

I declare all my interests as listed in the register.

My lords, there are two certainties about life – we are all born, and we will all die. Everything else in between is variable.

No one would countenance having areas in England with no maternity services or even only rudimentary midwifery, without access to NHS specialist 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 die each year in England, about three quarters of these will not have a sudden death. These people of all ages need care with a palliative approach.

My Lords let me explain what general care with a palliative approach and specialist palliative care are and why we need both. It is just the same as with other disciplines – 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”

Such care, as a routine in most cases, should be within the competencies of clinicians generally, provided 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.

But some people have complex problems, crises suddenly arise, emergencies occur. And 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 by teaching, being involved in research and providing advice to other clinicians. Palliative care runs alongside efforts to control disease – palliative care addresses distress, pain and suffering. It is not *either* treatment *or* palliative care; it is balanced decision-making with patients. With early palliative care patients live better, and they live longer, at no additional cost overall.

My Lords, if the specialist services are not in place and available, then in a crisis you can't be referred to them and your clinicians can't even get advice on what to do.

Sadly, an estimated 92,000 people each year in England would benefit from palliative care yet do not receive any at all, either from specialist palliative care professionals or generalists. The family suffers too. 83% of carers, around 400,000 a year, suffer significant psychological morbidity – and some of these are child carers.

Cicely Saunders, the founder of modern palliative care, said that “the way a person dies lives on in the memory of those left behind”. My Lords, when a child is not adequately prepared for loss, when they see clinical services failing to respond because services are not available 7 days a week, that child's trauma is compounded.

In May 2015 the Health Service Ombudsman's thematic report found six themes in failings in England:

- Not recognising that people are dying, and not responding to their needs;
- Poor symptom control;
- Poor communication;
- Inadequate out-of-hours services;
- 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 (CCGs) about their contracting, particularly for specialist palliative care.

Only 29 stated the number of their patients with some level of palliative care needs. 163 CCGs commissioned 7-day admission to specialist palliative care beds, but the beds per population varied greatly. 83% commissioned 7-day specialist palliative care services in patients' own homes, but 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 correlated poorly with the CCGs reported needs – a variation not accounted for by differing demography or geography.

The 2019 National Audit of Care at the End of Life similarly found that only 47% of hospitals have commissioned services providing face to face 7-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 affect those of Black, Asian or minority ethnic backgrounds. Older people, despite multiple comorbidities, 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 a hospice – a shift away from hospital. In London, where care home deaths are low, more people have 3 or more emergency admissions in the last 90 days of life. These variations are laid out in Public Health England’s Atlas of variation for palliative and end of life care. The Atlas aims to reduce unwarranted variation to improve health outcomes and value – but are the commissioners listening?

These inequities don’t make economic sense quite apart from being just plain wrong.

Care aligned with patients wishes could potentially shift 10% of these hospital deaths, freeing up £75million of services for those who could benefit from hospital care, because we know our hospital system is breaking under 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 report entitled “Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage”. That report clearly demonstrates that palliative care is an essential component of any health care system.

Where people are cared for and die is influenced by the local options. Good quality, community-based palliative care increases the chance of death at

home, but that is not always possible or desirable, so that appropriate and high-quality palliative care must be available in all settings.

My Lords, in Wales in 2008 a report, led by Viv Sugar, set a national strategy. It required fair access to specialist palliative care. Its aim for 24/7 services everywhere wasn't affordable, so we settled for 7-day specialist services with 24/7 advice available to any health or social care professional. It was all underpinned by a funding formula, evolved with the support of the Noble Lord, Lord Wigley, distributing new funding of just over £2 per head of population. I don't claim everything is perfect in Wales, but the improvements have stood the test of time.

This process led to my previous Access to Palliative Care Bills.

I have listened to the government's comments. This shorter Bill respects CCGs' autonomy in decisions. It only requires CCGs to publish a strategy covering the expected needs of adults and children in its area, how these will be met, specialist services provided and data collected to monitor progress.

This Bill provides the legislative framework required to ensure that recent government initiatives, Marie Curie's Daffodil standards for General Practice, and Ambitions for Palliative and End of Life Care framework are met.

- 1. each person is seen as an individual;*
- 2. each person gets fair access to care;*
- 3. their comfort and wellbeing are maximised;*
- 4. care is coordinated;*
- 5. all staff are prepared to care;*
- 6. each community prepared to help.*

The concepts of compassionate communities, programmes with volunteers and many hospice outreach services contribute, but core clinical services must to be commissioned to meet need, working across administrative boundaries.

This Bill enables realisation of the NHS Long Term Plan, which states that ‘With patients, families, local authorities and our voluntary sector partners at both national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care’.

I beg to move.