

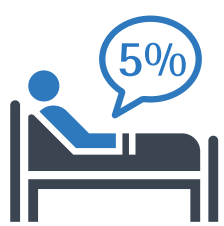
# Better care at the end of life


Three million people will die over the course of the next Parliament. Millions more will be bereaved. Yet there are significant variations in the quality of care that people experience depending on where they are.

There is an urgent need to improve end of life care in every setting and increase co-ordination between services.


We are campaigning together to call on the next Government to ensure people can access better quality care and support as they approach the end of their lives.

Around 50 per cent of people in the UK die in hospital. Fewer than 5 per cent of people say they want to die in hospital<sup>1</sup>






Hospital costs at the end of life can be more than five times the cost of social care in the community<sup>2</sup>




Polling of health and social care professionals finds that 73% agree that some of the money spent providing acute end of life care in hospitals could be better spent on free social care in the community<sup>3</sup>

Fewer than one in ten CCGs specifically commission dedicated nurse-staffed palliative support, advice and co-ordination for dying people, their families and carers on a 24/7 basis<sup>4</sup>



Just 10p in every £100 goes to research concerned with end of life care and terminal illness<sup>5</sup>





There is consensus on what needs to change. Now is the time for action. We are calling on every political party to urgently prioritise improving the quality of care for people approaching the end of their life.

WORKING IN PARTNERSHIP



Cicely Saunders International: Registered Charity No. 1087195; Hospice UK: Registered Charity in England and Wales No. 1014851, and in Scotland No. SC041112; Macmillan: Registered Charity in England and Wales No. 261017, Scotland No. SC039907 and the Isle of Man No. 604; Marie Curie: Registered Charity in England and Wales No. 207994 and in Scotland No. SC038731; Motor Neurone Disease Association: Registered Charity No. 294354; The National Council for Palliative Care: Registered Charity No. 1005671; Sue Ryder: Registered Charity in England and Wales No. 1052076 and in Scotland No. SC039578

This can be achieved by:

## 1 Making social care free and fast for terminally ill people and their families

At the moment, terminally ill people and their families wait weeks or even months for social care from their local authorities or exhaust their finances by purchasing their own care. Some will die waiting. Yet the Nuffield Trust estimates that hospital costs at the end of life can be more than five times the cost of social care and that higher social care costs are associated with lower levels of hospital admissions. Using the Marie Curie nursing service as an example, the Nuffield Trust found that where people at the end of life have access to social care and community nursing, costs were around £500 lower, even allowing for the commissioning costs of home-based nursing support.<sup>2</sup> Every expert review that has considered free social care at the end of life has seen the benefit of a reformed system, and seven out of 10 MPs support free social care at the end of life.<sup>6</sup>

## 2 A commitment to introduce 24/7 advice and support for terminally ill people and their families, wherever they are

One of the main reasons terminally ill people end up in hospital is because their condition changes in a perfectly normal way – such as a change in breathing – late at night, and their family panic with no one to turn to for advice. They end up calling emergency services and the terminally ill person is taken to hospital, often without any real need to be there. Only eight per cent of CCGs specifically commission dedicated nurse-staffed palliative support, advice and co-ordination for dying people, their families and carers on a 24/7 basis.<sup>4</sup> This has to improve because we can't choose what time of day we die.

## 3 Accelerating co-ordination between services

Too often important medical information about a terminally ill person and their family does not go with them when they enter a new care setting (like making the transition from hospital to care home). The new care provider has to start from scratch and this is often where crisis situations develop. This can land the terminally ill person back in hospital even though they don't want to be there. Every party is exploring ways to better integrate health and social care. End of life care is the logical place to start given the number of services that people who are terminally ill come into contact with and that the consequence of poor co-ordination can be unplanned and unnecessary hospital admission.

## 4 Increasing the proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families

Just 0.1 per cent of the total medical research budget (10p in every £100) goes to research concerned with end of life care and terminal illness.<sup>5</sup> Yet all of us die, often with a progressive illness, and all of us would benefit from better end of life and palliative care. The quality of care that can be offered to terminally ill and dying people and their families is limited by our knowledge. The more we know, the better the care that can be provided to people.

## 5 Improving data collection to improve care

Recent reports have highlighted deficiencies in care for people who are terminally ill. One of the barriers to improving care is a lack of feedback from patients and their families about their experiences and outcomes of care. Without this information, the NHS cannot properly plan great care for all people who are terminally ill. Real-time, electronic feedback, where it is possible, is a powerful tool and needs to be used extensively in hospitals, hospices, care homes and care at home services – this should be in place and used to drive improvement across the whole of the UK.

**We will all need end of life services. Most of us know someone who needs them now. As a society we have a responsibility to make them the best they can be.**

Collectively and individually our organisations have lots of ideas on how to deliver these policy recommendations to improve the care and support of people approaching the end of their lives. To find out more or to support the campaign please go to [www.endoflifecampaign.org](http://www.endoflifecampaign.org) or contact [eol@incisivehealth.com](mailto:eol@incisivehealth.com) who will make sure to direct you to the relevant organisations.