

Experiences of COVID-19 information and support in Norfolk and Waveney

Summary of the experiences of carers and cared-for
July 2020

Overview

About Healthwatch Norfolk

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather the views of local residents about health and social care services to ensure they are heard by the people responsible for commissioning and providing services.

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About the survey

We have been working with Norfolk health and social care organisations to look into residents' experiences of accessing information and support during the COVID-19 (coronavirus) outbreak in the UK. It was felt that the best way to collect this feedback would be through a survey, which was launched on 16th April 2020 and ran until 13th July 2020.

Every two weeks, survey results were compiled and shared with other partners, NHS trusts, and clinical commissioners. These reports can be found [on our website](#).

The aim of the survey was to gather constructive information from service users that might provide real-time insight into community need, experience and awareness of available support.

About this report

The final total for full, completed responses to the survey was 607. The report detailing all responses is available [on our website](#).

Of the total, 133 people told us they are carers. Of these, 50 carers answered the survey about the person that they care for.

This report mainly focuses on carers' responses relating to the experiences of the person they care for.

Results

Who answered the survey

- Two-thirds of respondents (33, 66%) care for a person aged 66 or above.
- Twenty-two respondents told us that the person they care for has a disability, however 16 respondents did not answer this question about disability.
- Nearly three quarters of respondents (37, 74%) told us that the person they care for was advised to self-isolate for at least 12 weeks because they are at risk due to a long term condition, are over 70, or for other health related reasons.

Practical support

Of those who were self-isolating and receiving practical support, the most common form of practical support came from the council with 7 respondents telling us that the council had provided support for the person they care for.

All respondents who have received care through the council told us that they were very satisfied or satisfied with the support. Suggestions for support which was not received but would be useful are below:

“What we need is ongoing support when and if the COVID crisis ends. Ongoing befriending service would be good and support with occasional DIY etc around the house.”

“An informative pamphlet including an identified contact name and number with simple points about what to do in an emergency and the help that is available would have been useful. In addition to shopping and ensuring bills are paid, I have liaised and monitored re. health issues and in particular, medication and have had to make the enquiries myself with health services. It wasn't clear what could be available in terms of food supplies and house repairs once the letter from the Clinical Commissioning Group had been received.”

Information about coronavirus

Respondents told us that the person they care for has found out information most commonly from television broadcasts (33, 66%) and through themselves as their carer (28, 56%).

The most common format which respondents would have preferred the person they care for to receive COVID-19 information was through a personal letter (32, 64%). This differs from the other survey respondents where only 13% of respondents told us their preferred option was a personal letter.

Respondents were asked what extra information or guidance would be beneficial, responses included:

- Wanting more information about “*what help is available*”, including “*how to obtain prescriptions from the pharmacy*” and “*how to access food*”.
- Two respondents mentioned a lack of information about how to support the mental health of the people they care for. One highlighted that “*it has not been made clear how a person with a severe mental illness can keep mentally and physically healthy in this unprecedented situation*”. The other told us that they “*have been able to keep mum updated and isolated but not been able to deal with the resulting depression and sence [sic] of giving up*”. One respondent indicated the difficulties in trying to explain the current situation to the person they care for: “*The person I care for has dementia so there is no understanding of what coronavirus is*”.

Appointments

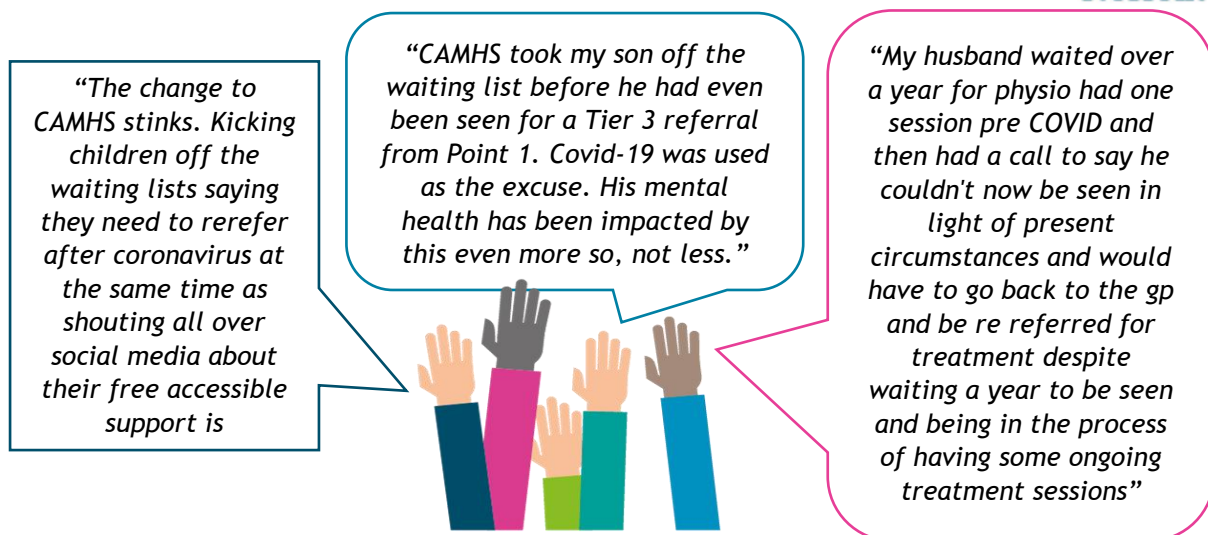
Regarding access to appointments and treatment, the most positive experiences related to GP appointments and pharmacies.

Two respondents told us of concerns with homecare. One respondent told us the person they care for “*has care at home from care company organised through the social services. Carers have NOT had appropriate PPE*” while another respondent told us that the “*home carer didn’t wash her hands*”.

The comment below illustrates how early appointments to reduce coronavirus risk may make it difficult to attend.

“The arrangements were good in that they separated people who are receiving routine treatment from patients with potential Covid-19. However, these ‘clean’ appointments are first thing in the morning. The timing makes sense in terms of logistics, but it is not easy if you need to get someone who is very frail and takes time to get up there.”

Respondents also told us how COVID-19 has made it “*very difficult to talk to a medical professional about ongoing conditions and it has felt as if everything has been pushed to one side because of coronavirus*”. Examples given by carers about the person they care for are presented below:

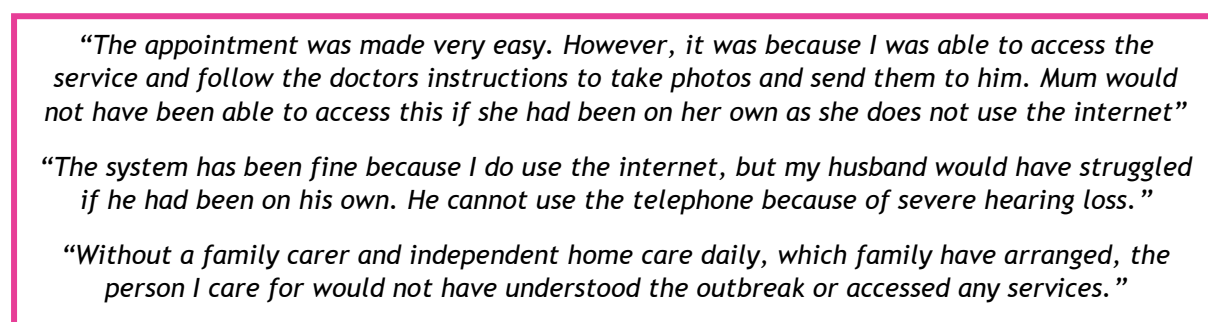


Using technology

Many respondents (30, 60%) told us that the person they care for currently uses the internet. However, this is a much lower proportion when compared to carers and non-carers who answered the survey themselves, where 95% of respondents told us they use the internet.

Consequently, several carers told us that *“not all individuals have access to on line or understand how to use it”* or that *“the individual I am main carer for cannot use modern technology”*.

Concerns were expressed about how these people would cope with using technology if they did not have a carer as illustrated below:



Support and shielding for vulnerable people

Respondents told us that there was some confusion around who should be shielding and that this could have an impact on wellbeing. One respondent told us that they would like *“an explanation of how the government system for assessing vulnerability works”*. Another carer was concerned that because their *“mum was not identified by anyone as needing shielding”* she only *“received one phone call late on into isolation”* and expressed concerns for *“other elderly in the borough”* who do not have family or friends to support them.

Some respondents told us that they believed the person they care for should have received practical support but that this did not materialise for them.



Finally, one carer told us that they would like support to continue in the future and that they “*would benefit from having regular contact with someone after virus - rather than being left as happened prior to virus*”.

Lack of support for carers themselves

Based on the feedback from all 133 carers who answered the survey, there was a feeling of lack of support for carers.

Some carers told us they felt “*abandoned*” and “*unsupported*”, with one respondent asking “*who looks after the carers!*”. Below are some comments expanding on these themes:

“As my husband's carer I'm very concerned about his numerous health problems and sometimes feel overwhelmed and a bit isolated by it all and feel as we are elderly don't really matter.”

“Caring is new to me following my wife having an operation and as well as full time working I found it increasingly difficult to do both. Whilst my wife was having conversations over operation and recovery there was no conversation with me the person that would be caring during the time in recovery”

“One call from a person in the social workers office but not the social worker, asked if there was a contingency plan if I became ill and could no longer be a carer, I said no and the caller laughed, in fact giggled throughout the conversation, disgraceful!”

“I feel unsupported as a carer as my physical burden of caring for a very disabled husband isn't mentioned”