

Macmillan Free Social Care at the End of Life Campaign Briefing



Briefing for: **Parliamentarians with an interest in social care and end of life issues**

Purpose: **To outline Macmillan's campaign for people at the end of life to have access to free social care**

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Introduction

Access to social care services, as part of a package of end of life care, can help people with cancer in the final weeks of life be cared for and die in their own home. However, currently the vast majority of cancer patients continue to die in expensive hospital beds because they can't access the social care support they need.

Macmillan and other charities – Help the Hospices, Marie Curie, Motor Neurone Disease Association, National Council for Palliative Care, Sue Ryder – have been campaigning throughout 2012 for free social care for people at the very end of life so that they can get the support they need to die at home. We are pleased that the Government stated in the Care and Support White Paper that it sees “much merit” in this principle and committed to assessing it through the Palliative Care Funding Review (PCFR) pilots. This briefing outlines the case for free social care at the end of life, what needs to happen to ensure it is delivered before the end of this Parliament and the steps the Government can take now to improve the integration of care at the end of life.

Macmillan has three key recommendations which we believe are critical to improving access to social care at the end of life and ensuring more people can die where they want:

- 1. We want the Government to deliver free social care for people who are on an electronic end of life care register, before the end of this Parliament**
- 2. We want electronic end of life registers to be implemented by every Clinical Commissioning Group**
- 3. We want the Adult Social Care Outcomes Framework to be updated to include an objective on delivering choice at the end of life.**

The current situation

Each year around 130,000 people in England die from cancer.¹ Three quarters (73%) want to die at home surrounded by their family and friends yet only 27% are currently able to do so.² Access to basic social care services – for example help with washing, turning the patient in bed, meal preparation – not only enhances a patient's quality of life but is also vital if people are to have a genuine choice at the end of life. Help with these relatively simple things, at such a fraught time, can remove the pressure felt by families and carers who might otherwise struggle to provide the care their loved one needs to stay

1 Office for National Statistics (ONS) Cancer mortality by sex and age group England 2010

2 Macmillan (Feb 2010), Online survey of 1,019 people living with cancer

at home. However despite the importance of social care, all too often people simply cannot access it.

The National Audit Office³ has highlighted that the process for accessing state-funded social care is complicated, lengthy, and is separate from the healthcare system. For patients who may only have weeks to live this fragmentation leads to delays that can prevent them receiving the care they need to die in the place of their choice.

Sara Padhiar-Tutton, Support & Outreach Worker, The Carers Centre

The stress of the means-test for social care can be very frustrating for people who feel that the time they have left with their loved one is running out. They just want to make the most of whatever time they do have and not waste it filling out forms and chasing different services. Paying for social care at the end of life can also have big financial implications for families as they want the best for their loved one but may not actually be able to fund the care they need.

Social care professionals, patients and carers also tell us that because the £23,250 means-test threshold is so severe people are put off from applying for the care they need, or may even refuse care because they are worried about the impact it will have on their families' finances after they die.

Alex Burton, who cared for his wife at the end of her life

Dorothy was in hospital for six weeks at the end of life and was admitted eight or nine times in her last year. During all this time no one told her she was at the end of life or asked her about what she wanted. No one offered us social care support. I believe it could have made a big difference because caring for someone can be so tiring and stressful, you never get to clock off. My biggest regret was not getting Dorothy home in the end. I'm going to have to live with that until I die.

The case for change – why do we need to make social care free?

There is a long way to go to turn the progress in the Care and Support White Paper into a firm commitment to implement free social care at the end of life. Ensuring the Draft Care and Support Bill Committee supports free social care is the first stage of this journey. We believe that there is a strong moral and economic case for this:

- 1. It will help deliver the Government's vision for integration and choice at the end of life** – the Care and Support White Paper reaffirmed the Government's commitment to delivering choice at the end of life through an integrated care system:

We want people to receive the best possible care at the end of their lives, including a choice over where they die. Integrated palliative care is central to this.

Free social care at the end of life would be a significant step towards realising this vision. As the Department of Health commissioned independent Palliative Care Funding Review (PCFR) made clear, removing the social care means test would allow for a coordinated package of care to be put in place, speeding up hospital discharge and allowing people to be cared for and die at home if they choose.

- 2. It is the right thing to do** – The End of Life Care Strategy, adopted by this Government, states, "how we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services." We only get one chance to get care right for

³ National Audit Office (2008) *End of life care*.

people at the end of life, however, the current system too often fails patients as well as their families, carers and loved ones.

- 3. It can save money through preventing 1) unnecessary delayed discharges and 2) emergency admissions** – We know swifter hospital discharge can save money. Through helping 228 patients at the point of discharge in 2009/10, a Macmillan Social Care Coordinator in Northamptonshire saved 326 bed days through reductions in delayed discharge and an estimated 140 bed days by preventing hospital readmissions. For every £1 invested in the social care post £2.24 was returned to the healthcare system.⁴

Research by the Nuffield Trust has also shown that greater access to social care support has the potential to reduce the need for admissions to hospital at the end of life. The latest figures show that 86% of all admissions in the last year of life (106,000) are emergency admissions with an average length of stay of 27 days. This **accounts for 2.8 million bed days in total**. Furthermore 89% of those who die in hospital do so following an emergency admission. Just a 10% reduction in the number of hospital admissions ending in death in England could potentially result in a saving of **£52 million**.⁵

Next steps towards free social care at the end of life

Macmillan is pleased that in the Care and Support White Paper the Government stated that it will double its investment in the PCFR pilot sites to enable them to assess free social care for people at the very end of life. We strongly support the gathering of data to fully demonstrate the benefits of the proposal and believe that we can add much value to this process, particularly in ensuring the voice of patients is heard. As such we want to work with the Government throughout the two year assessment process.

What action can Parliamentarians take now to help ensure free social care at the end of life is implemented by the end of this Parliament?

- Ask MPs and Lords on the Draft Care and Support Bill to support free social care for people who are on an electronic end of life register
- Write to the Secretary and Minister of State to show your support for free social care at the end of life and ask them to ensure the work to assess its benefits is taken forward quickly and comprehensively.

Improving end of life care now

As the PCFR pilots will not report until 2014, it is vital that steps are taken in the interim to improve end of life care for people and their families. There are two key areas in which Macmillan wants progress to be made.

1. Better use of electronic end of life care registers

What are end of life care registers and why are they important?

Electronic end of life care registers (or EPaCCS) record and share the care preferences for people who are approaching end of life. EPaCCS improve integration as they make

⁴ OPM (2012), *Economic and quality case study: Macmillan Social Care Coordinator – Northampton General Hospital*.

⁵ National End of Life Care Programme & National End of Life Care Intelligence Network (2012) *What do we know now that we didn't know a year ago?*

the providers of a person's care – including their GP, out-of-hours service, and hospital team – aware of a patient's wishes, allowing them to plan their care accordingly. This helps choice to be respected.

Where an electronic register is established, death in the preferred place of care (for those on the register) is as high as 70% whereas deaths in hospital have, in some instances, halved. Registers are not only an important coordination tool but being placed on a register would trigger a person's eligibility for free social care should it be introduced.

Latest developments

We are pleased that the Government used the opportunity of the White Paper to voice its support for EPaCCS and to reconfirm that work is underway to ensure they are implemented more widely. This is welcome, but concerted effort is needed to ensure that every new Clinical Commissioning Group implements an electronic end of life register and ensures that it is accessible by their counterparts in social care.

The Commissioning Outcomes Framework (COF) – Supporting the implementation of electronic end of life care registers

In the new health system, the COF will be used to hold Clinical Commissioning Groups to account. This framework will do much to set the priorities for the NHS at the local level and will be the main way in which performance is measured.

Yet, despite the universal acceptance of the importance of end of life care for both patients and families, the COF does not currently include any end of life indicator. This is a significant oversight and a missed opportunity to ensure all commissioners prioritise both giving people the choice to be cared for at home until they die, and the overall improvement of end of life care.

The inclusion of an indicator on preferred place of death in the COF would incentivise CCGs to improve end of life services in their area by implementing electronic end of life registers and other initiatives which support the delivery of choice at the end of life.

2. The Adult Social Care Outcomes Framework (ASCOF) – ensuring local authorities prioritise end of life care

In the new health and social care system the ASCOF will be used to benchmark the performance of local authorities. However, like the COF, end of life care is currently completely excluded. The inclusion of an indicator in the ASCOF on whether choice at the end of life was met, would help ensure that every local authority prioritise improving end of life care.

The 2013/14 iteration of the ASCOF will be published before the end of the year and we would like to see a clear commitment to the development of an indicator on choice at the end of life.

How can you help to ensure that cancer patients are supported at the end of life?

- Write to the Government and NHS Commissioning Board to ask how they plan to support the development of end of life indicators in the COF and ASCOF
- Write to your Clinical Commissioning Group to ask about their plans to implement an electronic end of life register in your area.