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23 July 2019

Dear Nora

During the second reading of your Private Members Bill that took place on Friday 14 June, I agreed to write regarding those issues that were raised on the day that I was not able to respond to in full at the time. I am sorry for the delay in doing so. For convenience, I have responded to each of these issues under their respective headings below.

Mandating Services

I stated in my speech that no other area of clinical care is mandated in primary legislation in the way proposed in this Bill for palliative care. Baroness Hollins asked me to confirm if there are other services which are mandated in primary legislation and gave midwifery services as an example. I said it was my understanding that no other service was mandated in this way but I would be happy to write to clarify if this was not correct.

On the matter of there being other clinical areas in primary legislation, Baroness Hollins is correct. Officials of the Department of Health and Social Care have advised me that there are a small number of NHS services that are mandated in primary legislation, including midwifery services. These were set out in the NHS Act 1977, was updated by the NHS Act 2006 which replaced certain provisions, and most recently significantly revised by the health and social care act 2012. The list set out in 1977 remains in place. However, it remains the case that this Bill would seek to prescribe the duties of commissioners about palliative care in a way that goes far beyond existing provisions for any other clinical areas.

In the NHS Act 1977, there is a general duty on the Secretary of State to provide, "to such extent as he considers necessary to meet all reasonable requirements to provide facilities for the care of expectant.... Mothers". This is extent of the service description, which has since been amended to reflect it is a Clinical commissioning Groups'(CCGs) responsibility. In contrast, Baroness Finlay's Bill would require CCGs to ensure that people in their area have access to:

- pain and symptom management;
- psychological support for patients and the or relatives; and
- information regarding the patient's conditions and palliative care.

The Bill would also create a duty for all clinical commissioning groups to publish a palliative care strategy as required by the above description, encompassing:

- the anticipated level of population need;
- how that need will be met; and
- methods of data collection and reporting.

The Bill sets out that these strategies would have to be reviewed and re-published every three years.

As I set out in my speech, legislating in detail as to what a local commissioner of health services must commission is contrary to the principle of local autonomy, established in primary legislation through the Health and Social Care Act 2012

Under the 2012 Act CCGs commission maternity services as they do most other health services. NHS England provides guidance and support as it does with other clinical specialties, but this is set out in guidance not legislation. I hope this answers Baroness Hollins question.

Hospital Admissions that could be avoided if palliative care was available

Lady Meacher asked if I would write to the Department of Health and Social Care about how many hospital admissions could be avoided if palliative care was provided. I was very happy to do this. Officials have advised that unfortunately to date, there is not robust evidence on how many hospital admissions in total could be avoided if palliative care is provided. A number of studies have explored this area however and identified benefits of palliative care, including reduction in emergency admissions and more people dying at home but as far as I am aware there has been no overall assessment of the number of hospital admissions that might be avoided. Obtaining a clear picture in this regard is not straightforward, as it is also the case that admission to hospital at the end of life may not be preventable; both for clinical reasons, and according to patient preference. As a patients' condition deteriorates and symptoms become uncomfortable or problematic, they, and their loved ones may prefer a hospital setting.

Whilst greater care and support in the community is important in supporting patients nearing the end of life to die in a in a place of their choosing, it is also important to identify those patients who are approaching the end of life so that appropriate care and support planning can be put place. As outlined in my speech, these are two areas in which NHS England's activity is keenly focussed. The NHS Long Term Plan set out significant new investment of £4.5 billion in primary and community care, providing enhanced support to those with the greatest need. The plan also announced that training would be rolled out to help staff identify and provide proactive and personalised care planning for everyone identified as being in their last year of life. In addition, end of life care is one of the new quality improvement areas for the revised GP Quality and Outcomes Framework. This will embed best practice in caring for those at the end of life in primary care networks across the county.

NHS England is also keen to understand the extent to which people approaching the end of life are receiving appropriate support and has introduced a new metric which reports the proportion of people with three or more emergency admissions in their final 90 days of life.

The National Survey of Bereaved People

Lord Balfe and Lord Low raised the issue of the National Survey of Bereaved People. I understand that a timetable cannot be provided for the next publication of this survey.

Since 2012 the National Survey of Bereaved People (VOICES) survey has provided valuable insight into the quality of care delivered to people in the last three months of their lives, highlighting variations in the quality of care delivered in different areas of the country and to different groups of patients. Following publication of the last set of survey results in June 2016, NHS England held a consultation on the future of the VOICES survey to seek views on the approach and relevance of the survey to ensure that it remained fit for purpose. Whilst the response showed that the VOICES survey remained a valuable tool, most respondents indicated that the VOICES survey would be more helpful if the sample size were made large enough to report at a local commissioner level.

Following this, work was undertaken to revise the survey and consider approaches to a larger sample size and then put in place arrangements to re-commission the VOICES survey. NHS England has been involved in discussions with the Office for National Statistics (ONS), which collects the death registration data used to identify survey recipients, about arrangements for access to the data for the new survey.

However, changes to the safeguarding arrangements on data-sharing, designed to ensure any concerns about care raised via the survey can be appropriately investigated, have so far prevented this work from going any further. The ONS has strict confidentiality standards on the handling of data, and to date NHS England proposals to move this issue forward has not satisfied the requirements of the ONS. Pending resolution of this issue, NHS England remains committed to gather intelligence and feedback about end of life care and is exploring other means of gathering this feedback. This includes looking at the deployment of end of life care survey tools in local NHS Sustainability and Transformation Partnerships/Integrated Care Systems.

However, there are no plans that I am aware of to put the VOICES survey or other information on palliative care on a more statutory footing though information arrangements are always kept under review in all areas of healthcare.

Baroness Jolly amendment

Finally, as I said during the debate I would be very happy to meet Baroness Jolly to discuss her amendment dealing with those very sensitive cases where there is conflict between families of those needing palliative care and the doctors providing treatment.

I hope this letter addresses the points that were raised. I am copying this letter to those Peers who spoke during the debate and will also place a copy in the House library.

With very best wishes
Diana

BARONESS BARRAN

Baroness Finlay of Llandaff
House of Lords