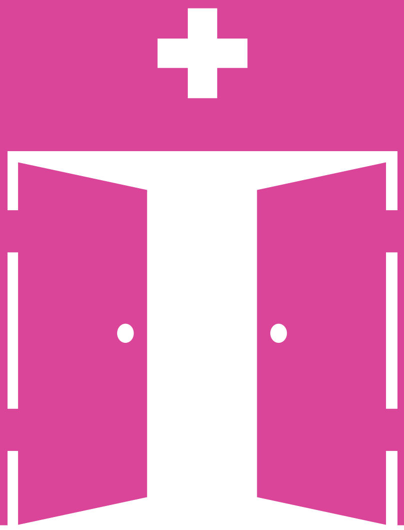


Carers' experiences of accessing GP services

healthwatch
Sheffield

Contents

Carers' experiences of accessing GP services

A carer is someone of any age who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. A carer in this report refers to adult carers, parent carers and young carers.

In 2014 NHS England published its **Commitment to Carers** aimed at improving the recognition and support for carers. In 2019, a framework of **Quality Markers** became available which provides some guidance for GP practices on how they can *"better identify and support carers of all ages"*. At the same time, data from the **GP Patient Survey** shows us that carers have a less positive experience of visiting their GP than non-carers, particularly in relation to some areas such as addressing their mental health needs.

This work was undertaken before Covid-19 impacted the way all health services were being delivered; our findings describe a pre-Covid world. We know that GP surgeries have been working very differently as a result of the pandemic – it's possible that some new ways of working have improved the experience of some carers, or in some instances they may have created more barriers to accessing primary care. The need to better understand how these changes have impacted on carers is reflected in the recommendations we have made.

What we did

We gathered the views and experiences of carers in Sheffield about going to the GP. We worked in partnership with the following local organisations who helped us collect the information, provided feedback on an earlier draft on this reportand helped us shape the recommendations:

- **Sheffield Carers Centre**
- **Sheffield Young Carers**
- **Sheffield Parent Carer Forum**

We wanted to know about the experiences of all carers including young carers and parent carers.

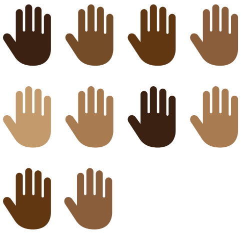
134 carers completed our survey, which ran from December 2019 until early March 2020. They went to **49** different GP practices across Sheffield although around half did not tell us the name of their GP surgery.

The questions were based on the Quality Markers. There were also open questions, allowing carers to share positive and negative experiences and make suggestions.

Some details about the people who completed our survey:

- The average age of participants was **46** years with the youngest respondent aged under **10** and the oldest aged over **80.**

The majority were women and **19%** were men.



Around **10** people[1] were members of the Black Asian and Minority Ethnic (BAME) community.

The majority told us they live with the person they care for.

- **20%** A fifth were young carers below the age of 18.
- **33%** A third told us they care for a someone below the age of 25.
- **25%** A quarter said they work more than 20 hours a week.

---

[1] We did not give participants pre-set categories for ethnicity so they could describe this in their own words. Due to the variety of answers, it is difficult to summarise the data and to provide a break-down of participants by ethnicity.

In addition to the surveys, we used other methods to understand some experiences in greater detail:

24 people took part in three focus groups, where we explored specific issues including the experiences of young carers and parent carers.

We collected **2** case studies of young carers

What we found

Carers felt not acknowledged and not supported

Mixed experiences

Some carers felt **positive about their GP**:

> *They treat me with respect, kindness and go out of their way to accommodate and support me in my role as carer and also as an individual too.*

Others however, told us that their GP **doesn't support them at all**:

> *There is not really any support for me or my wellbeing, despite the fact that I am a regular face at the surgery with the person I care for.*

Continuity

Only around a third **(34%)** of survey respondents said that **they did not have to keep telling staff that they are a carer,** as staff already knew. For others the lack of continuity and recognition was an issue:

> *In 8 years of going to the surgery I have no relationship with any GP and no-one I've seen more than once. There is no continuity of care or relationship. It is clear when I do go that they've not even looked at my records before I go in the room.*

Getting the right support seems to require effort

When asked **what doesn't work** for them as a carer, one person told us:

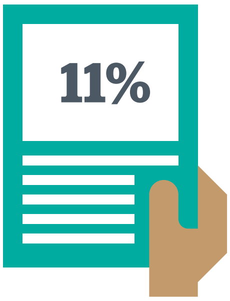
> *Not much but is that because I am not backward in coming forward and challenge where I disagree?*

Information

General information

Nearly half of survey respondents **(45%)** said they have seen **information for carers on display** but it was suggested that more information needs to be made available. One person explained they had taken carers information down to their surgery but this hadn't been put up.

Only **16%** were informed about their **rights to a carer's needs assessment or young carer's assessment**. In fact, one person explained that their spouse died before a carer's assessment was acted on.



Just **11%** were given a carer information pack.

Specific information

Less than a quarter **(22%)** were **offered information about other support services** that can help them. However, one person commented *"They offer services and advice when I ask for them"*.

Particular **kinds of information** carers suggested would be useful included contact names and numbers, and advice on balancing caring and personal life.

One person explained that they had requested details about the meetings of the **Patient Participation Group** but they were not sent these.

Looking after physical and mental health and offering support

Mixed experience

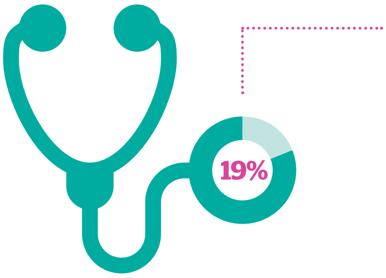
Some people reported positive experience such as being offered flu vaccinations but it seems to **depend on who saw them:**

> *Some but not all nurses and doctors at the surgery remind me to make appointments for things like smear tests, blood pressure, asthma etc. because they understand that I may not remember because of my caring role.*

Another person said:

> *Some GPs will support me in my role and are really good at making sure my mental health as well as my physical needs are discussed.*

Concerns about regular support



Less than a fifth of those who responded to our survey were **offered regular health checks.**

Only **18%** were **asked about their mental wellbeing** (e.g. feeling stressed or depressed).

Just under a quarter **(24%)** said they were **offered referrals to other support services** that can help them.

Appointments and access

Difficulties when booking appointments

Only about a third **(35%)** of survey participants said they were **offered flexibility with appointment times** working around their caring role.

Some **struggled** with the process of **booking appointments** for example where they had to ring early in the morning:

> *The system has changed, before you had to phone really really early. Now, it tells you how many people are in front of you in the queue. You still need to get up early for it though.*

Around a quarter **(26%)** said they were **given options on how to access support** when they can't get to the surgery because of their caring role (e.g. home visits or telephone consultations):

> *My GP only odd times have even given prescriptions over the phone to avoid coming out and it hurts us to know that my child are [sic] not worth their time!*

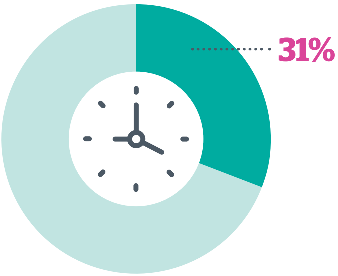
Some felt **reception staff were challenging:**

> *The doctors will give me a call back if I can get past reception team who will not willingly offer a call back.*

Some struggled with **online systems:**

> *Often difficult accessing appointments. I am signed up to online but not always available times so tend to just manage.*

During the appointment



Less than a third of survey respondents felt that they had **time to talk about their needs**

Some carers said it would be useful to have **appointments** where they could talk privately with their GP.

> *I got asked to stop talking at 8 minutes of a 10 min consultation (they were... running behind 30 minutes to which I did not complain). My issue at that consult was complex and hard to talk about.*

Staff attitudes

A number of people called for a **more compassionate attitude** from staff:

> *Be more understanding on reception about people's caring roles and the person they are caring for.*

Being listened to about the person they care for

The majority **(61%)** of carers who completed our survey said they are **involved in discussions about the healthcare of the person they care for:**

> *They are accepting of my opinion of my husband's condition/ needs as he cannot express this for himself.*

However, some called for **improving how carers are involved:**

> *Ensure there are easy ways for me to share information with them about the person I care for when it would help them.*

Experiences of young carers

We found some unique experiences of young carers.

Acknowledging young carers:

Young carers were **not always recognised** for their role:

> *My dad suffers from physical and mental disabilities. I have been caring for him as long as I can remember but I wasn't recognised as a carer until I was 12.*

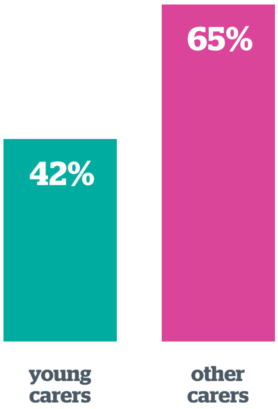
We heard that **staff could be more proactive in identifying young carers:**

> *It is important when the GP sees a patient with a diagnosis which could mean they need extra care at home, and if they have a young person with them – ask if they are a young carer.*

Involving young carers

Young carers **(42%)** were significantly **less likely** than other carers **(65%)** to be **involved in discussion about the healthcare of the person they care for.** However, young carers can offer valuable knowledge about the person they care for:

> *I have had a good experience with my GP. I was with my Mum at a GP appointment and the Doctor included me in the conversation. It was the same at the dentist, I told him I was a young carer and when my Mum had a seizure he called me in to help.*



Support and reassurance

It can be a **struggle growing up as a carer:**

> *My caring has changed as I have, when I was young I was anxious all the time, what if something has happened to dad, what will I find when I get back home. As I got older, I got more distanced from other people, I focussed on showing up at school, putting a smile on my face and getting home as soon as I could so that I felt like I was helping. My caring is linked to struggles I have in my life more recently.*

Young carers felt that **GPs are generally friendly** and said it was good to know the doctor they are seeing and that going to the doctor can give them a sense of "getting a solution". Some young carers said they need to **have a choice of the doctor's gender. They didn't like it when the doctor is judgmental** and associated a GP visit with "being scared" and "getting bad news". However, one young carer said:

> *It feels like people are naturally protective because we are children but what are they protecting us from? It should be easier to get information about my dad's conditions from health services.*

Young carers **(28%)** were significantly **more likely** than non-young carers **(8%)** to be given a **carer information pack**, However, one young carer told us about the importance of helping young carers understand information:

> *It helps if the GP actually acknowledges me when I am in the room – my GP made sure I understood what was happening. A lot of information is complicated, and they need to make sure we understand about the terms of their condition properly.*

Experiences of caring for a young person (including parent carers)

Gap in support for parent carers

None of those survey respondents who cared for a young person were given a **carer's information pack** compared to **16%** of those who didn't care for a young person.

Those who cared for a young person **(9%)** were significantly **less likely** than those who didn't care for a young person **(29%)** to **receive information about other support services that could help them.**

> *As a parent carer, I was totally unaware that my GP could support me in any way. This survey has surprised me. I am offered nothing from my surgery. I never ask for any support. Are they aware of my role? I don't know!*

Decisions about healthcare

Parent carers stated that consent was sought from the person cared for at different ages by different types of services. **This lack of consistency was felt to be a concern,** with a lack of clarity around what the correct approach was. Some parents were concerned that their child (either now or in the future) would be misunderstood by health professionals who didn't know them well, and they would **not get the support they needed to make the right decisions about their health.**

Awareness and understanding

It was suggested that GPs need to allow more time for **breaking information down** to make it accessible and offer more time to process what the GP is saying. Moreover, some parent carers suggested there needs to be a **greater understanding** around conditions such as **Autism, Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), etc.**

Good practice

We asked people about the good things their GP practice do to support carers. These included:

- **Being accommodating**
- **Being available when needed**
- **Acknowledging carers and valuing their knowledge about the person cared for**
- **Being attentive to both the needs of the carer and the person cared for and knowing them well**

Some specific practices that carers found useful included:

- **Providing flu vaccination**
- **Allowing others to collect prescriptions on carer's behalf**
- **Offering flexible options such as telephone appointments**
- **Being able to see the same GP to ensure continuity**
- **Regularly checking with carer about their mental health**
- **Responding promptly to requests for medication and appointments**
- **Offering call back and same-day appointments**
- **Providing information upon carer's request.**

Recommendations

Identifying carers

GPs should be more proactive in identifying carers. Staff need to be conscious of stereotypes about what is a 'typical carer' that may prevent them from identifying young carers and parent carers. Surgeries need to adopt a consistent approach in where/how they record this information, ideally at a point on the computer system which is easily visible.

Support for carers

GPs need to ensure that carers are offered regular health checks and are referred to relevant support services.

Information

Information for carers needs to be made more easily available. Having information on surgery websites is increasingly important.

Appointments

Staff should be supported and trained to recognise the need for flexible appointment options (such as home visits and phone appointments) and offer them. Carers should be offered the opportunity to discuss their own health issues in private and with sufficient time to do so.

Involvement

Carers should have an easy way to share information with their GP about the person they care for. Surgeries need to promote the voice of and involvement of carers in Patient Participation Groups (PPGs).

Young carers

Young carers need to be acknowledged and reassured in their role. Staff need to make sure that they understand the information relevant to their caring role.

Parent carers

Surgeries should take extra steps to identify and support parent carers as staff may fail to recognise their caring responsibilities over and above their parenting responsibilities. More opportunities to flag people in this role should be considered, for example could Ryegate Children's Centre include information about who is the parent carer of a child when sending a summary to the GP?

Consent

There needs to be more clarity and consistency of approach around seeking consent about healthcare decisions from young people cared for, and their parents.

Meeting need

Surgeries should access staff development to support better conversations around carers, which consider all their needs including mental health. Surgeries to support and promote staff uptake of the What Matters to You* training.

Identifying good practice and gaps

Surgeries should be encouraged to benchmark their current provision for carers, using the NHS England quality indicators as a tool. The Clinical Commissioning Group (CCG), Primary Care Networks (PCNs) and practices need to work collaboratively to identify and make improvement to carer experience using the quality markers.

Developing the use of the NHS England Quality Markers in the City

The CCG should widely promote the use of the Quality Markers including supporting practices to access relevant training and information.

Impact of Covid

The needs of carers should be considered as a specific group during engagement and consultation relating to Covid prompted service changes.

*To find out more about this training contact acp.sheffield@nhs.net

We worked in partnership with the following local organisations:

carerstrust
a Network Partner
Sheffield Carers Centre

SHEFFIELD YOUNG CARERS

Sheffield Parent Carer Forum

healthwatch
Sheffield

The Circle
33 Rockingham Lane
Sheffield S1 4FW

Telephone: (0114) 253 6688
Email: info@healthwatchsheffield.co.uk

Text: 0741 524 9657
www.healthwatchsheffield.co.uk