

NHS Not Making the Break for Carers

A report on the implementation of the Carers Strategy by primary care trusts

The Princess Royal Trust for Carers and Crossroads Care



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Executive summary

In November 2010, the Government published its refreshed Carers Strategy announcing that an additional £400m was to be allocated to primary care trusts (PCTs) in England over four years, 2011–15, to increase support for carers. The Government asked PCTs to work with local carers' organisations to publish plans and budgets showing how they would implement the refreshed Carers Strategy in England.

A year on, The Princess Royal Trust for Carers and Crossroads Care have investigated whether PCTs have published those plans and budgets, and whether the additional money made available has been used to increase services for carers or not.

During 2011, ministers have been concerned that PCTs are not following the requests of the Government and indeed the Prime Minister requested an investigation into how the money was being used.

This report finds that:

- 26% of PCTs have published plans post-dating the Government's publication of the refreshed Carers Strategy in November 2010.
- 13% of PCTs have published 2011/12 budgets regarding support for carers.
- Only 4% of PCTs are not investing anything in services for carers – compared with 8% in 2010/11.
- There has been no increase in total spending by PCTs on services for carers.
- The total amount to be spent by PCTs on services for carers in 2011/12 is £68.3m.

While PCTs have faced multiple challenges over the last 12 months, the Government has been clear about PCTs' responsibilities regarding carers. We find that many PCTs have failed to meet these responsibilities, while some have made large strides forward.

The Government took action during July to September 2011 to monitor progress made by PCTs and local carers' organisations have advised us that this resulted in some PCTs showing an increased willingness to engage. If Government sustains this level of focus, improvements will result.

The Government must continue to drive PCTs to work with local carers' organisations and local authorities to publish plans and budgets regarding services for carers. This is the only way that local carers and the wider population can hold PCTs to account. We call on the Government to ensure that all PCTs:

- Include a section on carers in the area's Joint Strategic Needs Assessment.
- Work with local carers, carers' organisations and local authorities to publish plans and budgets for 2012/13.
- Have these plans and budgets published on their websites before 30 September 2012.
- Are investing in services that are specifically for carers.
- Use the additional money to increase the availability of services for carers.

Introduction

The Government refreshed the Carers Strategy in November 2010¹, allocating an additional £400m over four years (2011–15) to the NHS for PCTs in England to provide breaks for young and adult carers. Consistent with the Government's localism policy, the additional £400m was not ring-fenced.

Through the NHS Operating Framework 2011/12, the Government requested that PCTs make plans and budgets publicly available to ensure that there was transparency and local accountability for how PCTs implemented the refreshed Carers Strategy and used this additional money.

On the anniversary of the refreshed Carers Strategy, our report aims to scrutinise whether PCTs have provided the transparency requested by the Government and needed by local people. Where we have found transparency lacking we have sought to create that transparency by reporting how much PCTs are planning to invest in carers' services during 2011/12.

This report has multiple audiences. We want Government ministers to understand that their commitments have made a difference to the availability of support for carers, but that focus must remain to turn first steps into the necessary giant leaps. We want PCTs and potential successor organisations (clinical commissioning groups) to understand why some PCTs have realised that it is in their own interests to invest sums as large as £2m in support for carers, and what more can be done to help carers, and the people they care for.

But most of all, this report is for carers.

The Government announcement of an additional £400m for carers is extremely significant for those carers who often sacrifice everything for other people. They feel that their struggle is being recognised and that they will finally receive support. We want carers to have the information and power to question their PCT about how much they are spending and what they are spending it on. If a PCT says they are spending £1m on services for carers, then a carer has the right to ask how they are spending it.

This report will focus on:

- Whether PCTs have published plans since the refreshed Carers Strategy in November 2010.
- Whether PCTs have published budgets for carers' services in 2011/12.
- How much PCTs are investing in services for carers in 2011/12.
- Whether the level of investment has increased against previous years.

PCTs have been operating in difficult circumstances over the last year with multiple priorities, restricted budgets, high staff turnover and the prospect of organisational change. Undoubtedly these factors have hindered the ability of PCTs to develop new plans and allocate large sums to services for carers.

However, the Government has clearly explained what the responsibilities of PCTs are relating to carers and it is the duty of PCTs to meet these responsibilities. The challenges do not remove these responsibilities and some PCTs are facing these challenges better by working positively with carers, carers' organisations and local authorities to invest in support that improves post-discharge care. This attitude is summed up by the Chief Executive of

¹ Department of Health (2010), *Recognised, valued and supported: Next steps for the Carers' Strategy*. London: Centre for Information

Torbay Care Trust: “We hope for the close involvement of a wide range of carers. They challenge agencies to do better.”

Torbay has recognised the value of involving carers in shaping services. There is regular contact between carers and senior managers and non-executive directors, reinforcing a culture of carer awareness and dialogue. Carers are also directly involved in evaluating services.

Fundamentally changing how the NHS supports carers can be done, and is being done in some areas. From the viewpoint of carers, it must be done everywhere and we hope that this report will help make this promise a reality.

Do you think people like Sue deserve support?

Sue’s husband has compression of the spinal cord causing poor mobility and extreme pain for much of every day. Sue’s caring role is both physically and emotionally demanding as she regularly has to help him move throughout the day, help him to the toilet during the night and support his pain management.

Sue was able to get a break to go on a trip to Scarborough with her sister. Sue desperately needed a rest and also wanted to rebuild her relationship with her sister which due to the demands of her caring role has significantly suffered. Sue just wanted the feeling of isolation to stop.

Methodology

From 21 September to 20 October 2011, we surveyed the websites of all 151 PCTs² to see if we could find any plans and budgets for carers' services. This entailed using the search function on their website and searching through general commissioning and operating plans, and their online list of publications. Acknowledging that PCTs will predominantly have joint strategies for carers with local authorities, we also repeated this exercise on the relevant local authority websites if we found nothing on the PCT or PCT cluster website. If no plans and budgets were found on the local authority website, we then used Google to search, using the area's name and the phrase 'carers strategy' or 'carers plan'.

If plans and budgets were still not found we contacted named contacts at PCTs.³ Sometimes these contacts were within their partner local authority. Often, these individuals did not or could not advise whether a plan and/or budget had been published. We therefore submitted a Freedom of Information request to the PCT asking for online links to their plans and budgets if they were published, and the relevant documents/information if they were not.

We have also sought to verify some information with local sources such as people in local authorities, carers' organisations and local information networks (LINKs). There were a few occasions when we made deductions from what PCTs reported due to inclusion of spend on services that could not be classified as services that support carers, even in an indirect sense through the person they are caring for.

Predominantly, we have accepted the figures that PCTs presented to us even if they included amounts spent on services where it could be said there was a dual purpose of supporting the carer and the patient. Some PCTs have tried to apportion this spending, while others have not, therefore, our reporting could be overestimating the actual spend on carers' services. This should be taken into account when comparing PCTs as some may have interpreted what they consider to be services for carers more widely than others. This highlights the importance of transparency and published budgets because they allow scrutiny which demands rigour and accuracy from PCTs.

36 PCTs did not respond to us so we have no financial information for their investment in carers' services.

A further 11 PCTs did respond but could not advise how much they were spending or were still undecided what the budget would be for 2011/12, despite it being seven months into the financial year.

As a result we do not have financial information for 47 PCTs and so, to give totals for all 151 PCTs, we have extrapolated from the results of the 104 PCTs for which we do have information.

This extrapolation is likely to overestimate the level of investment of those 47 PCTs we do not have financial information for. Not having decided on a budget for 2011/12, not being able to advise what their budget is or not responding to information requests could in some cases be interpreted as carers being a low priority. This could manifest itself in lower investment figures compared with those PCTs which have clearly shown carers to be a priority.

² We have used the total of PCTs to be 151, rather than 152, because there is now one whole NHS Hertfordshire.

³ We collected these details when completing the previous survey earlier this year for our report 'Any breakthrough for carers?'.

Have PCTs published plans and budgets to support carers?

PCTs defy Government demands for transparency

Every year, the Government publishes the NHS Operating Framework which sets out the priorities for the NHS and contains key actions that PCTs should perform. In the NHS Operating Framework for 2010/11,⁴ the Government requested PCTs to work with local authorities and carers' organisations to develop policies, plans and budgets to support carers and make them available to local people. These plans and budgets were to account for the Government's refreshed Carers Strategy of November 2010 that made available an additional £400m over four years (2011–15) in the budgets of PCTs.

In July 2011, we reported that only 9% of PCTs had plans published post-dating the refreshed Carers' Strategy.⁵ Budgetary information in any of the published plans was rare.

The Minister for Care Services, Paul Burstow MP, responded to questions in the House of Commons about this by advising that he would be taking assurance measures to confirm that PCTs were carrying out what had been requested.⁶

On 27 July 2011, the NHS Director of Performance wrote to Directors of Finance and Directors of Performance at Strategic Health Authorities (SHAs) requesting that they report by 2 September 2011 that all PCTs in their region had published plans for carers' services. Missing this date would only be expected in "exceptional circumstance".

Furthermore, the NHS Director of Performance advised that it would only be acceptable for PCTs to have plans pre-dating the refreshed Carers Strategy that were not updated, if the plans were "robust" and that the SHA could confirm that these PCTs had taken into account the refreshed Carers Strategy.

20 PCTs (13%) have published a budget and a plan for 2011/12

Our research has found that only 20 PCTs (13%) have published a budget for 2011/12. However, only 16 of these PCTs (11% of total) also have plans for 2011/12 that post-date the refreshed Carers Strategy. These 16 PCTs, which should be recognised for their transparency, are:

- NHS Barking and Dagenham,
- NHS Berkshire West
- NHS Bristol
- NHS Devon
- NHS Gateshead
- NHS Hertfordshire
- NHS Knowsley
- NHS Mid Essex
- NHS Norfolk
- NHS North Tyneside
- NHS Northumberland
- NHS Sandwell
- NHS Somerset

⁴ Department of Health (2010), 'The Operating Framework for the NHS in England 2011/12'. London: Centre of Information.

⁵ Conochie, G. & Davidson, W. (2011), 'Any Breakthrough for Carers?'. London: The Princess Royal Trust for Carers and Crossroads Care.

⁶ Paul Burstow MP, House of Commons Debate, 12 July 2011. Hansard Column 157. <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110712/debtext/110712-0001.htm#11071255000409>.

- NHS South Tyneside
- NHS Sunderland
- NHS Torbay.

The additional four PCTs that should be given credit for having budgets published for 2011/12, even if they do not have plans post-dating the refreshed Carers Strategy are:

- NHS Cumbria
- NHS Hereford
- NHS Newcastle
- NHS Sutton and Merton.

40 (26%) of PCTs have published updated plans for 2011/12

The action taken by Government in July appears to have prompted a response from PCTs as 40 PCTs (26%) have now published plans since the refreshed Carers Strategy in November 2010. Only 9% had done so when we reported in July 2011. Some PCTs have published plans earlier than they previously indicated that they would.

27 (18%) PCTs have new plans in consultation/development

In addition to these 40, there are another 27 PCTs (18%) that are either reviewing plans that were published before the refreshed Carers Strategy or are developing new ones. Some are due to publish their plans during November/December 2011, and most are planning to publish before March 2012. However, given that the refreshed Carers Strategy was published in November 2010 and the NHS Operating Framework in December 2010, we believe that one year is sufficient time to have completed this work.

58 (38%) of PCTs have plans for 2011/12 published before the refreshed Carers Strategy

A further 58 PCTs (38%) have plans that were published before the refreshed Carers Strategy and which are not being reviewed or updated to account for that Carers Strategy. It must be assumed that these PCTs believe their strategies to be “robust” enough and do not need to be amended to reflect the refreshed Carers’ Strategy. The public in these areas may be interested to compare these strategies with those of PCTs who have published since the refreshed Carers Strategy.

Table 1: PCT published plans

	Number of PCTs	Percentage of PCTs
Published plans for 2011/12 post refreshed Carers Strategy	40	26%
New plans in consultation/development	27	18%
Published plans for 2011/12 pre refreshed Carers Strategy	58	38%
Out-of-date published plans	16	11%
No published plans	10	7%

Enabling local accountability

If local carers and the wider population are to hold PCTs to account for implementing the refreshed Carers Strategy and the additional money, PCTs must publish up-to-date budgets and plans that incorporate the refreshed Carers Strategy.

It is illuminating that 16 of the 40 plans post-dating the refreshed Carers Strategy include a budget for 2011/12 but that only one plan from the 58 covering 2011/12 that pre-date the Carers’ Strategy do so. Part of the reason for this discrepancy is because if PCTs do include investment details in their carers’ plans, they only do so for the first year of what might be a three year plan. Therefore, plans that, for example are for the period 2009–12 would only

have investment figures for 2009/10. This illustrates the precarious nature of PCT commitment to funding carers' services.

However, a lower proportion of the plans pre-dating the refreshed Carer's Strategy contain investment details compared with those published since. This indicates that the request within the NHS Operating Framework for budgets to be made available to local people has made a difference, backed up by the assurance processes undertaken by the Government in July–September 2011.

Finally, it is interesting to note that joint plans produced by a PCT and partner local authority often include details of investment by the local authority but no detail regarding PCT investment. This lack of clarity by PCTs could reflect a desire to avoid scrutiny of their investment and possible resulting criticism.

An extra £1.4m for carers from NHS South of Tyne and Wear

This cluster of PCTs, comprising Gateshead, South Tyneside and Sunderland PCTs, found the refreshed Carers Strategy gave them compelling evidence that supporting carers needed radically more investment. They began working with carers and carers' organisation to shape new strategies which resulted in total spending increasing by £1.4m to £1.72m for 2011/12, with further increases planned. All plans and budgets have been fully published.

There will be an expansion of personalised breaks, continuation of Caring with Confidence, involvement in reablement services and investment in Carers' Centres to ensure carers access good information and advice throughout the carer pathway.

NHS South of Tyne and Wear believe that this will lead to more hidden carers being identified who will be more able to manage their caring role. They are also keen to ensure that the plans maximise outcomes to support other strategic priorities including intermediate care and self care, by aligning with the Long Term Conditions plans.

PCTs should be transparent about budgets

It is worth noting that 15 of the 20 PCTs which have published budgets for 2011/12 are some of the highest investors in carers' services among all PCTs. It seems that the more the PCT invests, the more likely it is to be open about how much it invests. This may be unsurprising but does reveal that two common explanations given by PCTs for not publishing budgets may, in part, cover a lack of confidence in their investment levels withstanding public scrutiny:

- 1) It is difficult to quantify the total spending because spending on carers can be contained within multiple budgets across various conditions and care pathways.
- 2) It is difficult to determine what counts as a service for a carer, when services for the person being cared for can benefit carers.

1) It is difficult to quantify the total spending because spending on carers can be contained within multiple budgets across various conditions and care pathways

For example, investment in services for carers can be contained within mental health, learning disabilities, dementia and stroke services, which makes collation and presentation of complete investment figures more difficult. This is a legitimate difficulty, but does not justify no reporting of investment. For instance, Southampton City PCT, Coventry PCT and South Gloucestershire PCT all reported a certain amount of investment while advising that there is spending contained within other budgets that they have been unable to quantify.

We are concerned that a lack of organisational knowledge about how much money is being spent could result in underinvestment.

We recommend that:

- PCTs should designate a staff member as the lead on carers with responsibility for calculating investment in carers throughout the PCT. Without this information a PCT cannot know whether the range of services that carers need are available or whether there are opportunities to reduce duplication or enhance cooperation.
- Commissioners should use The Carers' Hub website (www.carershub.org) to guide them through the process of understanding what services carers need to access, and auditing what is available.

2) *It is difficult to determine what counts as a service for a carer, when services for the person being cared for can benefit carers*

This argument stems from the PCT's approach to supporting carers, and what they classify as services commissioned to provide this support. A narrow definition would include services that are provided with the specific purpose of supporting carers while a broader definition could include services that are provided to support a disabled or seriously ill person but which also significantly benefit their carer.

This broader definition could include funding for a day care centre where many of the people attending may have a carer who would thus receive respite as a result. Of course, a day care centre could still be designed with the specific aim of supporting carers by only providing places to people who have a carer or allocating a specific number of places to people who have a carer, as does happen in some cases. Another example may be dementia information and advice programmes where it is often the carer who is seeking information and advice rather than the person with dementia.

The PCT may then have difficulty in working out what should count as spending on carers' services. However, NHS Stoke on Trent and NHS North East Essex tackled this problem by calculating the proportion or element of investment on such services that could be attributed towards supporting carers.

We recommend that other PCTs follow this example as it provides a more accurate estimation. In the main we accepted figures reported although we did discount some funding reported for services such as housing for single people with substance misuse problems and whole NHS Continuing Care budgets that were not just to provide respite for families. We considered that these did not even fit the broader definition of services for carers.

How much are PCTs spending on services for carers?

More PCTs are now investing in services for carers

The previous government first allocated additional money, £50m, to the NHS to increase support for carers in 2009/10, and this was repeated with an additional £100m in 2010/11. The current Government has included an additional £400m over four years, 2011–15, to increase NHS investment in services for carers.

This injection of additional money has had the desired effect to some extent as more PCTs are spending more money on services for carers than in 2008/09. Our research shows that in 2008/09, 33% of PCTs were not investing in any services for carers or could not advise if they were. In 2009/10, this figure had dropped to 20% and in 2010/11, only 8% of PCTs were not investing anything in services for carers.

We can report that in 2011/12, only 4% of PCTs are not investing anything in services for carers.

NHS Bristol: Making the break for adult and young carers

NHS Bristol recognises the value that carers provide and the impact that caring has on their own health. They understand that having a regular break from caring will enable a carer to look after their own health needs, which will in turn enable them to keep caring for longer.

That's why NHS Bristol has invested £830,000 in special breaks for carers, including young carers, from 2012 onwards, allocated as a result of the additional Department of Health funding given to PCTs. Any carer whose health is being impacted by caring is eligible.

Working with Bristol City Council, it will be able to deliver personalised breaks to carers in a variety of flexible ways. A break can mean anything from additional support to enable people to go away for a weekend together, to a radio to provide relief from the feeling of isolation. Even this can make a significant impact on someone's mental health and wellbeing.

NHS Bristol will work with voluntary sector colleagues to help provide these carers' breaks to the most appropriate people. It is aiming to have carers support workers based in primary care and acute hospitals who will be able to help people access breaks and provide support.

50% of PCTs invest between £100,001 and £500,000

We found that 50% of PCTs are planning to invest between £100,001 and £500,000 in carers' services in 2011/12, up from 34% in 2010/11. We found that 22% of PCTs in 2011/12 are spending between £500,001 and £1,000,000, up from 16% that did so last year.

A key marker for progress will be to ensure that all PCTs are investing more than £100,000 in 2012/13. Currently, 8% of PCTs are investing less than £100,000 in addition to the 4% that are not investing anything. This is unacceptable.

Attention should be focused on these PCTs to ensure that inequality of provision for carers in these areas compared with others does not widen. There should be scrutiny of how these PCTs perform against the indicators related to carers in the NHS Outcomes Framework compared with those PCTs who are investing more than £500,000 per annum.

Table 2: PCT investment levels

	Number of PCTs	% of PCTs
No investment	5	4%
Undecided	5	4%
Unable to advise	6	5%
£1–£100,000	9	8%
£100,001–£500,000	57	50%
£500,001–£1,000,000	25	22%
£1,000,001+	8	7%

* Percentages taken of the 115 PCTs we have received responses from rather than the whole 151.

When comparing how much PCTs are investing in carers services, the total spend is obviously useful as a guide. However, the overall budgets can vary significantly among PCTs. For instance, NHS Hartlepool's total baseline allocation is £183m for 2011/12, compared to £1.88bn for NHS Hampshire.

A more accurate comparison would be to look at how much is being spent on carers' services as a proportion of their total baseline allocation. In Appendix 1, we have listed alphabetically the level of total investment as reported by PCTs, which is also shown as a proportion of their total budget.

The top ten performing PCTs on this basis are:

- Kirklees
- Cornwall and Isles of Scilly
- Torbay
- Bristol
- Isle of Wight
- City and Hackney
- Leicestershire County and Rutland
- Halton and St Helens
- Stoke on Trent
- Salford

Prioritising the needs of carers – Torbay NHS Care Trust

The commitment of Torbay PCT to supporting carers goes back at least 12 years, even before integration of Health and Adult Social Care in 2005. Projects to develop support services for carers are subject to rigorous evaluation, which has led to increased investment in services such as Carers Support Workers being placed in all GP surgeries to identify both high levels of stress amongst 'ordinary' carers, producing significant health gains as a result.

"The introduction of the role of Carers Support Worker in our practices has produced many benefits. It facilitated early identification of people who are carers and offering practical and emotional support. As the population ages and more people live with long term disability the support for carers will remain a priority."

(Dr E Thomas: Torquay GP / Chair of Torbay Professional Executive Committee)

Evaluation of basing a specialist Carers Support Worker in the Hospital Discharge team has been shown to improve carers' experience in hospitals and facilitate smooth discharge. The PCT has looked for a return on investment in prevention and early identification of carers. A pilot project in a Brixham surgery (2009–11) for early identification of people with dementia and their carers demonstrated that there were significant savings in crisis prevention. Commissioners have agreed to this being extended to an additional seven practices.

"Carers support is worth investing in. As a GP I need to put myself constantly in the place of the people I deal with daily: 'What are they experiencing, what are they needing?' Carers often feel isolated and helpless; they may believe help is available but are unfamiliar with getting hold of it. I have found that supporting carers to care is the best solution for them and the patient they care for."

(Dr R Montgomery GP Brixham / Lead for Dementia)

No increase in total spending despite additional money

Although many PCTs have progressed as described above, there are slightly fewer PCTs investing more than £1m in carers' services in 2011/12 compared with 2010/11. Additionally, there are other PCTs that while still remaining in £100,001–£500,000 or £500,001–£1,000,000 brackets, have reduced their total spending from last year. This has resulted in a reduction in total spend by all PCTs of £2.4m in 2011/12 compared with 2010/11.

We are slightly cautious of this however as some of the larger reductions of reported spend by PCTs could be due to the PCT using a narrower version of what constitutes a carers service this year compared with last. This would result in them reporting a lower spend on services for carers. Thus, part of the reduction could be due to PCTs attempting to report more accurate levels of their investment.

However, undoubtedly some PCTs have reduced their investment in services for carers and that despite the Government making an additional £400m available over four years from 2011/12, there has been no overall increase in funding carers' services by the NHS this year. The total spend by all PCTs on all carers' services in 2011/12 is £68.3m.

Supporting carers can help the NHS meet the QIPP challenge

We have previously provided evidence from randomised controlled trials (RCTs) and peer reviewed journals to show that increasing support for carers:

- Improves health and wellbeing outcomes for patients and recipients of care.
- Improves health and wellbeing outcomes for carers, who suffer disproportionately high levels of ill-health.
- Reduces unwanted admissions, readmissions and delayed discharges in hospital settings.

These are overwhelming reasons why budget holders in PCTs (and future health commissioners), who are focussing on Quality, Innovation, Productivity and Prevention (QIPP) should increase allocations to support carers. Some of the evidence is reproduced below, with more available in 'Supporting Carers; the Case for Change'.⁷

Assisting carers to provide necessary care

Carers often provide the majority of care that would otherwise be the responsibility of health or social care professionals. Such carers need the appropriate knowledge and skills to care safely and in a way that promotes wellbeing for the person being cared for. Carers, therefore, must be included in care plans and receive support to help them provide care, such as training.

There have been some studies looking at the impact of supporting carers on patient wellbeing, mainly within the area of stroke care. One RCT found that support for the family of stroke patients is linked with reduced depression amongst stroke patients (17%–27%) and a reduced need for physiotherapy.⁸

Another RCT assessed the effectiveness of providing 3–5 sessions of personal care training to carers, each lasting 30–45 minutes. It resulted in a higher proportion of stroke patients achieving independence at an earlier stage, and reduced the need for physiotherapy and occupational therapy. There were also significant reductions in carer burden and improvements in mood and quality of life for carers and people being cared for.⁹

Evaluations of four re-ablement programmes in England found that carers play a crucial role and involving and supporting them can improve chances of long-term patient re-ablement.¹⁰

⁷ Conochie, G. (2011), 'Supporting Carers; the Case for Change'. London: The Princess Royal Trust for Carers and Crossroads Care

⁸ Mant, J et al (2000), 'Family Support for Stroke: a Randomised Controlled Trial'. *Lancet*, 356, 808–813.

⁹ Kalra, L et al (2004), 'Training Carers of Stroke Patients: Randomised Controlled Trial'. *British Medical Journal*, 328, 1099–1101.

Patel, et al. (2004), 'Training Care Givers of Stroke Patients: Economic Evaluation'. *BMJ*, 328, 1102–1107.

¹⁰ (2007), 'Homecare Re-ablement Workstream'. Care Services Efficiency Delivery Programme.

NHS Surrey: extra £1.9m to improve carer health and support people dying at home

NHS Surrey's board approved an additional £1.9m of funding to help support carers in 2011/12. This was identified as their share of the additional money from the Department of Health, and increases their total spend to £2.2m for 2011/12.

A new carers' break service is being launched in November 2011 which will allow GPs to refer carers who provide regular and substantial care, for a break. NHS Surrey believes this will increase health outcomes among carers. Another new service will support carers of people with a life-limiting illness. Hosted by Crossroads Care Surrey it will provide palliative care in the home and will increase the number of people able to die at home from the current 21%.

Preventing carers becoming patients

The Government has highlighted carers as a group experiencing health inequalities¹¹:

- A four year study of 392 carers and 427 people who were not carers aged 66–92, found that carers who were reporting feelings of strain had a 63% higher likelihood of death in that period than people who were not carers or carers not reporting strain.¹²
- Carers providing high levels of care are associated with a 23% higher risk of stroke.¹³
- 52% of carers providing substantial care in one study needed treatment for stress-related disorders.¹⁴
- 63% of those with a caring responsibility said they had health problems compared with 48% of those that do not have caring responsibilities.¹⁵
- Carers providing more than 50 hours of care per week are twice as likely to report ill-health as those not providing care.¹⁶

Reducing hospital admissions and delayed transfers of care

There is evidence to suggest that a significant number of hospital admissions are due to problems associated with the carer rather than the person admitted. One study found that problems associated with the carer contributed to readmission in 62% of cases. Carers of people readmitted were more likely than other carers to:¹⁷

- be experiencing ill health, fatigue and interrupted sleep
- be conducting at least one intimate task.

A whole systems study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% of those needing care were admitted to

¹¹ HM Government (2010), 'Healthy Lives, Healthy People: a Strategy for Public Health in England'. London: The Stationery Office.

¹² Schulz, R, Beach, S (1999), 'Caregiving as a Risk Factor for Mortality'. Journal of American Medical Association, 282 (23), 2215–2219.

¹³ Haley, W et al (2010), 'Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers'. Stroke, 41:331–336.

¹⁴ Henwood, M (1998), 'Ignored and Invisible: Carers' Experiences of the NHS'. Carers National Association.

¹⁵ Ipsos Mori (2011), 'GP Patient Survey, 2010/11'. London: Department of Health. <http://www.gp-patient.co.uk/results/>.

¹⁶ Census (2001). Office for National Statistics licensed under the Open Government Licence v.1.0.

¹⁷ Williams, E, Fitton, F (1991), 'Survey of Carers of Elderly Patients Discharged from Hospital'. British Journal of General Practice, 41, 105–108.

hospital because of the breakdown of a single carer on whom the person was mainly dependent.¹⁸

An RCT found that training carers of stroke patients reduced hospital days of patients, contributing to lower annual treatment costs of £4,043 per person,¹⁹ while another study looking at the impact of support for the family of stroke victims found it produced shorter length of hospital stays than in the control group.²⁰

¹⁸ Banks, P (1998) 'Carers: Making the Connections'. *Managing Community Care*, 6/6.

¹⁹ Kalra, L et al (2004), 'Training Carers of Stroke Patients: Randomised Controlled Trial'. *British Medical Journal*, 328, 1099–1101. Patel, et al (2004), 'Training Care Givers of Stroke Patients: Economic Evaluation'. *BMJ*, 328, 1102–1107.

²⁰ Dennis, M et al (1997), 'Evaluation of a Stroke Family Care Worker: Results of a Randomised Controlled Trial'. *BMJ*, 314, 1071–1076.

Conclusions

PCTs such as Bristol, Surrey and those within the cluster of NHS South of Tyne and Wear have specifically cited the Government's refreshed Carers Strategy and the additional money given to PCTs as reasons why they have increased investment in services for carers. Furthermore, the Government's monitoring of the request that PCTs do publish plans and budgets has increased the number of PCTs publishing updated plans and budgets.

This shows that Government action can and is having an influence in some PCT areas. The challenge is to replicate this throughout all PCTs.

Government must meet this challenge by redoubling efforts to ensure that all PCTs:

- Include a section on carers in the area's Joint Strategic Needs Assessment.
- Work with local carers, carers' organisations and local authorities to publish plans and budgets for 2012/13.
- Have these plans and budgets published on their websites before 30 September 2012.
- Are investing in services that are specifically for carers.
- Use the additional money to increase the availability of services for carers.

Some PCTs have refused to engage with local authorities and carers' organisations, and invest little in services for carers. However, we have heard from local carers' organisations that some engagement has begun as a result of Government action between July and September this year. This augurs well for 2012/13.

We understand that PCTs are facing a particularly difficult year in 2011/12, including tightening budgets. However, the evidence contained within this report, supported by various PCTs and GPs, indicates that addressing these difficulties necessitates extra investment in support for carers, not less.

Some PCTs have recognised that investing in support for carers prevents carers from becoming patients, enables patients to receive better support post-discharge, and reduces readmissions and delayed discharges. These are all crucial if PCTs, or their successor organisations, are to successfully meet the QIPP challenge of meeting increase demand with finite resources.

PCTs should realise that not only does increasing support for carers make economic sense, but that they also have a duty to support carers. This is a moral duty to support those who sacrifice so much to care for others and a duty of care to their patients who are often relying on support from these carers.

We owe it to carers like Simon

Simon is 13 years old and cares for his mother and younger brother. Simon's mum, Lisa, suffers from chronic back problems meaning Lisa's mobility is significantly impaired. Lisa relies heavily on Simon for help and support with everyday tasks including shopping, cleaning and preparing meals. There have also been times when Lisa has needed help to physically move around the house when her back is in spasm and she experiences loss of feelings in her legs.

Due to Lisa's mobility issues, Simon also helps care during the day and night for his four-year-old brother, who has recently developed speech, language and feeding problems. As they share a room, Simon's sleep pattern has been severely affected. Simon was able to attend a children's adventure trip for three days giving him the chance to meet other young people and try new activities, as he has become more isolated over the last three years.

Appendix 1: Information for individual PCTs on publication of plans and budgets, and spending levels

Primary care trust	Years covered by local strategy	Budget published	Total spend for 11/12	Spend as % of total PCT budget
Ashton, Leigh and Wigan PCT	2010–12	No	£450,000	0.079%
Barking and Dagenham PCT	2011–15	Yes	£35,000	0.010%
Barnet PCT	2009–12	No	£50,000	0.009%
Barnsley PCT	2010–13	No	No information	No information
Bassetlaw PCT	In development	No	No information	No information
Bath and North East Somerset PCT	2010–15	No	£220,000	0.077%
Bedfordshire PCT	Central Bedfordshire – 2011–14; Bedford Borough – 2010–13	No	No information	No information
Berkshire East PCT	2011/12	No	No information	No information
Berkshire West PCT	2011/12	Yes	£120,000	0.018%
Bexley Care Trust	In consultation	No	£0	0.000%
Birmingham East and North PCT	In consultation	No	Unable to advise	No information
Blackburn with Darwen PCT	2009–12	No	£145,551	0.050%
Blackpool PCT	2010–15	No	£322,000	0.110%
Bolton PCT	2009–12	No	No information	No information
Bournemouth and Poole Teaching PCT	2010–13	No	£171,000	0.030%
Bradford and Airedale Teaching PCT	2011–14	No	No information	No information
Brent Teaching PCT	2010–14	No	£195,000	0.035%

Brighton and Hove City PCT	2010–12	No	£654,000	0.136%
Bristol PCT	2011–12	Yes	£1,643,606	0.225%
Bromley PCT²¹	2007–10	No	£454,000	0.089%
Buckinghamshire PCT	2010–13	No	£600,000	0.084%
Bury PCT	2009–12	No	£391,350	0.124%
Calderdale PCT	2009–12	No	Unable to advise	Unable to advise
Cambridgeshire PCT	In development	No	£483,000	0.055%
Camden PCT	In consultation	No	£362,000	0.072%
Central and Eastern Cheshire PCT	2011–15	No	£360,000	0.050%
Central Lancashire PCT	2009–12	No	£284,243	0.037%
City and Hackney Teaching PCT	In consultation	No	£943,086	0.180%
Cornwall and Isles of Scilly PCT	2010–13	No	£2,885,612	0.315%
County Durham PCT	2009–13	No	£388,300	0.039%
Coventry Teaching PCT	2011–15	No	£230,761	0.039%
Croydon PCT	2011–16	No	Unable to advise	Unable to advise
Cumbria Teaching PCT	In development	Yes	£500,000	0.058%
Darlington PCT	2008–11	No	£111,841	0.061%
Derby City PCT	2009–12	No	£167,000	0.037%
Derbyshire County PCT	2009–14	No	£410,000	0.035%
Devon PCT	2011–13	Yes	£1,282,000	0.104%
Doncaster PCT	2006–09	No	Unable to advise	Unable to advise
Dorset PCT	2010–13	No	£100,000	0.015%
Dudley PCT	2007–12, revised	No	No	No information

²¹ Figures were supplied after compilation of statistics for this report, so were counted as 'no information' for the purposes of this report.

	March 11		information	
Ealing PCT	2006–16	No	No information	No information
East Lancashire Teaching PCT	2009–12	No	£291,167	0.042%
East Riding of Yorkshire PCT	2010–15	No	£500,000	0.102%
East Sussex Downs and Weald PCT	2010–15	No	£150,000	0.026%
Eastern and Coastal Kent PCT	2009–14	No	£657,515	0.051%
Enfield PCT	2005–10	No	No information	No information
Gateshead PCT	2011–12	Yes	£540,000	0.137%
Gloucestershire PCT	2009–11	No	£1,000,000	0.109%
Great Yarmouth and Waveney PCT	2011–15	No	No information	No information
Greenwich Teaching PCT	2011/12	No	No information	No information
Halton and St Helens PCT	In development	No	£1,000,000	0.167%
Hammersmith and Fulham PCT	2005–10	No	£100,000	0.028%
Hampshire PCT	2011–12	No	Not surveyed	Not surveyed
Haringey Teaching PCT	2009–14	No	No information	No information
Harrow PCT	2008–11	No	Unable to advise	Unable to advise
Hartlepool PCT	2006–07	No	No information	No information
Hastings and Rother PCT	2010–15	No	£150,000	0.045%
Havering PCT	No strategy	No	No information	No information
Heart of Birmingham Teaching PCT	In consultation	No	Unable to advise	Unable to advise
Herefordshire PCT	In development	Yes	£325,000	0.112%

Hertfordshire	2011–12	Yes	£850,229	0.050%
Heywood, Middleton and Rochdale PCT	In consultation	No	No information	No information
Hillingdon PCT	2011–15	No	£237,000	0.057%
Hounslow PCT	2008–11	No	£150,000	0.037%
Hull Teaching PCT	No strategy	No	£688,954	0.135%
Isle of Wight NHS PCT	2009–12	No	£564,474	0.216%
Islington PCT	2007–10	No	No information	No information
Kensington and Chelsea PCT	In development	No	£300,000	0.081%
Kingston PCT	2008–13	No	£80,000	0.029%
Kirklees PCT	2010–15	No	£2,388,000	0.352%
Knowsley PCT	2011–14	Yes	£291,000	0.087%
Lambeth PCT	2008–13	No	£254,270	0.040%
Leeds PCT	2009–12	No	£374,000	0.028%
Leicester City PCT	In development	No	Undecided	Undecided
Leicestershire County and Rutland PCT	In development	No	£1,600,000	0.172%
Lewisham PCT	No strategy	No	£260,000	0.049%
Lincolnshire Teaching PCT	2010–13	No	No information	No information
Liverpool PCT	2008–11	No	£352,051	0.035%
Luton PCT	In development	No	£0	0.000%
Manchester PCT	2008–11	No	£178,000	0.017%
Medway PCT	2009–14	No	£488,599	0.112%
Mid Essex PCT	2011/12	Yes	£345,775	0.067%
Middlesbrough PCT	2009–19	No	No information	No information
Milton Keynes PCT	No strategy	No	£60,000	0.017%
Newcastle PCT	2010–13	Yes	£165,000	0.032%

Newham PCT	No strategy	No	£250,000	0.044%
Norfolk PCT	2011–15	Yes	£500,000	0.042%
North East Essex PCT²²	2011/12	No	£600,000	0.110%
North East Lincolnshire Care Trust Plus	2009–12	No	£160,000	0.055%
North Lancashire Teaching PCT	2009–12	No	£577,000	0.100%
North Lincolnshire PCT	2009–14	No	£135,000	0.050%
North Somerset PCT	2008–11	No	£473,000	0.144%
North Staffordshire PCT	2011–16	No	Unable to advise	Unable to advise
North Tyneside PCT	2011/12	Yes	£117,000	0.031%
North Yorkshire and York PCT	2009–18	No	No information	No information
Northamptonshire Teaching PCT	2011–14	No	£416,000	0.040%
Northumberland Care Trust	2011–13	Yes	£0	0.000%
Nottingham City PCT	2008–11	No	£610,000	0.111%
Nottinghamshire County Teaching PCT	No strategy	No	£515,944	0.049%
Oldham PCT	In development	No	No information	No information
Oxfordshire PCT	2009–12	No	£700,000	0.077%
Peterborough PCT	In development	No	Undecided	Undecided
Plymouth Teaching PCT	2010–13	No	£526,000	0.118%
Portsmouth City Teaching PCT	2011–15	No	£101,000	0.029%
Redbridge PCT	2010–13	No	No information	No information
Redcar and Cleveland PCT	2009–14	No	No information	No information

²² Figures supplied after compilation of statistics for this report so were counted as ‘no information’ for the purposes of this report. The figures are also an estimate with ongoing work by the PCT to ascertain exact amounts.

Richmond and Twickenham PCT	2011–13	No	£281,000	0.098%
Rotherham PCT	2008–11	No	No information	No information
Salford PCT	2011–12	No	£701,000	0.147%
Sandwell PCT	2011–14	Yes	£451,000	0.077%
Sefton PCT	2010–13	No	No information	No information
Sheffield PCT	2010–13	No	£417,505	0.042%
Shropshire County PCT	2011–14	No	No information	No information
Solihull Care Trust	2010–15	No	Undecided	Undecided
Somerset PCT	2011/12	Yes	£1,084,500	0.127%
South Birmingham PCT	In consultation	No	No information	No information
South East Essex PCT	In development	No	Undecided	Undecided
South Gloucestershire PCT	2011–14	No	Unable to advise	Unable to advise
South Staffordshire PCT	2011–16 (draft)	No	No information	No information
South Tyneside (part of S of Tyne & Wear PCT)	2011–12	Yes	£450,000	0.145%
South West Essex PCT	In development	No	No information	No information
Southampton City PCT	2011–15	No	£190,000	0.046%
Southwark PCT	Not published	No	£99,719	0.018%
Stockport PCT	In development	No	Not surveyed	Not surveyed
Stockton-on-Tees Teaching PCT	2009–13	No	£38,000	0.012%
Stoke on Trent PCT	2009–11	No	£791,060	0.156%
Sunderland Teaching PCT	2011–12	Yes	£730,000	0.080%
Suffolk PCT	No strategy	No	Not surveyed	Not surveyed

Surrey PCT	2008–11	No	£2,200,000	0.131%
Sutton and Merton PCT	In development	Yes	£647,000	0.109%
Swindon PCT	2009–12	No	£311,000	0.100%
Tameside and Glossop PCT	In development	No	No information	No information
Telford and Wrekin PCT	In development	No	No information	No information
Torbay Care Trust	2011–12	Yes	£707,000	0.264%
Tower Hamlets PCT	In consultation	No	Undecided	Undecided
Trafford PCT	2010–12	No	£250,000	0.066%
Wakefield District PCT	2011–14	No	£258,000	0.041%
Walsall Teaching PCT	2007–08	No	£0	0.000%
Waltham Forest PCT	2010–15	No	£150,000	0.034%
Wandsworth PCT	2009–14	No	£542,000	0.096%
Warrington PCT	In development	No	£50,000	0.015%
Warwickshire PCT	2009/12	No	£120,944	0.015%
West Essex PCT	2011–12 (unpublished)	No	£263,000	0.061%
West Kent PCT	2009–14	No	£668,000	0.065%
West Sussex PCT	2010–15	No	£1,100,000	0.085%
Western Cheshire PCT	2009–12	No	£350,000	0.084%
Westminster PCT	2010–13	No	£300,000	0.061%
Wiltshire PCT	In consultation	No	£596,000	0.088%
Wirral PCT	2011–12	No	£759,900	0.121%
Wolverhampton City PCT	2010–13	No	£137,500	0.030%
Worcestershire PCT	2010–14	No	£620,000	0.072%

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