General Practice and Carers: Scope for change?

Lydia Yee and Roger Blunden

KING's FUND CENTRE

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The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up.
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Foreword

Over the last decade, we have witnessed substantial changes in the way support for carers has featured in the planning and development of health and social care services. Innovation and good practice have been associated largely with the efforts of voluntary organisations, social service departments and community health units. GPs and their practice teams have not tended to be in the forefront of these developments. Indeed, there have been times when general practice has been perceived as a no-go area for carers' service developments or, at best, the last frontier to be crossed in the task of changing attitudes and building a system of comprehensive support for carers.

This situation is changing quite rapidly, as this report shows. General practice is, in some respects, proving to be fertile territory for the development of better support for carers. Carers themselves have no doubt about the important part that GPs and their practice teams can play in helping them. The projects described here demonstrate what can be achieved.

In different part of the country, GPs and other staff working within local surgeries and health centres are beginning to take a hard look at the contributions that they make or could make to helping carers of elderly or disabled people living at home. Improvements are being put in place to identify carers within practice lists, to offer them health checks, to provide better information and to link them with a range of services within and beyond primary health care boundaries.

There is a danger that these early developmental experiments may prove to be short-lived and easily uprooted. Experience on the ground of those working to bring about change in general practice shows how painstaking and fragile the developmental process can be. As the authors of this report argue, developmental initiatives involving general practice and carers raise challenging questions for government, for local health and social care commissioning agencies and for primary care professionals.

The questions and answers given in this report provide food for thought for all who are interested in the development of primary care and community care. It is a timely report, coming as it does at the end of the second year of the new community care arrangements and at the beginning of a period when primary care-led commissioning will become more extensive. Insights offered here on the opportunities for change will, I hope, contribute to wider debates on policy and practice priorities in primary care.

Janice Robinson
Director
Community Care Programme
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Lydia Yee
Roger Blunden

Introduction

Many people, including carers, turn to their local GP surgery as a first port of call when problems arise, but how realistic is it to expect general practice staff to give carers sustained support? To what extent do they already do it? What might need to change and how might changes be introduced? The work behind this report started with the notion that there is an important role for general practice staff in the support of carers. The issues are explored in the context of two projects sponsored by the King's Fund Centre.

The aims of the report

First, we want to shed more light on the debate about how far general practice can go in helping carers. There is general agreement that supportive general practice is helpful for carers, but there is much less consensus about the feasibility of providing such support. It is sometimes argued that GPs are now busy technicians who do not have the time or the necessary skills to provide any more than a medical 'repair' service. There is considerable scepticism about the scope for GPs to play a major role in community care. Many people point to the differences in outlook between primary health care and social services, the problems arising from the diverse sources of funding and the resulting problems in providing care across the agency boundaries. We explore the practical issues, such as what carers want and expect from their GPs, what eases their task and what increases their stress. We draw some lessons about what may be feasible to expect.

Second, we report on two projects in which development workers worked with general practice, in an attempt to increase the support available to carers. We will focus on ways of working with general practices which may be more successful than others.

Third, in carrying out the work, we made contact with a large number of people who are working to change the way practices provide support to carers. Two national seminars were held in 1993/4 for GPs, development workers and carers, giving them the opportunity to build relationships in this area and to discuss practical aspects of working with GPs. Not surprisingly, few GPs attended; most participants were development workers interested in learning from other colleagues' experiences of improving general practice support for carers.

A key message highlighted at the seminars was that carers' support did not rest solely with GPs themselves but with the whole practice team. GPs were not expected to 'be all things to all people' or to 'have all the answers'. Receptionists, practice nurses and community nurses also had a role to play in offering carers practical support.

We have included a list of the organisations that we contacted and some contact points (see the Appendix, p.30), in the hope that this may offer a basis for some future networking and help overcome the feeling of isolation that many workers in the field experience.

Finally, we hope that the report will contribute to a wider debate about community care and in particular the interface between community care and primary care. Carers and the people they support have a wide spectrum of needs and this is one area in which effective joint working between health and social care agencies is essential.

The key questions we set out to address were:

- What do carers expect from their GPs and general practices?
- How feasible is it to expect general practices to become a major source of support to carers?
- How could general practice become more supportive of carers?
- How could changes best be fostered?

This report is for...

Development workers in general practice, commissioners of health and social services and general practice staff are the main groups addressed in this document. Development workers may be employed by a general practice or by a family health services authority (FHSA), by a social services department, a university project, or by one of the many voluntary organisations which seek to influence general practice.

We also hope this report will be read by people who commission primary care or community care services and who are interested in the overlapping agenda of these. Such people may work with district health authorities (DHAs), FHSAs (or newly-merged health commissions) or local authority social services departments. They are increasingly looking at ways of improving the effectiveness of services and targeting support on populations who require the most help. There seems to be a strong case for looking at the amount and nature of support given to carers. General practice is one source of such help. The interface between general practice and social services is also a key issue for commissioners, and the projects described here are relevant to that.

This report is about general practice and carers, but we think that much of what emerged is of more general relevance to people with an interest in primary care and in how such services can be developed. We hope, therefore, that some GPs and other general practice staff will find the report helpful.

Background to the projects

In 1991, the King's Fund Centre Carers' Unit received a Department of Health grant to develop and support a service development project aimed at improving support for carers by general practices. The Carers' Unit set out with the view that the key to improving primary care services to carers was to promote a greater understanding by GPs and carers of their relationship to each other. From previous development work, the King's Fund had learned the importance of involving carers from the start. Both projects therefore made this a priority.

The two projects which received support were:

- *The Hackney & Newham project* – based in the Department of General Practice and Primary Care at the Medical Colleges of St Bartholomew's and the Royal London Hospitals. This project worked with a number of general practices to set up ways in which carers could influence service provision. The aim was to create effective partnerships between general practice and carers that would improve the quality of life for patients and establish more sensitive and responsive support to carers.
- *The Sutton project* – based in the Housing and Social Services Department, working together with Sutton and Wandsworth FHSA. The project set out to explore and establish ways in which GP practices could be organised to support carers.

The overall aims of both these projects were to assist GPs in improving support for carers and to add practical experience to the management of GP services by testing out ways of working which emphasise carer involvement.

Chapter 1

WHO ARE CARERS AND HOW ARE GPs IMPORTANT TO THEM?

Individual GPs have an enormous influence and part to play in supporting many carers among their patients, but they are not alone. The entire general practice team plays a part too. The gatekeeper role of receptionists is well known and community nurses have access to other agencies who can offer help. It is however to GPs that many carers turn first, and it is GPs who have potentially the greatest weight and influence and whose choice to participate in community care can make the greatest difference to carers.

The caring role

Carers are the 6.8 m people who provide the bulk of community care for disabled people, elderly people and mentally ill people unable to manage at home without help. Caring is a job with no fixed hours, no wages, no preparation or training. Carers may be parents of a child with a learning disability, or a daughter looking after her elderly mother. Many carers are elderly and need medical care for themselves as well as support as carers. In recent years, much research has been undertaken on carers' lives and support needs. The King's Fund ten-point plan for carers, intended to guide professionals in statutory and voluntary agencies who are shaping policy and services is widely accepted as a practical and relevant document.[1]

Facts and figures

- 75 per cent of carers want help and advice from health professionals
- 40 per cent believe GPs are their best source of help and advice
- One in five carers never get a break from their caring responsibilities
- 27 per cent had not heard of 'community care'
- 74 per cent had not received a community care assessment for the person they care for
- 60 per cent of carers are themselves in need of medical attention

Source: Carers National Association Survey, 1992; General Household Survey, 1994.[2]

GPs and carers

> *'Carers and GPs are natural allies. GPs provide 90 per cent of primary care and carers provide 95 per cent of community care."*
>
> *Jill Pitkeathley, Director, Carers National Association*

If the person being cared for requires clinical attention or if the carer wants to make contact with other service providers, such as the local respite scheme, it is very often the GP who is approached first. A sympathetic response, access to the right kind of information, and being referred quickly to other agencies can all make a difference to how carers perceive their tasks. But problems that feel acute to stressed carers can escalate into a crisis and eventual breakdown of the caring situation if GPs and other professionals treat them as frivolous.

GPs do not generally view carers as allies or partners and seldom provide them with adequate information about the diagnosis and treatment of the people being cared for. Carers often complain that GPs take their caring role for granted, and this makes communication difficult. Because carers believe that the GP practice is the proper channel for gaining access to local services, they often get frustrated by inflexible working styles and failures of communication between health services and local authorities.

For their part, some GPs do not consider the needs of people without 'medical ailments' to be their responsibility and therefore see no reason for supporting them. Failure to attend to the needs of carers can result in the further isolation of carers and the (avoidable) risk of having two patients to treat.

There is no typical general practice. They organise their own working styles, their workload is unpredictable with different funding systems. They are often described as operating 'like a business'. However, staff work patterns and duties appear rigid in practices. This rigidity makes it difficult to reorganise staff to undertake specific carers' support. Getting staff together to think through possible initiatives which could be undertaken to support carers is difficult because staff rarely have regular staff meetings. This is partly historical (not used to working in this way) and partly due to a lack of resources to facilitate this process, like paying for staff time.

At present, general practice is undergoing major changes as a result of the NHS reforms, the impact of community care legislation and the shift from secondary care to primary care. GPs feel overloaded and many believe that asking carers what they need will uncover a 'bottomless pit' of demands which will further increase the burden on general practice. They see support for carers as 'social care' rather than a health care responsibility, and feel justified in not giving it their priority attention.

What carers want from their GPs

- Full information on the condition of the person they care for.
- Improved access to GPs themselves.
- Referral to appropriate statutory and voluntary services.
- Teamwork approach from primary health care professionals.
- Monitoring of their own health.

Chapter 2

WHAT THE PROJECTS DID

The Hackney & Newham project

The proposals for the work in Hackney & Newham were drawn up by medical school staff in the Department of General Practice and Primary Care, and this active involvement of an academic general practice department was a major reason for selecting the project for funding. They were supported by the City and East London FHSA, together with a number of other statutory and voluntary organisations.

There were already a number of initiatives under way in the two boroughs. In Hackney, a local voluntary organisation, TLC, was focusing on the needs of carers and had a development worker in post. In Newham, there was an active carers' group with both campaigning and support roles. A steering group for the work in both boroughs was constituted with representatives from each of the interested organisations.

Aims

In Hackney & Newham the aims were to:

- improve the amount and quality of support carers receive through general practice;
- develop in practical terms the concept of 'partnership' between general practice and carers, paying particular attention to achieving recognition of carers' expertise and skills.

One of the main challenges was to find ways both to communicate these aims to general practice staff and to carers and to set up effective working partnerships.

An outline of the work

A detailed account of project work can be found in reports available from the projects.[3,4]

Because the two boroughs were very different (see below), it was decided to appoint two part-time project workers, one for each borough. However, the overall approach to the work was similar and took place in three stages.

Stage 1

In stage 1 (from October 1992 to May 1993), the project workers held discussions with representatives of carers, general practices and other local organisations. As well as announcing the project and its aims, this gave project workers a general sense of carer awareness among GPs and other local agencies. Having the project based in the academic department of general practice proved a useful asset in creating interest among local GPs who seemed willing to collaborate with a department with which they had existing links and which added an air of respectability to the project.

Contact was maintained with carers throughout the project. Two carers' representatives were active members of the project steering group. In addition, the project workers established their own links with carers in each of the two boroughs, and these played an active part in various stages of the work.

Stage 1 identified some key messages from both carers and general practice staff.

Messages from carers

- Please don't only respond to me at face value – give me a chance to talk about being a carer
- Be patient – don't fob me off

- Hear (and interpret) what I say
- Give me useful information about available services, and help me to use it
- If necessary, refer me to other agencies, but explain why you are doing so
- Identify me as a carer

Messages from GPs

- How can we identify carers?
- How can we provide additional support when our resources are already overstretched (fear of 'Pandora's box')?
- How can we identify what additional support is available?
- How can we work collaboratively with a carer when the person being cared for is the patient of another practice?

Stage 2

It was decided to hold a short pilot phase, testing out working methods before getting more deeply involved with any particular practice.

The exploratory work had identified differences in practice organisation in the two boroughs. Practices in Newham tended to have a small number of staff, whereas the Hackney practices were more likely to be larger group practices with well-established practice teams. In addition, there was a change in project worker in Newham at this stage of the work. Two different approaches were therefore piloted in stage 2, which ran from June to October 1993.

In Hackney, two practices agreed to take part. One practice was keen to improve its information systems and took the opportunity to find out more about local support services for carers. The second practice expressed an interest in looking at how it identified and monitored carers among its patients.

In Newham (where the project worker had resigned and a replacement had not yet been appointed), seven practices were visited by the medical adviser to the FHSA, who managed and supervised the project staff. The aim of these visits was to talk to the practices about what they were already doing for carers and what they thought they could do to improve their service. Each Newham practice visited undertook to make some changes to their approach to carers (for example, by identifying the carers on their caseload by 'tagging' records to indicate a carer).

Stage 2 identified a number of useful lessons, including:

- Development work is labour-intensive.
- The intensive work with two practices in Hackney paid dividends. Both practices incorporated changes into their working methods and began to establish systems which could potentially be of benefit to carers.
- In Newham, the less intensive work with a larger number of practices did not seem to be effective. Although each practice had agreed to make some changes to its way of working, only one had actually done so by the end of the pilot phase.
- GPs and carers agree about the problems and the solutions. Carers want information and GPs want it too, so that they can pass it on. GPs want to give the support that carers would like to have, but they want to know how they can offer more effective support, given the constraints of time and resources. Carers want access to statutory and other services, especially social services; GPs would like to provide this access efficiently.

Stage 3

In the final stage, the workers concentrated on a number of practices in each district. In Hackney, three practices participated in development projects. One developed a system for special carer health checks; one carried out a practice survey of carers; and the third investigated how practice staff interview, offer support and give information to carers. In addition, work with two of the pilot practices continued, with the development of a carer information resource. Also, key people from health and social services were brought into a Hackney carers' focus group to explore ways of informing and influencing the development of services for carers.

Seven carers took the option of a special carer appointment with the GP. This proved successful and was generally welcomed by the carers concerned. The appointments also resulted in a number of referrals to other services. The practice has now agreed a system of identifying carers on its on-screen notes and of continuing special checks on an annual basis.

In the second Hackney practice, 22 carers were interviewed about ways in which the practice could give further support. A series of meetings between carers and practice staff have now been held, and the practice has nominated the senior receptionist as a named contact, to act as a link between carers and the appropriate practice staff member. The practice is also producing a leaflet for carers and an information resource.

The third practice has developed an information pack and trained reception staff in its use as a resource for carers.

In Newham, the project worker set up a series of group discussions involving staff from 13 practices. These discussions were designed to increase carer awareness – local carers attended the meetings – and to explore various ways in which the practices might develop the support that they give to carers. The group consisted initially of practice managers and reception staff, but later included GPs.

At the time of writing, it is not possible to identify *direct* benefit to carers from the work in Newham. Practice staff did report favourably on the workshops designed to increase their sensitivity to carer issues.

In Hackney, there have been some specific changes which do impact directly on carers. The follow-up interviews suggest that the introduction of carer appointments, nominating a carer contact person and producing carer information resources have all been well received. Follow-up work would be needed to establish the longer-term impact of these changes, and whether they are sustained.

In spite of these changes, the carers on the Hackney & Newham steering group expressed disappointment at what they saw as relatively small changes introduced by the project. However, there was acknowledgement that the project had contributed to local knowledge and established a basis for further carer-focused work with GPs.

A detailed account of the work in Hackney & Newham, including follow-up information and the lessons being drawn locally, is available from The GP/Carers Project, Department of General Practice, Queen Mary Westfield College, Mile End Road, London E1 4NS.[5]

The Sutton project

Sutton was chosen because of its long history of carer-focused initiatives across health and social care, with commitment from senior management much in evidence. When the project was being considered, it was one of the few areas in the country with an array of carers' activities in both the statutory and voluntary sectors – carers' support groups, development work with GP receptionists to raise awareness of carers' needs (our project was to build upon this work), a working group within social services devoted to raising awareness and contributing to Sutton's policy and planning on carers.

Aims

The Sutton project set out to:

- help GPs identify carers and establish different ways of working with practices to support carers;
- work with agencies, such as the FHSA and social services departments, to establish ways for GP practices to collaborate more effectively, for instance through making appropriate referrals;

- designate and equip one member of each practice to become the contact person for carers;
- develop specific activities to test out different ways of creating a 'seamless service' between social services and general practitioners.

An outline of the work

A full-time project worker was based in and employed by Sutton Social Services Department for two years. She worked within a number of GP practices in Sutton, helping them to identify their carers and getting one of the practices to designate the receptionist as its worker responsible for carers' issues. The worker was expected to work with clusters of practices for about three-to-four months each. A researcher was also employed at the end of the first year to evaluate service developments and outcomes from the project, in particular the benefits for carers.

Before the project worker arrived, a local steering group was established which did some valuable preliminary work. A local primary health care facilitator from the FHSA did much to alert local practices to the project and encourage GPs to take part. Fourteen GP practices expressed their interest in the Sutton project and three were selected from this for the initial cluster. For the others, they would be reinterviewed before the selection of the next and subsequent clusters to confirm their continued interest.

A working agreement

It was not easy to sell the concept of service development work to improve support for carers. GPs found it hard to understand the precise nature of the work and how they would benefit from the project. The Sutton worker tried to tackle this by creating a working agreement between the GP and the project (see below), intending to clarify each party's expectations of one another for the duration of the project work within each practice.

Agreement between Sutton Carers Development Unit and participating GP practices

The carers' project agrees to:

- provide time-limited practical assistance and support to practice staff, enabling the identification and implementation of agreed changes, to promote better support to carers.
- provide/facilitate training to raise awareness of carers' needs.
- provide information and local resources and support services, facilitating links with other organisations.
- facilitate the involvement of local carers.
- acknowledge and understand practice protocols and current issues within general practice.
- maintain confidentiality.
- ensure that the project is formally monitored and evaluated.

Participating practices agree to:

- share the aims and objectives of the project.
- enable all staff to take an active part in the project and to continue to promote service developments for carers.
- provide space within the practice for project staff.
- allow the project worker to attend practice meetings.
- provide an identified member of staff to assist in the facilitation of the work of the project.
- encourage the participation and involvement of local carers in the programme of work.
- participate in the monitoring and evaluation of the project (both informal and formal).

Signed: *Date:*

Unlike the Hackney & Newham project, the work in Sutton is in its second year of operation at the time of writing. The second year will continue to focus on the development work, evaluate the lessons learnt and ensure that these are absorbed into daily working procedures. The first year's development work was captured in an evaluation report.[6]

After one year, the impact of the project on the GPs and their practices varied. Most GPs saw their contribution to the project as being limited to identifying carers among their patients rather than offering them any tangible support.

Commitment and credibility

Establishing the project's credibility and winning the commitment of general practices were a challenge in themselves. Selling the concept of the project's aims was done either in practice meetings with GPs or individually with GPs as part of their busy schedules. Many would have preferred to have the development worker as an extra part of the practice team, who would offer support to carers on their behalf, rather than having to engage in the unfamiliar process of critically appraising the services that they themselves offered to carers. The project's task was to facilitate this process among GPs and practice staff, not to do the work directly.

Uneven development

As many practices as possible needed to be part of the project within the two-year development period in order to draw more conclusive lessons. It was decided by the project steering group that one way to achieve the involvement of a maximum number of general practices was to work with clusters of three practices, each for a three-to-four-month period. But the practices were at different levels of development and awareness of carers' issues, and for most of them, three-to-four months was not long enough to achieve much. Balance had to be sought between offering too much time to one practice and pulling out of other practices before people were clear about specific outcomes to be achieved. What happened was that some practices did not need as much as three-to-four months' support, yet they were clustered with practices which needed more time. At the end of the allocated period, these were abandoned, while the people in them were still unsure what they were doing. A more flexible system allowing the project worker to make her own judgments on when to stay or leave would meet this difficulty.

What benefit for carers?

A survey of 27 carers from the practices working with the project was conducted, which highlighted that carers were generally satisfied with the practice with which they were registered. Their satisfaction with the service focused on ease of communication with their GP, either via the telephone or during consultations. Communication – as an aspect of good practice – was identified as an issue to build on in subsequent general practice clusters.

Before the project started, none of the practices had formal mechanisms for identifying carers. GPs and practice staff relied on their memory to identify carers. With the project worker's help they started formally to identify carers from their records. Where practices were computerised, carers' details had been included within the system. Identifying carers is a fundamental precondition to providing support to carers, but the danger is for practices to spend their resources merely identifying carers and their needs, rather than meeting those needs.

Some of the practices had begun offering activities to carers, such as carers' training and support groups. It was hoped this would continue when the project worker was no longer working in the practices.

Finally, having a designated worker within the GP practice meant carers had a point of contact.

Chapter 3

LESSONS AND CONCLUSIONS

At the outset of this report we posed a number of questions:

- What do carers expect from general practices? How realistic are carers' expectations of general practice?
- What changes are required if general practice is to become more supportive of carers?
- How could any changes best be introduced?

We worked in two localities and the project encompassed a few dozen general practices: our findings are tentative. Much of the work is continuing. In Sutton, the project is still under way, and in Hackney & Newham, it is too early to see whether the project's developments will be carried forward. The projects have confirmed that carers' demands are relatively modest; they would like acknowledgement of their caring role, to be listened to and to gain access to other sources of support. They are not presenting general practice with a bottomless pit of demands but, nevertheless, the demands that they make appear to present a challenge to current arrangements in general practice.

How realistic are carers' expectations?

The projects set out with the idea that significant changes could be introduced into the way that general practices operate, and that these could achieve major improvements in the lives of carers and the people they care for. This was perhaps optimistic: although we have witnessed changes, we have also learnt that a great deal of effort is required to obtain relatively modest results. Part of the explanation for this lies in the particular local factors which operated in the two projects, and we discuss the lessons of that later in the chapter. But first there are important issues, relating to the current climate of community care and social policy, which contributed to the projects' difficulties and frustrated any prospect for change in this area.

Could GPs become a major source of support for carers?

Many general practice staff recognise the potential benefits of giving high-quality support to carers. They acknowledge that carers need information, support and access, via their GPs, to other services, especially social services. They recognise that giving all this would benefit their patients and would like to be in a position to give it. Nevertheless, carers are generally not treated as a priority group within general practices. Why is this so?

Recent changes in general practices, such as the new GP contracts and the advent of GP fundholding, emphasise other aspects of primary care and include incentives to concentrate on these. For example, at the time of this work, most general practices were working on a range of health promotion measures for which they would receive additional payment. Specific support for carers is not a priority in health promotion.

In addition, providing additional support to carers brings no obvious financial benefit to GPs. As one GP put it, 'I am running a business – you need to tell me what's in it for me.' While general practices have always been small businesses, the increased focus on this aspect in recent years and the way in which funding is linked to government health targets and local FHSA policies, via the contract, mean that any practice which proposes to change its procedures or priorities has to take account of the financial implications before it acts.

The new framework for community care, especially the new role of social services departments, is not at all clearly understood by many general practices. There seems to be a tendency for GPs to 'keep their heads down' and not get embroiled in the current community care upheavals.

As if the community care reforms were not enough, further changes in the purchasing of primary care and in the roles of GPs, DHAs and FHSAs were announced in October 1994 by the Department of Health.[7] These will add to the current confusion about the role of the general practice team in support of people such as carers.

Finally, there is the problem of confidentiality, especially when the carer and person cared for have different GPs. Many practices were concerned about this. To what extent is it proper for a GP to share information about someone with that person's carer? If the two people have different GPs, what can be done to reduce conflicts of confidentiality? Is it ethical to suggest that one of the parties change GP so that they are both under the same practice? These issues are under discussion in some of the project areas (see, for example, the Hackney & Newham progress report[5]) but confidentiality is definitely another barrier to closer GP support to carers.

Fear of carers

Many general practices fear that any encouragement given to carers to ask for support might overwhelm the practice. Increasingly, general practitioners themselves are being seen as precious, highly skilled technicians, whose job it is to identify and arrange treatment for medical conditions. The emotional and social problems which carers experience do not fit easily into this model. In the practices encountered by the projects, there was indeed a fear that the severity of problems at present under the surface could overwhelm GPs and practice staff already struggling to cope with a large workload.

The theory of the gateway

In theory, most people have ready access to a GP, who is able to refer them on to other sources of help, such as social services, benefits agencies and voluntary organisations. This has seldom been the reality. Many practices involved with the projects had a history of poor working relationships with other agencies. A common complaint was that social services did not respond to emergencies and did not keep the practice informed about their work with a patient. Practice staff did not often know how to get in touch with social services departments or other agencies.

The projects made poor progress in improving linkages between social services and GPs. The long-standing lack of dialogue between the two services and the mutual mistrust are not going to be easily dislodged, and the effects were too deep-seated and complex for the projects to deal with them in their short existence.

While it is no doubt important to foster trust between GPs and social services departments, there can be a danger of focusing too much on bridge-building between these agencies. Any joint working between general practice and social services (e.g. ensuring that each agency is aware of the other's role and the services offered) must be undertaken with a view to improving carers' support. This ensures that carers themselves remain central to the work programme.

In some of the project areas, links between social services and GPs are beginning to happen. In Hackney & Newham, the project had encouraged joint discussions between key social services staff and members of individual general practice teams, which has laid down promising foundations for more effective joint working. Sometimes bridge-building involves some very simple practical steps, such as making sure that practice staff have up-to-date contact names and telephone numbers for other agencies.

For all these reasons, we cannot look to current general practice as a major source of support to carers. Unless new incentives are introduced, at government and local levels, and practices make significant changes in the ways they operate, it is unlikely that sustained support for carers will emerge through the general practice system.

This is not to decry the efforts of individual practices, nor to be disparaging about the work of national and local carers' groups and others that are attempting to promote change.

Could anyone else provide the support that carers need?

If general practices cannot provide support to carers without major changes in policy, what are the alternatives? After all, a wide range of carers' support groups exist which provide specialist support, usually from people who themselves have had experience as carers. Some social services departments support this type of activity or provide direct support themselves.

However, these are not *alternatives* to a supportive general practice. Carers still need to consult their general practice, either about their own health or that of the person they care for. They still require a sympathetic hearing and understanding by their GP that their own health may be at risk. The GP and other members of the practice team still have an important contribution to make to the health of both carer and the person cared for. There are still advantages in practice staff seeing carers as partners. The general practice is still a useful source of information about other sources of help and support. The GP still has a role in referring people to other services and may also have an important role in community care assessment.[8]

While it is not sensible to see the general practice as the *sole* source of support to carers, it does have an important role to play, complementary to that of other statutory and voluntary services. In addition, the project found clear difficulties for carers in their relationships with GPs. Solving these problems involves in part closer working partnerships between practices and other services, but also implies that practices need to identify and behave sensitively towards people who may have substantial social as well as medical problems.

What needs to happen to enable GPs to be more supportive?

What changes are required if general practice is to become more supportive of carers? There are three levels of change:

- changes in government policy;
- changes in regional and local practice in commissioning services;
- changes within practices themselves, and with other local services and interest groups.

Government policy

In our view, Government needs to acknowledge that significant social problems exist and to support changes in policy and practice which will encourage both general practice support for groups with significant social problems and effective joint working between primary health care and social care agencies.

Carers are not the only group of people for whom these issues exist: there are also other groups of people who need to be treated sensitively by their general practices and who may require extra assistance from other agencies.

Government could increase the priority given to such groups of people by identifying them specifically in policy statements and by looking for ways of encouraging general practice to give them the added support they require. For example, carers could be included in future *Health of the Nation* targets. This carries the risk of slotting carers into the 'disease model of care', but it is a mechanism for placing carers' support prominently on the health care agenda. The concept of health promotion could be extended to include support for carers. Probably the most effective way of encouraging change at a national level would be to add financial incentives for general practices to identify and give added support to such people. Such an investment of resources into primary and community care would pay dividends in supporting a large unpaid source of care and in the prevention of crises and emergencies requiring far more costly solutions, both in cash and human terms.

Service commissioning

In our view, there is scope for DHAs, FHSAs and local authorities to address the issue of more effective support to carers (and others) through service commissioning. Indeed, the recently announced changes in the role of DHAs and FHSAs, together with an enhanced role for general practices in the commissioning process, may give new opportunities for change. In one of the pilot areas, an approach has been made to the FHSA to consider adding an additional clause to their contract with general practices, to encourage them to identify carers and provide additional support when required. This is one way in which, at a local level, the initiative could be taken.

Joint commissioning of services is also relevant. Carer support is an area where both health and social care agencies have important roles to play, as some local pioneering projects are demonstrating. For example, work currently under way in Wiltshire and Westminster is exploring the potential for joint commissioning of services for elderly people, across health, social and primary care services.[9,10]

Finally, the Government has now given the green light for GP commissioning. At the time of writing, it is too soon to say much about this, but the prospect of more GPs directly commissioning services and having an added role in the joint commissioning process may well have implications for the issues raised in our report.

Local changes

Despite our emphasis on the need for changes beyond the scope of individual general practices, and the limited opportunities for practices themselves, our projects did have some success in promoting change at local level. The projects highlighted what sorts of changes are required, namely identifying carers, arranging consultations so that carers can discuss their own problems, ensuring that carers get up-to-date information about other services, having effective referral and follow-up systems.

In order to enable GPs to pay more attention to social care, social services departments may also have to consider restructuring some of their procedures. For instance, when GPs are called out at night for an emergency, they often need a parallel social services emergency service with whom they can collaborate or to whom they can hand over. In Sutton, Crisis Care not only responds quickly, it also takes over the role of arranging and co-ordinating continuing support if required.

In order to strengthen the links between social care and medical care, forms of joint working could be set up, giving both agencies insight into each other's working methods and their joint role in supporting groups such as carers. For example, care managers could be established as part of the general practice team operating to support those patients with social care needs, including carers. There may also be scope for some GPs to spend some of their time working directly with social services departments. Both of these suggestions for more integrated working are possible, but financial and organisational problems would have to be resolved first. For example, who would pay for a care manager to work within a general practice, or for a GP to work with social services? Might fundholders buy time for themselves to contribute to collaborative ventures? Are there any financial incentives for practices to take on this sort of joint working, even if it results in a better service to patients? How would issues of confidentiality and clinical responsibility be handled? None of the problems are insurmountable, as is evident from care management and secondment initiatives up and down the country.

The projects reported here, and the other initiatives around the country are all adding to the stock of knowledge about ways of changing local services. It is also important to stress that changes in government policy and in commissioning arrangements will not themselves lead to a better deal for carers without a corresponding change in the ways in which practices operate. We discuss some of these change strategies below.

Introducing change

The development projects, together with the discussions of seminars conducted during the course of the project, indicate certain directions for change.

Work with the whole practice team

While the GP is a central member of the team and their support is crucial, other members of the team can often make an important contribution to the support of carers. For example, reception staff can help highlight the fact that someone is a carer and can make information available. Practice managers can set up tagging systems of patient records and can compile local information for carers. Nursing and other professionals can often play a major role in identifying carers as well helping them with the social and emotional problems they face.

Make links with other people working on the same issues

Many of the people who attended our seminars were surprised to find others working on the same issues and found this very supportive. One benefit of the seminars was the exchange of addresses and telephone numbers which took place.

Work locally with others interested in improving support for carers

It was important to identify allies who could locally support the project work. It was not always easy to work with other local groups with a similar interest. For example, in Newham, there was a strong local carers' group, which at the end of the project felt that it should have had much more influence over the project worker. In Hackney, the project successfully facilitated the setting-up of a local carers' focus group, involving a range of agencies.

Build on what the practice already does well

Most practices can be encouraged to identify areas of operation which work well and to develop these further to the advantage of carers. For example, one practice which already has a well-developed new-patient assessment system is now exploring ways of adding to this so that carers can be identified. Another practice is extending its appointment system so that carers can be offered a 'carer's appointment'. It is also important not to expect dramatic results from the practices. It often took long and painstaking work to achieve relatively modest outcomes. Generating increased awareness of issues and fostering dialogue between agencies could have long-term benefits.

Service development as a new way of working

Service development appeared to be a new concept within the practices. One difficulty highlighted in the Sutton project was selling the idea of service development work to general practices. It was difficult for GPs to understand how they were to benefit from the project and the precise nature of the work programme. (See Chapter 2 for more on this.)

Location of the projects

There were interesting differences in the location of the two projects. In Sutton, having the project located within the social services department proved invaluable in helping strengthen links between social services and GPs. In Hackney & Newham, the project was located within the academic department of general practice at a university medical school, and the fact that the project manager herself was a practising GP was a major advantage in gaining entry and credibility within general practices. The project worker in Hackney came from a social services background. This combination may have been one of the factors accounting for the relative success of the work in Hackney.

Role of the FHSA or new-style health commissions

Both projects were supported by the local FHSA, which provided additional credibility for work with GPs. The FHSA, as guardian for the planning, financing and managing of local health services provided by general practices, has a responsibility to ensure that local health needs are met. This would also include the needs of carers. FHSAs have a strategic role to play in linking and representing GPs to other agencies, namely social services departments. They can foster a dialogue between social services and GPs by making sure that social services departments are aware of how general practice functions and that GPs are kept up-to-date with the community care planning and assessment process so that they can be involved in these procedures to support carers.

Conclusion

This work has given us an invaluable opportunity to explore the world of carers and general practice. We discovered major problems in the ways in which some carers are dealt with in general practices. We also uncovered several reasons why this happens and why carers as a group are low on the general practice agenda. Our view is that, in order to achieve substantial improvements, significant changes are needed in the environment in which general practice operates. A new debate is under way around changing roles in primary and health care. We believe this report adds to the debate.

Appendix

USEFUL ORGANISATIONS WORKING WITH GENERAL PRACTICE

LONDON BOROUGHS REGION

Organisation	Contact	Main work area	Work base
National Schizophrenia Fellowship, London & South East Region, 3rd Floor, Station House, 150 Waterloo Rd, London SE1 8SB Tel: 071 928 7668	Amanda Doust, Area Manager	Sharing our knowledge and experience to help GPs and practice staff identify and respond appropriately to the mental health needs of their patients and families/carers. Direct primary care service provider delivering a home-based therapeutic support to patients with a major mental illness and their families/carers through the attachment of a mental health specialist to a GP practice. Pilot in Tottenham funded by LIG. Replication of service to other FHSAs being planned.	Central London, Waterloo

SOUTH THAMES REGION

National Schizophrenia Fellowship, National Office, Training Department, 28 Castle Street, Kingston-Upon-Thames, Surrey, TK1 1SS	Fred Carney, Director of Training	Courses for GPs. Information folder produced in conjunction with RCGP on care for schizophrenic patients and their families.	Kingston-Upon-Thames
Merton, Sutton & Wandsworth FHSA, 154-160 Upper Richmond Road, Putney, London, SW15 2SW Tel: 081 788 7255	Pauline McGaley-Towle	Promotion of development of quality and primary care in general practce. Liaisonwith health-related organisations in Sutton.	Sutton

SOUTH THAMES REGION

Organisation	Contact	Main work area	Work base
Cheam Family Practice (GPs) Queen Mary's Christian Care Foundation		Developing a network of social and practice support, counselling for patients in practice. Develop patient support groups. With Queen Mary's to provide respite care facilities for community groups. Rehab and convalescence facilities for people recovering from major surgery.	
Sutton GP/Carers Project Beeches Surgery, 9 Hill Road, Carshalton Beeches, Surrey. Tel: 081 647 6608	Gloria Challis	Receptionist for GP – helping carers with everyday needs, i.e information, assisting with appointments etc.	Charshalton

NORTH THAMES REGION

Enfield & Haringey FHSA Holbrook House, Cockfosters Road, Barnet, Herts, EN4 ODR Tel: 081 440 9384.	William Vineall	Two projects have been launched: a GP/Carers Development Worker, FHSA-funded but managed by Age Concern Haringey, to improve services provided by GPs to carers; a carers workshop, funded by the FHSA and Haringey Council meets bi-monthly to hear carers' views and so influence future services.	Herts
Barton House Health Centre, 233-235 Albion Road, London, N16 9JT. Tel: 071 249 5511	Dr. J Jenkins	Researching in GP practice to identify carers and explore their needs for support.	London, N16

NORTH THAMES REGION

Organisation	Contact	Main work area	Work base
Alzheimer's Disease Society 100 Farm Road, Edgware, HA8 9LT. Tel: 081 958 8324	Isle Boas	Send out information to GPs.	Barnet
Carers Support in Brent Ground Floor, Middlesex House, Northwick Road, Wembley, Middlesex HAO 1LF Tel: 081 810 6660	Julie Mallett	Link with GPs to provide assistance. Full-time GP/Carer Development Worker who works flexibly with GP practices. So far different practices have opted for an Information File, a rolling training programme for carers leading to support groups, and a training course for practice nurses and district nurses.	Brent

WALES REGION

Organisation	Contact	Main work area	Work base
Gwynedd Carers/PHCT Project 9 Bryn Glas Road, Holyhead Anglesey, Gwynedd, North Wales LL65 2ET Tel: 0407 760820	Mrs E Griffiths	Identification of carers, evaluation of provision for carers, resource materials, evaluating education of GPs and PHCT members.	Gwynedd
The Primary Care Team & Carers Powys Project Derwen, Cwmbach, Builth Wells, Powys Tel: 0982 553795	Mrs Jan Powell	Assisting primary care workers to recognise the role of carers and to meeting the needs of those caring for relatives or friends.	Powys
Powys Rural Council Watton Mount, BRECON, Powys, LD3 7AW Tel: 0874 622248	Angela Roberts/ Freda Sewery	Carers support worker, working with seven surgeries and linking with two social services areas. Identifying carers within practices giving them support, raising awareness of carers with statutory and voluntary sectors	Powys

EAST ANGLIAN REGION

Organisation	Contact	Main work area	Work base
Lifespan Healthcare NHS Trust Fulbourn, Cambridge, CB1 5EE Tel: 0223 884046	Ida Darwin	A one-person project researching carers needs and support mechanisms to raise carers profile. Compiled a local Carers Charter. Carers directory about to be commenced (Beryl Sarsfield – tel: 0223 834766)	Cambridge

NORTH EAST &YORKSHIRE REGION

Harrogate & Craven Carers Resource The Cottage, 50 Lancaster Park Road, Harrogate, North Yorks, HG2 7SF Tel: 0423 888000	Anne Smyth	Established by North Yorkshire Family Health Services Authority to help practices that wish to improve their support for carers, we offer help tailor-made to individual PCHT's requirements. Our team provides information, advice and support direct to carers and all those who work with them. We are also involved in awareness raising, training and planning.	Harrogate & Craven districts (one of four divisions of North Yorkshire)
Carers National Association Yorkshire & Humberside North West, Charlton House, 36 Hunslett Road, Leeds, LS10 1JN Tel: 0532 449228	Ann Wheeler	Input with GP training in Leeds, Northallerton and Kirklees. Production of a leaflet circulated to GP practices in North Yorkshire.	Yorkshire

WEST MIDLANDS REGION

Organisation	Contact	Main work area	Work base
Community Care Advisers Project Birmingham FHSA Aston Cross, 50 Rocky Lane, Aston, Birmingham, B6 5RQ Tel: 021 333 4444		Organisation of multi-disciplinary training events, development of service development strategies in specific areas, development of GP training initiative to address carers needs in assessment.	Birmingham

EAST ANGLIAN & OXFORD REGION

West Oxfordshire Carers Forum 22 Flemings Road, Woodstock, Oxon, OX2 1ND. Tel: 0993 813240	P Cozens-Walker	To assist in helping GPs to support carers in challenging the health authority to meet obligations to carers.	Oxford
Balmore Park Surgery Carers Project - "Who Cares?" 59a Hemdean Road, Caversham, Berkshire, RG5 3NG Tel: 0734 483414	Gabrielle Mauger	Created questionnaire for carers, analysed results and produced a report. Set up a practice 'carers' register. A 'Carers Support Group' meeting every 6-8 weeks with the team as facilitators. Aim to set up a carers helpline at the practice by the end of 1994.	Berkshire
Kettering & District Carers Carers Centre 1 Meadow Road, Kettering, NN16 8TZ Tel: 0536 414259	Jenny Coles/ Denise Mawby	Outreach work within GP surgeries. Planning a GP workshop for 1995.	North Northamptonshire

SOUTH WEST REGION

Organisation	Contact	Main work area	Work base
Cornwall Rural Community Council 9A River Street, Truro, Cornwall, TR1 2SQ Tel: 01872 73952	Pam Rabett	Pilot scheme running in 6 GP surgeries of Carers Stress Indicator and Checklist inserted into carers' notes. Identification of Carers – Presentation binder in each GP surgery in Cornwall containing 5 A4 information posters and contents of Carers Information Pack. To be placed with mazagines NOT behind reception!	Cornwall
NORTH WEST REGION			
Manchester FHSA 2A Higher Ardwick, Manchester, M12 6BX Tel: 061 276 9224	Penny Ozanne	Working with GPs and practice staff to develop primary care services for carers through actively identifying carers and providing an information resource.	Manchester
TRENT REGION			
Sheffield Carers Centre Project 14-18 West Bar Green, Sheffield, S1 2DH Tel: 0742 788942	Brenda Earl	Working with FHSA on a pilot project in one GP practice to find ways of identifying carers.	Sheffield
Carers Information & Support Service c/o 20 Kingswood Avenue, Bromley, Kent Tel: 081 460 2734	G Hibbert	Provide information for carers, training and practical services, open meetings, personal support via outreach workers. Hospital liaison, collective action for carers, i.e. in problems with local authority services and hospitals.	

TRENT REGION

Organisation	Contact	Main work area	Work base
ACT (Association for Children Life-Threatening or Terminal Conditions and their families) 65 St Michael's Hill, Bristol, BS2 8DZ Tel: 0272 221556	Stella Elston	Advocacy role for families caring for a child(ren) with life-threatening illness. ACT aims to make information available to all carers and professionals about support services for families throughout the country – statutory, voluntary and self-help groups. Will respond to telephone or written enquiries.	
Carers National Association/ Carers Impact c/o 25 Levens Close, Poulton-Le-Fylde, Lancashire, FY6 8NJ Tel: 0253 886185	Brenda Crosby	Training practice staff, suggesting improvements in admin to identify and help carers.	

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Over the last decade, we have witnessed substantial changes in the way support for carers has featured in the planning and development of health and social services. GPs and their practice teams, however, have not tended to be in the forefront of these developments, although there is general agreement that supportive general practice is helpful for carers.

But, how far can general practice go in helping carers? What do carers expect from their GPs and general practice? How could general practice become more supportive of carers, and how could changes best be fostered?

This timely reports sets out to answer these and other questions in the context of two projects sponsored by the King's Fund Centre.

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