Macmillan briefing: Estimation Day Debate on End of Life Care

Purpose: Briefing for MPs ahead of Estimation Day Debate on End of Life Care on Wednesday 2 March 2016
Date created: 25 February 2016
Contacts: Hannah Clifton, Public Affairs Officer, haclifton@macmillan.org.uk

Introduction

Around 480,000 people die in England each year; this is predicted to increase to 550,000 by 2035[1]. Dying, death and bereavement are important parts of everyone's lives but so much is unpredictable. It is therefore vital to offer people choice at this point of maximum vulnerability in their lives.

Macmillan believes wherever you are looked after, the most important thing is that you get the care you need, you are comfortable, your pain is controlled, so that you can die in the place and manner of your choosing.

In their 2015 manifesto, the Conservative party committed to support commissioners to combine better health and social care services for the terminally ill so that more people are able to die in a place of their choice. Since coming into post, we are pleased to see that Minister for Care Quality, Ben Gummer MP, has a keen sense of the unacceptable variation in end of life care. In his words 'excellence is a long, long way from universal' and he has acknowledged that this issue needs to be fixed.

- To deliver choice at the end of life, **Macmillan is calling on the Government to urgently fund and implement the *independent review of choice in End of Life Care***[2] (the Choice Review).
- **Macmillan supports the economic modelling provided in the Choice Review**, and believes that **investment in health and social care for people at end of life is a cost-effective spending decision**.
- **Evaluations of our Macmillan Specialist Care at Home**, which delivers choice at the end of life, **demonstrates the savings that can be made at a local level**.
- 'End of life' and 'palliative care' has been raised in Parliament over 300 times during 2015, and **we have seen many major reports** published by the Health Select Committee and Parliamentary and Health Service Ombudsman **highlighting the urgent need to improve end of life care**.
- It has been a year since the Choice Review was published. **There have been a lot of willing words from Government, but we are yet to see action**. A response was promised in autumn 2015, however, this has not been realised. Likewise, NHS England has made no substantial moves to prioritise or invest in palliative and end of life care. . **People at the end of life are not getting the right level of care**.

The Estimation Day Debate provides a welcome opportunity to;

- Highlight the urgent need to fund and implement the Choice Review which would address the inadequacies in end of life care, as set out in the many recent reports on the issue
- Ask the Minister about the ongoing delays to the Government's response to the Choice Review and for confirmation of the date by which the government will respond
- Ask the Minister what the role of NHSE and local authorities will be to delivering improved end of life care

[1] Office of National Statistics, (2013). 2012-based National Population Projections (Released: 6 November 2013). London: ONS. Available here.
[2] Department of Health, *What's important to me; A review of choice in End of Life Care*, February 2015. Available here.

1. Evidence: people's preferences at the end of life are not being met

- Just 5% of people in the UK say they want to die in hospital, yet this is where around 50% of people die.
- Three in four (73%) of people with cancer would prefer to die at home with the right support[3]. Less than a third (30%) do[4].
- Macmillan estimates that in 2012 around 36,400 cancer patients died in hospital when they would have preferred to die at home[5].
- Nearly one in every ten people who died with cancer in England in 2014 spent the last 48 hours of their lives without adequate pain relief.[6]
- People with cancer who receive inadequate pain relief at home are twice as likely to die somewhere they did not want to, compared with those who received complete pain relief[7].
- The Health Select Committee in March 2015 found that 'the experience that people approaching the end of life have varies and in too many cases is unacceptably poor'[8].
- The Parliamentary and Health Service Ombudsman detailed the 'unimaginable' anguish felt by too many people approaching the end of their lives and their families at present, as the wishes of dying people are not met[9].

2. The Choice Review: modelling of costs in delivering choice at end of life

The independent Choice Review published recommendations to government in February 2015. It provides a framework for enabling greater choice and high quality end of life care through a range of tangible policy solutions, enabling better commissioning and delivery of services.

The Choice Review used a person-centred model of care to assess the costs and benefits if the system was reformed to provide good personalised care that would deliver choices people want in their end of life care.

Moving from the current state to increased service availability in order to enable choice and improve care requires investment in the system. It was estimated that an extra £400m annually would need to be invested in NHS community services to achieve £370m savings in the acute sector (£30m net spend in the NHS); and a further £100m would need to be invested in local authority social care.

This proposed investment will:

- Deliver a significant increase in out of hospital care – including district nurses, allied health professionals, pharmacists, social care services, health care assistants and specialist palliative care teams – to ensure every dying person has access to **round-the-clock care** in the place of their choice, seven days a week
- Provide **greater coordination** and **integration** between services to improve the quality of end of life care and to support carers and families
- **Empower patients and carers** to be able to exercise greater choice in their place of death, through person-centred, coordinated care
- Deliver **reduction in hospital admissions** for people at the very end of their lives
- Support for the use of the **latest technologies** to support end of life care.

---

[3] Macmillan Cancer Support. Feb 2010 online survey of 1,019 people living with cancer (802 of whom were in employment or education at the time of diagnosis). Respondents were sourced from Macmillan's database of people affected by cancer in the UK who have agreed to take part in research. Survey results are unweighted

[4] England - Office of National Statistics. Cancer Registration Statistics, England, 2012 [cited July 2014]. Available here.

[5] Macmillan Cancer Support. 2014. Can we live with how we are dying?

[6] Office for National Statistics, 2015. National Survey of Bereaved People 2014 (VOICES). 9.4% of all respondents disagreed or strongly disagreed that the cancer patient had sufficient pain relief in the last two days of life (Q35). http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-407293 (accessed January 2016)

[7] Office for National Statistics, 2015. Bespoke analysis for Macmillan Cancer Support of the National Survey of Bereaved People 2014 (VOICES). Our interpretation of the analysis found that people with cancer who receive poor (partial or no) pain relief at home are twice as likely to not die where they wanted to compared to those who received complete pain relief (some or all of the time) (49% vs 23%). http://www.ons.gov.uk/ons/about-ons/business-transparency/freedom-of-information/what-can-i-request/published-ad-hoc-data/health/december-2015/index.html|

[8] Health Committee, *End of Life Care: Fifth report of session 2014-15, March 2015.* Available here.

[9] Parliamentary and Health Service Ombudsman, *Dying without dignity*, May 2015. Available here.

2.1 Financial impact and value for money

- Macmillan supports the person-centred model of care used in the Choice Review. The model is unique in that it provides a comprehensive picture of the evidence we currently have on costs[10].
- We believe calls for a gross £400 million above the current levels of investment in health and social care is a cost-effective spending decision. Investment in social care and community end of life services has been proven to lead to considerable savings in the cost of acute care downstream[11].
- Once offsetting savings delivered by this investment are realised, the net cost to the Exchequer will reach a steady state of £130 million net costs per annum by 2020–21, comprising:
    - £30 million of additional net spending on the NHS
    - £100 million of additional net spending on social care
- The model assumes that this additional expenditure will attract an additional £200 million of private contributions, comprising:
    - £50 million from the voluntary sector
    - £150 million of self-funded social care
- Some of the costed benefits of a national choice offer include :
    - A decrease in hospital unit costs and a reduction in the number of admissions and A&E visits per person, as community services and more widespread provision of specialist care reduces the number of admissions and A&E visits per person
    - An estimated 20% reduction in hospital deaths as people can exercise choice to die with appropriate care at home or in a hospice or care home.
- Additionally, there are numerous wider societal benefits of improving care for people at end of life (for example bereaved carers may return to work faster).
- Giving people the ability to have more control at the end of their life directly impacts their quality of life, which is likely to have positive economic impacts outside of the health system.

3. Macmillan Specialist Care at Home – Midhurst service

Established in 2006, the Midhurst service consists of a consultant-led, multidisciplinary team providing specialist palliative care through a range of interventions at home and in the community.

It offers access to care 7 days a week, as well as bereavement support. The service accepts referrals for any person living within the specified area, over the age of 18, who has any life limiting chronic progressive disease and is experiencing complex problems that are not responding to routine treatment. In 2014/15, 78% of referrals were for cancer patients. Patients are referred to the Midhurst service earlier than in other models of specialist palliative care, resulting in fewer unplanned A&E attendances, fewer nights in hospital and patients dying in their preferred place.

Core components of the service include:

- Early referral
- Clinical interventions in the home
- Triaging/single point of access
- Community-based, multidisciplinary, consultant-led, service
- Flexible mixed skills team including volunteers supporting service delivery
- A local education programme
- Proactive collaboration with primary care providers.

3.1 Successes of the Midhurst model

- Evaluation found contact with the Midhurst service resulted in:
    - Less unplanned A&E attendances and days in hospital
    - Increases in people achieving preferred place of death.

[10] Incorporating a range of services: NHS acute and community costs; specialist palliative care staffing; hospice inpatient costs; community pharmacy; social care costs including care home fees; domiciliary home care; and equipment and adaptation costs.
[11] Nuffield Trust, Social care and hospital use at the end of life, 2010. Available here.

- The broad range of clinical interventions on offer, not only help avoid the need for admission to hospital or hospice, and reduce the need for patients and carers to travel, they also provide the opportunity to develop a relationship of trust between the patient, carers, family members and the team, reducing stress and anxiety.

- The Midhurst service demonstrated the impact of early referral and intervention; and close and proactive collaborations with primary care and other service providers. The key contributors to its success were identified as:
    - Early referral (the majority of patients (63%) were referred to the service prior to an inpatient stay)
    - Breadth of services delivered at home
    - Role flexibility.

- Early referral to the Midhurst service allows a person's care to be planned with family and health professionals and therefore provides increased patient choice in their place of care and death, with 71%[12] of deaths occurring at home or in a care home at the time of the evaluation, rising to 82% in 2014/15.

3.2 Costs of delivering the Midhurst service

Replicating Macmillan's Midhurst service will depend greatly on any locality's existing infrastructure. However, the formal economic evaluation for the service concluded that the **overall financial impact for the health economy is reduced by 20%.**

Some of the key identified costs of delivery included:

- Total annual budget for Midhurst (at time of evaluation) stood at £1.01m. This translates into a cost of delivering the service of £1,827 per patient (as at 2009).

- The Macmillan Midhurst Service does not have an inpatient bed infrastructure to support and instead where required spot purchases beds. This could allow any service to scale to increase growing demand in the future.

- Due to the nature of the service 69% of costs are associated with employing the relevant staff rather than space for beds which account for around 12% of total costs.

- As a community service there is a relatively high spend on travel and subsidence (around 5%) and the involvement of the voluntary sector in the delivery of care (around 4%).

- The importance of senior clinical engagement to the success of the Midhurst service with Consultant and Associate Specialist spend accounting for 17% of the cost. This engagement is an important factor in building confidence in the service from those referring to it (including GPs and hospital consultants).

Macmillan believes that investment in the Choice Review presents value for money. A year on from its publication, it is now time for the Government to act and fully implement the Choice Review.

For further information please contact:
Hannah Clifton, Public Affairs Officer, hclifton@macmillan.org.uk **Tel.** 0207 091 3123
Twitter: @MacmillanPA **Website:** www.macmillan.org.uk/parliament

[12] At time of evaluation (2012).