



The Princess Royal Trust  
for Carers

Supported by



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

## *Executive summary*

### Context

There are more than 5 million carers in England and Wales, over a million of whom care for in excess of 50 hours a week – more than a full-time job. This number of carers with heavy caring commitments is similar to the total number of employees within the NHS. Indeed, calculations of the value of the support given by carers have put it at around the same level as the total of UK spending on health.

Nevertheless, carers are a group whose contribution to the work of the NHS has generally been under-recognised and under-valued in the past. In recent years this has started to change, with an increasing realisation among decision makers of the importance and value of the role of carers.

Four years ago the Government launched a National Strategy for Carers in which, for the first time, national policies were established to start responding to carers' issues. In the same year, the National Service Framework (NSF) for Mental Health specified that carers should have an annual assessment of their caring, physical and mental health needs and have their own written care plan. This was an important step because it was the first time a carer's

right to an assessment was included in NHS guidance, although only for carers of patients with severe mental illness.

Other National Service Frameworks have been established such as the NSF for Older People. The Older People's NSF has many references to carers but it does not have a specific standard on the carer's role.

The National Strategy for Carers identified the NHS as being the most important initial point of contact for carers. It specified some key roles for primary care staff. These included identifying patients who are carers or who have a carer; checking carers' physical and emotional health; informing carers that they can ask Social Services for an assessment of their own need; asking patients who have carers whether they are happy for health information about them to be told to their carer, and; signposting carers to other sources of support.

It is significant that these key roles for primary care defined by the National Strategy relate to the health of the carer. The strategy recognises that primary care has a wider role than just that of referring carers to the Social Services Department for support – important though that might also be.

### Recent research

In the last year, The Princess Royal Trust for Carers has published two important reports covering carers, their health needs and the provision of information and support to them by the NHS. The first, *Carers Speak Out*, looked at the needs of carers as identified by carers themselves based on the largest ever survey of their views ever conducted in the UK. The second was entitled *Focus on Carers and the NHS – identifying and supporting hidden carer: Good Practice Guide*, a report on findings from Scotland.

The *Carers Speak Out* report made a number of recommendations directly for the NHS and primary care. These included establishing systems in primary care to provide all carers with information; training programmes on carer awareness for health and social care staff; publicity and awareness raising to encourage people to identify themselves as carers; GP initiatives to support of carers, linked to clinical governance; pilot programmes to identify the most effective way of improving carers' health, and: examining ways of measuring carers' health over time and providing targets to bring about improvements in carers health.



# Primary Carers – identifying and providing support

## New opportunities within health

### GP contracts

Some Primary Care Trusts have used incentives and local protocols to encourage the development of work to identify and support carers in primary care. Primary Care Trusts may also be able to use new and changed contractual arrangements for primary care to help develop new initiatives. One of these changes has been the introduction of Personal Medical Services (PMS) contracts for GPs as an alternative to the national General Medical Services (GMS) contract. About a quarter of GPs are now on PMS contracts which are negotiated locally and can include additional services. This presents a possible mechanism for inclusion of services for carers. Research for this project found an example of a PCT that has entered into such an agreement with GPs.

PMS contracts will continue after the introduction of the new national GMS contract from April 2004. It had been hoped that the new contract would include a significant element relating to carers. In fact, out of a maximum of 1050 'points' available for quality of service, only three points relate to services for carers, namely whether the practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment.

The inclusion of an element, even a small one, relating to carers is welcome. However, it mentions only referrals to social services for assessment and does not give recognition to the way in which primary care itself responds to carers needs. It might even be argued that this reinforces the inappropriate notion that support for carers is solely the province of the Social Services Department. However,

the new GMS contract also provides for the inclusion of 'enhanced services', which may be determined either locally or nationally. This will present further opportunities to include factors relating to carers.

### Performance Indicators

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

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

As a mechanism for improving the range and quality of services provided for carers, the new contractual and modernisation arrangements for primary care can be summarised as a limited amount of progress, with some further opportunities, but much more remaining to be done.

### Benefits of supporting carers

It is clear from *Carers Speak Out* and other studies that the caring role can have a negative impact on the health of the carer. This impact on health increases demands on the NHS. Also, if

the carer's health fails or deteriorates, the statutory services will have to pick up some, or all, of the caring role, which in turn reduces the resources available for other priorities. Given that carers are providing their services for no remuneration, it makes sense to provide them with the support necessary to continue to provide that role. In promoting this area of work, it is important to recognise that improved services to carers can significantly help both the local and the government's health priorities.

Support for carers is likely to be both a cost-effective use of resources and something that is correct in principle. There is an equity issue here. It is wrong that there should be wide variations in the recognition of carers' needs and the support given to them in different areas of the UK. It is another example of the 'postcode lottery'.

## Purpose of the report *Primary Carers*

### Sharing best practice

In order to help overcome this postcode lottery in provision to carers, this Primary Care Project aimed to find the most effective ways within primary care to identify carers and encourage them to use the services available. The project findings are the results of: mapping the 36 existing and completed primary care projects across The Princess Royal Trusts for Carers network in England and Northern Ireland, by identifying the types of work undertaken by each scheme, the length of time for which it has been operating and how it is funded; identifying exemplars of good practice, and obtaining data about the experience of carers, carer support projects and GPs.

The mapping and the survey of carers' views found there were a number of examples of good practice in primary care aimed at supporting carers and protecting their health. However good practice is not yet happening systematically across the country, as recognition of the need for the work and support from Primary Care Trusts is not yet embedded practice.

### Three-part model

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

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

Projects vary in the extent to which they are working in these areas. Some work in all three. Most concentrate on systems for the identification and referral of carers. In all the areas where there are projects carers have benefited from being identified and referred for support of various kinds. They often particularly praised the services and support they receive from Carers' Centres.

Altogether, the 32 primary care projects and Carers' Centres with mainstream work in primary care represent 100 years experience in that work. There has been significant sharing of learning and experience across the network.

### Funding

Finding sufficient funding to develop the work within primary care has been an issue for Carers' Centres. The centres that have developed this work managed to raise funding from some combination of local NHS, local authority and private sources. Only just over a third of funding sources for work in primary care were NHS sources. Also, for many projects

funding was available for limited periods only. Short-term funding produces uncertainty, which can lead to higher levels of staff turnover and consequent loss of skills and knowledge.

## Recommendations

The National Strategy for Carers set out a five-point checklist so that GPs and primary care staff could better meet carers' health needs. The findings of this project suggest it is now appropriate to update and strengthen that original checklist, and a new 10-point checklist follows.

## A New Checklist for GPs and Primary Health Care Teams

- Have you identified those of your patients who are carers, and patients who have a carer?
- Do you refer carers to local sources of advocacy, help and support, including Carers' Centres or carers support groups?
- Do you take carers' special needs into account in terms of the way you allocate appointments, your procedures for issuing prescriptions and your arrangements in the waiting room?
- Do you check carers' physical and emotional health whenever a suitable opportunity arises, and at least once a year?
- Do you routinely tell carers that they can ask Social Services for an assessment of their own needs?
- Do you *always* ask patients who have carers whether they are happy for health information about them to be told to their carer?
- Do you give carers information about the diagnosis, treatment and prognosis

for the person they care for and about medication and its side effects?

- Do you arrange for carers to have information or training to help them to care safely, particularly on lifting, moving and handling the person they care for?
- Do you ensure that there are leaflets and notice boards in the surgery to give information to carers about services and support which are available and to encourage them to identify themselves as carers to the practice?
- Are you willing to help with the establishment of a surgery-based carers support group?

*The review completed for this report found that, in areas where there is a primary care project, a proportion of GPs work enthusiastically and to good effect with the project. However, many GPs are too busy to work with those projects. This means that the carers using those GP practices have no access to the services and support they could get if they were identified as carers and referred for support.*

*It is felt that work at the practice level to support carers is unlikely to become embedded in all areas unless there is also active support from both the local PCTs and the Government and Strategic Health Authorities. Without this, development is always going to be patchy and inconsistent and largely driven by local enthusiasts and champions. The following checklist for Primary Care Trusts is recommended to enable PCTs to give leadership in this work with carers:*

## A Checklist for Primary Care Trusts

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

- Do you plan to use the flexibility in Personal Medical Services contracts to encourage and reward GPs to extend and improve services for carers?
- Do you plan to use the options for enhanced services in the new General Medical Services contract to encourage and reward GPs to extend and improve services for carers?
- Have you made any assessment of the level and quality of support for carers provided by the primary care services which you commission?
- Do you commission services to support carers from a local Carers' Centre or other voluntary or statutory agency?
- Do you undertake or commission work to set up systems within primary care to identify carers and link them to support?
- Do you involve carers' representatives, as partners, in the planning of local services?
- Do you include carer awareness in the training you offer to members of primary care teams and provide financial support to practices wishing to undertake such training?
- Do you encourage and support the reward, in career or financial terms, of practice staff who undertake training in carers' issues and/or who act as a carers' link person?
- Do you monitor and promote consideration of the special needs and circumstances of carers in the way GP practices allocate appointments, their procedures for issuing prescriptions and their arrangements in the waiting room?

To support the two checklists above, the following is a suggested 10-point list of strategic actions that are needed to support action at the operational and commissioning levels of primary care. These action points will link together with the other checklists to help make them a reality. They are an 'Agenda for Change' to bring about the National Strategy for Carers' aspiration that the NHS becomes the most important initial point of contact for carers.

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

- Will you modify the system for performance managing and rating PCTs to give clearer recognition to the importance of improving services for carers?
- Will you set a new date by which GPs, members of primary care teams and Social Services staff are asked to identify carers in line with the national priorities guidance issued in September 1998?
- Will you modify existing National Service Frameworks (that do not include one) to include a standard relating to the recognition and support of carers, and ensure that such a standard is included in all future relevant NSFs?

- Will you establish and fund an 'Expert Carers Programme' in line with the Expert Patient Programme?
- Will you set targets for the establishment of carers' health checks in primary care?
- Will you ensure that PCTs and local authorities are properly funded to improve and extend support and services for carers in primary care?
- Will you use performance management frameworks to promote greater partnership working between the NHS and local authorities to support carers?
- Will you provide funding to introduce pilot programmes to identify the most effective ways of improving carers' health?
- Will you give the monitoring and improvement of carers' health a similar priority to that currently given to other target groups of patients, backed up by financial incentives and targets?
- Will you launch and fund a publicity and awareness raising campaign to encourage carers to identify themselves as such to their GPs?

*The above checklists are recommended to decision makers at every level.*

*There has already been much experience developed in how to identify and support carers in primary care. It is important that this development continues and that progress is built further. These recommendations are a key step towards giving carers the support that it is in the interests of the NHS to provide and which carers deserve.*

The research for, and publication of, this report has been generously supported by GlaxoSmithKline. The research is the first part of a three year project that focuses on carer support and primary care. In years two and three, there will be demonstration projects that build on the findings.



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