

Macmillan Briefing on the Care Bill

Briefing for: **MPs with an interest in the Care Bill**

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Introduction

Macmillan Cancer Support thinks the Care Bill is a crucial opportunity to improve the lives of cancer carers and people at the end of life.

There are approximately 905,000 cancer carers in England and currently 95% do not 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 support which must be addressed for their ambition to be realised.

Macmillan's two key priorities for the Care Bill:

1. Care Bill legislation must specify that health bodies and local authorities work together to identify carers and signpost them to the enhanced support outlined in the Bill as early on in their journey as possible.
2. The Government should reconfirm its commitment to make a decision on implementing free social care at the end of life by the end of this Parliament and provide cancer patients with the support they need to die in their preferred place of care.

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

There are close to a million people in England selflessly providing unpaid care to family and friends with cancer. 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 year¹**. Yet **half of cancer carers are not receiving any support** in return for giving on average almost 15 hours of support each week. The care they provide is having a substantial negative impact on their lives with nearly half saying it affects their relationships and wellbeing. As the number of cancer patients is set to double from two to four million by 2030, so too will the number of carers. We must capitalise on this opportunity to improve the lives of cancer carers now before the Bill is passed and the Government's agenda moves on.

Patrick, who cared for his wife Pam with cancer: "In two months we were simply swept into this medical world. Despite accompanying Pam to every clinic and consultation, **nobody identified me as her full-time carer or, at this stage, pointed me in any direction for help and support."**

*"I felt very isolated and vulnerable, increasingly so as Pam's illness progressed. I remember reminding myself that compared to what Pam had to deal with, my needs were secondary and I had to focus on meeting her needs, despite often feeling ill-equipped and unsure. I ended up being admitted to hospital with a severely inflamed gall bladder, probably brought on by stress according to the doctor. I feel very strongly that people looking after someone with cancer need more support. **I think politicians need to be aware of the central role carers play.**"*

¹ 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. 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.

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 a mere 5% have actually had one**. This is estimated to be lower than the proportion of all carers looking after people with other conditions and disabilities².

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**. A 2013 Carers Week survey of 2,000 carers found that over 70% of carers come into contact with health professionals (including GPs, doctors and nursing staff) during their journey. **Yet health professionals only identify 11% of carers and GPs only identify 7%**³.

Chantal Simon, Medical Director for Professional Development, Royal College of GPs:
*"GPs are currently only paid for supporting carers through their obligation to provide general medical services to all their registered patients. Although most GPs are very sympathetic to the needs of carers and appreciate the work that they do, **many GPs do not consider support of carers to be their job**. Practices are cutting back on medical services that they have always offered because of their income squeeze. **There is a need for a national framework or guidance on how the NHS can better identify and support carers.**"*

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. We are also delighted that local authorities must have regard to the importance of identifying carers under clause 2 – prevention.

However, as outlined above, cancer carers are mainly seen in health settings. **With cross-party recognition that more integration between health and social care is essential**, we are surprised that clause 2 does not explicitly mention the NHS. While we hope the duty will cover Health and Wellbeing Boards, two other bodies crucial to the effective identification of carers are NHS England and Clinical Commissioning Groups (CCGs). At present there is no sufficient explicit 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 work by the RCGP on CCG best practice guidance for supporting carers, although future funding is not guaranteed. However effective procedures and systems must be in place to identify carers **across a range of relevant bodies** while allowing local authorities to take a lead on this. In practice this would mean the roll out across England of these DH-funded initiatives which have already proved effective in promoting carer identification in healthcare settings⁴. Without the Government prioritising this and setting the direction in the Bill, identification and signposting to support will remain patchy and inconsistent.

Carers UK, Carers Trust and a cross-party group of MPs supported this in the Social Care (Local Sufficiency) and Identification of Carers Private Members' Bill 2012/13, highlighting the range of support for a requirement on health bodies to identify carers. Indeed,

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

³ Carers Week (2013) *Prepared to Care? Exploring the impact of caring on people's lives*.

⁴ CIRCLE, University of Leeds (2011), *New Approaches to Supporting Carers' Health and Wellbeing: Evidence from the National Carers' Strategy Demonstrator Sites Programme*, p62.

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 partners... to agree plans and budgets for identifying and supporting carers”.

Suggested questions to pose during the Second Reading debate:

- With only 5% of cancer carers receiving a carers’ assessment, does the Government recognise the seriousness of the problem facing cancer carers?
- With cross-party support for more integration between health and social care, how will the new duty to identify carers in the Bill apply to the NHS?
- How does the Government feel its commitment in the White Paper that NHS bodies and local authorities must work together to identify carers has been translated into the Bill?
- How long will the funding continue for the Government’s work with the RCGP on best practice guidance for supporting carers for GPs?

2. The importance of free social care and supporting people to die at home

Macmillan Cancer Support strongly believes that people with cancer who are in the final weeks of life should have the choice to die in their preferred place of care, 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 to be cared for and die in their own home. However, currently, the majority of cancer patients continue to die in expensive hospital beds or A&E departments.

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. We know that **the vast majority of cancer patients (73%) would prefer to die at home.** However, currently less than a third (29%) are able to. Macmillan estimates that in 2012 this meant 36,000 cancer patients died in hospital when they would have preferred to die at home.

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. **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?

Free social care at the end of life will help by **delivering 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.

Further initiatives

24/7 community nursing has been identified as being key to avoiding unnecessary end of life hospital admissions, reducing bed blocking and easing pressure on A&E. Even more important, and even less widely available, are **electronic palliative care coordination systems** (EPaCCS). They record and share the care preferences of people approaching the end of life between all the services providing their care. Where EPaCCS are used, in collaboration with a care plan, death in the preferred place of care is as high as 80%.

Following the Health White Paper in 2010, the Government committed to a **Choice Review** on end of life care by the end of 2013. We are still awaiting details on the review's scope.

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 necessary data through the PCFR pilots.

Macmillan recognises the importance of the PCFR pilots in providing data on how a system for funding end of life care can be implemented. On launching the pilots, the Government committed to introducing the new funding system in 2015, following the pilots' conclusion in 2014. **Macmillan is now seeking a firm commitment from the Government that they will make a decision by the end of this Parliament on free social care at the end of life.**

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 provides 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 and timetable for making a final decision and implementing the policy.

Suggested questions to pose during the Second Reading debate

- Will the Government make a commitment to make a decision on free social care at the end of life before the end of this Parliament?
- Is the Government confident that the pilots will be able to collect enough data to implement free social care at the end of life?
- What assessment has the Government made of the savings for hospitals of enabling patients at the end of life to be cared for and die at home?
- Can the Government set out further details of its upcoming Choice Review including its scope and timetable?

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