



The Princess Royal Trust  
*for Carers*

# Carers Speak Out Project

## Report on findings and recommendations



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## BUCKINGHAM PALACE

During the last year The Princess Royal Trust for Carers has been celebrating its tenth anniversary. Over the last ten years I have met many carers who are very passionate about their role and providing the best care they can.

Carers have often told me that they find caring both rewarding and demanding and, whether they have been caring for a short or a long time, access to information and support is vital. Unfortunately it has been said that even when the support and information is available the route to accessing it can be very difficult, consequently carers will often only hear about resources such as our Carers Centres when they reach breaking point.

Recognising this problem and working with carers who wish to be involved in initiating change has led the Trust to undertake the Carers Speak Out project. The aim of the project was to use a series of face-to-face consultation events and a questionnaire to find out what issues carers face day to day and what has changed for carers since the introduction of the National Strategy for Carers. I am delighted that nearly 4,000 carers took part, making it one of the largest carers consultations ever and that the research has provided some very compelling findings.

It is encouraging that the findings show that small changes have occurred over the last few years making things slightly better for new carers; however, it is evident that there is still a lot more that could be done.

I sincerely hope that the findings in this report will encourage the professional bodies that work with carers to review their working methods and see what changes they can make to support carers in their important role.



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# Introduction

Around 6.8 million adults in Britain are carers. They provide care and support, on an unpaid basis, to relatives, friends and neighbours who are sick, disabled or elderly and who would not otherwise be able to manage.

- 1.1 Around 3.8 million of these carers are the main support for the person they are looking after. Some 1.7 million carers spend 20 hours or more per week on caring tasks and around 680,000 care for more than fifty hours per week.<sup>1</sup>

## The National Strategy for Carers

- 1.2 In 1999 the British Government launched its National Strategy for Carers – the first ever by a Government in Britain. This document aimed to set out what the Government had been doing and what they planned to do for carers. To quote from the Prime Minister’s foreword:
- 1.3 “Carers will have better information. They will be better supported. They will be cared for better themselves. This makes a decisive change from what has gone before. While we will continue to make sure that help goes directly to people who need it, we will now ensure that help is offered to carers themselves as well – because helping carers is often a good way of helping those they’re caring for. Caring for carers is a vital element in caring for those who need care.”
- 1.4 The strategy represented the Government’s intentions about what service providers – local authorities, the NHS and others – should do for carers.
- 1.5 The Government’s emphasis in the document was in widening the focus of health and social care services to being not just on the client, patient or user but a focus which:  
“must see the person needing care and support within the whole environment of their family, their neighbourhood and their community. This must include their carer or carers.”
- The Government’s objective was, therefore, focused on “enabling those who choose to care, and whose care is wanted by another person, to do so without detriment to the carer’s inclusion in society and to their health. Our aim is to support people who choose to be carers.”
- 1.6 The strategy had three key approaches:  
“**Information for carers**, so that they become real partners in the provision of the care to the person they

are looking after, with the means to provide that care as well as they all wish to, and with wider and better sources of information about the help and services which are available to them.

**Support for carers**, from the communities in which they live, in the planning and provision of the services that they and the person they are caring for use, and in the development of policies in the workplace which will help them to combine employment with caring.  
**Care for carers**, so that they can make real choices about the way they run their lives, so that they can maintain their health, exercise independence, and so that their role can be recognised by policymakers and the statutory services.”

- 1.7 The strategy recognises the fact that the lives of those in caring relationships can become so intertwined that neither individual can have independence. It observes that too often building partnerships with carers in providing care fails to recognise that the carer is an individual in their own right. The strategy aimed to address this by:  
“empowering carers to make more choices for themselves and to have more control over their lives.”

The strategy covers aspects of the work of a range of bodies in the public, voluntary and private sectors.

- **Health Agencies:**  
The NHS is seen as the most important initial point of contact for many carers. Primary Care teams are seen as being able to identify carers and to refer them to services which can help them. Carers’ need for good information on the health needs and treatment of the person they are caring for is also recognised. The NHS also has clear responsibility for helping carers to maintain their own health, with local health professionals needing to be aware of the carer’s own health needs and how they can best help the carer.
- **Within local authorities:**  
Social Services should work with Health agencies to identify carers. Social Services also have the formal duty to carry out assessments of carers’ needs. This can help

service providers to judge the carer's state of health, their needs and wishes and their ability to continue to care or to bring informal caring to an end. Social Services are also charged with lead responsibility in arranging and funding services to allow carers to take a break from caring. Housing authorities may need to assess the carer's circumstances, wishes and needs in the provision of accommodation for themselves and the person being cared for. They should also provide an efficient and high quality service of adaptations needed by disabled people. Education – adult education is seen to have a key role in offering training, to empower carers, equip them with new skills and help them back to work when caring ends. Local education authorities also have a role to play to address the needs of young carers. Teachers and education welfare staff can provide guidance to young carers, make links for pupils to young carers' projects and work with social services to ensure that young carers do not carry inappropriate levels of caring responsibility.

- **Transport Authorities:**

Transport providers are urged to improve their services, especially for sick, elderly and disabled people and their carers. Voluntary and community transport services are also seen as playing a vital role.

### **Partnership, Joint Working, Involvement and Consultation**

- 1.8 A key element in the National Strategy in developing support for carers is that service providers are asked to see carers as partners in the provision of help to the person needing care. Providers must also involve carers as partners. Further, carers need statutory services to work together to provide the best possible care. Involving carers and carer organisations, alongside patients and users of services, is seen in the strategy as a way to ensure that those services are responsive. Authorities and organisations are urged to look for new ways of involving carers.
- 1.9 Health and social services authorities working with partner organisations, including carers and patients, are asked by the Strategy to develop their own strategies to improve the health of communities through health improvement programmes. Patients, service users and carers should also be consulted by health and social services on Joint Investment Plans.
- 1.10 Carers should also be consulted on local rural regeneration projects, the NHS survey of patients and carers views, local authority community strategies and housing service plans and finally on the patient partnership strategy at national level.

### **Carers Support Services and Carers Centres**

- 1.11 Carers Centres and other forms of support service may provide carers with information and advice, emotional support and counselling, training, practical help, social activities, breaks from caring, advocacy and support for involvement in local decision making. The Strategy sees such services as best run and managed by the voluntary sector and states that all carers should have access to a support service.
- 1.12 Health authorities and local authorities, acting jointly, are required to bring together organisations which support carers to assess local needs for support services for carers and how these should be provided. The Government asks that the authorities give priority in their joint investment plans to funding carer support services. Three national carer organisations, working with the Government, are to develop a national quality assurance scheme for local carer support services.

### **The Carers Speak Out Project**

- 1.13 The National Strategy for Carers provided a wide-ranging agenda to be taken forward for carers. The strategy was a very welcome development. However, signalling policy intentions across such a wide ranging agenda does not change services, either overnight or even in the short term. Indeed, the strategy emphasised that carers were not sufficiently high on the agenda of some organisations and in some service areas.
- 1.14 Three years on from the launch of the strategy, the *Carers Speak Out* project was undertaken in order to provide feedback to the Government on the implementation of its strategy for carers. The consultation project offered the opportunity to reflect on the changes that have occurred for carers since the national strategy was launched, and on what changes still need to be made to improve support for carers to help both them and the person they care for.
- 1.15 The aim of the *Carers Speak Out* project has been to consult with carers in order to find out what are their needs, priorities and issues. The project combined different consultation methods to explore carers' views. A postal questionnaire was sent, via Princess Royal Trust Carers' Centres, to over 8,000 carers across England, Wales, and Scotland. Around 2,800 replies were received and this provided data on carers' issues and needs.
- 1.16 The project also included running one national and eleven regional consultation events. These events brought carers together with senior professionals from social services and health and elected members from government and local government. Together they attracted an audience of over 1,000 carers plus 400



# Introduction

other people including professionals and decision-makers. Knowledge of carers' issues and needs was further developed through discussion and debate with carers who attended one of these consultation events. Following the events, a Good Practice Guide to Consultation with Carers has been produced by The Princess Royal Trust for Carers, incorporating many of the good practice points which emerged from running the events.

## The Carers Speak Out Survey

- 1.17 This report presents the findings of the survey distributed to over 8,000 carers in Spring 2002. The responses to the survey questionnaire and the comments from carers at the twelve consultation events offer a view from the experience of some 3,800 carers.
- 1.18 The survey questionnaire sought information in the following areas:
- Caring responsibilities and characteristics of carers
  - Carers' access to information, advice and support
  - Carers' knowledge, use of and views on Princess Royal Trust for Carers Centres
  - Use of the Internet
  - Carers' knowledge of and experience of carers' assessments
  - Carers' views on taking a short break from caring and help and support needed to take a break
  - Carers' views on how much their role is understood by professionals and to what extent they are being involved in and consulted about services
  - The impact of caring on carers' own health
  - Carers' biggest problems and what would make the biggest difference to them.
- 1.19 These and other key issues were also explored with carers in discussion groups and panel sessions at the twelve *Carers Speak Out* consultation events.

## Methodology of the Survey

- 1.20 A postal questionnaire was designed and piloted with a group of carers in Salford in March 2002. A revised version was sent out to around 8,270 carers in batches of 90 sent via the network of PRTC Carers Centres. Most of the questionnaires were dispatched in March and April and a small number of batches were distributed at consultation events in May. To make the sample more representative, Carers Centres were asked to select from their records a cross section of carers to participate in the survey, based on the known characteristics of carers in the population. Not all the centres were able to do this, and if not, they were asked to select randomly from the carers they had been in contact with.
- 1.21 Most questionnaires were returned in late April and early May. To allow for late returns and the few batches sent out late, a final cut-off date was made for June 21st 2002. 2,790 questionnaires were returned to the market research agency, MVA, for coding and analysis. This represents a response rate of 33%.
- 1.22 While the sample in the survey was mainly of people who had been in touch with their local PRTC Carers Centre, it did also include a number of carers who had previously not been in touch with PRTC. Some of the questionnaires were distributed to carers attending *Carers Speak Out* consultation events, and it had been an aim of the events to attract new and 'hidden' carers to the events. Overall, the sample is weighted towards carers who are in contact with PRTC Carers Centres and is not a random sample of all carers.

# Characteristics of carers in the survey



# Characteristics of carers in the survey

## National statistics on carers from the General Household Survey

- 2.1 The Office of National Statistics publishes details of carers and their characteristics following studies undertaken via the General Household Survey. The latest update of this statistical information on carers is the Carers 2000 report which was published in July 2002.<sup>2</sup> The report provides data on carers and their characteristics with which the profile of carers in the *Carers Speak Out* survey can be compared.
- 2.2 The *Carers 2000* report noted that there had been little change in the numbers of people caring since 1990. In 2000, around 16% of the population over 16 were caring for a sick, elderly or disabled person. This represents around 6.8 million adults. Around a third of carers are looking after someone living with them and the other two thirds were looking after someone living elsewhere. In terms of the most heavily committed carers, one quarter of carers spend at least 20 hours per week caring while one in ten carers care for more than fifty hours per week.

## Gender variations among carers

- 2.3 Women are more likely than men to be carers (18% of all women compared to 14% of all men). This is true in all age groups less than 65 years, with the difference being most marked in the 45-64 age group, where the *Carers 2000* report sees that the responsibility for caring falls "most particularly on women." (p4)  
Almost a third of women in this age group who were married or co-habiting were likely to be carers. Also, single and previously married women aged 30-44 were much more likely to be carers than their male counterparts. These women include daughters caring for their parents and lone mothers caring for sick or disabled children.

## Regional Variations

- 2.4 Adults living in the North East were more likely to be carers than those living in other regions (20% of adults). The North West, the South West and Wales also had high proportions of carers (18-19%). London had the lowest proportion of adults caring for someone (11%) with the proportion caring for someone living outside the household also being particularly low in London (7%) compared to the North East, the North West and Wales (11%-13%).

## Relationship Variations

- 2.5 Overall, the most common relationship of carers reported nationally was that the person being cared for was a parent or parent-in-law (38% and 14% respectively.) This was followed by other relatives 21%,

friends and neighbours (21%). The next category was those caring for a spouse (18%) followed by a son or daughter (5%) and finally child under 16 (3%).

- 2.6 However, these statistics change considerably when the group of carers is those more heavily committed carers who care for more than 20 hours per week. Here the most common relationship is that of spouse (45%), followed by parent/parent-in-law (41%) other relatives (11%) and son or daughter over 16 years (10%). The next category is those caring for a child aged under 16 (8%) and finally those caring for a friend or neighbour (7%).

## Carers in the Carers Speak Out Survey

- 2.7 The carers who had responded to the *Carers Speak Out* survey differ 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. The majority of carers in the survey had heavy caring commitments.
- 2.8 Exact comparisons with the national profile of carers cannot be made, as different questions were asked about the amount of time spent caring. The national profile of all carers gives the percentage of carers caring for 20 hours a week as 27% and 11% who care for more than 50 hours a week. In the *Carers Speak Out* survey around 92% of respondents were caring for more than 20 hours per week and 77% were caring for more than 50 hours per week. The sample in the *Carers Speak Out* survey therefore contained a higher proportion of carers with the heaviest caring commitments. Comparisons made in this section are therefore made with that group of carers within the national profile who have the heaviest commitments to caring.

## Age and Gender

- 2.9 The peak age for carers responding to the *Carers Speak Out* survey was 45-64 years, the next largest proportion being carers 65 years and over, and then carers under 44 years. In the national profile of carers, the peak age for carers who were caring more than 20 hours per week is also 45-64 years, but this is followed by the next largest proportion being under 44 years. This means that carers in the survey were somewhat older than carers in the national profile.

Age of Carer	Carers 2000 Carers caring for 20 hours per week + %	Carers Speak Out %
44 years or under	32	20
45-64 years	40	48
65 years or over	28	32

2.10 In terms of gender, 71% of the survey respondents were female and 29% were male, compared to 61% female and 39% male in those caring for more than 20 hours in the national profile. The proportion of female carers in the survey was therefore higher than the national profile.

#### Carers with a disability or long term illness

2.11 Among carers who responded to the survey, 39% reported that they had a disability or long-term illness themselves.

#### Employment Status

2.12 Only 21% of carers responding to the survey were employed while 79% were not, with 42% being retired and 37% not employed. Of the 21% who were employed, only a third were employed full-time (7%), with the other two thirds being split between those who work part-time (11%) and those who are self-employed(3%). Given that over three quarters of the carers in the survey were caring for more than 50 hours and that just under a third were over 65 years, this is not surprising. This means that working carers, and within those full-time working carers, were somewhat under represented in the sample compared to the national profile. In the Carers 2000 report, 45% of carers who were caring for more than 20 hours per week were also working, with 26% working full time and 19% working part time.

#### Relationship to the person cared for

2.13 The table shows the different percentages between the survey and the heavily-committed carers in the national profile, in terms of relationship to the person cared for.

#### Relationship of carer to main person cared for

Relationship	Carers 2000 Carers caring for 20 hours per week + %	Carers Speak Out %
Spouse/partner	45	44
Son/daughter	18	31
Parent/parent-in-law	41	20
Other relative or friend/neighbour	18	5

2.14 Among respondents to the *Carers Speak Out* survey, the most frequent relationship category was that of spouse or partner. In comparison to national profiles of carers, those caring for a parent or parent in law were under-represented in the survey and those caring for a son/daughter were over represented.

2.15 There was also a difference in age of the person cared for. The respondents in the survey were more likely to be caring for a spouse or son or daughter and less likely to be caring for parents. As can be seen in the table, the age of the people being cared for was younger in the *Carers Speak Out* survey than in the national profile.

#### Age of person being cared for

Age	Carers 2000 All Carers %	Carers Speak Out %
Under 16 years	4	13
16 - 44 years	10	22
45 - 64 years	16	19
65 - 74 years	18	15
75 - 84 years	33	19
Over 85 years	19	12

#### Disability or illness of the person being cared for

2.16 The table shows the frequency of the different illnesses or disabilities of the people being cared for. The most frequent categories were physical illness (27%) followed by a combination of physical illness and physical disability.

#### Disability or illness of person being cared for

Disability or Illness	% in survey
Physical illness – diabetes, arthritis, MS, ME, heart problems	27
Physical illness and physical disability – stroke, cerebral palsy	17
Old age or frailty (including Alzheimer's)	14
Learning disability – Downs syndrome, autism, Aspergers syndrome	14
Mental illness – schizophrenia, depression	7
Mental illness and physical illness – e.g. Parkinsons	5
Physical disability – blindness, deafness, unable to walk	5
Serious illness or disease – cancer, vascular conditions, lung disease	3
Mental illness and physical disability	3
Other	3

#### Duration of Caring

2.17 Among carers responding to the survey there were fewer carers who started caring more recently and more carers caring for longer than 10 years, when compared to the national profile. Around 13% of carers in the survey had been caring for 2 years or less, which compares to 36% in the national profile. However, the number of carers who had been caring for 3-9 years was the same in the survey as in the national profile of all carers.



# Characteristics of carers in the survey

## Length of time spent caring

Length of Time	Carers 2000 All Carers %	Carers Speak Out %
Less than 2 years	36	13
3-9 years	44	44
10 years or more	21	43

## Black and Minority Ethnic Carers

2.18 While 92% of carers responding to the survey described themselves as white, 8% of those responding described themselves as Black or Asian or from other minority ethnic groups. 4% were Asian or Asian British, 2% were Black or Black British, and 2% were from mixed or other backgrounds.

## Response to the survey by area

2.19 Survey results are reported for Scotland and Wales and by the four Health and Social Care Regions of England. The English regions are:

- North – North East, North West, Yorkshire & Humberside
- Midlands & Eastern – Midlands (West & East) East Anglia & Essex, Bedfordshire & Hertfordshire
- London – all London boroughs
- South – South West, Thames Valley, Dorset, Hampshire, Isle of Wight, Kent and Medway, Surrey & Sussex

## Response to the survey by area

Area	Number	Respondents to the survey %
Scotland	651	23
Wales	264	9
North	583	21
Midlands and Eastern	430	15
London	341	12
South	521	19

2.20 Compared to the national profile, carers in Scotland are somewhat over-represented in the survey (23% compared to 15%) and carers in Wales are under represented (9% rather than 18%). It is not possible to compare the geographic spread of carers in the survey exactly with the national profile for English regions, as the Carers 2000 report used the Government office regions to report geographic proportions while this report uses the Health and Social Care regions. We can say that the proportions of carers in the survey are broadly similar to those in the national profile.

## Summary – Carers in the survey

2.21 The carers who responded to the Carers Speak Out survey contained a high proportion with the heaviest caring commitments, with over nine out of ten caring for more than 20 hours a week and over three quarters caring for 50 hours a week or more. More heavily committed carers such as these are much more likely to be women, and the large majority of these carers will also live in the same household as the person cared for. The majority of the carers who responded to the survey are people spending much of their time caring for a spouse or partner or a son or daughter. Further, almost four of ten carers in the survey had a disability or long term illness themselves.

2.22 The carers in the survey were older than the average of all carers in the national profile. Four out of ten carers in the survey are over 65 years and three out of ten are over 75 years old. The sample for the survey also contained more carers who had been caring for a longer duration. Over four out of ten had been caring for 10 years or more, with 2 in 10 caring for 20 years or more and just over a third had been caring for 5 years or less.

# Information needs



# Information needs

## Access to information, advice and support

- 3.1 The National Strategy for Carers put it succinctly: “Good information is one of the main needs of carers. Information needs to be accessible, relevant and comprehensible”. (p.37).
- Our survey asked about sources of information and support which carers were told about when they first became carers. Although initial information from those sources is vital, the strategy also reminds us that: “Carers’ needs can change over time. Information which is needed at the beginning of a period of caring may be quite different from that which is needed later” (p.37). The strategy also noted that: “Carers often find it difficult to get information about either the type of response or the quality and standard of service they can expect from local agencies”(p.38). It correctly observed that: “Whilst almost all the information which carers need is already available somewhere, carers may not be aware of the existence of particular information to help them” (p.42).
- 3.2 So three years on, what does the provision of information and support for carers look like now? In addition to looking at information given to carers when they first became carers, this section also covers information about:
- the condition and health needs of the person being cared for;
  - key caring tasks
  - benefits and grants
  - ease of use of sources of help and advice and
  - use of the Internet

## “Signposting carers” – Information on first contact with services as a new carer

- 3.3 More than a third (36%) of carers in the survey said that they were not told about any of the usual sources of information and support when they became a carer. This figure seems unacceptably high but there is a substantial difference depending on how long someone has been a carer. There is an improving trend in the proportions of carers who say they were not directed to sources of information and support.

Duration of Caring	Carers not directed to sources of information and support %
Less than 2 years	18
3-5 years	29
6-9 years	35
10-19 years	45
20 years or more	51

- 3.4 There is a note of caution on the fact that the question asks about sources of information when the carer first began caring, and it may clearly be difficult for carers to remember across many years. However, the figures do indicate a consistently improving trend. The most favourable picture is given by those who have become carers within the last two years, i.e. since the national strategy was published. The figure for more recent carers (18%) although still high, is less than half the overall figure. The table shows a trend which has improved from the high figure among carers for more than 20 years where over 50% of carers were not told of sources of information and support when they began caring. The situation on signposting of carers therefore appears to have considerably improved, but with a need for further improvement to ensure that all carers are directed to source of information and support.
- 3.5 There is also a difference depending on the nature of the need of the person being cared for as can be seen in the table. Those caring for someone with a mental illness, a physical disability or a learning disability were even less likely to have been told about these sources of information and support. This contrasts with the responses of those caring for someone with old age and frailty or serious illness or disease – these carers had the lowest proportion of respondents who were not directed to sources of information and support.

Type of disability or illness of person being cared for	Carers not directed to sources of information and support %
Mental illness	47
Mental illness and physical disability	44
Physical disability	43
Learning disability	42
Mental illness and physical illness	40
Physical illness	40
Physical illness and physical disability	34
Serious illness or disease	27
Old age and frailty	24

- 3.6 The National Strategy noted that: “For many carers, the most important initial point of contact with services is with the NHS – with their General Practitioner, the community nurse, or another member of the primary care team. Others will begin to find out where to get information from initial contact with the social security benefits system”. This survey asked about the sources of information/support which carers were told about when they first became a carer.

- 3.7 Social Services were in the largest category of responses at 29% of carers in the survey giving them as the source of information and support they were directed to, with health staff recording only 16%. A local carers' group (25%), the PRTC Carers Centre (22%), or other support groups (13%) were the other sources to which carers had been directed when they first became a carer.
- 3.8 Similar to the findings related earlier in this section, there are also variations in what carers were told about different sources of support and information according to the nature of need of the person cared for. Those caring for people with old age or frailty or serious illness or disease were much more likely to have been told about a Carers' Centre (30% and 29%) or local carers group (39% and 31% respectively) than other carers responding to the survey. These groups were also more likely than the rest to have received information about Social Services, and also about health workers.
- 3.9 As with the previous question, those caring for people with a mental illness were significantly less likely than other carers to have received information about Social Services. Those caring for someone with a Learning Disability were significantly more likely (24%) than any other group of carers to say they were directed to other support groups as sources of information and support. It may be a matter of concern, for example, to Social Services Departments that over 90% of new carers of people with a mental illness and almost 75% of carers of people with a Learning Disability did not receive information about contacting them when they first became a carer.

#### **Information on the diagnosis and future development of the disability or illness of the person cared for**

- 3.10 The National Strategy made the obvious point that "Carers need good information on the health needs and treatment of the person they are caring for.....They need.....to recognise when they should urgently ask for professional help and where to get such help, especially when they are caring for someone with a mental health problem "(p.41).  
It is a matter of concern that over a quarter of respondents replied that they have been given no information in this area, and that less than a quarter have been given a lot of information. While the previous question referred to carers being told about sources of information and support at the time when they became a carer, this question refers to whether they are now in possession of information about the health needs and treatment of the person cared for.
- 3.11 While there are issues of patient confidentiality here, it may be that GPs and other clinicians need to be more pro-active in seeking the patient's consent for this key information to be passed on to the carer. Where consent is not given, information about health needs and treatment cannot be passed to the carer. However, health professionals should be prepared to review this decision regularly with the patient.
- 3.12 The position seems to be better for those who started caring more recently. The proportion of respondents who said they have been given no information is lowest (22%) among the newest carers. However, it remains the case that nearly a third of those who have been caring for more than 20 years are not in possession of that important information. Looking at specific groups of carers, those caring for people with a mental illness plus physical disability and those in the 'other' category are in the least favourable position, with approximately 37% in each case having had no information on the diagnosis and future development of the illness or disability of the person being cared for.

#### **Sources of information**

- 3.13 Not surprisingly, overall 62% of carers responding identified a Health service source as the main source of information about the disability or illness, with Consultant/specialist being the largest category of responses. There are considerable variations in the main source of information, when analysed by age, gender, relationship, living status and duration of caring of the carer, and by the nature of the disability or illness. Many of these factors are, of course, inter-related. The major variation relates to the relative weighting of the G.P and the Consultant/Specialist in giving information.
- 3.14 Male carers were more likely than female carers to have had information from a consultant (40%) or a GP (24%) than female carers (35% and 18%) respectively. This finding may reflect the different characteristics of male and female carers or it may be in line with previous findings of a bias towards male carers receiving more of certain types of support than female carers.<sup>3</sup>
- 3.15 Carers of someone with a learning disability are much more likely (21%) to regard self-help groups as a main source of information. As female carers are more likely than male carers to be caring for someone with a learning disability, they are also twice as likely (13%) as male carers to regard self-help groups as their main source of information.
- 3.16 From the carer's perspective these variations in the main source of information may not matter, so long as they are obtaining the information they need.



# Information needs

Nevertheless, it may be a cause of concern that 11% of respondents have identified a publication of some sort, rather than a professional or a local agency, as their major source of information about the diagnosis and future development of the person they are caring for. While such sources can clearly be useful additional sources it seems worrying that these sources are being cited by so many carers as their main sources of information about the health needs of the person they are caring for.

### Information given about key caring tasks

3.17 (It should be noted that all the analyses below on this topic exclude those for whom the question is not relevant).

The results of the survey on this topic do give cause for concern. Less than half (42%) of respondents have been given sufficient help/support or information about lifting, handling and moving. The position appears slightly better for more recent carers than for longer standing carers. While 38% for those caring for 20+ years said they had been given sufficient help or support on this caring task, the corresponding figures were 43% for those caring for less than two years and 44% for those caring for 3 to 5 years.

3.18 However, there is a considerable gender difference. More than half (51%) of male carers felt they had been given sufficient information on this topic, compared with only 37% of female carers. Again, the finding points to male carers being given better levels of support. Younger carers were also significantly less likely to have received such information – with only 35% among carers aged 44 years and under, 40% among carers aged 45-64 but 49% among carer aged 65 years or over. This could perhaps be due to perceptions about their physical capability.

3.19 Similarly only 42 % of carers responding have been given sufficient help/support or information on giving injections or the use of catheters/dialysis. Here, however, the position appears worse for the more recent carers (41% with sufficient information in those caring for up to 2 years) than the longer standing carers (50% for those caring for 20+ years). There is also a difference among responses from black and minority ethnic carers on this question, who are much less likely to say they have received sufficient help or information on this caring task – 23% with sufficient information compared to 45% of other carers. It should be noted that the numbers of black and minority ethnic carers responding on this question was small. However, earlier

work on services for black and minority ethnic carers indicates that they are a group of carers who frequently have problems with access to services and this finding serves to illustrate that point.

3.20 On help with key caring tasks, the overall position reported is considerably better in terms of carers being given sufficient support/help or information on the giving of medication, but even here, 30% reported that they have not been given what they perceive to be sufficient help or information. The position on help given with this caring task is better for more recent carers (24 % with insufficient information for those caring for up to 2 years) than for long-standing carers (35% of those caring for 20+ years).

3.21 Only 46% of carers responding had been given sufficient help/support or information about the side effects of medication, and in this case there does not appear to be a variation based on the duration of caring. There was a variation in responses based on the relationship to the person being cared for. A particularly low number (37%) of those caring for their parent/parent-in-law felt they had been given sufficient help/support/information in this area compared to those caring for a spouse (47%) or son/daughter (51).

### Help or support with caring or advice about benefits/grants

3.22 The major sources of help or support with caring or advice about benefits and grants are listed in the table. The largest group of responses were those who obtain this help from Social Services, followed by the PRTC Centre and a local carers' group. Informal sources, such as family and friends were also popular responses, followed by the Health Service. 12% said that they receive no help at all with caring or advice. These are more likely to be caring for people with physical or mental illnesses, and to have been caring for over three years. There were some variations in responses based on geographical region, age and time spent caring but the important thing is that carers receive the help they need, rather than where they get such help from.

Source of help or support	%
Social Services	38
PRT Carer's Centre	31
Local carers' group	31
Friends	19
Family	17
Health Service	15
No help received	12

### Ease of use of sources of help and advice

- 3.23 It is a matter of some concern that almost a third (32%) of carers found the sources of help and advice available to them to be either fairly or very difficult to use. Of those who found these sources to be either very or fairly difficult to use, over half (53%) said that this was due to lack of information on the help available. Nearly a third (29%) identified lack of time to use the service as a factor. Significantly, 26% identified transport or travelling difficulties and 17% identified their own lack of confidence as barriers to using sources of advice and help.
- 3.24 The proportion of those who found the sources very or fairly difficult to use was higher among younger carers (35 % for those aged under 45) than older carers (28% of those aged 65 or more). Those with most difficulty were caring for people who were aged 16 to 29 years. Other groups who found significantly more difficulty were those caring for more than one person; those caring for people with a physical illness or learning disability and those spending a longer time caring.
- 3.25 More black or minority ethnic carers found the sources of advice and help difficult to use (44%) than the other carers in the survey (30%). This is a further indication of problems of access to services for that group of carers.
- 3.26 Those who care for less than three hours a day are less likely to have difficulty in accessing help and support. This is perhaps not surprising, because they probably have more time to access that help, but, paradoxically, may not be the carers who most need it. Those caring for more than 8 hours a day were more likely to say they had difficulty.
- 3.27 There was a strong link between the carers who have most difficulty with the sources of advice and help and other questions indicating the amount of information which had been provide to the carer. Those who have most difficulty with sources of advice and help are also those who get most of their information about the diagnosis of the disability or illness of the person cared for from newspapers or leaflets, or the person cared for (rather than from contact with professionals) or by word of mouth ; who have not had sufficient information about the key caring tasks; who are less likely to think that key professional understand them; who are less likely to think that they have influence over services and who are more likely to think that it is difficult to obtain services.
- 3.28 Analysis of these findings has produced a picture of what we might call the “information-poor” carers, because there are a number of indicators of help, support and information which appear to be correlated. They are also correlated with the indicators of understanding by professionals, difficulty of access to

the services themselves and perceptions of influence over those services. These carers are not, as one might initially expect, more likely to be elderly and caring for the elderly. Rather they are more likely to be younger and caring for people with a mental illness, learning disability or physical disability. It may be therefore that characteristics of the person cared for and the services they need are as important as characteristics of the carer in this important area.

### Use of the Internet

- 3.29 The National Strategy signalled that “The Government intends to ensure that full use is made of information technology in providing information for carers which is up-to-date and easily accessible” (p.43).....We will also ensure that each Government department will provide, on the Internet, details of the services or benefits affecting carers for which it is responsible”.
- It was therefore appropriate to look at access to, and use of, the Internet by carers.
- 3.30 More than a third (35%) of carers responding had access to the Internet at home or work. This compares with around 40% of the total UK population having access to the Internet.<sup>4</sup> A further 8% of carers in the survey said they can access the Internet through other means. Perhaps surprisingly, access to the internet was greater among female carers than male carers (47% compared with 35%). Access among respondents decreased markedly as their age increased (63% of those under 44 compared with only 19% of those aged 65 plus).
- 3.31 The number of respondents with Internet access also decreased as time spent caring increased (59% of those caring for less than 3 hours per day compared with 37% of those caring for more than 15 hours). This may be a reflection of an age difference between such carers and/or differences in employment status. It is however potentially important because the value of access to the Internet is likely to be greater for those who spend most time caring.
- 3.32 Of those without access to the Internet, less than 1 out of 10 could see themselves gaining access in the next year. However, there is again an age variation here, because this figure increases to 18% for those under 44, but is only 5% for those aged over 65.
- 3.33 The most popular reasons for using the Internet are shown in the table. Searching for information and using e-mail (72%) were the most popular. Shopping and banking did not emerge as particularly popular, although both these services on the internet may be thought highly useful to heavily-committed carers. In terms of



# Information needs

variations between types of carer, use of e-mail declined as time spent caring increased. This is a surprising, as one might have expected e-mail to be particularly useful for those who spend a lot of time in their caring role.

Use of Internet	%
Information Search	78
E-mail	72
Holidays	23
Shopping	22
Banking	21
Reviews/what's on	15
Discussion groups	5
Other	5
Chat rooms	5

3.34 At the time the survey was conducted the PRTC website had only just been launched. It is not surprising, therefore, that of those carers who have access to the Internet, only 13% had visited the PRTC website. 29% had visited other carer or charity websites. This represents only a proportion of the information searches which carers are undertaking.

3.35 Relevant to this, respondents were asked which services would be of interest to them on a carers' website. The results are shown in the table. Over half specified on-line discussion with professionals as being of interest, followed closely by those wanting provision of information. Over a third specified shopping for special items and on-line discussion with other carers. There was a variation in the responses based on carer's age, with carers under 44 years being much more likely than older age groups of carers to express an interest in all services and particularly in online discussion with professionals, information services and online discussion with other carers.

Interest in services on carers' website	%
Online discussion with professionals (e.g. doctors, nurses)	53
Information	50
Online discussion with other carers	38
Shopping for special items (e.g. aids, medical products)	34
Shopping for general items	15
Other	6

3.36 There were also differences in the levels of interest in online discussion with other carers based on amount of time spent caring, with those caring for 15 hours or more per day being much more likely (41%) to be interested in this than carers who spent three hours a day or less caring (28%). Carers who were caring for longer periods each day were also more likely to say they were interested in using the internet for shopping for general items (17%) than carers who care for less than three hours (9%) Some of these services are, of course, already available on the internet.

# Consulting and involving carers and carer assessments



# Consulting and involving carers and carer assessments

4.1 On the theme of support for carers, the National Strategy made clear that the Government's objective of supporting carers to carry out their caring responsibilities would require a different response from service providers in the way they plan their services. The strategy said:

"service providers must see carers as partners in the provision of help to the person needing care, and must involve them as partners. ...

Involving carers and their organisations, alongside patients and users of services, is a way to ensure that those services are responsive." (p45)

The Strategy suggested areas for carer involvement and consultation as:

"...in discussions about the care of the person for whom they are caring, in planning processes, in commenting on particular services and on specific initiatives..." (p45)

Initiatives which were already introduced at the time of the National Strategy and which should involve carers are health improvement programmes, Joint Investment Plans, the NHS survey of patient's and carers views and local authority service and strategy planning. The strategy also said that health and local authorities should:

"communicate regularly and routinely with carers and their organisations". (p46)

The strategy also put forward a good practice checklist on involving carers. (Appendix 2)

4.2 Our survey asked carers whether they had been asked to give their views on services for the person they cared for and on services for themselves as carers. We asked carers which organisations had asked for their views and asked for comments on the way they were consulted about services. Finally on this topic, we also asked whether carers had been given any feedback about decisions made or changes which resulted from their views or those of other carers.

4.3 The National Strategy had emphasised the need for staff working in statutory services to:

"recognise the expertise, perspective and circumstances of carers and the people they are caring for." (p37).

We asked carers in our survey to what extent they felt that different professionals, staff and others working in the health and social care services understood their role as a carer. We also asked how much influence carers felt they had over services provided for the person they cared for.

4.4 The Strategy also rightly points out that "involving carers in service planning or provision must be relevant to carers and aim to achieve something for them." (p46).

A series of key steps are laid out in the strategy for health and local authorities to follow:

- Identify carers in the area and their needs
- Involve carers in assessments, or ask them to assess their own needs (p46)

On assessments, the Strategy recognised that the right which the Carers (Recognition and Services) Act of 1995 had given to carers who provide substantial care on a regular basis to an assessment from Social Services had only been implemented in a patchy way. The strategy said that:

"Carers should be entitled to expect at least an annual discussion of what they need, what is available, the help are receiving and the care provided."

Further, people who need care for more than 50 hours a week:

"should generally be in touch with Social Services and their carers should be receiving an assessment of their own needs." (p38)

The Carers and Disabled Children Act 2000 put into legislation in England key aspects of the National Strategy, including giving carers the right to an assessment of needs in their own right, even if the cared for person refuses an assessment themselves. Our survey asked whether carers were aware they could have an assessment of their own needs. We also asked whether carers had had an assessment and if they had, whether this had led to changes in the support or services being received.

## Partnership working and the involvement of carers

4.5 It is increasingly being acknowledged that carers make a huge contribution to the provision of health and social care in the UK. Expressing the contribution made by carers in financial terms puts it into context. Figures calculated by Carers UK in 2002 put the value of carers' contribution at £57.4 billion per year – a similar figure to the entire spending by the government on health.<sup>5</sup> Using the same method of calculation, the value of the annual contribution made by the carers responding to this survey amounts to £63.4 million. As they are such major contributors and stakeholders, carers feel that they want their contribution to be recognised. They also want to be involved in and consulted about the services which they and the person they are caring for receive.

## Are carers being consulted by service providers?

4.6 When reviewing this question we realised that there is a wide range of experience among carers and carer organisations of consultation by service providers. Many

service providers are concerned about the number of carers who are never involved in consultation. Yet, as we planned the Carers Speak Out survey, concern was also expressed by centres in the PRTC network that many carers were suffering from consultation fatigue. The reason often given for this was not that carers did not want service providers to listen to their views and hear about their experiences. Rather the reason seemed to be that those who had experienced consultation and involvement with statutory service providers found the experience too often to be a negative one, due to poor consultation practice or lack of feedback about results.

4.7 This informal feedback from Carers' Centres on how a number of carers were viewing consultation has been confirmed by recent detailed research with carers on consultation. The Joint Futures for Carers Report<sup>6</sup> looked at this issue for Scotland and highlighted the concerns of carers who were asked how they felt about consultation exercises they had been involved in. Carers were asked whether the agencies consulting them followed the good practice points detailed in the short checklist in the UK Strategy for Carers and in the National Strategy for Scotland's Carers<sup>7</sup>. The results gave cause for concern: "What does emerge in many areas is a picture of weak or indifferent practice with consistent adherence and resourced commitment to good consultation principles the exception rather than the rule"

With regard to the NHS, the report also comments: "significant numbers of NHS planning bodies never consult carers or their representatives when developing health plans and strategies important to carers and respond only partially when carers do express their views and needs, or not at all"

4.8 In our survey we asked a number of questions about consultation with carers. Firstly, we asked carers whether they had been asked to provide their views on the services provided for the person they care for and on services provided for themselves as carers. Only a third of carers (34%) had been asked for their views on services for the person being cared for and less than three in ten (29%) had been asked for their views on services for themselves.

4.9 There was a difference in responses based on the illness or disability of the person being cared for. Carers of those with mental illness and physical disability, learning disability or difficulty and old age and frailty were the most likely to be asked for their views. Carers of people suffering serious illness or disease (26%), physical illness or physical disability (27%) were the least likely to be asked for their views.

Type of disability or illness of person being cared for	Carers asked to give views on services for the person cared for %
Mental illness and physical disability	50
Learning disability	44
Old age and frailty	42
Learning disability	37
Mental illness	35
Mental illness and physical illness	28
Physical illness and physical disability	27
Physical illness	27
Serious illness or disease	26

#### Which organisations are consulting with carers?

4.10 We asked carers which organisations had asked for their views about services and the results are shown in the table. The high proportion of respondents listing The Princess Royal Trust for Carers possibly reflects the fact that Carers Centres both conduct consultation themselves and are frequently asked by local authorities to facilitate local consultation with carers.

It is notable that while half of the carers responding had been asked for their views by Social Services, fewer than two in ten had been asked for their views by NHS organisations. This finding is in accord with recent research on consultation with carers in Scotland. The Joint Futures report found that levels of carer consultation within the NHS were improving only slowly and from a very low base and that there were a number of barriers to NHS-led carer involvement.<sup>8</sup>

Organisation asking for views	%
Princess Royal Trust for Carers	56
Social Services	51
NHS organisation	18
Other	17

#### Are carers being given feedback following consultation?

4.11 The good practice guidelines recommended in the National Strategy emphasised the importance of giving feedback following consultation with carers: "Feedback – is very important. You know when, realistically, you will be in a position to provide feedback. Be honest and prepared to disappoint expectations of speedy and large-scale changes coming from the consultation process. Explain how and when you will be in a position to provide feedback, what changes you expect to see coming from the consultation exercise they have been involved in and give that feedback when you say you will." (Appendix 2).<sup>9</sup>



# Consulting and involving carers and carer assessments

4.12 We asked carers whether or not they were given any feedback about decisions made or changes which resulted from their views or those of carers consulted. Just over half (56%) of carers responding to the survey had been given this feedback.

4.13 Carers were invited to give comments on consultation and just less than half of those responding gave a view on the overall quality of consultation they had experienced. These were split with around two respondents reporting a negative view of consultation to every one who felt that consultation was generally good. Those giving views of consultation quality have been grouped as follows:

View about consultation of those who commented	%
Generally good consultation	31
Poor consultation practice	25
Consultation ineffective – does not lead to change	12
Difficult to get involved in consultation	6
Not enough weight given to my views	6
Consultation limited by lack of funding	4
Consultation not completely relevant	4
Lack of continuity in consultation process	4
Consultation takes too long	2
Quality of consultation varies by area	2

A range of comments were made by carers about their experience of consultation, in answer to the question:

## Please give any comments about the way you were consulted on services

“Usually initiated by me, response in general is good”

“I have had excellent help from [named] Social Worker”

“Our local carers centre is the only place to receive any care or consultation”

“There seems to be a gap between NHS/Social Services and myself that needs to be bridged”

“Social Services and NHS generally don’t see the role of the carer important and therefore don’t seek their views”

“Everybody has a “I will try to help in some way attitude”, but with no outcome at the end of it all! What’s the point?”

“Views are asked, but are certainly not taken into account”

## How much do professionals understand the carers’ role?

4.14 We asked carers how much they felt that a range of professionals and staff working in health and social care understood their role as carers. These included NHS Consultants or Specialists, GPs, other local NHS staff, Social Services staff, staff and volunteers of local voluntary groups and carers support workers. As can be seen in the table, GPs, and Carer Support Workers are felt by carers to have the best understanding of their role, followed by Social Services staff. NHS Consultants and other local NHS staff are felt by those carers responding to have least understanding of their role.

4.15 Although Social Services staff scored averagely well on the extent to which carers felt they understood the carer’s role overall, 17% of carers responding did not feel that Social Services staff understood their role at all. Given Social Services’ particular role in supporting and working with carers, this finding does give some cause for concern. There were significant variations in carers’ responses with regard to Social Services staff. Those caring for less than 8 hours per day were significantly less likely to believe that Social Services understand

## How well health and social care staff understand the carer’s role

Professional or staff role %	Understands carer a lot/quite a lot %	Understands carer some %	Does not understand carer at all %	Don’t know %
Carer Support Worker	52	12	6	30
GP	45	32	13	10
Voluntary group staff or volunteers	37	15	11	36
Social Services	34	30	17	19
NHS Consultant	28	28	21	23
Other local NHS staff	23	30	21	26

their role. The carers who were most likely to say that Social Services staff did not understand their caring role at all were those caring for people with a mental illness (28%) compared to those caring for people with old age or frailty (11%) or a physical disability (16%).

4.16 Carers of people with a mental illness or a learning disability were also more likely than other groups of carers to feel that local NHS staff did not understand their caring role. Looking at the responses about GPs, the significant factor was duration of caring. Carers who had begun caring in the last 2 years were more likely than carers of longer duration to say that GPs and other NHS staff understood their caring role. Thus, carers who had been caring for two years or less felt that their caring role was better understood by their GP (53%) – compared to 39% of carers who had been caring for 20 years plus. The newer carers also felt that local NHS Staff (31%) understood their caring role better than that felt by carers who had been caring for 20 years plus (18%).

### What influence do carers feel they have over service provision?

4.17 We asked carers what influence they feel they have, as a carer, over the services provided for the person they care for. Responses show that over six in ten feel they have some influence. Less than four out of ten (37%) of carers feel they have a lot or quite a lot of influence while just over a quarter (26%) feel that have some influence. The remaining carers felt they had only a little influence (18%) and around two out of ten carers feel they have no influence over services.

4.18 In terms of the degree of influence which carers felt they had over services, there were differences based on the amount of time they spent caring and on the illness or disability of the person cared for. The most heavily-committed carers, those who care for 15 or more hours per day, were more likely (39%) to say they had a lot or quite a lot of influence over services than those who care for less than three hours per day (31%).

Type of disability or illness of person being cared for	Carers who feel they have a lot or quite a lot of influence over services for the person being cared for %
Physical disability	46
Old age or frailty	44
Mental illness and physical illness	41
Physical illness and physical disability	38
Physical illness	37
Learning disability	31
Mental illness	24

As can be seen in the table, respondents were more likely to say they had a lot or quite a lot of influence over services if they were caring for someone with a physical disability or old age and frailty than those caring for someone with a learning disability or mental illness.

### Carer assessments

4.19 On carer assessments, we asked whether carers were aware they could have an assessment of their own needs, even if the person they cared for did not want an assessment. (This is a statutory right in England and Wales but not yet in Scotland). We also asked whether carers had had an assessment of their own needs as a carer and if they had requested an assessment or whether it was offered to them.

4.20 Only a quarter of carers responding had had an assessment of their needs and just over half of those responding (52%) were aware that they could have an assessment of their needs.

4.21 The finding on the level of carer assessments is in line with the low level of assessments recorded for councils in England through Social Services Performance Assessment Framework Indicators. The framework indicators show the number of carer assessments as a proportion of the total number of clients and carers receiving assessments. The average for councils in England is 21%, with a wide variation from 10% in London to 25% for Shire councils. Figures for individual councils also varied from 0% to 84%.<sup>10</sup> Carers, and the people they care for, who have not received assessments from Social Services would be outside the scope of the reported figures.

4.22 The low proportion of carers in the survey who had been given an assessment of their needs is a cause for concern. The sample of carers in the Carers Speak Out survey was biased towards more heavily-committed carers with over nine out ten respondents caring for 20 hours or more a week and nearly eight out of ten caring for 50 or more hours per week. This latter group of carers (over 2,100 carers in the survey) are those whom the National Strategy says "...should be receiving an assessment of their own needs".<sup>11</sup>

4.23 Even more concerning is that, with some exceptions within the overall figures, the trend in the number of carers receiving assessments appears to be a downward trend, compared to an earlier survey of carers. A survey undertaken in 1998 found that 38% of carers responding had had an assessment with 6% of respondents waiting for an assessment.<sup>12</sup> This 1998 survey was showing an upward trend from an earlier survey where the figures for carer assessments had been around 20%.<sup>13</sup> In 2002,



# Consulting and involving carers and carer assessments

despite Government intentions on carer assessments described in the National Strategy, the figures in the Carers Speak Out survey show a trend back to the low levels reported five years or more ago.

## Awareness of carer assessments

4.24 Carers aged 44 years and under were less aware of carer assessments. This variation is mainly due to the duration of caring, although there is also a weaker relationship with age of the carer, which remain after removing the effect of the duration of caring. Only 36% of respondents aged under 44 years were aware they could have an assessment compared to over 50% of carers aged 65 years or over.

The highest awareness of carer assessments was among respondents in Wales (six out of ten carers) and the South region (five out of ten). In other areas around four out of ten carers were aware they could have an assessment.

## How many carers have had an assessment of their needs?

4.25 As stated earlier, the National Strategy stressed the need for carer assessments for the most heavily committed carers. Although only a quarter of carers who responded had had an assessment of their needs, there was some variation in responses based on the amount of time spent caring. Among those caring for less than 3 hours per day, only 15% reported they had had an assessment. This rose to 22-23% among those who were caring between 3 and 14 hours a day and rose to 27% of those caring for 15 hours per day. However, the survey does highlight the stark fact that among those carers in the survey who are caring for more than 50 hours per week, more than 70% had not had an assessment.

4.26 Carers were more likely to have had an assessment of their needs if they were caring for a spouse or partner (29%), or if they were co-resident with the person they cared for (26%). They were also more likely to have had an assessment if they lived in the South Health & Social Care Region (31%) or in Wales (28%). The lowest levels of carer assessments were in the North (23%) and Midlands and Eastern (22%) regions and in Scotland (20%). However there is, as yet, no statutory duty in Scotland for carer assessments.

We also asked carers who had had an assessment whether they had requested it or if it had been offered to them. We found that carers who started caring more recently were much more likely to have been offered an assessment (75% of those carers for 2 years or less

compared to only 48% of those who had been caring for 20 years or more). A higher proportion of carers who were 65 years or older had also been offered assessments (67%) compared to younger carers 44 years and under (51%).

## Did carer assessments lead to changes in support or services?

4.27 We asked carers who had received an assessment whether this had led to changes in the support or services being received. Over half (56%) of respondents who had a carer assessment said it had led to such a change.

4.28 More carers living in Wales and Scotland had seen changes in services and support following an assessment than carers elsewhere. Two thirds of carers in Wales (67%) and just less than that (65%) in Scotland reported seeing a change in services following an assessment, compared to other areas. The region recording the lowest level of change following an assessment was the Midlands and Eastern region, at 42%.

There was also a difference in the proportion of respondents who were reporting changes to services and support following an assessment based on the duration of their caring as shown in the table. The proportion of carers who had seen changes following an assessment peaks with carers who had been caring for 3-5 years and is much higher for these than for other carers who have been caring for 20 years or more.

Duration of Caring	Have seen a change in support or services following assessment %
Less than 2 years	55
3-5 years	63
6-9 years	57
10-19 years	54
20 years or more	48

## What carers say about assessments and the assessment process

4.29 Comments from carers attending Carers Speak Out consultation events support the finding that only a minority of carers are having assessments of their needs. There follows a sample of the comments made and issues raised by carers about assessments and the assessment process:

### Awareness of carers' assessments

- Assessments are not being offered.
- Only one carer in the group had had a carers' assessment and only two carers were aware they

existed. There is more work to be done in advertising them to carers.

- Some people felt that they might have had a carer assessment but were unsure about whether they had, due to lack of feedback or outcomes from the process.
- Assessments are often not made until the carer is at breaking point.

#### The assessment process

- If the assessment process is complex and unclear it can stop people asking for services or support.
- There is a lack of privacy for carers, when assessments take place.
- Carers should be given the opportunity and support to consider their own needs prior to a carers' assessment taking place.
- Attitude is important – carers do not want paper exercises.
- Sometimes it can take 6-8 weeks just to have an assessment. Then you have to wait for the service. This feels like a waste of time when you know what you need. "I would rather not have the assessment. I would rather just go and see my doctor".
- The reason that some carers won't have an assessment done is that they feel they don't trust the social worker.
- Other carers won't have an assessment because it can cause embarrassment, a feeling that you are asking for too much or being a nuisance.

#### Changes made following an assessment

- Assessments should result in information on what is available, in the public, private and voluntary sectors.
- Services provided as result of assessment are not always suitable or available and can be of poor quality, i.e. respite care.

4.30 These comments and points reveal a variety of problems, issues and concerns for carers in the assessment process. The topic of assessments and changes to services for carers was also debated at the national Carers Speak Out consultation event. A number of key points emerged from that discussion. Firstly, it seemed clear that there is a lack of information about what services are available and how carers' needs can be met. The carer assessment system offers a means for providing information to carers about what is available to help them. Carers felt that in terms of assessment processes, there was a lack of consistency in processes and a lack of quality. Carers need both information and explanation about the assessment process. The question was asked as to why Government had not run a campaign to promote carer assessments?

# Carers health needs and local services for carers

5.1 Caring for Carers was the title of the National Strategy and it is a theme of great importance to carers. In considering care for carers, the National Strategy expressed the Government's aim as:

"to enable carers to make more choices for themselves and to have more control over their own lives – for their own health and wellbeing. We want services to recognise carers as individuals in their own right." (p55).

The Strategy stated that "carers have a right to have their own health needs met. They need help to maintain their own health, both mental & physical." (p55) and that "Carers have a right to expect that the NHS and social services should help them maintain their own health." (p56)

Our survey asked carers if they felt that caring had a negative impact on their own health and if so, in what ways their health was affected.

5.2 On local services for carers, the Strategy stated that new legislation would follow to enable local authorities to provide services to address carer's wishes and needs more directly. Following this, the Carers and Disabled Children Act 2000 put into legislation key aspects of the national strategy, including:

- allowing councils to give services to carers to help them care, separate from those provided for the person being cared for and allowing councils to charge for those services (a discretionary power for local authorities in England)
- giving local authorities a power (but not a duty) to provide direct payments to carers (for services for them, not for the person being cared for); for services to parent carers to children with disabilities
- giving local authorities a power (but not a duty) to offer vouchers for short term breaks (the implementation date for vouchers was April 2002).

However, local authorities have told the Association of Directors of Social Services<sup>14</sup> that they do not have the funding for the new infrastructure required to deliver these extra services to carers. Most authorities have said they have not yet developed the new services for carers. The exception to this are those services set up under the restricted terms of the Carers Grant, designed mainly to give carers a break from caring.

### Carers' own health

5.3 We asked carers if they felt that caring had had a negative impact on their own health. Overall, more than 8 out of 10 carers (85%) in the sample said that caring had had an impact on their health. Carers who were even more likely to feel that caring had an impact on their own

health were those carers who were female (89%); caring for a person with serious illness or disease (94%) or a person with mental and physical illness (90%); if they had been caring for periods between 10 & 20+ years or caring for 15 hours or more a day (both 89%). Carers aged 44-65 years were more likely to feel caring has a negative impact in their health than other age categories. This may be because it includes people who have been caring for some time whilst still being economically active.

5.4 For those carers who responded that caring had a negative impact on their health, we also asked how caring had affected them. Almost nine out of ten respondents felt that caring had affected their mental well-being (e.g. anxiety, stress, depression, lack of sleep). More than four out of ten (43%) felt that caring had affected their physical well-being (e.g. back pain or strain, other injury or strain). Also, nearly five out ten respondents said that caring left them no time to look after their own health. Male carers were more likely (80%) than female carers (34%) to say that caring left them no time to look after their own health. Non-employed carers were more likely (49%) than retired (41%) or working carers (36%) to say that caring affected their physical well-being

### Health and safety issues for carers

5.5 More than four out of ten carers in the survey felt that caring had affected them physically – through back pain or strain or other injury. Unsurprisingly, the proportion of carers saying their physical health had been affected was even higher among those caring for a person with a physical disability or illness, with over 5 out 10 carers affected.

The issue of safe caring had been highlighted in the National Strategy, which stated: "Many of the physical injuries from which carers suffer could be prevented if they were helped through proper training to learn how to move the person they are caring for in a safe and effective way" (p56)

However, as detailed in section 3 of this report, over half the carers responding also said they had not been given sufficient help, information or support with the key caring task of lifting, moving or handling the person cared for.

5.6 The issue of safe caring was also raised in discussion groups of carers at the Carers Speak Out regional consultation events. Many carers raised points about what they are expected to do, as opposed to what professionals are allowed or not allowed to do. The following comment is one of many that illustrates the point: "Why are carers expected to carry out tasks when professionals would need two people to carry it out?"



# Carers health needs and local services for carers

5.7 Carers discussing this issue felt that service providers operated double standards as regards concerns about physical injuries caused by lifting the person being cared for. Providers were concerned about preventing physical injury to paid carers because they had a legal responsibility, but they did not show the same concern for informal carers. Carers noted that it can take a very long time for them to receive equipment to help with moving or transferring the person they cared for. However, as soon as health and social care staff are helping as formal carers, the appropriate equipment was provided promptly. The fairness of this two-speed approach was questioned.

## Services for carers

5.8 We noted earlier that although legislation has paved the way for new services from local authorities to address carer's needs, most authorities feel they cannot offer extra services without additional funding being made available. Some new services have been made available for carers, using the Carers Grant funds (intended for breaks for carers). Birmingham City Council consulted with carers locally and then expanded their services to carers to include the following, which had been requested by carers:

- a scheme to provide mobile phones for carers
- paying fees for a college course
- paying for IT or other needed equipment at home e.g. a tumble drier
- paying for driving lessons, to help with the carers transport
- paying for lessons on a musical instrument

It is clear from these examples that when carers are consulted about use of funds, the way they define a break from caring may be much more diverse.

## Breaks for carers

5.9 In the survey we asked carers whether they wanted to take a short break from caring. We also asked what types of help they would need to take a break and what types of break they would like to have. More than 6 out of 10 carers responding to the survey (62%) said that they want

to take a short break from caring. As shown in the table, those carers who were more likely to want to take a break were female carers, carers aged 44 years or under, those caring for 15 hours a day and those carers looking after a son or daughter. Conversely, those carers who were less likely to want to take a break were male carers, those aged 65 years and over, those caring for a spouse/partner and those caring for three hours or less a day.

## What help do carers need to take a break?

5.10 The types of help and support which carers responding to the survey say they need to take a break from caring vary with age, employment status, where carers lived and time spent caring. Overall 65% of carers would need help with respite care, 34% help from a sitting service and 33% would need financial help.

5.11 The pattern of different types of help needed by different types of carer and in different caring situations is clearly complex. Providers of breaks clearly cannot take a "one size fits all" approach in providing support to carers to take breaks. Some of the relationships between types of carer and their needs seem clear and many would be expected. The proportion of carers who needed help with respite care increased with the age of the carer. This may relate to the fact that carers of 44 years and under are more likely to have friends and family they can call on to help with alternative care than carers aged 65 years or over. However, carers aged 44 years or under, those caring for 15 hours a day and those carers who were less likely to want to take a break were male carers, those aged 65 years or over, those caring for a spouse/partner and those caring for three hours or less a day.

5.12 Carers from black or minority ethnic backgrounds were much more likely to say they needed financial help (66%) or help with transport (27%) than the other carers in the sample (30% and 12% respectively). Also, carers from black or minority ethnic backgrounds were less likely to say they needed help with respite care (48%) or a sitting service (27%) than other carers in the sample (67% and 34% respectively).

Type of Carer	% who want to take a break	Type of carer	% who want to take a break
Female Carer	66	Male Carer	53
Aged 44 or under	67	Aged 65 or over	55
Co-resident carer	65	Carer living elsewhere	48
Black or ethnic minority background	77	White background	61
Caring for a son or daughter	70	Caring for a spouse or partner	58
Caring for someone with a learning disability	77	Caring for someone with a physical disability	50
Caring for 15 hours a day plus	67	Caring for 3 hours a day or less	34

Type of carer	% needing help with respite care	% needing a sitting service	% needing financial help	% needing help with transport
All	65	34	33	14
Carers aged 65 years or over	69	30	18	15
Carers aged 44 years or under	58	39	53	17
Employed	64	36	30	11
Not employed	61	37	47	15
Living in London	52	30	44	19
Living in Scotland	70	33	28	12
Caring for 15 hours or more	68	35	34	13
Caring for 3 hours or less	57	36	20	18

### What type of break do carers want to have?

5.13 We also asked carers what type of break from caring they would like to have. Overall, the most popular types of breaks carers say they want are time for themselves (53%) one week's holiday (51%) a weekend away (45%) a day out (34%) and time for leisure or recreation (33%). There were some differences in responses mainly based on the carer's age and whether or not they lived with the person they cared for. A higher proportion of carers 44 years and under wanted to take a break just to get extra sleep (34%) – this decreased to just 20% in carers 65 years and over. Carers aged 44 years and under were also more likely to want a break to have an evening out (40%) or to have time for themselves (61%) than carers aged 65 years or over (15% and 47% respectively). Carers who are co-resident with the person they care for are almost twice as likely to want a break to go shopping (22%) or for an evening out (29%) or for a day out (36%) than those who lived elsewhere (12% for shopping and 15% evening out 23% day out).

### Carers who say they do not want to take a break

5.14 While six out of ten carers responding to the survey did want to take a break, almost four out of ten carers in the survey said they would not like to take a break. Given the emphasis on carers' breaks as the major new service for carers this finding deserves some attention from policy makers and perhaps more research from carer organisations.

5.15 The way the questions on short breaks were put in the Carers Speak Out survey envisaged a break as time for the carer for themselves and to take time out and get away from the caring situation. Those carers who said they did not want a break of this type might benefit from some other type of support, either at home or a break taken jointly with the person being cared for.

Carers were more likely to say they did want to take a break from caring if they were caring for three hours or less per day, if they were not living in the same house as the person they cared for and if they were caring for a friend or neighbour rather than a relative. Those caring someone with physical disability, or those caring for a spouse or partner or carers aged 65 or over were also less likely to want to take a break than those in other caring situations.

### What are carers' biggest problems?

5.16 We asked carers to tell us what their biggest problems are. The main problems listed, with some illustrative comments from carers, were:

- No time off/no help at night/lack of sleep/relentlessness (14.7%);  
"My mother refuses to go anywhere away from home –she depends on me for everything"
- Problems with own mental well-being e.g. depression, lack of energy, anxiety, unhappy, stressed (10.4%);  
"My husband wants me by him constantly, he gets very anxious which is very tiring. I lose concentration easily."  
"I am not able to relax when I have time on my own"  
"I am impatient and stern due to lack of sleep"
- Physical difficulty coping with caring tasks/own physical health (8.4%);  
"Age is catching up on me, I run out of steam more quickly than I used to"
- Lack of spontaneity/no control over own life/no freedom/no privacy (8.4%);



# Carers health needs and local services for carers

“You do feel tied to the person you care for, it is very hard to have a separate life”

- Uncertainty about the future/coping with the deterioration of the person being cared for (7.3%);  
“Wondering whether my son will be able to look after himself and his affairs if my husband and I are no longer able to give him our support”
- Juggling responsibilities (6.2%);  
“Finding enough time to cope with my mother’s needs/children’s needs/work”
- Lack of financial support/low income (5.6%);
- Coping with specific problems with person being cared for e.g. incontinence, memory loss, mobility, personal hygiene (4.3%);  
“My wife’s mental attitude to simple things like putting on clean clothes”
- Lack of emotional support (3.4%);
- Generally more support needed (3.1%);
- Dealing with abuse/aggression/ moods/ negative attitude/ mental problems (3%);
- Lack of appropriate respite/day care/cost of (3%);
- Need for services/aids/facilities to be provided/accommodation unsuitable (2.7%);
- Transport/travel problems (2.2%);
- Lack of contact with/access to NHS/Social Services e.g. waiting times (2%)

A further 3% of those responding said they have no problems as a carer.

5.17 The main differences between what carers responding saw as their biggest problem varied with the age of the carer. Among respondents aged 65 years and over, a higher proportion (13%) said that their biggest problem was the physical difficulty of coping with caring tasks or their own physical health problems. They were also twice as likely to find that the uncertainty about the future or coping with deterioration of person cared for their biggest problem (10%) than those aged 44 years

and under (4.2%). Younger respondents (aged 44 years and under) were far more likely (10%) than those aged 45-64 years (6.5%) and those aged 65 years or more (4%), to find juggling responsibilities as their biggest problem (for example caring, studying, working).

## What would make the biggest difference to carers?

5.18 We also asked carers what would make the biggest difference to them as a carer, in an ideal world. A wide range of responses were given, as follows:

- More money/funds/ a 'decent' wage (11.5%);  
“A decent wage for a job well done and pension rights”  
  
“More money would help, I.C.A should not stop at pension age, as you still have to care for the patient. As you get older, you need more help as well.”
- Time off/regular breaks/ without guilt (9.9%);  
“To be able to have a holiday without the guilt”  
  
“More time for myself, time to get an undisrupted nights sleep”
- Access to appropriate respite care/more/free (9.5%);  
“Good quality and consistent respite care”
- More support/facilities generally/better information on what is available (8.9%);  
“Help and information offered rather than having to look and ask for it”  
  
“More positive practical help and advice from Social services and benefits agencies. More openness from authorities and more facilities for the person cared for in leisure and other activities, independent of carer.”
- Sharing the caring with someone else e.g. walking companion, take person cared for out, sitting service (6.8%);  
“More support and understanding when you feel you can’t go on, but you always do because nobody else will do it for you”
- Medical progress in treatment/more consideration of alternative treatments/pain relief (5.6%);

- Certainty over future continuity/development of care (3.8%);  
“To know where my son will live when I die”
- Practical improvements/facilities needed in home/improved accommodation (3.6%);
- Wider appreciation of stress/work involved in being a carer (3.1%);
- Friends/company/social contact/mentor/listening ear (2.6%).

The proportion of respondents who said that to have someone else sharing the caring (e.g. a walking companion, someone to take person cared for out, someone to help at night, sitting service) would make the biggest difference to them as a carer was highest among newer carers. Around 9% of those who had been caring for less than two years felt this would making the biggest difference to them, compared to 8% who had been caring for 6-9 years and just under 4% who had been caring for 20 years or more.

# Local support services for carers

6.1 In considering local care for carers, the National Strategy expressed the Government’s view that: “Carers’ needs may be heightened by their caring role, by their isolation and often by their inability to leave the house for very long because of the needs of the person they are caring for. Carers may be in particular need of support from sources of practical local help and from networks...” (p63)

Local support services for carers can come from Carers Centres or other forms of community support. The Government believes that “local support services for carers are best run and managed by the voluntary sector” (p65)

The Strategy notes that “some areas have well developed carer support services, providing a range of services to different groups of carers...and the centres have clear and close links with General Practitioners, local hospital services and other voluntary organisations”. By contrast, other areas have no support service for carers or the service may be embryonic or on a very shaky financial footing.” (p65)

The strategy states that “the Government believes that all carers should have access to support service” and “will ensure that health and social services identify carer support services in their area in their joint investment plans and give priority to funding these services” (p65)

The Strategy also states that the Government will “require health authorities and local authorities, acting jointly, to bring together the organisations in their locality which assist carers to assess exactly what the needs of carers in their area are and how local support services should best be provided.” (p66)

6.2 Our survey asked carers about what help they have planned if an emergency arose which stopped them caring. We also asked a number of questions about their awareness and usage of The Princess Royal Trust for Carers local Carers Centre. We asked how much they knew about the help and support available at their local Carers Centre. We also asked how often (if ever) they used their local centre and which services they used there. Finally we asked about their level of satisfaction with their local centre and their reasons for that.

### What help do carers have planned if an emergency arose?

6.3 We asked carers if they had any help planned to support the person they care for if an emergency arose which would stop them from caring. Six out of ten carers responding have help planned for an emergency.

Responses are as detailed in the table. Two thirds of respondents had help planned from other informal care sources, including family, friends and neighbours. Formal sources of help, including Social Services and local NHS staff, were cited by less than a quarter of carers.

Source of help in an emergency	%
Family	42
Social Services staff	16
Friends	14
Neighbours	9
Local NHS staff	6
Someone else	3

6.4 Almost 4 out of 10 carers responding to the survey have no help planned if an emergency arose. Those carers responding who were aged 44 years and under were more likely (48%) to have help planned from their family than carers aged 45-64 years (40%). Carers in the sample aged 44 years and under were also twice as likely to have emergency help planned from their friends (21%) than those aged 65 years or more (10%). This variation in responses ties in with other research which points to older carers having reduced networks so they have either no or fewer people to rely on as alternative carers.<sup>15</sup>

### Support from Carers Centres

6.5 We asked carers about their awareness and use of their local Princess Royal Trust Carers’ Centre. We also asked if carers were satisfied with the service provided by the Carers’ Centre. Awareness levels about support and services were 73% overall. Over a third of carers responding said they knew a lot or quite a lot (37%) about the support and services available at their local Carers’ Centre. A further 36% of respondents said they had some knowledge of the services and support available.

6.6 All respondents in the survey had been sent the survey questionnaire by their local PRTC Carers’ Centre, or had been given a survey at a PRTC-run Carers Speak Out consultation event. The Consultation events had aimed at contacting carers for the first time and contacting “hidden” carers. The Carers Centres had also worked with other organisations to invite carers to events. The result was that just over a quarter, (27%) of those responding had no previous knowledge of the support available to them at their local Carers’ Centre. Awareness of services available at a local PRTC Carers Centre was higher among respondents over 65 years (74%) than carers under 44 years (68%) and in Scotland (89%) and Wales (81%). Awareness was less for respondents from black and minority ethnic backgrounds (60%) than it was for other carers responding (74%).



# Local support services for carers

6.7 On frequency of usage of the local Carers Centre around 60% of those responding used the Carers Centre regularly or less frequently whereas 40% said they did not use the Carers Centre at all. Female carers were more likely than male carers to say they used their local Carers Centre. Carers who live in Scotland (37%) or Wales (35%) or London or Midlands and Eastern regions (both 29%) were also more likely to use their local Carers Centre once a month or more frequently.

6.8 Among those respondents using PRTC Carers Centres, the most popular services used were information and advice (78%) and personal support as a carer (56%). Advocacy – taking up issues with other organisations on behalf of the carer was listed by 25% of respondents and voicing carers' opinions to central and local government by 24% of respondents. Other services which carers responding had used included:

- Group discussions/meetings/conferences/interaction with other carers
- Use of alternative therapies such as reflexology, aromatherapy
- Courses/education facilities and leisure facilities

6.9 Over 90% of respondents were either very or fairly satisfied with their local PRT Carers Centre. Overall, only a very small proportion of respondents (1%) were dissatisfied with services. There were some variations in

satisfaction with PRTC Carers' centres services based on and where the carer lives. Highest satisfaction levels were found in Wales (92%) and Scotland (90%), followed by London (88%) and South (87%) regions. However, satisfaction in all regions was 84% or greater being satisfied with services.

Reasons given by respondents for satisfaction with Carers' Centre services were:

- Staff are good (kind, friendly, courteous) 32%
- Importance of services to carer (a lifeline, gave carer confidence, only organisation to help) 14%
- General good comments (e.g. about reliability) 12%
- Centre provides good/helpful information and advice 12%
- Centre provides vital services/support e.g. Young Carers Group (3%)

Among the small proportion (1%) who expressed some dissatisfaction and those who were neutral about services (8%), the reasons given were:

- services not used much/ carer too busy (11%)
- problems with accessing service e.g. inconvenient times, need help to attend (5%)
- specialist or detailed advice/information/representation needed which centre did not supply or centre short-staffed (4%)
- help or support not relevant to carer's situation (4%)
- lack of understanding of some needs (1%)

# Findings on specific groups of carers



# Findings on specific groups of carers

## Male and Female Carers

- 7.1 The *Carers Speak Out* survey has highlighted variations among responses of carers with certain characteristics and in certain caring situations. Some of these variations appear to highlight differences in practice which affect those groups of carers most. Some of these findings confirm trends reported in earlier research. The findings for the different groups are highlighted in this section.
- 7.2 The first group of differences to be highlighted are those between male and female carers. These are shown to have different characteristics and to be in different caring situations as can be seen in the table.

Caring Commitment	Male carers %	Female carers %
Caring for a spouse or partner	65	35
Caring for a son or daughter	14	37
Caring for someone with a physical illness	34	25
Caring for someone with old age or frailty	17	13
Caring for someone with a learning disability	5	17

- 7.3 There were differences which emerged in the survey in the responses of male and female carers on questions about information and support. These were: male carers were more likely to have had information from a consultant or a GP than female carers. Male carers were more likely to say they have been given sufficient help, support or information on lifting/moving/handling tasks than female carers. Female carers in the sample are more likely than male carers to have Internet access.
- 7.4 Female carers in the survey who use a PRTC Carers Centre are more likely than male carers to use the centre for personal support as a carer. They were also more likely to use the Carers Centre to take up issues on their behalf with other organisations and to voice carers' opinions to central and local government.
- 7.5 Female carers in the survey were more likely than male carers to feel that caring has a negative impact on their own health. The impact that carers in the survey said that caring had on their own health was also different for male and female carers. Female carers were more likely to say that caring had an effect on their physical well-being or their mental well being than male carers. Male carers were much more likely than female carers to say that caring left them no time to look after their own health.

- 7.6 Female carers in the survey were more likely to say they want a break from caring than male carers. However, this is likely to be related to the fact that a much greater proportion of male carers in the survey were looking after a spouse or partner and this group of carers was less likely to want to take a break from caring.

## Black and Minority Ethnic Carers

- 7.7 The proportion of carers in the survey who were from black or minority ethnic backgrounds was 8%. Firstly, these carers were in slightly different caring situations than other carers in the survey. The black and minority ethnic carers were more likely (39%) to be caring for a son or daughter than other carers (29%). They were less likely (28%) to be caring for a spouse or partner than other carers (45%).
- 7.8 In terms of difficulty accessing services, there were a number of differences. The black and minority ethnic carers in the survey were more likely to find sources of advice and help difficult to use compared to other carers in the survey. They were less likely to have been given sufficient help/support or information on the key caring task of use of injections, catheters or dialysis compared to other carers. They were also less aware about Princess Royal Trust Carers Centres than other carers in the survey.
- 7.9 There were also some differences in responses on taking a break from caring. Black and ethnic minority carers were more likely to want to take a break from caring compared to other carers. This finding may be related to the fact that more of the black and ethnic minority carers were caring for a son or daughter, a group who were more likely to want to take a break. They were also more likely to say they needed financial help or help with transport in order to take a break than other carers. They were less likely to say they needed help with respite care or a sitting service than the rest of carers in the survey.

## Longer term carers and newer carers

- 7.10 There were some differences in responses among carers in the survey based on the duration of their caring. In many cases, the difference was that the newer carers had a more positive response in terms of access to information and support, recognition as carers and influence over services for the person they cared for, when compared to carers who had been caring for longer durations. This appears to indicate practice changes with newer carers and service improvements affecting newer carers. The percentage of carers in the

survey who had started caring in the last two years or less was 12.5%. In a number of areas of the survey, these carers have more positive responses on their caring experience than longer term carers.

- 7.11 Carers were more likely to have been directed to sources of information, advice and support the more recently they became a carer. They were also more likely to feel that their caring role was better understood by their GP, by Social Services staff and by local NHS staff compared to carers who had been caring for twenty years plus.
- 7.12 The more recently a person had become a carer, the more likely they are to have been given information about the diagnosis and future development of the disability or illness of the person being cared for.
- 7.13 In one category of information, carer assessments, those who have started caring more recently were less aware of their entitlement than carers who had been caring for longer durations. The more recent carers were however much more likely to have been offered an assessment than carers who had been caring for longer. Following an assessment, carers who had been caring for durations of up to nine years were more likely to report they had seen changes in the service and support received than carers who had been caring for ten years or longer.
- 7.14 When carers were asked about what problems they experienced in getting services to help with the care of the person they cared for, those who had been caring for two years or less were twice as likely to report that they had experienced no problems in getting services than carers who had been caring for twenty years or more.

#### **Carers of people with mental illness or learning disability**

- 7.15 The health needs of the person cared for were a significant factor in the question of whether the carer had been directed to sources of information and help when they first began caring. Carers of people with mental illness, mental illness and physical disability or learning disability were more likely than groups of carers of people with other illnesses or carers of people in old age or with frailty to say they had not been directed to source of information and support. This response also indicates that these carers were much less likely to be directed to Carers Centres or local carers groups.
- 7.16 Carers of people with mental illness were more likely to say they received no help or support with caring or advice about benefits and grants.
- 7.17 The carers who were most likely to say that Social Services staff did not understand their caring role at all were those caring for people with a mental illness (28%)

compared to those caring for people with old age or frailty (11%) or a physical disability (16%). Carers of people with a mental illness or a learning disability were also more likely than other groups of carers to feel that local NHS staff did not understand their caring role.

- 7.18 Earlier research has pointed out the differences between carers of people with learning disabilities and carers of people with mental health problems and other groups of carers. In the case of carers with learning disabilities the philosophy and goals of normalisation create tensions between some carers and service providers. Service providers tend to focus on developing the autonomy of the cared for person. Carers of people with mental health problems have more difficulty than other carers in having their caring role recognised. It is recognised that such carers are frequently marginalised by psychiatrists who see their primary obligation to the patient and tend to do little systematically to support carers.<sup>16</sup> In this survey, carers of people with learning disabilities or with mental illness were much less likely than other carers to feel they had influence over services for the person they care for and this seems to be in line with previous research findings.
- 7.19 Around nine out of ten carers of people with mental illness and physical illness or with mental illness felt that caring had a negative impact on their own health, compared to over eight of ten carers overall.
- 7.20 Carers of people with mental illness and physical disability or learning disability or mental illness were the most likely among groups of carers to want to take a break from caring (84%, 71% and 65% respectively).

#### **Carers of people with serious illness or disease**

- 7.21 Over a quarter (26%) of carers of people with serious illness or disease (such as cancer, serious vascular conditions, lung disease) felt that local NHS staff did not understand their caring role at all.
- 7.22 Carers of people with serious illness or disease were the least likely to have been asked for their views about services for the person being cared for, at only half the proportion (26%) recorded for the carers with the highest response (52%).
- 7.23 These carers were more likely than any other group of carers (94%) to say that caring had a negative impact on their own health.

# Findings and recommendations

### Findings – Information for carers

- 8.1 Carers have a pressing need to be directed to good sources of information, help and support. This need can be most acute when they begin caring. There appears to have been a considerable improvement over the last 5 years in signposting carers to sources of information and support when they begin caring. However, around 2 in 10 carers who began caring in the last 2 years were still not directed to sources of information and support, so there is room for further improvement. Practice also needs to improve more for those carers who are caring for someone with a mental illness, learning disability or physical illness.
- 8.2 We can distinguish between two different types of information and support for carers. The first relates to the health needs and treatment of the person cared for. Subject to any patient confidentiality issues, there is no reason why carers should not be fully informed in this area. The second type is information about services and support which may or may not be available for the person being cared for or for the carer. Agencies and authorities should always be open and transparent about their policies for determining priorities i.e. about what is available and to whom, and engage carers in debate about what those priorities should be. However, given limited resources there is no value in giving information to individual carers by informing them about services and support which are not, in practice, available to them because of resource limitations and rationing. This type of information needs to be tailored to what is available in the local area.
- 8.3 Many carers feel that they have insufficient help, support or information provided to help them with key caring tasks. For example, three out of ten carers in the survey felt they had insufficient information on medication while more than half the carers in the survey felt they had insufficient information about the side effects of medication. As many as six out of ten did not have sufficient information help or support on the tasks of lifting, moving and handling the person they care for. The probable effects of this can be judged from the finding that more than four out of ten also reported physical effects from caring such as back pain or strain or other injury. In the Carers Speak Out consultation, carers pointed out that they were expected to carry out physical lifting tasks that would only be done by two people, if they were paid social or health care staff. Carers felt that Health and Safety concerns were for only paid staff and not for them. For example, carers felt that a two-speed system operated for providing lifting equipment. Equipment to help with lifting the person cared for was provided much more quickly for paid carers than it was for unpaid informal carers. The fairness of this was questioned.
- 8.4 Similarly, around six in ten carers said they had insufficient information, help or support with medical procedures such as giving injections and the use of catheters or dialysis. Also, the small number of black and minority ethnic carers who answered this question as relevant to their caring situation were even more likely (almost eight out of ten) to say they had insufficient information help or support with these aspects of caring.
- 8.5 Around a quarter of the carers in the survey have received no information about the diagnosis or future development of the illness or disability of the person they care for. While there are issues of patient confidentiality here, it may be that GPs and other clinicians need to be more pro-active in seeking the patient's consent for this key information to be passed on to the carer. Where consent is not given, information about health needs and treatment cannot be passed to the carer. However, health professionals should be prepared to review this decision regularly with the patient.
- 8.6 It is of concern that one in ten of the carers said that their main source of information about the diagnosis and future development of the illness or disability of the person they care for was either a publication, or information on the Internet. While such sources can clearly be useful additional sources it seems worrying that these sources are being cited by so many carers as their main sources of information about the health needs of the person they are caring for.
- 8.7 Carers receive help or support with caring, or advice about benefits and grants from a range of formal and informal sources but a minority of carers are receiving none. Also, a third of carers responding said they found the sources of advice and help difficult to use. Many lack time to get help or advice or are not confident enough to use the sources of help or advice available.
- 8.8 A significant minority of these carers were shown as lacking access to support, information and contact with health and social care professionals. A picture emerged of "information poor" carers, that is, those carers who have difficulties of access to information and support in some areas are also more likely to also have those difficulties in the other areas of information and support. They are also less likely to feel that professionals understand them or that they have influence on services. These carers who are



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deprived of information and advice are less likely to be elderly themselves or caring for the frail or elderly. They are more likely to be caring for people with a mental illness, a learning disability or physical illness. This raises the question of whether the difficulties of access to information and support are due as much or more to characteristics of the service used or needed as they are to the characteristics of the carer.

- 8.9 The value of information to carers can be shown by the contrast between this picture of “information poor” carers and the more positive experience reported by other carers. As reported in Section 7 of this report newer carers had a more positive response in terms of access to information and support, recognition as carers and influence over services for the person they cared for. There seemed to be a clear link between provision of information needed when carers begin caring and on the health needs and treatment of the person cared for, with more positive feelings by the carer across a range of aspects of the caring situation. In short, well-informed carers feel they have fewer problems.
- 8.10 More than a third of the carers had access to the Internet themselves and a further 8% could access the Internet outside home or work or through other people. Access levels to the Internet were higher among female carers. Among carers who use the Internet there was strong interest in a website which would enable online discussion with health professionals. This is an idea which is already being explored by The Princess Royal Trust for Carers. A third of carers who used the Internet were also interested in shopping for aids or other medical products. The most heavily committed carers were also more interested than other carers in the survey in using the Internet for general shopping.

## Recommendations – Information for carers

- 8.11 It is recommended that:
- In each local authority area, health agencies, and local authorities (with input from carer support organisations) should be required to establish a carers’ information strategy. This would be aimed at giving carers access to support and information at the time when they need it, including the time when they first become carers. Such a strategy should include the following areas:
- Establishing local registers of carers within relevant agencies together with policies for identifying carers.
  - Publicity and awareness raising to encourage people to identify themselves as carers

- Systems in primary care to provide all carers with information on the diagnosis, health status, likely future development, key caring tasks and medication 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 and aware of the importance of ensuring that carers have access to the information they need at the time when they need it (e.g. on discharge from hospital of the person being cared for)
  - Clear information about which services and support are available to carers, including transparency about the priorities for allocation of limited resources in this area
  - A range of options for the dissemination of information, taking account of the needs of different local communities and groups.
  - The maintenance of high quality information for carers, including processes for ensuring that information is kept up-to-date
  - Feedback from carers on the nature, quality and accessibility of information at the local level. Government should earmark funding for local authorities, health organisations and voluntary organisations to provide a carers’ information service, based on the strategy.
- 8.12 Central funding should be provided for local pilot and research projects aimed at increasing the usage of the Internet by carers. Carers Centres could develop usage by offering “Internet Café” facilities for carers to use the Internet.
- 8.13 Carers who use the Internet have a strong interest in online discussion with health professionals. Further development should be explored by carer organisations and health bodies as it could be of significant benefit to carers.

## Findings – Consulting and Involving Carers and Carer Assessments

- 8.14 Although there is a higher level of consultation with carers than there was previously, two thirds of carers said they have not been consulted on their views on services, either for the person they care for or for themselves as carers. NHS organisations appear to be consulting with carers much less than the level envisaged in the National Strategy for Carers.
- 8.15 Carers say that the quality of consultation with statutory service providers is variable and that there is still too much poor or indifferent consultation practice. Service providers appear not to be following known

- good practice guidelines in consultation with carers. For instance, only just over half the carers in the survey had ever received any feedback following consultation.
- 8.16 GPs are seen as the health professionals with the best understanding of the carer's role. Carer Initiatives in GP practices have undoubtedly contributed to the improved carer awareness among GPs. Such initiatives include carer support workers, carer identification, advertising carer help lines, devising and distributing booklets and information leaflets for carers. There are already some examples of useful information and good practice within primary care that could be followed. The Greater Glasgow Primary Care Trust produced an excellent booklet for carers, advertising a carers' helpline and other forms of support for carers. The Primary Care Trust also has a bookmark intended to raise awareness of good practice with carers among staff.
- 8.17 NHS Consultants or Specialists and other local NHS staff are felt to have less understanding of the caring role. Also, some carers, particularly those caring for a person with a mental illness did not think that Social Services understood their caring role.
- 8.18 Four in ten carers feel that they have little or no influence over the services provided. This feeling was more marked among carers of people with a learning disability or with mental illness. This finding seems to show that a substantial minority of carers are not being seen by service providers as "real partners" in the provision of care to the person they are looking after, as the Government had intended they should.
- 8.19 There is reason for serious concern about carer assessments, with few assessments being carried out and levels of concern among carers about the quality of assessments. Although three quarters of the carers in the survey were caring for 50 hours a week or more, only a quarter of respondents had had an assessment. Only just over half the carers in the survey were aware of carer assessments.
- 8.20 There appears to be a downward trend in the proportion of carers who have had assessments, reversing a growth trend which was reported in 1998. Within the overall low figures for assessments, there is evidence that initiatives or better practice in some areas have raised awareness of assessments, with levels of awareness among carers being higher in Wales and the South region of England.
- 8.21 The proportion of carers in the survey who had had an assessment was higher in Wales and in the South region of England. The proportion was also higher among those respondents who were caring for a spouse or partner. Carers who have begun caring more recently and older carers were more likely to have had assessments.
- 8.22 Among carers who have had an assessment, only just over half say that the assessment led to changes in support or services received. Again there were differences in two areas, with carers in Wales and Scotland more likely (67% and 65% respectively) to have seen changes in support or services following an assessment.
- 8.23 Given the low level of assessments being carried out this means that, overall, only one of seven (14%) of carers in the survey had had an assessment which led to a change in support or services. However, different practice on carers' assessments in Wales has led to better a better picture of carers' experience, with the proportion there being nearly 1 in 5 of carers (19%) who had seen a change in services or support. Clearly, although the figures on carers' assessments still need to improve in all areas, the practice on this in Wales has already led to improvements for carers and this offers an example for other to follow.
- 8.24 Carers face a number of barriers acting against them having an assessment. These range from a lack of awareness, poor assessment practice acting as a barrier and carer constraints such as embarrassment, perceived stigma or concerns about privacy during the assessment.
- 8.25 A significant opportunity is being missed to use the assessments process to reach out to carers, offer them information and find out their needs. The process could also be used to provide data on carers' needs within an area or region.

### **Recommendations – Consulting and Involving Carers and Carer Assessments**

- 8.26 It is recommended that:  
Government give full support to and promote the guidance on good practice in consultation with carers published as part of the Carers Speak Out project.
- 8.27 Appraisal, performance management and training programmes for the staff and executives of Primary Care Trusts and NHS Trusts should include specific elements relating to carer awareness.
- 8.28 The people who should have a major role in developing carer awareness within the NHS are Public Involvement managers, staff of Patient Advice and Liaison Services, and staff of Patient Forums (when they start in 2003). All these staff need to have specific and detailed training to make them aware of carers and their needs. The major national carer



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organisations could look at running a conference or seminar programme to develop this awareness. They should also work with the Commission for Public and Patient Involvement in Healthcare on longer term training issues for healthcare staff.

- 8.29 Primary Care Trusts should work with carer organisations to establish GP initiatives in support of carers. The funding or support could be in the form of a staff member seconded from the Primary Care Trust to work on the initiative. It is important that the Primary Care Trust owns the initiative and links it into clinical governance. The Princess Royal Trust for Carers and other carer organisations can advise on models to follow, based on their experience of establishing GP initiatives.
- 8.30 Strategic Health authorities and Health Boards should encourage GP practices to develop carer support initiatives.
- 8.31 There should be a Government publicity campaign to promote carer assessments, accompanied by ring-fenced funding so that carer assessments can be carried out. Carers with the greatest need should be offered assessments automatically. Given the issues of identifying this group of carers further work needs to be done with carer organisations to identify which carers have the greatest needs. A starting point for automatic assessments would be all those carers who care for 50 hours or more per week, prioritising those carers who have been caring for 5 years or more. However, all carers have a statutory right to have an assessment and it should also be made clear that it is a goal for all carers to be offered an assessment of their needs.
- 8.32 Government establish an initiative to find, document and disseminate best practice in carer's assessments. This should include carers receiving a copy of the assessment and the need for feedback from carers on the assessment process. Also, Government should require the recording of levels of carer assessments carried out also the recording of the number of people who have had their own assessment and who are known to have a carer. Local authorities should be required to report at least annually on numbers of carer assessments carried out and on carers needs as expressed through the assessments process.

## Findings – Carers' Health Needs and Local Services for Carers

- 8.33 Over eight out of ten carers responding in the survey said that caring had a negative impact on their own health. Almost nine out of ten carers in the survey

reported that they feel stress, anxiety, depression or loss of sleep, due to being a carer. Carers also saw the sheer relentlessness of caring and its effects on their mental and physical well-being as being their biggest problems.

- 8.34 More than six out of ten carers in the survey would like to take a break from caring. Those carers more likely to say they wanted a break were female, those caring for 15 hours a day or more, those caring for a son or daughter and carers aged 44 years or under. Carers need different types of help to take a break. Overall around two thirds of carers would need help with respite care, one third would need help from a sitting service and a third would need financial help, in order to take a break.
- 8.35 However, four out of ten carers in the survey said they would not like to take a break. Given the emphasis on carers' breaks as the major new service for carers this finding deserves some attention from policy makers and more research from carer organisations on the reasons for this. These carers might benefit from other types of support. Some local authorities have used the Carers Grant to fund different types of support for carers, including mobile phones, IT equipment or other equipment needed at home. There seems to be scope for extending this idea to all areas.

## Recommendations – Carers' Health Needs and Local Services for Carers

- 8.36 It is recommended that:  
Government introduce pilot programmes to identify the most effective way of improving carer's health within a locality. These pilots could be developed as "Expert Carer" initiatives. The pilots would tackle carers' health issues through a combination of: targeted information and support on key caring issues; advice and training to avoid physical injury; emotional support; courses on relaxation and stress management. Carers should receive alternative care and other support needed for them to be involved in the training and advice sessions run for them.
- 8.37 Government examine ways of measuring carer's health over time and providing targets and incentives to the NHS to bring about improvements in carers health.
- 8.38 Government examine ways of extending health and safety protection on lifting to cover unpaid as well as paid carers. Local authorities and health agencies should be resourced by central government to ensure that unpaid carers can be provided with lifting equipment where this would be provided to paid carers. Unpaid carers should receive the same training as paid health and social care staff on how to use

- equipment to lift or move the person being cared for.
- 8.39 Government require that a joint strategy is developed in each local authority area by health authorities, social services, carer organisations and carers to provide breaks to carers. Such strategies should be informed by existing good practice and innovation. The strategies should tie in with the local Carer Information Strategy Strategies should be updated regularly to enable unmet need to be looked at and to incorporate new ideas which would add to the diversity of breaks services.
- 8.40 Joint strategies to provide carers breaks should also include options for those carers who do not want to leave the caring situation to take a break. Such options might include breaks at home, breaks together with the person cared for or other support for recreation and leisure of other needs e.g. mobile phones, IT equipment and training to use the Internet.



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