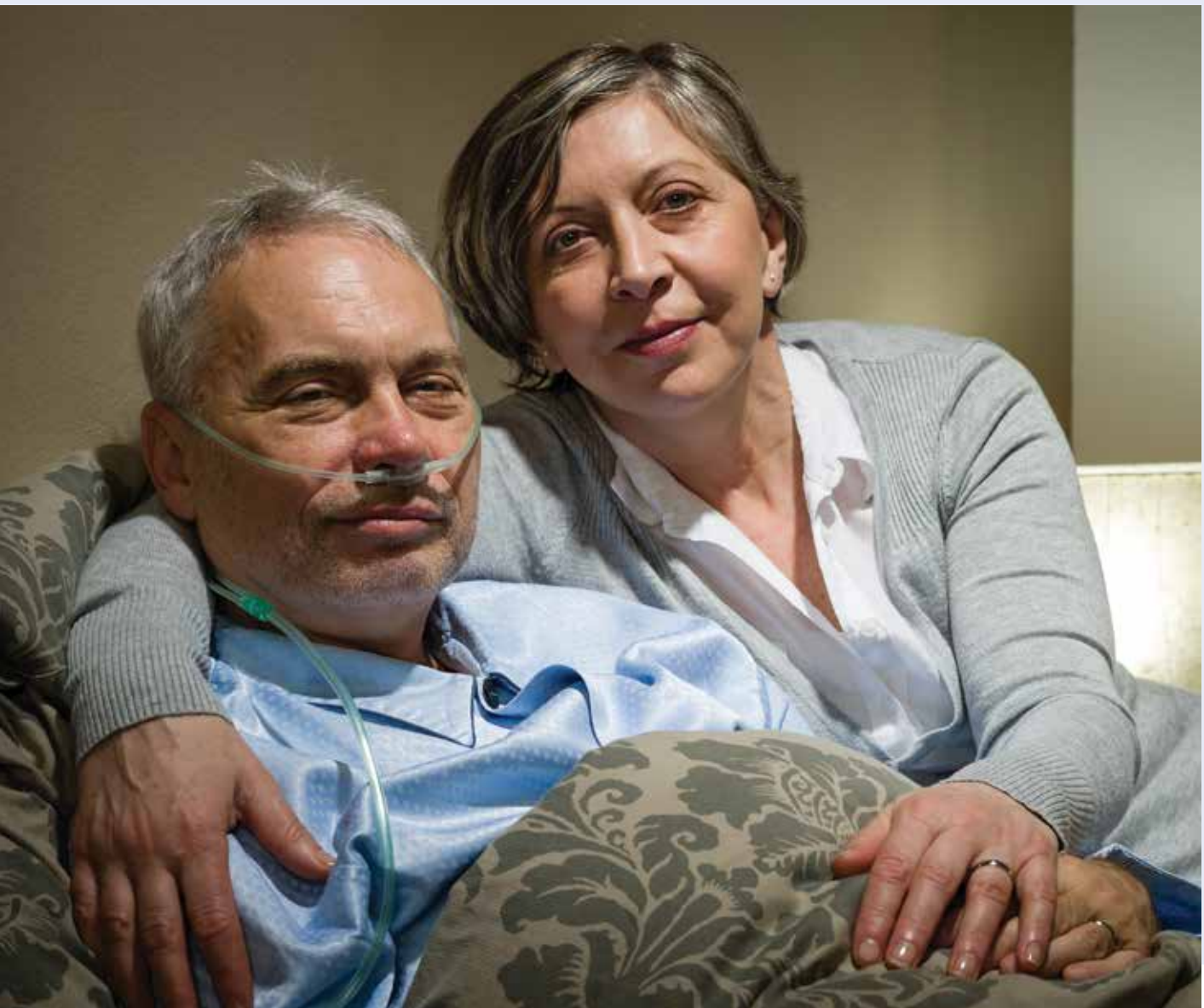


# On the brink

## The future of end of life care



The End of Life Care Coalition



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## The End of Life Care Coalition



We want to ensure that people **get the right services**, at the right time, in the right place.



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We are a coalition of seven major charities with considerable experience of supporting and understanding the needs of people approaching the end of their lives and their families and carers. We have been working together to highlight the lack of choice and the variable quality of care available to dying people and their families and carers.

The End of Life Care Coalition believes everyone should have greater choice and control over the things that are important to them at this point of maximum vulnerability in their lives.

This means putting into practice a comprehensive and consistent approach to end of life care that offers and fulfils individual choices and preferences, and helps to overcome the fear of lack of control that many feel at this difficult time.

We want to ensure that:

- people get the right services, at the right time, in the right place;
- people's preferences are heard, recorded, shared and acted upon;
- people receive support from health and care professionals who can deliver care with expertise and compassion; and
- people are informed about the treatment and care available to them, their condition, and how this might affect them over time.

We will continue to campaign until these ambitions are realised for everyone.

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## It is an inevitable fact that everyone will die. The vast majority of us will also care for someone who is dying

We all hope for a 'good' death and our health and care services have a duty to help us achieve that by delivering the best care for people approaching the end of their lives.

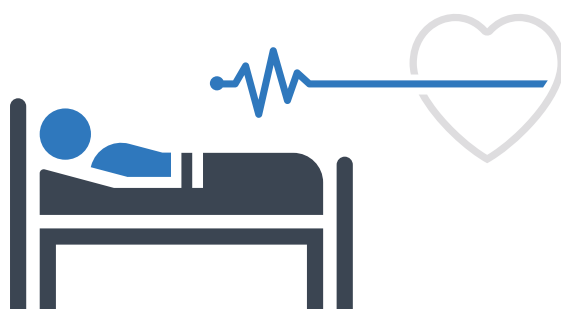
But today, too many people experience poor care as they approach the end of their life and die in hospital when they would rather be at home, in a care home or in a hospice.

“ The experience that people approaching the end of life have varies and in too many cases is unacceptably poor.

HEALTH SELECT COMMITTEE March 2015

“ End of life care is, sadly, a recurring and consistent theme in our casework... we see tragic cases where people's suffering could have been avoided or lessened with the right care and treatment as they approached the end of their lives. The anguish that this causes them and their loved ones is unimaginable.

PARLIAMENTARY AND HEALTH SERVICE OMBUDSMAN  
DYING WITHOUT DIGNITY May 2015



Since the Choice Review was published an estimated **48,000 people** in England have died with poor end of life care.<sup>1</sup>

In July 2014, recognising that end of life care was too poor for too many, the Government commissioned an independent expert review, *A Review of Choice in End of Life Care* (also known as the Choice Review). In February 2015 – after extensive consultation – the findings were published. The final report set out a comprehensive vision showing how end of life care services need to be reformed to give people greater choice and higher quality care at end of life.

### Key recommendations in the Independent Choice Review

- Establishing a 'national choice offer' focused on an individuals' end of life care needs by April 2020
- Establishing 24/7 end of life care outside of hospital in all areas by 2019
- Implementing shared electronic end of life care records by April 2018 in all areas
- A named responsible senior clinician for all people approaching the end of life
- Greater joint working to identify people who may need end of life care as early as possible
- A named responsible care coordinator for all people approaching the end of life

The Government has welcomed the Choice Review but we are still waiting for them to announce what they are planning to do.

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## Why are so many people dying in hospital rather than in the place they want to be?

One of the key elements of the 'choice offer' for people approaching the end of their lives is the opportunity to choose where they are cared for and where they die. Almost 470,000 people died in 2014 and over 220,000 of them died in hospital.<sup>2</sup> However, the latest survey of bereaved carers shows us that only 3% of those who stated a preference wanted to die in hospital.<sup>3</sup>

While there may be many reasons why someone is not able to die in their place of choice, too many people are not given any say in where they die.

According to the survey, over a third (37%) of people whose relative or loved one died in hospital **did not think they had enough choice** about where they died.<sup>3</sup>

“ At the moment, when it comes to making sure that people's last choices are met, we are too often failing them.

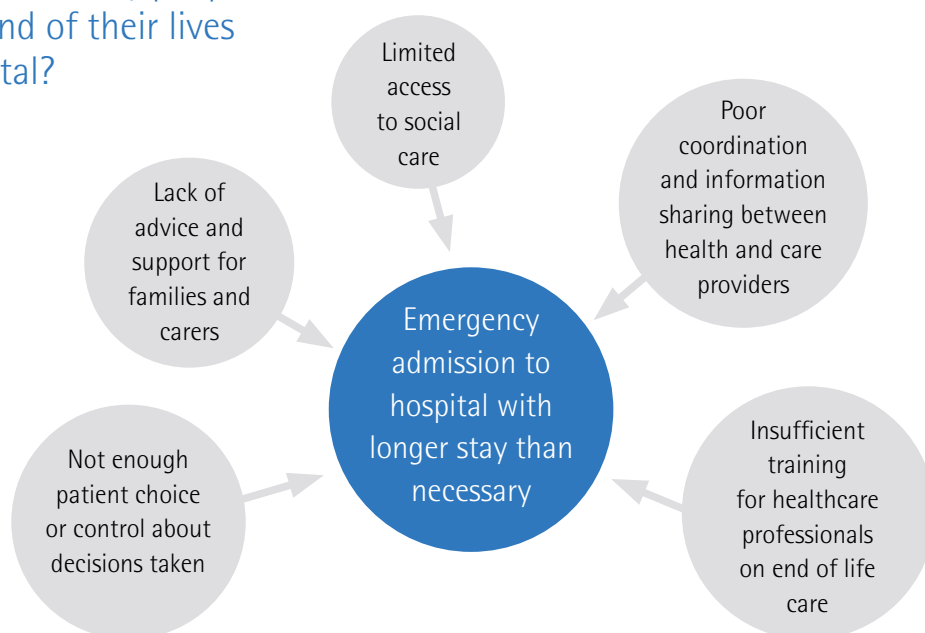
**CLAIRE HENRY MBE**

CHAIR OF THE CHOICE IN END OF LIFE CARE REVIEW BOARD

February 2015



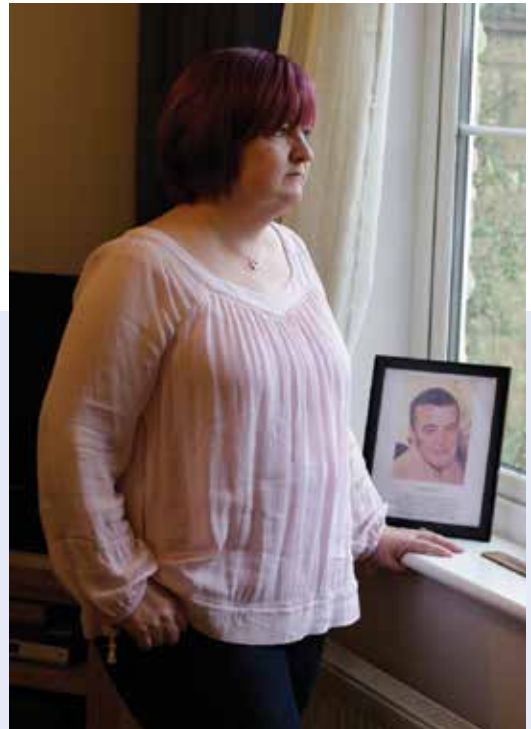
## Why are so many people at the end of their lives in hospital?



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### Marie's experience

"My brother Dave assumed he would be able to die at home. But I don't think any of us really knew what that meant – how his life would go and how he would die. Support services often weren't joined up. District nurses and carers working for different providers meant they weren't getting the same information the whole time, leading to mix ups with Dave's pain medication. Nursing someone at the end of their life is a privilege. To be able to make that as comfortable as possible for someone is the most important thing you can do. This should be possible for all families, carers and loved ones."



Almost 90% of those who die in hospital do so **following an emergency admission**,<sup>4</sup> but better support in the community could help prevent unnecessary admissions.

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## More choice and support for community services = fewer hospital admissions

Too many people approaching death are forced to spend long periods of time in hospital due to a lack of social care or alternative support options in their community. This is unsustainable.

Hospital admissions are rising to unsustainable levels across the country.

- In 2013–14, NHS hospitals in England admitted on average over 1,000 more patients per day than the previous year<sup>5</sup>
- In the first weekend of December 2015, 12 hospital trusts were unable to admit any more patients after running out of beds<sup>6</sup>

There are frequent reports of hospitals going on 'black alert' – meaning they cannot cope with the number of patients arriving at their doors. In December 2015, the majority of London's 18 trusts with A&E departments were said to be on 'black alert' on a daily basis.<sup>7</sup>

Frequently, a person approaching the end of their life may have a perfectly normal change in their symptoms, such as a change in breathing, which panics their family or carer. Due to a lack of advice or support services for families and carers, they are left with no option than to dial 999 and trigger a potentially unnecessary emergency admission.



### Nikki's experience

"It was my mother's dearest wish to die at home. We did everything we could to make this happen but it was challenging accessing the right support at the right time. I had immense difficulty getting the GP and health centre to take mum's situation seriously. It was only after repeated calls and visits to the health centre that I finally got a nurse to visit mum at home. While I totally agree that people should be able to choose where they want to die and it was comforting to know that I could give her that, it doesn't end there, families need to be properly supported. We need to have access to good quality advice any time, day or night. That's vital to help people die well."

In 2013–14, NHS hospitals in England admitted on average **over 1,000 more patients per day** than the previous year.<sup>5</sup>



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## It is critically important to support people approaching the end of their life

Over the last 50 years, there has been an increased medicalisation of dying that in many cases is not necessary. If the advances in palliative and specialist palliative care could be harnessed, more people could have a comfortable death in their homes or in a community-based setting.

In England in 2014, approximately 220,000<sup>8</sup> people died in hospital. We know that those who die in hospital spend an average of 13 days there.<sup>4</sup> Using these figures, we can estimate that people at the very end of their lives accounted for more than 2.86 million bed days – many of which would have been potentially unnecessary and unwanted.

Keeping people in hospital when they do not need or want to be there is also expensive. Hospital care in the final three months of life is estimated to cost an average of £4,500 per person who dies and the costs of care increase rapidly in the last weeks of life.<sup>9</sup>

Shifting care to out of hospital settings is often both better for patients and families and more cost-effective.

In its evaluation of the Marie Curie Nursing Service, the Nuffield Trust found that people who were cared for by a Marie Curie Nurse had total care costs of around £500 lower per person, even allowing for the commissioning costs of home based nursing support.<sup>10</sup> Most of the savings came from avoiding hospital costs. Only 8% of Marie Curie patients died in a hospital compared to 42% of people without a Marie Curie Nurse. Only 12% of Marie Curie patients experienced an emergency admission to hospital compared to 35% of people without a Marie Curie Nurse.<sup>9</sup> We think these results can be replicated by other palliative care nursing services.



If half of those who died in 2014 were given access to a service in the community that facilitates choice, an estimated over **£100 million could be saved.**<sup>11</sup>

### Helen's experience

"My father was diagnosed with Motor Neurone Disease (MND) and died seven weeks later in hospital. He didn't receive the care that he should have done either at home or in the nursing home. I feel very strongly when someone is diagnosed with a terminal illness palliative care should be offered straight away and it should be available in all settings - at home, nursing home, hospital or hospice. The nature of palliative care means that the whole person is cared for not just clinically but psychosocially and it can provide much needed support and care for family members including grief and bereavement. This would have been an incredible help for my whole family in what were very distressing circumstances."



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## What would make the difference?

Our organisations have considerable understanding and experience of ways to better deliver care at the end of life.

We fully support the independent Choice Review's comprehensive report and detailed recommendations to enable the introduction of a 'national choice offer', which would ensure good quality care for everyone approaching the end of their life.

To deliver this, we are calling for:

1. Well-funded high quality care available both inside and outside hospital for all who need it
2. Investment in palliative care specialists and generalist health and social care professionals with the knowledge, understanding and time to deliver choice and provide high quality care for people at the end of their lives
3. Access to good quality advice and support, including out of hours, to provide families and carers with practical assistance and guidance if the person they are caring for has a change in symptoms or needs additional help
4. Fully co-ordinated and integrated care across all teams and services supporting a person at the end of their life, including fair access to social care, using appropriate care plans in a joined-up way
5. Training for all health care professionals, so they know how to support someone approaching the end of their life confidently and sensitively
6. A higher proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families; currently it stands at just 0.1 per cent, or 10p in every £100.<sup>12</sup>



We can estimate that people at the very end of their lives accounted for more than **2.86 million bed days**.<sup>13</sup>

As a coalition of charities we are working hard to achieve these goals.

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### Tony and Dorothy's experience

"Our son's discharge was clearly the result of fully integrated consultation and co-operation conducted in the 16 hours between 4.30pm on one day and 8.30am on the next... as a result of [the Macmillan nurse] coordinating his discharge and support, Neil had a good death and our memories of his final hours are much more positive than they would have been had he died in hospital."



Providing high quality end of life care in the community is often both **better for patients and families** and more cost-effective.





Well-funded, high quality care available both inside and outside hospital for all who need it.

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- 5 Difference in annual admissions to English NHS Hospitals and English NHS commissioned activity in the independent sector between 2013-14 and 2014-15 divided by 365 days. Health and Social Care Information Centre. *Hospital Episode Statistics, Admitted Patient Care - England, 2014-15 and Hospital Episode Statistics, Admitted Patient Care, England - 2013-14*.
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- 13 Macmillan estimate based on the deaths in England in 2014 (Office for National Statistics. 2015. *Deaths by place of occurrence*. <http://www.ons.gov.uk/ons/about-ons/business-transparency/freedom-of-information/what-can-i-request/published-ad-hoc-data/health/november-2015/deaths-by-place-of-occurrence--england-and-wales--and-welsh-local-authorities-2014.xls> accessed January 2016) and the average number of days people who die in hospital spend there (National End of Life Care Intelligence Network. *What we know now 2013, New information collated by the National End of Life Care Intelligence Network. November 2013*)

