

Macmillan briefing on free social care at the end of life

Briefing for: People interested in choice at the end of life

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Date created: July 2014

The case for free social care at the end of life

We only get one chance to get the care right for someone at the end of their life. Yet people are often failed by a system ill-equipped to allow them to choose where they die. A finding of the Palliative Care Funding Review (PCFR) was that providing free social care to people at the end of life is key to allowing them to die in their preferred place of care.¹

The vast majority of cancer patients (73%) want to die at home. However, less than a third (29%) are able to. Macmillan estimates that in 2012 **36,400 cancer patients died in hospital in England when they would have preferred to die at home and if nothing is done then by 2020, another 220,000 will also have their dying wishes ignored.**

The Government stated in the Care and Support White Paper that it sees “**much merit**” in the principle of free social care at the end of life and committed to collect data through the PCFR pilots to make the economic case. Subsequently, the Joint Committee on the Draft Care and Support Bill called for free social care at the end of life to be introduced at the “**earliest opportunity**”.

During the Care Bill’s passage through Parliament the Care Services Minister, Norman Lamb, went as far as saying: *“I am not in a position to commit the Government, but, as the responsible Minister... I am determined that we achieve that objective.”*

However, **the Opposition has gone further** with Andy Burnham, Shadow Secretary of State for Health, confirming the Opposition’s commitment to the policy during his 2013 Conference speech: *“So we work to give people the right to be at home, with family around them and social care free as part of that”.*

Free social care at the end of life also has **strong support from key stakeholders** including the Dilnot Commission, patient groups and commissioners. The most recent Barker Commission said that there is a ‘strong case’ for free social care at the end of life. 73% of health and social care decision makers agree that some of the money spent looking after people at the end of life in hospital could be better spent providing more free social care services. **84% of MPs** believe the Government should do more to prevent people from dying in hospital, with **7 out of 10** supporting free social care at the end of life.

With the PCFR pilots expected to report in autumn 2014, we are keen to see a Government decision before the end of this Parliament on funding social care for people at the end of life. We also want the Opposition to actively support the policy.

‘We really needed some support with the practical side of life. Adrian struggled with even the most basic of tasks, such as tying his shoelaces. I was working full-time while trying to see as much of him as possible, and my mum was trying to keep our family business going at the same time as caring for Adrian. As a family, we really needed that extra support to give us more quality time with Adrian in his final weeks of life.’ **Vikki, who cared for her dad at the end of his life**

¹ Hughes-Hallett, T.; Craft, A.; Davies, C, 2011, Palliative Care Funding Review

The cost savings of delivering end of life care in the community

In a [new report](#), Macmillan estimates the potential savings of introducing free social care at the end of life, here is the data along with further evidence to support the policy:

- The average end of life hospital stay is 12.9 days², Macmillan estimates the **average cost of a final hospital stay is £3,770 while the cost of being at home is £1,870³**.
- 81% of people who died in England in 2012, who expressed a preference, wanted to be at home. In that year there were just under 229,000 deaths in hospital, we estimate that 181,780 people died in hospital in 2012 who would have preferred to die at home.
- This means that £69m is currently wasted on unnecessary hospital care for cancer patients at the end of life who would prefer to be at home, this increases to a potential saving of **£345m per year** for everyone at the end of life.
- Specifically for people living with cancer, if nothing is done then by 2020, 220,000 people with cancer in England will have died in hospital who wanted to die at home.

By helping to streamline services, facilitate timely hospital discharge and reduce avoidable admissions, one Northamptonshire Macmillan Social Care Coordinator **saved 466 bed days helping 228 patients at the point of hospital discharge in 2009/10, a saving of £149,586.**

- Higher levels of social care costs at the end of life lead to lower healthcare costs.⁴
- A significant proportion of those who die in hospital could be supported to die at home.⁵
- An April 2014 ICM poll of health and care professionals found three quarters agree that **money spent on people at the end of life in hospital could be better spent providing free social care**. Two thirds think **free social care at the end of life for everyone would lead to a saving** in the end of life health and social care budget.
- The poll also spoke to commissioners, one said: *'[free social care at the end of life is] likely to free up some of the acute beds... I mean, that's what costs us a huge amount of money. There are very tangible benefits by avoiding [unnecessary admissions].'*

Macmillan's report is available to view here:

www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/EndofLifereport-June2014.pdf

Implementing free social care at the end of life

Macmillan, with a coalition of charities, commissioned research into what free social care at the end of life might look like. The research found variability in the provision of social care at the end of life. If this policy is going to be implemented, the report recommends:

- More robust data to help commissioners monitor outcomes and also to help identify groups which are more likely to be neglected at the end of life.
- Raising confidence and awareness of commissioners, clinicians, patients and the public about entitlement, best practice and what services are available.
- A commitment to quality and outcomes-focused person-centred care through quality standards, guidance and mandatory training.

The report, published by OPM, is available to view here:

<http://www.opm.co.uk/wp-content/uploads/2014/06/How-could-free-social-care-at-end-of-life-work-in-practice.pdf>

**For further information please contact Tim Windle, Public Affairs Officer,
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² <http://www.endoflifecare-intelligence.org.uk/view?rid=771>

³ Macmillan Cancer Support, *Can we live with how we're dying?* June 2014

⁴ http://www.nuffieldtrust.org.uk/sites/files/nuffield/social_care_and_hospital_use-full_report_081210.pdf

⁵ <http://www.centreforwelfarereform.org/uploads/attachment/303/health-efficiencies.pdf>