

Macmillan Briefing on Carers issues

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Updated: **April 2014**

1. Introduction

Macmillan Cancer Support has welcomed the Care Bill as a crucial opportunity to improve the lives of carers and people at the end of life. We have warmly welcomed the Government's ambition to create a system in which everyone can get the care they need when they need it. However, there are still significant gaps in support which must be addressed in the Bill's statutory guidance. Macmillan is currently undertaking further scoping activity to identify other national and local levers that will improve the identification and support of carers and would welcome opinions from stakeholders on this.

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 statutory guidance must outline that local authorities have a duty to co-operate with health bodies when identifying carers.
- Macmillan should be consulted and involved in the development of national initiatives and strategies to ensure carers of people with cancer, who have specific needs, are represented.

3. Identification and signposting to support and information for carers

Local authorities and health bodies must work together in order to identify carers and signpost to 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 year¹. 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 it is too late.

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.

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.

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 disabilities².

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%³. 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 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.”

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

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. The co-operation clause 6 states that health bodies must 'co-operate' with councils in the exercise of their 'respective functions relating to carers'. We were delighted that the Care Minister made a strong commitment during the Care Bill Report Stage to include in statutory guidance the fact that local authorities must co-operate with health bodies in relation to their requirement to identify carers. We are now working with the Department of Health to ensure this is outlined clearly.

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. We are also pleased to see NHS England's 'Commitment to carers' action plan among other national and local initiatives to improve the identification of carers. Macmillan should remain closely involved in the development of these to ensure cancer carers, who have specific needs, are represented.

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."

5. How have Scotland and Wales tackled this issue?

Both the Welsh and Scottish Governments have recognised the seriousness of the identification 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.

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 and why

Local authorities and health bodies must work together in order to adequately identify carers with unmet needs and provide sufficient services for them. We believe that this could be achieved in part through statutory guidance stating the importance of working with health bodies on identifying carers with unmet needs through forums such as health and wellbeing boards. 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 identification⁷.

Macmillan is currently undertaking further scoping activity to identify other national and local levers that will improve the identification and support of carers and would welcome opinions from stakeholders on this.

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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