

## Macmillan Briefing for Second Reading of the Care Bill

Briefing for: **Peers with an interest in the Care Bill second reading**

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### Introduction

Macmillan Cancer Support thinks the Care Bill Second Reading is a crucial opportunity to raise awareness of the issues facing cancer carers and people at the end of life. There are approximately 905,000 cancer carers in England and 95% do not currently receive a carers' assessment. Similarly, more than 91% of cancer patients in England who died in hospital wanted to die elsewhere. We warmly welcome the Government's ambition to create a system in which everyone can get the care they need when they need it. However, there are currently significant gaps in the support given to cancer carers and patients nearing the end of life which must be addressed for their ambition to be realised.

### Macmillan's two key priorities for the Second Reading of the Care Bill

1. To ask the Government how this Bill will increase the number of cancer carers identified and signposted *by the NHS* to the enhanced support outlined in the Bill.
2. For the Government to reconfirm its commitment to make a decision on implementing free social care at the end of life by the end of this Parliament.

### 1. Identification and signposting to support and information for cancer carers

**During Second Reading we want to hear from Ministers how the Care Bill will increase the number of carers identified and signposted *by the NHS* to the enhanced support outlined in the Bill**

There are close to a million people in England selflessly providing unpaid care to family and friends with cancer. As the number of cancer patients is set to double from two to four million over the next 20 years, so too will the number of carers. These cancer carers are making a major contribution to society through improving patients' quality of life and **saving health and social care services nearly £12.1 billion per year<sup>1</sup>**. Yet half of cancer carers are not receiving any support in return for giving on average almost 15 hours of support each week, the equivalent of two extra working days, and it having a substantial impact on their lives. We must capitalise on this opportunity to improve the lives of cancer carers before the Bill is passed and the Government's agenda moves on.

### Unmet needs

The support cancer carers provide has a substantial negative impact on their lives. Nearly half say it affects their mental health and wellbeing. One in five say it affects their relationships and working life and 15% say it affects their household finances. **Almost half of cancer carers identify at least one type of support they are not currently receiving** that would help them and assist them with their caring duties. They are in real need of help but are not aware of who or where to turn to for support.

<sup>1</sup> Estimated annual economic value based on the estimated number of cancer carers in England and data on the number of hours of unpaid care they provide each week, multiplied by a unit cost for replacement care. Estimated number of cancer carers in England and data on the number of hours of unpaid care provided taken from Macmillan Cancer Support and Ipsos MORI research conducted in 2011. Report available [here](#). Unit cost of £18 an hour for replacement care is based on 2011 NHS Information Centre data. This estimate follows the same method as the 2011 Carers UK/University of Leeds paper which estimated the annual economic value of all UK carers at £119billion. Paper available [here](#).

### **Sharon, who cares for her mother with cancer**

With little support or information, Sharon found herself trying to find out what she needed to know about her mother's condition at a very difficult time where she was struggling to balance work and family duties. *"When we first found out that my mum was ill – I thought where do I start? I didn't see myself as a carer so taking that on board and finding support was hard. It was a big shock but having access to the right information was another bit of armour."*

### **Why are cancer carers not receiving support?**

Three in five people providing unpaid care to loved ones with cancer do not consider themselves to be 'carers'. They therefore lack awareness of carers' rights, such as the Local Authority Carers' Assessment, which is the gateway to statutory support. It is therefore of little surprise that only **one in three cancer carers have heard of a carers' assessment and only 5% have actually had one**. This is estimated to be lower than the proportion of all carers looking after people with other conditions and disabilities<sup>2</sup>. Of the very small number of cancer carers who have had a carers' assessment, the event that **most often prompted this was a referral by a GP**.

### **Health Manager from the West Midlands**

*"I would suggest we're still not very good at actually dealing with carers needs, although we like to think we are, I don't think we are that great."*

### **The Care Bill**

We are extremely pleased that **the Care Bill enhances rights for carers**, including placing a new duty on local authorities to undertake a carers' assessment for all carers regardless of their perceived level of need and eligibility for statutory services. We are also pleased that it places a new duty on local authorities to have regard to the importance of identifying carers. We are hopeful that both these new duties will do more to ensure that far more cancer carers are identified and receive the support they need.

**We are surprised that the Bill does not place a similar duty on the NHS**. As outlined above, the main way cancer carers are identified and signposted for help currently is not via local authorities but in health care settings. We hope that the new duty on local authorities will cover Health and Wellbeing Boards – which is the new forum where key leaders from the health and care systems now work together. However, this is only one of the new key decision-making bodies which make up the new NHS. Two additional health bodies which are crucial to the effective identification and signposting of carers are NHS England and Clinical Commissioning Groups (CCGs). At present there is no new requirement on either body to improve the support for carers.

It is encouraging that there are a number of Department of Health initiatives to provide additional support for carers within the NHS – such as the recently announced work with the Royal College of GPs on CCG best practice guidance for supporting carers. Various initiatives have been tried over the years but 9 out of 10 cancer carers are still not getting a carers' assessment. Now is the time for a step-change in how to tackle the problem. We want to see a policy framework that clearly incentivises both the NHS and local authorities to work together and holds both these systems to account.

Indeed, **the Government called for the same thing in its Care and Support White Paper**. It stated that "there is still an unacceptable variation in access to tailored support for carers," and outlined their requirement for "NHS organisations to work with their local authority

<sup>2</sup> Health and Social Care Information Centre (2013) *Community Care Statistics 2011-12: Social Services Activity Report, England*

partners... to agree plans and budgets for identifying and supporting carers.” **We feel this requirement has not yet been reflected in the Care Bill.**

## **How have Scotland and Wales tackled this issue?**

Both the Welsh and Scottish Governments have recognised the seriousness of this challenge and have taken steps to address it in legislation with statutory requirements on health boards to lead on published strategies outlining how they intend to identify and support carers. We are keen to hear directly from Ministers how they feel the Care Bill is properly addressing the need to identify and signpost cancer carers in NHS settings.

## **Suggested questions to pose during the Second Reading debate**

1. There are nearly a million cancer carers in England and currently only five per cent receive a carers’ assessment. Does the Government recognise the seriousness of the problem facing cancer carers?
2. How will the new carers duties in the Bill apply to the NHS? How will health bodies be incentivised to improve identification and signposting of carers?
3. How does the Government feel its commitment in the White Paper that NHS bodies and local authorities need to work together to identify carers has been translated into the Bill? If this commitment is not reflected in the Bill, where is it being realised?

## **2. The importance of free social care in supporting people to die at home**

**During the Second Reading Macmillan wants the Government to reconfirm that it intends to make a decision on implementing free social care at the end of life by the end of this Parliament**

Macmillan Cancer Support strongly believes that people with cancer who are in the final weeks of life should have the choice to die at home, surrounded by their friends and family. We know that access to social care services, as part of a package of end-of-life care, can help people nearing the end of life be cared for and die in their own home, if this is what they want. However, currently, the majority of cancer patients continue to die in expensive hospital beds, partly because they cannot access the social care support they need.

**Lacey and her family were not aware that social care was an option to help them support her Dad in the last weeks of his life:** *“My Dad wasn’t given the option to think about where he wanted to be when he died. We didn’t know that it was possible to get social care support – if someone had talked through the options with us we would have asked for more help. We all would have liked for him to have died at home or died in a hospice – they were the two places he felt safe and felt looked after.”*

## **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, currently, people are often failed by a system that is not equipped to allow them to choose where they want to die. Recent analysis shows that **91% of cancer patients in England** who die in hospital wanted to die elsewhere, with **65% wanting to die in their own homes**. At present, **only 29% of people with cancer** are able to be at home when they die.

All too often people cannot get the care they need as the process for accessing state-funded social care is complicated, lengthy, and separate from the healthcare system. This fragmentation can lead to delays that prevent people from receiving the care they need to die in the place of their choice. Research by Macmillan shows that **97% of health and social care professionals** identify the lack of financial integration between health and social care as a key barrier to people receiving the care they need at the end of life.

Furthermore, because the £23,250 **means-test threshold for care in the home is so low**, many 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.

This call also has **strong support from key stakeholders** – it is supported by the Dilnot Commission, patient groups, health and social care professionals and commissioners, and representatives. **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.

### How would free social care at the end of life help?

- **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 giving people a choice over where they die. As the Department of Health commissioned independent Palliative Care Funding Review (PCFR) made clear, removing the social care means test would enable a coordinated package of care to be put in place allowing people to be cared for and die at home if they choose.
- **It can save money through preventing emergency admissions to hospital** – research by the Nuffield Trust has shown that greater access to social care support can 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. Just a 10% reduction in the number of hospital admissions ending in death in England could potentially result in a saving of **£52 million**.

### Recent developments

Macmillan is pleased that 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 £1.8 million to collect the data necessary to assess the policy's benefits through the PCFR Pilots. We are also pleased that 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"** and that the Government confirmed that the Care Bill provided the statutory framework to implement free social care at end of life in the future.

We now need to turn this progress into a firm Government commitment to implement the policy. Nearly a year on from the White Paper's publication, the Second Reading debate is an opportunity for Ministers to provide a progress report on **how well the PCFR pilots are doing in collecting the necessary data to test the policy** and to reaffirm the Government's commitment to make a decision on delivering free social care for people at the end of life by the end of this Parliament.

### Suggested questions for the second reading

1. Will the Government state its commitment to implementing within this Parliament free social care for those at the end of their lives?
2. Can the Government confirm that the Care Bill allows for the implementation of this policy without the need for further primary legislation?
3. Can the Government provide a progress report on how the Palliative Care Funding Review pilots are doing in collecting the data needed to assess the policy?

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