

Macmillan briefing on free social care at the end of life

Purpose: To provide a briefing on improving care, support and choice for people at the end of life

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Date: June 2014

The case for free social care at end of life

Ahead of the General Election, Macmillan is calling on all parties to commit to ensuring everyone at the end of life is given free social care to support them to spend their final weeks and days in the place of their choosing.

We only get one chance to get care right for someone at the end of their life. Yet, currently, people are often failed by a system that is not equipped to allow them to choose where they want to die. The Palliative Care Funding Review (PCFR) found 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 do so. Macmillan estimates that in 2012 **36,400 cancer patients died in hospital in England when they would have preferred to die at home.**

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 £1.8m to collect data on it through the PCFR pilots. 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 Act’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.*”

Andy Burnham, Shadow Secretary of State for Health, confirmed 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 has **strong support from stakeholders** including the Dilnot Commission, patient groups and commissioners. The Barker Commission said ‘*there is little logical division between what is means tested under social care and what is free at the point of use as health care*’ and there is a ‘strong case’ for free social care at the end of life. 97% of health professionals surveyed by Macmillan believe the complexity of social care needs assessments is a barrier preventing people receiving appropriate social care at the end of life.

With the PCFR pilots due to report in Autumn 2014, we want a Government decision on funding social care for people at the end of life before the end of this Parliament. We also want all parties to support this policy in their manifestos ahead of the 2015 General Election.

‘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, Adrian, 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

There is now a range of data which points towards the financial benefits of caring for people in their own homes at the end of life:

- The **average cost of a patient's hospital and social care in their last year of life is £10,130**, of which £6,644 is hospital costs (climbing steeply in the last few months of life) and £3,486 social care costs (showing steady increase in the last 12 months).
- With over 465,000 deaths nationally in England in 2008 this represents **£4.7bn in final year hospital and social care costs**. The majority of increased costs are emergency hospital admissions – many of which are unnecessary. **A 10% reduction in hospital admissions could yield savings of around £57m in hospital costs**.
- Higher levels of social care costs at the end of life are associated with lower levels of inpatient admissions, inpatient bed days, outpatient attendances and A&E visits.²

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

- QIPP data suggests there are **potential net savings of £958** for every person who dies in the community rather than in hospital.³
- A significant proportion of those who die in hospital could be supported to die at home if appropriate health and social care packages were in place.⁴
- Implementing the Macmillan specialist palliative care at home model **reduced the total cost to the NHS of caring for people in the last year of life by 20%**.

Macmillan's specialist palliative care at home service, based in Midhurst, is based on a Swedish advanced home care model. A team works with other services in the community to deliver a flexible care package designed around the individual.

- **8 out of 10 health and social care professionals** polled by Macmillan in 2013 agreed that providing end-of-life care, including social care, in the community would save the NHS through, for example, swifter discharge and reducing unplanned admissions.
- We've also spoken to health commissioners anonymously. A Midlands commissioner said: *'Ideally, yes, we would like to see those services free at the point of delivery, because then they would complement our NHS services better and we could get a better and more seamless service in place.'*

Macmillan's next steps for gathering additional evidence

Macmillan and other end of life charities have commissioned a study looking at which existing examples of free end of life care would be best to base a comprehensive model of free social care at the end of life. We will publish the results in June 2014.

How can MPs and peers ensure support for people at the end of life?

To support people at the end of life we would be extremely grateful if you could:

- Write to the people in your party responsible for policy and manifesto development raising the issue of free social care at the end of life.
- Ask Parliamentary questions on the issues mentioned in this briefing. Please contact us using the details below if you would like suggested wording.

For further information please contact Tim Windle, Public Affairs Officer, TWindle@macmillan.org.uk, 0207 840 4946.

² http://www.nuffieldtrust.org.uk/sites/files/nuffield/social_care_and_hospital_use-full_report_081210.pdf

³ <http://www.endoflifecare-intelligence.org.uk/view?rid=464>

⁴ <http://www.centreforwelfarereform.org/uploads/attachment/303/health-efficiencies.pdf>