



Unpaid Carers: Access to Health

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What is Healthwatch?

Healthwatch North East Lincolnshire is the independent champion for people who use health and social care services. Healthwatch exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. Healthwatch share their views with those with the power to make change happen. We also help people find the information they need about services in their area. Healthwatch have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people. In summary, Healthwatch is here to:

- Help people find out about local care.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government know what people want from care.
- Encourage people running services to involve people in changes to care.



Introduction

Healthwatch North East Lincolnshire were approached by the Carers Support Service who had identified that unpaid carers were struggling to access Covid-19 vaccinations. This struggle was largely due to not being identified as an unpaid carer.

Healthwatch liaised with the Carers Support Service to facilitate deeper conversations with unpaid carers about their experiences, and enable them to express the barriers they faced when trying to access the Covid-19 vaccinations. Feedback received at this stage highlighted that whilst there had been difficulties faced by the majority of individuals in the community during this unprecedented time; for unpaid carers in particular, they were experiencing additional impacts from reduced day care services and respite opportunities, resulting in increased isolation and added pressure on their role as a carer.

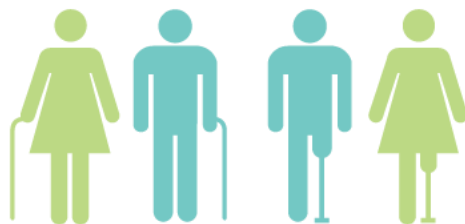
Comments we received at this stage included:

“On a couple of occasions I have had to phone 111 out of surgery hours and it takes ages to get an answer and then have to explain everything. Then someone has to ring you back usually 1-2 hours and if you are panicking about their health. It isn't very helpful. “

“For those who are not digital they just need to do things by phone or letter. Sometimes our own health just feels like another added problem.”

“Put on additional clinic appointments. For instance I could not attend an appt in the day or afternoon at Scunthorpe hospital as nobody available to stay with my mother until my brother finished work. The hospital eventually put on evening clinics for those not able to attend in the morning or afternoon. This was appreciated by me and was very helpful.”

Healthwatch therefore deemed it appropriate to extend our engagement beyond the Covid-19 vaccination programme, to explore further aspects of health and social care.



Methodology

Following the initial scoping session with service users of the Carers Support Service, Healthwatch consulted with its Independent Strategic Advisory Body (ISAB) to help inform the design of the wider engagement approach. The ISAB is a group of professionals who are experienced in the areas of Unpaid Carers, Children's Services, NHS Digital and Paediatric Health; and whose role is to give an independent lay perspective to the work that we do.

A survey was then compiled to answer the following aims:

- To understand if unpaid carers can access health services when they need them or if there are barriers in place to stop this happening.
- To understand if unpaid carers have been able to access the Covid-19 vaccination programme as set out by the Government along with other vaccination programmes, to determine any barriers or positive experiences they may have had.
- To determine what systems are in place for unpaid carers to enable them to self-manage their own health conditions.

From here Healthwatch project planned and co-produced an engagement strategy with the Carers Support Service to ensure that as many unpaid carers were reached as possible, to enable them to share their experiences of accessing health and social care.

The survey was available in printed and an online format and was regularly promoted at our outreach and engagement activity. The link to the online survey was also sent out by text message to all unpaid carers who were registered with the Carers Support Service and who had consented to receive this type of information. Healthwatch also had the opportunity to speak about the project on Viking FM to ensure as many unpaid carers as possible knew about the focus groups and survey.



In addition to the survey, Healthwatch also hosted a focus group for unpaid carers to attend and share their views with us. The focus group was hosted at the Carers Support Service to ensure accessibility for all unpaid carers, and two hours were allowed as a 'drop-in' style session with the nature of carers lives in mind. Further drop in sessions were held at Dementia Cafes and MS Support groups and Healthwatch also attended three further pre-established support groups for unpaid carers; Angel Carers, Parent Carers and Cleethorpes Carers. Additional to this, Healthwatch held one to one interviews with professional who work with unpaid carers.



About Unpaid Carers

An unpaid carer is a person who provides support, care and help to a family member or friend who would be unable to manage without their help. Care is provided for many reasons such as age, physical or mental illness, addiction, or disability, and anyone can become a carer at any age and any time in their life (Carers Trust, 2018). Unpaid carers may provide help with household tasks, personal care, finances, travel, medication, appointments, or provide emotional support and companionship to the person they care for without payment. An unpaid carer is different to a care assistant or care worker, who may perform similar tasks or duties but are employed to provide care and help (Carers Support, 2018). According to Carers UK, (2018) unpaid carers are often forgotten or taken for granted yet relatives, friends and family provide care estimated to be worth £132 billion; more than the NHS's annual budget in England of £124.7 billion (Kings Fund, 2018). The social care sector and NHS rely on carers, yet Carers UK suggest that carers often feel undervalued or unsupported (Carers UK, 2018). The report "State of Caring 2018" (Carers UK, 2018) found that being a carer can impact on the carers own physical and mental health, finances and ability to work, as 72% of carers had suffered mental health issues as a result of caring and 61% said that caring had affected their physical health, whilst 35% reported having to give up paid employment as they were unable to juggle work responsibilities with a caring role.

According to the Carers Trust there are 7 million carers in the UK, which is expected to rise by 3.4 million by 2030 (Carers Trust, 2018). It is estimated that unpaid carers save the UK economy £119 billion per year. Locally, there are 16,500 carers, who each contribute to their share of the £280 million they save the North East Lincolnshire economy every year (Carers Support Service). This equates to approximately 10.3% of the North East Lincolnshire population. Within North East Lincolnshire unpaid carers are evenly split across the Council Wards within the Borough; with 13% (total percentage of unpaid carers) in West Marsh and the lowest being 8.2% (total percentage of unpaid carers) in East Marsh. West Marsh and East Marsh being the two highest areas within North East Lincolnshire for deprivation. There is also an even split between male and female carers.



The Care Act 2014, states that in England all Councils should provide an assessment of the support needs of any adult with caring responsibilities (Care Act, 2014). However, the true number of carers may not be known as many carers do not identify themselves as a carer because they are looking after a family member or loved one and feel it is their duty. There may be many who are not being assessed, or accessing the help, support or financial benefits they may need or be entitled to (Carers Trust, 2018).

With regards to the Covid-19 vaccination programme, the Government identified unpaid carers as a priority group due to their responsibility for caring for some of the most vulnerable in our communities. Carers were sited under Group 6 of the prioritisation rollout, and were identified via the following measures:

- Having a Carers Flag on their primary care records as a result of registering as an unpaid carer with their GP.
- If in receipt of or entitled to Carer's Allowance, the Department for Work and Pensions would share this information with the vaccination programme.
- Being known to the local authority as a carer, and are receiving support following a statutory carers assessment.
- Being supported by a local carers' support organisation.
- Being a sole or primary carer who provides close personal care or face to face support for an elderly or disabled person who is clinically vulnerable to COVID-19.



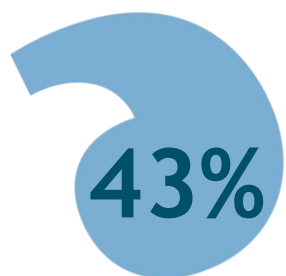


Demographic Information

Healthwatch North East Lincolnshire acknowledge that this may not be a fully representative sample of unpaid carers living in North East Lincolnshire, as only 171 carers completed the survey out of 16,500 in North East Lincolnshire. This equates to 1% of North East Lincolnshire's carer population. The results do include comments received at the focus groups, however results do not include their demographic information as this was not recorded at the drop in style sessions.

This study is based on the self-reported views and lived experiences of local unpaid carers with a caring responsibility for a wide range of reasons such as dementia, addiction, learning disability, frailty, physical and mental ill health. The unpaid carers who took part are caring at different stages in their own lives, eg: caring for spouses, elderly parents, and children. Some had retired, whilst others were trying to juggle caring with work or looking after other family members such as young children and others had disabilities of their own.

The majority of respondents (43%) were between the ages 50-64, another 26.5% were between the ages of 65-79, 22% were aged 35-49, 5% were between the ages of 25-34, 2% were young carers at 18-24 years old and another 2% were over the age of 80. The remaining respondents stated they would prefer not to say.



50-64 years old



65-79 years old



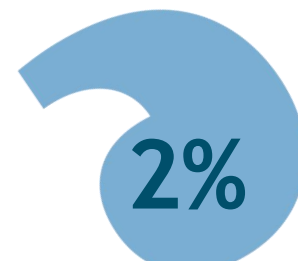
35-49 years old



25-34 years old

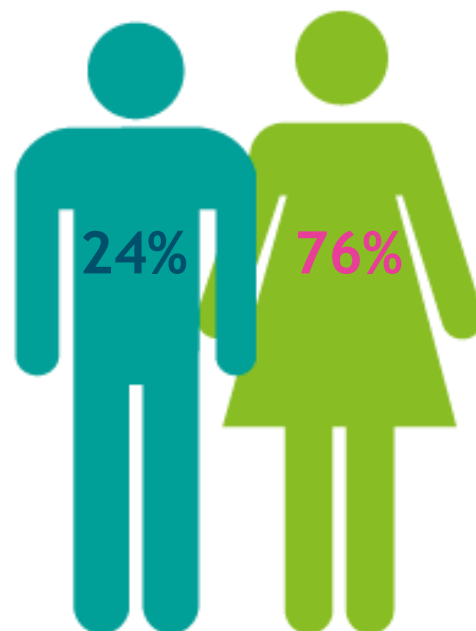


18-24 years old



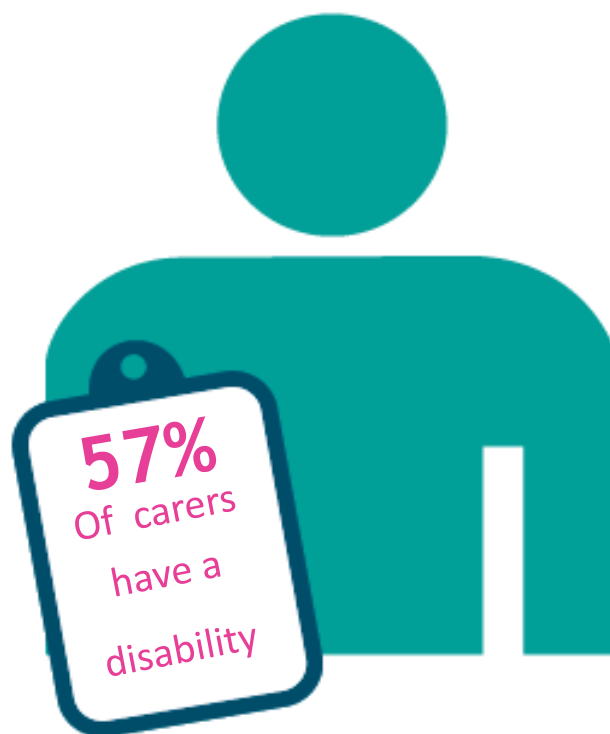
80+ years old

The majority of the carers who took part in our engagement told us they identify as women (76%) and the remaining 24% told us they identify as men. Other options were provided however none of our respondents identified as anything other than men or women.



Of those respondents, 60% stated they are married, 16% are single, 12% are living with their partners, 4% are divorced, 4% are in a relationship and not living together, 2% are in a civil partnership and 1% are widowed.

Over half of our respondents, consider themselves to have a disability (57%). 19% have a mental health condition. Another 19% stated they have a long-standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease or epilepsy. 18% stated that they have a physical impairment such as difficulty moving their arms or mobility issues. Others stated they are wheelchair users (3%), sensory impaired (8%) and have a learning difficulty/disability (5%).



Qualitative and Quantitative Findings



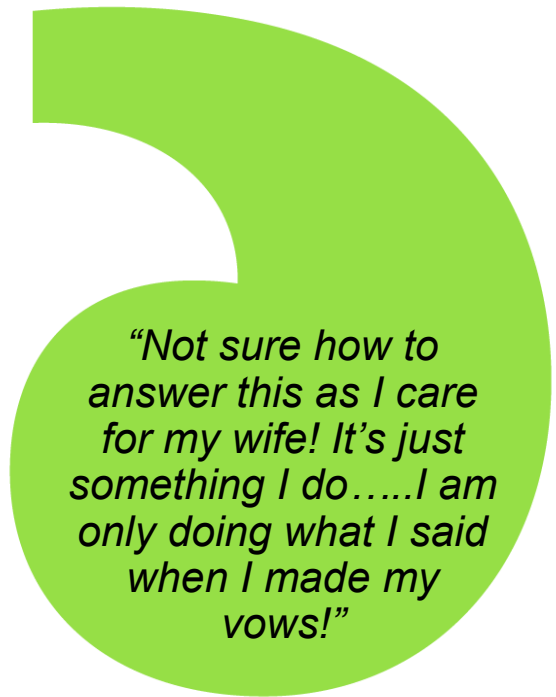
Do you help look after someone?

99% of our respondents said they help look after someone who *“needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support.”*

Do you consider yourself to be a carer?

Despite 99% of our respondents stating they help look after someone, only 94% actually consider themselves to be a carer.

“A carer is anyone, including children and adults, who looks after a family member, partner or friend. The care they give is unpaid.”



“Not sure how to answer this as I care for my wife! It’s just something I do.....I am only doing what I said when I made my vows!”

Do you feel that your own health and wellbeing takes a back seat due to your caring role?



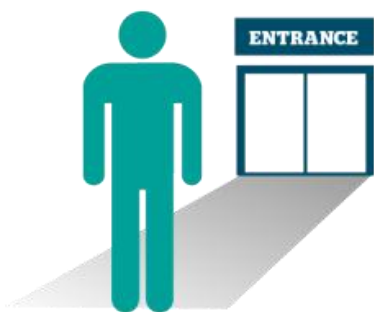
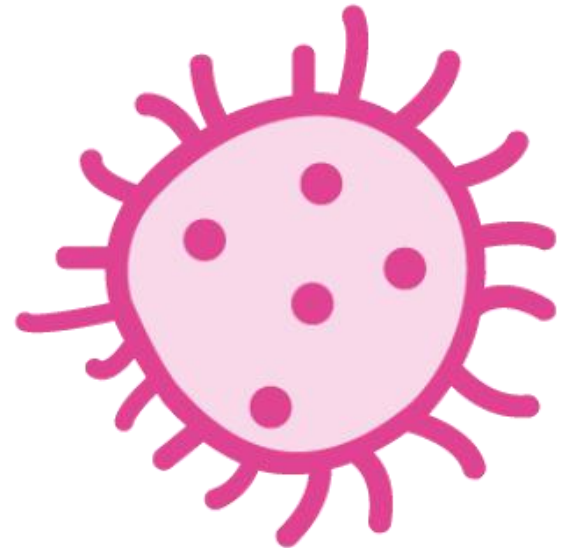
53% of respondents stated that they feel their own health and wellbeing *always* takes a back seat due to their caring role. 37% said that this happens *some of the time*. Whereas, 8% answered *rarely*, and 2% said *never*.

“My own health suffers on the back burner all the time.”



43 % of respondents said they are not offered a free Flu vaccination each year as a result of their caring role.

57 % of respondents said they were not identified as a priority to receive the Covid-19 vaccination as a result of their caring role.



68 % of respondents told us they had accessed health services in the past 12 months.

Have you had to miss a healthcare appointment as you could not fit it in with your caring role?

38% of respondents said that they have had to miss a healthcare appointment as they could not fit it in with their caring role.



“I feel like I don’t have the time to go for an appointment sometimes, and I’m anxious if my own health deteriorates.”

“Very limited free time”

“If i was to become ill we would struggle”

“I’ve been a carer now for many years, with detrimental effects on my mental and physical health and now I’m very ill with a lifelong illness and I struggle most days to look after myself, let alone another adult and house etc.. it’s a lonely life and I miss out on many social activities and life in general”

"I arrange appointments when a relative can be present which make arranging appointments difficult."

Were you able to book a date and time for a health care appointment around your caring responsibilities?

59% of respondents said that they were able to book a date and time for a healthcare appointment around their caring responsibilities.

"I do not arrange face to face consultations because of the taxi fare expenses and waiting time Nobody available to sit with my mother."

"I only have someone to help out on a Thursday or Friday"

"I always have to go to my doctors In the morning.. before work"

"I ask someone to look after children so I can go out the house for appointments "

Are you registered at your GP practice as a carer?

38%

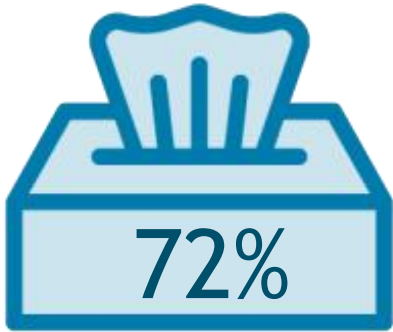
are registered with their GP as a carer

35%

are not sure if they are registered with their GP as a carer

27%

are not registered with their GP as a carer



72% said they were able to book an appointment at the same time as the person they care for.

38% of respondents said they have someone who can help them with a caring role, if they have to attend a medical appointment.

"I care for both parents and have no back up support apart from an aunt who lives over an hour away."



42% of respondent have accessed health services digitally, either by the internet or via mobile apps.

Challenges you Face Being a Carer

Always having to be there for them.

Keeping myself sane.

Being able to find time for myself.

Making sure that I give the right care all the time

Being always available.

Being unable to escape without problems.

When I'm ill myself, I still have to carry on.

Being able to sleep adequately and hold a full-time job.

Managing the stress

Not getting time to myself.

Getting professionals to listen.

It's 24/7, 365 days a year.

What is the biggest challenge you face being an unpaid carer?

Time away as a couple.

Personal health and exercise.

Unable to do things I wanted to do.

The emotional side of things, it's hard having to be strong when looking after a cancer patient.

Support for my own health and wellbeing.

Staying well in myself.

Being unable to leave the house without first arranging alternative care.

Understanding the needs of the person I care for.

The day-to-day not knowing, and the unexpected.

The hard work everyday, constant demands with no break myself.

Keeping on top of medical needs and paperwork.

Going to work and leaving them.

Loneliness.

I can't even go out to fetch my washing, even for two minutes, he needs constant supervision.

Very limited free time.

Keeping myself healthy.

Juggling home life and caring.

Challenges you Face as a Carer Accessing Health Care at

your GP Practice



Emerging Themes

Carers' Wellbeing:

Carers spoke of the impact on mental health and wellbeing as a result of the closures during the COVID-19 pandemic and the demands of their caring responsibilities.

"I've been a carer now for many years, with detrimental effects on my mental and physical health and now I'm very ill with a lifelong illness and I struggle most days to look after myself, let alone another adult and house etc.. it's a lonely life and I miss out on many social activities and life in general."

"Support for carers who look after people with physical and mental health needs is non-existent here. I've been asking for joined up support since 2013 and I still don't have access to mental health carers support. It is disgusting."

"Fed up hearing about problems due to COVID to mitigate waiting times etc."

"Juggling work, children with disabilities and my own mental health is very difficult."

The unpaid carers who we spoke to raised the following issues that are affecting their mental health and wellbeing:

- Demands of caring role.
- Isolation.
- Unable to get a break.
- Fear that the person they care for will hurt themselves.
- Struggled to access appointments due to no cover for caring role.
- Respondents stated that their caring responsibilities affected or sometimes affected their physical and emotional wellbeing, social life, finances, relationships, friendships or ability to work.
- Carers often have to miss their own healthcare appointments due to their own caring responsibilities, as 38% of our respondents told us.
- Carers have disabilities.
- They do not have a plan in place in case of an emergency.
- They worry about the future.



Emerging Themes

Support from Health Professionals

Healthwatch also identified a theme within feedback from unpaid carers who explained they feel their healthcare professionals could do more to support them with their caring role and responsibilities.

“I've registered with my GP as a carer. He doesn't acknowledge this... My husband can't answer their questions or give his symptoms quick enough for them. Caring would be easier if GP's actually acknowledged what the carer is saying, especially when the carer has known them for 46 years.”

“Visiting the GP is a joke because again they do not understand or recognise or even understand how challenging a carers role is.”



What Carers Would like to See?

“Improved access/flexibility with appointments”

The majority of our respondents said they would benefit from improved access to healthcare appointments due to difficulties with times and locations due to their caring responsibilities.

“Continuity of care”

Several carers said they find it difficult not having one familiar health care professional who has an extensive knowledge of the cared for person. Having this would relieve some of the pressure on the carer, reduce the risk of miscommunication/error and potentially enhance overall care.

“Compassion/understanding of my caring role from Healthcare Professionals”

A significant amount of carers told us they feel there is a need for improved attitudes and understanding towards unpaid carers, and *“recognition of the key role we play in maintaining the health and wellbeing of our cared for”*.

“Help with my emotional needs”

Generally, this suggestion was in relation to low level counselling at no cost, but others mentioned regular ‘check-ins’ from professionals, complementary therapies, a ‘key contact’ and semi-regular respite care.



Conclusion

The findings from our engagement found that only 94% of respondents considered themselves to be a carer, despite looking after someone who needs help because of their illness, frailty, disability, or mental health problem. Over half (53%) of these respondents stated that they feel their own health and wellbeing “always” take a back seat due to their caring role, and another 37% said that this happens “some of the time”. Whilst it was positive that 72% of respondents said they were able to book an appointment at the same time as the person they cared for, there were 38% of respondents also advised that they have had to miss a healthcare appointment as they could not fit it in with their caring role.

43% of respondents said that they are not routinely offered a free flu vaccination each year; and with regards to the Covid-19 vaccination, 57% said they were not identified as a priority to receive this. However this is unsurprising when only 38% of respondents are registered with their GP as a carer.

Carers spoke of many challenges they face as a result of being a carer that could impact on their own health and wellbeing. These included prioritizing their cared for person’s wellbeing over their own, finding time for themselves, managing stress, and having to carry on even when they themselves were unwell. Some respondents also stated it has affected their ability to maintain employment and maintain their households. Carers also spoke of the challenges they face in meeting the needs of their cared for person. These included understanding their care needs, keeping on top of paperwork and medical needs and safety and constant supervision. In terms of accessing healthcare, the main challenges reported were fitting appointments around care needs and accessing appropriate cover, appointments being available at suitable times, and a lack of understanding by services of the challenges and needs of carers.

In terms of the support carers would like, a wide range of responses were provided, with the highest needs being emotional support, health checks for carers, emergency care cover and being able to register with their GP as a carers. Social care related support also ranked highly in terms of responses and included needs for advice around direct payments, carers assessments, home adaptations, aids and equipment, lifting and handling, and benefits advice.

Healthwatch Recommendations:

Based on the feedback received from carers and local support services, Healthwatch North East Lincolnshire makes the following practical recommendations, that will support carers, but will also improve identification for future vaccine programme and other issues that may impact on carers.

1. GP Practices to consider nominating a Carers champion to ensure best practice is delivered when supporting Carers and their cared for individuals.
2. Primary care patient record systems to be developed to include a flag to highlight that a patient is a Carer. Where this is already in place, Practices to undertake a campaign to refresh and encourage patients to advise of their Carer status.
3. A campaign to be undertaken in partnership with healthcare and VCSE services who support Carers to encourage and support these individuals to register their Carer status with their GP Practice. Healthwatch would be happy to support in the coordination of this.
4. The local authority to develop a care and contingency plan to support the Carer and cared for individual that considers emergencies and future care needs for both caring parties.

What will happen next with this report?:

The report will be submitted to local commissioners and providers under the Healthwatch power to make reports and recommendations. Services have 20 days from receipt to respond.

Healthwatch North East Lincolnshire will monitor responses to our recommendations and keep members of the public and stakeholders informed of progress and actions to deliver improved services.

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Share your views with us

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Find out more about us and the work we do

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