

Macmillan Cancer Support's Submission to the Draft Care and Support Bill Committee

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1. Introduction

- 1.1. Macmillan Cancer Support welcomes the opportunity to comment on the draft Care and Support Bill.
- 1.2. As an organisation with a long history of providing palliative care and end of life services, we know that integrated health and social care is vital for giving those who want to the best chance of dying at home surrounded by their family and loved ones, rather than dying on an expensive hospital ward.
- 1.3. However, all too often our health and care systems let people down when they are at their most vulnerable and in the greatest need of seamless, personalised care. In fact, only 27% of cancer patients currently die at home. Macmillan supports the overall aim of this draft legislation to improve the quality and integration of care and support, and believes the draft Care and Support Bill Committee will play a critical role in ensuring this Bill improves both patient experiences and choice at the end of life.

2. Free social care for people on an end of life register – Macmillan's priority for the draft Care and Support Bill

- 2.1. Despite the fact that 73% of people with cancer would like to die at home, the majority continue to die in hospital.
- 2.2. To improve this situation, Macmillan believes it is vital that everyone on an end of life care register has access to free social care. Not only would this allow more people to be cared for in their own home until they die but it could also save the NHS money through speeding up hospital discharge and preventing emergency admissions to hospital.
- 2.3. To support this ambition, Macmillan has two calls for the pre-legislative stage of the Care and Support Bill:
 1. We urge the draft Care and Support Bill Committee, in its final report, to give its support to free social care at the end of life and acknowledge the positive impact it would make on patient choice and experience.
 2. Macmillan wants the Committee to ensure that the Care and Support Bill is drafted to allow for the implementation of free social care at the end of life without the need for further primary legislation.
- 2.4. Below we address specific questions detailed in the call for evidence.

3. Question 1 – What is your view of Part 1 of the draft Bill (care and support)? In your view, are there omissions in this Part of the draft Bill?

- 3.1. The Government made an explicit commitment in the Care and Support White Paper to improve choice at the end of life, so that many more people can achieve their wish to die at home surrounded by their families and loved ones. Macmillan is also pleased that the Government stated in the White Paper that it sees “much merit” in providing free social care as part of an integrated service at the end of life and allocated £1.8 million to assess the proposal through the Palliative Care Funding Review pilot sites.
- 3.2. However, due to the time required to assess free social care at the end of life, a decision on its implementation will not take place until 2014 at the very earliest.
- 3.3. Macmillan believes it is vitally important that free social care at the end of life remains high on the parliamentary and political agenda until the Government makes its decision. The draft Care and Support Bill Committee’s endorsement would demonstrate the cross-party backing for this policy needed to ensure the Government remains focused on improving care, including access to social care services, for people at the end of life.
- 3.4. We believe there is a strong moral and economic case, which we set out below in our answer to question 25, for the Committee to give its support for free social care at the end of life.

4. Question 25 – Does the draft Bill promote greater integration between health, social care and housing around hospital discharge?

Recommendation 1: Macmillan wants the draft Care and Support Bill Committee to support the principle of free social care at the end of life in its final report.

- 4.1. 73% of people with cancer would prefer to die at home,¹ but currently only 27% are able to do so.²
- 4.2. Access to social care support – for example help with washing, turning the patient in bed and meal preparation – as part of an integrated package of end of life care is vital for allowing more people to be cared for and die at home if they so choose. Help with these relatively simple things, at such a difficult time, can relieve the pressure felt by families and carers who might otherwise struggle to provide the care their loved ones need to stay at home in the last days and weeks of their life.

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

² Office for National Statistics (2010), Mortality statistics

Case Study: Malcolm, Cancer Voice

'When push came to shove, Monica should have been allowed to die at home – in her bedroom – as she wished. No-one talked to us about her choices in her last weeks of life, and we weren't told about the support that we might have been able to get to make her wish of dying at home a reality.'

- 4.3. However, despite the importance of this support, both the independent Palliative Care Funding Review and National Audit Office³ have highlighted that the process for accessing state-funded social care is overly complicated and lengthy. This is partly because it is carried out independently of the healthcare system. Delays often prevent choice from being exercised.
- 4.4. Furthermore, there is anecdotal evidence from social care professionals that people are put off from applying for the care they need, or may even refuse care, as they are worried about the impact it will have on their families' finances after they die. With the means-test threshold for social care support currently set at £23,250, people who have accrued modest savings over their lifetime could find themselves in financial difficulty as a result of paying for the support they need at the end of their lives.
- 4.5. We believe that people approaching the end of life and their families should not have to face this financial or emotional burden, nor be forced to go without the care that they desperately require.

Case Study: Kath, Macmillan Professional

'As a Macmillan Specialist Social Worker, I help people nearing the end of life to be discharged from hospital so that they can die at home surrounded by their loved ones. Unfortunately, I've seen lots of patients and families refusing the vital social care support they need at home when they find out that they have to pay for it. This means that families are left to cope alone at an extremely difficult time, which can leave them emotionally and physically exhausted. This strain can have a long-lasting impact on families. Sadly it can also lead to people being admitted to hospital right at the end of life when, with the correct care package in place, they could have stayed at home.'

- 4.6. Removing the social care means-test for those on an end of life care register would do much to deliver the Government's vision of integrated, patient-centred care for some of the most vulnerable people in society. We believe it would put a stop to health and social care providers – due to the fact their services are funded separately – having time-consuming debates about who should pay for and deliver different aspects of a person's end of life care. This would allow for an integrated package of care to be delivered, which would enable people to choose to be cared for at home until they die.

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

- 4.7. As well as helping to enable choice, free social care for people on an end of life care register also has the potential to save the NHS money through speeding up hospital discharge and preventing hospital admissions, as outlined in 4.8 – 4.10 below.
- 4.8. In 2009/10 a Macmillan Social Care Coordinator in Northamptonshire was able to give support at the point of discharge, free of charge, to 228 patients. This intervention resulted in a total of 466 bed days saved through reductions in delayed discharge and preventing hospital readmissions, and an overall saving of nearly £150,000. In this instance every £1 invested in the social care post generated £2.24 of monetised benefits to the healthcare system.⁴
- 4.9. The Nuffield Trust⁵ has also demonstrated that greater access to social care support has the potential to reduce the need for admissions to hospital at the end of life. Their research shows that the cost of caring for someone in hospital increases sharply in the final few months of life, rising to as much as £90,000 a person. Social care costs, however, are more predictable and constant, and home care is on average cheaper than care in hospital. These findings should temper concerns that free social care for people at the end of life would be too expensive.
- 4.10. The latest figures from the National End of Life Care Programme 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**.⁶
- 4.11. Given the strong moral and economic arguments for the introduction of free social care for people on an end of life care register, Macmillan wants the Government to commit to implementing it before the end of this Parliament. By supporting the principle of this policy, the draft Care and Support Bill Committee would demonstrate the cross party backing for free social care at the end of life and ensure the Government continues to prioritise delivering better social care support for some of the most vulnerable people in society.

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

⁵ The Nuffield Trust (2012), *Understanding patterns of health and social care at the end of life*

⁶ 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?*

5. Question 20 – Does the draft Bill make adequate provision to help people achieve personalised care and support and to manage the payment process?

Recommendation 2: Macmillan wants the draft Care and Support Bill Committee to ensure that the Care and Support Bill is drafted to best allow for the implementation of free social care at the end of life without the need for further primary legislation.

- 5.1. As we have set out above, removing the social care means-test for people at the end of life would allow for an integrated package of care to be put in place. This would enable more people to get out of hospital and be cared for and die at home, where they would prefer to be.
- 5.2. The Government made clear in the Care and Support White Paper that a decision on whether to introduce free social care at the end of life will occur after the Palliative Care Funding Review pilot sites have reported in 2014. By this time the Care and Support Bill will likely have passed through Parliament.
- 5.3. Macmillan is eager to ensure that the Care and Support Act allows for the delivery of free social care at the end of life, without the need for further primary legislation, should the Government decide to implement the policy after the pilots return their results. We are pleased that the draft Care and Support Bill Committee questioned DH Officials on this point during the evidence session on 13 December 2012 and requested a note on the powers necessary to give effect to free social care at the end of life.
- 5.4. We believe it is crucial that this note analyses whether the draft legislation – particularly clause 14 – as it is currently written accommodates the introduction of free social care for people on an end of life care register. If not, we would expect Officials to give details on how it should be amended so that free social care could be implemented.

6. Conclusion

Case Study: 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.’

- 6.1. We only get one chance to get care right for people at the end of life but too often people and families are failed by our care system when their needs are greatest.

- 6.2. Removing the social care means-test for people on an end of life care register would improve access to the care which is vital for enabling people to die at home and lift a stressful and punitive financial burden from families.
- 6.3. Moreover, as our population ages the number of people dying is increasing year on year. We simply cannot afford to continue to treat people in expensive hospital beds against their wishes – we have to act now if our health and social care systems are to cope. The PCFR estimates that, by 2031, 510,496 people will die each year in England, compared to 461,016 in 2010.⁷
- 6.4. Macmillan and many other charities concerned with improving end of life care would be grateful and reassured to see the draft Care and Support Bill Committee explicitly support free social care at the end of life. By endorsing this policy, and ensuring the Care and Support Bill is drafted to best allow free care and support at the end of life, the draft Care and Support Bill Committee will play a critical role in improving end of life care for all.

About Macmillan

One in three of us will get cancer and it's the toughest thing most of us will ever face. If you've been diagnosed with cancer, or a loved one has, you'll want a team of people in your corner supporting you every step of the way.

Macmillan Cancer Support is a UK charity working to improve the lives of people affected by cancer. We believe that every single person who is diagnosed with cancer should have access to the high-quality treatments and services they want and need at every stage of their cancer journey, no matter who they are, what part of the country they live in, or what type of cancer they have.

Further information

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⁷ Office for National Statistics (2010), Mortality statistics