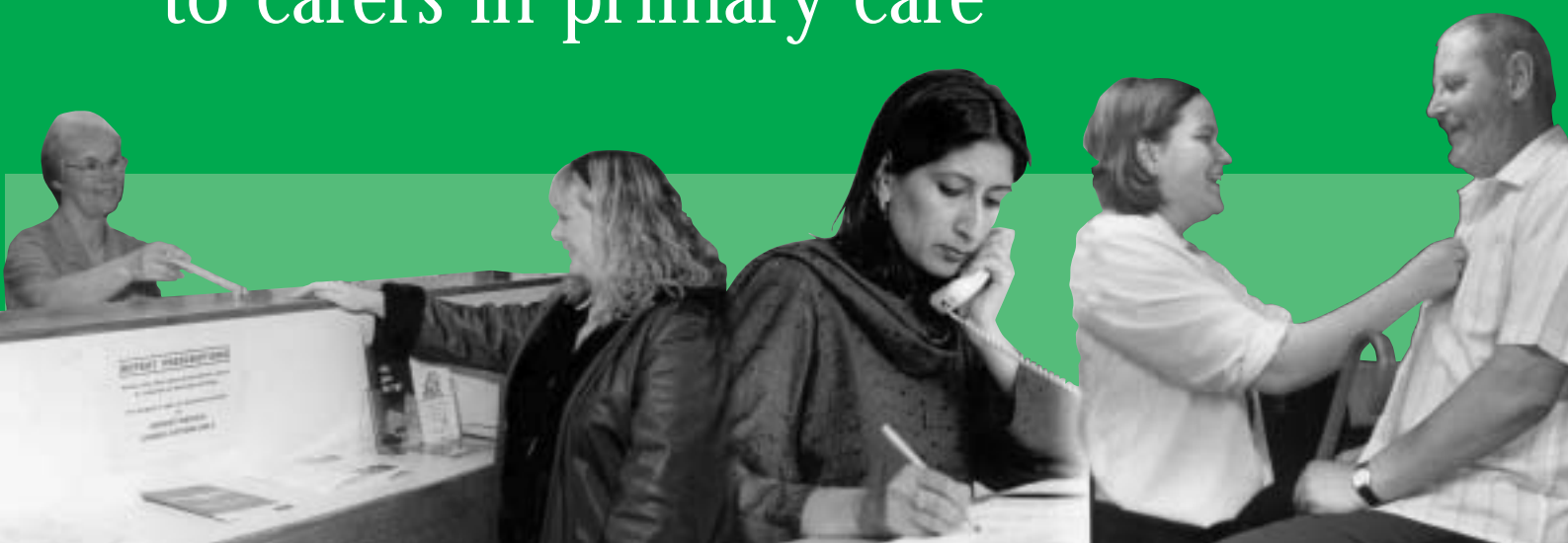




The Princess Royal Trust
for Carers

Primary Carers – identifying and providing support to carers in primary care



By Barbara Keeley and Malcolm Clarke

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Foreword

One in ten of the population in the UK 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 this report and other surveys have shown, 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 10 years ago and there are now more than 30 initiatives within primary care. 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. This report contains a review of good practice that will be useful for all those working in primary care to support carers.

This report also contains 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 and refer them to sources of support. 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 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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Section One:

Introduction

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

The recommendations are based on conclusions which emerged from a nine-month primary care project for The Princess Royal Trust for Carers. The project aimed to find the most effective ways within primary care to identify carers and encourage them to use the services available. The project findings are the results of a mapping exercise of 36 existing and completed primary care support initiatives across The Princess Royal Trust for Carers network in England and Northern Ireland and a survey of carers conducted through a postal questionnaire sent to carers, as well as four focus group discussions with carers. The mapping exercise and survey have also enabled a review of good practice in the work of identifying and supporting carers in primary care and a further review of examples of best practice.

The results of the research will be used to inform the development of a number of The Trust's carer support demonstration projects in primary care. A Good Practice Guide will also be produced to act as a toolkit for primary care project work by Carers' Centres within The Trust's network.

This report covers the following:

- Context of the project: carers and the caring relationship, legislation and guidance to provide support to carers and the role of primary care.
- Summary results of the mapping of primary care projects in The Princess Royal Trust for Carers network.

- Analysis of a survey of carers and related extracts from focus group discussions from four areas where there is an existing primary care project.
- Review of good practice in identifying and supporting carers.
- 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.

Section Two:

Context of the project

Carers and the caring relationship

A carer is someone who, unpaid, provides help and support to a relative, friend or neighbour who could not manage without that help due to frailty, long-term illness or disability.

There are about 5.2 million carers in England and Wales, and the contribution they make cannot be over-estimated. The 2001 Census tells us that more than a million of those carers care for more than 50 hours a week – more than a full-time job. By comparison, the NHS also employs over a million people and is the largest organisation of its kind in the world. 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 2001–02.¹

Despite these remarkable facts it could be said that carers are the forgotten army of our health and social care system. 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* for her research on carers' experience of the NHS.²

This report is intended as both a contribution to rectifying that deficiency and as an aid to identifying how primary care services can improve the range and quality of the support given to carers. It is hoped that the report will act as a valuable aid to practitioners and decision makers at every level who share our desire to improve the quality of life for carers and to recognise the contribution they make.

Carers are a diverse group, and have 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 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 need 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 live with the person they care for. This can cause particular pressures and create the need for breaks. Others do not, but they have to combine their caring role with their own domestic and work commitments, and this often creates a different set of problems.

Many carers do not perceive themselves as carers, but regard caring as part of their normal responsibility to their family or friends. They may feel guilty if they prioritise their own domestic, social or health needs, and therefore tend not to do so. Although many carers are willing to take on the role, others feel they have no choice. They may feel resentful about the caring role, but are unwilling to admit this even to themselves. 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.

Legislation and guidance to provide support to carers

There is now evidence of an increasing realisation among legislators and decision makers of the importance and value of the role of carers, and of the extent to which statutory services have failed to recognise both the importance of that role, and the implications for the carers themselves.

In 1986, Section 8 of the *Disabled Persons (Services Consultation Representation) Act*ⁱⁱⁱ outlined carers' rights for the first time by requiring local authorities to have regard to the carer's ability to provide or continue to care, when providing services to the disabled person. In 1989, *Caring for People*, the cornerstone of the then Government's community care reforms recognised that "helping carers to maintain their valuable contribution to the spectrum of care is both right and a sound investment".

In 1995, the *Carers (Recognition and Services) Act* gave carers the right to an assessment of their ability to care and required local authorities to take this into account when deciding which services to provide. This was strengthened when the *Carers and Disabled Children Act 2000*^{iv} was introduced. The Act enhanced the carer's right to an assessment, even when the cared for person refused an assessment or refused the delivery of services. The Act also enabled local authorities to provide services to carers in their own right

Four years ago the Government launched its National Strategy for Carers,

Caring about Carers^v, which recognised many issues on which carers had commented and carers organisations had campaigned. For the first time national policies were established to start to respond to carers' issues.

In the same year, Standard six of the National Service Framework (NSF) for Mental Health, *Caring about carers*, set down that "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"^{vi}. Thus the right of carers to an assessment was included in NHS guidance for the first time, although only for carers of people with severe mental illness. The National Service Framework reiterated the statutory right to assessment established four years previously, with the lead role for assessment being taken by Social Services.

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".^{vii}

There is no corresponding standard on the carer's role in other NSFs, although they do have many references to carers. This seems to be a significant omission, given that NSFs were established to improve services through setting national standards to drive up quality and tackle existing variations in care.

During the last year, The Princess Royal Trust for Carers published two

important reports. The first was entitled *Focus on Carers and the NHS – identifying and supporting hidden carers. Good Practice Guide*^x. The second, called *Carers Speak Out*, looked at the needs of carers as identified by carers themselves^x. It was based on the largest ever survey of the views of carers ever conducted in the UK, undertaken through both questionnaires and local focus groups.

Building on these documents and developments, The Trust identified a need for further work to be undertaken looking specifically at the role of primary care in supporting and responding to the needs of carers. This report summarises that work and is intended to contribute to the debate on how the aspirations of both legislation and the national strategy can be turned into practice that benefits carers.

The role of primary care

The National Strategy for Carers identified the NHS as being the single most important initial 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.



Context of the project

It is significant that these roles relates to the health of the carer, that is it recognises that primary care has a wider role than just that of referring carers to the Social Services Department or to the Carers' Centre for support – important though those referrals might be.

The *Carers Speak Out* report, published by The Princess Royal Trust for Carers in 2002, was based on an extensive survey of carers and the report made a number of recommendations directly for the NHS and primary care. These included:

- Systems in primary care to provide all carers with information...related to the person they are caring for (where patients had consented to this).
- Training programmes for health and social care staff to make them aware of carers...
- Establishing local registers of carers within relevant agencies together with a policy for identifying carers.
- Publicity and awareness raising to encourage people to identify themselves as carers.
- Primary Care Trusts should work with carer organisations to establish GP initiatives in support of carers. It is important the Primary Care Trust owns the initiative and links it to clinical governance.
- The Government should introduce pilot programmes to identify the most effective way of improving carers' health within a locality...
- The Government should examine ways of measuring carers' health over time and providing targets and incentives to the NHS to bring about improvements in carers health.

In this project, there were a number of examples of good practice in primary care

aimed at supporting carers and protecting their health. However, good practice is not happening systematically across the country, the picture is very patchy.

Good and innovative practice may occur because an individual working in a primary care setting (for example, a GP, a practice nurse or a practice manager) 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.

It may develop because the local Carers' Centre has managed to raise funding from some combination of local NHS, local authority and private sources to develop and promote a local scheme. A review of current practice on funding such schemes is included in this report. However, during the work for this report it became clear that project work to support carers in primary care has tended to have funding for limited periods only. This produces uncertainty, which can lead to higher levels of staff turnover and the consequent loss of the skills and knowledge. It can also lead to projects being unfinished and unevaluated. Loss of funding may lead to cynicism on the part of primary care professionals and carers themselves. We have seen letters written by GPs complaining strongly to Primary Care Trusts (PCTs) about the withdrawal of funding from valuable local projects and consequent loss of staff working to support carers within their practices.

In recent years, a number of significant changes to the contractual arrangements for primary care have been introduced. One of these has been the introduction of Personal Medical Services (PMS) contracts for GPs as an alternative to the national General Medical Services (GMS) contract. PMS contracts are negotiated locally with the NHS and can include

additional service requirements. About a quarter of GPs are now on PMS contracts. This presents a possible mechanism for inclusion of services for carers in the contractual requirements. Research for this project found at least one case where a PCT has entered into such an agreement with GPs.

PMS contracts will continue after the introduction of the new national GMS contract from April 2004. It had been hoped that the new contract would include a significant element relating to carers. In fact, out of a maximum of 1050 'points' available for quality of service, only three points relate to services for carers. This is Management Indicator 9, which states that: "The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment". The assessors' guidance states that: "The assessors should enquire of various team members what action they would take when they identify that a carer may benefit from social services assessment".

The inclusion of an element, even a small one, relating to carers is welcome. However, it is significant that it mentions only referrals to social services for assessment. It does not give recognition to the way in which primary care services can provide for carers. It might be argued that presenting it in this way reinforces the notion that support for carers is solely the province of the Social Services Department. Although Social Services have the lead on carers in local authorities, there is also a need for Primary Care Trusts to lead on issues for carers within primary care.

The new contract also provides for the inclusion of 'enhanced services' which are not part of the core contract undertaken by all GPs, and which may be determined either locally or nationally.

This will present further opportunities to include factors relating to carers.

The Modernisation Agenda for the NHS presents other opportunities for achieving local improvements in the range and quality of services which primary care can offer to carers. These include the adoption of local Clinical Governance frameworks and protocols, which set out local quality standards for the provision of services and practice monitoring and assessments by PCTs, which review the range and quality of services offered.

The new Commission for Health Audit and Improvement (CHAI) will take over the role of assessing the performance of PCTs. As with Hospital Trusts, this is now done through a scoring framework of 'stars' as measured against a series of key indicators. Few of the current PCT performance indicators have a direct relationship with services offered for carers. The use of key indicators offers the possibility of developing a wider range of performance indicators and targets for PCTs to meet carers' needs.

In promoting this area of work, it is appropriate to emphasise the links between improved services and support for carers and other Government health priorities. There has been clear evidence from *Carers Speak Out* and other studies of the negative impact on the health of the carer that the caring role can have. Potentially, this increases the level of demand on the NHS and, if the carer's health fails or deteriorates, the statutory services have to pick up some, or all, of the caring role, which in turn reduces the resources available for other priorities. Given that carers are providing their services for no remuneration, it makes sense to provide them with the support necessary to continue to provide that role.

The following quote by a carer in one of our focus groups illustrates vividly the difference primary care can make:

"I have to wait 10 days to see the GP. One time, when waiting for an appointment with my GP I ended up in hospital – I tried to see the GP about a condition which had gotten worse, but was given an appointment 10 days later. On the Sunday I collapsed and was in hospital for four days."

When carers collapse like this, it usually means emergency substitute care being provided for the person cared for. A priority appointment, recognising her key role as a carer might have prevented this, as would the new standard that all patients should be seen within 48 hours.

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. 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'.

As a mechanism for the improvement in the range and quality of services provided for carers, the new contractual and modernisation arrangements for primary care can be summarised as **a limited amount of progress, with some further opportunities, but much more remains to be done**. This conclusion highlights the need for this project, which specifically examined the existing primary care projects and mainstream work within in The Princess Royal Trust for Carers network.

The aims of the Primary Care Project have been as follows:

1. To map the existing projects by identifying the types of work undertaken by each scheme, the length of time for which it has been operating and how it is financed.
2. To identify exemplars of good practice.
3. To:
 - (a) find out which methodologies and mechanisms are most effective in helping to identify and encourage carers to utilise services available, and
 - (b) obtain qualitative and quantitative data about the experience of carers, carer support projects and GPs.
4. To make recommendations about the establishment of further demonstration projects to develop this area of work.

These areas are examined in the rest of the report.

Without Us...? Calculating the Value of carers' support, Carers UK, 2001

- ii Melanie Henwood, *Ignored and Invisible? Carers' experience of the NHS*, Carers National Association, 1998
- iii Department of Health, *Disabled Persons (Services Consultation Representation) Act 1986*, HMSO London, 1987
- iv Department of Health, *Caring for People: Community care in the next decade and beyond*, HMSO London, 1989
- v Department of Health, *Carers and Disabled Children Act 2000*, HMSO London, 2000
- vi *Caring about Carers: A National Strategy for Carers*, H M Government, 1999
- vii Department of Health, *National Service Framework for Mental Health*, 1999
- viii Department of Health, *National Service Framework for Mental Health- Standard six Caring about carers*, 1999
- ix *Focus on Carers and the NHS – identifying and supporting hidden carers. Good Practice Guide*, The Princess Royal Trust for Carers, 2003
- x Keeley and Clarke, *Carers Speak Out- report on findings and recommendations*, The Princess Royal Trust for Carers, 2002
- xi Section 5, Pages 24-29 in Keeley and Clarke, *Carers Speak Out – report on findings and recommendations*, The Princess Royal Trust for Carers, 2002

Section Three:

Mapping the primary care projects in the Princess Royal Trust for Carers network

Background to the Primary Care Projects

In 1999, The Princess Royal Trust for Carers published a short guide to good practice for carers', support workers and GP practices called *Seven and a half minutes is not enough*ⁱ, the first good practice guide published by The Trust for its network. At that point around 60 centres were working directly with primary care practices in some way, although a much smaller number had established projects.

This guide focussed on:

- Identifying carers using standardised procedures or research into carers' records
- Providing support to, and identifying the needs of, carers through carers' surgeries or carers' groups
- Providing information for carers through notice boards and information files
- The need for support and training in carers issues for primary care staff

The National Strategy for Carers had also given GPs and Primary Health Care

Teams a carers' checklist. The checklist covered identification of patients who are carers and patients who have a carer; making checks on carers' physical and emotional health whenever opportune and at least once a year; routinely telling carers that they can ask social services for an assessment of their own needs; *always* asking patients who have carers whether they are happy for health information about them to be told to their carer; being aware of local carers' support groups or Carers' Centres and telling carers about them

Identification of carers was seen as "essential"ⁱⁱ, at that time, as the Government had issued National Priorities Guidance in September 1998ⁱⁱⁱ

asking GPs, primary care teams and social services staff to identify carers by April 2000. The Government later deferred that target date and, so far, no new target date has been set for identifying carers within GP practices.

The earliest projects working with primary care were established by The Princess Royal Trust for Carers' Centres in 1995–6, although some projects followed on work with primary care which had started as early as 1992–3. Funding to establish projects came from Health Authorities, Health Action Zones or from The Princess Royal Trust for Carers Centres' own core funding.

The GlaxoSmithKline Primary Care Project

Four years on from the first guide, the GlaxoSmithKline 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. The aim of the evaluation was to find out the most effective ways of identifying carers and encouraging them to use the services available. The findings of the evaluation will be used to make recommendations for future projects and

initiatives, including a number of new pilot or demonstration projects.

The research to evaluate current projects started with a mapping exercise of the primary care projects that have been developed by The Princess Royal Trust Carers Centres in England and Northern Ireland. The research did not cover Wales or Scotland because there were no existing primary care projects in Wales and The Trust already had a project underway in Scotland to identify and document good practice in identifying and supporting carers. The results of the project in Scotland have now been published under the title *Focus on Carers and the NHS – identifying and supporting hidden carers*^{vi}.

The mapping involved completing a wide-ranging interview with each project by telephone. The telephone interview followed a template of questions covering:

- project objectives and activities;
- funding and funders;
- endorsements/support;
- governance;
- staffing and time staff spend on different activities;
- liaison with hospitals/Patient Advice and Liaison Services (PALS);
- GP practices worked with;
- number of referrals/other data;
- benchmarking data; service impact data;
- conferences/events organised; and
- literature written or publicity achieved.

The detailed mapping results are available on request in a separate document and will be incorporated into the Good Practice Guide.

Thirty-six primary care projects were mapped by interview. Some projects had ceased or were shortly to cease due to the expiry of their funding. A small number of projects were not yet fully operational, and one project was

researching need locally before establishing a new project.

A three-part model

A three-part model was developed to describe the work of identifying and supporting carers within primary care projects, as follows:

1. Identification and referral work

This involves establishing systems within practices to enable the practices to identify carers and refer them to the local Carers' Centres, which provide a wide range of support and advocacy for carers. It may also involve referrals to other agencies.

This may be further subdivided between:

- (i) Referral systems, where the practice refers the carer to the Carers Centre or other agency.
- (ii) Provision of information and support within the practice itself, including posters or notices, leaflets and information packs and referrals forms or pads.
- (iii) Carer support workers working on site, seeing carers on a one to one basis and undertaking home visits following referrals from the practice.
- (iv) Carer drop-ins or support groups, often run at the GP practice.
- (v) Providing feedback to the GP and other members of the Primary Health Care Team on outcomes for carers who are patients.

2. Identification and practice development work

This involves working with GP Practices and Primary Health Care Teams to increase their awareness of carers and to change the way in which they provide services for carers. This can be further classified into two categories:

- a. Changes to the way their 'routine' services are provided, to meet the special needs of carers. This could cover such areas as appointment systems, repeat prescription procedures or waiting room arrangements.
- b. New healthcare services for carers provided by or at GP practices, for example, carers clinics.

3. Strategic work

This involves working with the NHS at a strategic level, which, in practice, is likely to mean Strategic Health Authority or Primary Care Trust level, to influence the development of policy and the allocation of resources to improve the support and services given to carers

Systems for identifying carers or enabling carers to self-identify are a pre-requisite for either (1) or (2) in the model.

Results of the mapping

How long primary care projects/work had been established

Primary care projects varied greatly in how long they had been established with the three longest established projects being started between 8 and 11 years ago. Altogether, the 32 primary care projects and centres involved with primary care work represent 100 years of experience in that work.

Across the years, projects have shared their learning and experience with other staff in The Princess Royal Trust for Carers network and in other organisations working with primary care. There have also been a couple of events held to develop shared learning, the first at Peterborough in April 2002 and a second workshop and networking day held in London in February 2003. Toolkits and materials produced at one project have also been used and adapted at other projects.



Mapping the primary care projects

How long primary care projects/work has been established

Type of work and when established	Carers Centre location
Project – established 1996 or earlier	Carers Resource (Harrogate & Craven)
	Suffolk
	York and Selby
Project – established 1997–1998	Cares Sandwell
	Harrow
	Leeds
Project – established 1999–2000	Aylesbury Vale
	Barnet
	Brent
	Gateshead
	Gloucestershire
	Hertfordshire
	Share the Care (Lincoln)
	Peterborough
	South Buckinghamshire
	Southwark
Project – established 2001–2002	Belfast
	Bristol and South Gloucestershire
	North West Oxfordshire
	Richmond
	Salford
	Sedgefield Locality
	Sefton
	Teesdale and Wear Valley
Project – established 2003	Camden
	Islington
	Milton Keynes (6 month pilot)
	Winchester
Projects now finished	St Helens (research project 2002–03)
	Reading (project 2001–03 and funding not now available)
	Swindon (project 1999–2001)
	Worcestershire (project 2001–02 and funding not now available)

Type of work and when established	Carers Centre location
Mainstream work with primary care	Kennet, CLASP(Leicester), Sunderland
Mainstream work plus two primary care projects	Bristol and South Gloucestershire
Mainstream work following a primary care project	Lewisham (project ended 1998)

Five Carers' Centres did not run projects but undertook work with primary care as part of their mainstream work. In one of these four Carers' Centres the mainstream work followed a primary care project established in 1998.

Funding Amounts and Sources

Funding of primary care projects/work is variable in both amounts and funding sources, as can be seen from the tables. Funding available for work in primary care varied from £5,000 up to £125,000 or more per annum (where the latter amount was the mainstream or core funding for the Carers' Centre). Eight Carers' Centres funded their work with primary care from their mainstream or core funding rather than as projects with separate budgets.

The largest number of primary care projects that were funded separately from the core work of the Carers' Centre fell into the range of between £30,000 to £40,000, with nine projects in this funding range. The sources of funding for work with primary care is very variable – of 35 funding sources detailed by Carers' Centres only just over a third of the sources (14) were from the NHS. Ten centres were receiving some or all their funding for the work in primary care from Primary Care Trusts with one additional centre currently having one-off monies for six months from two local Primary Care Trusts because another funding source had run out. Out of the ten centres receiving funding for their work from Primary Care Trusts, five were receiving all their funding for the work from Primary Care Trusts (amounts from £5,000 to £40,000) while five were receiving only part of the funding from Primary Care Trusts, with other funding for the work coming from charitable trusts or from Social Services/local authority funding.

Amounts of funding for work with primary care

Funding range for work with Primary Care (per annum)	Number of projects/centres
Up to £10,000	4
£10,000 to £20,000	2
£20,000 to £30,000	3
£30,000 to £40,000	9
£40,000 to £50,000	2
£50,000+	2
Mainstream Funding	8
Not specified	2

Sources of funding for work with Primary Care

Source of Funding	Number of projects/centres
Primary Care Trust(s)	11
	(10 plus 1 one-off grant)
Health Authority/Health Action Zone	3
	(2 plus 1 one off grant)
Local Authority & Neighbourhood	7
Renewal Fund (NRF)	(5 Local Authority, 2 NRF)
Charitable Trusts & National Lottery	6
Other short-term/ one-off funds	2
From Centre's Core Funding	4
Not specified	2

One centre had a substantial three year core grant of £125,000 per annum from the National Lottery and hoped the local Primary Care Trusts (PCTs) would fund some of this work at the end of the three years, although it seemed clear that this amount was much larger than any funding being received from PCTs by other Carers' Centres we interviewed. One other centre had built up a substantial core funding from lottery, charitable trusts and European funding. This centre had not been so successful in developing funding agreements with the local PCT, which had turned down a request to extend funding for the developing work in primary care.



Mapping the primary care projects

Staffing levels of work with Primary Care

Number of staff working with Primary Care	Carers Centre Location (Hours worked by part-time staff)
One part-time	Richmond (hourly paid sessional)
	North West Oxfordshire (15 hours)
	Worcestershire (18.5 hours)
	Reading (20 hours)
	Belfast (25 hours)
	Gateshead (20 hours)
	Suffolk (20 Hours)
	Barnet (25 hours)
	Islington (28 hours)
	Sedgefield (30 hours)
	Peterborough (32 hours)
Two part time	Teesdale and Wear Valley (22.5 hours)
One full-time	Aylesbury Vale
	Camden
	Harrow
	Salford
	Cares Sandwell
	Southwark
One full-time plus one or more part-time workers	Bristol and South Gloucestershire (10 hours and 6 hours)
	Leeds (17.5 hours)
	South Buckinghamshire (21 hours)
Two full-time	Brent
	Gloucestershire
Three full-time plus sessional staff	Sefton
Work done by Carers Centre staff with additional funding for Primary Care work	York and Selby
Work done by Carers Centre staff	Bristol and South Gloucestershire
	Carers Resource (Harrogate & Craven)
	Hertfordshire
	CLASP (Leicester)
	Carers Lewisham
	Kennet
	Share the Care (Lincoln)
	Sunderland
	Winchester

Staffing of the work with primary care

The level of staffing of projects/centres work with primary care is variable in range as it is linked to funding available and overall staffing capacity of the centres.

Scope of the work with primary care

Projects were classified into three areas of work by scope as described by the three-part model: identification and referral work, practice development work and strategic work. All projects and centres (32) working on primary care have developed identification and referral systems, and some projects focus most or all their efforts on developing this type of carer support.

Over half the projects and centres (18) also work on practice development within primary care. A smaller number of projects and centres (8) work strategically with Primary Care Trusts, NHS Trusts and Strategic Health Authorities.

Evaluation of the impact of projects – carers survey and discussion groups

As identified earlier, one of the objectives of this project was to obtain qualitative and quantitative data about the experience of carers, carer support projects and GPs. The reasons for undertaking such a survey included an objective to evaluate the impact of such projects and find out what processes were most effective in helping to identify carers and encourage them to use the services available.

Evaluation of the impact of the projects presents some methodological difficulties, given that it was not possible to compare the current view of carers with their experience before a primary care project started. In almost every case, for reasons of lack of capacity to undertake such research, projects did not undertake work

to establish the baseline position before the project commenced. The only exception to this was a project by The Princess Royal Trust for Carers Centre in St. Helens which undertook a survey before its project commenced, but does not yet have that primary care project operational.

It was decided to survey carers in four of the areas with primary care projects. The areas were chosen to cover different regions of the country, demographically different types of community, and different types of scheme. The projects in those areas were well established with a sufficient database of carer referrals to enable a sample of carers to be drawn. The survey consisted of a postal questionnaire sent to carers and a focus discussion group with carers in each area.

Brief details of the projects in the four areas chosen for this more detailed work are:

Gloucester

The project has been running for four years. It is an 'identification and referral' project which promotes referrals from GP surgeries and Primary Health Care Team members. Many referrals come from elderly care nurses. It has undertaken a lot of outreach work in GP surgeries, and has worked with more than 1100 carers since inception. It works with about 85 practices in total, but particularly closely with about 12 practices.

Barnet

The project has been running for about three and a half years, and aims to undertake both carer support through 'identification and referral' and some 'practice development' with a dedicated worker working outreach in practices for much of the time. The project worked with more than 300 carers in 2002 and

has worked with about 25 of the 120 practices in the area.

Salford

This project started in 2001. It is primarily an 'identification and referral' project with some 'practice development' (depending on staffing). It has worked with all 54 practices in the area, supplying them with information, but only about 20 of these refer carers. It has worked with about 300 carers.

Sefton

This scheme started at the end of 2001. It is entirely an 'identification and referral' project, which concentrates on working

with district and community nurses rather than directly with GPs, and which hopes to influence GPs through these other primary care professionals. It is relatively highly staffed compared with most schemes, and has worked with about 1600 carers in 16 months

The results of the survey conducted in these areas are presented in the next section.

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- i Warner L, *Seven and a half minutes is not enough*, The Princess Royal Trust for Carers, 1999
 - ii Warner L, *Seven and a half minutes is not enough*, The Princess Royal Trust for Carers, 1999
 - iii *Modernizing Health and Social Services: National Priorities Guidance 1999/00-2001/02*, Department of Health, 1998
 - iv *Focus on Carers and the NHS – identifying and supporting hidden carers*, *Good Practice Guide*, The Princess Royal Trust for Carers, 2003

Scope of Work Undertaken

Scope of Work	Location
Identification and referral	Aylesbury Vale, Barnet, Belfast, Brent, Bristol and South Gloucestershire, Camden (planned), Gateshead, Gloucestershire, Harrow, Carers Resource (Harrogate & Craven), Hertfordshire, Islington, Kennet, Leeds, CLASP (Leicester), Carers Lewisham, Share the Care (Lincoln), Milton Keynes (pilot), North West Oxfordshire, Peterborough, Reading, Richmond, Salford, Cares Sandwell, Sedgefield Locality, Sefton, South Buckinghamshire, Southwark, Suffolk, Sunderland, Teesdale and Wear Valley, Worcestershire, Winchester, York and Selby
Identification and practice development	Aylesbury Vale, Barnet, Brent, Camden(planned), Hertfordshire, Islington, Leeds, CLASP(Leicester), Share the Care(Lincoln), Milton Keynes (pilot), Peterborough, Reading, Salford, Cares Sandwell, Sedgefield Locality, Southwark, Suffolk, Teesdale and Wear Valley, Worcestershire, York and Selby
Strategic work	Brent, Bristol and South Gloucestershire, Hertfordshire, Leeds, CLASP Leicester, Cares Sandwell, Southwark, Suffolk

Section Four:

The carers survey and focus groups

This report presents the findings of the survey distributed to 1,000 carers in Summer 2003 through four of The Princess Royal Trust for Carers Centres in Barnet, Gloucester, Salford and Sefton. Focus group discussions were also held with carers at these four centres in July 2003.

The survey questionnaire sought information on a number of areas, including the following:

- Caring responsibilities and characteristics of carers.
- Whether the GP and surgery staff knew the patient was a carer and whether primary care staff appear to take this into account when the carer is being seen for their own health needs.
- Carers' views of practice facilities: confidentiality at reception, ease or difficulty of seeing the GP, waiting times, difficulties waiting in the reception area with the person cared for.
- Carers' views of GP surgeries' awareness of their needs and responsibilities as a carer.
- Provision by the surgery of information about services for carers and information about the health needs and treatment of the person being cared for.

- The impact of caring on the carer's own health

These and other key issues were also explored with carers in the four focus discussion groups. Extracts from the comments that carers made at the focus groups are included in the analysis of the survey.

Methodology

An initial focus group discussion was held with a group of carers at one of the Carers' Centres and a postal questionnaire was designed and then piloted with carers in June 2003. A revised version was sent out to around 1,000 carers in four batches of 250 questionnaires sent out by Carers' Centres in Barnet, Gloucester, Salford and Sefton. The questionnaires were dispatched in late June and early July 2003. Two hundred and sixty six

questionnaires were returned, which represents a response rate of around 27%.

The four Carers' Centres distributing questionnaires were asked to select randomly from their records of carers referred to the centre from primary care. Because the sample was drawn from those carers who are in contact with The Princess Royal Trust for Carers Centres, it is not a random sample of all carers

Characteristics of carers – nationally and in the survey

The 2001 Census, for the first time, asked a question about whether people provided unpaid care for a family member of friend, and for how many hours. The census results showed that 5.2 million people in England and Wales are providing care, about one in ten of the population. Of these carers, just over two thirds (68%) are caring for less than 20 hours a week. Of the remaining third, 11% are caring for more than 20 hours per week and 21% were caring for more than 50 hours per week¹.

The Census 2001 totals for carers are different from earlier figures from the

General Household Survey and as a more detailed analysis of the data for carers from the Census was not available when this report was written, data from the General Household Survey is used here as a basis of comparison for the profile of carers in the survey. The *Carers 2000* report from the Office of National Statistics gives details of carers and their characteristics, following studies done via the General Household Surveyⁱⁱ.

Carers in the 2003 Carers Survey

In the carers survey for this project around 84% of respondents were caring for more than 20 hours per week compared to 32% in the Census and 62% were caring for more than 50 hours per week compared to 21% in the Census.

The carers who had responded to this survey differ in some respects from the carers in the national profile of all carers. However, there are many similarities between carers in the survey and the profiles of the more heavily committed carers in the national profile. As the majority of carers in the survey had heavy caring commitments, comparisons have been made with that group of carers within the national profile who have heavy caring commitments.

Age and gender

The peak age for carers responding to this carers survey was 45–64 years (49%), followed by carers 65 years and over (39%), and then carers 44 years and under (12%). This compares to figures of 40% aged 45–64 years and 28% of 65 years and over and 32% under 44 years in the national profile of carers who were caring more than 20 hours per week.

72% of the survey respondents were female and 28% were male, compared to

61% female and 39% male in carers caring more than 20 hours in the national profile. Nationally, statistics show that women are more likely than men to be carers (58% compared to 42%).ⁱⁱⁱ

This means that carers in the survey were older than carers in the national profile, and the survey also had a higher proportion of female carers.

Carers with a disability or long-term illness

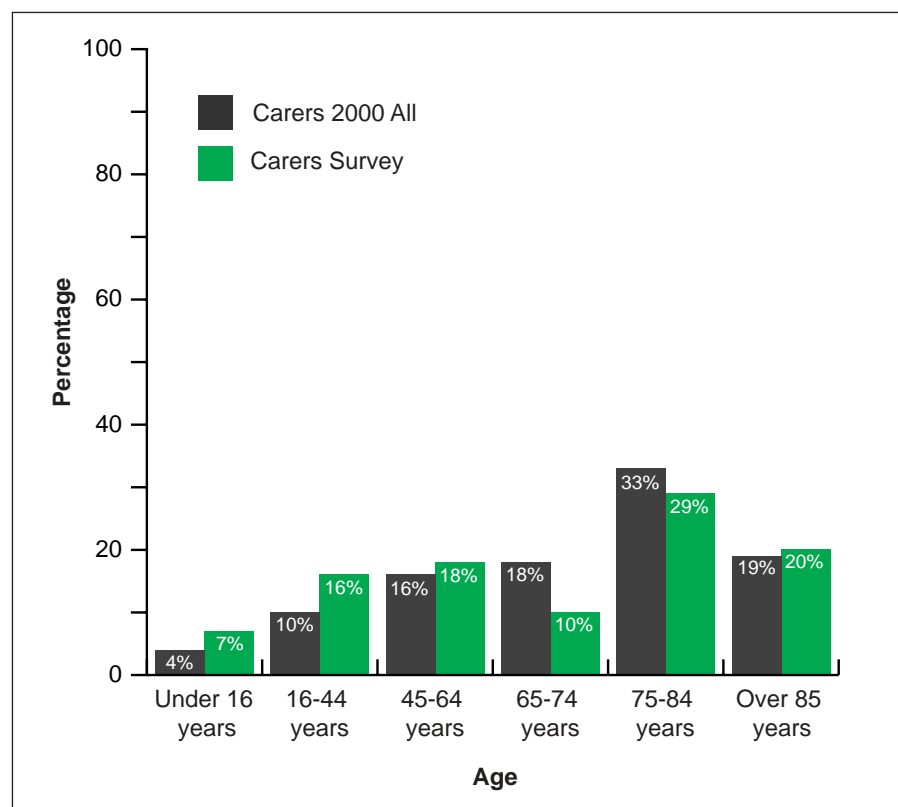
Among carers who responded to the survey, 42% reported that they had a disability or long-term illness themselves. This is in line with the national profile of carers where 50% of carers caring for more than 20 hours per week have a long-standing illness themselves and

35% said their illness limited their activities. In the context of a survey about carer support in primary care this is a key characteristic, as these carers have their own health needs. Their relationship with primary care and the extent to which their own health needs are being taken account is an important issue.

Employment Status

Only 23% of carers responding to the survey were employed while 77% were not, with 50% being retired and 27% not employed. Of the 23% who were employed, more than half were employed full-time (13%), with the others being split between those who work part-time (8%) and those who are self-employed (2%). This is not surprising, given that more than six out of ten of the carers in the

Age of person being cared for





The carers survey and focus groups

survey were caring for more than 50 hours and that almost four out of ten were over 65 years.

Working carers, and within those full-time working carers, were somewhat under represented in the sample compared to the national profile.

Relationship to the person cared for and age of person cared for

Among respondents to the survey, the most frequent relationship category was that of spouse or partner, followed by parent or parent-in-law. Direct comparisons with the national profile are difficult to make as the statistics in the national profile add to more than 100%, due to carers caring for more than one person.

Relationship of carer to main person cared for

Relationship	Carers Survey %
Spouse/partner	45
Son/daughter	20
Parent/parent-in-law	25
Other relative, friend or neighbour	10

In terms of the age of the person being cared for, the profile of carers in the survey was broadly similar to the national profile, although there were more respondents who were caring for young people under 16 years and from 16 to 44 years. The survey respondents were somewhat less likely than those in the national profile to be caring for a person aged 65 to 74 years. However, the survey was very similar to the national profile in terms of the proportions of those caring for a person aged 45–64 years, 75–84 years or over 85 years.

Disability or illness of the person being cared for

The table shows the frequency of the different illnesses or disabilities of the people being cared for. The most frequent categories were chronic ill health (35%) followed by old age or frailty (32%).

Duration of caring

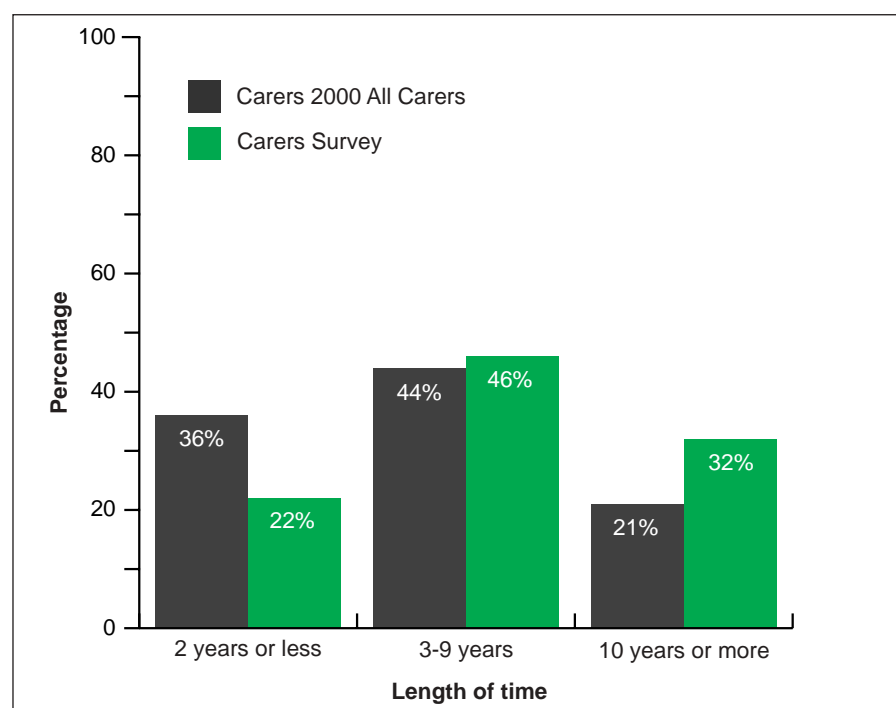
Around 22% of carers in the survey had been caring for two years or less, which compares to 36% in the national profile. Nearly half of carers responding had been caring for three to nine years and around a third had had been caring for 10 years or more.

Disability or illness of person being cared for

Disability or Illness	% in survey
Chronic ill health	35
Physical illness & physical disability	27
Old age or frailty	32
Learning disability	14
Mental illness	18
Serious illness or disease	12
Physical disability	5
Mental illness & physical illness	2
Other	1

(Note: The figures in the table add up to more than 100% because carers could identify more than one category.)

Length of time spent caring



Carers responding to the survey were more likely than carers in the national profile to have been caring for many years and less likely to have begun caring in recent years.

Black and Minority Ethnic Carers

Of carers responding to the survey, 94% described themselves as white and 6% described themselves as Black or Asian or from other minority ethnic groups. Of those, 3% were Asian or Asian British, 1% were Black or Black British, and 2% were from mixed or other backgrounds.

Summary – carers in the survey

The carers who responded to the survey included a higher proportion with heavy caring commitments, with over eight out of ten caring for more than 20 hours a week and over six out of ten caring for 50 hours a week or more. The majority of the carers who responded to the survey are people spending much of their time caring for a spouse or parent or parent-in-law. Significantly, more than four out of ten carers in the survey had a disability or long-term illness themselves.

The carers in the survey were older than the average of all carers in the national profile and slightly more likely to have been caring for a longer duration.

Analysis of carer responses

The analysis of carer responses is given under the following headings: Information needs of carers; Impact of caring on the carers' own health; Access to the GP surgery, Appointments and waiting room conditions; Awareness of needs and responsibilities of carers.

Effect of age variable in responses

It is worth noting that the age of the carer is a significant demographic variable in a number of the responses to the survey highlighted in this section.

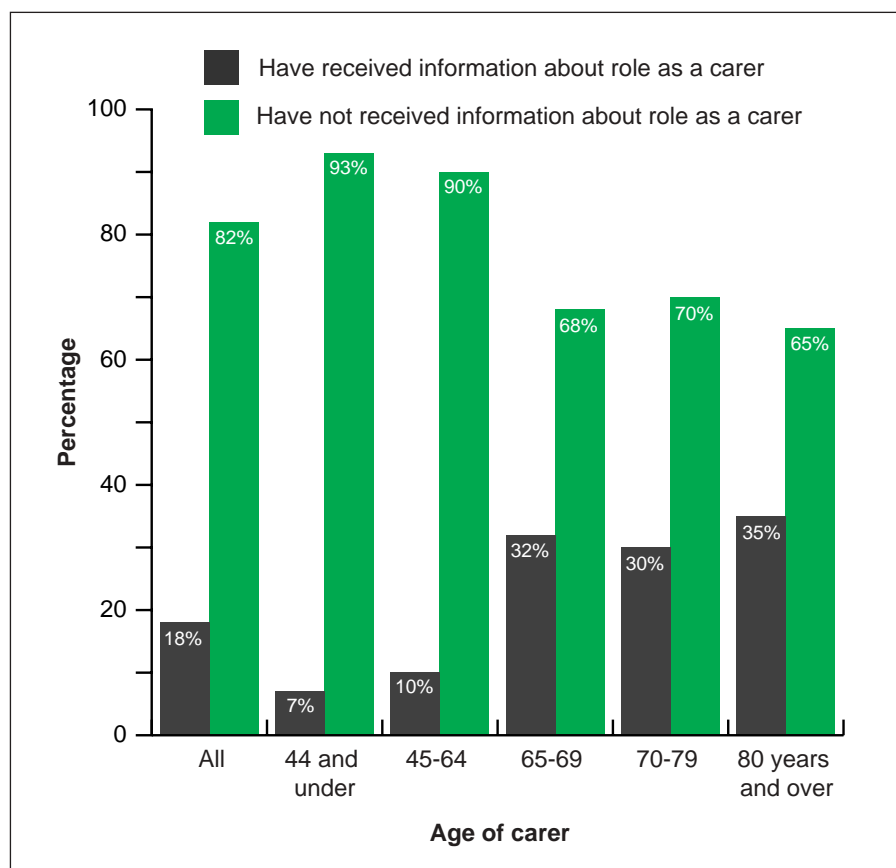
It has been asserted in research on health and public services that older people's responses are more positive than those of younger people when asked about their levels of satisfaction with health and other public services. A survey of public attitudes to the NHS in Scotland found a consistent pattern that younger people had lower satisfaction levels about NHS services. The same pattern emerged in responses to this survey, with the least positive responses being from

carers aged 44 years and under and the most positive responses tending to come from age groups of 65 years and over. It is unclear whether the tendency among older people to be less critical of health services relates to lower expectations of those services, or to differences in the quality of service or care provided to older people. This is an area that would seem to warrant more research.

Information needs of carers

Good information is rightly seen as one of the main needs of carers and information needs to be accessible, relevant and easy to understand. The National Strategy for Carers observed that while almost all the information carers need is

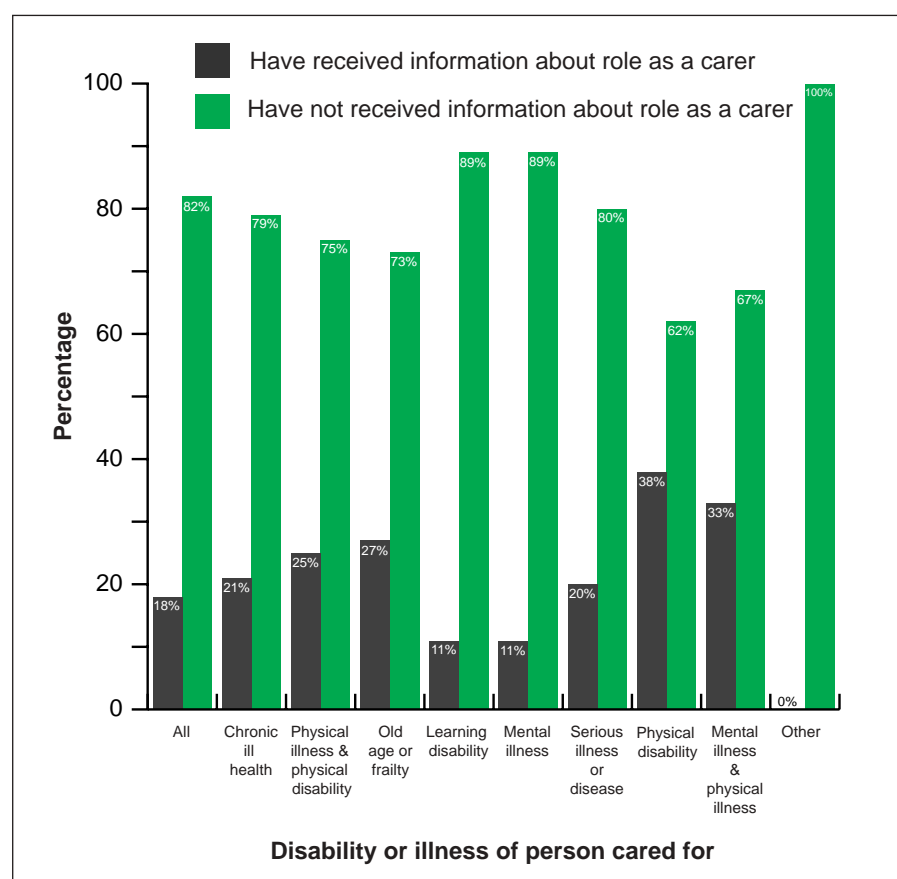
Information received at GP surgery about role as a carer – by age of carer





The carers survey and focus groups

Information received at GP surgery about role as a carer – by disability or illness of person cared for



information from the GP surgery, while less than in one in ten (7%) of carers aged 44 and under had received such information.

There was also a difference in carers receiving information based on disability or illness of the person being cared for. Nearly four in ten (38%) of those caring for a person with physical illness and physical disability being given information about their role as a carer, while just over one in ten (11%) of those caring for a person with a learning disability or mental illness were given such information. This disparity between those caring for people with a mental illness or a learning disability and other carers was seen in other areas of the survey and also reflects a pattern reported in the *Carers Speak Out* survey.^{vi}

Newer carers were also more likely to receive information with 31% of those who began caring in the last two years being given information about the caring role while only 11% of those caring for between five and nine years had been given such information.

A comment from a carer at a focus group confirmed this improvement:

"It is much better, the GP has helped more, there is more information than years ago."

On the quality of information about services to carers, carers were asked whether they agreed or disagreed that the information provided for them at the surgery was very good. Overall carers were not positive in their responses about the quality of the information they were given at the GP surgery, with only 16% agreeing that the information was very good, while 35% disagreed and 50% were either neutral on the question or said they didn't know.

already available somewhere, carers may not be aware of particular information to help them.

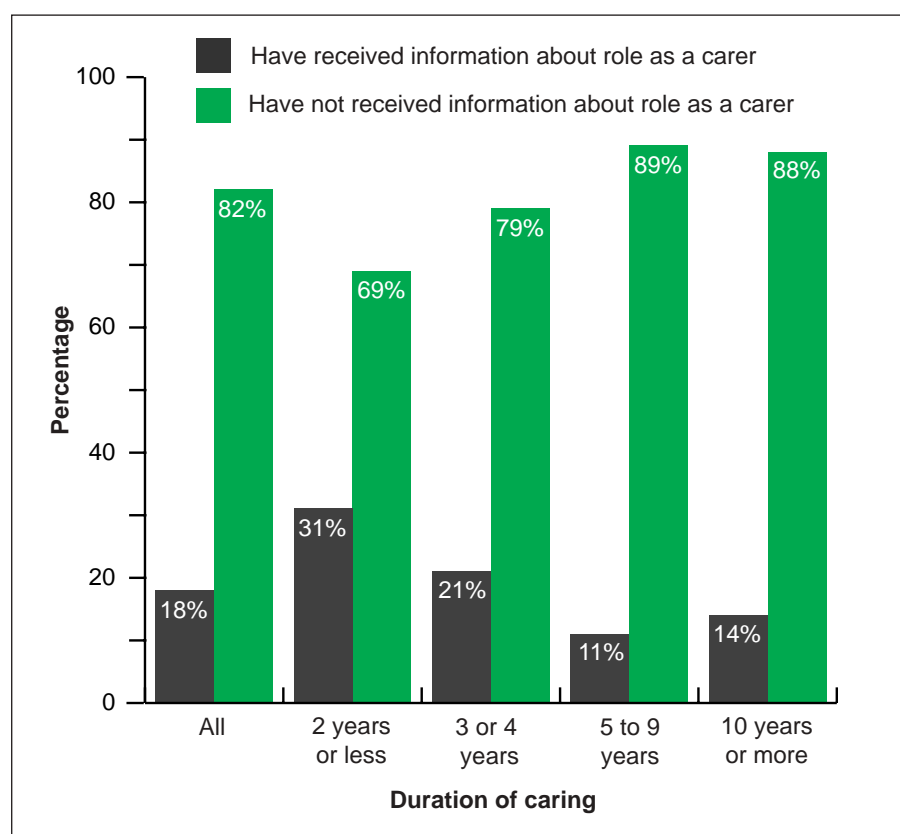
Carers were asked in the survey whether they had received information about their role as a carer from their GP surgery. Carers were also asked for their views on the quality of information provided by the surgery about services for carers and about the health needs and treatment of the person they cared for.

When asked whether they had received information on their role as a carer, 18% of those responding said they had received information from the GP surgery whereas 82% had not. This is a

surprising finding given that there were primary care projects operating in the areas where the survey was done.

An interesting finding of the survey was the extent to which receipt of services varied between carers of different types. On receiving information on their role as a carer, the most marked difference between groups of carers was based on the age of the carer and on the disability or illness of the person being cared for. Older carers were more likely to have received this information, with almost one in three (32%) of carers aged 65 years or over, and 35% of those aged 80 years and over having received

Information received at GP surgery about role as a carer – by duration of caring



As with other questions about information services, the most marked differences in responses were based on the age of carer and disability or illness of the person being cared for. Nearly three in ten (29%) carers aged 65 or over felt the information they were given was very good, while only one in ten (10%) carers aged 45–64 or 44 years and under felt this. Also while almost a quarter (24%) of those caring for someone with a physical illness or physical disability felt the quality of the information was very good, less than 9% of those caring for a person with a learning disability and 11% of those caring for someone with mental illness felt the information was very good.

In the focus groups there were echoes of similar problems for carers getting information they needed about services from the GP surgery:

“There are services available but we just didn’t know.”

“It took me three years to get information about respite care.”

“Nurses should have knowledge about respite care. I would like someone in the practice to know about respite.”

Some carers had reversed the usual information flow by bringing information about conditions or illnesses into the surgery:

“The local authority has an autism pack, we brought one for the surgery.”

“There is a local mental health toolkit. It’s a step forward, but only if they use it.”

Information about services for carers provided at the surgery – by disability or illness of person cared for

Disability or illness of person cared for	Agree or Strongly Agree %	Disagree or Strongly Disagree %	Neutral or Don’t know %
All	16	35	49
Chronic ill health	21	31	48
Physical illness & physical disability	21	31	48
Old age or frailty	24	29	46
Learning disability	9	34	59
Mental illness	11	43	46
Serious illness or disease	12	39	50
Physical disability	23	23	54
Mental illness & physical illness	33	50	17
Other	0	67	33



The carers survey and focus groups

Most carers in the focus groups reflected that they gained more information from the Carers' Centre and from voluntary agencies than they did from the GP surgery.

Information on diagnosis/treatment – “there was nothing from the GP practice, all information came from the Carers' Centre.”

“The Alzheimer's Society has bulletins, what you can expect – it warns you about it – memory, panics, giving diazepam.”

Carers responding to the survey were a little more positive about the quality of information on the health needs and treatment of the person being cared for. Of the carers responding, 29% agreed that this information was very good, 44% disagreed and 27% were either neutral or said they did not know.

Again, there were differences between groups of carers with different characteristics. The most marked difference was based on the relationship with the person being cared for. While over three in ten (35%) of those caring for a parent or parent-in-law and over four in ten (44%) of those caring for another relative thought the information they were given about the health needs and treatment of the person they cared for was very good, less than one in ten (8%) of those caring for a son or daughter felt that the information was very good.

In terms of the disability or illness of the person cared for, over a third (37%) of those caring for someone with serious illness or disease and 36% of those caring for someone with old age or frailty thought the quality of the information received about health needs and

Whether carers feel the information about the health needs and treatment of the person being cared for is very good – by relationship to person cared for

Relationship	Agree or Strongly	Disagree or Strongly	Neutral or Don't know
	Agree %	Disagree %	%
All	29	44	26
Spouse/partner	34	46	20
Parent/parent-in-law	35	30	34
Son/Daughter	8	59	33
Other relative	44	25	31
Someone else	33	44	22

Whether carers feel the information about the health needs and treatment of the person being cared for is very good – by disability or illness of person cared for

Disability or illness of person cared for	Agree or Strongly	Disagree or Strongly	Neutral or Don't know
	Agree %	Disagree %	%
All	29	44	26
Chronic ill health	36	40	23
Physical illness & physical disability	34	35	30
Old age or frailty	36	39	26
Learning disability	20	53	27
Mental illness	26	51	23
Serious illness or disease	37	40	23
Physical disability	31	31	39
Mental illness & physical illness	40	60	0
Other	67	33	0

treatment of the person cared for was very good, but this fell to only two in ten (20%) of those caring for a person with learning disability.

Again, comments made by carers at the focus groups echoed findings in the survey about differences for carers of people with learning disability or mental illness:

“The GP knows nothing about autism.”

“Not many GPs are au fait with Mental Health, should there be someone in the PCT, a professional in Mental Health?”

Impact of caring on the carers' own health

Over two thirds of carers (67%) responding to the survey felt that their own health had been adversely affected as a result of their caring role. This is in line with national findings, which state that while 39% of all carers feel that their health is affected by caring, this rises to 61% of those caring for more than 20 hours per week and 72% of those caring more than 50 hours per week. Symptoms reported nationally by those caring for more than 50 hours per week include feeling depressed (34%), having disturbed sleep (47%) and physical strain (24%). Of these carers with heavy caring commitments, 17% had to see their own GP about their symptoms.

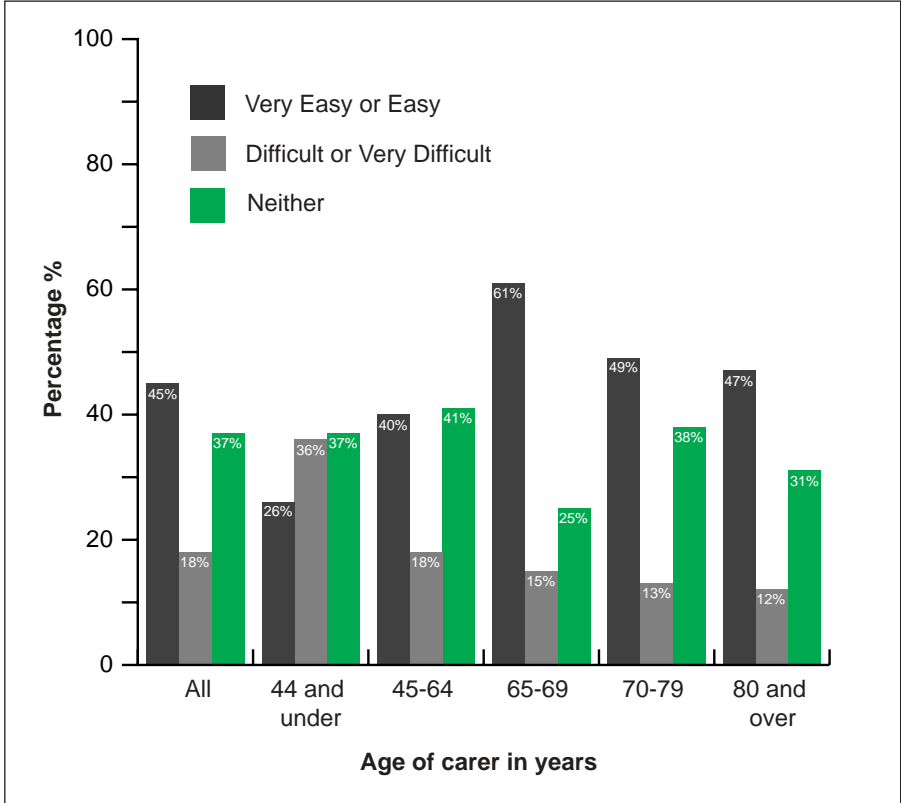
However, even visiting their own GP can require organising support at home for the person cared for. One quarter (26%) of the carers in our survey said they had to arrange for someone else to look after the person they are caring for so that they can visit the GP.

Access to the GP surgery, appointments and waiting room conditions

Ease of access to the GP for their own health needs is therefore a key issue for many carers. Carers were asked whether they found it easy or difficult to see their GP about their own health needs. Four out of ten carers (42%) found it easy while almost two out of ten carers (18%) found it difficult.

The differences between responses on this question relate mainly to the age of the carer and the disability or illness of the person cared for. Those caring for a person with a physical disability were more likely to find access to the GP

Whether carers feel it is easy or difficult to see their GP about their own health needs – by age of carer



surgery to be difficult or very difficult (21%) than other groups of carers.

Another marked contrast was based on the age of carers, with over a third of carers (36%) aged 44 years and under saying they found access to the GP surgery difficult or very difficult, while only 26% found it easy or very easy. By contrast, more than six in ten (61%) of those aged 65 or over felt that access to the surgery was easy or very easy while only 15% of that age group found it difficult.

The younger age group of carers is the group more likely to be juggling caring with other responsibilities such as employment,

childcare and other family commitments.

When carers were asked to comment on why they found it easy or difficult to see their own GP, a range of reasons emerged. Many carers giving a neutral response on this question actually went on to describe a situation of difficulty in access to the GP. An interesting picture emerges of the different situations encountered at different GP surgeries and practice is clearly very variable.



The carers survey and focus groups

Carers who found access to their GP easy or very easy made the following comments:

Appointment arranged on day I wish to see doctor
GP and staff are understanding
GP available twice a day and can usually fit me in
Nice group of doctors and receptionists, respectful
No pre-booking, regular open surgeries
People at surgery very helpful and considerate
Seen on the day appointment made
Staff will inform you when your GP is available
Surgery aware of my difficulties
They have urgent slots and I can have a telephone consultation

Many carers who ticked the responses for a neutral view on this question still seemed to be reporting difficulty getting access to their GP, as they commented:

Appointment times require several days notice
Appointments not easy to get
Can only attend if my son is available to help
Can't always leave my husband
I'm busy with little time for an appointment
Long waiting list for non-urgent appointment
Long waiting time for an appointment unless an emergency
No one to care for my husband
Often long wait for appointment
OK for emergencies but two week wait otherwise
One week waiting time

Waiting time to appointment can be up to ten days

Carers who said they found access to their GP difficult commented:

Always have to wait until next week
Appointment never available
Arranging for a sitter for my wife or her behaviour if she is with me
Difficult, live in rural area, poor transport
Difficulty getting appointment except for emergencies
Don't like to leave my husband
Hard to get appointment, usually 14 days
Have to care for my mother-in-law
Have to have someone to look after my wife
Have to take daughter with me in her buggy and her suction unit, which is heavy
Inflexibility of GP's schedule
Seven to ten day wait for appointment
She has terrible fear of being left on her own
Surgery hours inconvenient
Three-week wait for appointment
Time it takes to get appointment and arrange care
Two weeks waiting time for an appointment
Up to two week wait for appointment

Besides a number of carers reporting having to wait many days to get an appointment with the GP to discuss their own health needs, waiting times at the surgery may also be a barrier to carers accessing the GP surgery. Carers were asked whether they were discouraged

from visiting the GP surgery due to long waiting times. Around a fifth (21%) of carers agreed that they were discouraged by long waiting times and around three in ten (28%) were either neutral or said they did not know. Over half those responding disagreed with the statement that they were discouraged by long waiting times, so this is an issue for a minority of carers rather than the majority.

When carers have to attend an appointment with the person being cared for, waiting with that person in the waiting room was a problem to some carers. Almost a third of carers in the survey (32%) said they felt it was difficult to wait with the person being cared for in the waiting room.

Those carers who found this most difficult were those caring for someone with a physical disability (57%) or those caring for someone with a serious illness or disease (45%).

For those who did find the waiting room a difficult place, the following are some of the responses giving their reasons for the difficulty they experience:

Autistic child's behaviour
Can't cope with crowds
Doesn't like standing about, wanders around
Doesn't want outsiders to know about illness
Gets agitated
Gets panic attacks
Inadequate space for wheelchair user
Long waiting causes him anxiety
People staring
Prejudice against his condition
Problems with the wheelchair
Public places are very stressful for my son
Seeing other terminally ill people is upsetting

Serious bladder problems
Wheelchair access poor
Wheelchair and oxygen bottle are heavy to push

Comments from carers at the focus groups again echoed this survey finding, in that carers felt there was no distinction made in the arrangements despite them clearly having special needs. As one parent carer of a child with autism commented:

"There are no special arrangements for us."

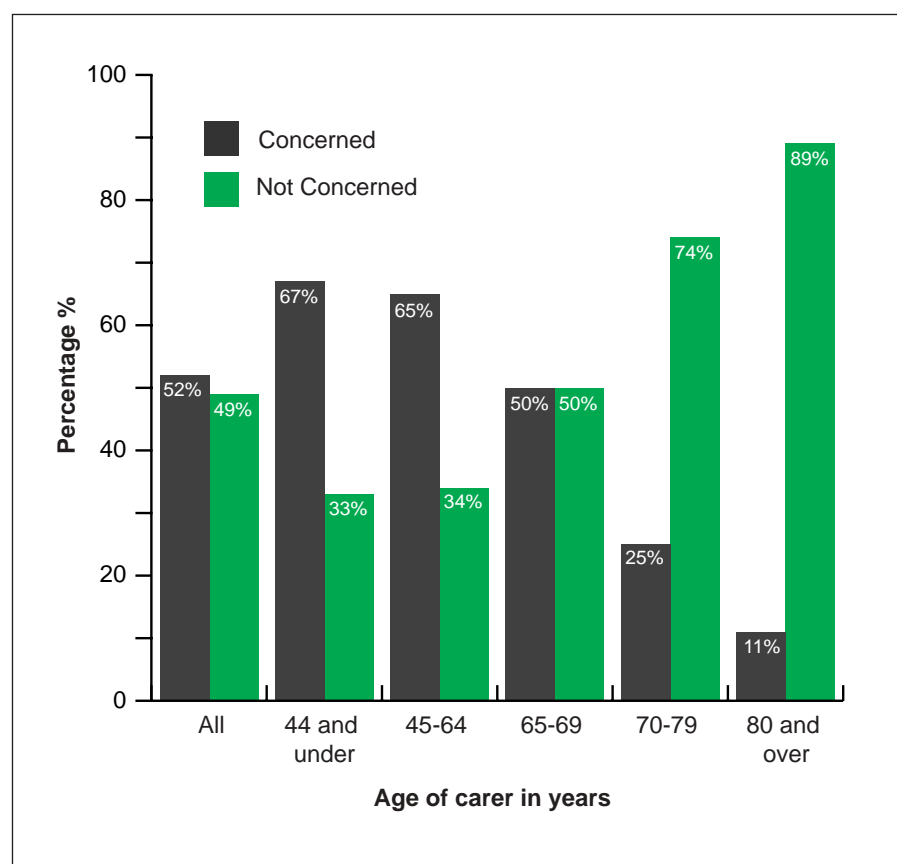
There are clearly a number of serious issues for some carers with the waiting room environment at their GP surgery.

A further barrier for carers is the concern that their conversation with reception staff at the GP surgery may be overheard. This turned out to be a concern to the majority of carers in the survey, with 51% saying they were concerned while 49% were not. There were marked differences in responses on this question based on the age of the carer and the disability or illness of the person being cared for.

Over two thirds of carers (67%) aged 44 years and under were concerned about confidentiality of their conversation, which fell to only a quarter (25%) of carers aged 70 to 79 and just over one in ten (11%) of those aged 80 and over.

Levels of concern were also highest among those caring for a person with learning disability (72%) or mental illness (60%), although concern was still high at over four in ten in almost all other groups of carers. Confidentiality and concern about being overheard is an issue that may be felt by the majority of patients. However, our survey indicates this as an issue for carers and it is an issue to which

Concerned about conversation being overheard when speaking to reception staff at GP surgery – by age of carer



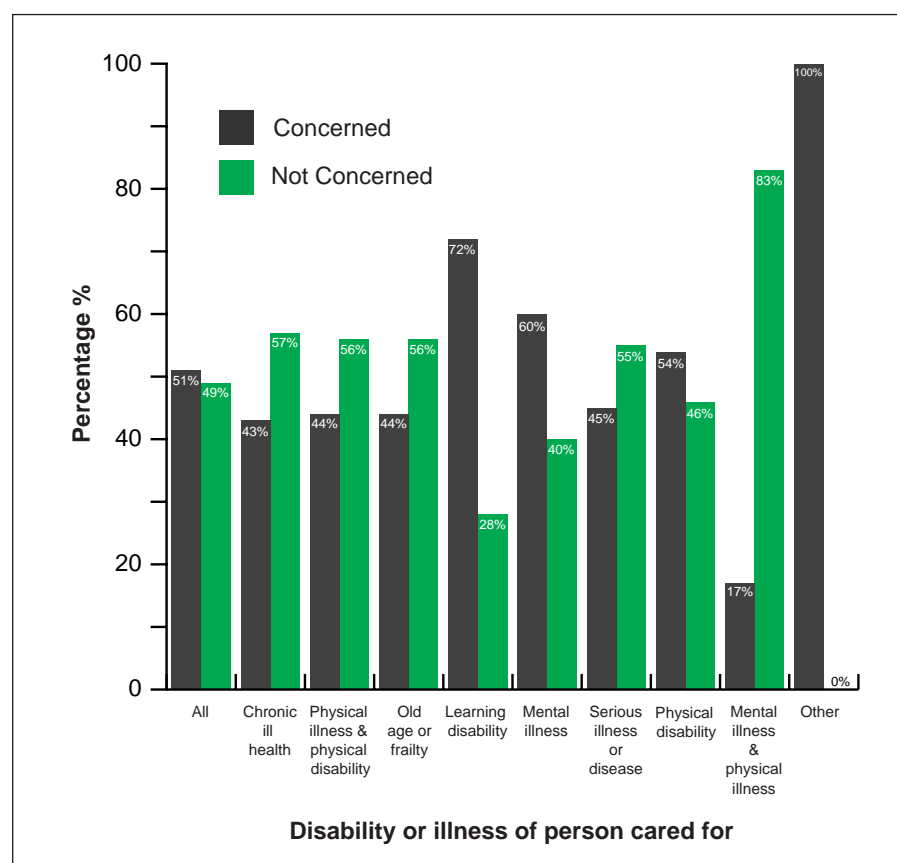
the NHS should give more attention.

It seems clear from the survey that while some GP surgeries take into account the carer's situation and their needs and responsibilities, others do not. This was confirmed by carers' responses to questions on these points. Carers were asked whether they felt their situation as a carer was taken into account when waiting to see the GP or nurse about their own health. Just over one third of carers (35%) felt their situation as a carer was taken into account, while almost two thirds (65%) felt it was not.



The carers survey and focus groups

Concerned about conversation being overheard when speaking to reception staff at GP surgery – by disability or illness of person being cared for



Awareness of the needs and responsibilities of carers

Carers were asked whether they agreed or disagreed that the GP surgery was fully aware of their needs and responsibilities as a carer. A third of carers (32%) responding felt that the GP surgery was aware, around a quarter (23%) felt that the surgery was not aware and the more than four of ten (44%) were neutral on this question or said they did not know.

Again there were differences in responses among different groups of carers, the most marked contrast being based on the age of the carer.

Among carers 44 years and under responding to the survey, only 20% felt the GP surgery staff were fully aware of their needs and responsibilities as a carer while 34% did not feel this. By contrast, a higher proportion of older carers felt the GP surgery did understand their needs and responsibilities, 41% of those aged 70 to 79 felt this.

A further question asked on the subject of access was whether carers felt that the staff at their GP surgery would benefit from training about carers. Overall, over three quarters of carers responding (77%) felt the staff would benefit from such training while less than one quarter (23%) felt they would not.

Whether carers agree or disagree that the GP surgery is fully aware of their needs and responsibilities as a carer – by age of carer.

Age of carer in years	Agree or Strongly Agree %	Disagree or Strongly Disagree %	Neutral or Don't know %
All	33	23	44
44 and under	20	34	47
45 to 64	30	28	42
65 to 69	35	14	50
70 to 79	41	21	39
80 and over	40	8	52

Conclusions on the survey

The survey gives a snapshot of the views and experiences of a random sample of carers who are in contact with their local Carers Centre in an area where there is a primary care project currently underway. In many cases, they are in contact with the Carers Centre as a direct result of that primary care project. In each of the four areas, the project has had considerable success in identifying carers and referring them to the local centre for support of various kinds.

The evidence from the focus groups confirms that many carers who have been identified and signposted to the Carers Centre in this way find the support and services which they can now access from the Centre to be extremely valuable.

It might be expected that the very process of introducing a system of carer identification and referral in primary care would raise awareness of carers' issues among GPs and primary care staff. Such a system might be thought to encourage the staff, at all levels, to 'think carer' about the way in which the practices deliver services themselves, as well as initiating a process of referral.

While this is happening in a number of individual practices, the results from the survey summarised above show that there are still considerable areas for concern in the way in which many GP surgeries in those areas deal with their carers. There remains much scope for improvements and changes in primary care to recognise the special needs and circumstances of carers. These findings are from four areas where there is an active project underway within primary care, and where therefore carer

awareness has been increased. One can speculate how much less satisfactory the situation may be for carers in areas where no such work is being undertaken.

Consequently, it is important to give attention to the practice development and strategic parts of the model of work within primary care, as well as to carer identification and referral. Systems which only seek to identify and refer carers to the local carers centre fail to maximise the opportunity and potential that exists to change the way primary care services operate.

There is also a risk that the small element of 'quality points' in the new GP contract, relating to the identification of carers, reinforces the view that carers are primarily a concern for Social Services. The points system only requires practices to develop systems to refer carers to Social Services for an assessment, and makes no mention of changes the practices can make to the way primary care services are delivered.

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- i *Census 2001: Informal Care*, ONS 2003
 - ii *Carers 2000, General Household Survey*, ONS 2002
 - iii *Carers 2000, General Household Survey*, ONS 2002
 - iv *Public Attitudes to the NHS in Scotland*, Scottish Executive Central Research Unit, 2001. See also *People's Panel: Older People Have Their Say*, Cabinet Office/MORI, 2000
 - v *Caring about Carers, A National Strategy for Carers*, HM Government, 1999
 - vi Keeley and Clarke, *Carers Speak Out Project*, The Princess Royal Trust for Carers, 2002
 - vii *Health Symptoms felt by Informal Carers: by number of hours spent caring, 2000/1: Social trends 33*, ONS, 2003

Section Five:

Good practice

The presentation of good practice in this section follows the three-part model outlined in Section Three. It is hoped that the findings, 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. It is important for those involved in this work to be aware of what has been done elsewhere, and learn from it as well as sharing their own experiences. It is also planned to develop a more extensive review of good practice as a tool kit for the projects in The Princess Royal Trust for Carers network.

Within the text examples of good practice have been highlighted. Space does not permit the mention of more than a small proportion of the exemplars of good practice which were put forward during the research. There are many other Carers' Centres and GP practices that are also exemplars of the same good practice, or alternative good approaches. The inclusion of an example in this section should not be taken to mean that it is the only example of its kind.

Identifying carers – overall guidance

It became clear as primary care projects were reviewed that there is limited value in identifying carers within primary care unless there is a plan to do something positive with that information. There have been initiatives to establish carers registers, but the wholesale identification of carers to develop a register has been resisted by many staff in GP surgeries, mainly due to workload reasons. The key

point about identifying carers or developing a carers register is that it must be clear how such a register will be used.

That is one of the reasons why the terms 'identification and referral' were linked in this research. Referral means the process of passing on the information that someone is a carer to an agency or individual, with a view to offering them some kind of assessment and support or a service adjusted to meet their needs. Although such referral will often be to another organisation, such as the local Carers' Centre, it could still be within the practice itself – to a carers support group that uses the practice premises or to another member of the practice staff or primary health care team. The identification of the carer might be used to initiate contact with them, or it might be used to respond more appropriately when the carer initiates contact to use a service (for example, when they request an appointment or a repeat prescription).

Because of workload issues, it may also be sensible initially to target the identification of carers with the highest level of caring commitment. There should be a relationship between the rate of identification of carers and the

capacity of the practice and other involved agencies to respond to the carers identified.

It seems appropriate to start with those with the highest level of commitment, because they are likely to include carers with the highest level of needs, and who therefore should be the highest priority for receiving support.

As an approximate rule of thumb, the average GP list size of just under 2,000 patients is 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. Intensity of caring, measured in hours, is clearly not the only indicator of need among carers, but given that these carers are devoting the most hours to caring, it is clearly one of the key aspects of their daily lives. Other aspects may be the level of care needs generated by the disability or illness of the person cared for and the primary care team should have knowledge of what this may be for various conditions. The team could build on their knowledge by asking the carers involved about their caring role.

A number of projects have produced guides and toolkits to aid the identification of carers in primary care. These include a tool kit for surgeries produced by South Buckingham Carers' Centre; and "How to support carers – a basic guide to setting up a carers' register to support carers in your practice", produced for Swindon PCG by Focus Swindon Carers' Centre and also distributed by Sedgfield Locality Carers' Centre.

There are various models of joint working between Carers' Centres and primary care. Harrogate and Craven Carers Centre has worked with primary care for many years using primary care link workers who work closely with individual practices, and regards this as a very effective model of working. Dr. Ward of Townend Surgeries, Settle confirmed this by referring to "the important co-ordinating role that the carers' link worker has developed ties in all the numerous strands of health, social care and benefits". Suffolk Carers Centre is one of the longest established primary care projects in The Princess Royal Trust for Carers network and it has now established carers' links with all the practices in the County of Suffolk. Gloucestershire Carers Centre also use a similar model. By contrast, Sefton Carers Centre tends to work more closely with community nurses rather than directly with GPs, and also find this to be very effective.

Good practice – the identification of carers

This section covers three different types of activity: firstly, extracting information from practice records and knowledge; secondly, making opportunistic use of practice contacts with carers, and, thirdly, encouraging self-identification by carers.

The choice of which method(s) to use is entirely one for local determination, probably at the practice or PCT level. In

making that choice, the resources available should be taken into account.

Extracting information from practice records and knowledge

It is possible to undertake 'trawling of records', that is, working systematically through all the individual patient records of the practice to identify all those who have a carer.

This may not be a cost-effective approach for several reasons. Firstly, it is labour-intensive, and therefore more costly. Secondly, the information that a patient has a carer may not always be recorded in the notes (indeed, the fact that it often isn't recorded, is precisely the problem). Thirdly, it does not prioritise the most heavily committed carers or those where the cared-for person's disability or illness may create stress leading to health issues for the carer.

There are some possible exceptions to this advice. Firstly, many practices have employed notes summarisers in recent years as part of the computerisation of records. If that activity is being undertaken anyway, it is appropriate to record the fact that a patient has a carer (or is a carer themselves) if this is recorded in the written notes, and include it in the information to be transferred onto the computerised records.

Secondly, it may be possible to undertake searches by disease, particularly where records are fully computerised, and can be easily interrogated. For example, a search of patients suffering from Alzheimer's disease may be an effective way of identifying a particular group of carers, many of whom will have a high level of caring commitment. A variation on this is to undertake a search by particular prescribed medicines that are given to



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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 be used, when next seeing them, to ask them if they have a carer.

Perhaps the most cost-effective way of utilising existing practice information is to start by pooling the knowledge of the primary health care team professionals. The GPs, nurses, receptionists and other professionals will already have a great deal of knowledge about the location of many carers, although they may not be aware of, or have given detailed consideration to, the special needs of those carers. When teams undertake such an exercise they are often surprised at how many names they come up with. One advantage of this method is also that the members of the team may have some understanding of the level of commitment of those carers, thus assisting with the identification of those with the greatest levels of 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 contact

The practice and 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. Some of these are listed below:

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, and the health and other implications of it.

The GPs and district nurses working from the Harewood practice in Lincoln identify carers on their home visits, follow this up with a letter and a form, and then record this in the computerised practice records.

Consideration for carers and the needs generated by their caring role during home visits can help prevent carers feeling ignored, as carers have frequently commented that they do. A carer in one of our focus groups spoke with passion, and some anger, about how members of the primary care team appeared to regard him:

“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.”

This carer, also a patient of the primary care team, felt he was seen as just the person who opens and closes the door when GPs were doing a home visit to the person he cares for, his mother. He longed for some minimal recognition from the GP of his caring role, and some concern about his ability to continue to fulfil it.

Carers in other focus groups showed that their GPs have been aware of them and their needs, as their comments show:

“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 in the surgery with the carer as a patient present an opportunity to identify their caring role, particularly if the carer’s own health condition may have arisen partly or wholly as a result of the demands of that role. A few perceptive questions which explore the causes of the presenting condition will often unearth the extent of this role, and its consequences for the carer’s health. 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.

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.

The Stanmore Medical Practice in Harrow use a questionnaire when registering new patients which asks if a person is a carer. They then keep details of the carer and cared for person in a contact book, which is used by Carers Centre staff to follow up carers and offer them support.

Use of other health events or checks

There are a range of other health events or checks undertaken at the GP surgery (for either the carer or the cared for person) that may present opportunities for identifying a caring role. These may include, for example, ‘flu jabs, over 75s health checks or well person clinics. Staff

involved with these should always be alert to the opportunity to identify carers, and enter this onto practice records.

In Leeds, the Carers' Centre Health Project 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 a system of yellow cards, which are given to carers for them to return to the practice so that records can be annotated. The practice then refers the carer to the Carers Centre.

Ordering or collection of repeat prescriptions

This presents another opportunity to identify carers, because a high proportion of patients who have carers also have medical conditions which require repeat prescriptions. The carer will usually be involved in the ordering or collections of the medication.

Lewisham Carers' Centre operates a scheme that involves attaching a simple post-it slip to repeat prescriptions inviting carers to identify themselves to the practice. Post-its were chosen for simplicity and to avoid staples.

Hospital discharge

This should involve liaison with carers, who can be identified as part of that process. This obviously requires close liaison between the hospital and primary care staff.

The need for liaison and providing information and support to carers at this crucial point was emphasised by carers in one of the focus groups discussions:

"The hospital should inform the GP (about the carer's role) and provide help to carers about what is available. Help about respite care. It is difficult to get this information; there are not enough social workers."

Encouraging self-identification by carers

Carers' notice boards and leaflets

These can be placed in surgery waiting rooms. They should ideally be separate from other notices and leaflets and be visually appealing. The use of posters or images of carers may help with this. Many carers do not identify themselves as such. It is important to recognise that the language and descriptions and questions asked may encourage them to do so. The leaflets should be kept up to date and replenished frequently.

Cares Sandwell Princess Royal Trust Carers' Centre establish 'carers' corners' in GP surgeries, with a resource file for each practice. The Milton Keynes Carers Project install high-quality, colourful notice boards in surgeries. Staff from the centre do the installation to save work for practice staff, and maintain and update the leaflet supply.

A letter to patients, patients' questionnaires, forms or registration cards

These can be used to encourage self-identification of carers. They can be

placed on seats in the waiting rooms or clinics, or handed to patients when they arrive at the reception desk. Alternatively, letters could be 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. It is, however, important to stress that it is the carer who is being asked to respond to the letter or questionnaire.

The Princess Royal Trust for Carers Good Practice Guide, Focus on Carers and the NHS – identifying and supporting hidden carers, estimates that a targeted mailing to 2000 patients would cost about £520 and would produce 120 positive responses.

Whichever method is used, the communication should be as simple as possible and written in clear language. It should also make it as easy as possible for the carer to reply, perhaps by using a tear-off reply slip.

Carers who self-identify should always be asked to do so to the practice itself, and not just to the local Carers Centre, so that the information can be entered into the practice's own records.

Recording the information within the practice

Having identified someone as a carer, it is then necessary for the practice to record that information within its operational systems. It is important that it is included in the normal patient record-keeping systems, as well as in any separate registers or lists of carers which the practice may want to keep, so that the fact that the patient is a carer is not overlooked when individual patient



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records are being consulted.

The next stage is to obtain the carers consent to be fully registered with the practice as a carer. This would include annotating their computer notes to record the fact that they are a carer (REED code 918A), together with some details about the care they provide. Notes for patients with a carer can be annotated with REED code 918F.

The information that someone is a carer, or has a carer, should be readily accessible to the health professional that is using the record. The value of having this recorded is likely to be considerably reduced if it is hidden away on a page of a computerised record which is not normally seen by the person consulting the record.

It is also important to obtain the written 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).

Ideally, paper records, where these are still used, should be tagged in some way, to easily identify carers and those with a carer.

Systems should also be put in place to maintain the accuracy of these records, as situations change, which they frequently do. Carers should also be asked to keep the practice notified of any changes in the situation. It may be helpful for the practice to have a named member of staff with specific responsibility for maintaining carer's records.

Good practice – the referral of identified carers

Referral was defined as the process of passing on the information that someone is a carer to an agency or individual, with

a view to offering them some kind of assessment and support or a service adjusted to meet their needs.

It is important to ask the carer what kinds of support they feel they most need. They should be given information about, and encouraged to consider, types of support which they may not have previously considered. They should feel that their role as a carer is recognised and accepted.

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

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 (similar to the letters GPs receive from consultants to whom they have referred patients). This feedback demonstrates to the practice that their effort has been worthwhile and that the patient has benefited from the referral.

The following list of types of support to which carers might be referred is not exhaustive, but does give an indication of what may be available. The carer could be referred directly by the practice, or given the information to enable them to make contact themselves.

Statutory assessment of needs

A statutory assessment of needs by the Social Services Department, as included in the checklist in the National Strategy for Carers.

Advocacy and/or financial information

This is usually available from the local Carers' Centre, or the Citizens' Advice Bureau if there is no local Carers' Centre. The number and address of the local Benefits Agency could also be important.

Short breaks from caring

These may be arranged by the Social Services Department or a Carers' Centre/voluntary agency.

In Reading, the Primary Care Trust is funding a 'breaks on prescription' scheme, under which the GP can supply a voucher to carers who need a break. The voucher can be exchanged with Crossroads who provide replacement care.

One to one support

This can usually be arranged by the Carers' Centre, or by providing access to services that may be already available in the practice, such as counselling.

Carers support group

This may be offered by the Carers' Centre. In some cases such groups are based at the GP practice itself.

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.

Inclusion on a carers' mailing list

For mail outs of information about support, events and services that may be available locally to carers – often produced by the local Carers' Centre.

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.

Health support/health checks

This should be available from the practice itself, perhaps in special sessions for carers.

A range of leisure or recreational activities to provide a break for carers

It may be important to ensure that carers have the opportunity for some time to themselves, and to participate in activities that are directed at improving the carer's own physical and mental health. Many activities can be included in this category. For example, Carers' Centres organise such diverse things as day trips for carers; horse riding; aromatherapy; beauty treatments and so on.

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

Good practice – changes within the GP practice itself

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.

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 with the way they operate. Most of the issues on this were identified in the carers survey reported in the previous section.

Appointments systems

These should recognise that carers and the people they care for often have special problems. If the appointment is for the carer, it often has to be at a time when the carer can arrange alternative care. Even when this is not necessary, there may be a limit on the time for which the carer can be away from home, which may make it impossible for the carer to wait if the surgery is running late. There may also be a limit on the time for which the cared for person can comfortably wait in the surgery with the carer.

When patients with an identified carer (or the carer themselves) ring the Orton practice in Peterborough for an appointment, the staff are aware that they are a carer from an on-screen tag and are authorised to make special appointment arrangements if necessary to fit in with the carer's situation.

Repeat prescription procedures

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

The Stanmore Medical Practice in Harrow keep three lists – a list of patients recently bereaved (who are offered sympathy and contacts for bereavement counselling); a list of families/households going through a difficult time (very sick patient or loss of a child), who don't have to wait for an appointment if they can be fitted in and the prescription phone-in list of patients who can phone in their prescription needs. Carers may be included on any of these lists. The Orton practice in Peterborough has certain times when repeat prescriptions can be phoned in, but does not apply this restriction to carers.

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 to their carer 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



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other patients. Advice should be sought about how to tone down surroundings for a condition such as autism as surgeries may have bright toys or displays, which could be upsetting to a child with autism.

Home visits

It may be appropriate to consider 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.

New services for carers

There are a range of new services which practices can consider to meet the health needs of carers. These can include:

Health checks or carers clinics

These recognise the potentially harmful effect that an extensive caring commitment can have on the carer, and the desirability of keeping the carer's health under regular review.

Dr. Campling and partners of Broughton House Surgery in Aylesbury have started to invite the carers assessed as having the most needs to carers' clinics. The carers are sent a health questionnaire in advance which asks about areas particularly relevant to carers' health (for example, sleep patterns, stress, and back pain). The content of this questionnaire was drawn up in conjunction with a carers group established at the practice. Carers attending the clinic are seen first by the GP to look at their health, and then by a support worker from the Carers Centre, to look at other ways in which they might be helped.

Specialist health care staff

It is common practice for GPs and for 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 an addition to the specialism.

In North East Leeds, the Primary Care Trust 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.

Practice-based carers support group and other non-clinical services

It has been recognised that the GP practice is often a place with which carers and cared for patients readily identify and are comfortable with, in a way which may not always apply to other locations or agencies. For this reason, it is a potentially suitable place base for a carers' support group, or other non-clinical services for carers.

The Harewood practice in Lincoln gives 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. The Orton practice in Peterborough has a practice-based carers group for carers identified by the GPs which meets monthly, with participation from the practice and the Carers' Centre. Issues discussed include topics such as short breaks, benefits and lifting, moving and handling.

Training for carers.

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".ⁱⁱⁱ The strategy also noted that this can particularly important at the start of caring. The *Carers Speak Out* 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. This is a key issue for primary care teams who need to be involved in and support training so that carers can learn to care safely.

Brent Carers' Centre held a series of 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.

Training and the expert carer

One of the more interesting developments in recent years has been the concept of the 'expert patient'. This concept is usually applied to patients with chronic conditions. It is about understanding and recognising the patient's skill and expertise in managing their own conditions. Key aspects are patient empowerment, choice and developing a dialogue with NHS professionals. Given the role carers play in caring for and being involved in the health needs and treatment of the person cared-for there is the analogous concept of the 'expert carer'. There would be clear benefit to other carers and to NHS staff in developing further the concept of the expert carer, particularly with chronic illnesses affecting children and young people or the elderly. Here the carer could benefit from developing their knowledge and information and skills and resources should be directed to support the carer (for example, help lines and training events). There is an initiative to develop an expert carer programme, for carers of people with the chronic condition Anorexia Nervosa and the Long Term Conditions Alliance are also looking at developing a scheme.

Good practice – strategic development

The previous sections have outlined areas of good practice at the surgery level. It is also important to examine the

potential for development at the more strategic levels of the Primary Care Trust (PCT), Strategic Health Authority and the Department of Health itself. This is presented under three related headings: GP contracts, practice quality assurance and the role of PCTs.

GP contracts

Reference was made in Section Two to the disappointingly low priority given to carers support in the new national GMS (General Medical Services) GP contract, and the fact that it only refers to the limited aspect of systems to refer carers to Social Services for assessment.

Nevertheless, there are other opportunities to encourage progress in this area. About a quarter of GPs have locally-negotiated PMS (Personal Medical Services) 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.

Reading PCT has included an element in its new incentive scheme for PMS practices to financially reward practices for setting up a scheme to register their carers.

Practice quality assurance

PCTs are responsible for establishing clinical governance protocols for the delivery of services by GPs. These can, and 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 into the National Service Framework for Mental Health should be included in other clinical areas. The clinical governance protocols present an opportunity for doing this. Similarly, the new arrangements for appraisal of GP practices could include elements relating to this area.

Milton Keynes Carers Project has worked with its PCT to include the support given to carers in the local clinical governance protocols.

Role of Primary Care Trusts

The new Commission for Health Audit and Inspection (CHAI) will assume responsibility for the audit and assessment of the performance of Primary Care Trusts. At present this is done by a system of star ratings, which do not contain an element relating to support for carers. This is a national rather than a local issue, but there is no doubt that the inclusion of such an element would act as a major spur to the direct involvement of PCTs in monitoring and promoting the improvement of support for carers.

The Commission for Healthcare Improvement 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."



Good practice

Carers' Centres can make their own assessment of the performance of their local PCT(s) in the support and services provided for carers.

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

PCTs have discretion in the financial allocations they make and the types of service development that they support. Some of the projects outlined in this report were financed in part or completely by PCTs, but a number of projects have been affected by the uncertainty caused by short-term funding, with consequent staff turnover and loss of skills and experience. PCTs should be encouraged to recognise the relevance of such projects to NHS objectives and the value of supporting them, financially and with longer-term contracts.

The relevance to NHS objectives of relatively small-scale help to carers was illustrated by the London Modernisation Board of the NHS, which has published a series of case studies as part of London's Older People's Service Development Programme. One of these is presented to illustrate "Preventing re-admissions, promoting independence and supporting carers". It refers to an elderly gentleman who had 21 hospital admissions in two and a

half years. It reports that: "On discharge he was visited at home and the Easycare assessment continued. A number of previously unknown (and/or undealt-with) issues which helped cause risk and anxiety and precipitate admission were found and discussed with the user and his wife. Many of these were for 'small' practical items and for non-health and social care services...There has only been one admission in the last four months..."

Dr. Ward, of Townend Surgeries, Settle 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."

PCTs do provide training programmes for practice staff. This training should include elements relating to the support for carers, and how to establish carers registers at practice level, and use them to improve the range and quality of service offered.

Milton Keynes Carers Project has organised training sessions for staff from local GP practices (who may be administrative and/or clinical staff) to help make them 'carer aware'. This has included case studies of carers' situations. Payment is made to cover the cost of replacement staff. Other Carers' Centres including Hertfordshire and Southwark have also undertaken training for primary care staff. It is evident that such increased 'carer awareness' leads to enthusiastic acceptance of the need for changes in the way the practice operates.

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.

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.

¹ Figures based on Census 2001 totals.

² *Focus on Carers and the NHS – identifying and supporting hidden carers, Good Practice Guide*, The Princess Royal Trust for Carers, 2003

³ *Caring About Carers, A National Strategy for Carers*, H M Government, 1999

⁴ The Eating Disorders Unit of Kings College London are working on developing the concept of Expert Carers of people with anorexia nervosa.

Section Six:

Conclusions and recommendations

The review in Section Two of this report (on changes in legislation and guidance as they affect the support for carers in primary care) concluded that there has been some progress and further opportunities had been created but that there is much still to be done. These conclusions were confirmed by both the mapping of the work being done by The Princess Royal Trust for Carers primary care projects (outlined in Section Three) and our survey of carers in four of those areas (summarised in Section Four). Carers in all those areas have benefited from being identified and referred for support of various kinds. They often particularly praised the services and support they receive from Carers' Centres.

Analysis of this work led to the identification of a three-part model of projects to support carers in primary care, namely:

- identification and referral;
- practice development and
- strategic work.

Projects vary in the extent to which they are working in the areas of the model. While some projects work in all three areas, most projects concentrate

on promoting and developing systems for identification and referral of carers. Many projects are hampered by short-term and uncertain funding.

In the National Strategy for Carers, the Government set out a five-point checklist for primary care so that GPs and primary care staff could better meet carers' health needs. The results of this project and the experience of those staff working within primary care to identify and support carers suggested that it is now

appropriate to update and strengthen that original checklist. A new recommended 10-point checklist for GPs and primary care staff is given below.

However, it is felt 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 the local PCTs, the Government, Department of Health and Strategic Health Authorities.

It is necessary for leadership in this work to come firstly from the PCT level in order to get it near to the top of the priority agenda. It can be hard for local Carers' Centres to develop the necessary degree of influence on that agenda. The review completed for this report found that in areas where there is a primary care project, a proportion of GPs work enthusiastically with the project. However, for many GPs workload issues mean that they feel they are too busy to work with those projects. This means that the carers using those GP practices are being denied access to the services and support they could get if they were identified as carers and referred for support. It also means that hard-pressed GPs and primary care professionals are dealing with some health problems of



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carers, or patients who have a carer, that could be alleviated if the patient was referred to the appropriate support agency by the GP practice.

A change of practice to improve and extend the support given to carers requires change at all levels. Direction and support from Government and the Department of Health is required. Without this, development is always going to be patchy and inconsistent and largely driven by local enthusiasts and champions. Accordingly, this report includes a 10-point checklist for Primary Care Trusts and a checklist for action by the Government, Department of Health and Strategic Health Authorities.

A New Checklist for GPs and Primary Health Care Teams

- **Have you identified those of your patients who are carers, and patients who have a carer?**

Identifying carers who are patients and patients who have a carer is still the key first step in helping carers and in understanding their caring role with its associated stresses and pressures. In Section Five of this report it was found that even GP practices with links to Carers' Centres were not always managing to identify all the carers with substantial needs. The task of identifying first the carers who require the most support need not be a very large one for a practice. There is now much experience of how to focus the work on this task, and good practice on this is described in Section Five of this report.

- **Do you refer carers to local sources of advocacy, help and**

support, including Carer's Centres or carers support groups?

Carers cope with a wide range of changes and difficulties and may have a variety of support needs. These will vary with each carer and at different stages of caring. Referring carers to their local Carers' Centre can open up opportunities for advocacy, help with benefits or other financial help or information. It can also help carers to meet others in the same situation and to be offered services such as breaks, alternative care, aromatherapy, counselling or opportunities for training. Some GP practices do not have in-depth specialist knowledge or expertise in conditions 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.

- **Do you take carers' special needs into account in terms of the way you allocate appointments, your procedures for issuing prescriptions and your arrangements in the waiting room?**

Around two thirds of those carers providing the most care say that their health has been affected by caring. Giving carers some priority in appointments may help to preserve their health and that of the person they care for. There has been much focus on patients being able to see their GP or a primary care professional quickly. However, carers may need

appointments at a specific time when they can find alternative care arrangements. Similarly, carers may not be able to drop off or collect prescriptions at the surgery and would benefit from being able to phone in prescription requirements and also from being advised about how to have the prescription collected and medication delivered for them.

A further problem for carers is the lack of confidentiality when talking to reception staff. The majority of carers in the survey felt this was a problem and such strong views may be held by other patients. The environment of the waiting room can present a further problem for those carers attending an appointment with the person they care for. Almost a third of the carers in our survey found this presented problems due to the condition of the person being cared for and the reactions of other patients to them. Changes to the physical environment are needed to take account of patients with autism or dementia or with needs to accommodate equipment such as wheelchairs, oxygen bottles or suction units. This is a longer term issue but small changes which make a big difference may also be addressed, such as using existing smaller rooms for patients to wait in, where the general waiting room is less suitable for them.

- **Do you check carers' physical and emotional health whenever a suitable opportunity arises, and at least once a year?**

Carers are regularly in touch with the NHS, having contact with GPs, district nurses and community nurses. While many of these contacts may concern 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. Both national statistics and surveys by The Princess Royal Trust for Carers have highlighted the health problems from which carers suffer, particularly nervous tension, depression and back pain or other physical injury. The establishment of health checks or clinics for carers is an example of good practice that could be widely replicated.

- **Do you routinely tell carers that they can ask Social Services for an assessment of their own needs?**

Primary care and local authority social services staff need to work together to meet the needs of carers. A survey carried out by The Princess Royal Trust for Carers in 2002 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 have the right to an assessment and it can be the key to them gaining new or changed services and support. It can help if GPs and primary care professionals routinely remind carers of this.

- **Do you *always* ask patients who have carers whether they are happy for health information about them to be told to their carer?**
- **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 this survey and the *Carers Speak Out* survey in 2002, many carers told us that

they were not being given information about the diagnosis, treatment or future development of the illness or disability of the person they cared for. Around a quarter of carers in the *Carers Speak Out* survey received no information and more than four out of ten carers in this survey were dissatisfied with the information they received. Also, in the same survey, three out of ten carers felt they had insufficient information about medication and more than half of carers felt they had insufficient information about its side effects.

While there may be issues of patient confidentiality in some cases, it is felt that GPs and other primary care professionals need to be pro-active in seeking the patient's consent for this key information to be passed on to the carer. The *Carers Speak Out* project found that carers who were given more information felt more positive about their caring role and the influence they had over services for the person they cared for.

- **Do you arrange for carers to have information or training to help them to care safely, particularly on lifting, moving and handling the person they care for?**

National statistics on health symptoms among carers reveal that around one in four carers caring for more than 50 hours a week suffer from physical strain. The National Strategy for Carers emphasised the risk of physical injury or strain that carers face through moving and lifting the person they care for. It also emphasised that the NHS "must help carers to learn the necessary skills so that they can care without risk on injury to themselves". Yet, the *Carers Speak Out* survey found that as many as six out of ten carers felt they did not have sufficient information, help or support with the tasks of lifting, moving

and handling. This is particularly important when patients first start caring and the primary care teams need to arrange information and training for carers at this point. Carers should no longer feel that they are expected to carry out, alone and without training, tasks which health and social care staff would only tackle in twos, with equipment and after receiving appropriate training.

- **Do you ensure that there are leaflets and notice boards in the surgery to give information to carers about services and support that is available and to encourage them to identify themselves as carers to the practice?**

Experience from primary care projects has shown that surgery waiting rooms can be a good place to make contact with carers and to provide them with up to date information that may help them. It also presents an opportunity to encourage carers to self identify with the practice.

A number of primary care projects have developed high quality notice boards and leaflet racks. One project has developed 'Carers' Corners' within GP practices. It is important that the leaflets are kept up to date and The Princess Royal Trust for Carers primary care projects undertake that task.

- **Are you willing to help with the establishment of a surgery-based carers support group?**

Some GP practices have 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



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the carers support group which is based in the local Carers' Centre. It is inappropriate to be prescriptive about this. The best practice depends on 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.

A Checklist for Primary Care Trusts

- **Do you plan to incorporate support for carers into your local protocols for clinical governance and GP and practice appraisals?**

If the 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 more limited than it need be. Also, wide variations between practices will continue to exist, creating further health inequalities for carers. PCTs can use the levers they have to encourage all practices to review and, where necessary, change their ways of working.

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

Locally-determined PMS contracts present an opportunity 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. The new GMS contract may also present opportunities to define such services after it is introduced next year.

- **Have you made any assessment of the level and quality of support for carers provided by the primary care services which you commission?**

It is important to know what is happening, or not happening, for carers in the local area. PCTs need to ask providers from whom they commission services to give them information about what they are doing to support carers. PCTs can also ask carers themselves. With such an assessment, it will be possible for the PCT to measure progress and to benchmark their own area against other comparable areas. The provision of such baseline data is also essential for monitoring the impact of new initiatives. Staff of Primary Care Trusts 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.

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

The research for this report left 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 and a variety of activities which help to relieve stress. The important

thing is that such support can contribute very positively to the maintenance of the carer's health and in many cases can actually prevent a breakdown of the caring situation. Such breakdowns often lead to the need for more services being provided by the NHS and other statutory agencies.

- **Do you undertake or commission work to set up systems within primary care to identify carers and link them to support?**

Support, whether it is from the statutory agencies or from the local Carers Centre, 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. Therefore, 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).

Despite the obvious value of this to the NHS, this research found that only a third of the local primary care projects which have been established to do this have received funding from the NHS. Short-term funding and funding insecurity has led to high staff turnover in the primary care projects, also a high level of vacancies, a loss of continuity and an inability in some cases to complete work that has been started. It is important that funding for projects is planned over a sufficiently long period to enable them to become properly established and to cover all the GP practices.

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

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, 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. This is already recognised by the NHS in Wales, where one of the non-executive directors on each Health Board is a carers' representative.

- **Do you include carer awareness in the training you offer to members of primary care teams and provide financial support to practices wishing to undertake such training?**
- **Do you encourage and support the reward, in career or financial terms, of practice staff who undertake training in carers' issues and/or who act as a carers' link person?**

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 go to constitute the development of quality services. Similarly, it may be important to reward and provide incentives for those staff that are willing to develop their skills in this area, particularly if they take on the responsibility of acting as a carers' link person in the GP practice. All of this will encourage the

commitment of practice staff to and their interest in projects for identifying carers and will also positively influence the way they do their job on a day to day basis.

- **Do you monitor and promote consideration of the special needs and circumstances of carers in the way GP practices allocate appointments, their procedures for issuing prescriptions and their arrangements in the waiting room?**

The previous two checklist points relate to promoting carer awareness and encouraging staff and practice staff development. It is also 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. The same priority should be given to these areas as is given to other comparable service delivery objectives (such as the ability to see a doctor within 48 hours).

A Checklist for Action by the Government, Department of Health and Strategic Health Authorities

To support the checklists for GPs and primary care teams and for Primary Care Trusts, the following is a suggested 10-point list of strategic actions that are needed to support action at the operational and commissioning levels of primary care. These action points will link together with the other checklists to help make them a reality. They are an 'agenda for change' to bring about the National Strategy for Carers' aspiration that the

NHS becomes the most important initial point of contact for carers.

- **Will you modify the system for performance managing and rating PCTs to give clearer recognition to the importance of improving services for carers?**

None of the present key performance indicators for the assessment of the performance of PCTs by the Commission for Health Improvement (shortly to become the Commission for Health Audit and Inspection) is directly related to services and support for carers. This deficiency does not help to promote the message of the National Strategy for Carers. It also does not help to foster the view in PCTs that this is an area of work that the Government considers important. PCTs need incentives and encouragement to give greater priority to this work. It is recommended that the performance indicators and framework be reviewed in this light.

- **Will you 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 and this acted as the spur for many valuable initiatives in primary care. The target date was subsequently deferred, and no new date has been set. As well as sending out a negative message about the importance of this work, this deferral has caused great uncertainty about the work that was started. It is important to set a new date as soon as possible.



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- **Will you modify existing National Service Frameworks (that do not include one) to include a standard relating to the recognition and support of carers, and ensure that such a standard is included in all future relevant NSFs?**

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.

- **Will you establish and fund an 'Expert Carers Programme' in line with the Expert Patient Programme**

The Expert Patient Programme has been one of the more innovative concepts to enter the thinking of the NHS in recent years. It is equally important to recognise and support 'expert 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. The establishment and funding of an Expert Carer Programme would therefore be a highly relevant and appropriate development of the concept. The self-management scheme for carers of the Long Term Conditions Alliance could provide the starting point for such an Expert Carers Programme.

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

The National Strategy for Carers identified the importance of establishing regular

health checks for carers. This was a good idea. However the research for this project had found that it remains an example of good practice operational in a few areas of primary care and has not yet reached the stage of widespread implementation. For wider replication 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.

- **Will you ensure that PCTs and Local Authorities are properly funded to improve and extend support and services for carers in primary care?**
- **Will you use performance management frameworks to promote greater partnership working between the NHS and Local Authorities to support carers?**

Initiatives to support carers, as identified in the National Strategy for Carers and in this report, need to be properly funded if they are to be effective. At present about 20% of the sources of funding for the primary care projects run by The Princess Royal Trust for Carers Centres are local authority sources. 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.

A breakdown of a caring situation may result in damage to the health of either the carer or the person cared for. It may also place large additional demands on the local authority for care service to replace the caring role. Therefore, it makes sense to see this as an appropriate area for close partnership working. Despite this, the research for this report found that

partnership working has not been fully developed in some areas. An effective strategy for carers cannot be developed by either the NHS or the local authority in isolation from the other.

- **Will you provide funding to introduce pilot programmes to identify the most effective ways of improving carers' health?**
- **Will you give the monitoring and improvement of carers' health a similar priority to that currently given to other target groups of patients, backed up by financial incentives and targets?**

It is increasingly being recognised 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 including mental health problems caused by the stress and isolation of the role, back trouble caused by lifting and handling and lack of adequate sleep. There is a need to establish pilot programmes to evaluate the most effective ways of tackling this issue. Maintaining and improving carers' health is right 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 is sound sense for the NHS to prioritise evidence-based research in this area.

If primary care staff 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.

This is closely related to the recommendations made about the use of flexibility in GP contracts and the funding provided for PCTs.

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- i Keeley and Clarke, *Carers Speak Out Project*, The Princess Royal Trust for Carers, 2002
 - ii *Health symptoms felt by informal carers*, ONS, 2001
 - iii Keeley and Clarke, *Carers Speak Out Project*, The Princess Royal Trust for Carers, 2002

- **Will you launch and fund a 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 also gives a clearer message of the importance that the Government attaches to the area. A national awareness campaign targeted at carers would be a powerful tool in taking this agenda forward. However, it must, be done in conjunction with the other recommendations in this report, to avoid raising expectations from carers which cannot be met.

The above checklists are recommended to decision-makers at every level. There has been much learned already about how to identify and support carers in primary care. It is important that that this learning continues and that progress is built further.

These recommendations are a key step towards giving carers the support that it is in the interests of the NHS to provide and which carers deserve. Implementing the recommendations could help to make carers no longer the 'forgotten army' but a 'recognised, valued and supported army' within health and social care.



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