Supporting Carers in Primary Care

Dedicated Services in GP Practices

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Introduction
The project was established as part of Northumberland’s Carers Health Checks Demonstrator Site, one of six such sites in the country, funded by the Department of Health. Carers Northumberland’s contribution to the Site initiated a formal partnership between North of Tyne PCT and Carers Northumberland in support of the PCT’s Strategic Plan 2008-13, that advocates an increase in the number and range of services provided by primary care and that ‘the specific needs of carers and their patients require addressing, particularly when the carer becomes ill themselves.”

Background
Through the Demonstrator Site partnership, two Carer Support Workers were appointed within Carers Northumberland, dedicated to the provision of support, information and awareness-raising to carers and staff in the primary care setting, with a specific focus on self-nominated GP practices.

The outcomes for the Demonstrator Site were that:

- Primary care teams support carers more effectively with their caring responsibilities and help to sustain the caring relationship
- Primary care teams are more confident in identifying carers and their specific needs
- Carers are more confident at acknowledging their own personal health needs and the ability to express their concerns
- Carers are more informed and access a range of support services and are less dependent upon the primary care team
- Patients with long-term conditions are more effectively supported through recognition of the needs of their carers
- Northumberland Care Trust is in a stronger position to bid for further funding to support carers as a pilot site

These objectives were to be achieved through a range of activities including:

- Advice to practices in the identification and support of carers, e.g. recruitment of carers champions, maintenance of carers information boards, health checks for carers
- Dedicated carer support available at primary care centres, e.g. regular carer information and support drop-ins with records of uptake and themes
- Establish agreed referral processes between Carers Northumberland and practices for continued support to identified carers
- Work with practices to identify areas of concern and determine appropriate carer support
- Where appropriate, referral to other VCS support; to Adult Social Care for Carer’s Needs Assessment or signposting to other agencies

The ultimate aim of the Demonstrator Site was to sustain the caring relationship and ensure carers have equal life choices by:

- Maintaining good mental and physical health
- Improving access to mainstream activities for short breaks
- Preparing for the future when caring reduces or ends, thus reducing the need for medical intervention
- Improving access to information and support
- Improving benefit uptake and help to return to work when caring ends
- Referring appropriately for Carer Needs Assessment
The initial timescale for the project was two years, from April 2009-March 2011. However the Department of Health subsequently reduced this to 18 months before the project began, and in reality, by the time full recruitment processes had been completed, including the required CRB checks, Support Workers were in post in February 2010, with only 13 months remaining to the end of the pilot project.

**Engaging with GP practices**
GP practices in Northumberland were offered the opportunity to benefit from the dedicated service of Carer Support Workers during the project period. All Northumberland practices were invited to apply to have a worker in their practice to maximise the benefit to carers and enable the gathering of evidence in relation to the effectiveness of the interventions to improve targeting of future resources.

This offer included:
- Free dedicated Carer Support Worker time to the end of March 2011
- Agreement of outcomes for both patients who are carers and practice staff, determined through working with the Practice Manager.
- Individual follow up from the Carer Support Worker in developing a detailed support plan for carers in the practice who have received a health check
- Support for the achievement of management points in relation to carers
- Negotiated backfill payment to support the involvement of the Practice Manager in the project

Practices who participated agreed to:
- Commitment from the Practice Manager to supporting the Carer Support Worker in the Practice
- Engagement of staff members, with the evaluation team, to establish a baseline around staff knowledge of carer issues, and to review the impact by the end of the project
- Undertake with the evaluation team a base line survey to identify current carers’ support in the Practice and to evaluate the difference the project made

Expressions of interest were invited from practices who would like to take advantage of the dedicated service, aiming for a geographical spread across the county and a mix of practices in terms of existing carer support: examples of those already supporting carers well but wishing to explore further potential, those offering some support and wanting to improve, and those who did not identify carers or provide targeted support but would like to.

We aimed to work with a maximum of six practices; expressions of interest were received from five initially, with four ultimately committing to the project. The practices involved were in Berwick, Morpeth, Hexham and Haltwhistle, providing a good geographical spread across the county from a mixture of ‘urban’ and rural settings.

A baseline survey was carried out with all staff at the start of the practices’ engagement in the project and repeated at the end, to allow us to establish the impact that participating in the project had on staff in the practices. Surveys were completed by staff in a wide range of roles in the practices including GPs, clinicians, nursing staff, administration staff and domestic staff and included questions to demonstrate their level of understanding and knowledge of carers in their practice including multiple choice and open questions (appendix 1).
The responses were compared and the findings analysed by Northumberland Care Trust. The findings were that participating in the project had a positive impact on staff teams in the practices and key points from the survey were:

- Three times as many staff were able to identify who might be a carer
- Staff are more likely to provide information and signpost carers to additional support
- More staff feel they should ask patients to register as a carer with the practice
- The number of staff who feel that they have enough knowledge and skills around carer issues has increased
- More staff have received training on carer issues

**Progress against outcomes**

*Primary care teams support carers more effectively with their caring responsibilities and help to sustain the caring relationship*

Carer Support Workers are accommodated in Carers Northumberland area offices, and each are allocated two practices to work with.

A baseline survey of all staff in participating GP Practices established levels and methods of carer support in the practice and knowledge of carers’ roles and issues. This survey will be repeated at the end of the project to identify any changes or improvements.

**Case study:** A Practice Nurse is dealing with a patient following the death of the person they cared for. The District Nurse asked the Carer Support Worker for information about bereavement support and is advised that Carers Northumberland continues to provide support to former carers even after the cared for person dies - The former carer receives support from Carers Northumberland to help them move on with their life after the bereavement. Information is given to the nurse with details of the nature of the support available. The Nurse subsequently refers former carers to Carers Northumberland for support after bereavement as well as when they are caring.

An information leaflet about confidentiality issues is developed to help health staff and carers recognise the issues and share information without breaching confidentiality.
Primary care teams are more confident in identifying carers and their specific needs

Carer Support Workers develop an action plan for each practice with individual Practice Managers; identify outcomes, actions, lead personnel, success measures and timescales. Action plans are reviewed after 6 months and at the end of the pilot.

A carer champion is identified in each practice to take responsibility for and lead on carer recognition and support. With an enthusiastic member of staff taking responsibility in this way, practice support for carers improved.

Carers Policies are reviewed in line with Department of Health guidance. The detail and impact of existing policies is wide-ranging. Policy review provides a platform for focusing on recognising, working with and supporting carers.

Procedures in some practices are developed to identify and record carers who are patients and carers of patients. Having procedures in place significantly increased the number of carers identified and recognised as carers.

Practice Managers reported that the amount of effort required to change existing templates to incorporate identification of carers was minimal. One estimated half a day’s work for one member of staff and awareness raising amongst the staff team.

Concerns about confidentiality are raised by staff in some practices.

Procedures are developed to enable practices to obtain permission to share information with carers so that they have the information they need to help them in their caring role.

An information leaflet – “Supporting Carers – Information for Health Staff” – is designed, produced and circulated to staff in participating practices.
Carers are more confident at acknowledging their own personal health needs and the ability to express their concerns.

Carers identified by practices are offered a health check and the opportunity to meet the Carer Support Worker attached to their practice.

Carers Northumberland receives a significant number of new registrations as a result of being part of the carer health checks pilot project. Carers are acknowledging their role and their own needs by accessing the support and services available to them.

Carers identify a range of areas of concern to them, enabling Carer Support Workers to provide information and signposting specific to the carers’ needs and informing Carers Northumberland’s development of support in the county.

- The number of staff who would never ask carers about their caring responsibilities or believed it is not their job decreased by 40%
- The number of staff who feel they had enough knowledge and skills on carer issues had almost doubled at the end of the project
- Confidence in relation to carers and sharing information increased by 34%
- Knowledge of resources available in the community to support carers increased by 31%
- There was a 68% increase in the number of staff who had attended training on carer issues

“Very worthwhile and useful project” - comment from a member of staff
Carers Northumberland staff have a better understanding of how GP practices work with and support carers.

The impact on a carer of having someone focus on them and their needs should not be underestimated. "It was so nice to have someone ask how I was for a change. Usually it's all about my husband and how he's doing, nobody ever asks me. I feel invisible most of the time." Carer

- Staff awareness of systems to identify carers in their practice increased significantly
- Knowledge of carer policy in practices increased by 54%
- Confidence in implementing support for carers in the practice increased by 30%

"The project was very beneficial in identifying carers and that their health is also a priority and we are able to care and support them". Comment from a nurse at the end of the project.

Carers are more informed and access a range of support services and are less dependent upon the primary care team

Carers identified by the practice are referred to Carers Northumberland for support, where they are able to access an information service, information about benefits, one-to-one and group support, funding for a break from caring, skills sessions, events, a range of other relevant activities and links to other support services.

Carer volunteers have undertaken training as peer evaluators and interview carers who had health checks, during the final weeks of the project, to find out the impact it has had on them. They have written their own report of their findings.

The Carer Support Workers link to patient groups to ensure carers’ views are taken into account and their role in patient care was recognised.

An information leaflet entitled “Get a Carers Health Check” is designed, produced and circulated to all known carers in Northumberland. Copies of the leaflet are also circulated to voluntary sector organisations of interest to carers (Appendix 2).
Case study: Mrs A was referred to GP Carer Support Worker by the “Carer Champion” who works on the reception desk after she visited the practice with her aunt whom she had recently begun caring for. Mrs A had just moved into the area to provide substantial care for her very elderly aunt (Mrs B) as a result of family concerns about Mrs B's ability to continue to manage living independently. The Carer Support Worker contacted Mrs A and arranged to meet with her at the practice, in private, away from her aunt, to discuss her caring role.

Mrs A was happy with her decision to care for her aunt, despite having to leave her job and move away from her home and family to do so. However, she was keen to access any support available and initially asked for practical guidance on benefits and how to discuss her Aunt's needs with Adult Care Services. The Carer Support Worker spent an hour with Mrs A discussing her entitlement to Carers Allowance, explaining the carers assessment process and discussing the support provided by Carers Northumberland in her local area, including Carers Emergency Card. Mrs A was also advised to register with the local GP and have a Carers Health Check.

The following week, Mrs A contacted the Carer Support Worker as she was concerned about her Aunt’s memory. Now she was spending every day with her aunt, she had observed specific behaviours which were causing her concern. Mrs A discussed her aunt’s recent behaviour with the Carer Support Worker who suggested that she discuss her concerns with her aunt’s GP and arrange for him to carry out basic capacity tests with a view to referral for more specialist support. Mrs A’s main concerns were around dealing with these episodes appropriately so as not to distress her aunt. Mrs A was keen to maintain her Aunt’s independence as much as possible as she knew how important this was to her. Mrs A stated that she found it very useful to be able to talk to someone away from the family unit who understood her concerns and was able to reassure her that she was “doing the right thing”. Mrs A was able to access 2 books about dementia and caring for someone with dementia through the Carer Support Worker at the practice and has found these to be very helpful and reassuring.

Mrs A called in on another occasion as she had found an exercise class in the local area which she thought she would enjoy as a way to get a break from her caring role. Also, Mrs A had been particularly active before becoming a full time carer and was worried that she was no longer able to exercise as much. However, in order to take advantage of the group she would need a GP referral. The CSW spoke with the Practice Nurse who agreed to meet with Mrs A, carry out the necessary health checks and make a “health” referral to the group as she felt it was important that Mrs A take some time out to consider her own health.

The CSW suggested that Mrs A apply to the Carers Support fund to help with the cost of the classes. Her application was successful and this money will cover the cost of the classes for 6 months, providing an opportunity to access the class and meet other people from the local area. Mrs A continues to “pop” into the surgery to chat with the CSW and is attending the new Carer Support Group which meets every month in the local hospital with support from the GP practice.

“Thank you so much for your support and ear, I do appreciate it.” Mrs A.
Patients with long-term conditions are more effectively supported through recognition of the needs of their carers.

Practices use records of patients with long term conditions to contact their carers about health checks and the support available from Carers Northumberland.

Community nurses were key to the success of carer health checks and the impact of the Carer Support Workers. Community nurses had knowledge of carers for patients they were visiting and were able to refer them to the Carer Support Worker for information and support.

Carer Support Workers offer joint home visits with District Nurses so that carers’ needs could be met at the same time as the patient’s.

- The number of staff who would never ask or inform carers or don’t believe it to be their job has dropped by 40%
- The number of staff who feel they have enough knowledge and skills on carers issues to enable them to support carers has increased

“It has been good to have a point of contact we have met” Quote from practice receptionist

“The carers health checks have been very valuable for carers and could contribute to identifying future potential health problems. It would be really good if funding could be made available to continue them”. Practice staff administrator.
**What did we learn?**
To work effectively with practices, it is important to invest time at the start in integrating with GP practice staff teams and helping them understand the aims of the project.

It is also important that practice staff ‘buy in’ to the action plan so that everyone embraces carer support as part of their day to day work; this takes time to achieve.

Standard procedures can be adapted to suit the needs of individual practices. Once in place, these can be a very useful tool allowing practices to be more supportive of carers and patients. Confidentiality was an important issue in all of the GP practices we worked in. Perceptions of what we were asking for in terms of patient information varied and it needed to be made very clear that Carers Northumberland were not asking GP practices to share patient details either of carers or cared for. The confidentiality leaflet piloted in the Union Brae practice was found to be a useful tool in terms of providing information to patients about sharing patient’s information with their carer.

Linking carer support to events at GP practices offers a useful opportunity for carers to be identified and directed to appropriate support for their situation, however, this needs to be planned into events where there is the time and capacity for carers to get information and talk about their circumstances. The experience during the pilot of linking to flu clinics was not particularly successful as these are too fast paced and the number of patients involved was too high to have an impact on identifying and registering carers.

In the practices where the GP Support Workers have been based we have seen an increase in the level of recognition given to carers by the staff in the practices and the implementation of systems to recognise and register carers in the practices has benefited practice staff teams and carers.

Community nursing team staff are key to identifying carers. Practice nurses and district nurses tend to spend more time with each patient than GPs and often see them in their own homes, where a family carer may be more easily identified.

Within the practice, where reception staff were more aware of carer issues, they were also helpful in identifying carers. However, confidentiality was a concern for some.

Some carers were reluctant to agree to the practice asking the GP support worker to contact them by phone, for example, if someone else at home may answer a phone call and be unhappy about the carer seeking support. Some carers said they would have preferred other contact methods to be available.

The level of self-referrals was low. Many carers do not identify themselves as a carer and therefore may be unlikely to approach the practice to be registered as a carer. Carers did pick up information from all of the practices so marketing of carer self-identification is extremely important and a permanent information point for carer information in each practice would help carers recognise themselves in this role and encourage them to use the available support.
The approach and support offered to carers in all of the practices varied widely. At the start of the pilot, there was very little systematic identification and registration of carers happening in the practices. Where there was a system in place to register carers, the numbers registered were very low. Most of the practices involved in the pilot have seen substantial increases in the number of carers they have identified and recorded on their carer register (up to 229%) but the number of carers on their carer registers is still low as a proportion of the patients registered at the practices.

**Recommendations**

Developing integrated working with GP practices across the County to support carers in future would allow us to build on the benefits of the work of the pilot. Using what we have learned from the pilot, CN can make a good offer to GP practices to provide commissioned support to assist in the development of policies and procedures for carer support, as well as procedures to enable them to refer carers to other appropriate support and preventative work to help carers avoid reaching crisis point before they seek any support.

In order to do this, CN needs to develop a toolkit based on the good practice that has emerged from the pilot, that can be tailored to suit individual practices. This would include:

- Standard presentation to staff about the importance of the carer’s role, DofH and care trust expectations and requirements
- Review of existing policies and procedures relevant to identifying and supporting carers
- Carer identification protocol
- Robust confidentiality procedures and information to help staff feel comfortable about identifying carers
- Identifying a carer ‘champion’ or ‘lead’ within the practice
- Carers need a range of ways to be contacted. Where the practice offers a carer the opportunity to be referred to CN for support, they should have the option to be contacted by a method that suits them including post, phone, mobile or e-mail.
- Developing promotional material that encourages those who care for someone to think of themselves as a ‘carer’
- Setting up a carer information point within the practice