

Macmillan Briefing on Carers issues

Briefing for: **Parliamentarians interested in carers issues ahead of Commons Second Reading**

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1. Introduction

Macmillan Cancer Support welcomes the Care Bill as a crucial opportunity to improve the lives of people selflessly providing unpaid care to loved ones with cancer. 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 identification of cancer carers which must be addressed for this ambition to be realised. Please find suggested **Second Reading questions** at the end of this briefing.

2. Executive Summary

- There are approximately 905,000 cancer carers in England, half of whom are not receiving any support despite it having a substantial impact on their lives.
- Cancer carers come into contact mostly with health professionals, who are not sufficiently identifying them, meaning only 5% receive a carers' assessment.
- The Care Bill places a duty on local authorities to identify carers which we warmly support. However, the duty does not cover health bodies meaning, until there is integration in the Bill, cancer carers will continue to slip through the net.

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

Care Bill regulations and guidance should specify that cancer carers must be identified and signposted by health and social care professionals to the enhanced support outlined in the Bill as early on in their journey as possible.

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. 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.

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**

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.

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.

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.**

“Eventually we had a visit from a Macmillan nurse... who pointed me in the direction of a Macmillan Support Centre that I visited a few times where they offered me support and advice at a time when I was struggling. 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, insecure and unsure. I lost about 20 pounds in weight and I know I was very stressed. 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.**”

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 a ‘carer’. 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 disabilities².

Of the very small number of cancer carers who have had an assessment, the event that **most often prompted this was a referral by a GP.** A 2013 Carers Week survey of over 2,000 carers found that over 70% of carers come into contact with health professionals (including GPs, doctors and nursing staff) during their journey, compared to 35% who come into contact with local authority staff. **Yet health professionals only identify one in ten carers³.** Carers UK also reported this as an issue in their *State of Caring 2013* report where they found that ‘67% of carers said their GP is aware of their caring responsibilities but gives them no extra help’.⁴

Chantal Simon, Medical Director for Professional Development, Royal College of General Practitioners (RCGP)

“GPs are currently only paid for supporting carers through their obligation to provide general medical services to all their registered patients. They are not obliged to support carers not registered with their practice. 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. We have already done this for General Practice. It would be good to roll out those principles across the NHS so that care for carers is joined up across the service.”

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 Carers UK (2013) *State of Caring*

4. 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 pleased that local authorities must have regard to the importance of identifying carers under clause 2 – prevention. We hope that both these new duties will do more to ensure that an increased number of cancer carers receive the support they need.

As outlined above, cancer carers are mainly seen in health settings and are less likely to have contact with local authorities. **With the cross-party recognition that more integration between health and social care is essential**, we are surprised clause 2 does not mention the NHS. While we hope the duty will cover Health and Wellbeing Boards, NHS England and Clinical Commissioning Groups (CCGs) are also crucial to the effective identification and signposting of carers. 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, and health professional groups such as the work by the RCGP on CCG best practice guidance for supporting carers. Various initiatives have been piloted in recent years, but with 95% of cancer carers still not getting a carers' assessment now is the time for a step-change in how to tackle the problem.

James Drummond, Lead Officer for Integrated Services, Torbay and Southern Devon Health and Care NHS Trust

“We know carers don't always recognise themselves as a carer and can remain 'hidden' from services and miss out on support because of this. In Torbay we understand that a 'whole system' approach is needed to support carers and that proactive identification is needed by the NHS. If we wait for carers to approach us we may not engage until there is a crisis. Proactive identification is good practice, but **national support is needed to spread this across the country**. It should be made clear that identifying carers and signposting them to support is the responsibility of **all health and social care professionals, not just local authorities**.”

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 and ensure they receive appropriate information and advice. 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 partners... to agree plans and budgets for identifying and supporting carers”.

5. 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 Local Health Boards (LHBs) to lead on published strategies outlining how they intend to identify and support carers. This has led to initiatives being put into place such as in the West Wales Hywel Dda Health Board who have been working with GPs to roll out an 'Investors in Carers' programme. In addition, LHBs across Wales have been undertaking Carer Awareness training with frontline staff.

Keith Bowen, Director, Carers Wales

“The Carers Strategies Measure (Wales) 2010 has provided an important impetus to the carers’ agenda in Wales. It has acted as a valuable catalyst to constructive work across Wales, led by LHBs, to identify carers and target relevant information to them. It has also helped galvanise efforts to increase awareness of carers’ issues via training for frontline professionals. It is early days but **initial indications are that the Measure has helped improve joint working at a local and national level.**”

In Scotland, each LHB has developed a Carer Information Strategy to identify and provide information and support to carers. NHS Education Scotland and the Scottish Social Services Council are working together with partners to develop core values, skills and knowledge to help staff across the whole health and social care workforce to work with carers⁵. Reports from LHBs outline success including **increased referrals to support by NHS staff**, and improved ‘carer awareness’.⁶

6. What we are calling for

Care Bill regulations and guidance should specify that carers must be identified and signposted by health and social care professionals to the enhanced support outlined in the Bill as early on as possible. We will be working with Peers and MPs to table amendments and working with Officials on regulations and guidance to ensure:

- Identification **takes place in every local authority area across England** and not in patches as is currently the case.
- Carers are identified **as early on in their journey as possible** when, in many cases, they just need signposting to appropriate information, help and advice, or existing support centres. This will mean fewer carers will reach crisis point further down the line when they are in need of more intensive support and resource from the NHS and local authorities. This in turn has the potential to **save money**.
- Effective procedures and systems are in place to identify carers **across a range of relevant bodies including NHS England, CCGs, primary care and hospital trusts** while allowing local authorities to take a lead on this. In practice this would mean the roll out across England of DH-funded initiatives which have already proved effective in promoting carer identification in healthcare settings⁷.

7. Suggested questions for Commons Second Reading

- 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?
- 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 need to work together to identify carers has been translated into the Bill? How will health bodies be incentivised to improve identification and signposting of carers?

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⁵ Carers Week (2013) *Prepared to Care? Exploring the impact of caring on people’s lives*

⁶ Scottish Government (2012) *Carer Information Strategy Learning and Sharing Event*

⁷ CIRCLE, University of Leeds (2011), *New Approaches to Supporting Carers’ Health and Wellbeing: Evidence from the National Carers’ Strategy Demonstrator Sites Programme*, p62