

## Macmillan Briefing on Carers issues

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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 carers which must be addressed for this ambition to be realised.

### 2. Executive Summary

- There are approximately 905,000 carers of people with cancer in England, half of whom are not receiving any support despite it having a substantial impact on their lives.
- Carers of people with cancer 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 provide services and in doing so identify carers with unmet needs, which we warmly support. However, the duty does not extend to health bodies, meaning carers will continue to slip through the net.

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

**Care Bill legislation should specify that local authorities must work with health bodies in order to adequately identify carers with unmet needs and provide sufficient services and support for them.**

There are close to a million people in England selflessly providing unpaid care to family and friends with cancer. These 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 nearly half of carers of people with cancer are not receiving any support in return for giving on average almost 15 hours of care 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 carers now before the Bill is passed and the Government's agenda moves on.

#### Unmet needs

The support carers of people with cancer 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 carers of people with cancer 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. 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.

**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.**”

**Why are carers of people with cancer 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 carers of people with cancer 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 carers of people with cancer 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. **Yet health professionals only identify one in ten carers and GPs only identify 7%<sup>3</sup>.** 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’.<sup>4</sup>

**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.**”

**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 in their populations with unmet needs** with the aim of early intervention and prevention of future needs under clause 2.

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

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

<sup>4</sup> Carers UK (2013) *State of Caring*

Yet at present there is no sufficient, explicit requirement on health bodies to do the same. As outlined above, carers of people with cancer are mainly seen in health settings and are less likely to have contact with local authorities. It is therefore **unlikely that local authorities will be able to identify the 47% of carers of people with cancer in their populations with unmet needs** unless they work closely with health bodies through forums such as health and wellbeing boards. **Given the cross-party recognition that more integration between health and social care is essential**, we are surprised clause 2 does not mention the NHS. The co-operation clause 6 states that health bodies must 'co-operate' with councils in the exercise of their 'respective functions relating to carers'. However this does not go far enough as neither the Care Bill nor the Health and Social Care Act sets out the NHS's function in identifying carers. It is therefore highly likely this responsibility will remain on local authorities and the NHS will have to do very little, if anything, to 'co-operate' to identify carers with unmet needs.

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 RCGP is working on CCG best practice guidance for supporting carers. However a **range of relevant bodies must have procedures and systems in place to identify carers** with unmet needs while allowing local authorities to take a lead on this. In practice this would include the national roll out of these DH-funded initiatives which have already proved effective in promoting carer identification in healthcare settings<sup>5</sup>.

**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 call** 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 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 such as the West Wales Hywel Dda Health Board's work with GPs to roll out an 'Investors in Carers' programme. In addition, LHBs across Wales have been undertaking Carer Awareness training with frontline staff.

<sup>5</sup> CIRCLE, University of Leeds (2011), *New Approaches to Supporting Carers' Health and Wellbeing: Evidence from the National Carers' Strategy Demonstrator Sites Programme*, p62.

### 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 carers<sup>6</sup>. Reports from LHBs outline success including **increased referrals to support by NHS staff**, and improved ‘carer awareness’.<sup>7</sup>

## 6. What we are calling for and why

Care Bill legislation should specify that local authorities need to work with health bodies in order to adequately identify carers with unmet needs and provide sufficient services for them. We will be working with MPs to table amendments and working with Officials on regulations and guidance to achieve this. Only then will:

- identification **take place in every local authority and health area across England** and not in patches as is currently the case.
- carers be 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 then achieve clause 2’s ultimate aim of preventing needs 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**.
- **health bodies have effective procedures and systems in place to identify carers with unmet needs 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<sup>8</sup>.

## 7. Suggested supplementary questions

- Does the Government recognise that local authorities will be unable to sufficiently identify carers with unmet needs unless they work closely with health bodies?
- With cross-party support for more integration between health and social care, how will the new requirement to identify carers with unmet needs in the Bill apply to the NHS if there is no respective function in the Health and Social Care Act?
- With only 5% of carers of people with cancer receiving a carers’ assessment, does the Government recognise the seriousness of the problem facing these carers?
- How does the Government feel its commitment in the White Paper that NHS bodies and local authorities must work together to identify and support carers has been translated into the Bill?

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<sup>6</sup> Carers Week (2013) *Prepared to Care? Exploring the impact of caring on people’s lives*

<sup>7</sup> Scottish Government (2012) *Carer Information Strategy Learning and Sharing Event*

<sup>8</sup> CIRCLE, University of Leeds (2011), *New Approaches to Supporting Carers’ Health and Wellbeing: Evidence from the National Carers’ Strategy Demonstrator Sites Programme*, p62