
Unpaid Carers Project

Experiences of Loneliness and Social Isolation

June 2022

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Summary of Findings

- We spoke to 30 people for this project, plus one case study. A majority of respondents were women from all over the Bolton area. The sample of respondents was not completely representative of all residents in Bolton, however this may also reflect a difference in those that take on a caring role.
- The carers in this study were most likely to be a parent, spouse, or child of the person they care for. These categories are presented in order of most selected.
- People described a range of frustrations with being a carer. Many of these emotions were related to the challenges of the day to day role and often linked to a lack of time for themselves, support to do things like work, or take a break.
- There were also some with a sense that services are not always easy to communicate with. For example, there is an expectation that services would call back and arrange support if offered, but this did not always take place. In addition, understanding a system which is often split across local Council and NHS could leave people feeling isolated; it takes time to understand how this all works.
- Those we heard from are dedicated to those they care for. There was therefore concern about the future, mainly that carers would be able to continue working and therefore have enough money to get by. The other concern related to the person they cared for, what would happen to them once the carer was too old to continue providing support. A few carers expressed that they felt caring had taken over their lives.
- Carers did not always feel valued and this may in part be due to the at times unregistered nature of their role. This might also be compounded by

difficulties in accessing self-care or formal medical services due to time constraints.

- Respite is an issue that has been explored by Healthwatch before and it once again played a part in people's experiences in this project. Essentially, respite was not always felt to be easy to access. Naturally, it can mean different things, not just a formal site where people can be left for a time, but also another person helping at home.
- There is a chart in the results section that shows the range of activities carers like or would like to do. Many of them are ordinary daily activities such as walking outside, meeting family, listening to music, or other hobbies.
- Use of technology was mainly related to information gathering.

Background

Every year, we (Healthwatch Bolton) consults the local community to find out what health and care topics matters to them so their feedback can influence our workplan. For our 2021/2022, the local community told us that 'mental health' was a priority for them. The Unpaid/Informal Carers Project fits with our priority of mental health.

In 2019, we undertook a similar project researching local carers experiences of loneliness and isolation. The respondents expressed the emotional and social impact their caring roles has on their life, what activities they would like to do to have a break from their caring role and highlighted several barriers to accessing information and support.

In 2022, in the light of the Covid-19 pandemic, we undertook a similar project to explore how the pandemic has exacerbated unpaid carers experience of loneliness and social isolation. It seeked to ascertain what support is available for carers, highlight their coping mechanisms and barriers to accessing support and information. We wanted to establish when carers reach out for help/or when they are offered help (from both statutory and third sector organisations) that enables and empowers them to fulfil their caring commitments. To this end, we wanted to give unpaid carers a voice in influencing and shaping future local carers strategies.

Definition of unpaid carer

An unpaid/informal carer is anyone, including children and adults, who look after a family member, partner or friend who need help because of their illness, frailty, disability, mental health condition or an addiction and cannot cope without their support.

Methodology

What did we ask people?

We asked people about their feelings and experiences of being an unpaid carer, how this impacts them and what sources of support they might have found.

Who did we talk to?

There were 30 respondents to the survey, though not every question was answered by all respondents.

Of the 30 respondents only 25 answered enough of the questions to be considered detailed respondents, with most of these other 5 only answering the first question.

We also gathered one case study.

How did we carry out the research?

The data for this report was collected by our unpaid/informal carers semi-structured survey which we ran on Survey Monkey (15.03.2022 to 18.04.2022). The survey was promoted at many face-to-face events in Bolton. We took paper copies of the survey so they could be completed by people who did not access online information. We conducted one telephone interview.

The survey was promoted in our monthly newsletters (March and April) and on our website and through our social media channels: Twitter, Instagram, and Facebook.

Bolton Carers Support promoted the survey via their Carers 'Contact' Newsletter. Bolton CVS promoted the survey in their Information Bulletin. Bolton Clinical

Commissioning Group and Greater Manchester Mental Health Trust shared the survey within their networks.

How will the work be disseminated?

This report will be available on our website in the reports section.

The findings and report will be shared with our local partners and contacts, which include commissioners such as the Local Authority and Clinical Commissioning Group/GM ICP/Bolton Locality Board, Greater Manchester Mental Health Trust, and Healthwatch England.

The findings of this work will also contribute the Carers Strategy currently being refreshed by Bolton Local Authority

Ethical Issues and Data Protection

No personal information will be collected. We never collect personal names, or addresses of anyone who returns a survey to us. We may ask people to sign up to our newsletter after completing one of our surveys, but this is done by an external link directly to our Mailchimp database.

We liaised with Bolton CCG to ensure they are fully aware of this project.

Healthwatch Bolton operates to the UK General Data Protection Regulations 2018. All information provided will be stored for the purposes of this project. If you would like to know the full details of how we comply to the GDPR regulations please refer to the privacy notice which is available on our website:

www.healthwatchbolton.co.uk.

Findings

This section details the full findings of the survey and case study undertaken for this project. Whilst this is a presentation of the results, some quotes are not included for readability.

Quotes are selected to help represent the key issues raised by respondents. The report aims to highlight both common experiences and less common but relevant ones.

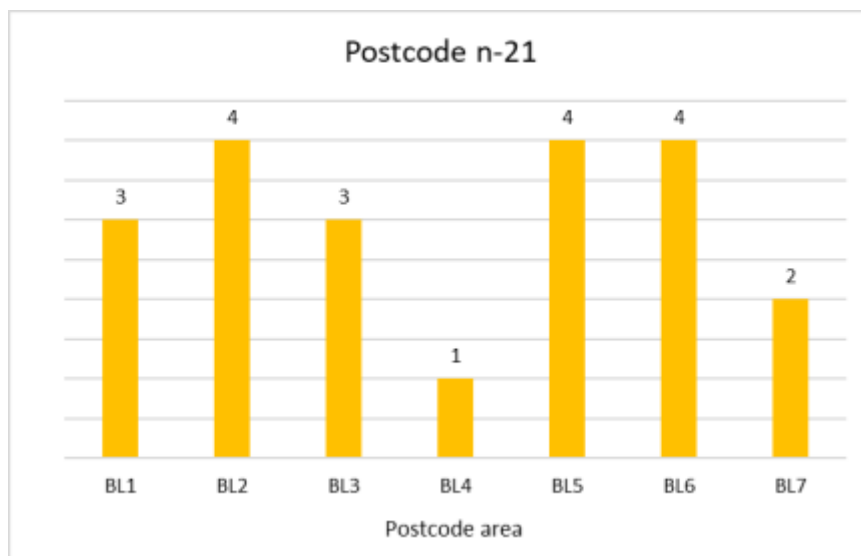
A summary of the report can be found at the start of the document. Recommendations follow at the end.

- There were a total of 30 respondents in our survey.
- The work took place between March – April 2022.
- The survey was conducted with Bolton residents.

Demographics

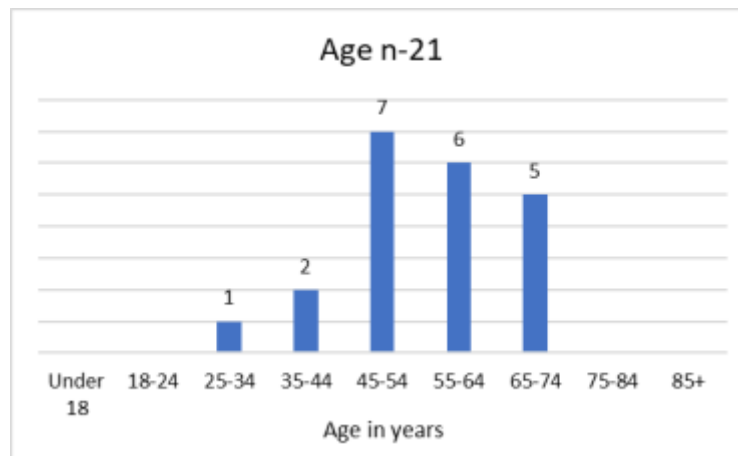
This section details the demographic characteristics of the respondents in this project. Not everyone answered each question and at times people could select more than one answer, which results in a higher number of responses than total respondents.

What is your postcode? (first 3 characters)



There were a range of geographic postcodes represented.

What is your age?



The majority of respondents were aged between 45 and 74.

Please tell us which gender you identify with?

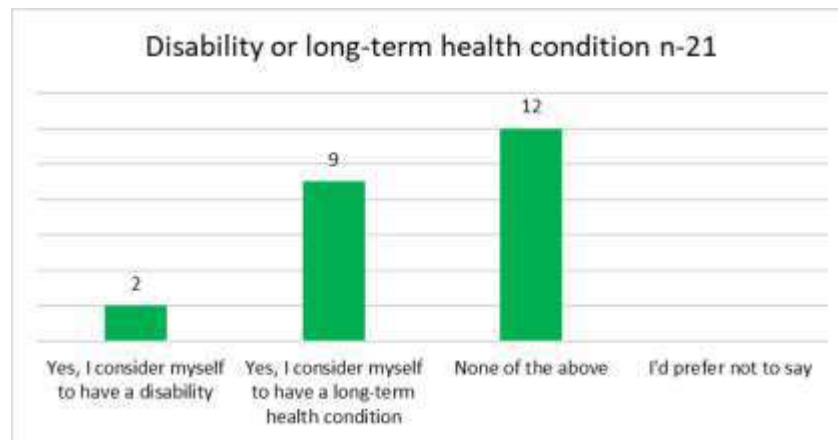
Women 20 (95%), men 1 (5%). Total 21.

No respondents identified with the optional categories of Intersex, Non-binary, I'd prefer not to say, Other (please specify).

Please tell us which sexual orientation you identify with?

Heterosexual/straight 20 (91%), Gay 1 (4%), I'd prefer to self-describe 1 (5%). Total 22.

Do you have a disability or a long-term health condition?



While over half said they did not have a disability or long-term condition, there were a significant number of people that selected 'long-term health condition'.

Is your gender different to the sex that was assigned to you at birth?

No 18 (86%), Yes 3 (14%). Total 21.

Nobody selected 'I'd prefer not to say'.

Please select your ethnic background

White: British/English/Northern Irish/Scottish/Welsh 16 (76%), White: Any other White background 2 (10%), Asian/Asian British: Bangladeshi 1 (5%), Any other Asian/Asian British background 1 (5%), Black / Black British: Caribbean 1 (5%).

Total 21.

There were no respondents selecting other ethnic groups from the full list provided.

Due to the small number of respondents the percentages related to the results for this question can be shifted by a small number of responses. Therefore, whilst the total for White or Other White groups of 86% is roughly similar to the overall total for Bolton, this remaining 15% represents just 3 non-White respondents.

Being an unpaid carer – background questions

Do you see yourself as a unpaid/informal carer?

Yes (26), Don't know (3). Total (29).

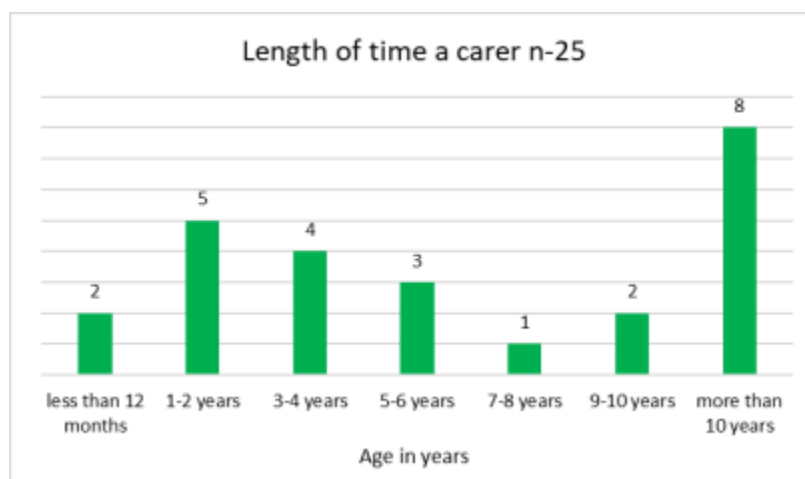
Most respondents identified as an unpaid carer (90%). We had no respondents state 'no' in response to this question.

What is your relationship to the person you provide care for?

Spouse (married or civil partnership) (5), partner (2), parent (12), son (3), daughter (4), sibling (1). Total 28, one person ticked two options.

Parent (43%), spouse (18%) and daughter (14%) were the three most common responses to this question. Due to the number of respondents there is not a big gap in between the categories with low response totals. This makes caring for a parent unpaid the most represented category.

How long have you been an unpaid/informal carer?



As can be seen in the chart the single most popular response showed people had been a carer for a long time 'more than ten years'.

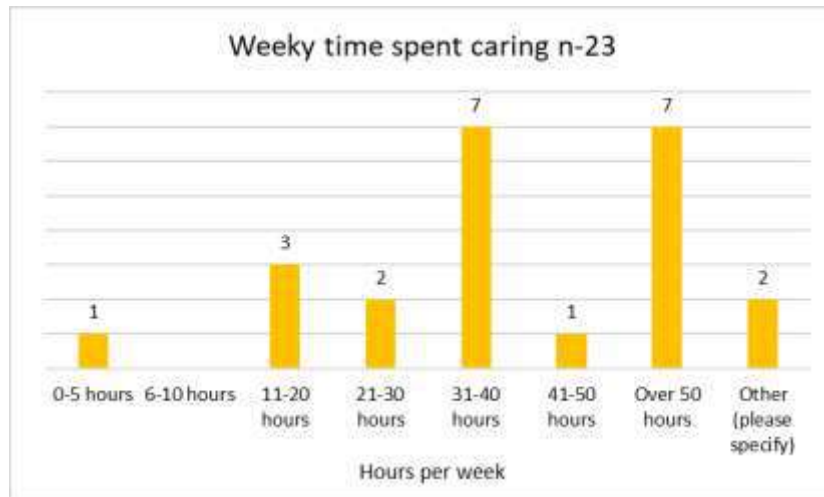
Defining the impact of being a carer is difficult from years alone, but if we assume that caring in an unpaid way requires a significant contribution in time and energy the chart shows that in this project most had been caring over one year already.

Have you told your GP practice that you are an unpaid carer?

Yes (14), No (4), Unsure (4), I didn't know about this (2). Total 24.

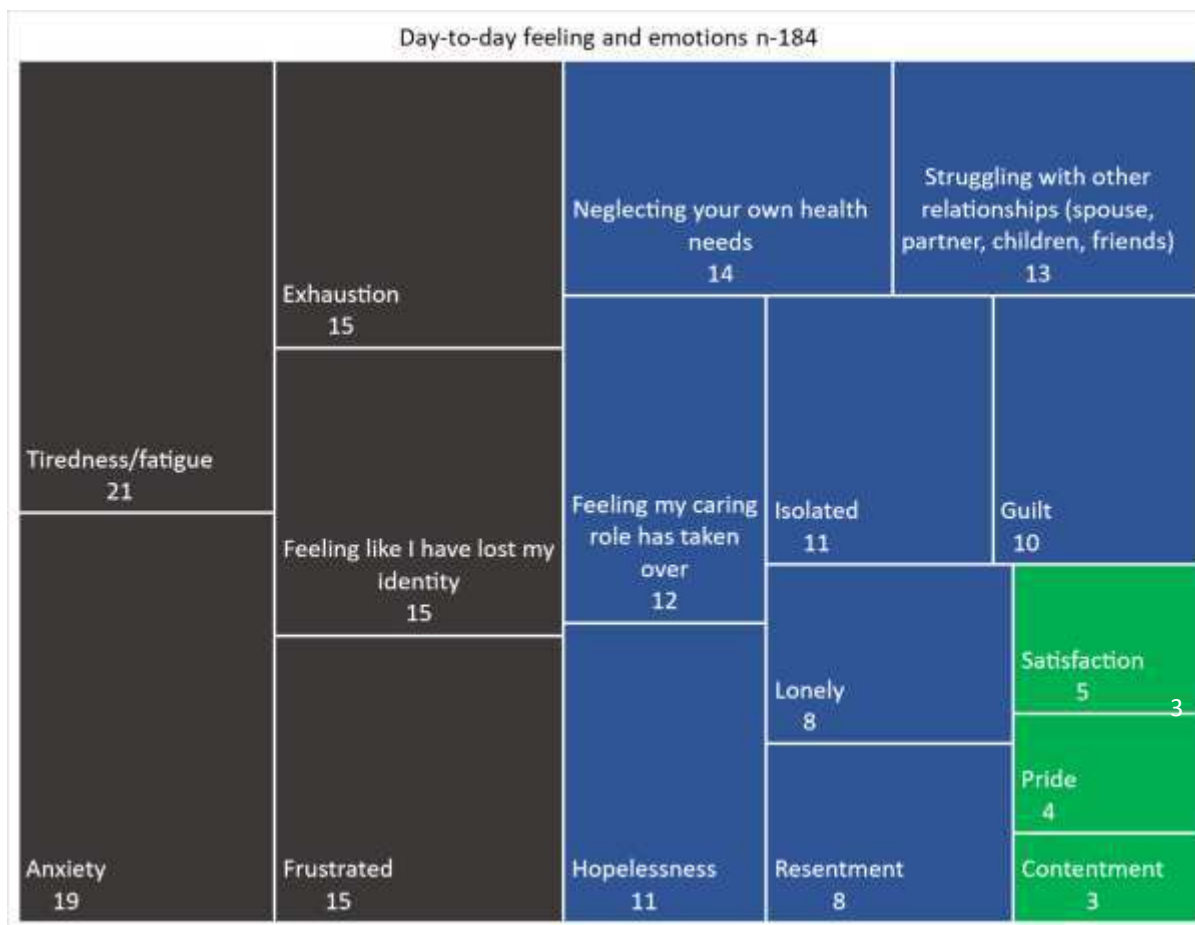
The majority of participants had told their GP they were a carer (58%). However, this still left a number that had either not done so (17%) or were unsure if they had (17%).

Approximately how much time do you spend caring for someone each week?



The chart shows participants estimate at how much time they spend caring each week. Much like the previous question around how long people have been caring, it is difficult to know just from the numbers what the impact of spending so long on caring is. However, it is likely the large numbers suggested here would have significant impact and approximate at least if not beyond what would be a working week in hours

As a carer, what feelings and emotions do you go through on a day-to-day basis?



The chart offers a visualisation of the emotions people ticked when asked to select how they feel from a range of options.

In addition there were two responses that said 'other' with the attached comments being '*stress*' and '*despair*'.

As a carer, what are your biggest frustrations?

People were asked to list their frustrations with being a carer, they could select more than one option.

Poor communication between services (10), Lack of information (11), Having to repeat yourself time and time again (6), Services letting you down (e.g. having to chase things when people do not come back to you) (11), Having to hit crisis before finding out about available support (12), Struggling to navigate the health and social care system (12), Professionals who only speak to the 'cared for' and not the carer (7). Total 74.

Nobody selected the option '*None, I don't have any frustrations*'.

Key issues with 16% of responses each were *'Having to hit crisis before finding out about available support'* and *'Struggling to navigate the health and social care system'*. We also heard from 15% of respondents a piece that *'Lack of information and Services letting you down (eg. having to chase things when people do not come back to you)'* were of concern. Finally, *'Poor communication between services'* comprised 14% of the selected statements.

There were five comments under the 'Other' option for this question:

"Under the circumstances we cope quite well. I think this is because we do not find it easy to ask for help."

"That no one asks how "you are" only asking the cared for person how they are."

"Loss of identity, no time to be me."

"Gave up asking for support a long time ago it's easier to just manage on my own."

"Working and also almost being a personal assistant to the person I care for."

As a carer, do you have any fears, worries, or concerns about the future?

We asked whether respondents had any concerns for the future and to tell us more about them.

Don't know/not sure (7), Yes, Please tell us more (17). Total 24.

There were no selections for 'No'.

Overall we had a majority say there were concerns (71%).

Several concerns related to what will happen to the cared for person in future:

"I fear what will happen to my daughter when I'm no longer able to care for her or when I'm no longer here".

"I worry about my [child's] future when I am older and not able to provide care for her."

Others faced challenges due to the time dedicated to caring:

“I worry about finances, if my partner will get better, & the fact I can't work - so when the inevitable happens, I will have nothing to fall back on.”

“Trying to care, work, look after my own family and find time for me.”

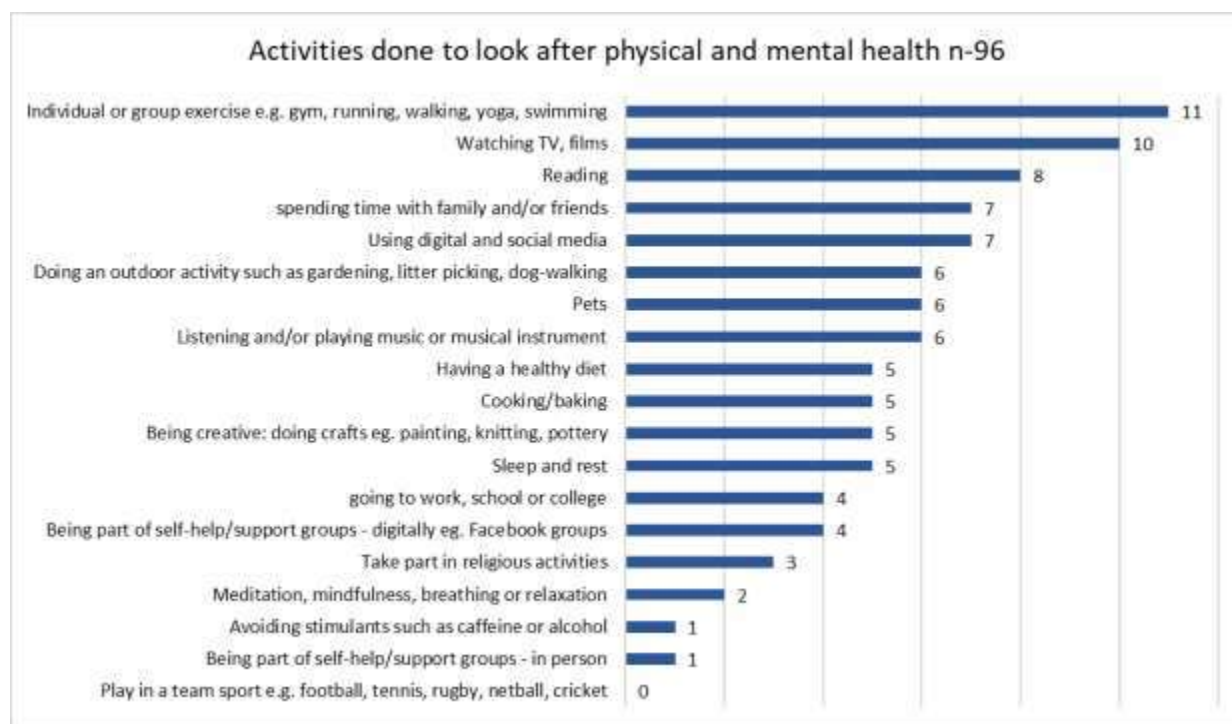
There was also concern about the unknown nature of what the future holds:

“Not a clue what the future holds?”

“I'm 60 now and been a carer for over 10 years and feel my life is over.”

Self-care

What do you do to look after your physical and mental wellbeing?



A range of activities were recorded as indicated in the chart above.

Do you do any of the following to help you cope?

We asked if people turned to various behaviours in order to cope with the effect of being a carer. People could select more than one answer.

Drinking alcohol (8), Eating unhealthier food (11), Withdraw from social situations (10). Total 29.

The result was alcohol (24%), unhealthy food (33%), and withdrawing socially (30%).

There were also a smaller number of people that selected 'Other (please specify)' (4).

"No"

"Sleeping too much"

"Over talk then people will listen"

"Drugs"

...are there any barriers that stop you doing the things to look after your physical and mental wellbeing?

In addition to the previous question we asked if there were any barriers to looking after physical and mental wellbeing that people could identify.

"Time"

"Availability of time given caring responsibilities."

"No one to look after the person who needs care if I go to exercise class etc."

"Having to cancel arrangements for "me time" due to attending various appointments etc., with the "cared for" person."

Energy levels

"Pure exhaustion. Fear and worry."

"Time? exhaustion from what has to be done."

Finances

"I can't drive (my partner, the one I care for, was always the driver), so we have to rely on others for help & feel isolated. I started driving lessons but it got too

expensive so I had to stop. We can't be spontaneous, everything has to be planned to the second, so we just don't bother going out because it's easier."

"Finances."

Feeling valued

***How valued do you feel your views and experience is as an unpaid carer?
(think about your contact with you GP, social care, health professionals)***

We asked how people felt about this area on a sliding scale. The scale went from 'highly valued' to 'not valued at all'.

The responses were Slightly valued (8), Not very valued (6), Not valued at all (7). Total 21.

No responses were received for 'Highly valued'.

This suggests respondents tended towards the negative when assessing their feelings towards this area.

Do you feel respected and listened to as a carer?

The survey included an open question on the idea of respect and being listened to as a carer. There were a number of themes as indicated by the quotes selected below, namely blaming yourself for not reaching out enough, that peer support groups are where opinion is most listened to and feeling unvalued because caring makes it hard to work.

Blame self

"Not really, but as mentioned before, I believe this is because I do not reach out to support organisations. I also feel that when I have reached out to organisations I have not felt that supported and/or listened to."

"Peer support networks."

"From other carers and people in similar situations."

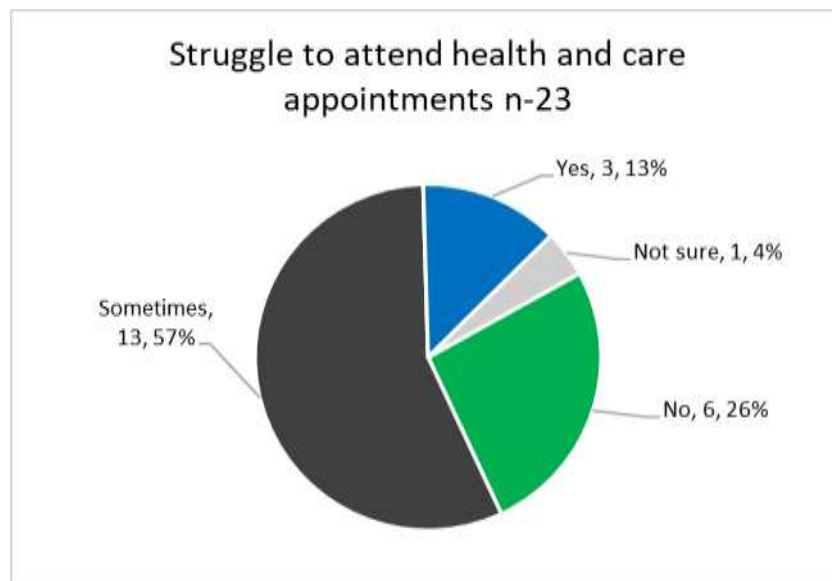
"As a Carer I have written articles and I support others using my experiences... I have been lucky enough to win an award for my group which is amazing so I suppose I am respected ... But many of us don't have a voice it's very very hard."

Not feeling valued

“I’m made to feel like I’m just unemployed and on benefits rather than caring for my poorly daughter.”

Access to healthcare

Do you struggle with attending health and care appointments because of your caring responsibilities, for example, seeing your GP?



We checked whether being a carer was also affecting ability to maintain health through related appointments.

As the chart above shows this did affect people 'sometimes'.

What would help you to access your own health and care appointments?

There were two areas that would help carers: More **flexibility** and more **cover for the person they care for**.

Flexibility

“More flexible times.”

“Priority booking, understanding that carers have less free time than most.”

“Late evening appointments would be better for me as I have family who can be here to take over the caring roll whilst I'm at any appointments.”

Cover for care

“Cover for my mother’s care.”

“Someone to help looking after the person I'm caring for.”

“Having someone to deputise for me.”

Where do you access information relevant to your caring role?

We heard that most people used the internet for information related to their role. There were a smaller number of people that referred directly to their social worker or services for information. There were also a number of respondents that did not access any relevant information at all.

Area	Responses
Online	Internet (4), friends (1), Social media networks (1), Various online platforms (1), Alzheimers.forum (1)
Directly from services	Local Authority social worker (1) <i>“Mostly social worker, however I only get they information after [I instigate] it.”</i> <i>“Only when in a crisis situation I reach out to MH services.”</i>
Local group	<i>“Bolton Carers support and peers.”</i>
Do not access information	(1) I don't (2), nowhere (2)

Respite

Are you able to access respite care for the person you care for?

Yes (3), No (13). Total 16.

The majority of people were unable to access respite care for the person they were caring for.

There were also a smaller number of people that selected 'Other (please specify)' (6). Within this, two people did not know about it, two did not want it, and two had faced difficulty either arranging the respite.

Though most comments here were not detailed one person said:

"Trying to sort respite care is a hard slog trying to find somewhere that has availability"

If you are not currently accessing respite care, what respite care would you like?

This was an open question, but the majority of responses (14) were variations on wanting some level of support to enable them to take time away from caring. In most cases this was something like a few hours a day or week:

"Someone to come for a few hours weekly."

"Someone to visit and check on my [daughter] while I was on holiday."

"Time for myself to do the things I enjoy. Would love a weekend away."

"2 or 3 days a month."

People did not therefore have a high demand for extra support, just to allow them a break here and there from their daily responsibilities.

Local groups

Do you access any local groups (not necessarily carer-specific)?

No (20), Yes (4). Total 24.

No respondents selected 'Not sure'.

When asked to elaborate the four respondents that selected 'yes', two respondents mentioned Bolton Carers Support and Asian Elders Resource Centre. One of the respondents mainly focused on fitness and crafts, but also talking therapy. Another respondent mentioned a group for older people.

What would make more local groups (e.g. support groups, libraries, leisure venues and facilities) more carer-friendly?

This was an open question and (17) people responded.

Whilst there were a range of responses, there were some key themes to highlight. One is the need for more diverse activities:

"It would be good if local groups offered more ethnically diverse activities."

We also heard a common theme around flexibility and responsiveness to carers needs:

"It would be good if there was more sessions where you can leave the person you care for, for an hour or so, so you can do the grocery shopping. I used to take my mum to a lovely group in Manchester but it's quite far to go for a few hours."

"Understanding, empathy, tolerance."

"Understanding carers needs."

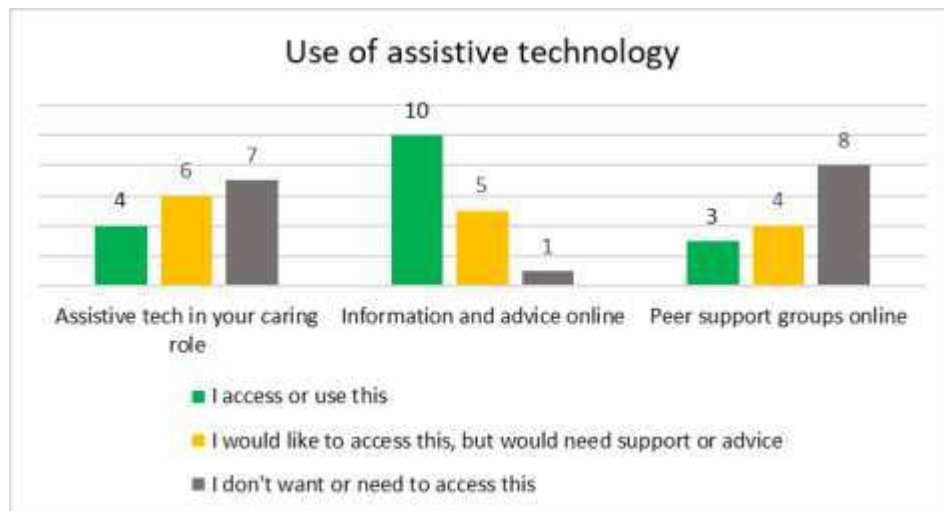
Some felt they didn't know what could be done or felt deflated by the experience:

"I guess there isn't much that can be done for people that can't get respite or if respite isn't suitable. Everyone tries, unfortunately the mark is always missed."

Assistive technology

Assistive technology is a device or system that helps you to do things in your everyday life such as medication reminders or systems that control different items around the home. Please tell us your thoughts on these.

We asked respondents some quantitative questions about their experience with assistive technology.



The chart shows that for those that access or use this type of support, it was technology for information and advice online that was most popular.

For those that would like to access but would need support or advice there was an even spread between the options of technology in caring role, information, and advice online, or peer support groups online.

Finally, regarding where assistive technology was not wanted, many selected in their caring role, or for peer support online.

The overall finding is that people were making most use of assistive technology for information or advice online. There was less desire for technology in their caring role, or for peer support groups.

Anything else?

If you had a magic wand, what would you wish for to make your caring role a little easier?

We asked a final more general question in case people had anything further to add. Some of the common themes are included below.

Making it easier

“Make processes easier for my son to get support.”

“Peer support , non-judgmental, tick box systems eradicated , simplified services ! I spent days/ months trying to sort Med/ prescriptions.”

"Support for those caring"

"Someone to check if everything was ok on a regular basis and tell me what help is available."

"A carer support worker to help navigate the benefit system."

"Carer Support Worker would be wonderful."

Respite and care support

"Easier access to and more availability of respite care."

"An increase in support in the home to allow more time for me"

"For my daughter to be able to be looked after by others and be happy and relaxed in their company."

Case study summary

A detailed case study of one carer is included in the appendix section. For ease of reading the whole text is placed there for readability.

In summary the case study illustrates some of the findings in the main report. Namely that isolation can come as an unexpected event and result in many years of new responsibilities for an individual or family.

The support of local groups is invaluable especially as navigating the health and care system is not simple; we heard Helping Hands in Bolton was one such place. That many care related services straddle the Local Authority and the NHS means it can be hard to know which is the right place to turn. Signposting by places such as Healthwatch Bolton and Bolton Carers Support can therefore play a part in helping people find support.

Final comments

The project has illustrated that unpaid carers face a range of challenges around their emotional reaction to caring long-term. Some of the reasons for these challenges might be many years spent caring, concern over the future, and

communication and difficulty understanding how related services for the person they care for work. We found access to respite was low, due to this not being well understood or not appropriate. Relatedly time away from caring was a key wish from carers.

We did not find strong evidence that carers were unable to access healthcare for themselves due to their role, but it did affect it somewhat.

Support groups were therefore important because they were easier to find out about and access.

Recommendations

Recommendations based on our findings.

- Regarding carer support, if there was easier more appropriate respite this might go some way to fulfilling the need for some time away from caring.
- Services should also continue to make their routes for referral and access easier to understand for carers. As much flexibility as possible would be supportive.
- GPs have already been encouraging patients to register as a carer and this should continue.
- Local groups offer a support system for those that access them. They should be supported to continue their work where possible.
- Technology was mainly used for the gathering information or advice. There might be ways that technology could be further explored to assist carers.

Acknowledgements

Our thanks go to the members of the public that have given their time to share their views. As ever this work could not be done without them.

Thanks to Bolton Clinical Commissioning Group, Bolton Carers Support, Bolton Dementia Support Group, Local Authority and Greater Manchester Mental Health Trust for their discussions prior to the project beginning.

We also had volunteer support on this project and would like to say thank you for this.

Appendix

Unpaid carer full list of questions

1. Do you see yourself as a unpaid/informal carer? (an unpaid/informal carer is anyone, including children and adults, who look after a family member, partner or friend who needs help because of their illness, frailty, disability, mental health condition or an addiction and cannot cope without their support)
2. What is your relationship to the person you provide care for?
3. How long have you been an unpaid/informal carer?
4. Have you told your GP practice that you are an unpaid carer. If not, please let them know.
5. Approximately how much time do you spend caring for someone each week?
6. As a carer, what feelings and emotions do you go through on a day-to-day basis? (please tick all that apply)
7. As a carer, what are your biggest frustrations?
8. As a carer, do you have any fears, worries, or concerns about the future?
9. What do you do to look after your physical and mental wellbeing? (please tick all that apply)
10. Do you do any of the following to help you cope?
11. Thinking about Q.9, are there any barriers that stop you doing the things to look after your physical and mental wellbeing?
12. Do you access any local groups (not necessarily carer-specific)?
13. Do you struggle with attending health and care appointments because of your caring responsibilities, for example, seeing your GP?

14. How valued do you feel your views and experience is as an unpaid carer?
(think about your contact with you GP, social care, health professionals)
15. Do you feel respected and listened to as a carer?
If yes then please tell us more
e.g. where you feel most respected and listened to.
16. What would help you to access your own health and care appointments?
17. Where do you access information relevant to your caring role? (e.g. Local Authority, support organisations, Citizens Advice, Healthwatch)
18. Assistive technology is a device or system that helps you to do things in your everyday life such as medication reminders or systems that control different items around the home. Please tell us your thoughts on these:
19. What would make more local groups (e.g. support groups, libraries, leisure venues and facilities) more carer-friendly?
20. Are you able to access respite care for the person you care for?
21. If you are not currently accessing respite care, what respite care would you like?
22. If you had a magic wand, what would you wish for to make your caring role a little easier? Eg. a carer support worker to be by my side on my journey)

Case study

Meena- (not her real name), identifies as an unpaid carer. For 23 years, she has been providing care for her daughter who is living with a severe and enduring mental health condition.

Do you see yourself as an unpaid carer? *“Yes, if you have some who is ill, you always think it is your responsibility to look after them. You do not always see yourself as a carer. A lot of genuine carers are missed because they do not recognise themselves as a carer.”*

Meena experiences a range of emotions on a daily basis. Caring gives her a sense of pride, satisfaction and contentment *“Over the last six/seven years, my daughter has a good quality of life. It’s all about giving someone the best quality of life. I am quite content knowing that I am doing whatever I can.”*

However, she also experiences anxiety, exhaustion, frustration, and hopelessness. Caring has also resulted in Meena losing her identity. She is grateful for her family support which helps combats feelings of loneliness. *“When things get difficult with her, I can feel really anxious. Paranoid schizophrenia is a distressing illness. People do not understand. They say my daughter is mad and look at how she is behaving. There is quite a lot of stigma around paranoid schizophrenia in the South Asian community. People see what is on the television about paranoid schizophrenia and they think my daughter is a danger. Things are getting better because of the community services. I am glad my daughter lives with me. We don’t leave her on her own. I have restricted my life quite a lot. It’s the nature of the illness. You do not know what they will get up to. I used to feel resentful and hopeless quite a lot when she was in and out of hospital. I would think ‘Is this going to be our life now? Initially, I felt really guilty. I thought ‘Where did I go wrong?’*

“I feel tired every day. I do motivate myself now. I do take her out. You must do things. Even if you are not well. Sometimes, I feel frustrated. I go into another room and let myself calm down.”

“One time I was an assertive, outgoing person. It’s because of isolation now. There are certain things we can’t do. We can’t mix with a lot of people. [However], I have a big family [This helps to reduce feelings of isolation and loneliness]. Initially, I struggled with my husband. He did not know anything about paranoid schizophrenia. Over the years he has a better understanding. We work together now.”

As a carer, Meena's biggest frustrations are:

Having to hit crisis before finding out about available support - *"It takes so long. It's passing the buck. Feel like I am being passed from one person to another. One time I had to sit with my daughter for two her days at home. At the time she had relapsed."*

Poor communication between services - *"It is poor. I've had this during Covid-19 pandemic. They [services] say they will ring you back. They don't even know if their own staff are in. GP surgery, receptionists – they should know if their staff are working."*

Lack of information - *"You go to the GP sometimes there's so much information scattered all over the place. If there was one leaflet with lots of important numbers for sources of help in Bolton. I think a small booklet with information numbers in it would be useful."*

What do you do to look after your physical and mental wellbeing?

"I joined Bolton Carers Support. They are very good. They provide a lot of functions for the carer and the person being cared for. There is no one in the house I can ask to sit with my daughter. Sometimes, I go to Bolton Carers Support and sometimes my husband goes. A lot of organisations do not provide space where you can go with the person you care for. I go to Asian Elders when they have carers events. I would like to spend more time with family and friends. It is always my daughter, my husband and me."

Do you do any of the following to help you cope? *"Sometimes I binge on unhealthier food."*

Are there any barriers that stop you doing things to look after your physical and mental wellbeing? *"Sometimes, if I want to join a class in the morning, I cannot leave my daughter on her own. There are a few things I cannot do."*

Do you struggle with attending health and care appointments because of your caring responsibilities? *"Yes, we have to juggle between my daughter and me. I was 60 years old that year I got ill. Since then my health has not been well."*

What would help you to access your own health and care appointments? *“For the past two years we have been having support workers to take my daughter out. It’s also a headache – if they do not come on time or if different support workers come.”*

Where do you access information relevant to your caring role? *“Bolton Carers Support. That’s where I found out about Healthwatch Bolton.”*

What would make more local groups more carer-friendly? *“Bolton Carers Support are really friendly. They speak to the person you are caring for. Some places do not talk to the person you are caring for. Bolton carers Support provide a safe environment.”*

Do you have any fears, worries, or concerns about the future? *“Yes, if you’re not there, who will look after the person you are caring for? Will it affect that person quite badly?”*

If you had a magic wand, what would you wish for to make your caring role a little easier?

“For my daughter to keep well. As long we get up every day and my daughter is fine and we can have a good day. It’s about having a good quality of life.”

Response from Bolton Hospitals NHS Foundation Trust

Thank you to everyone who took the time to share their views and experiences. The feedback will help us make changes that will make a difference to all those who dedicate their lives to supporting others.

The team of people who contribute towards a person's care expands far beyond the clinic room, hospital or doctor's surgery. Our carers are experts in what their loved ones need and bring a level of understanding that helps us to deliver person-centred care and treatment.

We know how difficult it can be to navigate services and are on a journey towards integrating health and social care services in Bolton to address this and make sure that everyone has access to the things that will help them to lead a healthier life for longer, no matter where they live in the borough.

There is always more we can do when it comes to evolving the services we provide so hope that our carers continue to speak up and work with us so we are able to shape our services around them.

Fiona Noden

Chief Executive, Bolton NHS Foundation Trust and Place Based Lead for Bolton

Response from Greater Manchester Integrated Care

It was good to see the contribution Primary Care and GP practices acknowledged in the report. The Primary Care Support and Development Team would like to assure carers that this agenda remains a key priority and will continue in the Bolton Quality Contract, specifically;

- Carers champion in every practice – usually a receptionist
- Primary Care Development team host 2/3 training events every year for the Champions
- Practices offer an annual health check to unpaid carers annually. This is comprehensive – includes aspects of physical health and discusses mental wellbeing
- Practices have a carers information board up in their waiting room

Lynda Helsby

Associate Director, Primary Care and Health Improvement – Bolton

NHS Greater Manchester Integrated Care

Response from Greater Manchester Mental Health NHS Foundation Trust

I completely support all the recommendations on page 23. Feedback from many carers I speak to (both anecdotally and through official channels) is often around lack of access to/knowledge around respite opportunities. I think this is particularly a challenge with mental health carers where the needs of the cared for can fluctuate quite dramatically.

Our revised Carer Information leaflets for our Bolton services reference how they can access local carer support through ourselves (carer support workers) and also local services (Bolton Carers Support) and I feel that staff can never promote this information enough.

Neil Grace

Lead for Service User and Carer Engagement



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