RCGP Supporting Carers in General Practice

Summary report on GP practice journeys towards improved carer identification and support
Carers are defined as:

‘...any person, adult or child, who provides unpaid support to a partner, relative or friend who couldn’t manage to live independently or whose health or well-being would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse.’

Importance of carers

Census data shows that currently up to one in eight people have carer responsibilities and this number is likely to increase in the future as the population ages (The Health and Social Care Information Centre², 2010). Unpaid carers are estimated to save the UK economy about £119 billion per annum and represent a workforce larger than the NHS (Carers UK, 2011³). Carers contribute hugely to society and they deserve to be recognised, supported and nurtured so that they can continue to care.

Caring can be very rewarding but it can adversely affect physical and mental health, resulting in social isolation and financial difficulty. Targeted, meaningful support at the right stage can enable carers to maintain their own health and wellbeing, care better and for longer and helps prevent breakdown of the care situation, which can result in emergency admission of the person that they care for.

Nine out of ten carers attend their local GP surgery every year, however, many do not identify themselves as a carer and are often not identified by the practice team either. General practices, with their holistic approach and long-term relationship with their patients, are ideally placed to identify and support their patients who are carers. Unfortunately, many practices currently struggle to identify and prioritise the needs of their carers and offer them appropriate support.

Aim of this report

As part of a Department of Health funded initiative to help to change this situation, the Royal College of General Practitioners (RCGP) invited applications from general practices around the country, as well as nominations from carer organisations, to describe their journeys towards improved carer identification and support. Ten practices were selected as representing exemplary support to carers that other practices could learn from.

These practices varied from singlehanded to large group practices, from rural dispensing practices to suburban and inner city practices.

This report collates the information provided by these exemplar practices. A number of common themes emerged, together with some innovative ideas and practical guidance on ways that practices can improve the services that they offer to their carers. The intended target audience for this report is the Department of Health, CCGs, RCGP, partner organisations such as Carers Trust and Carers UK, and interested practices who wish to follow the lead of these exemplar practices.

There is no longer any national funding to help practices to identify and support carers. Initiatives such as those described in this report can cost time and money to implement (practice staff time, expenses, such as postage, printing costs, rental of rooms etc.). Practices have many competing priorities some of which, unlike the identification and support of carers, attract payments.

¹ Supporting Carers: An action guide for general practitioners and their teams. 2nd ed.2011; London, RCGP
³ University of Leeds, Carers UK. Valuing Carers - calculating the value of unpaid care. 2011; London, Carers UK.
Notwithstanding these circumstances, the exemplar practices described here have found ways to develop their services for carers. The challenge is to inspire more practices to make carers a priority.

Summary of suggestions for GP practices

Practices wishing to improve identification and support of their carers may consider:

- Developing a practice policy for carers and appointing a carer lead(s)
- Involving carers and the patient participation group in the development of the carer strategy
- Ensuring that the whole practice team, clinical and non-clinical, are involved and to include attached community nursing staff
- Using a variety of methods to identify carers, including encouraging self-identification
- Developing and maintaining a carer register which needs to be regularly updated to remain accurate
- Supporting carers by providing information using a variety of different media
- Offering enhanced access and flexibility of appointments for carers to make it easier for them to access healthcare
- Offering carer health checks to monitor physical and mental health and annual influenza immunisation
- Signposting carers to where they can get more information and support
- Developing close links with local carer organisations, social services and the voluntary sector
- Participating in a CCG carer champion network where available

How were the exemplar practices inspired to prioritise carers?

The first step for improving carer identification and support is recognition of its importance and prioritising this amongst the many other competing demands within general practice.

The motivation for the ten practices to go the extra mile to support their carers included:

- Local PCT/CCG initiatives to train carer leads/champions in local practices
- Previous involvement in pilot projects to support carers
- Ongoing involvement and work with local carer organisations following these initiatives

A number of practices highlighted that they had attended RCGP ‘Supporting Carers’ workshops which had stimulated them to make changes and others had worked through the RCGP ‘Supporting Carers Action Guide’ www.rcgp.org.uk/carers.

For several practices it was the personal experiences, both positive and negative, of a staff member being a carer which led to the recognition of the importance of carer support.

It did not appear that any practices have had any financial incentive to motivate them to improve their services for carers. Although anecdotally there have previously been some local enhanced services devised by PCTs to encourage practices to address carer services. Also one of the practices initially made
improvement to their carer services after being involved in a local pilot project, which presumably did include some initial funding.

A number of the practices remarked how it was often one enthusiastic individual who started the initiative within the practice and then inspired and encouraged others to work alongside them as the changes started to gain momentum and pace.

Getting started and becoming carer friendly

Once carer identification and support had been prioritised, all the exemplar practices then took the same next steps of identifying a carer lead for the practice and developing a carer policy.

Example

One practice shared the challenge that at the start many staff members were aware that they had a lack of knowledge on how carers could be helped and supported so felt uncomfortable about raising the issue with patients and that registering carers was viewed as a ‘tick box exercise’ rather than useful.

A feeling of helplessness is often encountered at the start of a practice’s journey. It is very encouraging to note that the practice in the example above went on to describe how, once the team became more aware of what help was on offer from the local carer support services and other voluntary sector agencies, a practice policy on carers was developed and they became more confident to discuss carer issues with patients.

All practices made the point that it was important to have at least one practice member taking the lead as a carer lead or carer champion. This role does not have to be assigned to a member of the clinical staff and is often performed extremely well by the practice manager or a member of the reception staff. The lead person is able to act as the main contact person for carers, other staff members and the local carer organisations. They often maintain the practice resources for carers and take the lead in setting up new initiatives for carers. They may organise ongoing carer awareness training for the other staff members.

The concept of carer champion can be developed further.

Example

One practice that had had a carer champion in post for five years recently decided to extend the idea and have more than one champion. They now have a receptionist who is more ‘hands on’, plus a GP partner who takes strategic responsibility for carer support.

A carer policy was mentioned by most practices. This outlines how the practice intends to identify and support carers. A number of practices pointed out that this was an evolving document which required regular review and updating. A useful practical

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Most practices stressed the point that to work effectively as a ‘carer friendly’ practice all staff needed to be on board and actively involved. Many practices had organised carer awareness training for staff, often with the help of their local carer organisation, or had taken the opportunity to access training organised by the local PCT/CCG.

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suggestion came from one practice who reported that all staff members were required to read the document annually as part of the appraisal process, providing a way of ensuring they were kept up to date and were reminded about the carer agenda.

Involving carers themselves in planning the practice’s strategy from an early stage is essential. The exemplar practices tackled this in a number of ways. Some practices included questions about carer services in their patient survey. Other practices involved their Patient Participation Group (PPG) by either asking for feedback and suggestions from carer members of the PPG, or forming a separate carers group.

**How do exemplar practices improve the identification of carers?**

Before a practice can start to offer support to their carers they have to identify which of their patients have a caring role. For this to be successful, the practice needs first to cultivate a culture of ‘carer awareness’ in the whole practice team and a number of the practices have accomplished this through staff training and raising awareness.

A number of the practices emphasised the importance of coding carer status correctly within the clinical record, once someone has been identified as a carer, to ensure that this information is available to all who are involved in the care of a patient.

**Example**

One practice explained that they code carer status by ensuring that either the code, ‘Has a Carer’ or ‘Is a Carer’, is added to the patient’s records and that this is then put as a significant active problem, enabling all subsequent clinicians seeing the patient to be aware of this important information.

By correctly and consistently coding carers, practices can then create a carers register.

Most exemplar practices described how this register was then used to call carers in for influenza immunisation or health checks, or to send out newsletters or other information about relevant initiatives or events in the local area. Some of the practices used the carer register to add messages for carers on the right hand slip of prescriptions.

A number of the practices have developed a specific form for completion by carers. They can give their permission to be added onto the carers register and can request an opportunity to speak to the carer lead or for referral to the local carer organisation for further support.

All of the practices highlighted the importance of keeping the carer register up to date. This responsibility was often given to the carers lead. It is important that carers are removed from the register when the cared-for person moves into a care home or dies. It can be highly distressing to carers to receive communications after the cared-for person has died. One practice reviews and updates their list annually, another reviews their register monthly to ensure it is kept up to date.

**Carers know the person they care for better than anyone else.**

As part of the identification of carers process, many practices explained how they sought written permission from the cared-for person so that relevant medical information can be shared with their carer. Carers know the person they care for better than anyone else. This knowledge can be very useful in planning care and carers often play a vital role in implementing any care plan e.g. changes to medication. Engagement with carers is such a vital part of good patient care and gaining consent for information sharing ensures that this joint working can happen without breaching confidentiality.
### Carer identification methods and strategies

The exemplar practices described a wide variety of different methods and strategies to improve their identification of carers, including:

- Opportunistically by reception staff, GPs and practice nurses during patient encounters and consultations
- New patient checks and questionnaires; one practice included the questions “Do you care for somebody who could not manage without your help?” or “Are you cared for by somebody?” on their new patient questionnaire
- Adding carer questions to chronic disease templates
- Asking at chronic disease reviews or at NHS health checks
- When forms are received by the practice regarding applications for Disability Living Allowance (DDA) or Attendance Allowance
- Encouraging patients to self-identify by having posters in the surgery, a carer notice board in the waiting room, and including information about carers on the practice website, in the practice leaflets and in practice newsletters. One practice has information about carers on the rolling advertising on the electronic screen in the waiting room. Another practice has a slideshow about carers running in the waiting room
- Information or messages about carers can be printed on the right hand side of repeat prescription slips
- At multidisciplinary meetings to discuss palliative care patients, patients with long-term conditions and vulnerable patients. Importantly a number of practices highlighted that community nurses often have valuable information about housebound patients and can become an integral part of a practice’s carer support strategy
- At flu clinics a number of practices had carer awareness information available (posters and leaflets) and the practice carer lead/champion in attendance at their influenza clinic. Some practices invited the local carer organisation and other voluntary sector agencies to run information stalls
- Through social media; one practice mentions carers regularly in their practice blog and on Twitter
Once carers have been identified how do the exemplar practices support them?

The exemplar practices supported their carers in a wide variety of ways:

- Providing information for them in a range of formats
- Improving access for appointments
- Offering health checks
- Signposting onto support services

Information for Carers

- **Carer packs:** Most practices have developed carer packs to give to carers when they are first identified to inform them about the support that the practice offers its carers and introduce them to the local carer support services. As with all resources these need to be kept up to date and this was often a responsibility given to the carer lead. One practice encourages GPs to carry packs with them on home visits to housebound patients to give to their carers. Another practice has taken the decision to give a carer pack to all carers that their team comes into contact with, regardless of whether the carer is registered with the practice or not.

Example of the contents of a carer pack:

- Letter to carer informing them of practice carer incentives
- Letter to patient for consent to be given to the carer to have access to relevant medical information
- Carers’ leaflet
- List of local carer organisations, other relevant health agencies and resources
- Past carers’ newsletters from the practice and/or local carer organisation

- **Carer notice board:** Many of the practices have a carer information corner or carer notice board in the surgery, usually in the waiting area where carers can access information and find out about local initiatives to support carers. Posters on the notice board can encourage carers to come forward and identify themselves to the practice. It is often the responsibility of the carers to ensure that this information is updated. Often practices report including leaflets from local carer support organisations in this area for people to take away with them.

- **Practice websites:** Most of the practices have developed a dedicated section or page of their website for carers, including information on the support available at the surgery and also links to local and national carer support organisations.

- **Practice leaflets:** In some practices, leaflets have included sections in which carers are encouraged to make themselves known to the practice and may also include information about services available for carers within the practice and the local area.

- **Carer newsletters:** Newsletters have been introduced by a couple of the practices as a way of keeping their carers informed and updated on a regular basis. Others use mail shots targeted to initiatives of interest to their carers.

Enhanced access and flexibility of appointments

A number of practices felt that it was important to try to improve access to healthcare for carers, which is often an area of difficulty and contributes to the negative health outcomes that carers experience. Some offer flexibility with appointments, offering appointments outside normal clinic times and offering a home visit for those carers who cannot leave the cared-for person in order to attend a surgery appointment. One practice makes a point of ensuring that carers are always seen as quickly as possible after arrival at surgery to
minimise the time they are away from the cared-for person.

**Example**

One practice developed a ‘care card’ for carers. The idea was that the card could be used by carers when accessing services at the surgery. It would ensure that the receptionists were aware of their caring role and offer greater responsiveness and flexibility. Although the scheme was valued by carers, problems, such as abuse of the cards and complaints from other patients who were unhappy that they weren’t eligible for the cards, meant that the scheme was abandoned after a year. This illustrates the challenges of introducing new initiatives and highlights the importance of regular evaluation of them.

**Carer health checks**

There is substantial evidence that carers often neglect their own health and as a result experience health inequalities.

Sometimes this is for practical reasons, such as being unable to leave the cared-for person at home alone while they attend surgery appointments. Sometimes it is because they are so involved in caring that they are unable to prioritise their own health needs.

**Carers are at increased risk of physical and mental health problems including back pain, stress, depression and strokes and as a group have increased all cause mortality.**

The time spent caring can also reduce the amount of time and energy that a carer has for healthy activities, such as exercise and cooking healthy meals. As a consequence of these factors carers are at increased risk of physical and mental health problems including back pain, stress, depression and strokes and as a group have increased all cause mortality (Office for National Statistics, 2003).

In an effort to address this some of the exemplar practices offer health checks to identify problems and encourage carers to look after their own health so that they can continue to keep well and able to care.

Some of the exemplar practices offered health checks to carers at carer request and sometimes by annual invitation. Many carers will have chronic health problems of their own and be eligible for an annual check already and practices commented that for these patients it can be helpful to add on some questions at this review about how they are coping in their caring role. To ensure that this happened regularly and consistently a number of exemplar practices have added carer questions onto their chronic disease review templates. One practice elected for a targeted approach for carers, inviting those not on chronic disease registers and those not eligible for the NHS health check for a formal carer health check.

Some practices had decided to undertake health checks in dedicated carers clinics which took different forms in different practices. Some offered regular clinics where carers physical, mental and social care needs were all addressed in one clinic. The patient sees a health care worker (GP, practice nurse or healthcare assistant) to check their physical and mental health, as well as a support worker from the local carer organisation who could advise them about finances, carer breaks etc. Another practice sends a health assessment questionnaire and a screening blood test form in advance of the appointment and then reviews this data alongside physical observations like blood pressure, BMI, smoking, alcohol consumption etc. at the appointment.

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A number of practices have added a social supportive element to carers clinics where the PPG runs a tea/coffee bar at the clinic and PPG members welcome the patients to the clinic.

All of the exemplar practices proactively invite carers to have influenza immunisation every autumn. The clinic was also often used as an opportunity to offer support and information to carers and to encourage hidden carers to identify themselves. In many practices the local carer support organisation will attend and run an information stand.

**Signposting to local carer support services, social services and voluntary sector organisations**

All the exemplar practices have developed a close relationship with their local carer support organisations and highlighted this as a key aspect of their carer support services. Local carer organisations offer a variety of services including information about:

- Local carer support services
- Benefits advice
- Peer support
- Training
- Emergency planning
- Carer breaks
- Carer grants

General practices can find it challenging to keep up to date with what services and benefits are available locally and nationally for carers. The exemplar practices shared that they have found it makes sense to direct carers to their local carer support services, who have detailed and current knowledge about what is available, and can advise them or refer them on to other providers.

Practices varied in the ways that they referred or signposted patients to local carer support organisations. A number either used the referral form or card created by their local organisation, or added a box to their own carer form, where a carer could request referral onto the local organisation.

Many of the practices have taken joint working further and have invited their local carer organisations to have a regular presence within the surgery in an effort to offer more specialised support for carers and also raise the profile of carers. Sometimes this took the form of a carer support worker manning a stall in the waiting area once a month to offer information to patients.

A number of practices had taken the decision to host carer clinics run by a carer support worker, which practice staff can refer patients into. Other practices have taken the decision to run joint carer clinics alongside the carer organisation providing a ‘one stop shop’ for carers (see also carer clinic information above).

Some practices have forged links with other voluntary sector organisations such as Citizen’s Advice Bureaux (CAB), food banks etc. to ensure that their patients are aware of, and have access to, as many sources of support as possible.

**Carer support groups**

Although the local carer support organisation may run carer support groups, some of the ten exemplar practices have set up their own carer support group organised from the practice. This seems most often to have been accomplished with the support of the practice PPG, with input from carers. Carer support groups give carers the opportunity to meet other carers in a social context, providing peer support, and in some practices, include educational sessions or opportunities to obtain advice from the local carer support organisations, or other voluntary sector agencies.

A number of the exemplar practices offered one off special events to their carers.
Some practices have run a carer information stand at the Saturday morning influenza clinics. One practice combines this with a coffee morning run by the PPG with a raffle and tombola.

**How do the exemplar practices stay motivated to provide an excellent service to their carers?**

It is one thing to embark on the challenge to improve the identification and support of carers but quite another to maintain the effort and enthusiasm consistently over time to keep the initiative running successfully.

**Examples of innovative initiatives involving specific carer groups**

*Young carers rarely make themselves known to their GP and often avoid seeking help, although caring can impact significantly on their lives.*

- **Young carers:** Few of the practices had targeted young carers specifically. Young carers rarely make themselves known to their GP and often avoid seeking help, although caring can impact significantly on their lives. One practice became aware that they were failing to identify young carers. They found out about a scheme running at their local secondary school to get young carers together and give them support from a school carers champion. The school carers champion was invited to speak at the PPG and subsequently two members of the PPG went to an event at the school to talk about the practice carers group.
  - **Staff carers:** One practice has made a point of finding out whether any of their staff are carers and offering them support from the carers clinic and flexible working to fit in with their carer responsibilities.
  - **Ethnic minority group carers:** Carers from ethnic minorities can be very difficult to reach. One practice has set up educational sessions for patients from the Asian community to share experiences and illustrate the importance of carers looking after their own health.
  - **Increasing awareness of carers in the wider community:** One practice has been very involved with the local community to raise awareness of carers, working with local businesses, the community pharmacy and the local library. They also have articles about carers published in their local free newspaper. Another practice ran a carer information stall at a local festival.

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**Example**

One practice holds a ‘Strawberry Tea’ to which all carers are invited. They can meet other carers and a health development worker from the local carer support centre attends to answer questions.

The same practice also ran a series of complementary therapy sessions for carers, with the funding obtained from the local carer support organisation.
How to maintain carer services

Reading through the reports from the exemplary practices highlights the following factors as key to maintaining their services to carers:

- Team work
- An enthusiastic carer lead/champion - to ensure sustainability a number of practices have found it beneficial to have more than one practice member or even a small carers team to lead the initiative
- Regular meetings to keep the impetus going and encourage the team
- Celebration of achievements can be very helpful
- A local CCG carer champion network with representatives from all local practices gives the opportunity for support, encouragement and ongoing training for member practices. It is an opportunity to share experience and good ideas
- Close liaison with local carer support services. In Herefordshire the local carer service has entered into a formal agreement with local practices, whereby the carer leads attend a six monthly meeting and they offer feedback, information and training to practices
- Positive feedback from patients can encourage practices to continue to make carers a priority. A number of practices regretted not collating this in a formal way and would encourage others to do this at the start of a carer initiative. Members of the exemplary practice teams reflected how valuable it was to know that they had been able to make a significant difference to the life and experience of carers
- Regular review of the carer support means that the service offered will evolve over
Conclusions

This report on the exemplar practices initiative describes how ten motivated practices from around England have improved the identification and support of carers. The report has highlighted key features of a successful practice strategy and gives examples of good practice, which other practices would be able to adapt and implement in ways to suit them, their team and their carers.

A key question is how to inspire all practices to prioritise carers. As the health service faces increasing financial pressure at least in part due increased demand from rising numbers of elderly patients and patients with ever more complex health needs, it makes sense, both clinically and financially, to support carers well. Primary healthcare needs to understand that supporting carers will benefit practices by improving the care of their patients with long term conditions, palliative care patients and their elderly and vulnerable patients. This will help prevent unnecessary hospital admissions and save them work in the longer term. To inspire practices to start to prioritise carers it may be necessary for CCGs to spearhead a local carer initiative, perhaps by offering training for carer leads, organising a local carer champion network, facilitating links with local carer organisations etc.

A key message from the exemplar practices is the importance of embedding carer awareness and carer friendly concepts within the entire practice team structure and ethos. In this way, the identification and support of carers becomes second nature to all staff members and real noticeable changes and improvements can result. Although the process often relies on one enthusiastic or motivated individual to start the carer initiative within a practice, a team approach is vital for sustainability. A number of carer leads, or even a small working group, helps to ensure that the process grows and develops and gains momentum. A major component to this team approach has to be joined up working with the local carer support organisations and the community nursing team to create a long term sustainable carer support strategy.

The next steps and challenges are to get the message information and strategies about carer identification and support out to all GP practices so that they can implement some of these measures for themselves, and their patients and their carers can benefit from them. In a healthcare environment with increasing needs and complexities and rising pressures on resources in both primary and secondary care, highlighting the improvement in care of those with long term conditions and palliative care patients and reductions in hospital admissions, which can result from improved carer support, may help practices to find the motivation to try some of the strategies described in this report.

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