House of Lords short debate on ensuring the Clinical Commissioners respect the undertakings made in 'Our Commitments to you for end of life care: The Government Response to the Review of Choice in End of Life Care' – 1 March 2017

27 February 2017

**What is the purpose of this briefing?**

To provide you with further information ahead of the House of Lords short debate on ensuring the Clinical Commissioners respect the undertakings made in *Our Commitments to you for end of life care: The Government Response to the Review of Choice in End of Life Care*.

**The Government response to the Review of Choice at the end of life**

In July 2016, The Government published their response to *A Review of Choice in End of Life Care* (known as the Choice Review). Their document outlined seven commitments made by the Government which when delivered would ensure people have control over the care they receive and shape it around their personal preferences at the end of life. This included but was not limited to choice about place of death.

The two commitments made by the Government that are most relevant to this debate are:

- To engage with clinical commissioning groups and Health and Wellbeing Boards on improving end of life care provision through local strategic planning and commissioning; and
- To provide commissioners with data, tools and palliative care currencies to help identify palliative care needs in local areas and the best ways to commission services to meet those needs.

**Patchy availability of palliative and end of life care**

In England, the provision of and access to palliative and end of life care in the community is extremely varied with some areas providing extremely high quality services and others providing very little access to palliative care in the community at all. This is reflected in strategic priorities:

- A Marie Curie analysis conducted in December 2015, found that 52% of all Health and Wellbeing Boards in England made no mention of palliative and end of life care in their Health and Wellbeing Strategies. Only 35% had comprehensive plans for caring for people at the end of life.
- Our analysis of Sustainability and Transformation Plans (STPs) in late 2016 found that around 30% had no mention of palliative or end of life care at all (this analysis included draft plans – we are working with the End of Life Care Coalition to produce an updated analysis).

Through the *Ambitions Framework*, NHS England have said that they require local leaders and local professionals to act and to ensure that there is a local strategy for palliative and end of life care in place. However, to the best of our knowledge, they have not audited this or required Clinical Commissioning Groups (CCGs) or STPs to include palliative and end of life
care in their strategies.

**Demographic change is putting more pressure on services**

Our concern is that this is going to lead to deeper inequity in who has access to palliative and end of life care services. Already about 1 in 4 people who need access to some form of palliative care miss out. We know this is likely to grow in the future because the number of people dying each year is rising and because people are dying older with more complex conditions.

The current approach from NHS England, where areas that do not have a strategic approach to palliative and end of life care are not challenged, is likely to create a ‘postcode lottery’ around palliative and end of life care, in which the place someone lives will determine the quality of care they get at the end of life.

Every CCG and STP should have palliative and end of life care as a strategic priority – after all, there is no CCG or STP area where people don’t die! A major challenge for NHS England is how they will change the behaviours of CCGs and STPs who do not consider end of life care a priority.

**Progress since the publication of the Choice Review**

NHS England has set up the National End of Life Care Programme Board, chaired by Sir Bruce Keogh, to take forward the recommendations of the Choice Review. The voluntary sector has representation on this Board.

While we welcome the creation of the board, we have doubts about how effective it will be without any funding. The Choice Review recommended a net investment of £130m in community palliative care services and social care services in order to ensure that more people can get home from hospital.

It is clear that at the moment the system simply does not have the capacity to provide community-based palliative care for everyone who wishes to be cared for out of hospital. Delayed transfers of care jumped 29% between September 2015 and September 2016. Research suggests about 30% of these people will be in the last year of life.

From our own services we are seeing more and more patients struggling to get out of hospital, sometimes with waits over two weeks, even when on the fast track continuing health care (CHC) programme that is meant to get people home within 24 hours. We have seen patients die in hospital after extended waits for access to care in the community.

It is unclear to us how the Government intends to support more people to get out of hospital at the end of life without additional money to boost capacity – we need more than warm words on this issue.

**About Marie Curie**

Marie Curie is the leading charity for people with a terminal illness and their families. We:

- Provide direct care to people in our nine hospices across the UK and in their own homes;
- Offer a dedicated information and support service to people affected by terminal illness;
- Run the UK’s largest research programme into improving care for people with a terminal illness and their families;
- Campaign to ensure that everyone living with a terminal illness and their families and carers get access to the care and support they need.
- Work as part of the end of life care coalition to ensure everyone can get high quality care at the end of life.
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