

Carers' Views and Experiences of Accessing Support from their GP Practice

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Authors: Asha McDonagh and Chloe Gunstone



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About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard, and to address gaps in services quality and/or provision.

<u>About the Hertfordshire and West Essex Integrated</u> <u>Care System (ICS)</u>

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services¹. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council².

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how it can further support people to look after their heart health.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years³.

(hertsandwestessexics.org.uk)

¹ Integrated care systems: how will they work under the Health and Care Act? | The King's Fund (kingsfund.org.uk) ² Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System

³ <u>Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System</u> (hertsandwestessexics.org.uk)

<u>Hearing Patient Views about Primary Care in</u> <u>Hertfordshire and West Essex</u>

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care System (ICS) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented

Using patient and public feedback, each engagement project will focus on improving the relevant service(s) within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From November 2022 to February 2023 the Director of Primary Care Transformation at the ICB has requested Healthwatch Hertfordshire and Healthwatch Essex to explore whether unpaid carers are registered as a carer with their GP practice, and if so, whether they are receiving the additional support they should be entitled to.

Background

Unpaid Carers in the UK

The NHS describes an unpaid carer as anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction, and cannot cope without their support⁴. It is important to recognise that many carers do not see themselves as carers and it takes them an average of two years to acknowledge their role as a carer. This is often because it can be difficult for carers to see their caring role as separate from the relationship they have for whom they care for⁵.

In January 2023 the Office for National Statistics (ONS) published its Census 2021 data which revealed that across England and Wales, 5 million people aged five and over provided unpaid care⁶. Given the number of people not recognising themselves as a carer, it is likely

 ⁴ NHS commissioning » Who is considered a carer? (england.nhs.uk)
⁵ NHS commissioning » Who is considered a carer? (england.nhs.uk)

⁶ Provision of unpaid care - Office for National Statistics (ons.gov.uk)

that this figure is much higher, with Carers UK estimating that there are in fact 10.6 million unpaid carers in the UK⁷.

Carers are of great importance to the NHS and help relieve the burden on health and social care services. During the COVID-19 pandemic, the support cares provided equated to around £530 million per day, or the equivalent of £193 billion per year⁸.

Impact on Physical and Mental Health

Caring for someone can have a negative impact on an individual's physical health, with Carers UK identifying that one-fifth of carers feel that their physical health is "bad" or "very bad"⁹ and Carers Week finding that 46% of carers were concerned about the impact their caring role is having on their physical and mental health¹⁰. Common health problems include high blood pressure, arthritis, musculoskeletal pain, fatigue and difficulty sleeping. This is often because caring responsibilities can be physically demanding and exhausting on a an individual's body.

Carers are also more likely to be older people, with the majority aged between 55 and 74 years old¹¹. They are also more likely to have health issues themselves, with the 2021 GP Patient Survey finding that 60% of carers have a long-term condition or disability compared to 50% of non-carers³.

The demands and pressures of caring responsibilities often means that carers negate their own health and wellbeing and prioritise the needs of the person they care for before their own.

Caring not only affects an individual's physical health but can lead to poor mental health as well. In 2022 Carers UK found that 30% of carers said their mental health was either "bad" or "very bad" and over a quarter of (29%) "often" or "always" feel lonely. Carers are far more likely to experience anxiety and depression, as well as stress, isolation and loneliness as a result of their caring role and the demands their caring responsibilities impose.

With extra pressures on NHS services and the rising Cost of Living, it is likely that the health and wellbeing of carers will continue to decline, with 62% of carers reporting that the increase in the Cost of Living was having a negative impact on their mental and/or physical health¹².

Role of GP Services

Given the demands caring responsibilities impose, it is important that carers are supported by health and social care services. GP practices in particular play a significant part in

⁷ carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf (carersweek.org)

⁸ carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf (carersweek.org)

⁹ <u>cukstateofcaring2022report.pdf (carersuk.org)</u>

¹⁰ carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf (carersweek.org)

[&]quot;cukstateofcaring2022report.pdf (carersuk.org)

¹² cukstateofcaring2022report.pdf (carersuk.org)

ensuring carers are supported in their caring role, and for ensuring their physical and mental health is cared for. However, through national literature and local anecdotal feedback, we know that unpaid carers are always not always receiving the support they need from GP services.

If someone is registered as a carer with their GP practice, they should be offered the following additional support¹³:

- Free NHS annual health checks, flu vaccinations and repeat prescriptions
- Signposting to health and social care services, and information and support
- Flexibility when booking appointments, and arranging "double appointments" for carers and the person they care for
- Access to Carers Assessment and benefit checks
- Access to "Carer Champion" an allocated member of staff within each GP practice
- Discussions about physical and mental health and the impact of the caring role
- Involvement in the care planning of the person they care for

We greatly appreciated working with *Carers in Herts* and the insight and expertise they brought. Through our engagement with *Carers in Herts*, we found many carers are not getting the support to which they are entitled. According to *Carers in Herts*;

- Carers are not often aware they can register as a carer with their GP practice to access additional support
- Many cares are also not aware of their GP practices allocated carers champion
- Those who are registered frequently do not receive the support they are entitled to
- There is no equitable service across Hertfordshire, some practices support carers better than others
- Lack of recognition of the issues carers face and how this impact carers' physical and mental health

Carers UK found that nationally, 49% of carers felt that NHS staff did not provide them with the information, advice and support they need to be able to care well and safely, and 19% had to wait over a month for a GP appointment¹⁴. This research also found that many carers had difficulties contacting their GP practice and were not given any flexibility when making an appointment, despite mentioning they are a carer and the constraints of their caring responsibilities.

Anecdotally, local carers shared the struggles they face in accessing a GP appointment for themselves or the person they care for, and felt that there is a clear lack of recognition regarding the issues carers' face, and how the caring role can impact an individual's physical and mental health.

¹³ The importance of registering as a carer with your GP - Dementia UK

¹⁴ <u>cukstateofcaring2022report.pdf (carersuk.org)</u>

Identification of Carers

Carers are unlikely to receive the support listed above if they are not registered as a carer with their GP practice. However as emphasised, there are many carers who do not identify as a carer, seeing themselves as simply looking after a parent, child, partner, or friend. People become carers by gradually doing small tasks for someone which slowly increase, meaning it can take people a while to identify a carer – with Carers UK finding that for 51% of respondents it took a year to recognise themselves as a carer.

GP practices are in a unique position, in that they are usually the first place that carers have contact with the NHS, meaning that staff are well placed to recognise whether someone is, or is about to become a carer¹⁵. As such, it is important that GP practices are proactive in identifying carers, and in ensuring they are formally registered as a carer on their patient records.

Efforts are being made to improve the identification of unpaid carers, for example NHS Long Term Plan commits to better supporting and identifying carers and improving their health outcomes as well as the person they care for¹⁶. While in October 2022, NHS England distributed a letter to all GP practices to remind them of the importance of both identifying and supporting unpaid carers, and included guidance to help GP practices record and code unpaid carers correctly¹⁷.

<u>Aims</u>

The aims of this research include:

- To understand whether unpaid carers are registered as a carer with their GP, and if GP practices are encouraging carers to get registered.
- To explore whether those who are registered as a carer are aware, and receiving, the additional support they should expect from their GP practice.
- To understand whether carers know a Carers Champion, and whether their GP practice has allocated this role.
- To identify how GP practices could encourage carers to formally register as a carer, and how they could better support carers.

Methodology

Online Survey

To explore the above aims, we ran an online survey to hear from unpaid carers living in Hertfordshire. Participants had the option to request the survey in an alternative format to suit their needs, and/or contact us for support. Given the timescales, we decided an online

¹⁵ We can help GPs identify carers | Carers Support Centre

¹⁶ NHS England » NHS Long Term Plan

¹⁷ How-to-identify-and-support-unpaid-carers-October-2022.pdf (england.nhs.uk)

survey was the most feasible data collection method to give us an overview of the key issues carers face when accessing support from their GP practice.

One respondent requested a telephone interview, from which the findings have been incorporated. Although efforts were made through our communications to hear from those who do not identify as a carer, the majority of respondents have identified as a carer for many years. We would recommend that the Hertfordshire and West Essex ICB looks to further engage with carers, with a specific focus on hearing from those who might not self-identify. Young carers were also outside the scope of this engagement, as such we would recommend that the Hertfordshire and West Essex ICB looks to understand the challenges they may face.

The engagement period for the online survey ran from 17th November 2022 to 4th January 2023. The survey was promoted via social media and shared with NHS and other statutory services and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to share and distribute via their networks, contacts and social media channels.

Audit of GP Websites

To supplement the online survey, an audit of all GP practice websites was carried out to identify whether GP practice websites have information on how to register as a carer, as well as the benefits of registering as a carer. Findings from this audit have been included in the key findings below.





Demographics

Through our online survey, we heard from **622** carers living in Hertfordshire.¹⁸ **10%** were aged between 25 and 44 years old, **47%** were aged between 44 and 64 years old, and **26%** were aged between 65 and 74 years old. **16%** were aged over 75 years old. Given the small number of respondents aged under 44, we would recommend that the Hertfordshire and West Essex ICB considers conducting specific engagement with this age bracket.

Most respondents were female (78%) female and 20% were male. 81% were of a White British background and 14% were from an ethnically diverse background¹⁹.

17% considered themselves to have a disability and **33%** considered themselves to have a long-term condition.

Regarding caring responsibilities, **52%** dedicate over 50 hours per week to unpaid care, and 41% have been a carer for over 10 years.

Registering as a Carer

Although **73%** of respondents said that their GP practice knows they care for someone, only **68%** are formally registered as a carer with their GP practice. Lack of awareness about the need to, and/or the importance of registering, was the main reason why respondents are not formally registered as carers with their GP practice.

"I have never been offered or asked about my caring role by the surgery."

"Who tells you to register? How do you go about registering? Just tell them?"

"I didn't realise it was something that I should do. I just assumed that if they knew I was caring for my elderly mother with Alzheimer's that was sufficient."

Respondents also noted that they received either poor or no communication from their GP practice as to whether they are formally registered, meaning they could not be certain whether this information was listed on their patient records.

"I have told my doctor I am a carer but I'm not sure whether he registered this."

¹⁸ Please note that percentages do not always add up to 100% due to some respondents choosing not to share demographic data with us, or choosing the "prefer not to say" option.

¹⁹ Ethnicities engaged with included: Bangladeshi, Indian, Pakistani, other Asian/Asian British backgrounds, Black African, Black Caribbean, other Black/Black British backgrounds, Asian and White, Black Caribbean and White, White Irish, White Polish, White Italian and other White backgrounds.

"I asked if they know I am a carer and was told yes I was. But I am not sure if it means I am registered.."

Another significant barrier was the belief that there are no benefits to registering as a carer with their GP practice, with many respondents believing that it would make no difference to the support they, or the person they care for, receive.

"I feel that telling the surgery that I am an unpaid carer will not change anything for me even though my caring duties impact greatly upon my own wellbeing, mental and physical health."

"The surgery is not interested. It's not worth the time and effort."

For some respondents, practical barriers such as lack of time, caring and/or work responsibilities, and problems getting through to their GP practice has prevented them from registering as a carer. A few respondents said that the person they care for does not want them to be registered as a carer, in case this means healthcare professionals finding out about the problems they are facing.

"I have been far too busy with the demands of my life, husband and children."

"My partner does not wish it to be known that he has addiction issues."

Interestingly, men were less likely to register as a carer, with **66%** of men registered compared to **73%** of women. **64%** of men in comparison to **57%** of women were also less likely to be aware of the additional support GP practices can provide carers with.

Despite this, **86%** of those who are not currently registered said they would now register as a carer if they were given the opportunity and/or support to do so. In fact, in response to this survey, some respondents have taken the initiative to register or check if they are registered, with their GP practice.

"Your email prompted me to call my doctor. I have now been asked to email the surgery asking to be registered as a carer which I have now done. Was told a week for it to be processed."

"No one has asked me so I will contact and find out."

For those who are formally registered as a carer, the majority found out about the need and/or importance of registering through *Carers in Hertfordshire*. Other sources included: their GP practice (particularly receptionists, leaflets, and posters), charities and support groups, and word of mouth.

Interestingly, our audit of GP websites identified that across most websites, **(81%)** information about how to register as a carer, and **73%** explained why it is important to register as a carer. Although in some cases this information was given in general terms.

The majority of websites (**75%**) also had a form which patients could fill in to register themselves as a carer with the GP practice. However only a few had a consent form to share the information of the person being cared for.

Concerningly, over half (**58%**) of practice websites did not explain what an unpaid carer is. Given that there are many people do not identify themselves as a carer, and the length of time it often takes for someone to recognise their caring responsibilities, a definition as to what an unpaid carer is would prove useful in helping patients self-identify.

Barriers to Accessing their GP Practice

When asked what barriers they face in accessing their GP practice, the majority of respondents (**57%**) mentioned the inability to get through to their GP practice, particularly via telephone. Given their work and/or caring responsibilities, waiting up to or over an hour to speak to a receptionist to request an appointment or to raise a query is not always possible, and can prove very stressful.

"I can't spend hours on the phone waiting in a queue when I need to care for my son. It brings me to tears, it's so stressful."

"Takes 40 – 60 minutes waiting on the phone to speak to someone."

26% of respondents do not have time to access their GP practice, and **29%** said it is difficult to fit appointments around their caring and/or work responsibilities. This is exacerbated by the fact they often have to call at a certain time to try get an appointment, or visit their GP practice in person, with many carers unable leave the person they care for on their own, meaning this is not a feasible option.

"They only make appointments on the day and by the time I get round to phoning due to my caring responsibilities they are all gone."

"Leaving a husband in a house on this own is tricky as every day is different. It's hard to plan." A large number of respondents shared that they are not offered any flexibility when booking an appointment for themselves or the person they care for, even when they remind the receptionist that they are registered as a carer and need extra consideration.

"When I told them I was an unpaid carer I was told that it doesn't make any difference."

"It makes no difference if I am a carer to my GP, they do not care. Even when I'm on the phone trying to get an appointment and explain that I'm a carer, it means nothing to them. They don't care."

Respondents also shared that they are not offered any choice in the type of appointment they are given. For some carers, having a face-to-face appointment was important as they do not have access to online technology, or because their concern was one that needs to be physically examined. For others, the person they care for is housebound and requires a home visit, but was only offered a remote appointment, despite this being inadequate.

"My husband is housebound and it's hard to get home visits."

"GP surgery reluctant to give face-to-face appointments, I do not own a computer let alone a smartphone for online calls."

The general lack of appointments was problematic for respondents, with many being told there are no available appointments, or having to wait weeks to see a healthcare professional.

"GPs do not have available appointments, only emergency ones."

"Appointments never available unless ringing weeks in advance – 3+ weeks wait for appointments."

Positively, a few respondents shared that they have faced no barriers when trying to access their GP practice, noting that the GP practice is helpful and easily contactable.

"I don't face any barriers they are brilliant."

"No issues – my GP practice is very good."

Access to Support

Since being registered as a carer with their GP practice, **75%** have been offered an annual flu vaccination, **17%** have been offered an NHS annual health check, and **16%** have been offered access to a Carer Assessment and/or benefits checks.

However, it is important to note that **22%** have not been offered any of the support in the graph below, and **72%** were not aware they could even access this range of support from their GP practice. This information is displayed in the graph below.

Our audit of GP websites supports the above findings, with **63%** of websites only explaining in very basic terms the support carers should be entitled to, and **25%** did not provide this information at all. There were examples of good practice, for instance, one website said a practice nurse would be in contact to offer a referral for support and funded breaks, and others went into detail about the support carers should expect once registered.



For those who selected "other" the common responses included referral to a social prescriber or link worker and priority access to the COVID-19 vaccine.

NHS annual health check

An NHS annual health check should entail a physical examination, including measuring your height and weight, taking your blood pressure and doing a blood test. For carers, this should also include asking questions about their physical and mental health in relation to their caring role.

Out of the small number of respondents who had received an NHS annual health check, only **32%** said they had received a thorough examination of their physical and mental health. The majority felt it was treated a "tick-box exercise" and said that the healthcare professional did not ask whether their mental health is impacted by their caring role.

"Complete waste of time. They weighed me, did my height and blood pressure. Did not offer any support or advice. I was angry when I came out."

"Healthcare assistant was dismissive when I answered I had some dark days to questions on depression and suicidal thoughts."

Flexibility and Availability of Appointments

It is good practice to ensure that anyone registered as a carer is offered greater flexibility and availability when booking an appointment for either themselves, or the person they care for. Those registered as a carer should also be given the option to book a "double appointment" for themselves and the person they care for, or to provide more time to discuss concerns. This is particularly important given the time commitments and pressures of caring responsibilities, and many carers are in full-time or part-time employment, adding an additional barrier.

However, our engagement found that **76%** of carers did not receive greater flexibility when booking an appointment for themselves or someone else. Respondents felt that being registered as a carer made "no difference" to the appointment times available, leaving many feeling "unsupported" by their GP practice.

"Absolutely not. The service makes no allowance whatsoever."

"No. Never. They don't seem to care or understand how hard it is."

'I feel the practice is at breaking point and I must fight to get an appointment or consultation for myself, and it takes ages on the phone. So, I only contact them now for something serious as I think I'll be fobbed off with anything more minor than a serious health risk. I certainly don't think they would be interested in my daughter's needs (who is registered at a different practice), or anything related to my caring role.'

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A few respondents have been offered greater flexibility, including the provision of "double appointments", home visits and a choice of time and date.

"Yes - the practice knows to offer the person I care for longer appointments."

"Yes - the GP organised a home visit for us."

Mental and Physical Health

Likewise, by being registered as a carer, carers should expect healthcare professionals to discuss their physical and mental health in relation to their caring role. However, our this engagement found that **87%** of carers have not had their physical or mental health examined in regards to their caring role.

"Never in the past 40 years of caring for my son with complex needs."

'When I went to the doctor as my shoulder was playing up. They explained I'm a carer. I was told it was my fault for not working. my shoulder doesn't get enough use. As a carer, I lift my husband in and out of the bath and push his wheelchair."

Many respondents stressed that GPs need to be more aware of the impact caring for someone can have on many different facets of life, and felt it was important that healthcare professionals are proactive in asking carers about their caring role, and whether this is affecting their health and wellbeing.

"GPs need to be more aware of the huge burden/stress etc of being a carer has on mental health and well being, ability to earn / work, reduced social opportunities, loneliness, isolation, etc." Furthermore, many highlighted how carers are often hesitant to ask for emotional support, and presume that their GP would be dismissive of their concerns.

"I think the support I might have wanted to access would have been emotional support, and people are often really reticent about asking for this. I believe that if I had needed practical or medical support I would have approached the surgery without hesitation."

A few respondents noted that their GP practice is proactive in asking about their caring responsibilities, and whether this is impacting their physical or mental health. These respondents praised their GP practice for being attentive and empathetic.

"Yes. They are attentive with this. Even if I've phoned up about my husband, I am asked how I am, do I need anything."

"I recently made an appointment to discuss health concerns exacerbated by my caring role and was treated very sympathetically and supportively."

Signposting and Support

If an individual is registered as a carer, the GP practice should provide signposting information and support as part of good practice. However, we found that for **79%** of carers, this was not the case.

Unsurprisingly then, **71%** of respondents have looked for information and advice from elsewhere instead of contacting their GP practice. Key sources included: Carers in Hertfordshire, Hertfordshire County Council, other health and social care services, and other charities and support groups.

"No I researched the support available and found help that way."

Likewise, only **12%** of carers have been referred to, or encouraged to speak to, a social prescriber, and **28%** said they do not know what a social prescriber or link worker is.

Positively, the audit of GP practice websites found that **91%** of practice websites had signposting information available for carers. However, for the majority the information available was fairly basic and did not signpost to local support available in particular. There were examples of good practice, with some practice websites providing a "Carers Pack" for carers to download, containing a wealth of information and resources.

Carers Champion

A Carers Champion is an existing member of staff who facilitates the identification and support of carers within their GP practice. Carers Champions are the key information point and have the following responsibilities:

- Improving carer's health and wellbeing and ensuring they are healthy enough to care.
- Amplifying carer's voices and ensuring they are involved in discussions about the health of the person they care for.

However, this survey found that only **13%** of respondents know if their GP practice has a Carers Champion, although **63%** would seek information or support from a Carers Champion if given the opportunity.

For those that know that their GP practice has a Carers Champion, only **52%** had spoken to, or received support, from the Carers Champion. The majority of which had a positive experience, sharing that the information, advice, and support they received was very useful.

Concerningly, the audit of GP practice websites found that only **20%** of practice websites mentioned Carers Champion. Of the 20%, many did provide information on how to contact the Carers Champion, and a few noted how a Carers Champion can provide information and support.

"The Carers Champion has helped me to get a specific appointment time for my son."

"They were good, and I have confidence that she would be able to help if called upon."

Feeling Unsupported

Unsurprisingly then, only **23%** of carers described the support they receive from their GP practice as "very good" or "good", while **34%** described the support they receive as "bad" or "very bad". Most respondents **(44%)** were neutral, stating the support as "neither good nor bad".

The general sentiment amongst respondents was that they feel "alone", "unsupported" and often have to put aside their "own issues" in favour of the person they care for. For many carers, they would like to receive more support from their GP practice, and for healthcare professionals to have a better understanding of the challenges carers face, and how this can impact their physical and mental health.

"I suspect many like me are dropping through the cracks."

"As a carer I feel as though I have just been left to get on with it."

"Personally, I feel that I am on my own when it comes to support from my GP practice, which is disappointing. Perhaps GP practices could acknowledge that carers are supporting them as well as the person they are caring for."

Some carers often felt that they were made to feel guilty for seeking support, and many did not want to burden the NHS, despite desperately needing help.

"We are made to feel guilty seeking the advice of a GP even when we are in pain and discomfort."

"I have never been advised as indicated here or had check-ups, often when I tried to get help with things like weight which is an emotional issue linked to my caring role, it's been by telephone, and I feel like a fraud or guilty or not listened to as a carer."

"I do feel that because I am an unpaid carer and 57 years old that I'm not worthy of the doctor's extra time, but my caring role has taken a huge toll on my life and still does."





Personal Story: Angela's* Experience of Accessing Support

After completing our survey, Angela reached out to Healthwatch Hertfordshire to share her views and experience in more detail.

Angela and her partner care for multiple people. When we spoke, Angela called her GP practice a few days ago to see what support is available, and to ensure she is registered as a carer with her GP practice.

Angela noticed through speaking to her mother-in-law, that support provided to carers appears to vary between GP practices, noting that there is "no equitable service." She pointed out that carers often must proactively seek out support instead of it being offered to them, and suggests that GP practices can better support carers by providing more information and signposting.

Seeking Help

According to Angela, GP practices often struggle to identify and support carers, meaning the onus is on the carer to seek help, and to look for information and advice to support them in their caring role: **"You have to seek help yourself, the onus is on you to seek out your own help – which becomes harder the more you struggle and you have to be quite confident to seek that out. Professionals or GPs must be able to actively think about what other forms or support might this family or patient need."**

She also shared the difficulties her partner, who is also a carer, faced when trying to access support from their GP. Her partner has physical health issues, as well as depression and anxiety. Due to his caring responsibilities, her partner often struggles to take care of his own health needs. When Angela encouraged him to see a doctor because she was concerned that "he might drop dead", the doctor them told: **"I can't guarantee life, and my partners in his 40s. I wasn't asking him to guarantee life, we were just asking for help and support to address the health issues he has."**

Angela shared how her partner's mental health issues were addressed in isolation to his caring role: **"GP would** focus on one particular issue but not look at the bigger picture, he didn't see the fact he is a carer and the challenges that brings."

Making Improvements

Angela suggested that healthcare professionals should look at carers more holistically, and address their physical and mental health in relation to their caring responsibilities. She praised the support their Carers Champion provides, and the importance of this role: "GPs don't have a huge amount of time to spend with patients whereas Carers Champions can talk to carers holistically about the whole picture. The Carers Champion can identify where the GP can be most effective and look at other ways other people might be able to help." Angela was inspired to seek support from her Carers Champion after completing our survey. She had a positive experience, stating that the Carers Champion 'was kind and set my partner up with an appointment with the surgery's life and wellness coach'. However Angela had trouble the contacting the Carers Champion, stating that the 'only [way carers get] support is if you have the strength to push and chase for it.'

Angela also felt that although there is plenty of information about carers in her GP practice, she does not feel represented by the images used in the resources. Angela highlighted how most leaflets featured "grey-haired old people with walking frames" and felt that a wider diversity of carers needs to be presented in communication materials.

*A pseudonym has been used to protect the respondent's identity.

Positive Feedback

Although there are clear areas for improvements, we did hear many examples of good practice, with respondents praising their GP practices for being supportive, responsive, and offering greater choice and flexibility where possible to accommodate their caring responsibilities and/or the needs of the person they care for. Below are some examples of GP practices going above and beyond for carers, offering emotional as well as practical support.

"When I had a breakdown recently, the GP was extremely sympathetic as he is going through the caring process as well."

"One of the GPs has provided brilliant support for me in getting help for my son. I have received excellent support when I have approached for help with my mental health. Twice I have received a same day appointment. One GP after discussion supported a request to my employer for a month of reduced hours which helped me through an extremely challenging period."

"They are always kind, considerate, and helpful. When I'm upset they give me time to say/explain/ask what I need to. If the person I'm talking to cannot help they will always find someone that can, even if that's a call back phone call. They are willing to go above and beyond to help me as a carer even for someone who is not in their practice. The surgery has on occasions phoned me to ask how my husband (whom I care for) is and me, when we have been through a particularly bad patch or his been rushed into hospital. They couldn't be more caring. I feel they do very well, especially with the constraints Government is putting on them."

"I'm very lucky with my GP he is outstanding. He has supported me with my husband over the past 16 years and my daughter over the past 9 years. They both have complex medical conditions."

"My doctors and all their team to a fantastic job. They are very caring in everything they do."

Suggestions for Improvements

The findings outlined in this report indicate areas for improvements, however as part of the survey we asked carers how GP practices could better support them, and how they could encourage unpaid carers to formally register as a carer with their GP practice.

Encouraging Registration

When asked how GP practices could encourage unpaid carers to register as a carer with their GP practice, the majority of respondents said that there needs to be more promotion and advertisement about how to register as a carer, as well as the importance of registering. Respondents suggested that this could be through noticeboards, posters and leaflets within GP practices, as well as through online resources such as the GP practice website. Some respondents said that GP practices could also send out text messages and emails, asking patients if they have taken on caring responsibilities and/or to check whether their patient records are up to date.

"Annual communications or texts asking if you are a carer and to make sure you're registered."

"By proactively making information about registering as a carer accessible on boards in their GP practice, and through posters and leaflets."

"Posters in the waiting room and information on their website!"

Linked to this, most respondents felt that GP practices could do more to promote the benefits of registering as a carer, and the additional support they should be offered.

"Promote the benefits of registering as a carer – most people are probably not aware."

"Telling carers tangible things that will be a benefit to them and to the person they care for if they do."

Some respondents noted that GP practices could be more proactive in asking whether someone has a carer, of if they care for someone. Given that many people do not identify are a carer, using this term would not help them to self-identify, meaning it is important that other language and phrasing is used to help people recognise themselves as an unpaid carer. *"By GP practices telling people they are a carer as you do not realise until you are told. You just do what you have to do."*

"Additional fuss or label of carer, we are husband and wife. I accept that I sometimes must use the "carer" label as a way of conveying our different lifestyles and needs but this isn't something I am comfortable with."

Similarly, respondents said that offering more face-to-face appointments could help with the identification of carers, as these interactions tend to be more in-depth and pick up on subtle cues which would otherwise go unnoticed in a remote consultation. Face-to-face appointments are also when someone is likely to accompany the person they care for, providing another opportunity for GP practices to ask if they are a carer.

"The practice nursing staff and GPs could ask relevant questions of patients to find out if they are caring for someone or if they have a carer."

"When accompanying my husband for his appointments the doctor could ask me if I am a carer."

Provision of Support

When asked how GP practices could better support carers, the majority of respondents would like to see carers offered more available appointments, more flexibility when making an appointment for themselves and/or the person they are care for, as well as greater choice in the type of appointment offered, with many noting that remote or virtual consultations are not appropriate for addressing their or the person they care for needs.

"Offering flexibility when trying to book appointments. Be more understanding that the people you care for may need to see a particular doctor as they can't deal with change."

"Offer some flexibility when appointments are impossible to make due to caring responsibilities."

"Be more flexible when booking appointments and understanding that we can't call first thing and drop everything that same day to go to an appointment – it needs to be planned. And don't cancel last minute when we've put a lot of effort and resources into attending the appointment." Another common suggestion was that GP practices could increase the contact they have with carers, for example by inviting carers to an NHS annual health check and checking in with carers to see how they are coping and if they are facing any difficulties in regards to their physical or mental health. Some respondents suggested that the Carers Champion could be in an ideal position to offer this type of support.

"Keep in contact at least annually and offer longer appointments for answering questions and giving appropriate health checks."

"More contact, enquiries, encouragement and checking in with carers (and with the patient too) would make me feel less abandoned. I feel like I'm doing their job for them sometimes."

A large number of respondents said that GP practices could better support carers by showing carers greater compassion, understanding and empathy. They noted that GP practices need to acknowledge the pressures and responsibilities carers face, and listen to carers about how this can impact them emotionally, mentally and physically.

"I understand that they are busy but just listen to what I'm saying about the patient and understand when I ask for help with my own health to support me. I once went in with a continuous cough and because I left it for a few weeks I was told it couldn't be serious. Even though I explained that I was a carer and never had time to help myself. I just stood there and cried because I felt so ill."

"I find our surgery to be very unaware about the stress and anxiety that unpaid carers suffer. I dread getting in touch with our practice these days as I fear I will be told more of what they can't do than what they should do. The stress of caring has multiplied. Our GP surgery used to be the one place where I felt assured of some extra help at all. If I need (not want) help from our surgery, sometimes, I have to really stand my ground."

Some respondents felt that reception staff could receive more training in regards to identifying and supporting carers. A few respondents said that receptionists did not seem to check their patient records, and did not seem to respond appropriately when they told them that they are a carer.

"Train their telephone and reception staff to understand the strains that unpaid carers are under when trying to access healthcare."

"There should be more training done for staff about what a caring role is, and maybe speak to carers when they do training to get a carers' perspective."

Recommendations

Recommendations

Based on the findings outlined in this report, it is recommended that the Hertfordshire and West Essex ICB Primary Care Workstream should encourage GP practices to take forward the following recommendations. The ICB is providing significant support to enable GP practices to improve access and further investment of this will help address some of the challenges.

Identifying Carers

We know that there are many unpaid carers who do not identify themselves as a carer, and in turn are not receiving support with their caring role from health and care services. GP practices are often a first point of contact for unpaid carers, and in an ideal position to ensure they are identified. This could be through:

- 1. Providing information and resources (such as posters, leaflets) in their practice and on their website, outlining what it means to be an unpaid carer.
- 2. Encouraging patients to self-identify by distributing letters, text messages and emails to patients asking whether they have taken on caring responsibilities. This information could also be shared in the GP practice and on the practice website.
- 3. Encouraging patients to check their patient records are up-to-date.
- 4. Proactively asking patients if they have a carer, or if they are a carer.

For the above recommendations, consideration should be given to the language used, as many people do not resonate with the term "carer." Staff should also avoid making gendered or cultural assumptions about caring.

Encouraging Registration

Our findings highlighted that some unpaid carers are not formally registered as a carer with their GP practice, which often prevents them from accessing and finding out about the support available. GP practices could encourage registration by:

- 5. Ensuring that carers are aware of the need to, importance of, and benefits of registering as a carer with their GP practice. Information on how to register should be available within GP practices and on the practice website. Communications could also be delivered via text messages, letters and emails.
- 6. Sending confirmation to patients once they have registered as a carer with their GP practice either via letter, email or text message.

Access

The findings indicated that carers are facing difficulties accessing their GP, whether this be for themselves or the person they care for. GP practices should strive to improve access for carers by:

- 7. Continuing to improve telephone systems to reduce delays and waiting times.
- 8. Offering greater flexibility in contact hours and opening hours to account for caring responsibilities.
- 9. Reviewing and addressing waiting times for appointments for carers.
- 10. Being more mindful of caring responsibilities and demands when offering appointments.
- 11. Providing more choice and flexibility when offering appointments, including offering "double appointments" when necessary.

Support for Carers

Patients who are registered as a carer should receive additional support from their GP practice to help carers manage their health and wellbeing. GP practices should ensure carers feel supported in their caring role by:

- 12. Ensuring that they offer registered carers the following support on a regular basis:
 - NHS annual health check
 - Flu vaccinations
 - Carer Assessment
 - Benefits checks
- 13. Ensuring NHS annual health checks include a thorough examination of carers' physical and mental health.
- 14. Having discussions with carers about their physical and mental health, particularly in relation to their caring role.
- 15. Signposting carers to health and social care services, as well as support provided by the VCFSE sector.

- 16. Referring to, or encouraging, carers to speak to a social prescriber or link worker. Awareness about how social prescribers can support carers should also be raised.
- 17. Updating their websites to include the following information:
 - Benefits of registering as a carer, and the support they should receive.
 - Signposting information and support to local and national organisations.
- 18. Treating carers with respect, compassion and empathy, and acknowledging the demands of the caring role. Reminders and refresher training on engaging with carers should be considered.
- 19. Ensuring that receptionists are checking patient records to see if someone is registered as a carer, and offering greater flexibility when booking an appointment, where possible.

Carers Champion

Each GP practice should have a Carers Champion. Carers Champion play an important role in ensuring that carers feel supported and are a key point of contact should a carer having any concerns.

- 20. All GP practices should have a Carers Champion if they do not already.
- 21. If a GP practice has a Carers Champion, their contact details should be given to registered carers, available in GP practices, and provided on the GP practice website. An email, letter or text message to registered carers could also be distributed.





Appendix

Named GP Practices²⁰

District	Name of GP Practice	Respondents
Broxbourne	Amwell Surgery	4
	Cromwell and Wormley	2
	Medical Centre	
	Cuffley and Goffs Oak	3
	Surgeries	
	Hailey View Surgery	4
	High Street Surgery	1
	Park Lane Surgery	9
	Stanhope Surgery	1
	Stockwell Lodge Surgery	4
	The Limes Surgery	8
	The Maples	1
	Valley View Surgery	4
	Warden Lodge Surgery	5
Dacorum	Bennetts End Surgery	14
	Coleridge House Medical	1
	Centre	
	Everest House Surgery	4
	Fernville Surgery	6
	Gossoms End Surgery	2
	Grovehill Medical Centre	2
	Highfield Surgery	1
	Lincoln House Surgery	2
	Longmeadow Surgery	2
	Manor Street Surgery	4
	Markyate Surgery	1
	Parkwood Drive Surgery	16
	Rothschild Surgery	14
	Wood Hall Farm Medical	1
	Centre	
East Hertfordshire	Central Surgery	8
	Castlegate Surgery	3
	Church Street Surgery	8
	Dolphin House Surgery	7
	Hanscombe House Surgery	4
	Knebworth and Marymead	14
	Surgery	

²⁰ Please note that the total does not equate to the total number of respondents due to some respondents choosing not to share the name of the GP practice they are registered with.

	Much Hadham Health	2
		2
	Centre New River Health	8
	Parsonage Surgery	1
	Puckeridge & Standon	3
	Surgery	
	South Street Surgery	10
	Wallace House Surgery	7
Hertsmere	Annadale Medical Centre	3
	Attenborough Surgery	11
	Little Bushey Surgery	2
	Fairbrook Medical Centre	7
	Gateways Surgery	2
	Grove Medical Centre	4
	Highview Medical Centre	2
	Longrove Surgery	1
	Manor View Practice	14
	Parkfield Medical Centre	6
	Red House Surgery	6
	Schopwick Surgery	7
North Herts	Baldock Surgery	10
	Ashwell Surgery	1
	Bancroft Medical Centre	5
	Birchwood Surgery	5
	Buntingford Medical Centre	4
	Garden City Surgery	2
	Granta Medical Practice	2
	Larksfield Surgery Medical	1
	Partnership	
	Nevells Road Surgery	16
	Orford Lodge	1
	Portmill Surgery	4
	Regal Chambers Surgery	3
	Royston Health Centre	7
	Sollershott Surgery	2
	Whitwell Surgery	1
St. Albans	Colney Medical Centre	1
	Davenport House Surgery	8
	Grange Street Surgery	3
	Harvey House Surgery	6
	Hatfield Road Surgery	1
	The Lodge Surgery	10
		18
	The Maltings Surgery	
	The Elms Surgery	7
	Midway Surgery	11

	Parkbury Surgery	8
	Summerfield Health Centre	4
	The Village Surgery	6
Stevenage	Bedwell Medical Centre	14
Stevenage	Bedwell and Roebuck	8
	Surgeries	0
	Broadwater Surgery	
	• 1	1
	Chells Surgery	6
	King George Surgery	8
	Manor House Surgery	3
	Shephall Health Centre	1
	St. Nicholas Surgery	2
	Stanmore Medical Group	9
	Symonds Green Health	1
	Centre	
Three Rivers	Abbotswood Medical	3
	Centre	
	Baldwins Lane Surgery	1
	Chorleywood Medical	1
	Centre	
	The Colne Practice	3
	Consulting Rooms	4
	Gade Surgery	6
	Haverfield Surgery	3
	Kings Langley Surgery	7
	New Road Surgery	4
	Vine House Surgery	9
Watford	Bridgewater Surgeries	14
	Callowland Surgery	2
	Garston Medical Centre	4
	Sheepcot Medical Centre	6
	Suthergrey House Medical	6
	Centre	
	Watford Health Centre	3
Welwyn and Hatfield	Bridge Cottage Surgery	10
	Burvill House Surgery	4
	The Garden City Practice	5
	Hall Grove Surgery	5
	Lister House Surgery	6
	Peartree Surgery	7
	Potterells Medical Centre	5
	Spring House Medical	1
	Centre	
	Wrafton House Surgery	3
	wratton nouse surgery	3