

(Version 3 - 27 July 1998)
RESEARCH REPORT

EIGHT HOURS A DAY AND TAKEN FOR GRANTED?
You just get on with it, don't you?

Research commissioned by The Princess Royal Trust for Carers
Research supported by Glaxo Wellcome

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FOREWORD

There are 6 million carers in the UK. But who are they?

A carer is anybody who is helping to look after a partner, relative or friend who because of illness, old age or disability may not be able to manage at home without help.

Between them, it is estimated that carers save the government £34 billion every year¹. How? By caring for somebody at home – be it a partner with MS, an elderly mother who has had a stroke and is now developing Alzheimer's Disease, or a young child with cerebral palsy. Without the care provided by friends or relatives, many of these people would find themselves unable to live within the community. The alternative is often costly residential care.

This report focuses on those for whom caring is a full time concern. There are nearly one million people who are caring for 50 hours a week or more for a partner, relative or friend², spending more than 8 hours a day in their caring role.

In return they are eligible, providing they are under retirement age, for the basic carers allowance of £38.70 a week. Even if they worked a 'standard' working week (35 hours) this would work out at little more than one pound an hour.

This resource of unpaid, committed partners, friends and relatives is truly at the heart of community care. Without them the policy would be unworkable. But any valuable human resource needs looking after if it is to continue to work well.

This report shows that the unpaid work of carers is seriously undervalued. Together with health professionals and social services they form a vital part of the team supporting the patient in their care, but all too frequently their role within the team is overlooked.

They are seldom consulted – even on such basic issues as the hospital discharge of the person they care for. Training is not automatically available as it would be for a paid social or healthcare worker undertaking similar tasks. Frequently, nobody stops to ask them if they can cope. The report reveals that carers are taken for granted and left to get on with it.

The situation is particularly bad for carers of working age. Those over 65 may be seen as needing support but younger carers may be trying to balance the demands of family and career as well as caring. To assume that they can drop everything to care for a friend or relative seems absurd. It is hardly surprising that in this survey

¹ The Institute of Actuaries

² General Household Survey (GHS) 1995 - 0.9m people were caring for more than 50 hours each week, an increase from the previous GHS of 1990 which indicated that 0.75m were caring for more than 50 hours each week.

those who had expressed the greatest concern over the support that was on offer to them were aged under 65.

The unmet needs of carers have an impact on both health and social services. Both of these agencies are regularly in contact with carers; both of them may find themselves with higher costs if carers' needs are not identified and met. Neither should take carers for granted and leave them to "just get on with it".

Carers need information about services, such as social security benefits and respite care, and access to them. They also need and value opportunities to be recognised and express themselves as individuals, whether by meeting other carers, discussion with sympathetic listeners, or through participating in group activities.

One worrying aspect is that this survey was conducted among carers in contact with Carers Centres which are part of The Princess Royal Trust for Carers network. They are already aware of their position and have found support. How much worse is it for those with full-time caring responsibilities who have not found their way to sources of help and support?

Finally, this report is published at a time when the Government is seeking to develop a national strategy for carers. We hope that by highlighting the views of carers on the support that is available to them the report makes a useful contribution to this process.

David Butler
Chief Executive, The Princess Royal Trust for Carers

EIGHT HOURS A DAY AND TAKEN FOR GRANTED SUMMARY OF KEY FINDINGS

Of the 1346 carers who were caring for eight hours or more every day.

- 71% were caring for somebody for 15 hours or more every day.
- 63% had been caring for more than 5 years.
- 50% were caring for partners; 24% for parents or parents-in-law; and 22% for children with special needs.
- 94% are providing crucial medical care, but only 33% had received any training or guidance of any kind and only 20% identified any training needs.
- 70% of those aged 16-64 who have experience of hospital discharge procedures said that nobody asked them if they could cope before discharging somebody from hospital into their care at home.
- 71% of carers of working age believed that GPs were unaware of the needs of carers.
- The most valued support available to carers was a listening ear. 59% of carers stated they had received this from a Carers Centre.
- 45% of carers voiced as their major concern what would happen to the person they cared for if they were unable to continue caring, through death, ill health, old age or the growing demands of the caring role.

INTRODUCTION AND METHOD

The survey, supported by funding from Glaxo Wellcome, was conducted through the network of Princess Royal Trust Carers Centres.

There are currently 68 Princess Royal Trust Carers Centres across the UK, through which The Princess Royal Trust for Carers supports around 35,000 carers a year. Carers Centres provide information, support and practical help to all carers, irrespective of age or the condition of the person being cared for.

A total of 23 Carers Centres took part and 7,000 postal questionnaires were distributed to a random sample of carers. The questionnaire was written and designed by market research company BMRB.

Just under thirty per cent of the confidential questionnaires were returned. Digitab undertook statistical analysis of the 1,985 questionnaires returned by the deadline.

The large majority of respondents were those with intensive caring responsibilities. (fig 1). To ensure that the survey provided useful information on this group of carers it was decided to process the results again, using as the base for calculation only those carers caring for 8 hours or more each day.

The report includes the experiences of a number of former carers (see fig 2). These former carers were asked to answer the questionnaire with reference to the last year that they were caring for somebody.

The research is therefore not indicative of the pressures upon the UK's six million carers, but much more reflective of those who care more intensively, the 0.9m caring for 50 hours or more each week.

The results will be used to help local Princess Royal Trust Carers Centres develop effective and appropriate services for carers, to evaluate the impact of Carers Centres upon the lives of carers, and to aid The Princess Royal Trust for Carers in developing future strategies for meeting carers' needs.

Figs on this page

Fig 1 - Q. 11 - hours caring each day - all respondents.

(up to 3 hours per day– 9%; 4-7 hours 9%; 8-14 hours 24%; 15hours + 58%)

Fig. 2 Q1 – currently caring for somebody - 83% currently caring, 17% used to

RESULTS

WHO ARE THE EIGHT-HOURS-A-DAY CARERS?

The respondents were split 76% female, 24% male³.

Our sample had nearly twice as many women caring for husbands as vice versa. But among the men it was far more likely that they were caring for a spouse than any other relative (more than three times more common than care for a parent).

Over 90% of carers lived in the carer's home or a joint home although 7% lived in the home of the person that they cared for. This could suggest that for 7% the caring role had necessitated the carer moving house (fig. 5).

Although half of respondents were caring for a spouse (fig. 4), 24% of respondents were caring for a parent or a parent-in-law – a role reversal which could lead to conflict and stress. With the ageing population this could be an increasing problem.

Between the ages of 45 and 74 people are most likely to be cared for by a spouse/partner, but those in the 75-84 age group are equally likely to be cared for by a spouse/partner as by an adult son or daughter.

Those over 85 years are much more likely to be cared for by an adult child. But this hides some intensive care of the elderly by elderly carers: 9% of our sample consisted of people over 75 caring for others over 75.

By far the largest proportion of carers, 48%, were aged between 45-64.

In total, nearly two thirds (65%) of those caring for 8 hours or more each day were below retirement age. Many of these carers may have left paid employment to care, and so the stress of caring is likely to be compounded by difficulties associated with a reduced family income.

In addition, the 17% of carers aged under 44 are more likely to have young children or teenagers at home, once again placing increased strain on family relationships, finances and of course on the carer.

Figs on this page:

Fig 3. Q2 - number of people looked after (89% one, 8% two; 3% three+;)

Fig 4 Q3 - relationship to cared-for (50% spouse/partner; 22% child; 22% parent; 2% parent-in-law; 4% other relative; 1% friend/neighbour; 1%other;)

³ Analysis of the General Household Survey 1990 for those caring for twenty hours or more per week gave a breakdown of 63% female and 37%. A comparative analysis of the 1995 figures is not yet available.

Fig 5 Q4 - where do you live (46% together in my home; 7% together in their home; 44% in our joint home; 6% don't live together;)

Fig 6 Q14 - age of carer (2% 16-29; 15% 30-44; 48% 45-64; 22% 65-74; 11% 75-84; 1% 85+)

Fig 7 Q6 - age of cared-for (9% under 16; 8% 16-29; 9% 30-44; 19% - 45-64; 18% 65-74; 22% 75-84; 18% 85+)

FIFTY HOURS OR MORE DEMANDS UPON THE CARER

All of the carers we are focusing on are caring for somebody for more than eight hours a day. But 71% indicated that they were regularly caring for 15 hours a day or more.

52% of those caring for at least 15 hours a day are caring for a spouse or partner. The remainder are mostly caring for a child or a parent. The amount of time spent caring does not appear to vary with age (see figs 11 and 12)

This suggests that in many cases their responsibilities continued not only during normal waking hours, but during some part of the night as well. If, as a carer living in the same house as the person that you care for, the only time you get to yourself is when you're asleep, how do you cope if your sleep is regularly disturbed as well?

Nor is a carer's role a short term one. 63% of the sample had been looking after somebody for five years or more, with 16% caring for 20 years or more (fig 13). Of those who had been caring for 20 or more years, the majority were caring for a child, while those caring for between one and fifteen years were more likely to be caring for a spouse/partner, parent or parent in law, other relative or friend/neighbour (figs. 14 to 19).

41% of those caring for more than 15 hours a day have also been caring for 10 years or more!

Many of the tasks undertaken involved personal care and mobility (see figs 20-26). All these tasks are physically demanding, particularly when you consider that the majority of those being cared for are adults, with 58% aged 65 or over.

A large number of carers were caring for somebody with medical needs. 94% of the carers responding helped ensure that the person that they were caring for took their pills, and 23% were changing dressings. 13% give injections, and here proper training is vital. The other main forms of nursing care that carers listed included dealing with incontinence or catheters, dealing with nebulisers and inhalers, inserting eye drops, applying cream or ointment, and administering physiotherapy or massage.

It is also alarming that these physically demanding tasks are often carried out by people who are themselves elderly and frail: 73% of those aged 75-84 are regularly washing and bathing the person they care for.

Training received

Astonishingly, despite the dangers associated with lifting and moving people⁴ only 3% of our survey claim to have been taught how to lift properly (9% of those who mention receiving any training at all), although 95% regularly or occasionally wash or bathe the person they care for, and 96% regularly or occasionally help with dressing.

Equally worryingly, some 56 people in the survey said they regularly or occasionally give injections, but only 21 (38%) claim to have been shown how to do this. The most common form of training received is changing dressings. Although 23% of respondents were changing dressings, only 7% had received guidance or training in this. The table (fig. 27) shows an apparently vast “training shortfall” compared to the tasks actually being undertaken by carers.

Where help is provided it is usually (46%) by a district or community nurse.

There was a high level of non-response to the question on training, probably due to the fact that this was an open question.

Identified training needs

Surprisingly, when asked in what areas guidance or training was needed, only 20% listed any areas in which this would be helpful, with the highest demands (3% in each case) being for guidance in lifting and handling, and dealing with mental health problems/dementia. It should be noted that again this was an open question, with a high level of non-response.

Nevertheless, knowing what we do about the demands on carers, the number of hours they spend caring for someone, and the tasks they undertake, their stated need for guidance and advice seems disproportionately low. This may be due to isolation as a result of caring, and a lack of awareness that, in certain tasks, training might be needed.

As we have found, carers often feel their views are not taken into account by those professionals with whom they have most contact. If they believe that professionals put a low value on the full-time care they provide it may make it difficult for carers to identify their own training and support needs.

Carers generally focus more on the needs of the person they are caring for than on their own needs – we know that the majority of first enquiries by carers at Carers Centres are for some additional service or aid that will help the person that they are caring for. Only after a number of contacts with Carers Centre staff are carers persuaded to recognise their own needs for support, training and time for themselves without feeling guilty. Again there is a very strong feeling that you just get on with it as best you can.

⁴ Smedley et al (1995), Manual Handling Activities and Risk of Low Back Pain in Nurses, Occupational and Environmental Medicine indicated that 200,000 nurses suffer a back injury every year. Many of these have to leave nursing for good and many suffer lasting effects.

There is a danger that carers will only ask for help for themselves when it becomes impossible to continue – a crisis that might have been prevented were support provided earlier on.

Figs on this page

Fig.8 Q11 hours caring each day

- total: 29% 8-14; 71% 15 hours plus (pie chart)

Q11 hours caring each day

- pie charts for 8 and 15 hours:
- Fig 9: 8 hours – male 22%; female 77%
- Fig 10: 15 hours - male 24%; female 75%
- Fig 11: 8 hours ages - age 16-29 2%; 30-44 – 15%; 45-64 – 49%; 65-74 – 20%; 75-84 – 10%; 85+ - 1%
- Fig. 12: 15 hours ages - age 16-29 – 2%; 30-44 – 14%; 45-64 – 46%; 65-74 – 22%; 75-84 – 11%; 85+ - 2%

Fig 13 Q12 - length of time caring (3% less than a year; 16% one to three years; 18% three to five; 24% five to ten; 14% ten to fifteen; 9% fifteen to twenty; 16% twenty or more)

Figs 14-19 Q12 - length of time caring: different diagrams for the following categories by years caring:

- spouse/partner (fig 14): less than 6 mths -1% ; less than 1 year – 3% 1-3 years – 19%; 3-5 years – 21%; 5-10 years – 24%; 10-15 years – 15%; 15-20 years –8% ; 20+ years –9%
- child (fig 15): less than 6 mths – 0%; less than 1 year – 1%; 1-3 years – 7%; 3-5 years – 8%; 5-10 years – 19%; 10-15 years – 15%; 15-20 years – 13%; 20+ years – 37%
- parent and parent in law (total of both) (fig 16): less than 6 mths – ½%; less than 1 year – 5%; 1-3 years – 17%; 3-5 years – 20%; 5-10 years – 27%; 10-15 years – 14% ; 15-20 years – 8%; 20+ years – 8 ½%
- other relative (fig 17): less than 6 mths – 0%; less than 1 year – 4%; 1-3 years – 13%; 3-5 years – 13%; 5-10 years – 30%; 10-15 years – 15%; 15-20 years – 9%; 20+ years – 17%
- friend or neighbour (fig 18): less than 6 mths – 0%; less than 1 year – 0%; 1-3 years – 30%; 3-5 years – 0%; 5-10 years – 40%; 10-15 years – 20%; 15-20 years – 0%; 20+ years – 10%
- other (fig 19): less than 6 mths – 0%; less than 1 year – 6%; 1-3 years – 11%; 3-5 years – 17%; 5-10 years – 0%; 10-15 years – 11%; 15-20 years – 17%; 20+ years – 39%

Q7 carers providing help with – individual pie charts

- fig. 20: dressing: regularly 75%; occasionally 21%; never 4%

- fig 21: washing and bathing: regularly 75%; occasionally 18%; never 5%
- fig. 22: shaving/and or cutting nails: regularly 75%; occasionally 15%; never 10%
- fig. 23: using the toilet: regularly 59%; occasionally 26%; never 16%
- fig. 24: food and drink: regularly 78%; occasionally 14%; never 8%
- fig. 25: walking: regularly 71%; occasionally 19%; never 10%
- fig. 26: moving around the house: regularly 62%; occasionally 26%; never 12%

Fig. 27 training shortfall

The table below reports actual figures for each of the questions

	Help Provided (Regularly & Occasionally)	Training Received	Training Needed
Lifting	c1100*	38	47
Dressing	1149	15	3
Washing & Bathing	1160	35	17
Shaving &/or cutting nails	965	8	-
Using the toilet	877	-	8
Food and drink	1077	25	-
Walking	929	2	-
Moving around the house	908	37	-

* (No question on lifting in Q 7. This figure is a rough estimate based on answers on Washing & Bathing and Dressing.)

Giving medicines

Ensuring they take their pills	1213	36	-
Giving injections	56	21	-
Changing dressings	309	93	-

ARE CARERS REGARDED AS PART OF THE HEALTHCARE TEAM?

Respondents were asked whether they agreed or disagreed with these statements:

- In my experience many GPs are unaware of the needs of carers
- In my experience, nobody asks the carer if they can cope before they send someone home from hospital

In each case the total of respondents agreeing was broadly similar (see figs 28-29). It indicates that the needs of carers, as individuals needing support in their own right, are often not being addressed. It also suggests that they are often not regarded as part of the healthcare team and underlines the low value accorded to their role. If similar views were expressed within a paid workforce it would indicate a state of low morale which called for immediate action.

Women are slightly more likely to agree with the above propositions than men, suggesting that the medical profession and other authorities may have a slightly greater tendency to assume women will be able to cope than men.

Assumptions about the younger carer?

The survey revealed a markedly lower satisfaction with the support from healthcare professionals among carers of working age than among carers in the older groups. (see figs. 30-39).

Those who have had the best experiences with GPs, hospital discharge and other authorities are those carers of 65 and over. Carers who have the strongest views are those of working age – with 70% of carers under 64 years with experience of discharge reporting that they weren't consulted before the patient was discharged from hospital and 71% that many GPs were unaware of the needs of carers.

There may be an assumption that if you are reasonably young and healthy you will be fully able to cope with taking on the responsibilities of a carer. This is despite the fact that it is largely those in the younger age groups, 30-44 and 45-64, who will already have responsibilities for children or have a career, or both. Or it may be that those of working age had higher expectations of support services.

If those in the younger age groups are involved in caring situations which are likely to continue for some time, then this dissatisfaction is a potential time bomb as the caring load increases. How long will it be before the carer cannot cope any longer?

One reason for the impact of age on these answers could be that over 65 carers are more likely to have health needs themselves. As both social workers and GPs are client/patient focused, the needs of older carers are perhaps more likely to be addressed.

The response to the survey suggests that this client/patient focus often results in the needs and views of carers, particularly younger carers, being overlooked. But without the support of the carer who continues to provide care for more than 50 hours a week, there would be greater demands on both the GP and social services. The support previously given by the carer would need to be sourced, and funded, from outside the home.

Experience has shown that it is more effective, and cheaper, to identify carers' needs and provide support early on rather than have to implement emergency measures at a later date. Nevertheless it appears that the willingness of carers to just get on with it is often being taken for granted.

Figs on this page:

Fig 28 Q13a - in my experience many GPs are unaware of the needs of carers (calculation without the not stateds and don't know/no experience) Totals across all ages : stronga 39%; slighta 28%; neither 14%; slightd 9%; strongd 10%

Fig 29 Q13b - home from hospital [without not stateds and don't know/no experience] Totals across all ages: stronga 49%; slighta 19%; neither 12%; slightd 10%; strongd 11%

In my experience many GPs are unaware of the needs of carers.

- Fig 30: over 75s: stronga 32%; slighta 30%; neither 14%; slightd 10%; strongd 15%
- Fig 31: 65-74 years: stronga 32%; slighta 27%; neither 17%; slightd 10%; strongd 13%
- Fig 32: aged 45-64: stronga 43%; slighta 27%; neither 12%; slightd 9%; strongd 10%
- Fig 33: aged 30-44: stronga 41%; slighta 30%; neither 18%; slightd 6%; strongd 5%
- Fig 34: aged 16-29: stronga 39%; slighta 44%; neither 11%; slightd 6%; strongd 0%

In my experience, nobody asks the carer if they can cope before they send someone home for hospital.

- Fig 35: over 75s: stronga 41%; slighta 18%; neither 9%; slightd 16%; strongd 16%
- Fig 36: 65-74 years: stronga 46%; slighta 20%; neither 15%; slightd 5%; strongd 15%
- Fig 37: aged 45-64: stronga 52%; slighta 18%; neither 10%; slightd 10%; strongd 9%
- Fig 38: aged 30-44: stronga 50%; slighta 20%; neither 13%; slightd 11%; strongd 7%
- Fig 39: aged 16-29: stronga 37%; slighta 32%; neither 32%; slightd 0%; strongd 0%

THE IMPACT OF CARERS CENTRES IN ADDRESSING THE NEEDS OF CARERS

Princess Royal Trust Carers Centres aim to value the role of carers, to address their needs as individuals, take time to listen to their concerns and their views, and to improve the quality of their lives.

The main forms of help received as a result of contacting the Carers Centre were being able to speak to someone who listens, mentioned by 59%; links with other carers, 35%; help and advice with Social Security benefits for themselves, 33%; and help in dealing with officials, 29%.

In addition, through the Carers Centre, carers were also able to access help for the person they cared for, with 40% of those receiving help accessing Social Security benefits for this person, 23% day care, 16% help with transport, 14% help with medical care, and 9% residential care.

Women seem to have received slightly more listening ear support and social activities than men. Nevertheless a listening ear is the most mentioned form of support received by both sexes. Women also seem to have gained links with carers to a slightly greater extent than men.

On the other hand it appears that men have somewhat greater success than women at gaining Social Security benefits for themselves and for the person they care for and medical care for the person they care for.

To assess the less tangible benefits obtained through their contact with Carers Centres, carers were asked to respond to six statements. The major benefit was "It's just knowing there is someone there when I need them" with 80% agreeing. 59% of carers agreed that "If the Carers Centre had not been there I wouldn't have known where to turn for help", 53% of respondents agreed with the statement "I feel less stressed", 54% stated "I have met other people in the same situation" and a further 41% agreed that they had more self confidence.

Parents caring for children were less likely than others to mention reduced stress or increased self-confidence as effects of using the Carers Centre. It may be that caring for children is less stressful or that its stresses are harder to address.

Conversations with carers indicate that those carers who feel supported, have self-confidence, are under less stress and not isolated, find it easier to cope with the demands of the caring role. Princess Royal Trust Carers Centres aim to provide support before the carer reaches breaking point.

FUTURE CONCERNS

Finally, carers were asked to indicate their concerns for the future. Although many failed to answer this question, those who did showed that there was a consensus.

45% of respondents voiced their major concern as what would happen to the person they cared for if they were unable to continue caring, through death, ill health, old age or increased demands of the caring role.

A further 33% were concerned about cuts in funding for carers' services.

RECOMMENDATIONS

The Princess Royal Trust for Carers recommends that:

Statutory authorities should not assume that a relative will automatically be able to put their life on hold in order to become a carer.

Carers should be involved in decision-making about the future care of the person they are looking after.

When a patient is discharged from hospital and needs intensive home care it is essential that the full team – health, social services and the carer – should be consulted and work together.

Primary healthcare and community care teams should be aware of the needs of carers and should be expected, at the very least, to identify carers and refer them to Carers Centres or other agencies that can provide support.

Services should address the long-term concern of carers about what will happen when they are no longer able to care.

There should be a consistent level of support, both practical and emotional, offered to carers nationwide – before they reach crisis point.

A higher value must be placed on the role of carers by statutory authorities. Their role as equal partners in providing community care must be acknowledged in order to continue with the policy effectively.

CASE STUDIES

Margaret Seymour

Margaret Seymour, 60, from Surrey, cares for her son for over 15 hours a day. She has received no training and feels that GPs do not listen to her concerns. Colin, 26, is severely disabled, he cannot talk or walk unaided and needs help dressing, bathing and eating. Since drawing her pension, Margaret says she is financially worse off, as she can no longer claim invalid care allowance.

Having cared for her son all his life, Margaret is able to tell when he is unwell. Nine years ago she decided her son needed urgent medical attention. "I took him to hospital and told the doctors he was ill but no one would listen to me. When they finally did blood tests, the results were so extreme that they thought the samples had been switched." Colin had very high levels of salt and was dehydrated. "We were told he only had a few hours to live. We are very lucky he pulled through."

Margaret now has a letter from her doctor stating that if she believes her son needs medical attention, hospital staff must listen to her, and carry out tests to check his salt levels. She carries the letter everywhere she goes in case of emergency.

"Medical professionals should listen to carers and take advantage of their experience. I have been caring for my son for 26 years, so I can tell when there is something wrong with him."

Bob Williams

Bob Williams, 43, was a farm manager until he left work six years ago to care for his wife who has MS. Caring is now a round the clock responsibility – he has to help his wife with every aspect of daily living, and has given up his voluntary work because he no longer has the time.

As the person with the major responsibility for his wife's care he finds it absurd that health and social workers will talk to each other about his wife's care but not involve him in the discussions or pass on information.

"The Carers Centre has given me a voice in what is happening, but to start with I wasn't getting the help I needed. The GP has to listen to me now, simply because my wife cannot speak.

"Carers must be consulted and informed. The decisions that are being made affect the life of the carer as well as the patient. I feel that I now need information on how my wife's illness is likely to progress, but nobody's telling me what to expect."

APPENDIX 1

THE PRINCESS ROYAL TRUST FOR CARERS BACKGROUND INFORMATION

The Princess Royal Trust for Carers aims to provide, through its network of Carers Centres, the help and support that carers⁵ need at times and in ways that they most want. It also aims to raise awareness of the needs of carers and to encourage more carers to seek the support that will make their role easier.

The formation of The Princess Royal Trust for Carers (PRTC) was announced by Her Royal Highness The Princess Royal on 13 October 1991. The PRTC aims to establish a network of Carers Centres across the country - one in each local authority area - and there are now nearly 70 Princess Royal Trust Carers Centres across England, Wales, Scotland and Northern Ireland. It estimates that the network of Carers Centres is in contact with around 35,000 carers on a regular basis, and this figure continues to grow.

Princess Royal Trust Carers Centres provide information, support and advice to carers within their local area. The precise range of services will be determined through local consultation with carers but may include access to respite care, information on benefits, training in lifting and handling, as well as drop-in centres, a help-line, advocacy, time for the carer to talk over their own stresses and frustrations without feeling guilty, and social events.

Each Centre is funded through The Princess Royal Trust for Carers in partnership with the local authority, with the PRTC providing one third of the core funding for the first three years.

The PRTC also runs a "Carers in Employment" programme, advising employers on the development of flexible policies to enable carers to continue in paid employment.

An educational bursary scheme run by The Princess Royal Trust for Carers provides grants to carers to enable them to take up educational or recreational opportunities giving them a focus outside their caring responsibilities. Grants have been given for courses as diverse as sign language interpretation, aromatherapy and piloting narrow boats.

The Princess Royal Trust for Carers depends for its income on voluntary donations - from individuals, companies, fundraising groups, and charitable trusts.

⁵ A carer is defined as anybody who is helping to care for a partner, relative or friend who because of ill health, old age or disability would be unable to manage at home without help. A carer could be the parent of a disabled child or the daughter of an elderly man who has suffered a stroke for example. Many carers will simply identify themselves as husband, daughter or neighbour.

The PRTC is the only national charity working to provide a wide range of information and services focused solely on the needs of carers across the UK. Some organisations (eg Alzheimer's Disease Society) support carers of those living with a particular disease or disability, although their primary focus may be the cared-for rather than the carer. Other organisations (eg Crossroads, Carers National Association) provide specific services to carers or lobby central government on their behalf.

Appendix 2

Copies of the original questionnaire and statistical breakdown of this survey may be supplied on request from Press Office, The Princess Royal Trust for Carers, 142 Minories, London EC3N 1LS.