
END OF LIFE CARE COALITION

Statement on End of Life Care and the Long-Term Plan for the NHS

The case for improving end of life care

Improving end of life care must be a prominent part of the NHS Long Term Plan. It will help the health and care system deliver its broader system priorities, increase efficiency in the use of finite resources, and deliver better outcomes for people and families.

Too many people experience poor care as they approach the end of their lifeⁱ. Many dying people spend their last months and weeks in hospital – even though most of them do not want or need to be there. On average, people in their last year of life are admitted to hospital 2.28 times and have over 30 bed days in hospital – some have many more.ⁱⁱ Not only is this distressing for patients and their carers, but it also drives up costs for the NHS.

Good end of life care is a high value intervention: it improves outcomes for patients and carers, at the same or lower overall cost to the NHS.

The NHS Long Term Plan presents a crucial opportunity to address the unmet need of people approaching the end of life, while improving costs and efficiency for the NHS. The need for high quality end of life care over the next decadeⁱⁱⁱ is projected to increase dramatically, so this opportunity must not be missed.

Community-based end of life care plays a critical role

Community end of life care is one of the few interventions shown to be effective in reducing reliance on emergency and acute care, largely through preventing avoidable emergency admissions. In England there were over 1.5m Emergency Admissions for people in the last year of life in 2016, accounting for 9 million days spent in hospital at a cost of £2bn to the NHS.^{iv} Emergency admissions for people approaching the end of life are increasing.^v NHS costs are projected to double in the next 20 years. High quality palliative care could result in 60,000 fewer deaths in hospital, saving over £180 million each year^{vi}.

Despite this, community end of life care is still under-resourced, poorly coordinated and a low local priority for those planning future health and care services.

There is a critical need for better out of hospital care to ensure every person approaching the end of their life, and their family and carers, has access to appropriate care, treatment and support. Without the right investment, strategic planning and prioritisation, the NHS will continue to see unnecessary rising emergency admissions and delayed transfers of care – with negative impacts across the health and care systems.

The NHS Long Term Plan work presents an excellent opportunity for workstreams within NHS England to support the delivery of improvements in end of life care for everyone, reducing people's reliance on acute settings for care.

We know that where interventions to improve care have been implemented:

- Provision of palliative care to patients with cancer leads to a reduction in repeat emergency admissions in their last 30 days of life compared to those without^{vii}
- Services such as the Macmillan Specialist Care at Home can lead to fewer A&E attendances and fewer days in hospital^{viii}
- Services such as the Marie Curie's Nursing Service can result in reduced hospital care costs of £1,140 per person due to a 58% reduction in emergency admissions^{ix}

The need for strong leadership persists

In July 2016, the Government published ‘*Our commitment to you for end of life care*’. It outlined over 50 commitments around end of life care, including to support people to have honest discussions with care professionals about their needs and preferences, make informed choices about their care, and develop personalised care plans. Progress since then has been limited, with few tangible outcomes.

This is particularly visible in a lack of engagement from STPs. An analysis of STP plans undertaken by the End of Life Care Coalition showed that over 40% of local STPs have little or no focus on end of life care^x.

Given the crucial role STPs are playing in driving forward change in local health economies, this represents a missed opportunity to bring about the type of service changes that are needed in end of life care – namely, a shift in resource out of hospitals and into community settings. In order for choice at the end of life to be realised, it is crucial that it is made a priority in long-term planning for the NHS to ensure adequate resource to meet the rising need and demand on services.

The End of Life Care Coalition is calling for high quality, personalised care for people approaching the end of their life, wherever and whenever they need it. We maintain that the Long Term Plan for the NHS in England, must demonstrate a reinvigorated commitment to improving coordination of care between services, providing a range of high quality community care options and improving the quality of end of life care in hospital

What would make the difference?

Embedding the priorities of the National End of Life Care Commitment into the NHS Long Term Plan would help deliver integrated and personalised care and support for people approaching the end of their life. It would also enable the health and care system to be more resilient in its response to demographic change over the next 10 years.

As a coalition of charities, we also believe that it is important to deliver:

1. Investment in community-based services providing end of life care, to ensure that the right care is available, regardless of care setting, for people approaching the end of their lives.
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 coordinated 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. Further investment in systems such as EPaCCS to improve the recording and sharing of information relating to peoples’ preferences for end of life care.
7. 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 percent, or 10p in every £100^{xi}.

ⁱ The End of Life Care Coalition, *On the brink: The future of end of life care*, 2016, available at <http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf>

ⁱⁱ Nuffield Trust, *Shifting the balance of care*, 2017, available at: <https://www.nuffieldtrust.org.uk/files/2017-02/shifting-thebalance-of-care-report-web-final.pdf> (accessed September 2018)

ⁱⁱⁱ Etkind S et al, *How many people will need palliative care in 2040? Past trends, future projections and implications for services*. BMC Medicine, May 2017

^{iv} Marie Curie, *Emergency admissions: Data briefing*, Mar 2018, available at <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/emergency-admissions-briefing-paper-2018.pdf>

^v Sleeman KE et al, *Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data*. Alzheimer's and Dementia, Jan 2018

^{vi} Nuffield Trust, *Shifting the balance of care*, 2017, available at: <https://www.nuffieldtrust.org.uk/files/2017-02/shifting-the-balance-of-care-report-web-final.pdf> (accessed August 2017)

^{vii} Henson LA et al, *Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis*. Journal of Clinical Oncology, Feb 2015

^{viii} University of Nottingham, *Macmillan Specialist Care at Home: Independent Evaluation*. November 2016.

^{ix} Chitnis X et al, *The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life*, Nuffield Trust, 2012

^x *End of Life Care Coalition analysis of STP plans*, 2017

^{xi} UK Health Research Analysis 2009/10 *UK Clinical Research Collaboration 2012*.