Improving Outcomes for Carers via GP Surgeries: Implications for Commissioners

1 Introduction

Carers Bucks is an independent charity that supports the wellbeing of unpaid (often family) carers of all ages in Buckinghamshire. The Institute of Public Care (IPC) at Oxford Brookes University works to deliver better health and social care outcomes across the UK. IPC aims to drive improvement and innovation in care, and to generate new learning for the benefit of people, organisations and communities.

This paper reports on a pilot project, funded by the Chiltern Clinical Commissioning Group, which sought to help GPs identify previously unknown carers and improve the carer experience and wellbeing outcomes by offering carers a free health and wellbeing check with a carer support worker and (where appropriate) giving them a social prescription to access services provided by Carers Bucks. IPC worked with Carers Bucks to analyse the data and map learning from the project to the commissioning cycle. This resulted in a set of recommendations for commissioners which are summarised towards the end of the paper.

2 A hidden population

Carers UK estimate that there are around 6.5 million people who provide unpaid care for a disabled, seriously-ill or older loved one in the UK. It is also estimated that carers save the state £132 billion a year – close to the cost of a second NHS (Buckner and Yeandle, 2015). Yet, even though there are so many carers, saving the state a phenomenal amount of money, we know they tend not to get the support they need because they are often hidden in plain sight. People caring for a family member don’t always identify with the label ‘carer’ because they see themselves first and foremost as the daughter, husband, sibling, wife, son, mother of the person they care for. Their caring role is something that is often an extension of the relationship they have with the person they care for. Sometimes neither the carer nor the person they care for want the label ‘carer’ to be used because it is an admission of the reality of the situation and emphasises a change in the nature of their relationship (IPC, 2017). Furthermore, professionals have not historically seen the need to identify carers or, in some cases, seen the identification of carers as part of their role. This lack of identification and recognition of the role carers play and the impact it has on their own lives has added to the negative sense of wellbeing and quality of life outcomes that carers experience.
The Care Act 2014 strengthened the rights and recognition of carers within the social care system by giving carers rights to assessment and support for their own needs. However, only a small proportion are identified as carers by social care and health bodies, and many are missing out on the support or services they need.

In 2016 only a third of carers who responded to the Carers UK survey, and had a carer’s assessment in the last year, felt that the support they needed to look after their own mental and physical health was properly considered. One in five who had a carer’s assessment said they received little or no helpful information or advice and did not know where to go for support with caring. Half of carers expected their quality of life to get worse in the next year (Carers UK, 2016).

3 Carers and GPs

Caring can exacerbate pre-existing health problems or lead to new health problems for the carer. Carers UK (2014) found that carers were less likely to actively engage in health promoting behaviours such as exercise and maintaining a balanced diet because of their caring responsibilities. GPs are well placed to identify carers because they often accompany the person they care for to GP appointments and if they experience any health problems of their own, one of the first places they are likely to go for help is the GP. This is not just because the GP is where we all tend to go when we have a health problem, it is also because we all know that GPs exist but we don’t all know that carers centres exist. Furthermore, even if the issue we are facing is more of a social care issue than a health issue, social services tends to be the place of last resort rather than the first port of call. Hence GPs seem to come into contact with and have the opportunity to identify more carers than any other single health or social care service.

GPs are encouraged to have a protocol for identifying carers, but most carers still go unrecognised not least because caring itself is not a medical problem. Addressing carers’ needs for respite, information, advice and training are effective ways to support carers, but if carers are not identified they are unlikely to access even small amounts of support that might make a difference (Carduff et al, 2016).

It is estimated that around 20% of patients consult their GP for what is primarily a social problem (Low Commission, 2015). It has been suggested that referral to a social prescribing service could reduce this pressure. Social prescribing, sometimes referred to as community referral, is a means of enabling GPs to refer people to a range of local, non-clinical services. Recognising that people’s health is determined primarily by a range of social, economic and environmental factors, social prescribing seeks to address people’s needs in a holistic way.
4 **What did we do?**

Carers Bucks ran carers’ clinics by placing a carer support worker from Carers Bucks in GP surgeries in the Amersham and Chesham locality. The carer clinics had two elements: a health MOT and a discussion using the Carers Star aimed at providing information, advice and guidance on caring. A healthcare assistant conducted the health MOT and any health issues were referred to the GP. The carer support worker then spent some time talking through the Carers Star. This included discussing options for improving the outcomes in areas the carer was struggling and providing information, guidance and support that might help.

The Carers Star has been developed for use with a wide range of carers, both full time and part time. The Carers Star was developed with the Carers Trust and SEEL (Social Enterprise of East Lothian) with part-funding through the Scottish Government Change Fund. The Carers Star covers seven key outcome areas:

- **Health**: managing physical and mental health, healthy lifestyle, doctors and other health services
- **The caring role**: skills, understanding, practical caring, legal issues, planning ahead, communicating with professionals
- **Managing at home**: day-to-day tasks and the suitability of your home – or that of the person you care for if you don’t live with them
- **Time for yourself**: social life, activities, breaks from hands-on caring
- **How you feel**: feeling supported, dealing with anxiety or stress, managing any difficulties in a key relationship
- **Finances**: benefits, debts, managing money, legal issues
- **Work**: balancing your work with your caring role if you work or want to work

The Carers Star is underpinned by a Journey of Change that has five steps:

1. Cause for concern  
2. Getting help  
3. Making changes  
4. Finding what works  
5. As good as it can be

**Health**

Interventions for carers whose initial health scores were low included a basic health check from a health care assistant covering height, weight, BMI, blood pressure and blood tests. The carer support worker would then look at whether the carer makes time to exercise and, if not, what barriers are currently in place to prevent that, as well as looking at how the carer manages any existing health conditions.
The caring role

Interventions for carers whose initial scores for the caring role were low included booking carers on to Carers Bucks learning and development courses, such as Caring for Someone with Dementia, Lasting Power of Attorney, Understanding Direct Payments and Emergency Planning. In some cases Carers Bucks used emergency funding to help with moving and handling training so that carers could minimise the potential damage to their backs from lifting the person they cared for. The carer support worker also signposted carers to the various support groups run by Carers Bucks.

Managing at home

Interventions for carers whose initial scores for managing at home were low, included referrals to Telecare. Telecare ranges from pendant alarms, to fall detectors, bed occupancy sensors, magi plugs to stop sinks and basins from overflowing, and key safes. The package also makes use of the Red Cross lifting service (currently being trialled as a contract with the ambulance service), which means if the cared-for person falls, the Red Cross will come to the home to assist. The carer support worker also signposted to Age UK for their cleaning and gardening services if appropriate.

Time for yourself

Interventions for carers whose initial scores for time for yourself were low included the carer support worker talking in detail with the carer as to why they have little or no time for themselves – was it a reality of their caring role, or a hitherto unchallenged perception? The carer support worker would explore ideas such as a day centre, or a befriender or the possibility of carers coming into the home in order to give the carer some time to themselves.

How You Feel

Interventions for carers whose initial scores for how you feel were low included Carers Bucks Learning and Development courses that focus more on the emotional impact of caring, such as Managing Stress, Looking After Yourself, and Caring and You. Carers Bucks linked up with Bucks Adult Learning to deliver courses for carers on Practical Gardening and Creative Writing which the carer support worker would signpost carers too. For those carers wanting something in addition to or instead of a support group, the carer support worker would signpost carers to the Bucks Carers Choir. Finally some carers were offered free sessions with a qualified counsellor at Carers Bucks.

Finances

Interventions for carers whose initial scores for finances were low included awareness raising that attendance allowance is not means tested and referral to a Carers Bucks benefit advisor.

Work

Interventions for carers who initially scored low for work included referral to support worker at Carers Bucks who specialises in the challenges faced by working carers.
All the interventions and signposting as a result of attending a Carers Clinic were designed to help and support the carer in their caring role and, in many cases, to put something in place to avoid the caring role breaking down. In all cases the carer support worker gave the carer a call three months after their initial appointment to see how they were getting on and to complete the Carers Star with them again.

5 What did we find?

5.1 Participants
A total of 203 carers attended the carers clinics, 53 (26%) were male and 150 (74%) were female. The vast majority were White British (97%), only 3% of carers that attended the clinics were from the Black, Asian, or minority ethnic community.

Approximately a quarter of carers were caring for a loved one with dementia and another quarter were caring for someone with a physical disability. The rest were caring for people with learning disabilities, mental health conditions, neurological conditions, cancer or elderly relatives.

Table 1: Conditions

<table>
<thead>
<tr>
<th>Cared-For Condition</th>
<th>Percentage of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Disability (including stroke)</td>
<td>24%</td>
</tr>
<tr>
<td>Dementia</td>
<td>25%</td>
</tr>
<tr>
<td>Learning Disability (including autism)</td>
<td>18%</td>
</tr>
<tr>
<td>Elderly/Frail</td>
<td>18%</td>
</tr>
<tr>
<td>Mental Health</td>
<td>6%</td>
</tr>
<tr>
<td>Neurological (including MS and Parkinson’s)</td>
<td>7%</td>
</tr>
<tr>
<td>Cancer</td>
<td>2%</td>
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</tbody>
</table>

Over half of the carers who attended the carers’ clinics were caring for their spouse, just under a quarter were caring for a parent / parent-in-law and almost another quarter were caring for their child (including adult children).

Table 2: Relationships

<table>
<thead>
<tr>
<th>Caring For Whom</th>
<th>Percentage of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband</td>
<td>38%</td>
</tr>
<tr>
<td>Wife</td>
<td>17%</td>
</tr>
<tr>
<td>Parent/Parent-In-Law</td>
<td>23%</td>
</tr>
<tr>
<td>Child (including adult children)</td>
<td>21%</td>
</tr>
<tr>
<td>Friend</td>
<td>1%</td>
</tr>
</tbody>
</table>
5.2 Carers Star

The maximum score using the Carers Star is 35. The initial scores at the carers’ clinics ranged from 21 to 35 and averaged 29. The Carers Star was then repeated three months later with each carer. The repeat scores ranged from 24 to 35 and averaged 31. The change in score over the three month period ranged from no change to 12 and averaged 2.

Just under half of the carers made a gain in ‘how you feel’ which focuses on the emotional impact of caring. Nearly a fifth made gains in ‘time for yourself’ which focuses on supporting the carer to make time for themselves.

Table 3: Carers Star

<table>
<thead>
<tr>
<th>Carers Star Domain</th>
<th>Percentage of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>6%</td>
</tr>
<tr>
<td>Caring role</td>
<td>13%</td>
</tr>
<tr>
<td>How you feel</td>
<td>44%</td>
</tr>
<tr>
<td>Finances</td>
<td>14%</td>
</tr>
<tr>
<td>Work</td>
<td>1%</td>
</tr>
<tr>
<td>Time for yourself</td>
<td>19%</td>
</tr>
<tr>
<td>Managing at home</td>
<td>7%</td>
</tr>
</tbody>
</table>

There was no single intervention that worked best for carers. This is probably because the carer support worker and Carers Bucks take a person-centred approach to the support they offer. For some it was access to support groups, for others it was the opportunity to engage with training courses. Some carers just needed someone to talk to and the carers’ clinic provided that opportunity, for others the chance to talk to a trained counsellor was the thing that helped.

Carers were asked to comment on the support they received via the carers’ clinics. Analysis of the comments identified three key themes:

- Carers appreciated the clinics because they felt it was rare for anyone to ‘care’ for them.
- Carers felt listened to, which again was something they commented rarely happened.
- Carers received useful information about support they didn’t know existed.

In summary, simply attending the carers’ clinic was the thing that helped most because it gave carers (most of whom had not previously received any support) the chance to talk to someone who understood, an opportunity to off load and a safe space to be honest about their situation.
6 What are the implications for commissioners?

Implications for commissioning are considered below against the Institute of Public Care commissioning cycle.

Figure 1: Commissioning Cycle

6.1 Analyse

Analysis involves undertaking needs analysis to identify the current and likely future needs of the population; mapping and reviewing services across agencies to understand provider strengths and weaknesses and identifying the resources available and agreeing future resources across agencies. Understanding the carer population and identifying more hidden carers will require:
Carer organisations working with GP surgeries to raise awareness of carer issues and how to identify carers effectively by running carers clinics and developing a carer register.

Clinical Commissioning Groups to understand the potential impact that identifying carers can have on reducing recurring visits to GP surgeries.

Sharing information with commissioners in social care to develop a shared understanding of the estimated future demand.

6.2 Plan
Planning services and support involves shaping the market and co-designing services or support. To plan carers clinics in GP surgeries commissioners need to:

- Put the carer voice at the centre of strategic planning for carers’ clinics by involving them in the planning process from the beginning.
- Support small GP practices to work in partnership to deliver carers’ clinics.
- Work with carers organisations to develop or expand a Carers Investors Award for GP surgeries.

6.3 Do
Doing involves ensuring that the services needed are delivered as planned. Delivering effective carers clinics in GP surgeries means that commissioners need to:

- Support carer organisations to train primary health care staff to identify carers (particularly those carers who do not recognise themselves as carers).
- Use the carer register for targeted information on flu vaccines, longer and more flexible appointments, additional health checks, etc.

6.4 Review
Reviewing involves monitoring the impact of services and support. Reviewing services and support is the best place for commissioners to start when considering whether they support carers to achieve wellbeing outcomes and what, if anything, needs to be done differently. In reviewing carers clinics commissioners should:

- Actively seek out and listen to the voice of carers. Work with carers to design both the review questions and the methods for collecting the data.
- Measure carer outcomes using quality of life measures such as the Carers Star and clinical measures such as the ‘Patient Health Questionnaire’ and the ‘Cognitive Impairment Test’.
7 Further Information

For more information contact Carers Bucks on mail@carersbucks.org or Sarah Broadhurst at the Institute of Public Care on sbroadhurst@brookes.ac.uk or call Sarah for an informal chat on (01865) 790312.

8 References


