Carers Feedback

An insight into Carers experiences during the pandemic

February 2022

Contents

healthwatch
Warrington

Carers Feedback Event

Have your say about carers services and make your voice heard.

the Gateway, Sankey Street
WA1- 1SR
WEDNESDAY
8th September 2021
12pm-2pm

Book via Eventbrite or

✉ Contact@healthwatchwarrington.co.uk ☎ 01925 246 893

www.healthwatchwarrington.co.uk

Introduction

As part of the priorities for 2021/2022 a Carers theme was chosen by the public as an important issue for Warrington. Healthwatch Warrington arranged an event, to encourage feedback from Carers on how they dealt with the COVID-19 pandemic.

As an independent organisation, we gathered views via our website, Virtual Voices service and facilitated an event so Carers were able to attend the workshop physically.

Disclaimer

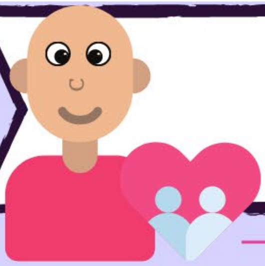
This report relates to our findings taken from the Carers Feedback Event ,Virtual Voices and a survey. Our report does not represent the experiences of all patients but only those who contributed by completing our survey.

Methodology

We held a feedback event for Carers to attend and share their experiences. Those who were not able to attend were sent copies of the questions for them to have their say.
We sent out some of the questions via our Virtual Voices, and had some feedback from PA's thanks to the support of Warrington Disability Partnership.

We asked six key questions:

1. Are there any services or support groups that have had a positive impact on you as a Carer. If so which ones? How did they make a difference?
2. What support do you feel would help you in your caring role?
3. Have you experienced any issues with respite? If so, what?
4. Do you feel isolated as a Carer? If so, what do you feel could be put in place to ease this?
5. As a Carer do you advocate for those you care for at medical appointments. If so let us know your experiences, what is good and what could be improved?
6. What issues with COVID-19 did you face / are still facing as a Carer?



Carers Event Feedback

healthwatch Warrington
YOUR health and social care champions

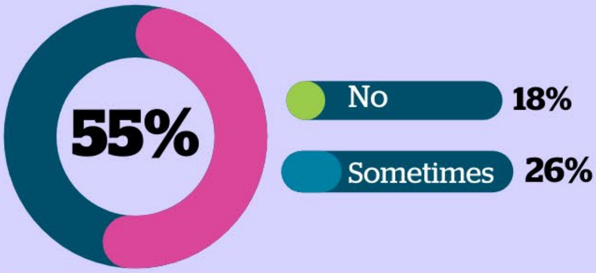
Services or support groups that have had a positive impact for carers

Support needed to help in a caring role

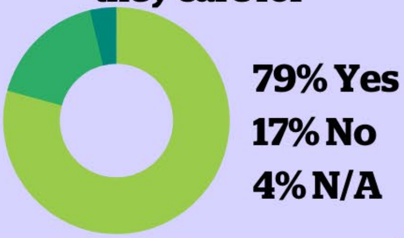
90% Agreed Respite Care was good- **WHEN** they could access it.

10% Carers viewed respite care as them personally failing at being a carer

Felt isolated as a carer

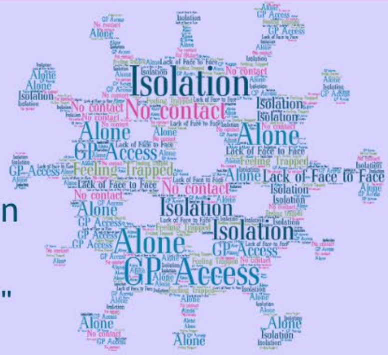


Advocate for those that they care for



Issues faced with Covid

"over reliance on digital communication"



Over half of those we spoke to hadn't taken part in the Carers Strategy

Findings

Are there any services or support groups that have had a positive impact on you as a Carer. If so which ones? How did they make a difference?

There were several organisations that were mentioned multiple times but the front runner was Warrington Disability Partnership. Others were:

- Wired Carers
- Walton Centre
- Stroke Association
- VTSS

What support do you feel would help you in your caring role?

The most common answer for this was *respite care*, many expressed that it was a struggle for them to find suitable care at a time that suited them. *"Difficult to access due to lack of accessibility for respite"* Lack of peer support due to the pandemic and a lack of social activities available for Carers to enjoy and know their loved ones were safe. *"more empathy and understanding ,extra peer support."*

We received a lot of feedback about the financial implications of being a Carer and how more funding is needed. *"peer support and better funding", "we only get one night of respite funded", "more money for Carers would really help and also help with transport"*

> *Financially we struggle, we alsio have to pay for a PA.*

Have you experienced any issues with respite? If so, what?

90% of those who answered the survey said that they had no issues with respite WHEN they could book it. Many Carers we spoke to only had 1 night funded and couldn't afford to pay for any extra. Others said that being able to block book beds for respite would help. *"Short timescales"* for booking and there isn't much availability *"Yes , although the service is amazing I have to book too far in advance , If I have an emergency I am lost?" "Service is great just cannot do anything at short notice ,my husband needs full time care"* Many respite places are not in Warrington. *"Access and only funded for one night and most are out of Warrington so I have to travel" there"*

> *Ad hoc support does not exist in Warrington we need some action*

The pandemic and ever-changing guidelines stopped Carers being able to plan- *"Not knowing what to expect and how to plan for respite, government restrictions are so confusing"*

10% of respondents said that they felt a stigma about Respite care

"There can be a stigma around leaving your loved one in respite". several people commented that they have never used it but didn't go into detail.

> *No I have never used it, I would feel like a failure*

Do you feel isolated as a Carer? If so, what do you feel could be put in place to ease this?

55% of respondents say that they felt isolated being a Carer and this isolation only got worse during the pandemic. 26% said they sometimes feel isolated.

> *You feel you are on your own and just have to get on with it because all services are so stretched. Having more support outside of working hours for Carers would be useful*

The common theme in response to this question was that Carers would like more contact from organisations to check on their wellbeing. *"Yes , would help if we had more sitting services and befriending"* More befriending services and social gatherings would help with the **"Carers strain"** *"Yes - would be good to get welfare calls"*

> *Carers strain can be an issue at times*

As a Carer do you advocate for those you care for at medical appointments. If so let us know your experiences, what is good and what could be improved?

79% of those that responded said that they were an advocate at appointments, the majority of those were happy and found that doctors and consultants were understanding and supportive of them advocating, 17% said that they didn't advocate due to the person they care for having capacity, access to a worker to support them or just support with transportation to the appointment.

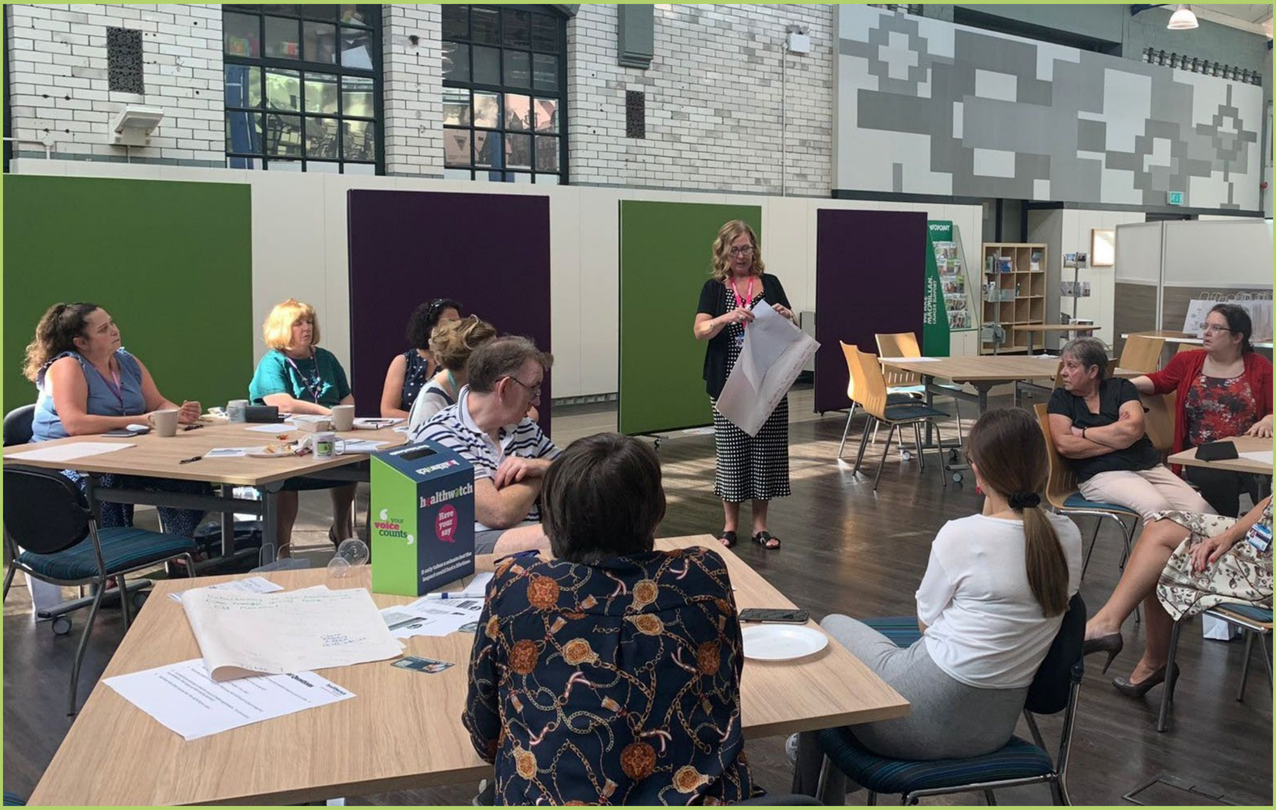
Comments were made regarding availability of appointments for Carers, and appointments being too short for those who need support. *"Need more flexibility for Carers appts" "Yes, they need to ensure that there is no doubt about a Carers presence at medical appointments."*

> Time available needs to be increased for patient and Carer

What issues with COVID-19 did you face / are still facing as a Carer?

The main themes that arose from this question was an *"Over reliance on digital communication"* and a *"Lack of communication unless asked for"*
Carers felt isolated more than usual and *"Unsupported, due to the restrictions, none of the groups dad went to were on, also family members who had been supportive before COVID-19 took a step back"*
One parent who cares for their child commented *"No respite and that is hard to explain to a younger person"*
Many Carers who answered our survey or joined in the discussion at our feedback session missed access to services. Many used the Contact Centre and felt frustrated that these were still not open but clubs and shops were.

> *From a service prospective there are a lot of strategies but there is a lack of funds to do it*



Conclusion

The feedback from our event and information we received virtually through our Virtual Voices panel and our website, described a large range of views from Carers. These included a lack of respite care in Warrington, availability in an emergency and a lack of funding for Carers to access respite care. There is also a stigma around using respite for a small group of Carers who feel that accessing this would make them seem like a failure.

Carers felt isolated and alone as many of their activities and support to feel connected were cancelled due to the pandemic. A consensus was that Carers wanted more befriending services and wellbeing checks or even a simple welfare check would help them to feel heard and less isolated. They felt that Carers Strain was a big issue.

At Healthwatch we work in partnership with Warrington Borough Council Social Care, and attend the Carers Partnership Board. This report will be shared with the local authority, so it will complement the ongoing work for the Warrington Carers Strategy.

Recommendations will also be discussed. We would like to take this opportunity to thank all the Carers and their families for their vital participation, and also our partners who enabled feedback.

Recommendations

1 Summary report to be shared at with WBC Social Care and shared with the Carers Partnership Board

2 Healthwatch Warrington to continue to attend the Carers Partnership Board

3 Healthwatch Warrington can offer ongoing dialogue with Carers and can share messages with partners via social media.

With Thanks

Thank you to all the Carers that contributed to our surveys and feedback event, as well as Wired Carers and Warrington Disability Partnership.

Comments

What support do you feel would help you in your caring role?

- Weekly checks to see how I am coping
- More support from social care, I worked and looked after my dad without any help or input until his condition deteriorated
- Uncertain at the moment but time will tell as the situation progresses. However, I appreciate the inclusion in the e-mail shots which come out from Sarah allowing me to select what I want to opt into.
- More support from Macmillan , emailed them 3 times for family supoort - no reply
- More interaction with other Carers
- Respite - at short notice for emergencies
- Peer support and agencies with more empathy
- It is difficult to plan in advance as the timescales were limited
- Peer support and the Contact Center open again
- With Warrington Community living
- More empathy and understanding, extra peer support
- More peer support groups and befriending service
- More day care options
- More lived experience groups
- I am in supported living
- Face to Face support again ,that was our only outing
- Being able to block book beds for respite
- We only get one night of respite funded
- More wellbeing checks
- Financially we struggle, we also have to pay for a PA
- Healthwatch - public events where your face is heard
- Care Co Ordinator's
- Information can be hit and miss
- More activity sessions (fun ones)
- Telephone befriending service
- There is a gap , need more care Co-ordinator's in services
- More small grants to be made available to small groups for activities
- More activities and empathy from services
- More disability advisors ,CAB are great but its a national line so long waiting times
- More support from Carers services
- More social activities
- Peer support and better funding
- More money for Carers would really help and also help with transport
- Difficult to access due to lack of accessibility for respite

Comments

Have you experienced any issues with respite? If so,what?

- There can be a stigma around leaving your loved one in respite
- Yes - timescales are ridiculous, I cannot book in advance
- Yes, they stopped doing respite where my husband used to go and now the new place will only book a few weeks in advance making it so difficult for me to plan anything far in advance
- Yes - access and only funded for one night and most are out of Warrington so I have to travel there

Do you feel isolated as a Carer? If so, what do you feel could be put in place to ease this?

- More contact with social workers ,anyone really
- Yes, you feel you are on your own and just have to get on with it because all services are so stretched. Having more support out of working hours for working Carers would be useful
- As a Carer yes. My neighbours are very good though.
- Regular phone calls would really help with this ,just knowing that someone was there to listen and face to face support
- Sometimes ,but I have great family and friends
- Yes, I cannot visit the Contact Centre but all the charities are operating I am not good on the phone I want to speak to someone in person
- All Carers feel isolated , even with family, as it is 24 - 7 . With my daughter respite was the only thing that kept me sane at times to meet friends for a coffee etc
- No I have good family and friends
- Yes , would help if we had more sitting services and befriending
- To raise awareness
- In supported living it was hard to be in all the time
- Yes we both do at times and no face to face makes it difficult
- Yes - would be good to get welfare calls
- Yes more support from local authority for young people that are being cared for
- Yes
- More social activities for both the Carers and person being cared for
- I have close friends that help
- Yes ,more social groups not just information sessions
- Carers strain can be an issue at times
- More Care Co-ordinator's in services
- Yes - more social gatherings fully accessible
- Yes, especially if you do not use technology well
- I have a very strong support group but i know others that don’t

Comments

As a Carer do you advocate for those you care for at medical appointments. If so let us know your experiences, what is good and what could be improved?

- Help with wheelchair plus checking how I am
- Yes, on most occasions I could advocate for my dad but some consultants insisted on speaking direct to him, despite me advising he is very deaf, he often came out of the appointment confused and I then had to discuss and explain to him what was happening. I appreciate confidentiality but when a patient is deaf and has dementia it is invariably the Carer who has the insight into the patients condition
- Yes. The need to ensure that there is no doubt about a Carers presence at medical appointments.
- Yes – E-consult appts and on phone
- Our doctor is amazing ,they are under immense pressure they are a credit to the NHS
- Yes I do and our GP at Guardian St is fantastic
- I do and it is very good
- No I attend with her
- Yes she is under 16 - they are amazing
- No he still has capacity
- Our doctor is very good but the entrance for Stockton Heath is difficult to navigate in a mobilized scooter
- I have a worker that comes with me so I can understand
- I just need support to get him there
- Need more flexibility for Carers appts
- Time available, needs to be increased for patient and Carer
- Yes she is under 16 , GP and specialist very good
- Yes and physical accessibility can be an issue
- Yes - GP access since COVID has been difficult
- Information and advice could be improved
- Yes more advice about what is available as a Carer
- Would like to return to face to face appts
- More social activities and peer support
- Yes - our specialist is great
- School could be more understanding, I feel so guilty that there are days I struggle to get him to school , a taxi service would be great but my condition is not deemed serious enough to warrant this
- Yes, better access for us
- Yes, difficulty getting through to our GP
- Our GP is excellent - Guardian Medical Centre
- Yes - difficult to get appointments due to COVID

Comments

What Issues with COVID-19 did you face / are still facing as a Carer?

- No contact unless I ask for it -no phone calls
- Feeling isolated and unsupported, due to the restrictions none of the group's dad went to were on, also family members who had been supportive before COVID 19 took a step back, therefore if they usually took him out for a few hours to give me a break, this stopped happening.
- None.
- All social and care services are stretched this .has made it hard for them and us as Carers
- Like everyone, I felt isolated and missed my grandchildren and the support I normally have
- Many, he does not understand that we can't go to our classes and day trips which he loved
- Access to services and the feeling of being trapped
- At least we did not get COVID but we did feel very alone without family
- I am lucky she has some mobility so we could get out but she missed her friends terribly
- Would like to be out and about more
- Feeling alone without my family
- Contact Centre not open so cannot speak to anyone face to face
- Being away from family and friends
- Why can nightclubs be open but the Contact Centre is not? Not everyone wants to speak online or a phone
- We had all of our activities apart from our daily walk stopped
- All services are stretched due to COVID
- From a service prospective there are a lot of strategies but there is a lack of funds to do it
- Lack of face to face appts
- No respite and that is hard to explain to a younger person
- Missing the support I normally receive
- Same as everyone I found it difficult
- Access to the activities that we used to frequent
- I miss the support and groups
- Alone
- Missing loved ones
- There is over reliance on digital communications
- Isolation missing grandchildren
- Missing our social activities
- Loss of friends and fear for my husband
- Isolation and struggling to keep healthy
- Homeschooling was so difficult , I felt like he was falling behind
- Not knowing what to expect and how to plan for respite, government restrictions are so confusing
- Isolation and missing peer support, I don't do Zoom
- Same as so many feeling low and not knowing what is going to happen in next few months
- Not knowing whether to plan anything with restrictions
- Access to services - Contact Center still closed

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