

## National Council for Palliative Care (NCPC) Briefing The Government's National Commitment For End Of Life Care

What does this mean for you? It confirms the need to get involved in your local Sustainability & Transformation Programme to promote end of life care

*"Our commitment is that every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected"* – **Ben Gummer MP, Parliamentary Under-Secretary for Care Quality 2015-16**

### End of life is defined as:

*Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:*

- a) advanced, progressive, incurable conditions;*
- b) general frailty and co-existing conditions that mean they are expected to die within 12 months;*
- c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition;*
- d) life-threatening acute conditions caused by sudden catastrophic events*

**Source:** Annex G: *"One Chance to Get It Right"* 2014<sup>1</sup>

### What is the National Commitment for end of life care and why is it important?

On 5 July 2016 the government published its new National Commitment for end of life care, in which it set out its vision and ambitions to improve end of life care in England, as well as a detailed policy programme to achieve them. This was contained in *"Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care"*<sup>2</sup>.

It is the way that the government decided to respond to *"What's Important to Me. A review of choice in end of life care"*<sup>3</sup> – the report of the independent board set up by government to advise on how people's quality and experience of care at the end of life could be improved, known as the 'Choice Review' published in February 2015.

It is aligned with the five Priorities for Care of the Dying Person set out by the Leadership Alliance for the Care of Dying People in *"One Chance to Get It Right"* 2014<sup>1</sup> and the *"Ambitions for Palliative and End of Life Care"*<sup>4</sup> outlined by the National Palliative and End of Life Care

Partnership in September 2015.

The government plans that the future of end of life care in England will be implemented in the context of wider changes to how healthcare is delivered as set out in the NHS Five Year Forward View.<sup>5,6</sup> It also states that improvements to end of life care should not occur in isolation and they should be threaded through the most effective New Models of Care<sup>7</sup> that will deliver the new, transformed NHS. Sustainability and Transformation Plans (STPs)<sup>8</sup> should fully take into account the contribution that sustainable, efficiently designed end of life care services can make to achieving better outcomes for dying people.

This is the most comprehensive national policy announcement about end of life care since the 2008 End of Life Care Strategy. It sets the agenda for end of life care for the rest of this parliament (due to run to 2020). It is the detailed programme against which government and public bodies should be held accountable.

### What are its objectives?

**“In making this Commitment, we are sending out the message that high quality personalised care has to be universal. We are determined to end variation in care due to geography, age, diagnosis, background or means. This is a national commitment to high quality care for all.”**

*Source: Page 11 Introduction: “Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care”<sup>1</sup>*

The National Commitment’s ambition is *“for everyone approaching the end of life to receive high quality care that reflects their individual needs, choices and preference”*

Two linked themes in particular underpin the government’s approach in making its National Commitment:

- 1. Universalism:** the government’s commitment is that everyone should have access to the right care in the right place at the right time, and that this should apply for children at the end of life as much as it should for adults.
- 2. An end to variation:** the government recognises that although many people receive excellent end of life care, that is not the case for everybody: *“our care of dying people is variable, haphazard and, at times shockingly poor”<sup>1</sup>* The National Commitment is clear that people’s access to high quality care should not vary by reason of their diagnosis, age, life circumstances, or where they are being cared for.

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<sup>1</sup> Ben Gummer MP, Parliamentary Under-Secretary of State for Care Quality, in his Foreword to the National Commitment

## What does the National Commitment actually say?

It sets out six commitments to everyone approaching the end of life. These are:

1. **honest discussions** about your needs and preferences
2. being able to make **informed choices** about your care
3. **personalised care plans** for everyone, to be reviewed and revised with you throughout the duration of your illness
4. the opportunity to **share your personalised care plans** with your care professionals
5. the **involvement of your family, carers and the people who are important to you** in discussions about your care, to the extent you wish
6. **knowing who to contact** at any time

## How is the National Commitment going to be delivered?

The National Commitment identifies more than 60 activities and projects that are intended to support its delivery. These will be carried out by organisations across the system, including the Department of Health (DH), NHS England, Public Health England (PHE), Health Education England (HEE), the Care Quality Commission (CQC) as well as within the voluntary sector. These have been grouped under seven themes:

1. More **personalised care**
2. Improving **care quality**
3. Identifying and spreading **innovation**
4. **Leadership and commissioning**
5. Improving end of life care **education, training and workforce provision & planning**
6. **Partnership working** with system partners and the voluntary sector
7. Strengthening **accountability, measurement and transparency**

Key actions within those seven themes include:

1. An emphasis on **integrated personal commissioning** and the development of **personal budgets** as tools to drive personalised care
2. Commitment to **digital record-sharing**, to enable people's personal care plans and wishes to be accessible and understood by their care teams. This will be achieved through roll-out of Electronic Palliative Care Coordination Systems (EPaCCS) in all areas by 2020, with inclusion of end of life care within the Summary Care Record as a minimum interim requirement, as well as links to the work of the National Information Board (NIB) to enable people to access and add information to their own records and plans
3. NHS England will ensure that **all its relevant major programmes - urgent and emergency care, cancer and dementia - include end of life care** as a key component
4. An extensive work programme for Health Education England on **strengthening competencies curricula and external workforce planning**

5. **Strengthened accountability for CCGs** through publicly available metrics. End of life care has been included in the CCG Improvement and Assessment Framework (CCG IAF). Initially the key indicator is tracking changes in percentage of hospital deaths within each CCG; these will be published on the MyNHS website. This will be replaced by a new metric, measuring progress on both choice and quality in end of life care, to be included in the CCG IAF by June 2018.
6. During autumn 2016, **NHS England and the DH will hold roadshows** across the country to showcase innovative practice in end of life care
7. NHS England will chair a **system-wide Governance Board**, involving statutory and voluntary sector partners, to oversee delivery of the National Commitment
8. The government will **publish an update on progress** towards achieving the National Commitment after one year

### **How does the National Commitment fit with other strategies and reports about end of life care?**

The National Commitment for end of life care is the way that the government decided to respond to *“What’s Important to Me. A review of choice in end of life care”*. The National Commitment is consistent with and strongly endorses *“Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020”*. It identifies the Ambitions framework for high quality care as being a core document for local health and care leaders and commissioners: *“we want to ensure that every local area commissions services that support the implementation of the Ambitions framework”*.

The government will be writing to Chairs of **Health and Wellbeing Boards** to ensure end of life care is at the forefront of their thinking. Hospice UK<sup>9</sup> recently reported that 57% of HWBs do not include the needs of dying adults and children in their key strategies that inform local service planning.

The national **End of Life Care strategy 2008** has not been formally superseded. However, it is now eight years old, and was published under a different policy and implementation architecture – before the advent of NHS England, Public Health England, HEE, HWBs and CCGs. It is best viewed as one of the vital stepping stones on the journey towards improving end of life care, with the Ambitions framework and now the National Commitment being the most recent and for the next few years the most relevant.

### **What about the Five Year Forward View and all the NHS transformation programmes?**

The National Commitment makes it clear that end of life care should be seen as a key component of all the major transformation programmes that the NHS is carrying out to improve services.

In particular, it states that local Sustainability and Transformation Plans (STPs) will be assessed on end of life care. A key thread in STPs is an ongoing need to focus on continuous improvement and innovation. This enables local end of life care providers, and other interested people and parties, to engage with their local STP leads<sup>10</sup> about how the local STP will improve end of life care and that local end of life care community should be involved in the creation and

implementation of local plans.. *“STPs should fully take into account the contribution that sustainable, efficiently designed end of life care services can make to achieving better outcomes for dying people”*

### **Did the government accept every recommendation of the Choice Review?**

The government accepted and acted on many of the recommendations of the Choice Review. Annex A of the National Commitment sets out the Review’s individual recommendations and the details of the government’s response to them.

The government did not accept the Review’s recommendation that an additional £130 million be allocated to end of life care in the 2015 Spending Review. Instead, ministers took the view that improving end of life care would be better achieved by making it a core priority within all of the NHS’s transformation programmes. This has some logic to it; centrally allocated funds would be heavily eroded by the time they reached frontline budgets. However the logic only holds good if end of life care does indeed become a core priority for the health and care system. NCPC’s experience is that there is a need for eternal vigilance to make sure it does not get left off local and national agendas. If this enables end of life care to be fully absorbed into the mainstream of NHS and social care practice and thinking, so that it is no longer siloed, that will be a good outcome.

In terms of the commitment that to the public that you will “know who to contact at any time” about your end of life care, the National Commitment identifies a variety of means by which this could be achieved, but does not recommend any one in particular. These include care coordinator models and named GPs. NCPC is working to develop models for care coordination as part of the National Commitment work.

The National Commitment recognised the key role that the Dying Matters coalition has in empowering the public to understand and discuss dying. However it had little to say about public health approaches to palliative care. Hence the importance of the National Commitment’s endorsement of the Ambitions framework, which includes “each community is prepared to care” as one of its six ambitions, with public health approaches and community development being a key component of that. This is one of the most important areas for practice innovation.

## What will NCPC be doing?

NCPC is leading or supporting a number of the work programmes and contributing to evidence based practice and co-design that will support the National Commitment. These include:

1. Developing the Ambitions partnership website into a knowledge hub to share good practice models
2. The Building on the Best programme to improve end of life care in acute hospitals
3. Identifying a variety of asset based approaches to education and training
4. A public awareness campaign on the benefits of record-sharing
5. Identifying care coordination models
6. Identifying and evaluating examples of 24/7 access to palliative and end of life care models
7. Exploring barriers and enablers to providing pain management for people at home at the end of life
8. NCPC Community Pathfinders are implementing the new Dying Well Community Charter
9. Making a film to prepare and empower people to have discussions about end of life care with clinicians

NCPC will also be working with its voluntary sector colleagues in the End of Life Care Coalition of charities<sup>2</sup> to support the implementation of the National Commitment, including providing practical support for individual work programmes. We will also be maintaining our campaigning pressure on the DH and other statutory bodies to make sure that the ambitions of the National Commitment genuinely do deliver improvements in end of life care for everyone.

Finally, Ben Gummer MP, who was the minister responsible for end of life care at the time the National Commitment was published, has been moved to a new role in the Cabinet Office following Theresa May becoming Prime Minister and the subsequent reshuffle. The new minister for end of life care is David Mowat MP. NCPC and the End of Life Care Coalition have written to him about the National Commitment and hope that he will be able to maintain and increase the momentum behind it.

This short briefing was written by Simon Chapman, NCPC's Director of Policy & External Affairs & Sally Picken, NCPC Associate. We hope that you have found it helpful. We would very much like to know your thoughts on the National Commitment and how it is being implemented. Please e-mail us with any comments or questions at [policy@ncpc.org.uk](mailto:policy@ncpc.org.uk)

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<sup>2</sup> The End of Life Care Coalition of charities is: NCPC, the Cecily Saunders Institute, Hospice UK, Macmillan Cancer Support, Marie Curie, the MND Association and Sue Ryder

## References

- <sup>1</sup> Leadership Alliance for the Care of Dying People (2014). ***One Chance to Get it Right***. London: LACDP. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf).
- <sup>2</sup> Department for Health (2016). ***Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care***. Available at: <https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response>
- <sup>3</sup> Department for Health (2015). ***What's Important to Me. A review of choice in end of life care***. London: DH. Available at: <https://www.gov.uk/government/publications/choice-in-end-of-life-care>
- <sup>4</sup> National Palliative and End of Life Care Partnership (2015). ***Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020***. London: NHS England. Available at: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>
- <sup>5</sup> NHS England (2014). ***Five Year Forward View***. Available at <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
- <sup>6</sup> NHS England (2015). ***Delivering the Forward View: NHS planning guidance 2016/17 – 2020/21***. London: NHS England. Available at: <https://www.england.nhs.uk/wp-content/uploads/2015/12/planning-guid-16-17-20-21.pdf>.
- <sup>7</sup> NHS England (2106). ***New Care Models of Care: Vanguard - Developing a blueprint for the future of NHS and care services***. Available at: [https://www.england.nhs.uk/wp-content/uploads/2015/11/new\\_care\\_models.pdf](https://www.england.nhs.uk/wp-content/uploads/2015/11/new_care_models.pdf)
- <sup>8</sup> NHS England (2015). ***Sustainability and Transformation Plans***. More details available at <https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/stp>
- <sup>9</sup> Hospice UK (2016). ***"A low priority? How local health and care plans overlook the needs of dying people"*** Available at: <https://www.hospiceuk.org/media-centre/press-releases/details/2016/05/19/needs-of-dying-people-not-a-priority-for-many-health-and-wellbeing-boards-and-clinical-commissioning-groups>
- <sup>10</sup> STP leads are published here <https://www.england.nhs.uk/2016/03/leaders-confirmed/>
- <sup>11</sup> Page 33 <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>