



Not just a patient: Summary report

Carers' Information Service
Amy Deakin (Communications and Publications Officer)
May 2017

Introduction

'Carers support some of the most vulnerable people in our community. Due to the higher health risks of caring for someone, it's crucial that they receive the right help and healthcare to meet their needs.'

We hope that this research will shed light on GP support for carers in the borough, enabling partners, practice managers and health decision-makers to make more informed choices about the nature and delivery of services. We also hope that GPs and practice staff will become more aware of the issues and challenges affecting carers at their surgery. By working together, we can ensure that both carers and the patients they care for are empowered to look after their health and wellbeing.'

Helen Thompson
Carers' Information Service Manager

Executive summary

The Carers' Information Service surveyed 205 adult carers registered with a GP in the London Borough of Croydon about their experience of using GP services. Our research found:

- 61% of carers say their GP knows about their caring role.
- 82% of carers have not been informed of carer support available in the community.
- 59% of carers have not been offered an NHS Health Check by their GP.
- Over a third (35%) of carers have not been offered the annual flu jab.
- Almost half (49%) of carers want their GP to tell them about local carer support.

In general, carers are positive about the healthcare they receive, but want more specific carer support. Carers who provide positive feedback frequently identify a particular GP or practice staff member who understood their situation and treated them with compassion and respect.

Common issues carers experienced with GP services included:

- A lack of support for their own needs as carers.
- Difficulties getting appointments.
- A lack of support for the cared for person.
- Information not being shared with the carer about the cared for.
- A negative or unsympathetic attitude from certain GPs and practice staff.

Based on the feedback we received from carers, the Carers' Information Service would like to see:

- GPs and reception staff proactively identifying carers at their surgery e.g. through questions on registration forms and looking out for people who support patients to appointments.
- GP surgeries in Croydon ensuring that, once identified, carers are provided with information about the Carers Support Centre, and are referred directly if in need of support.
- GPs informing eligible carers about the annual flu jab and the NHS Health Check, with information specifically aimed at carers clearly displayed in surgeries.
- Surgeries considering more flexible appointments for carers if needed.
- GPs and reception staff demonstrating carer awareness, listening to their needs and treating them at all times with dignity and respect.
- GPs treating carers as equal partners in care, sharing information in the patient's best interests with informed patient consent.

Background

Carers - the hidden support network

A carer provides unpaid support to a family member, friend, partner or neighbour who needs help due to illness, disability or old age. In the UK, around 6.5 million people have a caring role (*Facts About Carers*, Carers UK, 2015) and the number continues to grow; it is now estimated that three in five of us will become carers at some time in our lives. (Carers UK, 2015).

There are over 33,000 unpaid carers living in the London Borough of Croydon (ONS, 2011). Carers provide vital care and support to some of the most vulnerable people in the local community, **saving local state services an estimated £600 million every year** (Buckner L. and Yeandle S., 2015).

The impact of caring on health

Whilst caring can be incredibly rewarding, it can also be highly challenging and stressful. Research has shown that carers are at increased risk of long-term health problems, including back pain, high blood pressure, mental health problems and stroke (Royal College of General Practitioners, 2013). Those providing the highest levels of care without support face a **63% higher chance of death than non-carers** (Beach, S. and Schulz, R., 2010).

Carers themselves report that caring takes a toll on their wellbeing. A 2012 survey by national carers' charity Carers UK of over 3000 carers found that **83% of carers felt that caring had a negative impact on their health, rising to 87% for mental health.**

The 'crucial role' of GPs in carer healthcare

'The carer's primary care team has a crucial role in... supporting and maintaining carer health and wellbeing [and]... in identifying carers.' (*An integrated approach to identifying and assessing carer health and wellbeing*, NHS Carers' Toolkit, NHS England, 2016)

In the NHS Carers' Toolkit, NHS England strongly recommends that health and social care organisations such as GPs work together with other partner agencies in identifying, assessing and supporting the wellbeing of carers. This is in line with statutory guidance to the Care Act 2014, which emphasises the importance of GPs as a first point of contact with services (Department of Health, 2014).

The Royal College of General Practitioners (RCGP) *Supporting Carers* guidance similarly stresses the key role played by GPs in supporting carer health. Good practice highlighted in the RCGP guidance recommends that GPs:

- Proactively identify carers using their service.
- Direct carers to local carer and patient support services.
- Work collaboratively with carers on patient care.
- Are aware of mental health issues for carers and screen annually for depression.
- Provide access to flexible appointments to fit in with caring responsibilities.
- Ensure carers' overall health is properly monitored, for example by issuing reminders to carers to have an NHS health check and a flu jab.

On a local level, carers in Croydon have identified better GP support as beneficial to their needs. The 2017 *Carer Engagement* report from Croydon Council, based on a borough-wide survey and a series of focus groups, recommended that the council should 'work with GP practices to identify carers earlier' and that 'GPs should promote carers services and refer carers to the Carers' Support Centre on George Street.' (2017)

Supporting carers is not only beneficial to carers themselves; it also benefits the cared for person and the NHS. Research shows that good carer support can reduce hospital admissions, in both carers and cared for

patients (Purdy, 2010). A 2016 report on A&E admissions from Carers UK, *Pressure Points*, found that **over half (55%) of carers surveyed said that more support for the cared for person could have prevented admission into hospital.**

As well as reducing pressure on services, there is some evidence to suggest that effective support for carers can lead to long-term financial savings for GP practices and clinical commissioning groups. For example, according to NHS commissioning guidance, **putting carer support in place to prevent long-term health risk saves around £4 for every £1 a CCG spends** (NHS England, 2014).

Our research

The Carers' Information Service conducted a survey in March 2017 to provide a snapshot of carer healthcare and support from GP services in the London Borough of Croydon. The survey was sent to carers registered with a GP in the London Borough of Croydon via the Carers' Information Service mailing list, and was available in both a paper and electronic format. A total of 205 adult carers responded to the survey.

Findings

Positive GP experience - but a need for more carer support

Carers were generally positive about their experience with their GP regarding their healthcare. Showing understanding of the challenges of being a carer and making any necessary adjustments to meet carers' individual needs, as well as those of the cared for person, had a significant positive impact on carers' perceptions.

Carers' comments:

'Always superb care for both me and my mum.' (Carer for an adult with a physical disability)

'My GP is fantastic, very sympathetic to my needs as a carer and that of my son's.' (Carer)

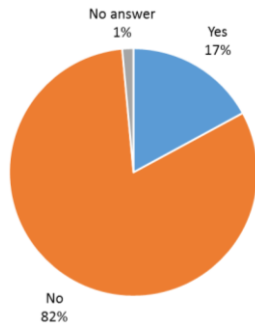
'I think that my GPs at the practice on the whole do a phenomenal job.' (Carer)

'Our GP service is very caring towards us. They take the time to listen to our needs. They always make sure we are taking care of ourselves.' (Parent carer)

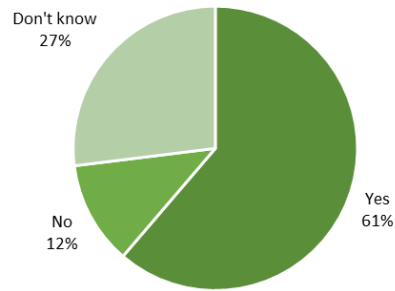
'My doctor cares for carers. They understand what a carer ha[s] to put up [with].' (Carer)

Despite primarily positive comments on GP healthcare, carers wanted more specific information and support for their needs as carers. Of the carers we surveyed, 82% have never been informed of carer support via their GP. This is in spite of the fact that the majority of carers (61%) state that their GP is aware of their caring role.

Has your GP informed you of local carer support in Croydon?



Does your main GP know you are a carer?



It's therefore clear that the issue lies not in GPs not realising carers are carers, but rather GPs realising the crucial role they play in directing carers to the help and support they need:

Carers' comments:

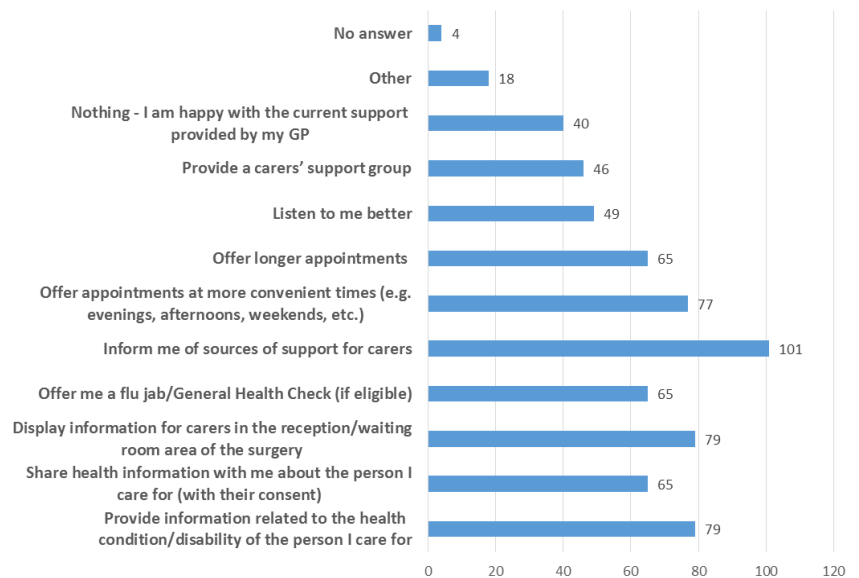
'It felt like a long time until the practice recognised 1/ my husband's illness 2/ my role as his carer.' (Carer for husband with dementia)

'Despite the fact I am a registered carer and it is on [their] computer [that] my son has autism, my GP surgery does not recognise me as a carer and the reception staff have no awareness when it comes to autism.' (Carer)

'My GPs are very good but they do not understand the stress I am under and do not encourage me to talk to them about my many problems.' (Carer)

The most frequently identified form of support that carers wanted to see from their GP was better signposting to local carer support. **Almost half (49%) of carers wanted to be signposted to local carer support by their GP, with a further 38.5% asking for information for carers available in the reception/waiting room area of the surgery.**

Support carers would like to see from their GP to help with their caring role



The impact of unsupported caring on carer wellbeing

A number of the carers we surveyed were experiencing significant strain and psychological distress, both as a result of their caring role and the lack of support they were receiving. This is not uncommon; **around 40% of carers show signs of psychological distress and/or depression** (Pinquart, M., Sorensen, S., 2003).

Carers' comments:

'I am 70 [and] sick myself, had [a] heart attack and open heart surgery since becoming a carer six years ago. My mum is 92 with many health problems. I have not been offered any help from either my GP or my mums... My mother is difficult and my life is on hold and I could scream sometimes.' (Carer)

*"My GP keeps assessing me with anxiety or depression scales. **Does not ask about stress related to my daughter's mental health issues.** He also does not refer me to [the] medical specialist resources I need. **I think they see parents with [children with mental health problems] as histrionic, [with] no referrals made for supportive services for me or my daughter.**"* (Carer)

Carers experiencing significant stress and mental health problems wanted to see a greater understanding of the challenges and strains of caring from their GP. Directing carers to appropriate carer support in addition to medical treatment would go some way towards addressing these concerns.

Recommendation

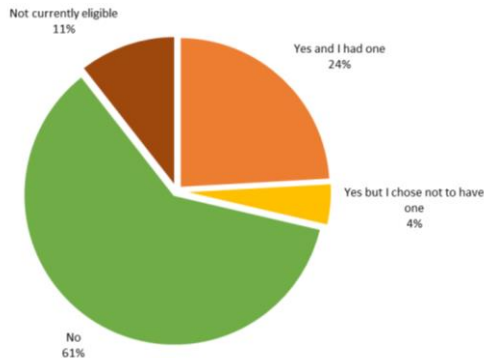
The Carers' Information Service would like to see Croydon's GPs informing carers of local carer support, such as the Carers Support Centre, the one stop shop for carers in Croydon. GPs may also wish to consider displaying information for carers prominently available in their surgery, so that carers are aware of what is available.

Health Checks and flu jabs

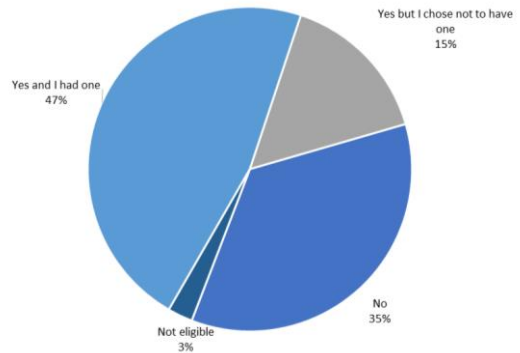
A concerning number of carers had not been offered basic preventative healthcare measures to help them take good care of their health. For example, **59% of the carers surveyed have not been offered an NHS Health Check by their GP despite being eligible for the service, and over a third (35%) have never been offered the annual flu jab.**

Given the higher health risks linked to a caring role, it is concerning that carers are not being told what they are entitled to. Carers themselves told us they wanted to be given this information. **32% of carers surveyed felt that their GP could support them better by offering the NHS Health Check and flu jab**, empowering them to take care of their own health and wellbeing through proactive healthcare monitoring.

Has your GP offered you an NHS Health Check?



Has your GP offered you an annual flu jab?



Carers' comments:

*'Generally good support from GP's, however **little monitoring of my health as a carer or checks on family's ability to cope.**'* (Carer)

*'**My GP does not acknowledge the importance of [the] health of carers. I have been diagnosed with hypothyroidism since I took on my carer role but my GP does not show any interest or proactiveness in offering me better, regular checkups.**'* (Carer)

Recommendation

Due to the higher health risks of caring, the Carers' Information Service would like to see GPs ensure that eligible registered carers at their practice are offered the annual flu jab and NHS Health Check, and that information specifically aimed at carers about these services is clearly displayed in surgeries.

Flexible, accessible appointments

*'I am usually asked to ring the surgery at 8am, but in vain. **So I ring the surgery day after day, until I am lucky.**'* (Carer)

Availability of appointments and waiting times was an issue for over a third of carers we surveyed, with **38% wanting appointments outside usual hours** and **32% wanting longer appointments**. Whilst carers acknowledged the pressures surgeries were under, many struggled to fit in appointments around a busy and demanding caring role, and found that the usual appointment time was not long enough to discuss the health needs of the person they cared for.

Carers' comments:

'I often have to wait weeks for appointments as I have such a small time frame I can attend appointments without taking my daughter who I care for with me. She goes to school an hour away from where we live and this leaves me with 3 hours.' (Parent carer)

*'No more than 1 condition per appointment is not always possible otherwise we would be there all the time. **They always put 'mother is concerned' making me sound as if I'm making things up.**'* (Carer)

Home visits were also a problem for carers. Carers commented that it took effort and persistence on the carer's part to obtain the home visit for the cared for person, and some carers were unable to get a home visit at all.

Carers' comments:

'Even though my GP said he'd help and get a home visit organised, nothing happened. I gave up and sorted it out myself.' (Carer)

'The person I care for has autism and will not go to the surgery. As a result she has not seen a doctor or nurse for several years.' (Carer)

Recommendation

The Carers' Information Service would like to see GP surgeries taking the needs of carers into account when managing appointments. Specifically, carers should be offered longer appointment times on request to discuss more complex issues, and be provided with more flexible appointments which can be fitted in around the caring role. The Carers' Information Service would also like to see surgeries considering the impact on carers as well as patients when designing and implementing home visiting policies.

Listening to carers' needs

Staff empathy was of great importance to carers. A number of carers identified a particular GP or practice staff member who understood their situation and treated them with compassion and respect.

Carers' comments:

'Dr C. looks after my wife and me. She is superb and has been very, very supportive ever since we registered with her. She is caring, but down to earth and competent at the same time.' (Carer)

'The staff [at my practice are] exemplary. Not only is this an efficient practice but everyone cares as well... A while ago one of the nurses pushed me to seek help for a serious problem and helped solve it for me. Her kind intervention changed my life.' (Carer)

Whilst the majority of carers felt their GP treated them with understanding, respect and dignity, a significant minority said that their GP was unsympathetic of their situation or even critical of their ability to provide care. As a carer was told by her GP, **'If you can't organise yourself properly to stay on top of the medication prescription, you're not fit to be his carer.'**

Of the carers we surveyed, **24% wanted their GP to listen to them better.** Carers who held negative views of their GP manner frequently highlighted that their GP was 'judgemental', lacked patience and did not listen to their concerns. Some carers commented on a 'luck of the draw' experience, particularly for emergency appointments where they could not see their usual GP:

Carers' comments:

'My practice has many GPs. One is excellent but currently on maternity leave. A couple treat you like you're an idiot, or I feel they do. I feel they are treating one symptom alone without taking into consideration how it affects other conditions.' (Parent carer)

Recommendation

Whilst it is highly positive to see that many individual GPs are providing outstanding levels of care, the Carers' Information Service is concerned that carers are not always receiving appropriate consideration, compassion and understanding from GPs and practice staff. We would like to see GP practice managers

ensuring that their staff are 'carer aware' and understand the challenges carers face. To support practice managers, the Carers' Information Service has produced guidance on carer support for GP practices, which can be sent out on request.

Partnership in care?

The RCGP *Supporting Carers* guidance states that: '**the relationship between carer and GP practice is a special one and should be recognised as a partnership in care.**' This is not always the case. Whilst the majority of carers were positive about their GP, some felt their GP did not listen to their concerns regarding the cared for person's care and treatment, leaving the carer out of the conversation. Taking the carer's views in proper account would help alleviate these carers' concerns, treating the carer as a truly equal partner in the patient's care.

Carers' comments:

*'GP made a referral to CAMHS for my son. **Doctors didn't listen properly and didn't seem interested in my concerns.***' (Parent carer)

A lack of information and information sharing was another key priority for carers. **39% of carers wanted information** from their GP related to the health condition/disability of the person they cared for and **32% wanted their GP to share information about their healthcare, with the patient's consent.**

Carers' comments:

*'I was very pleased with the service offered by my GP when my mother was first diagnosed. However, **I am sometimes not informed about decisions relating to my mother's healthcare.** Although I have asked to be informed due to the nature of my mother's illness. For instance **she's been given blood tests by the district nurse without my knowledge, which led to confusion and embarrassment for me at a subsequent hospital appointment I attended with my mother.***' (Carer)

Recommendation

The Carers' Information Service wants to see GPs treating carers as equal partners in care, sharing information appropriately about the patient with the carer in the patient's best interests with informed patient consent. As the RCGP *Supporting Carers* guidance states, '**finding ways to share information appropriately can make a critical difference to the ability and confidence of carers in their caring roles.**' (2011)

Conclusion

Overall, carers are broadly positive about the healthcare they receive from their GP, but would like to be informed of carer support available to them. We therefore recommend that all surgeries in Croydon ensure that registered and identified carers are provided with information about the Carers Support Centre, and that carers are referred directly if in need of support.

GPs can refer carers for information, advice and support using the online referral form:

www.carersinfo.org.uk/useful-information/gps. Completed forms can be sent to enquiries@carersinfo.org.uk. Leaflets about our service can be sent on request by contacting amydeakin@carersinfo.org.uk.

The Carers' Information Service is working with GP surgeries and Croydon Clinical Commissioning Group (CCG) to ensure carers receive the support they need from their GP. GPs and practice managers can access our GP Carers Pack with information, a checklist and resources to help clinical and reception staff inform and

support carers at their practice. For more information about the Carers' Information Service GP Project and to receive a pack, contact Amy Deakin on 020 8649 6288 or email amydeakin@carersinfo.org.uk.

About the Carers' Information Service

The Carers' Information Service provides information, advice and support to unpaid carers in Croydon looking after someone who needs support due to illness, disability or old age. The service runs the Carers Support Centre, the one stop shop for carers in Croydon. The Carers' Information Service is part of The Whitgift Foundation.

Further information

This report is a summary of research undertaken by the Carers' Information Service in March 2017. For further detail, see the full report, *Not Just a Patient: GP Support for Carers in Croydon*, available on the Carers' Information Service website: www.carersinfo.org.uk. This report was written by Amy Deakin, Communications and Publications Officer at the Carers' Information Service.

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