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Access to Palliative Care Bill [HL]
Second Reading613

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DUP	Democratic Unionist Party
GP	Green Party
Ind Lab	Independent Labour
Ind LD	Independent Liberal Democrat
Ind SD	Independent Social Democrat
Ind UU	Independent Ulster Unionist
Lab	Labour
Lab Co-op	Labour and Co-operative Party
LD	Liberal Democrat
LD Ind	Liberal Democrat Independent
Non-afl	Non-affiliated
PC	Plaid Cymru
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House of Lords

Friday 14 June 2019

10 am

Prayers—read by the Lord Bishop of Coventry.

Access to Palliative Care Bill [HL] Second Reading

10.06 am

Moved by **Baroness Finlay of Llandaff**

That the Bill be now read a second time.

Baroness Finlay of Llandaff (CB): My Lords, I declare my interests as listed in the register.

There are two certainties about life: we are all born and we all die. Everything else in between is variable. No one would countenance having areas in England with no maternity services, or only rudimentary midwifery without access to NHS obstetric care in the event of a complication, so why do we leave end-of-life care in some areas to services provided only through the voluntary sector, supported by fundraising and donations? Currently, around 470,000 people of all ages die each year in England; about three-quarters of them will not have a sudden death. These people of all ages—from babies right up to people over 100—need care with a palliative approach.

Let me explain what general care with a palliative approach is and what specialist palliative care is, and why we need both. It is the same as with other disciplines. For example, your GP manages your diabetes, but if it is complex or difficult to control, you see a specialist—a diabetologist. Palliative care is defined in the Bill as,

“care which is delivered to seek to improve the quality of life of persons with life-limiting illness or approaching the end of life, through the prevention and relief of suffering by means of early identification, assessment, treatment and management of pain and other problems whether physical, psychological, social or spiritual”.

In most cases, as a matter of routine, palliative care should be within the competences of clinicians generally, provided that they have had training in the fundamentals of such care. For many, a palliative approach is needed from diagnosis, even though death may be a long way off.

However, some people have complex problems. Crises suddenly arise and emergencies occur, meaning that they need more than their clinical team can offer. These people need specialist palliative care from doctors, nurses and allied health professionals with specialist training. Specialist services also drive up standards through teaching, being involved in research and providing other clinicians with advice. The courses that I set up from Cardiff have educated thousands of doctors around the world; they have also been replicated at universities in Europe and beyond, such as Australia and North America.

Palliative care runs alongside efforts to control disease. It addresses distress, pain and suffering. It is not a case of either treatment or palliative care; it is about balanced decision-making for patients. With early palliative care, patients live better and longer at no additional cost

overall. Specialist services can now reach hard-to-reach groups, such as prisoners and the homeless, which were previously out of sight and out of mind. If these specialist services are not in place and available, you cannot be referred to them in a crisis and your clinicians cannot get advice on what to do.

It has been heartening to see such widespread support for my Bill from those providing palliative and end-of-life care, from other clinical services and from patients and relatives. They are all too aware of the current gaps in provision. Sadly, an estimated 92,000 people each year in England would benefit from palliative care but do not receive any at all, either from specialist palliative care professionals or generalists. The family suffers too: 83% of carers—around 400,000 people per year—suffer significant psychological morbidity. Some of them are child carers. Cicely Saunders, the founder of the modern palliative care movement, said that the way a person dies lives on in the memory of those left behind. When a child is not adequately prepared for loss and sees clinical services fail to respond because they are not available seven days a week, their trauma is compounded.

In May 2015, the Parliamentary and Health Service Ombudsman’s thematic report found six themes in failings in England, including,

“Not recognising that people are dying, and not responding to their needs ... Poor symptom control ... Poor communication ... Inadequate out-of-hours service ... Poor care planning ... Delays in diagnosis and referrals for treatment”.

Last year, I published the results of a freedom of information request to all 209 clinical commissioning groups about their contracting, in particular for specialist palliative care. Only 29 stated the number of their patients with some level of palliative care needs. Some 163 CCGs commissioned seven-day admission to specialist palliative care beds, but the beds per head of population varied greatly. Some 83% commissioned seven-day specialist palliative care services in patients’ homes where out-of-hours services relied heavily on third sector hospice provision. The budgets for specialist palliative care ranged from £52 to £2,330 per patient per annum, but they correlated poorly with the clinical commissioning groups’ reported needs, a variation that could not be accounted for by differing demography or geography.

In 2019, the *National Audit of Care at the End of Life* similarly found that only 47% of hospitals have commissioned services to provide face-to-face seven-day palliative care. Less than half include end-of-life training in staff induction, and only 55% of relatives in the audit felt that staff communicated sensitively. Variations are evident by diagnosis, with cancer patients more likely to access any level of palliative care and inequities overall adversely affecting those of black, Asian and minority ethnic backgrounds. Older people, despite multiple co-morbidities, often have less access to palliative care. Those in more deprived areas are more likely to die in hospital and less likely to die in a hospice, even though the national trend is for more people to die at home, in a care home or in a hospice; that is, a shift away from hospital. In London, care home deaths are low, and more people have three or more emergency admissions in the last 90 days of life. These variations are laid out in Public Health England’s *NHS Atlas of Variation for Palliative and End of Life Care in England*.

[BARONESS FINLAY OF LLANDAFF]

The atlas aims to reduce unwarranted variation and to improve health outcomes and value, but are the commissioners listening?

These inequities do not make economic sense, quite apart from being just plain wrong. Care aligned with patients' wishes could potentially shift 10% of these hospital deaths—in line with patients' wishes, and I stress that—freeing up around £75 million-worth of services for those who could benefit from hospital care. We know that our hospital system is breaking under the current strains. This type of cost saving from better palliative care with better access to pain relief has been reported on internationally by the Lancet commission in *Alleviating the Access Abyss in Palliative Care and Pain Relief—An Imperative of Universal Health Coverage*. The report clearly demonstrates that palliative care is an essential component of any comprehensive healthcare system.

Where people are cared for and die is influenced by local options. Good-quality community-based palliative care increases the chance of death at home, but that is not always possible or desirable, so appropriate and high-quality palliative care must be available in all settings. In Wales in 2008, a report led by Viv Sugar set out a national strategy. It required fair access to specialist palliative care. Its aim for 24/7 services everywhere was not affordable, so we settled for seven-day specialist services with 24/7 advice available to any healthcare or social care professional across Wales. This was underpinned by a simple funding formula that was developed with the support of the noble Lord, Lord Wigley. It distributed new funding of just over £2 per head of population. I do not claim that everything in Wales is perfect, but the improvements that we achieved have stood the test of time. This process led to my previous Access to Palliative Care Bills.

However, I have listened to the Government's comments. This shorter Bill respects England's different format for the NHS. It respects the autonomy of CCGs in decision-making. It only requires CCGs to publish a strategy covering the expected needs of adults and children in its area, how they will be met and the specialist services to be provided, with data collected to monitor progress. All the other details that were previously included in my other Bills can easily be put into guidance or a code of practice. This Bill provides the legislative framework required to ensure that recent government initiatives such as the Marie Curie "Daffodil Standards" for general practice and the *Ambitions for Palliative and End of Life Care* framework, established through a coalition of a vast number of providers in England, are met. They require each person to be seen as an individual. Each person gets fair access to care and their comfort and well-being are maximised; care is co-ordinated, all staff are prepared to care and each community is prepared to help. The concept of compassionate communities, programmes with volunteers and many hospice outreach service contributes, but the core clinical services must be commissioned to meet need, working across administrative boundaries.

The CCG strategy should cover community, hospital and hospice with in-reach to nursing homes, prisons and other places of care. The specialist palliative care

team needs to become involved early in order to work to relieve pain and suffering, supporting and working alongside other clinical services as well as providing care for those with complex needs. CCGs should commission services on a seven-day basis, because disease does not respect the clock or the calendar.

I hope that the Government will come to see that this Bill would help to deliver better care tailored to those in need. We know what to do; we are just not doing it for everyone who could benefit. The Bill would enable the realisation of the *NHS Long Term Plan*, which states:

"With patients, families, local authorities and our voluntary sector partners at both a national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care".

I beg to move.

10.19 am

Viscount Bridgeman (Con): My Lords, I congratulate the noble Baroness, Lady Finlay, on her magnificent overview of the background to the Bill and on her patience in waiting for an opportunity for it to be read.

For some years I was the chairman of an independent hospital which, unusually, contains a hospice within its property and is part of the same charity. I had conversations with the current director of the hospice and he is totally behind the Bill, effectively, to close the wide disparity of the attention given by different CCGs across England in the resources they allocate to ensuring that palliative care is available to patients 24/7. It was interesting to hear the noble Baroness's example of the Welsh experience, from which we can learn.

Well-organised palliative care services not only give comfort to patients who need it but represent a saving to the NHS by reducing the expense of unplanned admissions. Furthermore, the well-structured arrangements make it easier for experienced palliative care doctors—of which there is certainly not a surplus—to give valuable training to their generalist colleagues. The noble Baroness has given the advantages of those pacts in rather greater detail.

Turning to the provisions of the Bill, Clause 1 provides a general statement of intent and is a useful link to previous discussions in this House and elsewhere. However, by itself, it has limited teeth and a former CCG commissioner tells me that the task is often given to a junior member of the staff to satisfy the department of the CCG's good intentions without the CCG feeling it necessary to do much about it.

However, Clause 2 is the valuable core of this short Bill as it imposes on all CCGs the obligations to prepare and publish a strategy on providing for palliative needs, identifying the needs of adults and children and how those needs will be met, and the circumstances in which palliative care services apply. It will, I hope, ensure that all patients throughout England will be assured of well-established palliative care provisions.

On the position of the Government, their reaction to the 2015-16 Bill was disappointing. The then Minister's view was that palliative care was,

"best tackled by clinicians, ideally together with patients, carers and loved ones".—[*Official Report*, 23/10/15; col. 942.]

I agree, provided the patient is within the responsibility of a CCG that has well set up palliative care facilities. However, if the patient is in the area of a CCG that is not well organised, the answer, I fear, is, “Well, tough”. That is not good enough.

Sadly, it appears that the Government’s position has not changed. In a Written Answer in another place on 14 May 2019, my honourable friend Caroline Dinéage stated at reply No. 252553 that,

“the funding and commissioning of palliative and end of life care is a local matter, over which individual National Health Services commissioners have responsibility”.

That is all fine, but the sad fact remains that the service across England is, in the words of the noble Baroness, Lady Finlay, “patchy”. That is why Clause 2 is urgently needed.

I welcome the noble Baroness’s initiative. I hope the Bill has swift passage through your Lordships’ House and that the Secretary of State for Health and Social Care, whoever he or she may be, will take on board the need for, in effect, an England-wide level playing field in the provision of palliative care.

10.24 am

Baroness Brinton (LD): My Lords, I echo the congratulations to the noble Baroness on her Private Member’s Bill, which takes us considerably further forward than the debate we have had over the past two to three years—indeed, for much longer. For far too long, patients across England have been victims of a system of palliative care that lacks not only consistency but the resources to help them.

Currently there is no method of accountability to ensure that CCGs are able to serve patients to the best of their ability. The situation is begging for a catalyst that will both empower CCGs and hold them to account for the work that they do. I echo the points of the noble Viscount, Lord Bridgeman, about the CCGs giving junior staff the responsibility for demonstrating that they have achieved the service level. I will give some illustrations later.

The standard of variation between the lowest budgets allocated for some patients by CCGs and the highest is quite extraordinary. No patient deserves to receive care so lacking that it is not palliative care at all. As the noble Baroness, Lady Finlay, said, we all have experience of comparing and contrasting. I had experience of two people who died at almost the same time. One had a brilliant palliative care service, working well with the hospital, the community and the county council adult social services—and, indeed, as this was a young mother, with the psychiatric support required for her children who were about to become, and then became, orphaned. In the second case, the patient was stuck in a hospital which refused to say that they were at the point at which they needed palliative care at a hospice. When that moment was recognised, the hospital said that they were too ill to be moved. This blocked a hospital bed for two weeks when the most appropriate care for the patient would have been elsewhere, as well as costing the district hospital. That was about training—both previous speakers have mentioned training and support—and it is absolutely vital that there is training throughout the system.

I appreciate that the noble Baroness, Lady Finlay, has tried to reduce the scope of the Bill, perhaps to gain support from the Government, but I am concerned that the latest version does not include the duty of clinical commissioning groups to provide patients with support to meet their preferences in care, which was in a previous version of the Bill, and support on advance decisions to refuse treatment under Section 24 of the Mental Capacity Act 2005. It would be useful to know why this has been removed. We know from recent cases that advance decisions are still poorly understood and inconsistently implemented—sometimes with tragic consequences—leading to that poor death to which the noble Baroness referred.

For most of my time I want to focus on access to palliative care for babies and children. This is an area in which I have worked for some time and I am grateful to the briefing from Together for Short Lives and for the work of the All-Party Parliamentary Group for Children Who Need Palliative Care and its excellent report. I am a member of that APPG but I did not take part in the inquiry.

This particular group seem at the moment, across the country, to be facing the most appalling cuts to services—partly, I suspect, because CCGs strapped for cash are trying to use the argument that this is not palliative care but social care. I know this from my own experience in south-west Hertfordshire, where we fought for two years to keep Nascot Lawn open for children. It was run by the local NHS, with support from the county council, and the parents won two judicial reviews against the CCG, which was not following procedure. The CCG then basically did a deal with the county and closed it down before any alternative provision was ready. Eighteen months on, one parent has still not had a respite weekend because there is no provision appropriate enough for her severely ill child.

That is the consequence of the postcode lottery. This is not a minor difference in care, and until CCGs are fully held accountable for the services they offer, and as long as they can hide behind not having the money to do it, we do not have a palliative care service commissioned by CCGs fairly across the country.

Together for Short Lives points to five areas in England where children currently face real difficulties. The first is access to palliative care out of hours and at weekends. That has already been highlighted as a general problem, but for children’s services—where limited beds, support and community nurses are available—this can turn into a real crisis. Many parents have told me that the only resource they have is to take their child to A&E, where they frequently know more about their child’s very complex condition than the A&E staff and the community nurses who have been on the end of a phone line during office hours.

Secondly, access to short breaks and respite care is a dreadful problem at the moment. We are not talking about parents having a nice weekend away but about them getting perhaps two nights a month when they are not on 24-hour duty looking after their children, getting up six, eight or 10 times a night when alarms go off, tubes get caught up or there are other issues. This is critical. In the case of Nascot Lawn, one set of parents decided they could not manage without that care,

[BARONESS BRINTON]

and as a result that child is now has full-time support from the NHS, costing considerably more than the respite care that was available in the past. This sort of scandal needs to be addressed, and it comes squarely back to CCGs and funding issues.

These children also need age-appropriate palliative care and a smooth transition into adult services. We talk about this all the time on general health issues, but for these children, many of whom may not reach adulthood for long, there is an enormous difference in service. They also require level 4 consultant support. My noble friend Lady Finlay talked about the importance of having the right specialist support. These children's conditions are often so complex that they need fast access to that support, and at the moment, it is often not there.

Finally, just as much as adults, these children and their families need access to advanced care planning, which brings me full circle, back to my comment at the start. I look forward to hearing from the noble Baroness why that has been removed. My concern is that having something like that only in the code of practice is not good enough. Even statutory guidance is slightly dicey. It probably ought to be in the Bill. Children and adults in their final days of life should not be victims of poor management decisions by financiers and of lack of communication. The Bill comes at a very appropriate time: the conditions many people are facing are dire. Patients and their families cannot be faced with misunderstanding and having to fight their way through a maze of extraordinary decisions about what is social care and what is palliative care and whether it is provided by Marie Curie or a helper coming to the home. The Bill maps out a way forward. The Welsh example is excellent and needs to be followed. Even with the reduction in cash, the excellence of the Welsh example lies in the fact that agencies started to work together. I have talked to families who have experienced that in Wales, and they have seen an enormous difference.

10.32 am

Baroness Hollins (CB): My Lords, I draw attention to my interests as set out in the register. I applaud my noble friend's persistence in introducing this very important Bill. I am particularly pleased to see Clause 1(b), which recognises the need for psychological support for the person and their relatives.

According to Hospice UK, most hospices face cost pressures and their efforts to improve and extend access to palliative and end-of-life care to meet unmet need will be achieved only if local health and social care decision-makers play their part. If only death could be funded the NHS on the same basis as birth. I suspect that one of the reasons that it is not is because we do not talk about death in our society in an informed way. We need much better and wider education about death so that healthcare staff and relatives are not afraid to raise the subject and that death is something that people think and talk about prior to its impending arrival.

Marie Curie, the charity providing expert care and support for people living with a terminal illness and their families, has highlighted that each year in the UK as many as 150,000 terminally ill people do not

receive adequate care and support at the end of life. I encourage noble Lords to come to listen to Irene Tuffrey-Wijne, the world's first professor in learning disability and palliative care, deliver the Marie Curie lecture in the House of Lords next Wednesday. I declare an interest as Professor Tuffrey-Wijne is a former PhD student of mine. She will be looking at the challenges faced at the end of their lives by people with learning disabilities. There are many reasons why access to high-quality palliative care may not be available, but the reasons are compounded for people with learning disabilities, on whom I will focus my brief comments today.

There are more than 1 million people with learning disabilities in England. This is an ageing population, which means that growing numbers of them will need palliative care. Public Health England estimates that around 3,400 people with learning disabilities die in England each year. For decades, concerns have been raised about the health inequalities faced by this group, and this inequality becomes even more serious within end-of-life care provision. There have been shocking cases of failure in care leading to avoidable deaths and poor-quality end-of-life care. The Confidential Inquiry into Premature Deaths of People with Learning Disabilities, which published its findings in 2013, found that the deaths of people with learning disabilities are often not anticipated and are poorly planned for and poorly co-ordinated. The subsequent learning disability mortality review programme now aims to review all deaths of people with learning disabilities in England. Its recently published third annual report states that 71 adults with learning disabilities whose deaths were reviewed by the programme—that is 8% of reviewed deaths—received care that fell so far short of good practice that it significantly impacted on their well-being or directly contributed to their cause of death. Reasons included a lack of co-ordination of care and poor-quality end-of-life care.

In the new *NHS Long Term Plan*, learning disability is highlighted as an NHS priority for improvements in care quality and outcomes, and reducing health inequalities for people with learning disabilities is specifically highlighted as an area of concern and in urgent need of improvement. On page 41 is a commitment to,

“ensure that reasonable adjustments are made so that wider NHS services can support, listen to, and help improve the health and wellbeing of people with learning disabilities”

On page 52 it states:

“The whole NHS will improve its understanding of the needs of people with learning disabilities”,

and stresses the need to work more effectively with people with learning disabilities and their families.

A 2015 white paper by the European Association for Palliative Care noted significant inequalities in access to palliative care for people with learning disabilities and found that good palliative care is more dependent on the commitment of dedicated individuals than on good policies, systems or guidelines. It recommended that policymakers prioritise equitable palliative care specifically for people with learning disabilities and commit adequate resources to it.

So what problems have been unearthed by the national mortality review programme? The recent annual report found that a key problem is the difficulty in recognising that the end of life is approaching or that palliative care is needed. Recognition is the first step in ensuring good access. A significant recommendation for 2019 from the authors of the mortality review is that the Department of Health and Social Care should prioritise certain programmes of work: those that support the recognition of deteriorating health or early signs of illness in people with learning disabilities. Why is this so complex? There are many reasons, including communication challenges, polypharmacy and the fact that many people with learning disabilities have high levels of comorbidity, some of which have been lifelong. Such comorbidity can obscure the signs of advancing illness or increasing frailty.

Professor Tuffrey-Wijne's research programme at Kingston University and St George's, University of London has found that people with learning disabilities are often excluded from knowing about death and are not told about terminal illness, so their death education is even more lacking. This means that they are inadequately prepared for what is happening to them and are not involved in making the decisions that affect them. This is relevant to the Mental Capacity Act and issues about how to empower this group and enhance their capacity for decision-making. Improving access to palliative care for people with learning disabilities must include ensuring that staff in all healthcare settings learn how to assess the needs of this group, how to make reasonable adjustments and how to communicate with them.

The new government proposal for mandatory learning disability training for all NHS staff, which has been out for consultation, is an important step in the right direction. I would welcome an update on the progress of the consultation and its relevance to the Bill. However, staff training alone is not enough to address existing inequalities and to prevent a repeat of some of the tragic situations that have been widely reported. Good palliative care provision for people with learning disabilities is just too haphazard. A clear policy focus is needed to ensure that people get the right end-of-life care, in the right place, at the right time. I always say that if we could get it right for people with learning disabilities, we could get it right for everybody else.

Preventable deaths must be prevented, and unpreventable deaths must be well supported. There is an urgent need for further understanding and knowledge about how health and social care services can make that happen, so research into this area is also an urgent priority. I hope that my noble friend will keep this vulnerable group in mind as the Bill progresses.

I understand that there is the possibility of an amendment to this important Bill with respect to very sick infants and their parents. Speaking as a former president of the British Medical Association and as a doctor, I know how distressing conflict between doctors and the parents of unwell children can be. I am also aware that not enough is done at the moment to mitigate those conflicts. Having worked with the parents of Charlie Gard, I am in awe of their humility and willingness to sit around the table with those who opposed them at a critical time for their son, who sadly died.

Together with senior doctors, lawyers and ethicists, they have crafted a very modest proposal which I strongly believe will improve the situation for parents and doctors alike. Acceptance of their amendment would save public money through the avoidance of court fees and the unnecessary prolongation of treatment, and would help protect the bond between patients and those responsible for their medical care. I trust that the Minister will engage with the interested parties at her earliest convenience, because I know how widely these measures are supported in this and the other place. I wish my noble friend good speed with her Bill.

10.41 am

The Lord Bishop of Coventry: My Lords, I declare an interest as a patron of Mary Ann Evans Hospice in Nuneaton.

One of the privileges of my calling has been to accompany people in the latter stages of their lives, visiting their bedsides, preparing them in soul and spirit for the next stage of their lives, and watching over their bodies when death has finally come for them. Through it all, I have tried to support their loved ones as they have travelled this hard road, all the time admiring the skills, diligence and compassion of nurses and medics in hospitals and hospices. I have seen that there is such a thing as a good, and even a beautiful, death.

"Lord, lettest thou thy servant depart in peace",

is an ancient prayer of a Jewish sage. Whether people pray or not, a peaceful death is surely a near-universal hope, deep in the human heart, and it is why I am very glad to support the Bill introduced by the noble Baroness, Lady Finlay. With other noble Lords, I pay enormous tribute to her unswerving commitment to excellent and equitable palliative care for every person at every time, in every place, as the noble Baroness, Lady Hollins, has just said.

Of course, it is to be acknowledged that there is much to rejoice in. It is now more possible for people to die in physical peace than perhaps at any other point in human history, especially in the UK with our global leadership in the field. The compassion and skill of palliative care teams are a marvel. Our hospices are phenomenal, and the way that they were generated and remain sustained by local communities shows the deep longing for a peaceful death by ordinary people, for themselves and for their loved ones.

Nevertheless, it seems self-evident that the existing provision needs strengthening in disciplined and systematic ways. The 2011 NICE guidelines are laudatory. They set a high standard but, as we have heard already, clear evidence has been marshalled by Marie Curie, the BMA and others that they are not being reached everywhere and by everyone, and there is more such evidence now than at the time of the predecessor Bill. Indeed, the proportionately few references to palliative and end-of-life care in the 2019 *NHS Long Term Plan* do not inspire confidence that they will be given the priority they deserve.

I speak as a generalist but, to me, it seems that the Bill will provide that priority—that it will turn the NICE guidelines, the Government's 2016 national strategy on end-of-life care and the present NHS plan into actual practice. It will provide—if I may be so bold as to draw on medical terms—a detailed diagnosis of the

[THE LORD BISHOP OF COVENTRY]

deficit and a remedy to put right the gaps in provision that have already been noted in terms of geography, ethnicity, age, income, type of illness and so on. It will help to ensure that everybody has access to the help that everyone needs, everywhere.

With its emphasis on both specialist and generalist palliative care and support services, and its focus on the needs of the person, the Bill will surely create a new culture of communication and co-operation between the three spheres of care—home, hospice and hospital. Each has its role to play and, used well, each will provide the care that is most suitable at any particular point.

Of course, given the origins of hospices in the good works and initiatives of local people—I think of one of my predecessors founding the Warwick hospice—hospices are unevenly distributed. With its focus on local responsibility through the CCG, the Bill will, as we have heard, highlight that patchiness and therefore, I imagine, reveal new funding challenges where hospice care is thin. However, even where provision is thicker on the ground than in other places, I am conscious of the constant and very pressing funding pressures that hospices presently find themselves under, with 78%, I gather, drawing on reserves.

The Bill will ensure that those realities are faced head on, yet at the same time I entirely agree that significant economic benefits are to be found in the better co-ordination of care between hospital, home and hospice, as envisaged by the Bill. Not least through its attention to psychological support and its requirement for information to be shared, the Bill gives in a very interesting way real agency to those in need of care and to their loved ones.

Most people will want to remain in their homes for the maximum amount of time. One's home is not only a better environment to be but, as the 2018 IPPR report shows, it is good for the budget. However, home care will need co-ordinated support—specialist and generalist. For those who want to die at home—up to 82%, according to the Office for National Statistics—I hope that the Bill will encourage the development of the hospice-at-home service, making effective palliative care truly present in the place of need.

Although I welcome the Bill's reference to psychological support, I would be interested to know whether the noble Baroness would welcome an amendment at some point to give greater prominence to spiritual support in line with the WHO's definition of palliative care. I realise that "spiritual problems" are included in the Bill's interpretation but I am conscious that, in recent audits of the NICE guidelines, the statements involving religious and spiritual needs or complementary therapy received especially low scores and therefore might need particular vigilance.

As I indicated in my opening words, I have found that very many people reach out for some sort of spiritual care as they approach death. Here, I am not sure that the Bill fully realises its intentions for holistic care and for the whole person's needs to be met. The ancient prayer that I mentioned earlier was by a very elderly man, Simeon. It was when his spirit was at peace that he felt able to release the life that he could sense was fading away and come to terms with his own mortality.

10.49 am

Lord Browne of Ladyton (Lab): My Lords, I thank and congratulate the noble Baroness, Lady Finlay, on introducing this Bill to your Lordships' House. I commend her for her persistence on this issue and for the excellent introductory speech she has made. This Bill deserves to, and I suspect will, garner support from all parts of the House. It is only to be hoped that, on this occasion, the Government Front Bench will join the chorus of support; we shall see.

I am significantly out of my comfort zone debating England's health policy in your Lordships' House. I was a Member of Parliament in the west of Scotland for 13 years, for all but two of which we had a Scottish Parliament, and therefore devolved responsibility for health matters. I do not even have a wealth of anecdotes or experience to share with the House; I did not learn very much about health policy during that time. So why, noble Lords may ask, am I taking up precious time to make a contribution to this debate? In explaining why, I will make the one point I want to make.

For the past week or so, I have been preparing to make a contribution to a debate that took place yesterday on inequalities. During the course of my research, I came across an excellent document from Marie Curie, for which I understand the noble Baroness, Lady Finlay, has management responsibility. For those who would like to read it, the document is dated April 2015 and is entitled *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. I thought I would find evidence of inequality in there and to my horror I did—in spades. Then, I noticed that this debate was taking place, so I did not deploy this argument yesterday but kept it for today. I am pleased to see that we have the same Minister today. She made an excellent contribution to yesterday's debate and showed a significant degree of empathy for the issues being raised. But I am hoping that she has learned a lesson from yesterday, which I will ask her to implement today.

I do not feel the need to add to the vast amount of evidence of disparity of provision and quality in this space. I went back and read the 2015 debate, and I think I get the Government's position. I say to the Minister, with all humility and respect, that it will not be any response to this debate to remind us that the United Kingdom sits at the top of some perceived league table on palliative care. That is no answer to the people who suffer from this inequity. It is no answer to those who suffer from care that is not the best it could be. Equally—the recording of this is important—I hope that the people who provide the best palliative care in this country are congratulated on doing what they do at a superb level. But that is no answer to the people who suffer from inequity or from what is not the best care. With respect, it is no answer to say that the infrastructure of the provision of health in this country now puts the responsibility at a local level, and that we do a disservice to localism or local provision if we try to deal with this.

The reason is simple—yesterday's debate was redolent of it. We know that, if we allow inequity and inequalities to persist, they get worse. They do not cure themselves; they get worse and they become the norm. People put up with it, yet they have no reason to put up with it if

something better can be provided. We also know that, whether or not the responsible mechanism for the delivery of the best is local, in an inequitable environment it requires some authority with an aerial view to see where there is better, why there is a difference and how it can be done.

With all due respect to everyone who will contribute to this debate, the noble Baroness, Lady Finlay, has offered the Government an elegant solution to a problem which even the Government accept exists. It is an elegant, easy solution. It should be embraced, and resources should be devoted to implementing that decision once embraced; then the local people can get on and deliver it.

10.54 am

Lord Low of Dalston (CB): My Lords, I too welcome this Bill and congratulate the noble Baroness, Lady Finlay, for bringing it back to the House. I welcome the Bill because, if enacted, it should certainly improve access to palliative care for dying people. However, as has been said, the Bill does not include some of the provisions contained in earlier versions of the Bill as introduced in 2015 and 2016. The noble Baroness has acknowledged this and says that it is in the interests of getting a shorter Bill. However, if the Bill is to ensure the highest standards of care for those who need palliative care, these provisions need to be recognised in some form, whether in the Bill itself or, as the noble Baroness has suggested, in a code of practice.

The first of these provisions relates to supporting individual care preferences. Like the noble Baroness, Lady Brinton, I am disappointed that this latest version of the Bill does not include a duty on clinical commissioning groups to provide patients with support to meet their preferences in care, or support on advance decisions to refuse treatment under Section 24 of the Mental Capacity Act 2005, both of which I was very pleased to see in Clause 1 of the 2016 Bill. I believe these provisions should be embraced in any palliative care framework, for three reasons.

First, there is clear evidence that documenting care preferences through the process of advance care planning increases use of hospice and palliative care and prevents emergency hospitalisation towards the end of life. It increases patient and family satisfaction and reduces stress, anxiety and depression in surviving relatives. The importance of clearly documenting care preferences was highlighted in the recent case of an unidentified clinical commissioning group against P. In this case, a nursing home did not agree with the withdrawal of artificial nutrition and hydration for religious reasons. The patient's family had to go to court to have their loved one's previously stated wishes respected. Documented care preferences—that is to say, putting advance decisions to refuse treatment in writing—would have avoided this tragic and stressful situation, as the patient's wishes could have been honoured without her family having to go to court.

Secondly, we talk about personalised end-of-life care in the ambitions framework and in the *NHS Long Term Plan*, but we know that healthcare professionals do not always understand and implement the Mental Capacity Act 2005, resulting in tragic consequences. For example, in the case of Brenda Grant, life-sustaining

treatment was provided against the patient's wishes for 22 months because those responsible for her care did not pay attention to her legally binding advance decision. More recently, Jillian Rushton received life-sustaining treatment over several years even though she had taken great pains to refuse it. This was because her GP failed to ensure that her legally binding advance decision was properly communicated to hospital staff.

Thirdly, if we are to make a genuine commitment to person-centred end-of-life care and move away from traditional paternalistic approaches, maintaining an explicit focus on individual care preferences in key documents such as this Bill is vital. For all these reasons, I would like to see the points about preferences in care and advance decisions, if not reintroduced into the Bill, certainly recognised as part of the palliative care framework.

The second provision needing to be reintroduced relates to education and training. I would also like to see the comprehensive section on supporting health and care professionals to provide care, particularly in line with the Mental Capacity Act, which appears in Clause 3 of the 2016 Bill, incorporated into the palliative care framework. While the BMA and the Royal College of Physicians have developed excellent guidance on clinically assisted nutrition and hydration, it is clear that not all health and care professionals learn about and implement these guidelines. Giving legal weight to ensuring that all health and care professionals have the necessary knowledge, skills, attitudes and behaviours needed to care for people with palliative care needs is essential if person-centred end-of-life care is to become a reality.

The third provision needing to be reintroduced relates to research. I am sorry to see no mention of research to improve the data we have on palliative care, such as was part of the previous Bill. This is crucial if we are to measure and analyse the effectiveness of palliative care and see where improvements could be made. Moreover, with no information about whether the VOICES survey of bereaved people will be rerun, placing on a statutory footing data collection and research on advances in end-of-life care assumes an enhanced importance. The VOICES surveys provided much-needed information on quality and co-ordination of care, efficacy of pain relief, and quality of communication between healthcare professionals and the patient's loved ones, among other things. It is vital either that the VOICES survey is reintroduced or that alternative methods of collecting a wide range of data on the quality of care and symptom control at the end of life are developed. Therefore, I hope that the noble Baroness may be willing to add such provisions to her Bill.

Finally, palliative care is not always sufficient. It cannot relieve all the pain and suffering of all dying patients. It is not a panacea. While in the vast majority of cases palliative care can give dying people a good death, it is important to be clear that it will not always be effective, nor will it be suitable for a small but significant minority of people approaching the end of life. That being so, it is important to say that a comprehensive end-of-life care regime must necessarily include a safeguarded assisted dying component for those who want it.

11.02 am

Baroness Hamwee (LD): My Lords, the noble Baroness, Lady Finlay, is a very powerful advocate. As we have heard, the House wants her to do even more, but she has explained her strategy quite clearly.

I have never felt it appropriate to speak entirely from my own experience in your Lordships' Chamber, but today I will. After all, we are all informed by our own observations and incidents from our own lives, although I acknowledge that emotion is not the best basis for argument. My remarks focus on support by palliative care services for the family and friends of a patient. I absolutely take the point about equality and equity made by the noble Lord, Lord Browne. As a family member and friend of someone who died recently, I have been lucky enough to have had that support.

The patient did not have immediate family and when the palliative care team visited, they were met with a small group of her friends who were all involved with her support. I am sure that they encounter a great variety of people, but among my reactions at that first meeting was how well they coped with a group of articulate professionals, who were not short of questions and, in the nicest way, demands. My strongest impression was how reassuring they were. We may have been professionals, including as it happens two from the medical world, but this was unknown territory for us. The anxiety among this competent group was very high. We all felt such concern for our friend, such anxiety to ensure the best care for her and such a feeling of helplessness as to how to go about it, as well of course as to what to expect in the progression of her disease.

I pay tribute to the wonderful Dr Lucy Bernard-Qureshi, nurses Nichola Brown and David Cofino-Gonzalez, and the Camden, north-east Westminster and Islington palliative care team. They treated their patient so respectfully. They addressed questions to her, before asking us, and never talked over her, even when it was very unlikely that she was at all aware of their presence. They seemed to have all the time in the world for us and our anxieties, as well as for her—although I am sure they did not. I believe the phrase “support for ... relatives” in Clause 1(b) of the Bill should be construed very widely.

At our first meeting with the team, the doctor was shadowed by a medical student. He told me that this was his one day of training in palliative care. I am sure it was a very intensive day, but even so, training is something for all health professionals, not only palliative care specialists. I felt I should volunteer to help role-play as part of the training on his course.

The team enabled my cousin to be at home until her death, as she wanted, and they supported her own decision regarding nutrition and hydration—she had left a very clear advance decision. That could not have happened without the team nor a number of very impressive carers, which takes me to my next point. I do not know the countries of origin of all the carers. At least one was an EU citizen and I suspect others were not British or EEA nationals by birth. The UK and the health service need people like them. Although this is not a debate about immigration, it is relevant because I suspect much palliative care at home could not work without 24/7 carers.

I discovered afterwards that neither of the principal carers who were with my cousin at her death had previously been with a patient at that point—they coped admirably—because most patients do not die at home. It was not in our minds but it is a reminder about how much palliative care can save the NHS budget. Above all, it enabled my cousin to depart in peace.

11.07 am

Lord Balfe (Con): My Lords, I add my congratulations to the noble Baroness, Lady Finlay, who has been consistent in pursuing not just palliative care but the whole area of end-of-life situations. She is much to be admired.

I welcome this Bill and I can see the difficulty in adding new clauses. It is rather like an extended Grand National; for every new clause you add, there is another hedge for people to fall at. I have a lot of sympathy for the aim of this Bill and its length. I see this Bill as putting down a very important signpost. I did not speak in yesterday's debate, but one thing that comes through clearly is not only that people are living longer but that there is a big challenge for the future in the third generation and its life in society. This is part of it.

I welcome the proposal to produce a strategy. There is of course a dichotomy between postcodes and local determination. When people go to vote, they vote for a national government and a national health service. To my mind, it is perfectly consistent with local determination for a national framework to be established, which says to local bodies, “You have freedom at a certain level, but you must work within these overall policy guidelines”. That is quite legitimate and I think it is a good thing to do.

I want to move on to another area, which is also to do with palliative care and on which we have had support from the noble Baroness—the Dying to Work campaign. We talk about palliative care, but there are many people in society who are diagnosed with terminal diseases but do not know when the termination date is. There is and has been a tendency for HR departments in companies to say, “Right, you're ill, we'll push you out”. That can often mean loss of income, which is serious for a family, a loss of respect and the feeling that they are valued, which is important for a family, and a loss of death in service benefits, which can be quite vital to a family.

I am sorry that the noble Lord, Lord Kennedy, is not here, but I had tremendous support from him for the campaign run by the General and Municipal Workers' Union and the TUC to get companies to voluntarily sign up to the code looking to protect people who are at work and diagnosed with a terminal illness. I am sorry to have to say to the Minister that I detect a great lethargy in government that is not helpful. I ask her, in looking at the overall area of terminal care, to remember the person who set up this campaign, Jacci Woodcock, who was recently honoured in the honours list, and that this has all-party support, from not only the noble Lord, Lord Kennedy, but Pauline Latham in the House of Commons, who is Jacci's MP, and many other people who are looking forward to strengthening this area of palliative care. Sadly, Jacci's health is beginning to fade.

Palliative care is a huge field that covers many things. I cannot remember who made the very obvious comment that we are all going to die one day; it is a case of where the palliative care begins. If you are diagnosed with a terminal illness and you are at work, I suggest that that is one part of it. I do not seek to add it to the Bill because of my earlier comment on its limitations, but I seek to add it to the debate.

11.12 am

Baroness O’Loan (CB): My Lords, I am very pleased to support the noble Baroness, Lady Finlay, for the way she introduced this very important Bill into your Lordships’ House. It is not just about the provision of medical palliative care, which might be the narrow definition of palliative care; rather, it seeks to ensure equal access to the provision of holistic palliative care—psychological support and understanding as well as medication.

I know that the Government have previously said that they are in full agreement with the Bill’s underlying intentions. I hope that they will now be able to accept that it is indeed time, in 2019, to ensure that palliative care, in its widest sense, becomes a mainstream service, rather than something that one might be lucky enough to access. For living with life-limiting and terminal illness is not something that affects the patient only; rather, it has an effect, usually a lasting one, on those who love them, live with them, and walk with them on this difficult, and on occasion even humorous and gentle journey.

I will talk in particular about Clause 1(b), which seeks to establish an obligation to ensure that people have access to appropriate health services, including psychological support for the person and their relatives. Some of those relatives will be very small when they encounter death for the first time. We all know that it is very difficult to lose someone whom we love. Even when we are old and grey, it is difficult and we mourn—and mourning and grief stay with us to some extent for the rest of our lives. It can have a very significant impact on our lives. For a little child, death can not only rob them of the mother, father, sibling or relative, but in so doing also rob them of the fullness of their future.

When a little child loses a close relative, perhaps a parent, a sibling or a much-loved granny, the loss is compounded by so many things, which those who really want to care for them—their carers, the parent perhaps, older siblings, aunts and uncles, who are mourning too—may not recognise. They may not have the understanding of the impact of grief on a little child until great damage has been done. It is often not that they are neglecting the child in any way; rather, a combination of circumstances may lead to an inability to recognise what the child needs and to provide it.

The Royal College of Psychiatrists has identified some of the relevant issues and some of the things that we need to think about. How close is the child to the person who died? How involved was that person in their lives? Was the death expected or sudden? Was it traumatic? How did those around the child respond? Adults have a way of dealing with grief that is perhaps different from the ways in which children react. Even little babies know loss—they know that their mother

or father is no longer there for them. They do not often know why, and people describe the situation in words that they do not understand and involve comprehension of major concepts that may be beyond the child, such as the fact that the person they love is not coming back. That is hard for us to understand; for a little child it can be totally incomprehensible.

I think of one little boy I knew who was two and a half when his father died. He used to sit every day waiting for his father to come home. After his father died, he continued to sit on the doorstep with his big golden Labrador, waiting and waiting. His father never came home, and he had been told that his father was not coming home. He just withdrew into himself as he sat on that step and he stopped talking completely. That led to a need for a more therapeutic service. If children can be helped to talk and to express themselves, perhaps through play, they can cope better and are less likely to have emotional disturbances later in life.

One of the things that is very important for a child, because death is such a difficult time, is what happens at a funeral. People often do not know: should they keep the child out, or try to pretend that life is going on as normal? There are those who can help. A holistic palliative care system would provide that.

We know that children get very angry about death. They get angry because the person they have lost is essential to their sense of safety and stability. They can become aggressive, even in play. They can become irritable or inconsolable. They can have nightmares. They can be worried because they have been up and down to a hospital to visit a sick person. Hospitals are not places for small children, who are, for the most part, visiting sick people. They may even be afraid that the surviving carer will die, too. That can be a very real fear, but they are afraid to articulate it, lest it happen. They may be sad and unable to articulate their sadness without help.

Children may believe that they caused the death. They often take responsibility for things that happened for which they have no responsibility. Like the noble Baroness, Lady Hamwee, I do not easily move into the personal, but in my case, at the age of 13, I was sent to get new medication from the chemist for my father, who was very sick. I got the medication and brought it home. He used it, had a massive heart attack and died. My conclusion was that by bringing the new medication into the house I had caused his death. I could not talk to anyone about it because I needed to support my mother. How do you put this sense that you have caused something into words? You do not want to upset people but you are tormented by what is going on in your head. There are those who can help people in this situation, who can provide support through illness and dying and into the future—people to whom the child can speak freely, and who have the training and the expertise to help them to articulate and to work through what has happened. So many children currently do not get help.

Some 3.5% of children aged five to 16 have experienced the death of a parent or sibling. Bereavement has such an impact on their social, psychological and educational outcomes. Akerman showed in 2014 that most children experience negative impact and that childhood bereavement

[BARONESS O'LOAN]

can have an impact up to the age of 30, although there are limitations on that when family background is taken into account. But there is evidence that specialist interventions and programmes can be helpful. It is reported that even those not exhibiting clinical levels of distress can benefit from longer-term programmes that normalise their grief and strengthen their coping capacities.

The most effective way to do this is to adopt a holistic approach that attempts to strengthen the protective factors in a child's life, supporting not just the child but the surviving parent and working to strengthen communication and warmth in the family. It can seem very mundane—but there is nothing mundane about a home that has lost a loved one. Those who really want to help their children might be in a very difficult place. Someone who has worked with a child before death, and helps them begin to understand what has happened after death, will help to assuage the anger which, if unacknowledged, may lead to poor performance at school, anti-social behaviour and withdrawal into other problems.

What the noble Baroness, Lady Finlay, seeks for the child relatives of those who need palliative care is not unachievable. In the end, research shows that it may help prevent situations arising which might cost infinitely more in terms of response. I am happy to support the Bill and I thank the noble Baroness for it.

11.20 am

Baroness Meacher (CB): My Lords, along with others I applaud the noble Baroness, Lady Finlay, for proposing this important Private Member's Bill. It is surely a cruel anomaly that NHS funding for palliative care seems to depend on where you happen to receive that care, whether it is in hospital, in a hospice or at home, when there is no more important time to have proper funding for high-quality care. I should declare my interest in this debate as chair of Dignity in Dying—a non-remunerated position, I must emphasise.

The explanation for the Government's refusal to support an earlier palliative care Bill, given by the noble Lord, Lord Prior, when he was Parliamentary Under-Secretary of State at the Department of Health was quite extraordinary. I do not blame the then Minister: he was giving the Government's position. Nevertheless, he talked about palliative care as an issue best tackled by clinicians, ideally with patients, carers and loved ones involved. Is there any NHS care to which that description does not apply? All NHS care is of course about clinicians providing the care and, we hope, relating to patients, carers and others. The issue is whether the NHS funds those clinicians who provide the care in palliative care settings, and of course it should.

Marie Curie has raised the opportunity cost of not providing comprehensive palliative care across the country. This is one of the most important points for the Government to take seriously. The charity refers to the 1.6 million emergency admissions in the last year of people's lives, which amount to 11 million hospital days—an enormous cost implication. I would be grateful if the Minister would ask the department how many

of those hospital admissions could have been avoided if palliative care in the community had been available everywhere. I emphasise that the NHS needs to know that information. What would those savings be and how would they compare with the cost of providing the necessary palliative care? My hunch is that the investment in comprehensive palliative care would be found to be cost-effective for the NHS, quite apart from the huge benefits to patients and their families.

As the noble Baroness, Lady Brinton, and the noble Lord, Lord Low, have indicated, a number of provisions included in earlier versions of the Bill are not included in this one. I hope we can do something about that in Committee. I understand the analogy used by the noble Lord, Lord Balfe, about hedges, but these are little hedges as far as the Government are concerned. Yet these little hedges could have a massive impact on improving end-of-life care.

In particular, along with others, I want to see introduced in Committee a duty on clinical commissioning groups to fund support for patients to meet their preferences in care. Too often, people do not receive the care that they really want, which is ridiculous. It is terribly costly and terrible for the patient. Most importantly, I want advance decisions to refuse treatment to be included in the Bill. These are advance decisions under Section 24 of the Mental Capacity Act 2005. The process of advance care planning increases the use of hospices and palliative care, and prevents hospitalisation towards the end of life. The process also improves communication between the patient, their family and the healthcare professionals, while reducing stress, anxiety and depression, as others have said. It is a tragedy that only about 4% of people in this country have completed an advance decision. It cannot continue like that if we really want good-quality end-of-life care. I hope noble Lords will support introducing advance care planning in some way into the Bill in Committee. I can think of few things that are so important if we want patients to drive what they receive as care at the end of their lives. These changes would mark a significant step away from traditional paternalistic approaches to healthcare at the end of life, and towards truly person-centred care.

I also strongly recommend that a clause as set out in Clause 3 of the 2016 Bill on supporting professionals to provide care, particularly in line with the Mental Capacity Act, be introduced into the current version. We know that healthcare professionals do not always understand and implement the Mental Capacity Act. Others have referred to the tragic consequences in the recent cases of Brenda Grant and Jillian Rushton; I will not repeat the comments of my noble friend Lord Low. Reintroducing Clause 3 of the 2016 Bill would help to avoid such cases in the future.

Finally, I put it on record that while good palliative care can relieve pain and suffering for the great majority of dying people, there are some whose suffering is outside or beyond the scope of palliative care. As Professor Irene Higginson, one of our foremost experts in palliative care research, said recently:

“More than 85% of palliative care patients have no severe symptoms by the time they die”.

Of course, this means that up to 15% of patients do suffer extreme or very severe symptoms before they die. Some of these patients will have their symptoms partially controlled, but others will not and they will experience the most dreadful suffering in the weeks before their death. In the autumn, Dignity in Dying will publish a report on such deaths; I have just read that report and it was deeply distressing to do so. Some of these deaths can be described only as barbaric. We would not do that to a rat, let alone to a cat or dog. It is really shocking.

The important point here is that however much access to palliative care is improved—I am a huge supporter of comprehensive, high-quality palliative care—there will be people outside the scope of that care. One example was of course Geoff Whaley, who may have been in one of the least traumatic and barbaric situations that I have come across. But for him, it was certainly something he could not cope with. He was a motor neurone disease patient who could not bear the prospect of being unable to move anything at all: not being able to speak, swallow, eat and drink, or to breathe without a ventilator. Some people seem able to cope rather better than others with these things but if someone cannot, it seems to me that they should not have to. Some symptoms simply cannot be palliated; in that situation, a number of patients will want to be able to choose the timing of their death.

It is not surprising that 86% of the population want access to an assisted death to be legalised, with strong safeguards—I, along with everybody else I work with, strongly support that. We want this to be legalised. I want to raise the issue of patient choice at the very end of life in Committee, while recognising that this Bill is not the right vehicle to introduce assisted dying. Here, the hedge would be far too large. However, high-quality palliative care for all, including safeguarded assisted dying for the small minority who suffer unbearably, is the hallmark of an ethical, patient-centred, end-of-life healthcare system.

11.28 am

Lord Sheikh (Con): My Lords, I pay tribute to the noble Baroness, Lady Finlay, for tabling this Bill. It is an important Bill and I have the pleasure to speak in support of it. I begin my contribution by making reference to the conversations I had with Dame Cicely Saunders. Dame Cicely was a pioneer of the modern hospice, which takes a holistic approach to palliative care, managing physical symptoms and tailoring care to meet the social, emotional and spiritual needs at the end of a person's life.

I met Dame Cicely Saunders because I support the hospice movement. She recognised the important role that hospices play in palliative care. In fact, I have a connection with St Christopher's Hospice, which was founded by Dame Cicely. She emphasised to me that there is much more to be done to improve palliative care.

I have spoken in opposition to assisted dying in your Lordships' House and at other meetings. I feel that we should not debate ending the lives of people who are suffering. We owe a duty to people who are ill—in fact, to all people—not to give up on them. A right to die can easily become a duty to die. The law

should not affirm that some lives are not worth living. A vulnerable person may start to think that they are better off dead, but those tempted to think about themselves in this way need protection and care, as no life is less worth living than another. Life is sacred. I believe our time would be better spent discussing how the state, the medical profession, hospices and society at large could better take care of people who are vulnerable in the final years of their lives.

To prepare for my speech in support of the Bill today, I had discussions with St Christopher's Hospice, which was able to provide me with some additional information. St Christopher's Hospice fully endorses the Bill, as it will ensure high-quality care for all dying people and that those close to them have access to care and support, whenever and wherever they need it. I must emphasise that hospices and the voluntary sector do not have the resources and capacity to provide palliative care for everyone who needs it. We ought to take a holistic approach to these issues.

Palliative care focuses on maximum quality of life. It seems inhuman to me that specialist and generalist palliative care is not accessible to everyone. I am grateful, therefore, to the noble Baroness, Lady Finlay, for providing us with an opportunity to remedy this inequality. Every year, approximately 500,000 people die in England. This figure is set to increase by 26% by 2040, due to England's ageing population, and it is suggested that the demand for palliative care will rise by 40% in this time. The funding and commissioning of palliative care is a responsibility the Government should undertake diligently. For three-quarters of people, death is not sudden but expected. I was shocked to discover that, as recently as May 2016, it was identified that 27% of clinical commissioning groups did not have a strategy to address end-of-life care. Increasing numbers of patients express their wish to die at home—this reflects 81% of patients, according to families who responded to the National Survey of Bereaved People in 2016.

Despite this, the majority of people still die in hospital, with only 23.6% of deaths in England taking place at home. What is required is a strategy for clinical commissioning groups to provide appropriate palliative care services. I am therefore pleased that the Bill seeks assurance that clinical commissioning groups will take palliative care needs seriously. They will need to review and prepare strategies as necessary and at least every three years.

The Bill also provides for the clinical commissioning groups to establish parameters for their strategies. The strategies will need to establish what palliative care needs are locally, develop an approach to combating these needs, provide for specialist palliative care needs and ensure that methods of reporting and collecting the necessary data are available, so that patients have the best possible service. I note that around three-quarters of people will need some form of palliative care when they die but, at present, the palliative care needs of an estimated 118,000 people are not being met.

Figures from Marie Curie suggest that one in four people in the UK do not receive the care and support they need at the end of their life. The noble Baroness, Lady Finlay, stated that the report *Dying without Dignity*

[LORD SHEIKH]

by the Parliamentary and Health Service Ombudsman found that the key themes in complaints about end-of-life care are: not recognising that people are dying; not responding to their needs; poor symptom control; poor communication and inadequate out-of-hours service; poor care planning; and delays in diagnosis and referral for treatment.

Politicians often talk of a postcode lottery for certain services, but this can be seen no more profoundly than in palliative care. At present, there is no parity in accessible care across England. For instance, there appear to be wide discrepancies in access to beds between some areas. As there is disjointed health and social care provision across England for people nearing the end of life, there needs to be better co-ordination and standardisation between services for end-of-life care.

The Bill rightly places duties on clinical commissioning groups to ensure that palliative care is accessible to all patients of all ages. There also needs to be better communication with the patients themselves. Patients of course rely on the guidance of their carers and medical professionals, but they also need to know that their voices are being heard. They need to be able to express their concerns and have them listened to.

When people are in their final days, we often speak of wanting to stop their suffering. *A Time and a Place*, a report published by the Sue Ryder charity in July 2013, notes that, when asked what they want at the end of life, 78% of people want to be free from pain and discomfort. Even with the huge medical advances we have seen, it is not always possible to completely remove someone's pain. We need to do all we can to remove the worries from patients and improve their quality of life as much as we can. The Bill has the provision to ensure that patients have access to appropriate health services, such as pain and symptom management.

We also need to engage in constructive dialogue with patients' families. It puts great strain on families to know that their loved ones are suffering and have discomfort in their final days. In addition, according to project work carried out by the BMA, a key concern of patients at the end of life is their family members' well-being and the impact their passing will have on them. Psychological support provisions will help relatives in the short and long term, as well as reduce anxiety for patients.

I therefore welcome the Bill, which will ensure that there is an obligation on clinical commissioning groups to provide support for families, as well as patients, and provides an assurance that all parties involved are well informed about the support services available to them. I end by saying that death is one thing we can all be certain of, but we cannot currently be certain that, in our dying days, we will have the help we need. I hope that this discussion is continued by the Bill's progression, so that palliative care receives the recognition and support it so greatly deserves.

11.40 am

Baroness Jolly (LD): My Lords, I too am grateful to the noble Baroness, Lady Finlay, for introducing this Bill. I know that it is an issue close to her heart and

one on which she speaks with unparalleled authority. I thank her also for the useful briefing that many of us received last week. She has my complete support.

We have heard compelling arguments from around the House in support of the Bill. One or two contributions have been personal and very moving—including those of my noble friend Lady Hamwee and the noble Baroness, Lady O'Loan, who talked about supporting grieving children. Many on these Benches will remember a friend, a Liberal MP who died just before Christmas in a terrible car accident just over 30 years ago. His wife was left with two small children and suddenly discovered that there was no support for them. She set up a charity which is still running, Penhaligon's Friends, to do just that: to help, support and counsel grieving children and families. Support is there if you know where to look for it.

The noble Baroness, Lady Hollins, spoke about palliative care for those with learning disability. I should declare an interest in that I am chair of a charity, Home Farm Trust, which provides learning disability services to more than 2,000 adults in England. We built just over two years ago some homes specially designed for older people with learning disability. End of life was factored into the design of the houses. They would look like ordinary domestic residences if you were to walk past them. The aim was to keep the individual in their home until they died. We trained carers and worked with local GPs—it can be done.

I have a couple of questions for the Minister. Can she tell the House who ensures that CCGs commission appropriate palliative care for their region and that there is no postcode lottery? What is the inspection regime for such services?

My contribution to this debate follows meetings with Chris Gard and Connie Yates, the parents of Charlie, who, tragically and in highly public circumstances, died in July 2017. The case was painful for all involved: the parents and the medical professionals working at Great Ormond Street Hospital. Those of us who watched the whole thing play out on the six o'clock news night after night could see the pain not for the parents but the clinicians involved. There had been a breakdown in communication between the parents and medical professionals over an experimental treatment for mitochondrial disease. Great Ormond Street Hospital and Charlie Gard's parents entered a lengthy and distressing dispute involving a series of court proceedings. The case clearly illustrated problems with current dispute resolution systems.

The court proceedings caused enormous emotional harm and stress to the parents and medical professionals alike. Both, of course, wanted to do what they thought was best for Charlie. Instead of a smooth and efficient process aimed at resolving conflict, we saw huge entrenchment and precious time lost while Charlie's health deteriorated. Worse, parents and medical professionals were pitted against one another in the full glare of the media. This helped no one.

Since then, Connie and Chris have dedicated themselves to preventing escalation of conflict and protecting the doctor-patient relationship. Although it is not yet before your Lordships' House, I give notice that I

intend to table an amendment for debate in Committee and I beg the leave of the House briefly to outline its purpose—I apologise to the noble Lord, Lord Balfe, who does not like amendments, but I promise him that it is very important.

Broadly, the amendment would do three things. First, it would require the Secretary of State to put in place measures to improve access to mediation where conflict was in prospect. Secondly, it would provide for ethics advice and the means necessary to obtain second opinions swiftly. Thirdly, it would prevent court orders being made to prevent parents seeking treatment where that treatment was not harmful and where another reputable hospital was willing to provide it. In essence, this final provision is about the right to try. It enables parents and medical professionals to look elsewhere together in the best interest of the child.

It is my view, and the consensus view of medical ethics, that if a treatment is not harmful and reputable doctors are willing to provide it, no one should be prevented from seeking it. Here, I pay tribute to Tessa Jowell, a cherished colleague of so many here, who in her final speech in this House advocated for the right to try innovative cancer treatments.

These high-profile cases are not isolated. Many similar, painful disputes are happening right now but we are just not hearing about them, mainly due to reporting restrictions. Such conflicts are bad for doctors, bad for patients, bad for our NHS and bad for the children whose care is under consideration. Our current systems are inadequate to address them and are in desperate need of reform. It is this that my amendment will seek to address. I am grateful to the noble Baroness, Lady Finlay, for the opportunity of doing so in the context of her Bill.

Over the past year, we have been working with NHS medical professionals, world-leading ethicists, mediators and legal experts to formulate a proposal that will help prevent avoidable conflict and ensure that hospitals and parents affected have the help they need. I have been in conversation for some months with the noble Baroness, Lady Finlay, and we agree that her Bill is an appropriate vehicle for what we are trying to achieve. In tabling the amendment, I know that I have considerable support from Peers on all sides of the House and among the wider public. I would be grateful if the Minister agreed to meet me to discuss the amendment.

11.47 am

Baroness Thornton (Lab): My Lords, I thank the noble Baroness, Lady Finlay, for introducing this Bill, which is close to her heart, as we all know. I thank all noble Lords for a great debate. I thank the Library, the BMA, Dignity in Dying, Marie Curie and others for their briefings. I declare my interest as a member of a CCG, as set out in the register.

I particularly enjoyed—if that is the right expression—the noble Baroness’s introduction to the Bill. It reminded us yet again how privileged we are to have a Member of the House with such expertise and experience. As we all know, the Bill aims to,

“make provision for clinical commissioning groups to ensure that persons in their area have access to specialist and generalist palliative care and appropriate support services”.

I want to say how much I valued the contributions from the noble Baronesses, Lady Hamwee and Lady O’Loan, whose personal experiences add enormously to our debate. Frankly, I am too close to various experiences to talk about them myself, but I appreciated the fact that they had the courage to do so and thank them for it.

If enacted, the Bill would require CCGs to ensure that individuals with palliative care needs have access to “appropriate health services”. This obligation, as noble Lords have said, would include, but not be limited to, ensuring access to pain and symptom management; psychological support for individuals and their relatives, particularly children; and information regarding an individual’s condition and palliative care. It would place a duty on CCGs to publish that strategy. The question is: can they deliver the strategy? That is the theme that has run through all noble Lords’ contributions.

I thought the briefing we received from Marie Curie was very important: it justifies very succinctly why the Bill is necessary. It tells us that every year 150,000 people in the UK do not receive the care and support they need at the end of their lives. It tells us that more than 5.5 million people will die in England, around 75% of whom will need some form of palliative care and significant action at the end of their lives. It tells us that in 2016, there were more than 1.6 million emergency admissions, as the noble Baroness, Lady Meacher, mentioned, which amounted to 11 million days in hospital and cost the NHS £2.5 billion. If CCGs do not put strategies in place to ensure access to palliative care and appropriate support for people at the end of their lives, it will cost the NHS more money than is necessary—money that could be spent on palliative care. That is the challenge the Minister needs to address in her remarks.

All the briefing we have had points to the importance of the Bill and I add my voice to those of the noble Baroness, Lady Brinton, on behalf of children, and the noble Baroness, Lady Hollins, on behalf of those who approach the end of life with learning difficulties—their contributions were very important. I think the whole House agrees that the best possible palliative care is vital, so my questions have already been asked by other noble Lords. These concern individual care preferences, which are absent from the Bill, having been included in previous Bills. I appreciate that the noble Baroness, Lady Finlay, said that codes of practice will be written to incorporate those issues that are not in the Bill and had been in previous Bills concerning end-of-life care, but there is a problem. I know that the noble Lord, Lord Balfe, does not want there to be any amendments, but the truth is that if we want the Bill to be effective, we have to consider that codes of practice may not be enforceable. Given that we have legislation already that is not being enforced, we have to question the effectiveness of the delivery of the ambitions that are in this Private Member’s Bill.

I am not going to rehearse the issues raised by other noble Lords about Brenda Grant and Jill Rushton, or the case raised by the noble Lord, Lord Low, about P3 and the care home. We know there are enormous challenges. Personalised end-of-life care, which is a key component, is not being delivered with any consistency

[BARONESS THORNTON]

across the piece. There is an absence of education and training from the Bill: it is a shame that that is not there. The need to ensure that palliative care is in line with the Mental Capacity Act, as set out in Clause 3 of the 2016 Bill, should be reintroduced into this current version. While the BMA and the Royal College of Physicians have developed excellent guidance on clinically assisted nutrition and hydration, it is clear that not all health and care professionals learn about and implement these guidelines. I have personal experience, not many months ago, of the assisted nutrition and hydration of a relative.

Finally, other noble Lords have addressed the absence of any research element in the Bill. Will the noble Baroness, Lady Finlay, explain that? Robust data is crucial to measuring and analysing the effectiveness of palliative care and considering where improvements could be made. Can the Minister say whether the National Survey of Bereaved People will be revived? It seems even more important now to place data collection and research on advances in end-of-life care on a statutory footing. The issue for the Minister is whether the Government will be able to deliver on the Bill if we put it on the statute book, as I hope we will. Because we are wasting our time if the answer to that is, “not really”, or if there is an equivocation about it.

I end by agreeing passionately with my noble friend Lord Browne about the need to address the inequities and inequalities in palliative care. We need leadership, funding, monitoring, research and drive in order for the Bill to be implemented once we get it on the statute book, and we will certainly support the noble Baroness in doing that.

11.55 am

Baroness Barran (Con): My Lords, I start by expressing my great respect for the noble Baroness, Lady Finlay, and her long-standing contribution to palliative and end-of-life care, not just in the UK but worldwide. As noble Lords have all said, every one of us in your Lordships' House has had experience of death, whether, tragically, in our role as parents, as children, as friends or as family members, so this debate touches every one of us personally in a particular way. I also recognise the invaluable and tireless work of all the end-of-life care charities, staff and volunteers around the country.

While we know that the vast majority of services are delivering excellent end-of-life care to patients, we also know that more needs to be done to meet our ambition to reduce variation in care at the end of life and to ensure that everyone can access care of the highest quality with the greatest possible choice. Of course, I include children in that, as the noble Baroness, Lady O'Loan, articulated so clearly. I therefore understand the intention of the Bill, which is to improve end-of-life care and tackle the variations in provision, whether those be regional variations or variations touching more vulnerable groups, such as those with learning difficulties, as the noble Baroness, Lady Hollins, explained.

As we have heard, the Bill seeks to introduce a range of measures relating to the provision of palliative and end-of-life care services and to create a duty on all clinical commissioning groups to publish a palliative care strategy including these service elements. I fear that

I am going to disappoint my noble friend Lord Bridgeman and the noble Lord, Lord Browne of Ladyton, when I say that the Government believe that decisions regarding the configuration of services and the approach to meeting need in a local population are for clinicians, commissioners and providers—of course, taken in consultation with patients as far as is practicable. I will try to explain later in my speech what measures we are introducing which mean that these inequalities—in the words of the noble Lord, Lord Browne of Ladyton—do not persist.

No other area of clinical care is mandated in this way in primary legislation. We believe that such an approach would set an unhelpful precedent and suggest that each condition, service or treatment pathway should also be enshrined and stipulated in legislation, along with the need for a corresponding local plan. We are concerned that this could unhelpfully and unnecessarily complicate local planning and interfere with best practice decision-making.

Clinical commissioning groups are bound by a duty to commission health services based on the assessed needs of their local populations, and palliative care is covered by this general stipulation. However, I accept that—as many noble Lords including my noble friend Lord Sheikh pointed out—there are significant variations in the provision of palliative care across clinical commissioning groups in England, including in access to 24/7 specialists in hospital and the percentage of people dying in their own homes. The noble Baroness, Lady Jolly, echoed by the noble Baroness, Lady Thornton, raised points about how we oversee the commissioning by CCGs of end-of-life services and the inspection regime. On support, NHS England works with local area teams to support CCGs and sustainability and transformation partnership areas to develop and improve their end-of-life services. On inspection, the CQC inspects end-of-life care providers on the quality of their services, including on the choice indicators in place at death, and where there are three or more emergency admissions to hospital in the final three months of life. The status of the GP palliative care register also helps to assess performance. However, in recognising that the intention behind the Bill is to ensure that everyone can access high-quality end-of-life care, I will set out some of the key progress that has been made over the last few years and what steps will be taken as we continue to drive up the quality of services.

As noble Lords know, choice at the end of life is the centrepiece of the Government's drive to improve end-of-life care. Where there is real choice, and where it is personalised and matched by healthcare services that respond in an effective and timely way that places patients, families and carers at the centre of decision-making, the NHS gets it right. In *Our Commitment to You for End of Life Care*, published in July 2016, we set out what everyone should expect from their care at the end of life, and the actions being taken to make high quality and personalisation a reality for all and to reduce the variation in end-of-life care. NHS England is responsible for delivering the commitment, in partnership with system partners and other key stakeholders, through its end-of-life care programme board. This has led to improvements in hospital care, where the CQC had found gaps, and to innovation in

community-based care. The noble Lord, Lord Low of Dalston, and the noble Baronesses, Lady Brinton and Lady Hamwee, all mentioned training. That has now been introduced to the curriculum for doctors and nurses. We obviously acknowledge that there is more to do.

Looking to the future, on 9 January 2019 NHS England published its long-term plan for the NHS. This set out key actions to drive improvement in end-of-life care and to support choice over the coming years, including a focus on culture change, which the right reverend Prelate the Bishop of Coventry so wisely observed. As part of this, we are accelerating the rollout of personal health budgets to up to 200,000 people, including those with palliative and end-of-life care needs benefiting from a PHB, by 2023-24. We are rolling out further training to help staff identify and provide personalised care planning for everyone identified as being in their last year of life, improving care, reducing emergency admissions and supporting more people to die in the place that they have chosen.

We are putting in £4.5 billion of new investment to fund expanded community multidisciplinary teams, providing rapid and targeted support to those identified as having the greatest risks and needs, including those at the end of their lives. We are upgrading NHS support to all care home residents and making end-of-life care one of two new quality improvement areas for the revised GP quality and outcomes framework. We are match-funding CCGs which commit to increase their investment in local children's palliative and end-of-life care services—raised rightly raised by the noble Baroness, Lady Brinton—by up to £7 million a year by 2023-24. However, we recognise that we need to do more, particularly because home and hospice are the preferred places of care and death for many people, yet 47% of all deaths currently occur in hospital. The £4.5 billion that NHS England is investing in primary and community care will go some way to addressing this.

Furthermore, earlier identification of patients approaching the end of life is crucial. It means effective care planning can take place, and people can express their views on the interventions that they may or may not wish to receive. I note the concern of my noble friend Lord Balfe about the Dying to Work campaign and undertake to highlight this to my honourable friend the Minister in the other place. However, all employees with progressive or debilitating diseases are protected against any discriminatory conduct by the Equality Act. The noble Baroness, Lady Meacher, asked me to write to the department about how many hospital admissions could be avoided if palliative care is provided. I am happy to undertake to do that. I would be equally delighted to meet the noble Baroness, Lady Jolly, to discuss her amendment, which touches on such an important and sensitive area.

In conclusion, I again thank the noble Baroness, Lady Finlay, for raising the issue of end-of-life care through this Bill and giving the Government a chance to set out our plans to achieve continued improvements. If she has any continuing concerns, I will of course write to the Minister in my department suggesting that they have a meeting, so she can explore them more. In general, I hope that my response has reassured noble

Lords that the Government are taking action and are absolutely committed to improving end-of-life care through the choice commitments and the initiatives in the long term—

Baroness Hollins: The Minister asserted that no other condition is mandated and that this would set a precedent. Surely midwifery services are mandated? Birth and death are just either ends of life. I do not quite understand.

Baroness Barran: I will have to write to the noble Baroness to confirm. I questioned and triple-checked that point with the department, so I undertake to write and clarify it if there was a misunderstanding. I hope she will accept that. To recap, our view remains that legislation is not required on this issue.

12.08 pm

Baroness Finlay of Llandaff: My Lords, I am most grateful to all noble Lords who have given up their Friday to speak in this debate on the Bill. As the Minister said, this touches us all personally. The accounts from the noble Baronesses, Lady Hamwee and Lady O'Loan, in particular brought a lump to the throat of many of us and exemplified the importance of excellence in care for everybody. There is only one chance to get it right. You cannot have a re-run; you cannot have another go.

Many noble Lords, including the noble Viscount, Lord Bridgeman, the noble Baronesses, Lady Brinton and Lady Hollins, and the right reverend Prelate the Bishop of Coventry addressed the fact that the Bill would close a gap. The right reverend Prelate spoke about peace at the end. I reassure him that spiritual care goes way beyond religious boundaries. It is striking how many people profess to have no faith at all but actually seek some kind of solace through faith at the end when they are facing their own existential crisis. As the noble Baroness, Lady O'Loan, pointed out, good care has to be holistic.

The noble Baroness, Lady Meacher, pointed out the opportunity cost of not providing good palliative care. While I understand the amount that the Government are doing, they are not adequately addressing the opportunity costs that are being missed. I am afraid that they are plugging small gaps without having an overall national strategy. Yes, education is going on, but there is still too little, particularly around communication skills.

Several noble Lords asked why the reference to the Mental Capacity Act was not on the face of this Bill. We already have that in legislation, and I was advised that it was repetitive to put it in this legislation because that Act applies to everybody and provides provision for advance care planning and legally binding advance decisions to refuse treatment. Legislation does not in itself make sure that everybody complies. It is there, and it is giving a strong message. It is educating and upskilling professionals who will make sure that things happen properly, particularly around advance care planning.

I wish I could share the Government's optimism about personal health budgets. I am worried that people who are suddenly in a crisis and in complete turmoil may find it very difficult to access the services

[BARONESS FINLAY OF LLANDAFF]

that they would want to buy, particularly if those services are just not provided in their area. I am still not convinced that personal health budgets will solve the problem. As the noble Baroness, Lady Brinton, pointed out, A&E is not the place for the predicted death of either children or adults. However, I must pay tribute to A&E departments, which deal with death day in, day out. They do it remarkably well and in the most incredibly difficult circumstances. In Wales we have actually put in place an ambulance service lead on end-of-life care to help upskill all the paramedics and ambulance crews, because they are often the ones who arrive at the scene.

I was asked about research. There is a difficulty with metrics. At the moment we measure death and disability in our national metrics; we do not measure pain and suffering. The Lancet Commission has underlined the importance of developing appropriate metrics against which we can measure what we are doing. Research is absolutely fundamental, and with all the Brexit negotiations I am concerned that funding may become more difficult. Again, I was advised that, to give this Bill a chance of moving forwards, I should take some of the details off the face of the Bill and allow them to go into a code of practice. Of course, I would hope that a code of practice to go along with it would become mandatory.

In my last moments I will address the overwhelming courage of Chris Gard and Connie Yates, who have taken their deeply traumatic experience forward and have wanted to ensure the right to try. They have done it with phenomenal dignity. Along with the noble Baroness, Lady Jolly, I have met them on several occasions. This Bill would be an appropriate place to put the requirement for access to mediation and the right to try, as has already been referred to. Indeed, many people facing the end of life and disease progress are desperate for a right to try and will say, "Even if it does not benefit me, I want to enter a trial of some

sort because the results will benefit other people". People are phenomenally generous when faced with real difficulties themselves.

I am very grateful to those who have highlighted the problem of children, because they have often been overlooked, as the noble Baroness, Lady O'Loan, pointed out. On average, one in 30 children is bereaved of a parent or relative. I remind the House that that means that one in 10 of all schoolchildren has suffered a major bereavement, because there are bereavements beyond those of parents and children. Again, it is in schools and so on that we need to have in-reach from specialist services to upskill teachers to cope, particularly when a whole class is bereaved. That happens, sadly, all too often.

The current bereavement services for children are there in the voluntary sector, and they are overwhelmed. They are coping with only the tip of the iceberg. That is the problem with the voluntary sector. On the investment to which the Minister referred. I remind her that Hospice UK data shows that the voluntary sector is now struggling, is having to cut back and is having to delay expansion and improvements to meet clear need even in the patches where we have voluntary sector hospices, because they are finding it so difficult to bring in the funds to meet the needs that they identify.

So, while all the Government's initiatives are to be applauded, and many services around the country and many thousands of patients are getting excellent care, we should not rest until we know that it is really available for everybody. We should not accept black holes. I am disappointed by the Government's response, but I am heartened by the support that I have had from around the House. I beg to move.

Bill read a second time and committed to a Committee of the Whole House.

House adjourned at 12.16 pm.