



The Princess Royal Trust
for Carers

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Barclays Carers Speak Out Project Executive Summary

Introduction

Around 6.8 million adults in Britain are carers, the majority being the main support for the person they are looking after. They provide care and support, on an unpaid basis to relatives, friends and neighbours who are sick, disabled, elderly and who would not otherwise be able to manage. A quarter of carers spend twenty hours or more per week on caring tasks and one in ten spends more than fifty hours per week on this.

In 1999, the Government launched its National Strategy for Carers which set out the Government's intentions about what service providers should do for carers. The emphasis was to widen the focus of health and social care services to being not just on the client, patient or user

but also on carers. The strategy had three key approaches: *Information for carers*, *Support for carers* and *Care for carers*. It covered the work of the public, voluntary and private sectors. A key element was that service planners and providers should see carers as partners in the provision of help to the person needing care.

Three years on from the launch of the strategy, the *Carers Speak Out* project was undertaken in order to see what the situation looks like now. The aim has been to consult with carers about their needs, priorities and issues, through both a widely-distributed questionnaire and one national and eleven regional consultation events. The responses to the survey questionnaire and the comments

from carers at the twelve consultation events offer a view from the experience of 3,800 carers.

The carers who responded to the survey differ somewhat from the national profile of all carers. However, there are many similarities between them and the more heavily-committed carers in the national profile. The majority of carers in the survey had heavy caring commitments. Carers such as these are much more likely to be women. The large majority of these carers also live in the same household as the person cared for, usually caring for a spouse or partner or a son or daughter. Almost four of ten carers in the survey had a disability or long term illness themselves.

Principal Findings

Information needs

Carers have a pressing need to be directed to good sources of information, help and support. 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. Nevertheless there remains room for further improvement because around two in ten carers who began caring in the last 2 years were not directed to sources of information and support. Practice particularly needs to improve more for those who are caring for someone with a mental illness, learning disability or physical illness.

We can distinguish between two different types of information and support. 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 is 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 and they should engage carers in debate about what those priorities should be. However, given limited resources there is no value in giving information to individual carers 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.

Many carers feel that they have insufficient help, support or information provided to help them with the key caring tasks. For example, three out of ten carers had insufficient information on medication for the person cared for while more than half 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 carers reported physical effects such as back pain or strain or other injury. Carers pointed out that they were expected to carry out physical lifting tasks that would only be done by two people, if those people were paid social or health care staff. 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.

Around a quarter of the carers 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. It is of concern that one in ten 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.

Carers receive help or support with caring, or advice about benefits and grants from a range of sources, but a minority of respondents are receiving none. Also, a third of carers found the sources of advice and help difficult to use. Many carers lack time to get help or advice or are not confident enough to use the sources of help or advice available.

Consulting and involving carers and carer assessments

NHS organisations appear to be consulting with carers much less

than the level envisaged in the National Strategy for Carers. There is still too much poor or indifferent consultation practice and service providers appear not to be following known good practice guidelines. For instance, only just over half the carers in the survey had ever received feedback following consultation.

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, they also produce a bookmark intended to raise awareness of good practice with carers among staff.

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.

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 are not being seen by service providers as "real partners".

There is reason for serious concern about carer assessments, with few assessments being carried out and concern among

carers about the quality of assessments. 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. However, within the overall low figures, there is evidence that initiatives in some areas have raised awareness of assessments, with levels of awareness among carers being markedly higher in both Wales and the South region of England. The proportion of carers in the survey who had had an assessment was also 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.

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 to have seen changes in support or services following an assessment. However, given the low level of assessments being carried out this means that, overall, only one in seven carers (14%) had had an assessment which led to a change in support or services. However, different practice on carers' assessments in Wales has led to a better picture of carers' experience, with the proportion there being nearly one in five of carers (19%) who had seen a change in services or support. Clearly, although the figures on carer 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. 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.

Carers health needs and local services

Over eight out of ten carers said that caring had a negative impact on their own health. Almost nine out of ten 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.

The majority of carers would like to take a break from caring. Those 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, to take a break.

However, 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 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.

A picture emerged from the survey of "information poor" carers. These are carers who have difficulties accessing information and support in some areas and who are also more likely to have similar difficulties in 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 deprived of information and advice are less likely to be elderly themselves and caring for the frail or elderly and are more likely to be caring for people with a mental illness, a learning disability or physical illness.

By contrast, the survey also pointed to the beneficial effects to carers of providing more information to them. There were some real differences in experience among carers in the survey based on the duration of their caring. 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 about their caring experience than longer term carers. This more positive response was apparent 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.

The newer carers were more likely to have been directed to sources of information and support when they first began caring. They were also more likely to have been given information about the diagnosis and future development of the disability or illness of the person they care for. They were more likely to have been offered a carer assessment. This appears to indicate practice changes and service improvements affecting newer carers. The newer carers were more likely to feel that their caring role was understood by health and social care professionals. They were also more likely to say they had no problems getting services to help with the person they cared for.

Recommendations

1. Agencies in each local authority area 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:
 - Local registers of carers
 - Publicity and awareness
 - Systems 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)
 - Carers awareness training programmes for health and social care staff
 - Information about which services and support are available to carers
 - A range of dissemination methods taking account of the needs of different local communities and groups.
 - Processes for ensuring that information is kept up-to-date
 - Feedback from carers on the nature, quality and accessibility of information.
2. Government should earmark funding for local authorities and health organisations and voluntary organisations to provide a carers' information strategy.
3. Central funding should be provided for local pilot and research projects aimed at increasing the usage of the Internet by carers.
4. Further development of the use of the Internet for online discussion with health professionals should be explored by carer organisations and health bodies.
5. Government should give full support to and promote the guidance on good practice in consultation with carers published as part of the *Carers Speak Out* project.
6. Appraisal, performance management and training programmes for the staff and executives of Primary Care Trusts and NHS Trusts, including Patient Advice and Liaison Services should include specific elements relating to carer awareness.
7. The major national carer organisations should consider 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. 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.
9. Strategic Health Authorities, Primary Care Trusts and Health Boards should encourage GP practices to develop carer support initiatives.
10. There should be a Government publicity campaign to promote carer assessments, accompanied by ring-fenced funding so that such assessments can be carried out. Carers with the greatest need should be offered assessments automatically. Further work needs to be done with carer organisations to develop a definition of carers with the greatest needs.
11. The Government should establish an initiative to find, document and disseminate best practice in carer assessments. Also, Government should require the accurate recording of both the numbers of carer assessments carried out and 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.
12. The Government should introduce pilot programmes to identify the most effective way of improving carers' health. These pilots could be developed as "Expert Carer" initiatives.
13. The Government should examine ways of measuring carers health over time and providing targets and incentives to the NHS to bring about improvements in carers health.
14. The Government should examine ways of extending health and safety protection on lifting cared-for people to cover unpaid as well as paid carers. Local authorities or health agencies should be resourced 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.
15. The Government should require that in each local authority area, a joint strategy to provide breaks to carers is developed by health authorities, social services, carer organisations and carers. Such strategies should be informed by existing good practice and innovation. The strategies should tie in with the local Carer Information Strategy and 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.
16. Joint strategies to provide carers breaks should also include options for assisting those carers who do not want to leave the caring situation to take a break.



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