on-Trent South (Robert Flello) made that point strongly. The opening section of the information sheet that comes with the pathway cites the absolute importance of discussion with the family. Staff must talk to the patient and their family as much as they need and want, to explain what is happening and why. That is non-negotiable. Any failure to do so is completely unacceptable.

The hon. Member for West Lancashire (Rosie Cooper) mentioned documentation, which is best practice and should always happen so that everyone can see what has been discussed. She also mentioned the constitution, and we are considering how we can give it greater traction. There is a sense that everyone agrees with the constitution, but what value is it? How can we make the constitution provide real power to patients in the NHS?

I agree with the shadow Minister's concerns about translating across the whole system something that has been designed by experts. Such translation can be problematic and needs further attention.

Rosie Cooper*rose—*

Norman Lamb: I am conscious that time is tight. I will write to the hon. Lady. If she wants to raise issues with me later, I will be happy to address them, but I need to respond to the debate.

From what people have said, it is clear that there are too many cases where patients have been put on the pathway without proper explanation, without the

8 Jan 2013 : Column 58WH

involvement of their family and sometimes without any notification, which is totally unacceptable. Yet again, we see how right Dame Cicely Saunders was when she said:

“How people die remains in the memory of those who live on”.

The impact is profound. My wife works for Cruse Bereavement Care, which does magnificent work helping people who have suffered bereavement. We have a duty to give such people the best possible experience as they lose a loved one.

On 26 November, I hosted a round-table meeting with patients, families and professionals—both supporters and critics of the pathway were represented—and at that meeting I announced that we will appoint an independent chair to consider how the LCP is used and experienced and to examine the accusations made in the press. We expect to announce the chair of that review very soon, and we expect that the chair will want to identify a small panel of independent experts from a range of backgrounds, including representatives from faith groups, which is important. I reassure hon. Members that the review will be independent.

The Liverpool care pathway is internationally recognised as good practice, and it is widely supported by organisations involved in end-of-life care. If people do not feel that they have received the best care or, worse, if patients cease to trust the pathway, that is a problem that needs to be addressed.

Training is fundamental, as the hon. Members for Hackney South and Shoreditch and for Congleton and the shadow Minister said, and it will be considered as part of the review. The review will systematically examine the experience of the Liverpool care pathway by patients, families and health professionals, and it will seek evidence to support or refute the accusations and to see where improvements might be needed. The review will hear directly from families. There will be a session dedicated to families so that they can tell the panel about their experiences.

The review will also consider the role of financial incentives in the use of the LCP. Like my hon. Friend the Member for Southport, the hon. Member for West Lancashire and others, I have concerns about the use of financial incentives. The review will report both to the Department of Health and to the NHS Commissioning Board by the summer.

Everyone wants their loved ones' final hours to be as pain-free and dignified as possible. Used as intended, the Liverpool care pathway can help achieve that. The pathway prioritises comfort, dignity and appropriate care, but all that is undermined if the public distrust the pathway and if clinicians do not apply it properly. We do not dismiss people's concerns, which I take extremely seriously. Instead, we have to ensure that care in the last few days and hours of life is always of the highest standard. Reinforcing the absolute importance of involving patients and their families in discussions on their care and treatment is essential.

8 Jan 2013 : Column 59WH