

Working together to support carers
A Good Practice Guide for carers support workers and GP practices

Seven and a half minutes is not enough

The Princess Royal Trust for Carers

Contents

Foreword

Summary

Introduction and method

Project Overview

The Princess Royal Trust Carers Centre, Aberdeen

The Princess Royal Trust Brent Carers Centre

The Princess Royal Trust Suffolk Carers Centre

First catch your GP!

Stage 1: identifying carers

Stage 2: providing support

providing support to and identifying the needs of carers

providing support to those working with carers

Stage 3: evaluation and cost effectiveness

Other questions we considered

Case studies

Conclusion and recommendations

Other related projects

References / further reading

APPENDIX 1

The Princess Royal Trust for Carers, background information

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Foreword

This Good Practice Guide, *Seven and a half minutes is not enough*, examines the experiences of a number of Princess Royal Trust Carers Centres working within primary care practices. We believe that these experiences will be of value to others – both GP and primary care practices and carer support projects – in developing effective support for carers.

The Government's National Strategy for Carers¹ recognises that for many carers the most important initial point of contact with any services is with the NHS, with their GP, the community nurse or another member of the primary care team. The Strategy suggests that GPs and primary care teams need to see their own role as part of a wider network of support for carers.

However, the research report by The Princess Royal Trust for Carers, *Taken for Granted*, revealed that the large majority of carers questioned believed that GPs were unaware of the needs of carers (67 per cent of respondents agreed with this statement).²

There is clearly a gap to be filled between the support that carers expect and what GPs can deliver in the typical appointment time of seven and a half minutes.

But there are strong reasons why GPs should identify and support carers. Where carers are supported, and in receipt of benefits to which they are entitled, stress levels can be reduced. Lower stress can make it less likely that the carer would reach crisis point – a situation that may require two emergency admissions, for both the carer and the cared-for. It should, therefore, be possible for GPs to save money by supporting carers, as well as improving the quality of life for carers and cared-for.

This good practice guide suggests that GPs can also save time by supporting carers – by working with specialist organisations who can address the carer's needs outside the GP consultation time and reduce the number of inappropriate queries taken by GPs. The proposal is that everybody should win – GPs with lower demands on time and budgets; carers with better support as a result of a joined-up approach; and carers support workers with an effective form of outreach in order to identify and support greater numbers of carers.

We know that GPs cannot do everything they may wish in just seven and a half minutes, but we also know that GPs have a very valuable role to play as gatekeepers. When approached by patients who do not even realise that they are carers, GPs can open the gate to greater support or, conversely, the carer can leave without even realising that the gate exists.

Seven and a half minutes may not be enough, but the support that GPs can offer to carers does not necessarily have to be bounded by this time constraint. We hope that this good practice guide gives shows how this could be achieved.

David Butler
Chief Executive, The Princess Royal Trust for Carers

¹ *Caring about Carers – A National Strategy for Carers*, HM Government, published February 1999

² *Eight hours a day and taken for granted?*, The Princess Royal Trust for Carers, published September 1998.

Summary of findings (or dos and don'ts)

For GPs

Do

- contact other GP practices to see what has worked elsewhere
- have leaflets and carer noticeboards that will attract those who have not previously identified themselves as carers
- try and find out how many people registered with the practice are carers (initial audit followed by tagging carers' notes and regular questions at patient interviews and health-checks)
- include a carer question on the regular over-75s healthcheck. The over-75 patient may not themselves be a carer but may have a carer living with them
- check with your GP practice computer software supplier to ask if there is a "carer" code that can be added to notes – if so how
- have a specific named contact for carers. This could be either a member of staff within the GP practice or a visiting carer support worker to whom carers can be referred
- ensure that all members of the primary care team are aware of and take a pro-active role in identifying and supporting carers
- have a carers support worker who is visible to GPs, so reminding GPs of carers regularly
- ensure that the carers worker is seen to have the status to operate alongside GPs and be seen as part of the team
- set up specific services for carers – carers surgeries usually have appointments of 40-45 minutes per carer with the carer support worker and are good at solving specific problems and providing in-depth support to individual carers; regular carers groups are more useful at combating feelings of isolation and loneliness
- set a budget for a carers support worker that also includes an element of funding for telephone, photocopier, post, production of posters and other overheads
- ensure that your named carers contact worker receives support from a specialist carers worker who can help with complex problems and debriefing
- provide a quick and easy referral system that enables carers to either contact the carers worker or a nearby carers support project direct or be referred by the primary healthcare team
- find out about the support for carers, both one-to-one and group support, that can be accessed through the Carers Centre
- ensure that the project secures a commitment to ongoing funding to maintain the support for surgery based services

For GPs

Don't

- wait for carers to identify themselves as carers
- believe that supporting carers will cost you too much in terms of time and money
- assume that you have to do it all by yourself without any specialist support

For carer support projects

Do

- make contact with the lay member / Social Services member on the Primary Care Group (PCG) to ensure that carers make it on to the PCG agenda
- propose that there should be carer awareness training across the PCG framework
- become a resource – have a high profile regionally, attend team meetings, make links within the health authority network
- try and get a foot in the door and build up trust with GPs and primary healthcare teams

- let GPs know that you have relevant experience and/or qualifications
- find out what's happening already and whether there are any specific pots of money available that could be bid against to support carers through Health Action Zones, Health Improvement Programmes, or Healthy Living Centres for example
- keep persevering
- address information to the practice manager
- network, network, network
- maintain a quality service through training and supervision of GP practice staff acting as carer contacts
- ensure that the project secures a commitment to ongoing funding to maintain the support for surgery based services
- develop hard evidence of good practices to share with others
- contact other projects who have done this before
- work with and encourage your GP practice to do the things listed above

For carer support projects:

Don't

- expect the GP to read information on the services that carers support workers can offer (but do ensure that GPs have access to the information)
- expect GPs to digest a directory that answers every question a carer may ask
- expect GPs to come to you
- get downhearted if it doesn't work immediately. It can often take several years to get a project funded and working effectively
- spend lots of time and energy producing information that covers everything you ever wanted to know about carers, unless it's going to be useful for the carers support worker

Introduction and method

The good practice guide has been developed as a response to the needs of the 80 Carers Centres within The Princess Royal Trust for Carers (PRTC) network.

Well-structured comprehensive work with carers in local communities is still at a relatively early stage. For example, the first Princess Royal Trust Carers Centres were only established in October 1992. One result of this is that there have been relatively few publications which provide the straightforward guidance and practical advice needed to plan projects at a local level, looking at the potential pitfalls, costings and management issues. The idea of producing a series of good practice guides was suggested by the network of Princess Royal Trust Carers Centres.

In 1998, we contacted the network of Princess Royal Trust Carers Centres and asked what the first good practice guide should cover. The overwhelming response was for a publication that examined work with GPs and primary care.

The PRTC network was then contacted again to gain an overview of the projects already taking place in this area. Around sixty Princess Royal Trust Carers Centres are working directly with primary care practices in some way, and from this sample it was decided to focus on three projects taking different approaches in different areas of the country.

Detailed follow-up work, interviews and visits were conducted with these three Carers Centres, questioning not only the Carers Centres but also the GPs with which they work and the carers who have received support as a direct result of the project.

Project overview

The Princess Royal Trust Carers Centre, Aberdeen

The Princess Royal Trust Carers Centre in Aberdeen was established in 1994 following development work by Voluntary Service Aberdeen. The Carers Centre has remained a line-managed project but now employs four staff working directly with carers and other sessional staff to run specific projects and groups with 25 volunteers. It is in regular direct contact with around 1,400 carers and many others through other local groups. It covers the Grampian Health Board area (Aberdeen City, Aberdeenshire and Moray).

The Carers Centre works directly with a number of GP practices, with which it has individual agreements, via the Grampian Health Board, concerning the funding and the services to be provided. The first service agreement to be set up was with the Denburn Health Centre, North Practice in central Aberdeen, where services started on 1 September 1997. The Princess Royal Trust Carers Centre is contracted to provide a monthly three-hour "Carers Advice" session on the surgery premises, plus the provision of information leaflets and posters, at £60 per month.

Following the success of the Denburn project, the Carers Centre is now developing a similar service with an adjacent practice in the city centre – the Viaduct Medical Practice, East Wing. Both of these GP practices are a short walk from the Princess Royal Trust Carers Centre, ensuring that carers can get easy access to support between the regular times of the carers advice sessions.

In addition, a further scheme started in April 1998 covering the provision of information to carers through 10 GP practices in South Aberdeenshire, a scattered rural area, and will shortly be starting in neighbouring Moray, where 20 GP practices will be targeted. There are also leaflet racks containing information from social services and the Carers Centre in a further 25 GP practices in Aberdeen City.

Project overview

The Princess Royal Trust Brent Carers Centre

Carers Support Brent was first set up as a voluntary organisation in April 1993. In 1995, following a successful application by The Princess Royal Trust for Carers to the National Lottery Charities Board, The Princess Royal Trust Brent Carers Centre was established to build on and expand the work of Carers Support Brent. The Carers Centre now employs eight staff and is in contact with around 1,000 carers on a regular basis.

The first post of primary care development worker was funded in December 1993 for an initial three years. Funding was provided by Brent Health Authority, via the London Initiative Zone. The current funding for the post, of £27,000 per annum, covers the salary of the development worker and on-costs and is now included within the core funding received from Brent Health Authority, Brent Council and the National Lottery Charities Board, via The Princess Royal Trust for Carers.

In total, the project is targeting 88 GP practices, with over 150 individual GPs, within the London Borough of Brent and the approach has largely depended upon the response received from the GP practice. In some practices it is simply a matter of providing information to staff and noticeboards for carers, and encouraging referrals to the Carers Centre. In other practices a more hands-on approach has been possible, illustrating to GPs how they can tag carers' notes within the widely used computer records system and set up carer surgeries in practice premises.

The success of one project funded initially through COPC (Community Orientated Primary Care) monies has led one GP practice, Dr Tansley & Partners, Chalkhill Health Centre, Brent, with 6,000 registered patients, to develop it further. The practice uses its own budget to continue funding a carer support worker who works one day a week within the GP practice, contacting patients, holding carers surgeries, making home visits, running carers groups and advising the primary care team. The carer support worker is line-managed within the practice by the practice manager but retains informal links with, and receives further support from, the Brent Carers Centre.

Project overview

Suffolk Carers, part of The Princess Royal Trust Carers Centre network

Suffolk Carers was originally set up under the management of Suffolk ACRE (Action for Communities in Rural England) in 1988. Ten years later it had grown to employ the equivalent of seven full time staff, in regular contact with around 1,500 carers. In October 1998, Suffolk Carers became independent of ACRE and joined the network of Princess Royal Trust Carers Centres.

Direct work with GP practices began in April 1995, based on a proposal developed jointly by Suffolk Health Authority and Suffolk Carers. Initially funding of £17,000 per annum was provided for two years before the GP development worker post became a core-funded position (the funding now, with inflation, is £17,467). The funding allows for a 20-hour post, together with associated transport costs and a limited literature/publications budget. The post is the subject of a joint service agreement with Suffolk Social Services and Suffolk Health.

The aim of the post is to reach and provide support to carers through every GP surgery across Suffolk. There are a total of 90 GP surgeries in the county and as a result of work to date, around 50 per cent of GP practices in the county have become involved.

The project initially started by setting up carer support groups within GP practices but has moved towards more direct work with individual carers.

Due to the limited hours and funding of the project a "carers link" is identified in each surgery. The carers link receives one-to-one training from Suffolk Carers' GP development worker, together with a pack of information and sample leaflets, and is expected to signpost and refer carers to more specialist support if appropriate. In addition, the GP development worker runs a number of "carer surgeries" within GP practices. More intensive longer-term support with individual carers outside the GP practice is provided by one of the team of carers workers within Suffolk Carers, as part of the organisation's core work.

To strengthen the working relationship, the GP development worker now takes part in the regular induction and training sessions run by Suffolk Health for non-clinical members of primary care practices (eg practice managers, receptionists).

FIRST CATCH YOUR GP!

“The first lot of information went in the bin. It looked too glossy – like a drugs company.”
Community nurse, Denburn Health Centre, Aberdeen.

“My father was disabled and my mother cared for him for 20 years. I know that she had to find out for herself all the information she needed. I spoke to Karen [community nurse in the adjacent Denburn Health Centre who has helped develop the carers project within the surgery] and decided we should set up carer support and get the Carers Centre in monthly.”
Dr Ritchie, The Viaduct Medical Practice, Aberdeen (project due to start January 1999).

“Carers should be covered in the core medicine course. We must be aware of the fact that carers numbers are going to increase.”

Dr Tansley, Chalkhill Health Centre, London Borough of Brent.

Where Carers Centres have been successful in working within GP practices it seems to be due to a number of factors:

- direct personal contact between the Carer Centre and a GP/member of practice personnel, becoming part of the professional network
- existing knowledge and interest of practice member in issues surrounding caring
- determined efforts and persistency by the Carers Centre

Unfortunately, there is no quick or easy route to gaining acceptance with GPs. Any information will have to compete with guidelines and circulars from local health authorities and other official bodies, magazines covering the latest working practices, and information from drugs companies on new products. Instead Carers Centres need to rely on networking through existing routes such as the PCGs in England, and meeting the right person within the practice. This may be the practice manager or could be somebody else who already has a specific interest or experience in caring issues.

In many GP practices one of the most effective ways is to identify the person responsible for development of the practice and quality issues – usually the practice manager. The argument is that to develop the GP practice and improve the quality of service offered to patients, it is essential to support carers. The practice manager can subsequently be a useful advocate within the practice.

IDENTIFYING CARERS

The biggest problem remains that support is only available to those who have been identified, either by themselves, by a GP, or via some other route, as a carer. Although services such as Carers Centres are often easily accessible, carers are more likely to use them if they have been recommended by people they know and respect – perhaps a friend, or a professional such as a GP or practice nurse.

Identification of carers is therefore essential. The Government has already recognised the necessity to identify carers with the National Priorities Guidance for the health and social services in England, issued in September 1998³ which asks GPs, primary care teams and

³ *Modernising Health and Social Services: National Priorities Guidance 1999/00 – 2001/02*. Department of Health.

social services staff to identify carers by April 2000. But to be effective this needs standardised procedures or research into carers' records.

The major examples of good practice in this area were found in Brent at the Dr Tansley & Partners, Chalkhill Health Centre, a group practice, and Crawford Avenue Health Centre.

Following initial contacts from the Carers Centre, work to identify carers started at Chalkhill Health Centre, which has 6,000 patients. Following the identification of 50 carers, largely by the receptionist and secretarial team, it was then decided to take the project further and secure funding.

Procedures are now in place to ask questions that identify if somebody is a carer during new patient health-checks, and also as part of the regular over-75s checks carried out by the practice nurse. Support is currently being provided to around 100 carers on a regular basis within the practice, with many others receiving ongoing support from the Brent Carers Centre.

At the Crawford Avenue Health Centre in Brent, patients over 75 years of age were contacted by phone to invite them in for healthchecks and at the same time were asked about their caring role. Funding to cover the out-of-hours working was provided by the Carers Centre as a pilot project. In total, 101 patients aged over 75 years were contacted over the 45-hour period of the pilot, of whom 58 either were carers or had carers – a very high proportion of the sample. Each carer identified was sent information on the Brent Carers Centre and other organisations offering help and support to elderly people. Support was given to enable carers to claim benefits (eg Invalid Care Allowance and Attendance Allowance) and, in addition, more detailed one-to-one work was carried out with 13 carers by the Carers Centre. The telephone calls also enabled the practice to identify some preventive healthcare needs of patients within the sample, for example chiropody appointments.

Questions to identify carers within the over-75s health-checks also started at the Denburn practice in Aberdeen in 1997 and have since become part of the standard practice for the primary care team.

In some Brent GP practices it was recognised that although there was a willingness to identify carers and tag them using the computerised carer code developed by REED (code 918a for a patient who is also a carer and code 918f for a patient who has a carer), some GPs were not at ease with the technology. To counter this the Carers Centre worker learnt how to use the codes and demonstrated their use to other GPs when the issue arose.

Tagging is also in operation at the Ixworth Surgery in Suffolk. Both carers and cared-for are tagged both on the practice computer system and on the Lloyd George patient record envelope, so that any doctor or staff member accessing their data will be aware of a patient's caring responsibilities.

Where carers have been identified and records tagged, carers have reported that the regular acknowledgement of their caring role is valuable recognition, a visible sign of the importance of the carer. It reflects well on the GP practice while boosting the self-esteem of the carer. Carers who feel part of a healthcare team may be more likely to use the GP practice efficiently, and possibly under less stress than somebody who feels excluded so bringing benefits for GPs, appointment times and prescription costs.

SELF-IDENTIFICATION OF CARERS

Self-identification of carers was largely through two methods:

1. carers noticeboard: detailing typical carers' situations and queries and inviting patients to make an appointment with the carers worker through the receptionist, to visit the Carers Centre, or simply to post their phone number to a carers support worker
1. leaflets for carers: some with tear-off self-referral forms to be sent to the Carers Centre, inviting a carers worker to make contact

Where tagging or identification of carers was not already taking place this seemed to be largely attributable to two causes:

1. a belief that it was the responsibility of the patient to identify themselves as a carer to their GP, and to have identified their needs for support as a carer
1. a reluctance to spend a large amount of time updating records, either on paper or on computer, with carer-codes, if there was a chance that the practice could shortly be changing to a completely different system

The first justification suggests a lack of understanding on the part of primary care practitioners of carers of the large number of "hidden" carers who have not been identified as carers by themselves or anybody else. This may highlight a training need.

The second response is perhaps inevitable in a busy practice and may perhaps only be reconciled either when the April 2000 deadline under the National Priorities Guidance approaches or if there is a strong commitment to identifying carers at a senior level within the practice.

It does raise the question of whether standard practices for identifying or tagging carers should be adopted in health authorities or Primary Care Groups for example.

Practice based nurses found that the standard nursing assessment was the same as that used in hospital. Consequently it was very clinical, and so does not include questions on carers. The community nursing team at the Denburn Health Centre in Aberdeen has amended the standard model for its own use to include questions on caring and carers.

Finally, it should be noted that in practices where carers have been tagged or identified there is recognition of the intrinsic need to then provide some additional support to carers. The bigger the identified need, the more resources you need to tackle it.

PROVIDING SUPPORT TO AND IDENTIFYING THE NEEDS OF CARERS

Two Carers Centres began by starting carer support groups run within GP practices, usually run by a Carers Centre worker (eg Brent, Suffolk). Both projects have now moved the focus within the GP practices to carers surgeries, referrals and one-to-one work, although groups still provide useful support for isolated carers, often following initial contacts with carers:

“You tend not to reach hidden carers by setting up groups – instead you just attract those people who have always felt comfortable with support groups and so are more likely to be plugged into the services.”

Jacqui Martin, Suffolk Carers.

The additional problem with support groups can come when there is no external facilitation available. If a carer has already been identified as a “problem patient” within the practice, there may be a reluctance to invite that carer into the group for fear that they may be a “disruptive influence”.

Carer surgeries

The most common forum for meeting carers’ needs and discussing individual problems in depth is the carer surgery, where carers have an individual one-to-one meeting, not with a GP but with a carer support worker. The GP’s involvement is in referring the carer to the carers support worker to start with, although carers can also self-refer if appropriate.

Usually run within the GP practice at a regular time each month, and at the Chalkhill Health Centre once a week, appointments for the carers surgery are 40-45 minutes in length. This appeared to be standard over all three Carers Centres.

Analysis of work by The Princess Royal Trust Swindon Carers Network suggested estimates of the support needed can be based on the practice population eg:

- Practice population of 8,000 + requires seven hours per week
- Practice population of 5,000-8,000 requires five hours per week
- Practice population of 3,000-5,000 requires four hours per week
- Practice population of 2,000 and under requires three hours per week

Appointments were:

- time limited
- held in a private room
- subject to the same confidentiality rules as other appointments within the GP practice

Interviews or appointments covered a wide range of subjects including:

- benefits
- statutory respite care
- council tax
- housing
- support available from other voluntary organisations

Interestingly, there was a very low drop-out or non-attendance rate for the carer surgery sessions.

“Carers get great support from somebody ringing them up and inviting them in for an appointment or setting up a home visit. It’s seen as a very valuable service.”

Alison Linyard, The Princess Royal Trust Brent Carers Centre

Suffolk had earlier trialled a more open, drop-in service “but the booking-in service seemed to be preferred by the GPs we were working with – they saw it as putting things on a firm footing and providing good service.”
Jacqui Martin, Suffolk Carers.

“We realised... that in most cases the patients needed to be seen individually and would not benefit from group work..... [now] any patient who has expressed an interest or a need relating to their care role is given an appointment in a monthly session. This particular approach has worked extremely well and we are now finding that the patients are talking to other carers who need similar help.”
Drena Black, practice manager, The Surgery, High Street, Lowestoft.

“There’s a designated time in which carers’ problems can be dealt with. It saves me contacting all the agencies myself – instead I just get patients to come back. It makes it so much easier for me. Every month I have two or three carers that I’ve referred on to Jan [Jan Wells, the carers support worker from the Aberdeen Carers Centre].”
Dr Pratt, Denburn Health Centre, Aberdeen.

“The carer support worker has a very strong listening/counselling role. You can’t physically do that in seven and a half minutes. GPs don’t have the time, particularly in areas where we are dealing with asylum seekers and coming up against language problems as well.

“The carers worker needs to be a professional with relevant experience. They must be seen as part of the primary care team. Good communication is what makes it work.”
Dr Tansley, Chalkhill Health Centre, London Borough of Brent.

Primary care workers including doctors, community nurses, practice managers and receptionists reported that the physical presence of the carers support worker within the surgery on a regular basis was a valuable reminder to them to refer carers for support.

An earlier project in Brent, where a worker from the Carers Centre ran a carers surgery at another GP practice for two hours a week for six months, led to a large number of carer referrals. At the end of the six-month period the budget could not be continued by the GP practice and, although the Carers Centre has stayed in contact with the GP practice, the lack of a visible presence has meant that the number of referrals has considerably reduced.

The Brent Carers Centre has also worked with other GP practices to influence the development of services for carers, working with link workers and putting in place training on carers for primary care teams.

In Suffolk, due to the large rural area being covered by a single GP Development worker (a 20-hour-a-week post) it would not have been feasible to have a dedicated carer support worker in each of the 90 practices being targeted.

Instead the role of the GP Development Worker is to identify within each surgery or practice a “carers link”. The carers link is usually a practice manager, practice nurse or receptionist who may already have knowledge of caring either through personal or family experience. The aim is that each carers link will champion the cause of carers within the surgery and will act as a central point for any carer trying to get support. In essence, they are taking on the additional role of carer support worker on top of their core responsibilities for the practice.

When this system works well, it works very well. Not only is the “carers link” present in the practice much more regularly than any external carer support worker could physically be, but

they are automatically a part of the GP team. Back-up and expertise is provided by the GP development worker who undertakes one-to-one training with the carers link, and develops information packages for use within each practice containing localised information. If more intensive work or support is needed then the carer can be referred to the Suffolk Carers support worker.

In Ixworth Surgery, Sue Nutt, practice manager, is the carers link. In addition to providing carers with individual support – eg ensuring that Occupational Therapists are contacted for assessments, and benefits are claimed – she also runs a regular carers group, which also organises social events like the Christmas party. Her experience and involvement within the practice encourages all members of the practice staff to identify carers, and tag them on computer and paper records.

The development worker from Suffolk Carers has been running a carers surgery within the High Street practice, Lowestoft, and the practice manager is now participating in this. Similarly, at Beccles GP practice a carers drop-in service is facilitated by both the carers link within the practice and the GP worker from Suffolk Carers.

In each case, because the work is taking place within the surgery there is a very high feeling of “ownership” of the carers project – it’s not just an area of work that is nothing to do with GPs at all.

However, as it is not automatically a core responsibility there are drawbacks.

The success, or otherwise, of the initiative does depend upon the commitment and involvement of the local “carers link”.

If the “carers link” does not have the full support of other members of the practice, or the status to insist on this, then the support can be tokenism. This could mean that, at worse, the time available for this activity can be reduced or squeezed out by other demands, meaning that it does not work well even as a referral service.

Although support for the “carers link” is provided by Suffolk Carers, because this is not a direct line-management responsibility it can be difficult to insist on remedial action if services are not being provided to a high enough standard or the expected numbers of carers are simply not being identified. The basic message is to encourage the work that is already happening, and hopefully foster improvements without being so critical as to be discouraging.

INFORMATION LEAFLETS, NOTICEBOARDS AND DATABASES

Each Carers Centre had a visible presence within GP surgeries – often with specific carer noticeboards as well as a range of leaflets available.

However, where these were the sole means of reaching carers, and the information was not being followed up by referrals from GPs, the numbers of carers contacting the Carers Centre for support was minimal. For example, across South Aberdeenshire a concentrated noticeboard, leaflet and poster campaign generated six contacts from new carers over a three-month period.

As with all other information, those people who don't currently recognise themselves as carers will not look at noticeboards, leaflets or posters on "caring". Only when a friend, colleague or person in authority, such as a GP, encourages them to recognise the term "carer" will this material be relevant.

But carers noticeboards do have a purpose:

- in reminding GP practice staff and carers of the practice's commitment to supporting carers
- in providing up-to-date information for those who have recognised themselves as carers already

Generally, the doctors and practice staff were happier referring queries through to the carers support worker rather than hunting for information themselves, but in practices where there had been a strong tradition of supporting carers in the past this was not always the case.

"The GPs told us that they were interested in having more information. They particularly wanted to know about the other voluntary organisations working within Brent. But that sort of information definitely works best when given face to face – it's part of building up the relationships."

Alison Linyard, primary care development worker, Brent Carers Centre.

"It would be useful to have up-to-date information on some of the queries that we regularly get from carers – like where to go for a wheelchair or how to get a walking-stick. That way we wouldn't have to wait to refer people to Mary [the carers support worker]. We don't want every bit of information – just for the most common queries. "

Wendy Stewart-Smith, deputy practice manager, Chalkhill Health Centre, London Borough of Brent.

PROVIDING SUPPORT TO THOSE WORKING WITH CARERS

Working directly with carers can be stressful. Anybody in this role, whether carer support worker, receptionist or GP practice manager, must be aware of the problems that carers are likely to come to them with, and the great strain that carers are often under. So it is essential that anybody in this position is well-supported in their role and receives the independent support that will enable them to debrief and discuss any concerns arising from carer consultations.

Carers support workers who work out of Carers Centres usually have a clear support mechanism through the Carers Centre manager. This is essential, as some carers support workers have found that there is a perceived gap in status between their role and that of a GP.

In Suffolk the “carers links”, although line-managed within the GP practice do receive ongoing support, information and one-to-one training from the GP development worker. The next challenge is to develop opportunities for the carers links within Suffolk to come together to share experiences and participate in training as a group.

COST EFFECTIVENESS

Although it can take some time to establish a carers support project within a GP practice, it has proved to be a very effective way of contacting carers, so the benefits for carers, particularly those previously not in contact with support services, are undisputed.

Where projects were given targets to reach, the main measure given was the number of carers seen each week or month. This is an easy and reliable method of judging activity, although it does not necessarily indicate the outcome of any such appointment.

In the Chalkhill Health Centre in Brent for example, the carers support worker produces a regular monthly report, circulated to GPs, on which patients have been seen and any resulting action taken.

Across Suffolk they now receive a larger number of referrals from the pre-paid leaflets available through GPs surgeries than through Social Services – a reversal of the trend across the remainder of the UK.

Other than such activity reports, the response to outcomes was largely anecdotal.

“I’m absolutely certain that some patients come to see us less..... Some people are going to the carers group rather than taking up 20 minutes of a GPs time in surgery.”
Dr Tansley, Chalkhill Health Centre, London Borough of Brent.

“The chasing round and phone-tag when secretaries are trying to find support for a carer has stopped now.”
Wendy Stewart-Smith, deputy practice manager, Chalkhill Health Centre, London Borough of Brent.

“The GPs have found that regular consultations with carers no longer overrun - a five minute appointment does not become half an hour and the routine prescribing of anti-depressants and anxiolytics for carers has steadily reduced.”
Dr Harpur, Ixworth Surgery, Suffolk.

“Especially for payments for this, that and the other, it’s helpful knowing that there is somebody who can deal with it just twenty feet away from my desk. It’s a service. I know it saves me a lot of time and a fair bit of effort, and that it is of great benefit to carers and patients.”
Dr Pratt, Denburn Health Centre, Aberdeen.

To be able to judge the effectiveness for GPs of providing support for carers through GP practices in any more scientific method would require detailed record keeping, not only by the carer support worker, but also more crucially by the GP practice as a whole. Records would need to be kept both before and after carer-support measures were implemented. Only then would it be feasible to gauge the impact of carer support upon measures such as:

- appointment times and overruns
- inappropriate enquiries
- prescription needs
- emergency and out-of-hours enquiries
- stress, exhaustion, back-injuries and other carer-related symptoms

More quantifiable measures would probably make it easier to persuade other GP practices to support carers, but the costs of this initial research and monitoring activity have not been met within projects to date, most of which run on minimal funding.

OTHER QUESTIONS WE CONSIDERED

Is this a role for volunteers?

Because of the problems of getting access to GP surgeries to start with, it appears to be important that the carers support worker is seen as having professional specialist knowledge and the status to function with the GP practice team. At present, this would seem to rule out the use of volunteers for the core functions of carer support, although there is a role for volunteers in updating and making good noticeboards and information displays.

What about training for GPs and primary care staff?

Brent and Suffolk Carers Centres both provided staff and expertise for the regular induction and training programmes for practice staff (receptionists, practice nurses etc) but there was no such regular training programme in place for GPs within local health authorities.

Although CPD (Continuing Professional Development) programmes take place for GPs, GPs can choose which sessions to do, providing they fulfil their annual requirement of hours in training. So although CPD sessions may be a good way of updating interested GPs on carers' issues, they will not necessarily reach those GPs who have no interest in the issue and are currently not working to identify or support carers through their practice.

Anybody who does want to set up a CPD session needs to get it accredited, which is done by a local GP representative appointed by the Royal College of General Practitioners (contact the Royal College of General Practitioners for details of local representatives). Other handy hints are to work with other groups to include a session on carers as part of a bigger programme that is expected to be well-attended, and to find an attractive venue for the training to take place.

CASE STUDIES

Mrs A, Brent

Mrs A cares for her husband following a stroke

"My husband had a stroke and I kept going to the doctor's surgery with lots of queries – like how to move my husband. When he left hospital I was promised a nurse, physio and social worker. The physio, nurse and chiropodist visited but abandoned us after a few visits. It's difficult because my husband will do his exercises for the physio but not for me. So I kept going to the doctors for advice.

"It was the receptionist who pointed out that I was a carer and advised me to contact The Princess Royal Trust Brent Carers Centre.

"I found it gave me strength and help. I was kind of stressed out before I got in contact. The Carers Centre got me onto their "Look After Yourself" course – a couple of hours a week just for me. I could relax and my mind went blank. It meant that when I got home I had more strength to carry on.

"The Carers Centre has got me daycare for my husband now which helps. But it's also the little things that make a difference, particularly when you're a new carer, like talking to somebody else at the monthly carers group and learning how to relax."

Mrs B, Brent

Mrs B looks after both her ageing mother and her husband who has heart and lung problems. Her caring situation was highlighted by through a project which identified carers through over-75s health checks.

"I got a letter from the practice telling me about the carers group. It's much easier to talk to the Carers Centre than it is to talk to the GP about my situation. The GP doesn't have the time.

"I now get offered respite but it's only two weeks a year. If I want to go on holiday to see my family in India I need six weeks respite care." (The Princess Royal Trust Brent Carers Centre is working with Mrs B in support of her application to the local authority for appropriate respite.)

Ms C, Brent

Mrs C cares for her two-and-a-half-year-old child who has cerebral palsy.

"When I first came to England I got no help at all. Then a year ago I moved to Brent and went to the Chalkhill Health Centre. As soon as arrived at the Health Centre with my child they realised that I was a carer and I was told how to get the support that I needed.

"To start with I spoke to Karen [the carers support worker based at the health centre one day a week] and she helped me apply for the benefits I was entitled to. Since then I have managed to get a grant for a washing machine and another one towards driving lessons. Before it took one week for the estate agent to fix the heating, but now if something goes wrong I speak to the Carers Centre and they help me sort it out quickly.

"Once a month I go to the carers meeting at the surgery. It's good to talk to somebody else who understands what you're going through. You know you're not alone then."

Mrs D, Suffolk

Mrs D, cares for her husband who has dementia and prostate cancer. Mr and Mrs D are a retired couple.

“A few years ago the stress really got to me. It was so bad that it prompted Sue at the Ixworth Surgery to set up the carers group. Of course I knew that the doctor supported me but I just jogged along – as well as having lots of battles with the hospital about my husband’s treatment.

“As well as practical things like making sure that we’re claiming the right benefits, I now go to the carers group. I have got family but there is a limit to what you can ask somebody else to do, so you really end up thinking you’re on your own. It’s better now that I know there are other people in the same situation. And I know from the carers group just how important it is to look after yourself if you’re going to carry on with the work as a carer.

“I can talk about things in the group and it means that I don’t always need to go and see the doctor to discuss a problem now.”

Mrs E, Suffolk, cares for her 80-year-old husband with arthritis and Parkinson’s disease.

“My previous GP was good but nobody ever asked me if I needed help or whether I was coping. I was a bit out on a limb.

“Then in February 1998 I came to Ixworth. I saw Sue [Sue Nutt, practice manager, the carers link at the Ixworth Surgery], had a chat, and realised that I was a carer. Since then I’ve got the carers allowance and I’ve been able to get an occupational therapist who’s helped me get things like a special loo seat and grab handles on the door.

“I now know that there’s somebody there if I need them.”

Mr F, Suffolk

Mr F cares for his wife with MS. Mr & Mrs F retired to Suffolk.

“Where we lived before we got no support at all – the only thing was the district nurse coming to give my wife injections. You marry for better or worse so you just get on with it, you don’t realise that you’ve become a carer – I didn’t even know the meaning of the word.

“They realised I was a carer as soon as I turned up at the GP practice. They’ve helped us get respite care twice a year, a special mattress and cushions. I can’t always get to the carers group but I know that if I’ve got any problems at all I can just call up and have a chat.”

Mrs G, Aberdeen

Mrs G and her husband both have epilepsy. Mr G has a much more severe form than his wife and recently underwent brain surgery, which led to a personality change.

“Dr Pratt did actually ask me how I was, and referred me for counselling following my husband's surgery, because he could see how stressful it was. Then at the beginning of 1998 we were having problems claiming Disability Living Allowance (DLA). I filled out all the forms but they rejected the claim so I went to see Dr Pratt.

“The doctor referred me to Jan Wells [from The Princess Royal Trust Carers Centre who runs a regular carers surgery within the GP practice] and she challenged the decision. Eventually we got the DLA.

“Now I know that the Carers Centre is there I've got information on the bleeper system and other things that I might be entitled to. It's easy to pop in and get information from the Carers Centre and it makes things much quicker.”

CONCLUSION AND RECOMMENDATIONS

Supporting carers through GP practices is effective for GPs. It can save GPs both money and time with shorter appointment times, a reduced number of inappropriate queries, and potential reductions in prescription costs.

In order to further define economic advantages for GPs, more work is needed.

Supporting carers through GP practices is also effective for carers support projects which can identify a large number of hidden carers, and for carers who are able to get help where they expect to find it.

From current experience, the best model seems to be a carers worker based within a GP practice (ideally one day a week) but forming part of a bigger team that is supported, trained, and kept up-to-date with developments by the Carers Centre or another independent carers organisation.

Carers surgeries within GP practices ensure that GPs retain “ownership” of their carers and gain an increased awareness of the issues. If the commitment also includes some form of funding for the post, then the commitment and ownership of the GP practice is even higher.

To work efficiently the service must be effective, reliable and confidential, and provided on a long-term basis.

Currently projects are being taken up by those GPs who already have an interest in or personal experience of caring. Including carers issues as part of medical students core study at university would ensure that all medical professionals who came into contact with carers would have a greater awareness of the issues. It should also ensure that more GPs are willing to participate in carer-support projects in the future.

RECOMMENDATIONS TO POLICY MAKERS:

Nationally:

- Information on carers and carer-sensitive practices to be included in preliminary training for GPs and other health professionals (nurses, pharmacists etc)
- Every GP practice should be encouraged to run regular carers surgeries or support groups within their premises
- Carer identification, as required by the Government's National Priorities Guidance by April 2000, to be measured after this date
- Following implementation of carer identification, carer tagging and referral to local carers support projects to be part of the core targets for GP practices
- Carers support workers based within GP practices must have access to independent specialist advice and management
- Funding to be ear-marked within health authority budgets for carer support through GP practices

Regionally:

- Carer identification/tagging to be standardised across local health authority areas
- The body deciding priorities for GPs and other primary care teams must include representation from carers
- At local planning level work with GPs and carers must be covered within the local authority community care plan

OTHER RELATED PROJECTS

The following are a selection of some of the other related projects run by Princess Royal Trust Carers Centres.

BASILDON

The Princess Royal Trust Basildon and Castle Point Carers Centre

The Carers Centre contacted all the practice managers and managed to get leaflets, information packs and posters sited within many GP practices and has had a number of carers referred to the Carers Centre as a result.

Contact Sheila Loveridge, The Princess Royal Trust Basildon and Castle Point Carers Centre, Tel: 01268 280441

GLOUCESTERSHIRE

The Princess Royal Trust Gloucestershire Carers Project

Gloucestershire Carers Project jointly manages a Primary Health Information Project. Advice sessions are run on a weekly or fortnightly basis in four GP practices. Carers are referred by GPs, surgery staff or they self-refer. Advice is also given over the telephone or in the carer's home. The project is also working with practice administration staff towards tagging carers records.

Contact Charlotte Bentham, Tel: 01452 386283

HARROGATE

The Princess Royal Trust Harrogate Carers Resource

Carers Resource has established close links with most local general practices. Initiatives include carer noticeboards, training staff, and facilitating reviews of practice policy and protocols for carers. In one GP practice, funding was secured to place a specialist carer support officer within the practice for 20 hours a week for 11 months. The carer support officer was recruited, trained, managed and supported by Carers Resource. The primary care team identified and referred carers. This work is continuing in other GP practices in the area.

Contact Anne Smyth, The Princess Royal Trust Carers Resource (Harrogate & Craven) Tel: 01423 500555

HERTFORDSHIRE

The Princess Royal Trust Carers in Hertfordshire

A resource pack was developed and distributed to primary health care teams with guidelines on how to develop carer support policies within GP practices and details of the various local and national organisations to which GPs/primary care workers may wish to refer carers.

Contact Sue Reeve, The Princess Royal Trust Carers in Hertfordshire, Tel: 01920 486677

KENNET

The Princess Royal Trust Kennet Carers Centre

The Carers Centre has set up a carers registration system with Marlborough Surgery where carers can request for their notes to be marked within the GP practice and their details to be passed on to the Carers Centre for further support.

Contact Christine Green, The Princess Royal Trust Kennet Carers Centre, Tel: 01672 564265

LEEDS

Leeds Carers Health Project

The Princess Royal Trust Leeds Carers Centre worked with a number of other organisations, including the Health Authority, Social Services, CNA, Leeds Community and Mental Health Trust for example. Activities included training for primary care teams, including the United Leeds Teaching Hospital and nursing courses at the University of Leeds. Support was set up for carers within two hospitals, information days for carers across the area were advertised in health centres, pharmacies and GP practices, and a monthly carer surgery was piloted at one medical centre.

Contact Tracey Boardman, The Princess Royal Trust Leeds Carers Centre, Tel: 0113 246 8338

LONDON

The Princess Royal Trust Barnet Carers Centre

The Carers Centre worked with the local hospital to produce a hospital discharge information pack for patients and carers highlighting the local services available.

Contact John Chappell, The Princess Royal Trust Barnet Carers Centre, Tel: 0181 343 9698

Carers Lewisham, planning to become a member of The Princess Royal Trust Carers Centre network

A three-year project was commissioned by Lambeth, Southwark and Lewisham Health Authority to highlight the needs of carers and to find ways in which general practices could better support the carers registered with them. The project worked with 18 GP practices, raising awareness of carers needs and offering advice and support to individual carers referred by the primary care team.

The Princess Royal Trust Sutton Carers Centre

The Carers Centre recruited a volunteer to visit every GP practice in the borough, identify a key contact and supply information. The contacts have resulted in a number of referrals, by phone, from GPs. The carers support worker has also attended a number of primary health care team meetings to raise awareness of carers issues.

Contact Eddie Parsons, The Princess Royal Trust Sutton Carers Centre, Tel: 0181 296 5611

The Princess Royal Trust Wandsworth Carers Centre

The Carers Centre produced a brief "carers directory" for GPs to keep on their desks and ran a series of training sessions in 33 local GP practices.

Contact Bridget Clery, The Princess Royal Trust Wandsworth Carers Centre, Tel: 0181 877 1200

MALDON

The Princess Royal Trust Maldon Carers Centre

The Carers Centre circulates newsletters, leaflets and posters to GP practices and has circulated a card with contact details to every GP in the area. Few referrals have been made to date.

Contact Janet Cable, The Princess Royal Trust Maldon Carers Centre, Tel: 01621 851640

NORTH & WEST OXFORDSHIRE

The Princess Royal Trust Carers Centre (North & West Oxfordshire)

The Carers Centre has noticeboards in approximately half the GP practices in the area and is working to install more. In addition, the Carers Centre has staff based within a rural GP practice holding a weekly session for carers as well as talking to practice staff and has a base for three mornings a week at a local community hospital. The Carers Centre is involved on a regional level doing presentations to GP trainees, GP forums, and practice meetings; is involved with all three PCGs in the area; and, working closely with the Health Authority, is developing an action plan on raising awareness of carers across primary care.

Contact Judith Marsh, The Princess Royal Trust Carers Centre (North & West Oxfordshire)
Tel: 01295 264545

NORTH TYNESIDE

The Princess Royal Trust North Tyneside Carers Centre

The Carers Centre contacted practice managers and primary care staff across the area, attended PCG meetings, provided information materials for GP practices, and set up a number of sessions for carers in GP practices. The Carers Centre used a number of volunteers to visit primary care staff and update noticeboards, for example.

Contact Isabel Regan, The Princess Royal Trust North Tyneside Carers Centre, Tel: 0191 295 4321

READING

The Princess Royal Trust Carers Centre, Reading & Central Berkshire

The Carers Centre conducted a survey of the support already available to carers through GP surgeries. Training was developed for primary care teams as well as sessions for carers groups on how they could make the most of their relationship with the primary care team. With the survey to GPs indicating that only one out of 20 practices tagged carers' records, carers attending the carers group session were encouraged to request that their GP marked their caring responsibilities on their records.

Contact Penny Henrion, The Princess Royal Trust Carers Centre, Reading & Central Berkshire, Tel: 0118 950 3941

SANDWELL

CARES, Sandwell, part of The Princess Royal Trust Carers Centre Network

CARES has appointed a primary care development worker, specifically to work with carers of older people, as it has the highest proportion of older people in the West Midlands. CARES also works closely with the elderly persons' care co-ordinator located within a GP surgery.

Contact Geoff Foster, CARES, Tel: 0121 558 7725

SOUTH BUCKINGHAMSHIRE

The Princess Royal Trust South Buckinghamshire Carers Centre

The Carers Centre worked with Buckinghamshire Health Authority health promotion department in order to set up a seminar for GPs and health care teams. As a result of the two-day seminar, one surgery started a carers group, two surgeries started tagging carers' notes and the Carers Centre received a number of referrals from GP practices. A similar seminar planned for the next year had a much lower response.

Contact Patti Vincent, The Princess Royal Trust South Buckinghamshire Carers Centre, Tel: 01494 463536

SWINDON

The Princess Royal Trust Swindon Carers Network

A pilot project, funded by the Health Authority and The Princess Royal Trust for Cares, enabled two part-time staff to work directly with five GP practices in order to provide independent support to carers. Service Quality Initiative (SQI) funding, through the Health Authority, funded staff in individual practices to develop identification and registration processes for carers. Following the pilot project, the Swindon Carers Network has put forward proposals for support to be spread to all GP practices in the area. Carer development workers would advise and work with staff in each GP practice, usually practice nurses, building up practice-based services and expertise, and offering independent support as appropriate.

Contact Deb Bignell, The Princess Royal Trust Swindon Carers Network, on Tel: 01793 531133

Scotland:

In Scotland, The Princess Royal Trust for Carers has launched a new campaign across the central belt of Scotland and Tayside, funded by Prudential, and endorsed by the Minister of Health, the Secretary of State for Scotland and the BMA (Scotland) among others. The campaign aims to encourage GPs and health practitioners to identify carers on their patient list and direct them to support services and was launched with a conference for GPs. The project is at a development stage and will be written up in detail in due course.

DUMFRIES & GALLOWAY

The Princess Royal Trust Dumfries & Galloway Carers Centre

The Carers Centre has recently started working with a local GP practice following an approach from the practice nurse who was organising a carers information evening. The carers support worker will also be attending the nurses' team meeting to raise awareness of carers issues.

Contact Claudine Brindle, The Princess Royal Trust Dumfries & Galloway Carers Centre, Tel: 01387 248600

GLASGOW

The Princess Royal Trust Dixon Community Carers Centre

As part of the Prudential GP Initiative, the Carers Centre has installed permanent displays in three health centres and monthly outreach displays in 24 smaller GP practices, with business card dispensers across all GP practices.

Contact Julie Young, The Princess Royal Trust Dixon Community Carers Centre, Tel: 0141 423 0728

The Princess Royal Trust Glasgow East End Carers Centre

The Carers Centre ran a carers support project in the Bridgeton Health Centre. A specific referral form has been designed for use within the practice, carer noticeboards have been established, and a regular drop-in session set up, as well as meetings and information

sessions held with practice staff. Referrals were also taken direct from Glasgow Royal Infirmary following hospital discharge procedures.
Contact Sylvia McCracken, The Princess Royal Trust Glasgow East End Carers Centre, Tel: 0141 764 0550

HIGHLANDS

The Princess Royal Trust Highland Carers Project

A seven-month project ran within the Inverness & Culloden Healthcare Co-operative covering 43 GPs. The aim was for a worker from the Highland Carers Project to work in four GP practices, with the practice manager, to help staff draw up a carer strategy appropriate for each GP practice. Some of the activities included a new information pack and materials for carers, training for primary healthcare teams, carers noticeboards in GP practices, carer identification and a carer contact in a number of GP practices. The results have been fed back to the co-operative.

Contact Sheena Munro, The Princess Royal Trust Highland Carers Project, Tel: 01463 718817

LOTHIAN

The Princess Royal Trust Carers Centre, Voice of Carers Across Lothian, Edinburgh
The Carers Centre is producing and installing carer noticeboards for 20 GP practices, and is concentrating on carer self-referral to the Carers Centre via information in the GP practice waiting room.

Contact Seb Fischer, The Princess Royal Trust Carers Centre, Tel: 0131 622 6666

REFERENCES / FURTHER READING

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Lesley Warner & Stephen Wexler
The Princess Royal Trust for Carers, 1998

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Pat Gay & Rimple Poonia
MSW Health, 1996

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Lydia Yee and Roger Blunden
Kings Fund, 1995

Putting Carers onto the Agenda in General Practice.
Jeannette Naish & Rosie Benaim

University of London, 1995

Working with Primary Care for Carers
CNA, 1995

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Sutton GP/Carers Project, 1997

Stress in Informal Carers of Hospitalised Elderly Patients.
R Liston, L Mann, & Bannerjee
Journal of the Royal College of Physicians, 1995

APPENDIX 1

The Princess Royal Trust for Carers, background information

The Princess Royal Trust for Carers exists to make it easier for carers to cope by providing information, support and practical help. Working through its network of Carers Centres, it also aims to raise awareness of the needs of carers and to encourage more carers to seek the support that will make their role easier.

Her Royal Highness The Princess Royal announced the formation of The Princess Royal Trust for Carers (PRTC) on 13 October 1991. The PRTC aims to establish a network of Carers Centres across the country – one in each local authority area – and there are now nearly 80 Princess Royal Trust Carers Centres across England, Wales, Scotland and Northern Ireland. It estimates that the network of Carers Centres is in contact with around 45,000 carers on a regular basis, and this figure continues to grow.

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

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

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

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

The Princess Royal Trust for Carers depends upon voluntary donations from individuals, companies, fundraising groups, and charitable trusts for the large majority of its income – and has recently received its first grant from the Department of Health.

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