

Together *we* care



The Princess Royal Trust  
*for Carers*

# Best Practice, Better Practices – A New Deal for Carers in Primary Care



By Malcolm Clarke and Stuart Riley

With assistance from colleagues at The Princess Royal Trust for Carers'  
Network of Carers' Centres

Supported by



## Acknowledgements

This report builds on and up-dates the research and evaluation of primary care initiatives carried out in 2003 for the publication *Primary Carers – identifying and providing support to carers in primary care* and presents the findings from three demonstration projects across England. The work forms part of a Primary Care Project funded by GlaxoSmithKline and managed by The Princess Royal Trust for Carers.

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# Foreword

Three years have passed since The Princess Royal Trust for Carers publication *Primary Carers – identifying and providing support to carers in primary care* explored the substantial learning from its Network of Carers' Centres working within primary care settings in identifying and supporting carers. Its conclusion highlighted the importance of embedding this work at practice level by encouragement and support from local Primary Care Trusts, Strategic Health Authorities and the Government. Changes of policy and practice are required at all levels. Since that time the NHS is being restructured and the White Paper, *Our health, our care, our say* speaks of a 'New Deal' for carers. Family carers have an even greater role to play in the new Health and Social Care agenda.

One in ten of the UK population are unpaid carers. Over a million of those carers care for more than 50 hours a week – a number approaching in scale the number of staff employed by the NHS. The NHS benefits greatly from the contribution made by those unpaid carers, as carers help the NHS understand the needs of the person they care for as well as providing the vital care that many patients rely on.

As outlined in this report and as the ever increasing body of evidence shows, being a carer frequently has an impact on the carer's own health. Carers can suffer from stress and depression due to the demands of their caring role. They can also suffer physical strain due to lifting or moving the person they care for. It is clearly vital that carers are given information and support, to protect their own health and to help them continue caring. As carers have much contact with primary care, GPs and primary care professionals can play a key role in identifying carers and referring them to sources of advice and help.

The Princess Royal Trust for Carers Network of Carers' Centres has developed considerable expertise in working within primary care to identify and support carers. Projects began over 13 years ago and there are now more than 51 initiatives within primary care, an increase of 44% within the last three years. These initiatives work with primary care across counties, cities and boroughs and in rural areas.

The work of these primary care projects has brought benefits to many thousands of carers by connecting them to sources of support and information, often at the time they most need that help. The work also helps to raise awareness of carers among GPs and primary care professionals. Training and awareness sessions have been run for many hundreds of staff from primary care. Expanding on the work outlined in *Primary Carers*, this report contains a review of good practice, and findings from a detailed analysis of three demonstration projects across England that will be useful for all those working in primary care to support carers.

This report concludes with important recommendations about extending this work much more widely within primary care. The recommendations show how Primary Care Trusts can lead this agenda. They can use local protocols and local contract negotiations to encourage and support the work to identify carers, refer them to sources of support and establish clear systems of evaluation. The report also offers a list of suggested action for Government, the Department of Health and Strategic Health Authorities to support the work at commissioning, auditing and operational levels.

Carers are key partners in the provision of care by the NHS. Identifying carers and finding ways of supporting and working with them is not optional but essential for primary care. I commend this report to NHS colleagues.



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Trustee, The Princess Royal Trust for Carers

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## Section One:

# Introduction

**The foundation for this report is a three year Primary Care Project conducted by The Princess Royal Trust for Carers and its network of Carers' Centres across England.**

The report proposes a series of recommendations for the Government, the new Strategic Health Authorities and Primary Care Trusts, and GPs and Primary Health Care Teams, with the aim of improving the way primary care services identify and support carers.

The project was divided into two stages. The first stage aimed to find the most effective ways within primary care to identify carers and encourage them to use the services available. This culminated in the publication in 2003 of *Primary Carers – identifying and providing support to carers in primary care* which presented checklists for those involved at different levels in the NHS. The recommendations were based on conclusions from a mapping exercise of the 36 primary care carer support initiatives across The Princess Royal Trust Carers Centre Network in England and Northern Ireland, a postal survey of carers, as well as four focus group discussions with carers. The second stage, upon which this report is based, updates the mapping

exercise, reviews best practice in identifying and supporting carers in primary care, and presents the detailed findings from three demonstration projects.

Subsequent to, and directly emanating from the project, a good practice guide has been produced to act as a toolkit for primary care work by Carers' Centres within The Trust's network. A learning module on carers and primary care was also produced for the website of the British Medical Journal. In addition, The Trust has developed a website for anyone working professionally with carers, focusing initially on health professionals. There are also regular Caring Awards (supported by simplyhealth) for best practice carer support within primary care and a separate carers GP Award. The Trust is now commencing a two year partnership with The Royal College of General Practitioners to improve the services to carers within primary care.

This report covers the following:

- The back-ground to the project and the rapidly changing context: carers and caring, carers' rights and policy guidance to support carers, and the role of primary care as gatekeeper.
- An update of the mapping of primary care projects in The Princess Royal Trust for Carers' Centre Network in England.
- A review of good practice in identifying and supporting carers.
- A summary of the results from the demonstration projects.
- Recommendations in the form of checklists for GPs and Primary Health Care Teams, for Primary Care Trusts and for the Government and Strategic Health Authorities.

<sup>1</sup> Keeley and Clarke, *Primary Carers – identifying and providing support to carers in primary care*, The Princess Royal Trust for Carers, 2003

## Section Two:

# Background to carers support and primary care

## Carers and caring; Who are carers?

**A carer is someone who, without payment, looks after or provides help and support to a partner, child, relative, friend or neighbour who could not manage without help due to age, physical or mental illness, addiction or disability.**

Anyone can be a carer. A carer can be a man or a woman (42% of carers are men). Carers can be from any ethnic, social or religious background, and of any age group (there are an estimated 175,000 carers under the age of 18 in the UK).

Carers are all individuals and come from diverse groups facing a range of caring situations. Some of these develop slowly, for example as parents become gradually more dependent in old age. Others arise suddenly and unexpectedly, for instance as the result of an accident. Some caring roles last for only a few weeks or months.

Others last for years, for example parents of children with a disability often care from the birth of the child until their own death.

The census tells us that there are 5.2 million carers in England and Wales, and the contribution they make cannot be over-estimated. 1.2 million of those carers care

for more than 50 hours a week – more than a full-time job. By comparison, although the NHS is the largest organisation of its kind in the world, it actually employs less people than the number of carers in the UK.

The nature of the care provided also varies widely. Some caring situations involve continuous and intimate personal care throughout the day and often throughout the night as well. Others involve less intensive care but which needs to be carried out regularly, for example, visiting to make sure the cared for person is all right and assisting them with domestic tasks. In other situations the intensity of the caring role can vary greatly and suddenly, for example where the person cared for has acute episodes of an illness such as schizophrenia.

Many carers do not perceive themselves

as carers, but regard caring as part of their normal responsibility to their family or friends. Although many carers are willing to take on the role, others feel they have no choice. Many carers have health problems of their own which they may neglect. These health problems are often caused or exacerbated by the physical and emotional demands of their caring role.

## The value of recognising carers

Calculations of the value of carer support estimate it at around the same as the total of UK spending on health – around £57 billion in 2001–02<sup>i</sup>. Three quarters of carers are worse off financially because of their caring role and carers who provide high levels of care are more than twice as likely to suffer from poor health compared to people without caring responsibilities<sup>ii</sup>.

However, for many years the role of carers in our society, including their contribution to the work of the NHS, has generally been under-recognised and under-valued. Melanie Henwood summed this up in 1998 by her choice of the title *Ignored and Invisible*<sup>iii</sup> for her research on carers' experience of the NHS.

## Carers and Health – policy background:

### Carers' Assessments

Carers have a right to an assessment of their needs – and this right has been extended by successive pieces of legislation. This assessment is undertaken by the Local Authority, and is the passport to a number of support services for carers (e.g. breaks from caring). (*Carers (Recognition and Services) Act 1995, Carers and Disabled Children's Act 2000, Carers (Equal Opportunities) Act 2004*). Health services have a key role in ensuring carers can access these rights and services. The 2004 Act places a duty on primary care to give 'due consideration' to a request from Local Authorities for the planning or provision of services to carers.<sup>iv</sup>

### Carers' Strategy

- The 1999 National Carers' Strategy identified the NHS as being the single most important point of contact for many carers. It further identified some key roles for primary care staff, stating that they should:
  - Identify patients who are carers and patients who have a carer;
  - Check carers' physical and emotional health wherever a suitable opportunity arises, and at least once a year;
  - Inform carers routinely that they can ask Social Services for an assessment of their own need;
  - Ask patients who have carers whether they are happy for health information about them to be told to their carer; and
  - Signpost carers to other sources of support such as support groups and the local Carers' Centre.

### National Service Framework

Carers of people with mental-ill health have rights under the National Service Framework<sup>vi</sup> - "all individuals who provide regular and substantive care for a person on the Care Programme Approach should have an assessment of their caring, physical and mental health needs repeated on at least an annual basis, and have their own written care plan which is given to them and implemented in discussion with them". In establishing this standard on carers in the NSF for Mental Health, the Department of Health acknowledged that the implementation of the carers' right to an assessment was "...patchy. Assessments are not always carried out. Some carers are offered very sensitive practical and emotional support. But others receive very little, or no help".

Carers of people with long term conditions should have access to appropriate support and services that recognise their needs both in their role as a carer and in their own right. They are to be supported by health services, involved in the planning of care, treated as partners and receive a range of services. Staff working with carers are to receive carer awareness training.<sup>vii</sup>

### Carers' Equal Opportunities

Policy guidance for the 2004 Act<sup>viii</sup> advises that the NHS and Local Authorities develop a multi-agency strategy and ensure that agreed protocols are in place from partner organisations in providing support to carers.

### GP Contracts

The new GMS contract for GPs offers 3 points if 'the practice has a protocol for the identification of carers and a mechanism for referral of carers for Social Services Assessment'.<sup>ix</sup> The new PMS contract offers a mechanism for inclusion of carers in contractual requirements.

### NHS Performance Framework

Two core standards from the new performance framework for the NHS in place from April 2005 relate to carers<sup>x</sup>: C14 relates to systems to ensure that patients, relatives and carers have suitable and accessible information about services and complaints; and C17 requires organisations to take account of the views of patients and carers in planning and delivering services.

## Recent Research by The Princess Royal Trust for Carers

Over the past few years, The Princess Royal Trust for Carers has been involved in several initiatives which focus on health and primary care. Two reports were of particular importance. The first was entitled *Focus on Carers and the NHS – identifying and supporting hidden carers Good Practice Guide*<sup>xi</sup>. The second, called *Carers Speak Out*<sup>xii</sup>, looked at the needs of carers as identified by carers themselves. It was based on the largest survey of the views of carers ever conducted in the UK, undertaken through both questionnaires and local focus groups. The report *Primary Carers*<sup>xiii</sup> was undertaken partly as a response to these surveys. Since then, in 2004 The Trust has produced a report on the impact of caring on carers' health which consisted of a comprehensive survey conducted throughout the UK<sup>xiv</sup>. It found that of 70% of carers who cared for more than 50 hours per week, almost half the carers were suffering ill-health as a result of their caring role including back injury, high blood pressure, depression, stress or nervous tension, headaches and panic attacks. The minimum help required to improve carers' own health was on average a not unreasonable seven hours extra support per week.



# Background to carers support and primary care

## Why should health services identify and support carers?

### Carers are partners:

Carers are partners in the provision of health care to those they care for. Supporting them is a sound investment in continuity of care.

### Carers are patients too:

Research has shown clear detriments to the health of those who take on a caring role – particularly where the caring role is substantial. Identifying carers opens up the opportunity of addressing these issues in a practical way with individual carers and thereby improving the health and wellbeing of carer patients.

### There are other resources out there:

Carers referred to voluntary organisations can receive a range of support services which may have a considerable impact on their lives and ability to continue to care.

Carers referred to the Local Authority for an assessment can gain access to additional support in their caring role reducing the extent to which they may need to rely on health resources.

In order to implement these principles in the context of primary care, the report *Primary Carers*<sup>xiii</sup> made a number of recommendations directly for primary care to take up at a practice level and to Primary Care Trusts, Strategic Health Authorities and the Department of Health at a strategic level. Some of these recommendations had already been highlighted in an extensive survey of carers in The Trust's Carers Speak Out<sup>xiv</sup> report in 2002. These included:

- Establishing clear systems in primary care for identifying carers by all practice staff;

- Telling carers routinely that they can ask Social Services for an assessment of their needs;
- Creating systems to check and improve the health of carers;
- Providing information to carers (subject to consent) about diagnosis, treatment and prognosis for the person they care for and medications and their side effects; and
- Establishing methods for staff in practices to refer carers to local sources of advocacy and support including their local Princess Royal Trust Carers' Centres or local carers' support organisation.

## Recent NHS changes and their implications for carers

### Restructuring

Since Primary Carers<sup>xiii</sup> there has been some progress at national, regional and local levels as outlined in the updates in this report. However, latterly 2005/6 has been a time of major re-structuring within health with a reduction in the number of Strategic Health Authorities to nine and of Primary Care Trusts to 152 across the country. There have been major changes in personnel, roles and structures. Some NHS bodies have experienced significant financial pressures. Carers' Centres have reported much greater difficulties in engaging at all levels related to primary care on carers' issues. There is a perceived danger of the progress made for carers in primary care and health in general being lost with all the changes.

### The New White Paper

This transition in Health comes at a time when the new White Paper on Health and Social Care: *Our health, our care, our say*<sup>xv</sup> (with emphasis on *our*) is promoting a 'New Deal for Carers', comprising:

- An update and extension to the 1999 Strategy for Carers;
- Encouragement to Councils and PCTs to nominate leads for carers services;
- A helpline for carers;
- The provision of local, short-term, home-based respite support for carers; and
- The establishment of an Expert Carers Programme.

## Partnering a New Deal – The Way Forward

The work of the projects outlined in this report point the way forward for the implementation of the White Paper and other statutory developments. They provide primary care with experience and expertise, and offer examples of good practice aimed at supporting carers and protecting their health. However, good practice within primary care is not happening systematically across the country. The picture is very patchy. Good and innovative practice may only occur because an individual working in a primary care setting has developed an awareness of carers' issues (perhaps as a result of personal experience or the promotional activities of the local Carers' Centre) and wishes to improve the service offered to carers.

Roughly two million people become carers each year and carers' health issues caused by physical and mental ill-health, lack of support, isolation and financial

stress, and lack of information will place cost on the NHS.

Support for carers is likely to be a cost-effective use of resources, and it is correct in principle. Carers are a particular group whose special needs have largely gone unrecognised. As a carer in Lewisham put it in one of our focus groups:

*"I am a carer and it really does need to be dealt with a little differently because you are up against so many barriers."*

There is an equity issue here. It is inequitable that there should be wide variations in the recognition of carers' needs and the support given to them in different areas of the UK. It is another example of the 'postcode lottery'.

With the increasing evidence of the cost incurred by the lack of intervention for carers, and with the emerging requirements in legislation and the national standards, it is vital to improve the range and quality of services commissioned in primary care for carers. The primary care projects within The Princess Royal Trust Network of Carers' Centres have built up an effective body of knowledge, experience and most importantly answers to these requirements. The purpose of this report therefore is to examine best practice of carers' support within primary care and offer pointers and solutions for the way forward.

- i *Without Us...? Calculating the Value of Carers' Support*, Carers UK, 2001
- ii *In Poor Health – the impact of caring on health*, Carers UK, 2004
- iii Melanie Henwood, *Ignored and Invisible? Carers' experience of the NHS*, Carers National Association, 1998
- iv Department of Health, *Carers (Equal Opportunities) Act*, HMSO London, 2004
- v *Caring About Carers: A National Strategy for Carers*, HM Government, 1999
- vi Department of Health, *National Service Framework for Mental Health*, 1999
- vii Department of Health, *The National Service Framework for Long Term Conditions*, 2005
- viii Elaine Cass, *Practice Guide 5 implementing the Carers (Equal Opportunities) Act 2004*, SCIE, 2005
- ix Department of Health, *Quality and Outcomes Framework Guidance*, 2004
- x Department of Health, *Standards for Better Health*, 2005
- xi *Focus on Carers and the NHS – identifying and supporting hidden carers. Good Practice Guide*, The Princess Royal Trust for Carers, 2003
- xii Keeley and Clarke, *Carers Speak Out – report on findings and recommendations*, The Princess Royal Trust for Carers, 2002
- xiii Keeley and Clarke, *Primary Carers – identifying and providing support to carers in primary care*, The Princess Royal Trust for Carers, 2003
- xiv Jane Cheffings, *Carers Health Survey*, The Princess Royal Trust for Carers, 2004
- xv Department of Health, *Our health, our care, our say: a new direction for community services*, HMSO London, 2006

## Section Three:

# Primary care work across The Princess Royal Trust for Carers Network

## Background

The Princess Royal Trust for Carers Primary Care Project

The Primary Care Project was commissioned by The Princess Royal Trust for Carers to evaluate the work of primary care and GP projects across The Trust's network. In 2003 *Primary Carers*<sup>1</sup> was the first report to arise out of the project.

*Primary Carers*<sup>1</sup> identified 36 projects working across the network of Carers' Centres within primary care. They had been working for various lengths of time, with varying sources and levels of resources.

In terms of the work they were doing, most were working directly with GP surgeries, concentrating mostly on identification and referral of carers. A small number were also working strategically with PCTs locally.

There have also been positive developments with professional bodies. The Trust is currently embarking on a partnership with The Royal College of General Practitioners, entitled 'Carers in Practice', which will focus on identifying and referring carers through primary care, informing carers on what they can expect

from their Primary Health Care Team, and informing primary health care teams about carers' issues.

Following a seminar run by The Princess Royal Trust for Carers at the NHS Confederation annual conference in 2005, The Trust was invited to run a 'Carers' Masterclass' at the Confederation in 2006, at which this report was launched.

### A three part model

*Primary Carers*<sup>1</sup> identified a three part model to describe the work of identifying and supporting carers within primary care:-

1. Identification of carers and referral of them to other agencies for support;
2. Practice development work to achieve change in the way the practice

itself delivers its services; and  
3. Identification and strategic work with Strategic Health Authorities and Primary Care Trusts to influence the development of policy and allocation of resources.

*Dr. Eric Ward, of Townend Surgeries, Settle, Yorks, has summed up the relevance of support to carers in the following terms: "Good support to carers will no doubt reduce the need for hospital admission, respite care admissions etc. In the long term overall costs to health and social services should be less. This is the long-term approach, which should be adopted by health care planners and finance departments"*

### Projects in 2006

There are now over 50 such projects who, between them, have approximately 125 years of experience of primary care work. The distribution of work between the elements of the model is shown in Table 1. It will be noted that there has been a significant increase in all three areas of work, with a dramatic increase in strategic work.

## Results of mapping

Projects share their learning and experience with colleagues in The Princess Royal Trust for Carers and other organisations through seminars and workshops and the production of a 'toolkit' for primary care. Wheels need not always be re-invented!

There are wide variations in the amount of funding for the projects as shown in Table 2.

Table 3 shows the sources of funding. It will be noted that well over half of the projects receive no funding at all from the NHS, despite the value of this work to NHS objectives.

Tables 4 and 5 summarise the locations of the projects and the amount of staff time allocated to primary care work. It will be readily seen that these projects represent excellent value for money and achieve some remarkable outputs for relatively little expenditure.

However, there remain many areas of the country which do not benefit from a project this kind and we would recommend that PCTs in those areas give serious consideration to the establishment of such projects.

Table1: Scope of primary care work, 2006

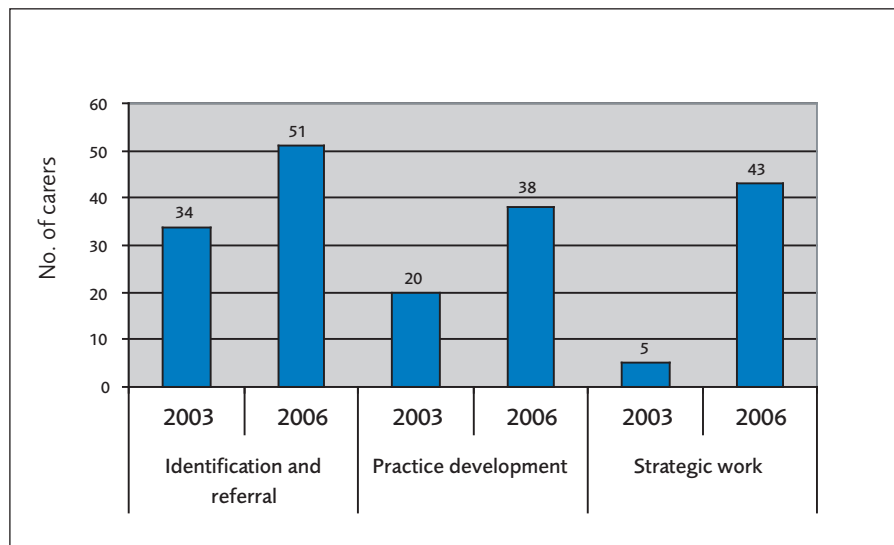


Table 2: Amounts of funding for work with primary care, 2006

Funding range for work with Primary Care (per annum)	Number of projects/centres
Up to £10,000	2
£10,000 to £20,000	4
£20,000 to £30,000	7
£30,000 to £40,000	0
£40,000 to £50,000	7
£50,000 +	11
Mainstream Funding	5
Not specified	13

Table 3: Sources of funding for work with primary care, 2006

Sources of Funding	Number of projects/centres
Primary Care Trust(s) solely	8
PCT & Local Authorities	5
PCT & Centre Core Funding	6
Local Authority ( Incl. neighbourhood renewal and the carers grants)	5
Voluntary donations (incl. grants and fundraising)	7
Voluntary donations & centre core funding	1
Voluntary donations & Local Authority	2
From centre's core funding	8
Not specified	6



# Primary Care Work Across The Princess Royal Trust for Carers Network

Table 4: Staffing levels of work with Primary Care, 2006

Number of staff working with primary care	Carers' Centre Location (number of hours worked on primary care work per week)	
One part-time	Barnet (30 hours)	
	Belfast (25 hours)	
	Carers Link (Hyndburn & Ribble Valley) (21 hours)	
	Islington (4 days per week)	
	Kennet (7 hours)	
	Lewisham (32 hours)	
	North West Oxfordshire (30 hours)	
	Richmond (17.5 hours)	
	Hammersmith & Fulham (17.5 hours)	
One part-time & centre staff	Cumbria (Eden) (18+ hours)	
Two part-time	Leeds (41 hours)	
One full-time	Camden ( 37.5 hours)	
	Harrow (not specified)	
	Salford (not specified)	
	Sandwell (37 hours)	
	South Warwickshire (35 hours)	
	Southwark (36 hours)	
	Winchester (10 hours)	
	West Lancashire (2.5 days/week)	
	One full-time plus one or more part-time workers	Brent (56 hours)
		West Sussex – Worthing (38 hrs)
Hillingdon (8 hours)		
Two full-time plus one or more part-time workers	Share the Care (Lincoln) (121.5 hours)	
	Bucks (min 74 hours)	
Two full-time supported by department manager	Carers First (87 hours)	
One full-time plus one or more volunteers	City & Hackney (35 hours)	
Two full-time plus one or more volunteers	Gloucestershire (not specified)	
Centre staff	Berks –Reading (7 hours)	
	Greenwich (10.5 hours)	
	Carers Resource (Harrogate & Craven) (85hrs)	
Not specified	Gateshead	
	Leicestershire (CLASP)	
	St Helens	
	Bucks (Milton Keynes)	

Table 5: Staffing levels of work with Primary Care

Range of hours worked on Primary Care (per week)	Number of projects/centres
Less than 10	4
10-20	5
20-30	6
30-40	9
40-50	1
50-60	1
60-70	0
70 +	5
Not Specified / too varied	20

<sup>1</sup>Keeley and Clarke, Primary Carers – identifying and providing support to carers in primary care, The Princess Royal Trust for Carers, 2003

## Section Four:

# The Demonstration Projects

## Introduction and methodology

Three demonstration projects were established in different parts of the country. The objective was to provide the local Carers' Centre with resources to enable work with a number of local GP practices aimed at:

- (a) improving their carer awareness;
- (b) improving the 'carer friendliness' of their services; and
- (c) establishing effective systems for carer identification and referral.

The locations chosen were Scarborough & Ryedale, Bristol & South Gloucestershire, and Lewisham. This gave a good demographic and geographic mix. Scarborough & Ryedale worked with two practices; Bristol & South Gloucestershire with four; and Lewisham with 17. In two of the locations, Bristol and Scarborough, some development work had already been undertaken with some of the practices although not as intensively as that undertaken during the project.

As part of the work a "before and after" study was incorporated so that it could examine the impact of certain aspects of the work undertaken by the centres. There were two elements to the study - a quantitative element and a qualitative one.

The quantitative element involved three surveys – one of carers themselves, one of practice staff and one of practice managers. Each survey was undertaken at the beginning of the project and again at the end to enable us to measure any change which had taken place.

The response rates were generally good, ranging in the different locations and in the different phases of the study up to 37% for carers, 60% for practice staff and 100% for practice managers.

The qualitative work involved interviewing carers face to face. This was done because it was felt important to supplement the 'cold' data from the surveys with some personal accounts of experiences from the carers themselves. Therefore small focus groups of three carers were held in each of the locations which were repeated at the end of the project. In addition, each of the members of those groups had a telephone interview after three months.

By definition, the carers contacted in the project were in contact with the Carers' Centres and therefore had already been identified by some process. In that sense, they are not representative of carers generally, and are likely to be more aware of their role as carers and of their rights than other carers. However, many of them were 'hidden carers' before the project started.

The following sections summarise the results found by the project.

## The practice staff attitude survey

This survey looked at 20 statements of staff attitudes towards the support and services provided for carers by their practice. Staff were asked to give their response on a five-point scale ranging from "strongly agree" to "strongly disagree" which were scored on scale of five (strongly agree) down to one (strongly disagree), and the mean scores calculated. The overall comparison of the 'before' and 'after' scores is given below, listed in the order of maximum change. On scales of this kind, any change of more than, say, 0.25 is generally regarded as representing a significant shift of attitude.

## Practice staff attitudes before and after

(Diff is the difference between the "before" and "after" measures)

	<b>Before All</b>	<b>After All</b>	<b>Diff All</b>	<b>Diff Lewisham</b>
The surgery works, with others, to ensure that carers have the training and guidance to care safely	3.19	3.71	0.52	0.94
Practice staff are trained to support carers effectively	3.03	3.49	0.46	1.40
The practice offers signposting for carers to other sources of expert information	3.68	4.03	0.35	0.64
Staff are provided with information on local and national developments for carers	3.18	3.52	0.34	1.00
Carers help to develop, evaluate and update the information the practice provides	3.00	3.31	0.31	1.01
Those cared for are asked whether information about their health can be discussed with their carer	3.85	4.16	0.31	1.02
The practice gives information about a carer's right to an assessment	3.48	3.78	0.30	1.44
The practice gives a wide range of information about relevant local services to carers	3.69	3.97	0.28	0.97
The practice supplies information to carers on looking after their health	3.69	3.95	0.26	0.59
There is a carer support group in the area	4.00	4.24	0.24	0.40
Carers can view their own records	3.65	3.88	0.23	0.46
Different methods of information giving are offered to carers, including face-to-face discussion	3.67	3.89	0.22	0.62
The practice has a staff member with specific responsibility for supporting carers	3.28	3.45	0.17	1.33
The practice should alter the services it provides, where possible, to meet carers' specific needs.	3.45	3.60	0.15	0.35
The practice ensures carers are supported following bereavement	3.94	4.02	0.08	0.56
Primary care staff help carers with tasks such as catheterisation, giving injections & lifting.	3.89	3.94	0.05	0.33
The way information is communicated to carers takes into account any disabilities or impairments	3.76	3.80	0.04	0.64
Many patients who are carers have not yet been identified as carers by the practice	3.63	3.64	0.01	0.21
Many patients, who care for others, will not see themselves as carers	4.04	4.05	0.01	0.07
The practice is proactive in giving information to carers	3.84	3.85	0.01	0.32
<b>Average</b>	<b>3.60</b>	<b>3.82</b>	<b>0.22</b>	<b>0.72</b>



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It will be seen that all scores have increased, a number quite significantly so, particularly those relating to training and guidance for carers; practice staff training on carers' support; signposting for carers and staff being given information about carers issues. The overall change is from 3.60 to 3.82.

The figures do however hide a varied picture between the three areas. Both Bristol & South Gloucestershire (3.63) and Scarborough & Ryedale (3.75) had a considerably higher overall starting position than Lewisham (3.22). There was virtually no overall change in the former two, whereas in Lewisham there was a very large shift up to 3.94 (+ 0.72).

There were also differences between Bristol and Scarborough. In Bristol there was relatively little change on most of the indicators, whereas in Scarborough & Ryedale there were some significant moves in both directions. For example, there were strong increases in the indicators relating to carers' training and signposting for carers and increases on all those relating to the identification and referral of carers. This was however counterbalanced by decreases in the indicator relating to primary care staff helping with clinical tasks.

The only large decrease in Bristol & South Gloucestershire was a decrease in staff perception that many carers have not yet been identified as such. There was also a decrease in Scarborough & Ryedale, but an increase in Lewisham. This is interesting because in both the former places, as everywhere, there are still very many hidden carers. It seems that in those places, staff are more inclined to believe that they have 'cracked it' as a result of the work which they have done, whereas in Lewisham that work has made staff more inclined to realise just how big the task is. This is confirmed in Scarborough &

Ryedale, although not in Bristol & South Gloucestershire by a reduction in the belief that the practice should alter the services it provides in order to meet carers' needs.

The differences between Bristol & South Gloucestershire and Scarborough & Ryedale, on the one hand, and Lewisham on the other, are no doubt partially explained by the fact that some more intensive work was already underway in those two places, which also probably explains why their starting point was higher.

It is worth looking specifically at the Lewisham figures which represent a significant shift of attitude among the practice staff. Every indicator has moved in a positive direction, some dramatically so, such as the practice giving information about the carer's right to an assessment, training for practice staff to support carers, the practice having a staff member with specific responsibility for carers, the practice giving out information about local services and training and guidance being given to carers.

Changes of this magnitude cannot be due to chance, and must relate to the activities undertaken within the practice during the period of the project. It demonstrates what can be achieved. The lessons of Lewisham in particular should be applied elsewhere.

## The practice managers' survey

Six practice managers responded in the 'before' survey and 14 in the 'after' survey. There was a particular change in Lewisham where there was no response in the 'before' survey but nine in the 'after' survey. This in itself is significant, since it shows the increased motivation as a result of the work undertaken.

The number of practices saying that they have a system for identification of carers was four out of six before and 13 out of 14 after. It may well be that the non-responses in the before survey included many more who did not have a system, which may have been a factor in the non-response.

The number of practices using the methods used to identify carers are shown overleaf:

	After
Identifying carers during normal consultations and home visits	13
Encouraging self-identification by carers	12
Identifying carers routinely at new patient registration	11
Identifying carers at 'flu jab sessions	10
Extracting information from practice records and knowledge	7
Identifying carers at health checks	7
Identifying carers through repeat prescription systems	6
Identifying carers at over-75 health checks	4
Identifying carers at well-person clinics	3
Identifying carers through hospital discharge procedures	1
Total number of respondents	13

The table above shows that a range of methods are used. There are two methods which seem particularly under-used in relation to their potential, namely use of prescription systems and, particularly, identifying carers through hospital discharge procedures, which is apparently only used by one practice.

We explored further the 12 methods encouraging self-identification, shown in the table below: Again, a range of methods are used.

	After
Leaflets in the surgery	8
Specific carers notice board	6
Notices on general notice board	6
Letters to patients	1
Questionnaires or forms in the waiting room	1
Other	3
Total number of respondents	12



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When asked how the information is kept up to date, the managers gave varying responses with most saying that it is done on an opportunistic basis when information is received or when the patient attends the practice. Half of the practices said that there is a named person whose job it is to keep the system up to date.

The Carers' Centres reported that the practices had referred the following numbers of carers during the project: Scarborough & Ryedale – 63; Bristol & South Gloucestershire – 478; Lewisham – 220. This is a total of 761 newly identified carers, the majority of whom would not have been identified were it not for the work of the projects. This is quite a high level of activity, which represents an approximate rate per 1000 patients of 5 in Scarborough & Ryedale, 14 in Bristol & South Gloucestershire and 2.6 in Lewisham. It should be borne in mind that Lewisham were working with a far greater number of practices and population size than the other two areas. This compares with an expected total of 100 carers per 1000 patients, of whom about 20 will be caring for more than 50 hours per week. Some additional carers will have already been identified before the projects started. The figures do however illustrate just how large is the target number of carers to be identified.

We also asked the practice managers, through the surveys, how many carers, and how many patients with carers, were recorded on the practice systems.

These questions had a high level of non-response, the reasons for which may be a matter of speculation. This meant that it is statistically unreliable to break this down between the three areas. However, from the answers received, overall in the before study the managers identified levels of 1.1 patients per 1000 as having a carer, and 3.7 who were carers. These rose to 2.4 and 6.3 respectively in the after study.

It is encouraging that there was an increase over the course of the projects. However, the apparent discrepancy with the figures produced by the centres suggests that many carers who are being identified and referred by the practices are not being recorded as such in their record keeping systems. If true, this is a matter of concern because it means that the practices cannot use the information for other purposes and have no way of monitoring their own performance in this area.

When asked whether the carer identification scheme had reduced, left unchanged or increased the workload of practice members, the managers identified a marginal increase for most staff categories.

The managers did not identify any increase in the number of changes made to practice systems under various headings as a result of the systematic identification of carers. Only six such changes were identified at the beginning of the project, with the same number at the end, despite the fact that there were more respondents at the end. This is disappointing because it appears to indicate that the practice managers see the importance of carer identification in terms of referral to other agencies rather than changes in the way the practice itself operates. There was a not dissimilar picture regarding new services for carers. Three were identified at the start, and five at the end. These included a practice-based carers group and training for carers.

There was a small increase in the proportion of practices which had provided staff training on carers' issues, but there were still less than half that had done so. This had been mainly provided to receptionists and practice managers.

## The carers' survey

In total just under 300 carers responded to the surveys. 84% of these were caring for one person; 11% for two people and 5% for three or more.

The analysis of people cared for showed that approximately half were the spouse or partner, with most of the remainder being split approximately equally between parents and children. The average age of the person cared for was 60, but this hides 'peaks' at the lower and upper ends of the scale, and is only a couple of years older than the average age of the carers in this study.

69% of the carers in the 'before' study were female, rising to 73% in the 'after' study, reflecting the national position. The majority of carers in the survey (80% in the 'before' study and 70% in the 'after' study) classified themselves as "White British" with the second largest category being "Black or Black British" (9% in the 'before' study rising to 13% in the 'after' study, which probably reflects a higher return from Lewisham in the 'after' study).

The nature of the disability or illness of the person cared for in the 'after' survey is shown below, in percentages of respondents mentioning (rebased to 100 because it was possible for more than one category to be ticked).

	% of responses
Chronic ill-health - e.g. diabetes, arthritis, MS, ME, heart problems	20
Old age or frailty, including Alzheimer's	15
Physical illness and physical disability - e.g. stroke, cerebral palsy	14
Learning disability - e.g. Down's syndrome, autism, Asperger's syndrome	13
Mental illness - e.g. schizophrenia, depression	8
Physical illness	7
Other serious illness or disease - e.g. cancer, vascular conditions, lung disease	7
Physical disability and mental illness	6
Other	10

Total number of responses	100
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The level of caring commitment and responsibility is shown by the fact that almost two-thirds of the carers spend 50 or more hours per week on their caring responsibilities. The mean length of time of these caring responsibilities was nearly nine years in the 'before' study and 11.5 years for the 'after' study.

Approximately half of the carers reported that they themselves also have a

disability or long-term illness. Two-thirds reported that their own health had been adversely affected as a result of their role as a carer.

We then asked in what way had their health been affected, the responses to which in the 'after' study (which was similar in this case to the 'before' study), are reproduced below (respondents could tick more than one category).

	% of responses
Your physical well-being	69
Your mental well-being	67
No time to look after my own health	61
Other	24

Total number of respondents	100
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This confirms what we already know from national research, that caring does have considerable adverse effects on carers' health for a high proportion of carers. The health consequences listed by carers included:

- Great tiredness;
- Depression and mental health problems;
- Stress;
- Back problems;
- Eating disorders;
- Feelings of guilt;
- Inability to recover quickly from routine ailments;
- Heart problems;
- High blood pressure;
- Irritable bowel syndrome; and
- Tinnitus.



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In addition, carers identified a range of other adverse social consequences, such as inability to get out of the house; lack of social life; and no time for themselves. In practice, of course, it is impossible to separate the so-called social issues from their health consequences. Thus a lack of opportunity to meet friends might well have adverse consequences on the carer's mental health.

Half the carers were retired, with a further quarter not being in employment even though they are below retirement age. Only 18% were in employment, which was part-time for more than half of these. Only 28% shared the caring responsibilities with someone else. 62% of these shared it with one other person. 27% of these other people in the 'before' study, falling to 15% in the 'after' study are aged 18 or under. This may indicate that the number of young carers is even higher than usually identified, because many of them are not the primary carer.

In the large majority of cases (88% before and 80% after) the carer and the cared for are registered with the same practice.

The following sections look at the key issues of the change which occurred over the course of the project

At the beginning of the project 69 % of carers said that the GP and surgery staff knew that they were a carer whereas in the 'after' survey this had risen to 79%. At the start only 15% of carers said they had received information about their role as a carer from the practice. This had risen to 27% in the 'after' survey. The proportion of carers who feel that their situation as a carer is taken into account when they want to see the GP or nurse about their own health rose from 33% to 44%. When asked on a four-point scale if the GP surgery is aware of their needs and responsibilities as a carer, there was an increase in the

mean score from 2.66 to 2.79 i.e. an increase in practice awareness. All of these are welcome and significant findings.

About a third of carers were significantly concerned that others can overhear their conversation when speaking to the reception staff and this proportion did not alter much over the course of the project. The proportion of carers who reported experiencing difficulty for themselves and the cared-for person when waiting in the waiting area increased from 26% to 39%. It is difficult to interpret this, but it may be due to variations in the nature of the disability or illness of the person cared for since it seems unlikely to be due to a deterioration in the situations at the surgeries. This is consistent with another change, namely the increase from 28% to 38% in the proportion of carers who said they need someone to look after the cared for person in order for them to be able to visit the GP surgery.

Carers were asked how easy it is for them to see the GP about their own health needs on a three-point scale. There was a slight movement towards it being more difficult, which might be due to variations in the circumstances of the carer, or, perhaps more likely, might be due to other changes which are referred to below.

There was effectively no change in the declared extent to which carers are discouraged from visiting the surgery because of the expected waiting time; the carers' view of whether the services provided for carers at the surgery is very good; their view of the quality of the information about the health needs and treatment of the cared for person, and whether there is any extra information which they would like to see.

There was a slight increase, from 24% to 29% in the proportion who said that their GP had put them in touch with the Carers' Centre. When asked if the GP surgery had ever contacted a range of other agencies on their behalf, the following results were obtained:-

	Before	After	All
Social Services	20	31	51
Carers' Centre	14	20	34
Benefits Agency	14	15	29
Housing Department	8	10	18
Other non-statutory agency providing carers support services	3	7	10
Local Councillor	1	4	5
Other	12	15	27
Number of responses	5	64	115

Although all categories increased over the time of the project, which is welcome, it should be noted that, considering that there were 140 replies 'before' and 153 'after', these numbers are not high. Even the score for reference to Social Services is only about a sixth of carers 'before' and a fifth 'after'. In this context it should be remembered that the GP contract payment for establishing a carers register includes the requirement that carers are referred to Social Services.

The proportion of carers who think that the surgery staff would benefit from training about carers remained very high (82% - 84%). This is not really consistent with the staff attitude findings on whether practice staff are trained to support carers effectively, which showed a significant increase.

We asked carers to say how important they thought a range of services to be. In each case the perceived importance was very high in both the 'before' and 'after' surveys with a range from 74% to 98% saying it was important.

When we look at the availability of these services, in the table below, it is encouraging that all are perceived to have increased in availability, many quite substantially. The biggest increase reported was the identification of carers on the computer system.

The smallest move was in "appointment times allocated to carers" which has improved by only 1%. It seems clear that during the course of the project, carers have perceived little improvement in their access to appointments. This may well be due to the changes in appointments systems generally, following the 'advance access' targets set for GPs, which coincided with the period of this study.

## The qualitative work

As one would expect, the discussions with the carers revealed a range of circumstances and attitudes on the extent to which GP practices recognise and meet the needs of carers. The first round of interviews revealed a number of problems being experienced by the carers in their dealings with the GP practices in obtaining the support they need. Carer S at Scarborough said:

*"When I saw the doctor that morning and explained, all he said [was] 'we can get hold of somebody if you need help' and that is all the doctors or the staff at the surgery have said. They have been no help whatsoever. No phone numbers, no advice. So it was the leaflets, well it is a little booklet, which I noticed."*

### Measure of perceived availability: % of those who answered saying service was available

	Before %	After %
Identification of carers on the computer system	20	44
A member of staff who knows about services for carers	29	43
Carers being able to order prescriptions by telephone	32	39
Sign asking carers to identify themselves	7	32
Someone based in the surgery to liaise between the carer and the GP	22	30
Appointment times allocated to carers	15	16



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Although help was being offered in a general sense, it was not particularly proactive and it was the leaflet from the Carers' Centre which was seen as being more useful. The same carer later stated that no-one at the practice had interested themselves in whether she had a problem with prescriptions. As will be seen below, the same carer had a different perspective toward the end of the project.

In Bristol, Carer R, was also put in touch with support from the Carers' Centre as a result of a notice in the surgery:

*"One day I thought to myself I just can't handle this and I had better go and have a word with the GP, and just happened to see J's name on the board ,and I thought, well I will try here at least that will be the start."*

The same carer summarised the GP's approach thus:

*"No I went on for several years you know and it was affecting my health and I can't remember the GP ever saying you know that you need some help domestically or anything like that or I'll give you the medication or something."*

In Lewisham, Carer C who has a son with autism made a similar point:

*"Well he certainly didn't mention it to me. In fact I am still not really fully aware whether my GP knows that I am a carer, although I did fill in a questionnaire. Whenever I have tried to get appointments and things it has never kind of registered that I might be having difficulty elsewhere."*

The carers did not generally have any criticism of the quality of clinical care

provided for them, quite the contrary, and, indeed in many cases did not see it as part of the practice role to provide support to them as carers.

The second round of interviews did reveal some limited evidence of change. In Scarborough, Carer S described the changed situation, and the value of both a dedicated person looking after carers' interests at the surgery and carers' support meetings at the surgery:

*"Things have greatly improved in the last couple of months. We have got, I suppose you would call them a liaison, (one of the ladies behind the desk is, it says on the board, a liaison officer), that if we have any problems and that instead of contacting Ryedale Carers, if it is their closed date (because they are not open every day of the week), we can ring this lady at Ayton surgery and talk about any problem...we have and sort it out."*

*We have also started to have meetings at Ayton surgery which was arranged by the Ryedale Carers and the group surgery, and...our first meeting was basic first aid. It started off rather like at school. Very nice room and coffee bar and tables and notepaper and pencils, and it started off very formal about blood pressure. But then we all partake of what things were happening to the people that we care for, suffering from blood pressure or when we moved them from wheelchairs quickly...and it became more of a general chat about things, and you felt more informed about things and it was a really nice meeting. It was just over an hour and you could relate to things as a carer, and there were ten of us...and I felt a little bit*

*more knowledgeable, a little bit more safe that there is somebody out there thinking about us and trying to help us and inform us why these things are happening."*

She summed up the general situation thus:

*"If we continue having these meetings like I say at the surgery with this sort of slow improvement in the GPs relationship with us as the carers, if this continues to improve at this speed if it continues I hope and pray that it continues because I feel like there is somebody else there who is helping us. We are not forgotten about because everybody, sort of in the village sort of, yes you are getting on fine. They just isolate you and they don't bother but there is somebody there advising you and helping you."*

Carer A quoted the doctor's response to his situation following a problem which was affecting his ability to care:

*"Well my surgery I had a particular time when I had a terrible pain the heel I could hardly walk and I was falling over...and I went to the doctor and he said oh you are a carer we must have you right."*

In Lewisham Carer T identified her support as being more due to the Carers' Centre than the practice:

*"It really was [that] I learnt a lot from the workshops that helped me a lot especially at the beginning when we didn't know what to expect with dementia. It really was looking it up on the internet and reading all we could and information obviously from*

*coming to the workshops. So the carers have done much more for me than the actual GPs. The carers' group and what have you I learnt more from them than GP."*

Carer C also had problems with her hospital discharge:

*"It is just the discharge afterwards and that. I got the family arranged to look after things and they discharged me and that and I was straight back. As soon as I got home I was straight back into the caring role, managing with crutches and bandages and things which I found very hard."*

All the groups emphasised the value of the work done by their Carers' Centres. As Carer A in Scarborough put it:

*"It is a support network which I find extremely useful and that I really do. Strange people at first that come into their home and help you to sort out great problems. Little problems that seem great and you get these sorted out when you can't even at the local doctor's surgery, you just get a sentence or you don't get any help whatsoever. Somebody there is what I find is good."*

In a memorable phrase, Carer R described how being recognised and identified as a carer and referred to the Carers' Centre has helped him:

*"And then I became an official carer and everything hopefully, touch wood, has worked well since then."*

## The views of the project managers

The three project managers have summarised their views on how the projects went.

Their collated views on the attitudes of primary care staff at start of the project can be summarised as follows:-

### Before

- GPs were often unwilling to refer to the Carers' Centre due to several reasons, including uncertainty about what happens to carers' support if the funding ends and misconceptions regarding the voluntary sector e.g. that it is comprised of volunteers and do gooders who are not professionals and are not permanent;
- Many primary care staff were unaware of the concept of carers, and tended to only focus on the cared for needs;
- Practices often tended to be of the medical model & condition focused. Often such referrals as there were focused on the cared for medical condition;
- Practices were doubtful about referring carers for what they perceive to be intangibles – emotional or preventative support;
- Due to issues regarding patient confidentiality, at the start of the project some referrals had nothing on them other than the carers' name, address, date of birth, telephone number, that the carer had given consent to the referral and the referring GP name. Practices often felt they could not discuss or disclose the cared for condition;

- Primary care staff were often predominately unaware of services available to support carers including Carers' Assessments or where to refer them;
- Some surgeries were not keen on the idea of a carers' register and were not convinced about using codes to identify carers, often because they didn't seem to be able to see the purpose of this or to understand the long term nature of caring;
- Some staff did not understand the distinction between carers and care workers or assistants;
- Some staff were not clear as to who could be a carer, which was wrongly seen as an older people's issue, definitely not young persons;
- It was not seen as an issue that would affect practices, or, crucially, one that could reduce practice workload in the long-term. Practices hadn't thought of the benefits to the practice of identifying and then referring or signposting carers; and
- Some practices hadn't thought of carers health as an area of particular concern.

Their collated views on the attitudes of practice staff at the end of the project can be summarised as follows:-

### After

- Practices have increased carer identification, awareness and understanding of carers' issues and the benefits of proactive support and prevention of break down of the caring situation, although practices still tend to see referring carers to a project as the main method of offering support;



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- GPs were more actively referring carers and asking for advice and support for themselves and referring their own staff; (including primary care staff themselves);
  - Through education & collaborative working, GPs were more flexible on the confidentiality issue;
  - Education to reinforce the safety issues for the cared for regarding potential overdosing etc helped to encourage practices to take an inclusive approach with complex medicine management;
  - However there was a constant need to keep the project at the forefront of the minds of key staff. GPs were mentioned as more difficult to engage and convince than other practice staff;
  - Practice managers and carer link workers were more open to the idea of using READ codes to set up a carers register. This may be related to both the influence of PCTs, and extensive discussion as part of the project. Practices better understood the value of 'tagging' carers' notes;
  - In principle most practice staff think that supporting carers is a good idea. The difficulties seemed to be in convincing the rest of the team to see that the support and identification of carers is part of their role, not somebody else's and to persuade them to use the resources available to do so;
  - There was heightened awareness of how Carers' Centres actually work with and support carers, and their level of professionalism which has resulted in an increase in contact and referrals;
  - There was an increase in 'hidden' carers identifying themselves as carers
  - Carers' Centre staff attended practice meetings, and there was increased use of the primary care toolkit and messages on repeat prescriptions;
  - Practices had a better understanding that anyone can be a carer, at any time, and there was a reduced perception of stereotypes;
  - There was an improved understanding of the effects of caring on the carers' health and well being;
  - There was more understanding of the role carers play in society and the money they save the Government;
  - Practices have been requesting regular support and awareness training; and
  - There was a development of understanding that carers don't always identify themselves as carers.
- The project managers identified the following other 'spin offs' from the project:-
- Partnership working was developed with other professionals e.g. with Consultant Nurses for older people and vulnerable adults, consulting with carers around their experiences of the hospital discharge process and how they can improve the ways they work with carers. Other partnership working was developed with Community Workers and advanced Primary Care Nurses;
  - Carers groups were established in surgeries and health centres, often well attended;
  - Carers identified by the project were referred on to other Carers' Centre services, and given intensive support during hospital discharge;
  - Work which helped avoid hospital admissions was highlighted as good practice by the Audit Commission in their report "Supporting the Needs of Carers of Older People";
  - Identification and support was given to less 'traditional' categories of carers who are very often isolated such as those caring for people with drug and alcohol misuse issues, gay and lesbian carers, and carers of people who are HIV positive;
  - Young carers were identified and referred to young carers' projects;
  - There was measured impact on avoidance of dual admission to hospital if the carer's own health breaks down, by the primary focus on support services for the carer;
  - Development work assisted the PCT pilot flu vaccination for carers prior to the inclusion in the at-risk list nationally;
  - More referrals were coming from GP surgeries outside of the project;
  - Carers who self refer are increasingly saying that they saw leaflets or posters at their GP surgery;
  - Other surgeries now want to work with the Carers' Centres; and
  - There is increased contact with primary care mental health workers.

## Conclusion

Identification of carers is of key importance. If they remain hidden, discussions about how and by whom support should be provided remain largely academic. Hidden carers, according to the Carers' Centre projects, were identified by a variety of means such as practice staff, leaflets, notice boards prescriptions but there is very little evidence of practice recording carers' details. Perhaps the single most significant finding was that although practice staff and practice managers say that carer identification has increased, the response by the managers on the number of carers identified for their practices shows that it is orders of magnitude below the level which we know it should be. There is much work still to do and carers are missing out on the benefits that identification can bring.

Perhaps inevitably, a mixed picture emerges from this evaluation of the project. The surveys of practice staff and carers reveal clear evidence of positive change in the attitudes of those staff, on a number of key dimensions, and an increasing recognition of the caring role. However, there is little or no evidence of change on some other indicators. There was evidence of a deterioration in the ease of obtaining carer-friendly appointments, although this is likely to be due to wider changes in appointments systems to meet national targets. This suggests that strong levers may be needed to achieve real change.

The qualitative interviews and focus groups revealed limited evidence of positive change over the period of the project, but there were some examples of changed approaches and their benefit. It seems that the main benefit is not so much in changes in the way the practices themselves provide their services, but more in an increased awareness of carers'

situations and the support services which are provided by others, particularly the Carers' Centres. There was evidence that the carers are, by and large, satisfied with the clinical services of their GP practices, and don't necessarily expect more support directly from them.

The interviews did however highlight, yet again, both the demanding nature of the caring role and the value of the support provided by The Princess Royal Trust Carers' Centres. It was the identification and referral – whether self-referral or referral by a GP practice – to the Carers' Centre which has made the main difference to the carers.

Those involved with managing the project believe that it has resulted in significant positive changes of attitude and behaviour, which is encouraging. In Section Six: Conclusions and Recommendations, we discuss where we think this work should now be taken.

## Section Five:

# Good practice

We hope that this summary of good practice, based on the experience gained by numerous valuable projects across the country, will act as a guide and a resource for those who wish to develop this work. Within the text we have highlighted examples of good practice using a three-part model, although space does not permit the mention of more than a small proportion of these.

## Identification

There is very limited value in identifying carers and keeping a 'register' of them unless that information is put to use in improving services for carers.

'Register' means a method of identifying within practice records those patients who are carers and those who have carers, with the facility to identify them collectively. This will most often be done by use of the appropriate READ codes within the practice computer system.

It is important that registers should be assessed not only as processes but also in terms of the number of carers identified. As an approximate rule of thumb, 2,000 patients on a GP list are likely to include about 200 carers. Of these, about 67 are

likely to be caring for more than 20 hours per week, including about 40 caring for more than 50 hours per week.

Systems should also be put in place to maintain the accuracy of these records, as situations change, which they frequently do. Carers should be asked to keep the practice notified of any changes in the situation

If the register is not used to its full potential, then carers will not be supported to the extent to which they should be. Furthermore, if primary care staff can clearly identify the benefits to their patients and themselves, in reduced workload, they are much more likely to be motivated to identify carers and to keep the register up to date.

*Primary Carers<sup>1</sup> identified three different*

types of activity for the identification of carers namely:

- i. Extracting information from practice records and knowledge;
- ii. Making opportunistic use of practice contacts with carers; and
- iii. Encouraging self-identification by carers.

To which we may add:

- iv. The notification to the practice by the local Carers' Centre.

*Greenwich PCT have issued a protocol entitled 'Supporting Patients who are Carers' in conjunction with the Carers Centre. This incorporates many of the ideas which have been put forward in Primary Carers<sup>1</sup> and elsewhere, and gives advice to practices on how to proceed.*

*Islington PCT have accredited a written protocol on the identification and referral of carers produced by the local Carers' Centre and Camden PCT have also supported a protocol developed by the Carers Centre, which included leaflets, a carers information pack and was supported by visits to practices. Leeds and Worcestershire also have protocols.*

A number of projects e.g. Bucks and Swindon have produced guides and toolkits to aid the identification of carers in primary care.

There are various models of joint working between Carers' Centres and primary care. Many projects use primary care link workers who work closely with individual practices. By contrast, other centres have worked more closely with community nurses rather than directly with GPs, and also find this to be very effective.

## Extraction from records

Simply working through all the individual patient records of the practice to identify all those who have a carer is unlikely to be an effective approach. It is very labour-intensive and the information that a patient has a carer may not always be recorded in the notes (indeed, the fact that it often is not recorded, is precisely the problem).

It is possible to undertake searches of computerised records by relevant characteristics, for example, a search of patients suffering from Alzheimer's disease. A variation on this is to undertake a search by prescribed medicines that are given to patients with a particular medical condition who are likely to have a carer. These methods could be used to initiate an approach to the patient, either by writing to them or placing a marker on their computer record to enable this to be followed up when next seeing them.

The Dearden Avenue practice in Salford carried out a computerised search of all patients aged over 70 who were not in residential homes and wrote to their next of kin asking them if they were the patient's carer. In 60% of cases, a carer was identified. This enabled follow-up information to be sent telling the carer about support which is available, including having an assessment of their own needs.

The most cost-effective way of utilising existing practice information is pooling the knowledge of the GPs, nurses, receptionists and other professionals.

When teams undertake such an exercise, they are often surprised at how many names they come up with. One advantage of this method is that those members of the team may have some understanding of the intensity of the caring commitment.

Dr. Campling and partners of Broughton House Surgery in Aylesbury asked every member of staff to identify carers they knew of, and sent out a leaflet to them asking for their consent to be added to the carers database.

## Making use of normal contacts

The primary care team have many opportunities to identify carers through their normal contact with patients – either with the person cared for and/or with the carer.

Normal consultations, including home visits:

The consultation could be with either the carer or the cared for person, and presents an obvious opportunity to identify a caring situation.

Primary Carers<sup>4</sup> noted that consideration for carers during home visits can help prevent carers feeling ignored:

*"The district nurses come on visits about my mother's ulcers but I feel invisible. No one says: 'How are you coping?' If you say: 'This is getting on top of me' then you get a few words of sympathy. The doctors also treat me like I am invisible, they come in and sort out mother then they just go."*

However, other carers commented on how their GPs have been aware of them and their needs

*"The doctor used to bring my notes as well when he made a home visit."*

*"I had a phone call out of the blue from the GP, to check up if everything was OK."*

Similarly, consultations with the carer as a patient present an opportunity to identify their caring role. It cannot be assumed that carers themselves will always make this link, or volunteer information about the demands that the caring role makes on them.

Practice nurses from The Limes practice in Salford do home visits for patients who appear to have a carer and run through a series of questions with the patient and the carer about who does certain tasks. They then fill in a referral card for the Primary Health Care Team (PHC) so that other professionals know about the situation and referrals are made to sources of advice and support.

The Greenwich protocol states 'all consultations provide an opportunity for the GP, Nurse, Physiotherapist etc. to enquire as to whether or not the person they are seeing as the patient is (as well as being unwell) caring for somebody or being cared for by somebody'.

Carers Leeds provides members of the PHC Team with a three-part yellow card, one part of which is used to update practice records and one part of which can be posted to the Carers' Centre. York and Selby use a referral form which members of the Primary Care Teams are encouraged to fill in when they meet a carer, and this is then forwarded to the Carers' Centre who send out a carers pack to the person identified.



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### New patient registrations

These should, as a matter of routine, include a question to identify whether the patient is a carer or has a carer.

*Carers Leeds produces a Practice New Patients' Questionnaire for use when registering new patients which asks if the patient is a carer. The Stanmore Medical Practice in Harrow has done the same. The Greenwich protocol also requires information about how the practice supports carers to be included in a new patient pack, and separately identifies young and adult carers.*

### Use of other health events

Other health events undertaken at the GP surgery present opportunities for identifying a caring role. These may include, for example, 'flu jabs, over 75s health checks or well-person clinics. In 2005 the eligibility for jabs was extended to carers. It is important that this opportunity is used to update practice records about the caring role.

*The Carers' Centre Health Project in Leeds has worked throughout the city to train primary care staff to identify carers at over 75 checks and at flu jabs sessions, or when the carers have other contacts with practice staff. The project has yellow cards, which are given to carers for them to return to the practice so that records can be annotated.*

### Repeat prescriptions

The ordering or collection of repeat prescriptions can be used to identify carers, because a high proportion of patients who have carers also have medical conditions which require repeat prescriptions.

*The Greenwich protocol requires that 'each practice will ensure that at least once a year it runs a two-month campaign to identify both adult and young carers using a global message on the bottom of its prescriptions' and that it 'will ensure that at least once a*

*year for a four-week period it works with its local pharmacy to encourage carers to identify themselves to their GP practice by using specially printed post-its on all repeat prescriptions'. Each year Lewisham Carers Centre also operates such a post-it scheme. Post-its were chosen for simplicity and to avoid staples.*

### Hospital discharge

Hospital discharge is often the point at which a carers role starts, frequently completely unexpectedly. GPs who are notified of a discharge have a role in this as well as the hospital itself.

*In Durham a questionnaire on this topic was sent to all hospitals serving the area which resulted in a strategy document entitled 'Hospital discharge planning, are carers' truly involved?' and a seminar for hospital team leaders and PCT staff. This has resulted in a leaflet called 'Is someone close to you coming out of hospital?' which was widely-distributed to community health outlets.*

### Self-identification

*Notice boards, posters, fliers and practice leaflets:*

**Carers' notice boards, posters, fliers and registration cards should be visible in surgery waiting rooms. It is important that the language and descriptions used are readily understood. The materials should be kept up to date and replenished frequently.**

*Carers Leeds provide text for practice leaflets. The Greenwich protocol specifies that there should be two prominent posters – one targeting adult carers and one targeting young carers – and that electronic messaging, where it exists, should be used for this purpose. It makes reference to appropriate terminology and also specifies that there should be carers registration vouchers in the*

*waiting or reception areas. Carers Sandwell establish 'carers' corners' in GP surgeries, with a resource file for each practice.*

### Letters

A letter to patients can be used to encourage self-identification of carers. They can be handed to patients when they arrive at the reception desk or sent to patients at home, which will reach those unlikely or unable to visit the surgery. This could be to all patients or to a selected sub-set of patients based on diagnosis, medication or other information. The Princess Royal Trust for Carers Good Practice Guide, *Focus on Carers and the NHS – identifying and supporting hidden carers*<sup>1</sup> estimates that a targeted mailing to 2000 patients would produce 120 positive responses. It should be easy for the carer to reply, perhaps by using a pre-paid tear-off reply slip.

### Carers identified by the local Carers' Centres

There should be a mechanism for the information about carers known to the local Carers' Centres to be fed into practice information systems.

*York and Selby Carers' Centre informs practices who their carers are as part of a mailing every 6 months which also includes updates on the services offered by the centre. Worcestershire Association of Carers has developed a Carers GP Registration card for carers to take to surgeries. The response to this is monitored by the PCT as part of its contract monitoring. Carers Resource (Harrogate & Craven) provide detailed information to practices about which carers the practices are supporting and which they are not.*

## Recording the information within the practice

The information that someone is a carer, or has a carer, should be readily accessible to any health professional who is using the record.

It is appropriate to obtain the carer's consent to be registered with the practice as a carer. It is also very important to obtain the consent of the cared for person that the carer can have access to clinical information about them, and for their records to be cross-referenced with those of the carer (if they both use the same GP practice).

The method of recording involves using READ codes 918A for the carer, and 918F for a patient with a carer.

## Referral

### General points

It is important to ask the carer what kinds of support they need. They should be given information about types of support which they may not have previously considered.

*The Harewood practice in Lincoln has had the philosophy of regarding carers as fellow members of the healthcare team, sharing the care of the patient.*

There are a wide range of types of support which carers' might need, and a wide range of organisations which might give that support. The carer could be referred directly by the practice, or given the information to enable them to make contact themselves.

In those cases where the practice makes a referral to the local Carers' Centre, it is good practice for the centre to write back to the GP acknowledging the referral and indicating the support and assistance which the centre has been able to provide to the carer.

*York and Selby Carers' Centre have developed 'condition specific' contact cards for distribution to carers via GPs. These list approximately six to nine key organisations relating to that condition, led by the Carers' Centre.*

*Carers Resource (Harrogate & Craven) have practice agreements and provide a comprehensive service for their practices. They have demonstrated significant savings of time for other professionals, increased income generated for the carers and a positive impact on carers' health. Greenwich practices offer well-carer health checks and a carers information pack. One section of the three-part Leeds yellow cards given by the practices to carers gives general information about services for carers.*

As a practice nurse in Harrogate put it:

*"It's an excellent service. Patients I have referred in the past year have often come back looking as if a great weight had been lifted off their shoulders. They appreciate having someone focus on them and their needs. It saves me loads of time having someone else to provide emotional support and give the practical ongoing support we can't provide"*

### Statutory assessment of needs

Many carers have a statutory right to an assessment of their needs by the Local Authority. Practices which are receiving contractual payment for identifying carers are required to refer them for such assessments.

*Carers Resource (Harrogate & Craven) have a contract with the local PCT which links specialist carer support officers with the Single Assessment Process Teams, which work at the interface of health and social care, to ensure that carers' needs are*

*addressed properly through this emerging new system. The Greenwich protocol identifies the requirement to refer carers for an assessment.*

### Advocacy and/or financial information

Support of this kind is usually available from the local Carers' Centre, or the Citizens' Advice Bureau as well as relevant statutory bodies. Evidence of the impact of such referrals has been provided.

*Carers in Hertfordshire undertook a survey of carers who had been identified by local GPs to compare the outcomes for those who were in contact with Carers in Herts with those who were not<sup>6</sup>. Twice as many carers in contact with Carers in Hertfordshire were well informed about their rights compared with the latter group, and no less than five times as many had had a benefits check.*

*Carers Resource (Harrogate & Craven) provide this type of support. The Greenwich protocol provides a list of local agencies, as does the Leeds three-part yellow card.*

### Short breaks

It is important to ensure that carers have the opportunity to live their own life, visit family and friends, and, if they so wish, to participate in activities that are directed at improving their own physical and mental health. Many Carers' Centres organise such diverse things as day trips for carers; horse riding; aromatherapy; beauty treatments and so on. Short breaks may be arranged by the Social Services Department or a Carers' Centre or another voluntary agency.

*Many Carers' Centres provide support of this kind. For example, Sefton provides a range of activities as diverse as reflexology and horse riding.*

*In Reading, the Primary Care Trust has funded a 'breaks on prescription' scheme, under which the GP can supply a voucher to carers who need a break. The voucher can be*



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exchanged with Crossroads – Caring for Carers who provide replacement care.

## General support

Carers' support groups may be organised by the Carers' Centre. The GP practice can be a place with which carers readily identify and are comfortable with. For this reason, it is a potentially suitable place on which to base a carers' support group, or other non-clinical services for carers.

*One to one support can usually be arranged by the Carers' Centre, or by the GP practice itself providing access to services that may be already available, such as counselling.*

*There is a monthly 'carers drop-in' at Street Lane practice in Roundhay, Leeds for carers of older people, where carers can come for advice or just to share problems. Services such as aromatherapy massage are also available.*

*The Harewood practice in Lincoln has given meeting facilities to a carers forum for carers who care for patients of the practice, but does participate directly in it, regarding it as the private forum of the carers.*

*In Lewisham there is a 'community prescribing project' operated by local voluntary sector agencies, to which the GP can refer patients, who may include carers, for types of non-clinical support that the practice is unable to provide directly, but which the GP thinks would be of assistance.*

## Referral to other GP practices

This is relevant where the carer is registered at a different practice to that of the cared for, and the carers role is identified by the practice of the cared for.

*The Greenwich protocol includes a form called 'patient who is carer referral' for communicating with other practices.*

## Changes within the practice

### General points

This may be sub-divided into two categories: firstly, changes to the routine services that the practice offers to all patients, to take into account the circumstances of carers, and, secondly, new services which are specifically targeted at carers.

These changes are more likely to occur if two things happen:-

- i. All practice staff have undergone training in carer awareness.

*Islington PCT is one of those which has provided carer awareness training to Primary Health Care Team staff in conjunction with its local Carers' Centre.*

- ii. Practices appoint a carer specialist or champion to take ownership of the carers register and propose and monitor the implementation of carer-friendly policies and procedures. It is common practice for GPs and nurses, in particular, to have specialist roles within a practice, to improve the quality of services offered to its patients. These are often related to medical conditions, such as diabetes, or to particular groups of patients, for example the elderly. It may be appropriate to consider carers as being a specialism.

A note of caution is appropriate here. If (ii) is implemented without (i), there is a danger that carers issues will not be 'owned' by all staff and will be seen as exclusively the concern of the specialist, which would be undesirable.

*Almost all practices in Islington have a carer specialist and it is included in the Greenwich protocol where the 'champions' attend a carers' policy forum.*

## Changes to routine services

Almost all of the services which GP practices offer can be made more 'carer friendly' than has traditionally been the case.

## Appointments

Appointments systems should recognise the particular circumstances of carers, which may affect when they can come for an appointment, how long they can wait in the surgery, or when they can ring up. The circumstances of each individual carer is different and this should be recognised by the practice staff.

The carer may also wish to discuss issues around the health of the cared for as well as their own health. Indeed, the former will often be affecting the latter in a significant way.

*The Leeds carers protocol suggests double appointments for carers so that they can discuss the health of the cared for as well as their own health. It also suggests that carers who have difficulty in making appointments could be offered the otherwise embargoed 'book on the day' appointments in advance.*

*When patients with an identified carer (or the carer themselves) ring the Orton practice in Peterborough for an appointment, the staff are authorised to make special appointment arrangements if necessary to fit in with the carer's situation.*

*Worcestershire Association of Carers suggest a five-point plan for carer and cared for appointments: advance booking; appointments when there might be least*

waiting time build-up; appointments later in the day; double appointments; appointments in downstairs rooms if cared-for mobility is impaired. They also appeal for a recognition that carers are not being 'difficult'!

## Repeat prescription procedures

These can cause problems for carers, if ordering by telephone is not permitted or is limited to particular times of day. Similarly, it may be difficult for carers to pick up prescriptions.

*The Orton practice in Peterborough has certain times when repeat prescriptions can be 'phoned in but does not apply this restriction to carers. In similar vein, the Greenwich protocol specifies that there should be a separate time for carers to call. The Worcestershire Association of Carers asks that practices recognise that carers might legitimately request advance or extra prescriptions to cover holidays or when respite care is being given.*

## Waiting rooms

Waiting rooms nearly always lack privacy, which can cause problems for carers who are looking after patients who find it difficult to wait in public, or whose behaviour can cause difficulties or embarrassment due to the reaction of other patients. If accommodation permits, carers accompanying patients with these needs (for example, a child with autism or a patient with dementia) should be offered a smaller or quieter area to wait where the person being cared for will not be affected so much by the bustle of the waiting room or the reaction of other patients.

A carer in Lewisham gave an example of the difficulties carers can face:

*"There was an instance a few months ago when I had to see the doctor on a personal appointment for me and it*

*was the only appointment that I could get and I had to take xxx with me but there was a big hoo-ha because they said can he stay in the waiting room while I go in because I didn't want him in there and they were saying 'well, will he be okay? We can't take responsibility for him'. And I said 'but what can I do?' In the end they did agree to let him go behind the screen and sit with them there but it was quite unnerving for me because I didn't know what was going to happen and it was okay but you know it was like they didn't know I was a carer when they booked the appointment."*

## Home visits

It may be appropriate to undertake home visits for some carers, or the person they care for, to take account of the caring situation even if the particular presenting medical condition might not normally indicate that this is appropriate. This should be offered automatically in appropriate cases and carers should not be made to feel guilty if they make such a request.

*The Greenwich protocol requires a sensitive approach, and suggests that longer times be allowed for such visits to enable the carers' health to also be examined.*

## Health checks

Offering health checks or carers clinics recognises the potentially harmful effect that an extensive caring commitment can have on the health of the carer, and the desirability of keeping the carer's health under regular review.

*A project in Sedgefield combines a carers' health check with 'flu jabs and the opportunity to meet with a support worker from the Carers' Centre, to look at other ways in which they might be helped. One carer*

*commented "I nearly didn't come as I didn't think I could spare the time, but I'm really pleased now that I did...it made me realise that my health is important too". The pilot has proved to be very successful and the Carers' Centre is now hopeful of rolling it out to other practices.*

*Greenwich practices offer well carer health checks and the PCT has produced a carers health check risk assessment action sheet.*

*In North East Leeds, the PCT has funded two GP practice-based Older People and Carers Support Nurses with, as the name implies, specific responsibility for carers as well as the older patients. They assess need and work with a network of agencies (both statutory and non-statutory) to try to meet it. The scheme, which started as a pilot project, has been evaluated and found to be of value to patients, carers and the policy objectives of the NHS.*



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## Strategic work

It is important to examine the potential for development at the more strategic levels of the new PCTs, SHAs and the Department of Health itself.

### The role of PCTs – the GP contract

The national GMS (General Medical Services) GP contract, gives three points (management indicator nine), out of 1050, in the Quality and Outcomes Framework (QOF)<sup>iii</sup> for the establishment of a system to identify carers and refer them to the Local Authority for an assessment.

Although this is a disappointingly low number of points, the number of practices taking up this option has been very high. There do however appear to be two other problems:

1. Because the points available are relatively low, this indicator has probably not been audited as robustly as some others; and
2. It refers to a process, not an outcome. As shown in section on the demonstration projects (section four), it is possible to gain the points for this whilst still only identifying a small proportion of carers. It should be audited against the number of carers identified compared with the expected number.

Some areas have however taken welcome initiatives in this area.

*In Greenwich, Neighbourhood Renewal Funding (NRF) has been used to support a pilot project around the Greenwich protocol which enables carer support to be delivered in three phases: basic support, intermediate support and intensive support. Two practices are working at each level, and targets have*

*been set to measure the outcomes. The NRF funding has also been used to provide publicity in all surgeries.*

*Worcester PCT have included the use of a GP registration card provided by the Carers' Centre in their monitoring of GP practices against QOF management standard 9.*

There are other opportunities to encourage progress in this area. Some practices have locally-negotiated Personal Medical Services (PMS) contracts. It is open to PCTs to negotiate with those GPs for the inclusion of systems and services to improve the level and quality of support given to carers. Similarly, the new GMS contract has within it the option of payments for locally or nationally determined 'enhanced services'. This should be one focus for local discussions with PCTs and Strategic Health Authorities about how to improve primary care support and services for carers.

The Scottish Executive have produced a framework for 'Enhanced Services – Services for Carers' which comprises the following specifications:

- a. *Produce and maintain a register of people who are carers. In addition medical notes will include a flag to indicate that this person is a carer; and*
- b. *Effectively liaise with relevant outside local carer agencies and social work services. This will involve each participating GP practice :*
  - i. *Identifying one person from within the practice team to act as an appropriate liaison officer for the practice with relevant local carer agencies and social work services; and*
  - ii. *Agreeing a referral process for referring carers from the practice to relevant outside carer agencies and social work services, to ensure carers can access appropriate information*

*and support from these agencies/services at an early stage in their caring role. This will include co-operating with relevant outside local care agencies in any initiative designed to alert carers to the support they offer.*

### The role of PCTs – service development

PCTs are responsible for establishing clinical governance protocols for the delivery of services by GPs. These should address the extent and manner in which the role of carers is recognised and supported. In other words, the principles which have been incorporated, for example, into the National Service Framework for Mental Health should be included in other clinical areas. Similarly, arrangements for appraisal of GP practices could include elements relating to this area.

PCTs provide training programmes for practice staff. This training should include carer awareness, how to establish carers' registers at practice level, and how to support carers and improve the range and quality of service offered.

PCTs have discretion in the financial allocations they make and the types of service development that they support. PCTs should recognise the relevance of such projects to NHS objectives and the value of supporting them, financially and with longer-term contracts.

PCTs can also assist in other ways. For example, they can organise local conferences or listening events to give local carers an opportunity to contribute their views and experience to debates on service improvements.

The old star rating system has been replaced by a new system of Core Standards based on self-assessment

which the Board has to sign up to. Two of those are as follows:

- Standard C14c – Healthcare organisations have systems in place to ensure that patients, their relatives and carers are assured that organisations act appropriately on any concerns and, where appropriate, make changes to ensure improvements in service delivery; and
- Standard C17 – The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services.

There are examples of PCTs adopting good and innovative approaches in this area some of which would contribute to meeting these standards:

*The Commission for Healthcare Improvement (as was) in its report on Airedale Primary Care Trust, identified the PCT's work with carers as an area of 'notable practice', describing it as follows: 'This innovative project works in conjunction with Social Services to map and explore how carers are supported and needs are met. This encourages practices to record carers' details on patients' records'.*

*Carers In Herts undertook a 'carers challenge audit' of the eight PCTs in their area using a quality assurance tool, and produced a report back to each PCT. It developed a Red/Amber/Green categorisation for PCTs.*

*Wandsworth PCT has employed a carers development worker. That worker was able to ensure that the role of carers was championed and recognised in the development of a Long Term Conditions Strategy which included five cross-cutting recommendations to improve support to carers which will apply to a range of*

*organisations and providers.*

*Redbridge PCT have supported a Carers' Centre project called 'Carers Choosing Health' aimed, as its name implies, at improving carers' health.*

*Swindon PCT has developed a generic set of five standards for support for carers to be applied to all services provided and commissioned by the PCT. These cover information, staff training, record keeping, carers 'leads' and 'champions' attending meetings at the Carers' Centre, appointment systems, carer health checks, carer involvement in service development and evaluation, and carers support groups.*

*Leeds Carers' Centre Health Project, working with five PCTs in Leeds, has run a Carers Conference, three mini conferences and seven listening events as part of the project's strategic work on raising awareness of carers issues and providing training for primary care staff to enable them to identify and support carers.*

### Carers training

The National Strategy for Carers made clear that "the NHS must help carers to learn the necessary skills so that they can care without risk of injury to themselves"<sup>iv</sup>. The strategy also noted that this can be particularly important at the start of caring. Untrained new carers are sometimes thrown into a situation that would never be allowed for paid care staff. The *Carers Speak Out*<sup>v</sup> survey found that as many as six out of ten carers did not have sufficient information, help or support with the tasks of moving, lifting and handling the person cared-for. National statistics on health symptoms among carers also reveal that one in four carers who were caring more than 50 hours a week suffered physical strain. However, it is about much more than moving and handling.

We are very pleased that *Our health, our care, our say*<sup>vi</sup> has accepted the recommendation in *Primary Carers* that an Expert Carers Programme (ECP) should be introduced, building on the model of the Expert Patients Programme.

It is appropriate to identify some good practice about how this should be implemented, which emerged from a mapping exercise of 266 organisations involved with carers training, which The Princess Royal Trust for Carers recently undertook on behalf of The Department of Health:

- Carers should be involved in decisions about the content and delivery styles of any programmes;
- The programme should include the concept of the carer exercising choice about the amount of caring which is undertaken;
- Drawing from the Expert Patients Programme the concept of carers themselves doing the training, and being trained as trainers, is important;
- Whilst the similarities with the Expert Patients Programme are acknowledged, it is also important to recognise the differences for carers training. The former is about caring for oneself, whilst the latter is both about that and caring for someone else;
- It is important that it should not be too health focused, or be seen to mainly aimed at reducing the demands on the NHS (even though effective support for carers will undoubtedly do that) Some carers have already expressed suspicion of this;



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1. 'Carers' should not be seen as an homogenous group. There are great differences in carers needs, based on their personal situations, and the longevity and nature of the caring need, which should affect both the content and delivery style of training provided; and
2. The special circumstances of young carers, in particular, should be recognised.

The mapping exercise revealed a wide range of possible areas for inclusion in the ECP:

- Moving and handling;
- Carers' rights;
- Coping with stress/coping strategies;
- Services for carers;
- Information for carers;
- Communication skills;
- Looking after yourself;
- Advocacy;
- First Aid;
- Medication;
- The effect of caring on other relationships of the carer;
- The changed relationship with the cared for;
- Bereavement counselling;
- Training for life after caring including new skills or refresher courses;
- Influencing local decision-making/influencing public perception/acting as a carers' representative;

- Starting/running a local carers group; and
- Palliative care.

Many Carers' Centres are already involved in the training of carers, covering a wide range of areas often with the support of their PCTs.

*Brent Carers Centre held information and support events for carers, covering a wide range of areas including specific advice on caring for people with particular conditions; lifting and handling; first aid; nutrition; managing stress; exercise and relaxation. These courses were either held on one day or once a week in the afternoon over three weeks. Carers Resource (Harrogate & Craven) holds contracts with its PCT for memory clinics and palliative care training. Wandsworth Carers' Centre is involved with a local back care project*

- i *Focus on Carers and the NHS – identifying and supporting hidden carers. Good Practice Guide, The Princess Royal Trust for Carers, 2003*
- ii *Identifying and supporting carers through the GP surgery-what difference does it make, Carers in Hertfordshire 2005*
- iii *Department of Health, Quality and Outcomes Framework Guidance, 2004*
- iv *Caring About Carers: A National Strategy for Carers, HM Government, 1999*
- v *Keeley and Clarke, Carers Speak Out – report on findings and recommendations, The Princess Royal Trust for Carers, 2002*
- vi *Department of Health, Our health, our care, our say: a new direction for community services, HMSO London, 2006*
- vii *Keeley and Clarke, Primary Carers – Identifying and providing support to carers in primary care, The Princess Royal Trust for Carers, 2003*

## Section Six:

# Conclusions and recommendations

In the final section of *Primary Carers*<sup>i</sup> we presented three checklists of recommendations – one for GPs and Primary Health Care Teams, one for Primary Care Trusts and one for the Government and Strategic Health Authorities. These were seen as a successor to the 5-point checklist set out by the Government in its *National Strategy for Carers in 1999*<sup>ii</sup>.

Within the last few months the Government's White Paper *Our health, our care, our say*<sup>iii</sup> has committed the Government to 'a new deal for carers'.

The opportunity under the new GP contract for GPs to be paid, albeit a relatively small amount, for the establishment of a carers register to enable carers to be referred to the Local Authority for an assessment has been operative for a year, and the large majority of GPs have taken this up. The new Core Standards assessment for PCTs requires them to consult carers, among others, on the provision of services.

*Primary Carers*<sup>i</sup> concluded that work at the practice level to support carers is unlikely to become embedded in all areas unless there is support and encouragement for this from both the

local PCTs and the Government and SHAs. Without this, development is always going to be patchy and inconsistent, and largely driven by local enthusiasts and champions. Accordingly we have also produced 10-point checklists for both PCTs and the Government and SHAs.

We have updated the three checklists in the light of developments since *Primary Carers*<sup>i</sup> was written. In fact, many of the recommendations remain similar, if not identical, because the issues and deficiencies remain the same in many areas.

## A new checklist for GPs and Primary Health Care Teams

### 1. How many of your patients who

**are carers, and patients who have a carer, have you identified? Are you implementing all of the methods for carer identification outlined in the report?**

Identifying carers who are patients and patients who have a carer remains an essential pre-condition for any effective improvement in the support given to carers by primary care services. In the last checklist we asked whether practices had identified their patients who are carers or who have a carer.

We have re-phrased the question. We have done so because although under the new contract, the large majority of practices have claimed the relatively small amount available for establishing a register and referring carers for assessment, there is strong evidence to suggest that the number of carers identified is still only a small proportion of the number of carers out there. Even GP practices with good and well established links to Carers' Centres are not always managing to identify even all the carers with substantial needs. Identifying some carers may be enough to meet the requirements of the new contract but is not enough to make a real change to those



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carers' lives. If we take a typical five-doctor practice looking after about 8000 patients, about 800 of these will be carers, of which about 270 will be caring for more than 20 hours a week, including about 160 who are caring for more than 50 hours a week – considerably more than a full-time job. These figures should be used as a benchmark by practices to self-assess how well they are doing in identifying carers. This report outlines many methods of identifying carers which should be examined by practices.

## **2. Do you refer carers to local sources of advocacy, help and support, including an assessment by the Local Authority and Carers' Centres or carers support groups?**

The contractual requirement under the QOF framework is to refer carers' to the Local Authority for an assessment of their needs. It is assumed therefore that this is happening in those practices which receive this payment but it needs to be monitored. A survey carried out by The Princess Royal Trust for Carers in 2002<sup>v</sup> found that over 70% of carers who were caring for more than 50 hours per week had not had an assessment of their needs. Yet, among carers who had had an assessment, over half had seen a change to the support or services that they received. Heavily committed carers in particular should have an assessment.

But whilst this assessment is very important, it is only part of the picture. Carers cope with a wide range of challenges and difficulties and may have a variety of support needs, not all of which may be picked up by the formal assessment. Also, there is no need to wait for that assessment before putting carers in touch with sources of support to meet their needs which will vary between carers at

different stages of caring. The network of Carers' Centres run by The Princess Royal Trust for Carers and other agencies can offer opportunities for advocacy and help with benefits or other financial information. The chance to meet others in the same situation and to be offered services such as short breaks, 'pampering', counselling or opportunities for training. Also, some GP practices do not have in-depth specialist knowledge or expertise in some conditions which give rise to caring situations such as learning disabilities or mental illness. There are national and local organisations that do specialise in these conditions and can provide information and support to carers. Practices that link with other organisations in this way can also benefit by keeping up to date with developments in knowledge about the condition.

## **3. Do you take carers' special needs into account in terms of the way you allocate appointments?**

Appointments can be a particular problem for carers who often have less flexibility than other patients about when they can attend for an appointment, because it may need to be timed to fit in with their caring responsibilities (thus an early morning appointment may often be unsuitable) or when they can arrange alternative care. For the same reasons they may have less flexibility than other patients to wait if a surgery is running late. There is strong evidence that the health of carers is adversely affected by their caring role. Giving carers priority in appointments may help to preserve their health and that of the person they care for, and in certain circumstances can avoid hospital admissions. There has been a centrally-driven policy priority to ensure that patients can see their GP within 48 hours or a healthcare professional within 24 hours. In

some cases this has led to problems of patients trying to get through on the phone in the early morning to try to obtain appointments which are 'released' that morning. This can be much more difficult for carers to do. It is significant that in our demonstration projects, this is one area in which there was not improvement as perceived by the carers. We are not suggesting a prescriptive model here, but merely that practices should be carer-sensitive in the way in which they devise their systems, and flexible in their approach to the needs of carers.

## **4. Do you take carers' particular home circumstances into account in your procedures for issuing prescriptions and for home visits?**

Prescriptions is another area where carers often experience particular problems. They often have less ability than other patients to drop off or collect prescriptions at the surgery and would benefit from being able to phone in prescription requirements and being advised about how to have the prescription collected and medication delivered for them. Similarly, the home circumstances of the carer may make it difficult for them to attend surgery for their appointment, even if the condition itself would not normally merit a home visit. GPs and their staff should be prepared to respond sensitively to this. It is also good practice to take along the medical records of the carer when making a home visit for the cared for, and check on the carer's health at the same time.

## **5. Do you take carers' particular needs into account in your arrangements in the waiting room?**

A further problem for carers identified in surveys and in our demonstration projects

is the waiting room arrangements. Sometimes this may be due to embarrassment about the behaviour or nature of the medical condition of the person being cared for and the reactions of other patients to them. Another problem is the lack of confidentiality when talking to reception staff. Although this is not confined to carers, it is probably a more frequent problem for them than for other patients, particularly if they are asking for special arrangements. Changes to the physical environment are needed to take into account the circumstances of, say, patients with autism or dementia or those with equipment such as wheelchairs or oxygen bottles. This is a longer-term issue but sometimes small changes can be made which can make a big difference, such as using existing smaller rooms for patients to wait in when the general waiting room is less suitable for them.

#### **6. Do you check carers' health whenever a suitable opportunity arises, and at least once a year?**

The White Paper<sup>iii</sup> states that the NHS will develop a new Health 'Life Check' service to help people particularly at critical points in their lives. Given the evidence about the adverse effect on carers own health of the caring role, and the often serious consequences of a breakdown in carers' health, it makes sense for the NHS to monitor carers' health, just as it does for other groups such as diabetics or those with heart problems. Some practices have introduced such checks, sometimes in carers' clinics which are combined with advice being given on other areas by a Carers' Centre worker. Carers are regularly in touch with the NHS, having contact with GPs, district nurses and community nurses. While many of these contacts may be about the health needs of

the person cared for, they also present an opportunity for the primary care professional to review the carer's own health and their ability to continue caring.

#### **7. Do you ask patients who have carers whether they are happy for health information about them to be told to their carer and do you give carers information about the diagnosis, treatment and prognosis for the person they care for and about medication and its side effects?**

In the *Carers Speak Out*<sup>v</sup> survey in 2002 many carers told us that they were not being given adequate information about the diagnosis, treatment, medication or future development of the illness or disability of the person they cared for.

While there may be issues of patient confidentiality in some cases, it is more often a problem of GPs and other primary care professionals not being sufficiently pro-active in seeking the patient's consent for this key information to be passed on to the carer. The evidence suggests that carers who are given more information feel more positive about their caring role and the influence they have over services for the person they care for. If the oft-repeated mantra that carers are partners in care is to mean what it says, this is an essential requirement.

#### **8. Do you arrange for your staff to have information and training to make them 'carer aware' and to ensure that all relevant practice systems and protocols reflect the needs of carers? Will you identify a member of staff to take the lead on carers' issues?**

One of the best ways to ensure that practice systems reflect the needs of

carers is to give all staff – clinical and administrative – training in carer awareness. The local Carers' Centre will often be more than happy to do this. This can be very effective in promoting the opportunistic identification of carers arising out of the routine contacts the practice has with its patients. This can then be followed by a review of practice protocols and procedures, preferably with some direct involvement from either the Carers' Centre or from carers within the practice, to ensure that they properly respond to the needs of carers. We have found repeated evidence of the impact of such awareness training and the motivation of staff which can result from it. This should be complemented by the appointment of a member of staff to take the lead on carers' issues, and ensure that all aspects of the practice organisation are carer friendly.

#### **9. Are you willing to actively encourage the involvement of local Carers' Centres and carers' organisations in the work of your surgery?**

Many practices have a regular visit from a carers' worker from the local Carers' Centre or organisation to provide advice and support to carers in a clinic, and have found this an invaluable aid to their work and of great value to their patients who are carers. Some GP practices have also established practice-based support groups, which complement services delivered in the surgery by the local Carers' Centre. In some cases practice staff participate in the group, whereas in others the surgery makes a room available for the group, but does not participate directly in it. In other areas the carers support group is based in the local Carers' Centre. The best practice depends on



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local arrangements and what carers find to be of value. The important thing is to recognise that the local GP practice can often be an appropriate place for such developments.

## **10. Will you use the opportunities presented by practice based commissioning to develop services and support for carers?**

Practice based commissioning will give GPs and other members of Primary Health Care Teams greater influence and control over how their local PCTs use resources. Potentially this presents a powerful opportunity to improve support and services for carers. This can apply not only to services commissioned from other parts of the NHS, but from other agencies as well. For example, greater priority could be given to the commissioning of services from the local Carers' Centre, some of which might be delivered 'on-site' at local surgeries.

## **A Checklist for Primary Care Trusts and Strategic Health Authorities**

### **1. Do you produce a local protocol for systems within primary care to identify carers and link them to support, and do you commission work to set up such systems within primary care?**

Support cannot be offered to carers who have not yet been identified. Primary care is one of the most important and frequently used avenues by which carers come into contact with statutory agencies. It is important that systems are set up within primary care to identify carers and link them to support. Identification by

itself is of limited value because it can only affect the services offered by the practice itself (and may not even do that).

It is unrealistic to expect the practices themselves to be aware of and develop all the available methods. A number of PCTs have developed local protocols to assist practices to do this or have adopted protocols developed by their local Carers' Centre. Other PCTs have produced local standards against which to assess practices. There is also no point in re-inventing wheels either between PCTs or between practices.

Despite the obvious value of such development work to the NHS, many of the local primary care projects that have been established to do this have received no funding from the NHS, and the funding for some of those which have, has been withdrawn or not renewed. It is very important that funding is planned over a sufficiently long period to enable the schemes to become properly established and to cover all the GP practices.

### **2. When monitoring the implementation of QOF management standard 9 relating to the identification of carers, will you examine the numbers of carers identified as well as the process?**

The standard refers to the practice having a protocol for the identification of carers and their referral for a Social Services assessment. As written, this is rather vague, and makes no reference to the effectiveness of the protocol in identifying carers. Our research has indicated that it is possible to have a protocol in place, but still not identify a significant proportion of the carers.

There is a danger that audit and monitoring will examine the processes rather than their outcome. There is a

further danger that because it is only worth three points out of 1050 in the overall framework, that it is not given the same priority for detailed audit as other elements in the framework.

We know approximately how many carers to expect in a given practice population and this should be used as the benchmark information against which to assess practices' performance.

### **3. Do you involve carers' representatives, as partners, in the planning of local services?**

PCT Boards are now required to confirm their compliance, or otherwise, with a number of Core Standards. Two of these are as follows :

*Standard C14c – Healthcare organisations have systems in place to ensure that patients, their relatives and carers are assured that organisations act appropriately on any concerns and, where appropriate, make changes to ensure improvements in service delivery.*

*Standard C17 – The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services.*

These are demanding standards, and the inclusion of carers in both of them is significant. Standard 14c is generally interpreted in the context of responses to formal complaints. However, 'concerns' should be wider than formal individual complaints, and should include views on overall service provision and development and the extent to which it recognises and responds to the needs of carers. We believe that when the Healthcare Commission publishes the results of this quality assurance exercise, there will be many places in which concerns have been

expressed about the inadequate response to carers' issues, but where the PCT has declared itself compliant with C14c.

Standard C17 requires PCTs to seek the views of carers and take them into account. Again, there are many PCTs who do not do a great deal to actively seek the views of carers but we predict that the overwhelming majority of PCTs will have declared themselves compliant with these standards.

This is important because there are many areas in which the input of carers would be valuable in local implementation schemes and other planning forums. These should include, for example, the planning and design of new primary care facilities through the LIFT programme; service protocols which should take account of the special needs of carers; and system planning to avoid hospital admissions and delayed discharges. Carers have a specific and unique contribution to make, based on their experiences, which can add value to the process and make a positive contribution to the achievement of NHS objectives.

#### **4. Do you make assessments of the level and quality of support for carers provided by the primary care services that you commission and do you incorporate support for carers into your local protocols for clinical governance and GP and practice appraisals ?**

PCTs have an important role in promoting and initiating good practice. If a Primary Care Trust relies solely on those GPs who are already interested in and committed to the needs of carers to take this agenda forward, progress will be much more limited than it need be. Also, wide variations between practices will continue to exist, creating further health

inequalities for carers. PCTs should use their levers to review progress and where necessary encourage practices to change their ways of working.

The PCT should build up a picture of what is happening for carers in its area by asking those from whom it commissions services to provide information about what they are doing to support carers. With such an assessment, it will be possible to measure progress and to benchmark your area against other comparable areas. The provision of such baseline data is also essential for monitoring the impact of new initiatives. PCT staff may themselves be carers and they could be included, both in the assessment and to give input to ensure that family-friendly policies reflect the needs of staff who are carers.

It is important to look at the way practices deliver their day to day services, and the extent to which that recognises and responds to the special needs of carers. Appointments, prescriptions and waiting room arrangements are three such areas. We have identified these in the checklist for practices but it is important that PCTs give comparable priority to monitoring these areas as is given to other service delivery objectives, such as meeting the targets on the ability to see a doctor or healthcare professional within 48 or 24 hours. For carers, these issues can be just as important as the more high profile targets.

#### **5. Do you use the flexibility in PMS contracts and the options for enhanced services in the GMS contract to encourage and reward GPs to extend and improve services for carers?**

The contractual arrangements with GPs present opportunities on a local basis to negotiate and agree with practices about

the introduction of initiatives to extend and improve practice-based services for carers. This might include a range of things, such as 'Well Carers' clinics or the establishment of dedicated nursing support to patients and their carers.

#### **6. Do you commission services to support carers from a local Carers' Centre or other voluntary or statutory agency?**

Our research on this project and on previous ones leaves us in no doubt that carers find the range of services offered by local Carers' Centres and other voluntary agencies to be immensely valuable in supporting them. These include diverse services such as financial and benefits advice, counselling, alternative care, training and a variety of activities which help to relieve stress. Various projects have provided testimony to the value of such support and services, some of which can be offered in the GP surgeries. Such support can contribute very positively to the maintenance of the carer's health and in many cases actually prevent a breakdown of the caring situation, which would lead to more services being provided by the NHS and other statutory agencies.

Despite this, the funding for such work is often short-term and insecure, leading to failure to develop its full potential, key staff leaving for other jobs and an overload of cases for the staff involved. There has been evidence within the last year that such work can be particularly vulnerable during periods of financial pressure. We would recommend that PCTs take a longer-term view when assessing the value of this work and relate it to other policy objectives such as avoidance of hospital admissions.



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## **7. Do you include carer awareness in the training you offer to members of primary care teams and encourage practices to have a 'carers lead'?**

PCTs support the training and development of GP practice staff, either financially and/or through direct provision of training. This is a significant element in their role of developing primary care. It is important that staff are provided with training in carer awareness, along with all the other clinical and administrative areas which constitute the development of quality services. Many practices have found that it is valuable to have a lead member of staff responsible for carers issues. All of this will encourage the interest in, and commitment of, practice staff to their projects for identifying carers and will also positively influence the way they do their job on a day to day basis.

## **8. Do you include carer awareness in the training for your own staff, members of the PCT Board and Professional Executive Committee?**

It is equally important for PCT staff and anyone involved in strategic planning and decision making to receive training in carer awareness. This should apply at all levels.

## **9. Do you ensure that the needs of and services for carers are considered by the partnership with the Local Authority and other agencies ?**

A key theme of *Our health, our care, our say*<sup>iii</sup> as it has been of numerous other requirements and guidance from Government has been the need for the NHS, Local Authorities and the non-statutory sectors to work in partnership. This is probably even more true in the area

of support for carers than in many others. The relationship between PCTs and the Local Authority needs to be much more than simply getting GPs to refer carers for an assessment, as implied by the QOF Management Standard 9. There should be an integrated strategy for carers in each area, to which all agencies are signed up. The 2004vi Act places a duty on primary care to give 'due consideration' to a request from Local Authorities for the planning or provision of services to carers.

## **10. Do you ensure that the needs of and services for young carers are included in strategies for children's services ?**

PCTs are also required to work in partnership with Local Authorities and other agencies, through Children's Trusts and other organisational mechanisms in the development of integrated strategies for children's services. Young carers should be identified as a specific group of children at risk, and services and support should be planned accordingly. There should be a specific strategy for young carers in each area. It is important that there should be close links between that strategy and the adult services, who are likely to be involved in many of the family circumstances of young carers, and that the new organisational separation between children's and adult services provided by the Local Authority should not work to the detriment of young carers.

## **A checklist for the Government**

### **1. Will you strengthen the system for performance managing and rating PCTs to give clearer recognition to the importance of providing support**

### **for carers and introduce a statutory duty on PCTs to promote the health of carers?**

Although carers are mentioned in a number of the quality assurance standards for PCTs used by the Healthcare Commission, none of them is exclusively related to services and support for carers. This does not help to promote the message of the National Strategy for Carers or the philosophy of the recent White Paper. PCTs need incentives and encouragement to give greater priority to this work. It is recommended that the quality assurance framework be reviewed in this light.

The provisions of the Bill introduced into Parliament by Barbara Keeley M.P would impose a statutory duty on PCTs to promote and safeguard the health and welfare of carers, and we believe that this proposal, if implemented, would be a huge step forward for carers.

### **2. Will you ensure that Non-Executives appointed to the PCTs include people who can demonstrate an understanding of carers issues?**

It is important that those ultimately responsible for the work and performance of PCTs include people who have an understanding of carers issues. The NHS in Wales recognised this by having a carers representative on each Health Board. It is hoped that those appointed to the new PCTs will include a significant proportion of people who have this knowledge and experience. If this proves not to be the case, it is recommended that the person specification for future appointments be amended accordingly.

### **3. Will you strengthen and widen the requirement to identify carers and**

**set a new date by which GPs, members of primary care teams and Social Services staff are asked to identify carers in line with the national priorities guidance issued in September 1998?**

The Government originally set a target date of April 2000 for the identification of carers. This was subsequently deferred, but no new date has been set. As well as sending out a negative message about the importance of this work, this deferral caused great uncertainty about the work that was started. It is important to set a new date as soon as possible.

This should be considered in conjunction with the new GP contract which was introduced in 2005. This gave an optional three points (out of 1050) for GPs who established systems for identifying carers and referring them to the Local Authority for an assessment.

Even though the large majority of GPs have opted to establish such a system and are being paid for so doing, we do not believe that this is adequate and should be modified in three ways :

1. The number of points should be increased, or;
2. It should include referral to other relevant agencies as well as for Local Authority Assessments;
3. It should be widened to relate to the services provided by the GPs themselves.

In this context, we support the provisions of Barbara Keeley's Bill to require PCTs to 'ensure that effective procedures exist to identify patients who are carers'.

**4. Will you ensure that all relevant National Service Frameworks include a standard relating to the recognition and support of carers?**

Standard six of the National Service Framework for Mental Health relates specifically to carers. Other relevant NSFs, such as that for Older People, mention carers but do not include a specific standard relating to them. It is important that the role of carers is specifically recognised in NSF standards and is not just referred to in less specific terms.

**5. Will you consult widely and ensure flexibility in the implementation of the Expert Carers' Programme heralded in the White Paper?**

In the checklist in *Primary Carers*<sup>i</sup> we called for a national Expert Carers Programme. Those directly involved with carers issues will be delighted that the Government has agreed to do this. It is important to recognise and support the role of carers, given the extent to which the NHS and other statutory services actually rely on the knowledge and experience of carers in the management of many chronic conditions. Part of that support involves training. But it is important to have flexibility in the implementation of this programme.

In the Good Practice section of this report we have identified a range of issues which need to be considered when the Expert Carers Programme is formulated and we recommend that these are fully taken into account.

**6. Will you set targets for the establishment of carers' health checks in primary care?**

As outlined in the White Paper<sup>iii</sup> 'spearhead PCTs' will pilot NHS 'Life Checks'. It is now firmly established that the health of carers, particularly those with a heavy caring commitment, is likely to suffer as a result of their caring role. The effects can cover a diverse range of

conditions, some of which were identified by the carers in our latest study and are listed in Section 4: The Demonstration Projects. Maintaining and improving carers' health is correct in principle. It is also a cost-effective way of maintaining the essential support for the cared for person. It can reduce hospital admissions or other forms of alternative care. Therefore it makes sense for the NHS to prioritise this area.

The National Strategy for Carers<sup>ii</sup> identified the importance of establishing regular health checks for carers. This is taking place in some practices but there are insufficient incentives for it to be very widely implemented. If primary care is to give appropriate priority to the monitoring and improvement of carers' health, there needs to be a framework of financial rewards payments and targets, analogous to those given for other target groups of patients, such as those suffering from diabetes or heart disease. The GP contract should be amended to provide such incentives. It will be necessary to set targets for the introduction of a structured programme of health checks offered to carers, and guidance on how this can be done.

**7. Will you ensure that PCTs and local authorities are funded to improve and extend support and services for carers in primary care?**

Initiatives to support carers, as identified in the National Strategy for Carers<sup>ii</sup> in *Primary Carers*<sup>i</sup> and in this report, need to be properly funded if they are to be effective. It is appropriate that this work should be developed as a partnership between the NHS and Local Authorities, because it impacts on both the demand for services and the statutory role of both. Pooling of budgets under new



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partnership arrangements should assist this. An effective strategy for carers cannot be developed by either the NHS or the Local Authority in isolation from the other. It is important that the resources devoted to supporting carers do not suffer as a result of the Carers' Grant no longer being ring-fenced.

## **8. Will you ensure that there is funding to introduce pilot programmes to identify the most effective ways of improving carers' health, and to encourage the development of carer-friendly services in primary care?**

This is an area in which innovative schemes should be encouraged and the learning disseminated. Many of the programmes and projects run by The Princess Royal Trust Carers Centres have insecure and short-term funding. At times of financial pressure, they often do not receive the priority they merit, often resulting in high staff turnover. There is an argument for a national programme of such schemes, perhaps as part of the NHS research programme.

## **9. Will you run a national publicity and awareness raising campaign to encourage carers to identify themselves as such to their GPs?**

The Government undertakes a lot of national campaigns to promote its priorities, including many in the area of health promotion. A national campaign is a cost-effective way of getting the message across, both because it avoids the inefficiency of replicating campaign planning and design work across the country, and it gives a clear message of the importance attached to the area by the Government. We believe that a national

awareness campaign targeted at carers would be a powerful tool in taking this agenda forward. However, it must, of course, be done in conjunction with the other recommendations in this report to avoid raising expectations from carers that cannot be met.

## **10. Will you introduce into legislation the proposals contained in Barbara Keeley's Bill to require GP practices to take the needs of carers into account in the provision of their services?**

Further impetus is needed to achieve real change in the way these services are delivered. Although we have identified examples of good practice, these are far from universal. There is a need to require PCTs to ensure that the needs of carers are taken into account in the operation of appointments systems, prescription procedures and waiting room arrangements. Legislation would be an effective way of ensuring this, but if this is not possible, then the performance management framework should be used robustly for this purpose.

**In conclusion, we repeat the comments we made at the end of *Primary Carers*<sup>i</sup>. There has been much learned already about how to identify and support carers in primary care. It is important that we continue to learn from existing projects and to build upon the progress already made, and above all, to translate this learning into real and permanent change in services throughout the country, not just in isolated pockets of good practice. Only in this way will the commendable aspiration of the latest White Paper<sup>iii</sup> to give a new deal to carers become a reality. These recommendations are a key step**

**towards giving carers the support which is in the interests of the NHS to provide and which carers deserve and we commend them to decision-makers at every level. Let us make the 'forgotten army' of carers a 'recognised, valued and supported army' within health and social care.**

- i Keeley and Clarke, *Primary Carers – identifying and providing support to carers in primary care*, The Princess Royal Trust for Carers, 2003
- ii *Caring About Carers: A National Strategy for Carers*, HM Government, 1999
- iii Department of Health, *Our health, our care, our say: a new direction for community services*, HMSO London, 2006
- iv Jane Cheffings, *Carers Health Survey*, The Princess Royal Trust for Carers, 2004
- v Keeley and Clarke, *Carers Speak Out – report on findings and recommendations*, The Princess Royal Trust for Carers, 2002
- vi Department of Health, *Carers (Equal Opportunities) Act*, HMSO London, 2004



Every day more and more people in the UK face the demands of caring for a family member or friend. Caring can cause isolation and financial, emotional and health problems. We exist to help unpaid carers of all ages by providing access to information, advice and support services. We also campaign to bring about change in both policy and attitudes towards carers' issues.

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