

The Impact on Unpaid Carers - Living with Coronavirus/Covid-19.
December 2020 - March 2021.



Summary

Healthwatch Stockton-on-Tees have engaged with local unpaid carers to find out their views and experiences of the Coronavirus/COVID-19 pandemic, and how this has impacted on their lives and their health and wellbeing. Engagement with Healthwatch champions, volunteers, and carers support services in the local area have enabled us to contact carers. Eleven carers provided case studies and an additional twenty carers completed the survey.

The overall findings of this engagement, based on what carers have told us, show that:

- The Coronavirus/COVID-19 pandemic has had a profound impact on the mental health and wellbeing of unpaid carers. This has been the result of changes to the support and contact from health and social care services and the demands of the caring role. Attempts to navigate the social care system and concerns about the welfare of the person that they are caring for has also had a negative impact on the mental health of carers.
- Additional factors impacting on the mental health and wellbeing of carers have been identified.
- Carers have had positive experiences of health and social care services and have valued the communication, regular contact and the quality of care that those services have provided.
- Visiting restrictions at some of the care homes in the Stockton-on-Tees area have been confusing and conflicting. Facilitation of contact and communication at some care homes has been lacking, leaving carers feeling worried and helpless, and not knowing if their loved one is well.
- It is important that carers have regular contact with health and social care services to help support those that they are caring for. Carers need to feel valued, and it is important that they have someone to talk to.
- Receiving support and information from local services has helped carers cope day-to-day.
- Carers need support and guidance, with information that is easy and clear to understand, and to know that there are a range of support services (especially mental health services) available to them and the person that they are caring for.

Based on the findings, the following recommendations have been made:

1. Ensure that carers are able to take breaks and that the return of essential services is prioritised.
2. Place high priority on guidance, information and advice for carers that is adapted to their needs.
3. Prioritise carers health and wellbeing and deliver targeted mental health for carers and those that they care for.

4. Provide more guidance to care homes in relation to visiting policies, and to ensure priority in facilitating contact and communication between carers and those that they care for.
5. Delivery of healthcare appointments that take into account the different communication needs of carers.
6. Health and Social Care Services to provide appropriate and regular contact and communication with carers to support them in their caring role.

Introduction

Local Healthwatch have been set up across England to create a strong, independent consumer champion with the aim to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs.
- Support people to find the right health and social care services for them by providing appropriate information, advice and signposting.

Healthwatch Stockton-on-Tees works with local people, patients, service users, carers, community groups, organisations, service providers and commissioners to get the best out of local health and social care services. This doesn't just mean improving services today but influencing and shaping services to meet the needs of the local communities tomorrow.

Healthwatch Stockton-on-Tees is steered by a Board of volunteers, commissioned by the Local Authority and accountable to the public. Healthwatch Stockton-on-Tees are the only non-statutory body whose sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak-out on their behalf. The service is managed by Pioneering Care Partnership, a leading third-sector charitable organisation aiming to improve health, wellbeing and learning for all.

Healthwatch has:

The statutory right to be listened to:

- Providers and Commissioners must respond to Healthwatch within 20 days of submission of requests for information or reports.
- The statutory power to Enter & View publicly funded health and social care services.
- A statutory seat on the Health and Wellbeing Board.

Background and Methodology:

In April 2020, Healthwatch Stockton-on-Tees engaged with local people to find out their views and experiences of the Coronavirus/COVID-19 pandemic, and how this impacted on their lives and their mental health and wellbeing. Unpaid carers told us that their mental health had been affected due to the demands of their caring role and their worries and concerns about the wellbeing of those that they are caring for.

In October 2020, Carers UK published a report based on their research into the continued impact of the coronavirus (COVID-19) pandemic on unpaid carers (Caring behind closed doors: six months on). The findings show that:

- In April 2020, 70% of carers were providing more care than before the COVID-19 pandemic. In October 2020, 81% of carers were providing more care. Carers reported that this was due to the increase in needs of the person that they care for and local services reducing or closing.
- Almost two-thirds of carers say that their mental health has worsened as a result of the COVID-19 pandemic.
- Almost two-thirds of carers have not been able to take any breaks from their caring role during the COVID-19 pandemic.
- Carers are struggling to continue care and are reporting high levels of fatigue and stress, with almost three quarters reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.
- Nearly half of carers say they are reaching breaking point.
- Carers were already seven times more likely to be lonely than the average person, and recent restrictions and shielding have stripped away the support networks carers have, leaving many feeling isolated.

During the Coronavirus/COVID-19 pandemic, carers support services within the Stockton-on-Tees area have highlighted a range of difficulties that unpaid carers have been experiencing. In December 2020 - March 2021, Healthwatch Stockton-on-Tees have engaged with unpaid carers to further ascertain their views and experiences of their own mental health and wellbeing during the pandemic.

The engagement has been supported by the local Healthwatch Champions and volunteers and the following local carers support services:

- Teesside Dementia Link Service (TDLS)
- Eastern Ravens Trust
- 'Finding Me' group (Catalyst)
- The Dementia Hub
- Stockton Carers Support Service
- Age UK

A mixed methods approach to contacts with carers has taken into account the diversity of communication needs and contact preferences of carers throughout this engagement. Carers have responded with written narratives/case studies.

Surveys were also provided to those carers who have had contact with TDLS. Carers that have provided us with their contact number as part of their case study/narratives have been contacted via telephone. This has enabled us to provide clarification of how their narratives will be used, for what purpose, and to provide carers with the opportunity to expand on their narratives if they wish. Where appropriate, relevant signposting and information has been provided to carers.

Healthwatch Stockton-on-Tees received eleven case study narratives and twenty survey responses from carers. The total responses provided within the findings of this report relate to the twenty survey responses. However, based on what carers have told us, the case study sentiment themes and narratives have been used to highlight the findings of the surveys. This has enabled us to identify what has been working well and areas for improvement in relation to; carers mental health and wellbeing, communication and contact with health and social care services, and guidance and support for carers during the pandemic.

The information provided has supported us to make recommendations based on our findings, with the aim to better support the health and wellbeing of carers within Stockton-on-Tees.

Findings

Q1. Has your mental health and wellbeing been affected by the Coronavirus/Covid-19 pandemic?

Seventeen carers answered 'yes'. Carers have told us that they experience depression and low mood, stress and anxiety, exhaustion, loneliness, loss, abandonment, crying, lack of confidence and emotional difficulties.

Carers were asked if they would like to share more about their experiences of this. Carers told us that their mental health and wellbeing had been affected due to:

- The demands of the caring role.
- Reduced access to support services.
- Not being able to receive the usual support from family and friends.
- Isolation.
- Lack of communication.
- Feeling that no one cares.
- Not being able to get a break.
- Disturbed sleep.
- The loss of a loved one that they had once cared for.
- Not being able to see the person they care for at their nursing home and knowing that they are declining or experiencing distress.
- The fear that the person they care for will hurt themselves.
- The fear of the breakdown in relationships with care staff impacting on the vital care of their loved one.
- Attempting to navigate the social care system.
- Having to fight to try and get any kind of support.
- Lack of mental health support for the person that they are caring for.

'depression and worry, not being able to sleep. Everything has been turned upside down'

Q2. If your mental health and wellbeing have been affected, are you now receiving the support you need?

Eight carers told us that they are not receiving the support they need. Carers told us that they *'don't know which way to turn'* and that they *'need someone to guide'* them to where it is that they can get the help and support they need.

Nine carers told us that they're receiving the support they need from:

- The Teesside Dementia Link Service (TDLS) with regular phone calls/chats, garden visits and monthly craft packs.
- Mark and Gail providing the TDLS are both *'friendly', 'supportive'* and *'caring'*.
- Zoom quizzes from the Dementia Hub.

- Going out for walks with the Teesside Dementia Group.
- Medication deliveries from the Pharmacy.
- Supportive family members.
- Having a support bubble with someone who can offer a welcomed break from caring.
- Delivery of meals from 'Parsley Box'. They are 'inexpensive' and 'nice to eat'.

Q3. Have you found it easy to find clear and understandable information to help you with your own mental health and wellbeing?

Ten carers answered 'Yes'. Carers told us that their main sources of information were from:

- Online resources from TDLS.
- The Memory Clinic.
- The Dementia Hub.
- Publications from the Alzheimer's Society.
- Communicating with others whilst out walking with the Teesside Dementia Group.
- Phone contact with the GP.
- Regular 'Digital what's on' emails.

Ten carers told us that they had not found it easy to find clear and understandable information to help with their own mental health and wellbeing. Several carers have expressed frustration at being told to 'look after yourself' when their time and resources are needed to care for another. Carers have reported that they have not received information when they have needed it and that 'everything is very complicated'.

Q4. Has your health for other conditions been affected by the pandemic?

Eleven carers answered 'yes'

Carers were asked if they would like to share more about this.

Carers have told us that they have experienced:

- An increase in panic attacks.
- Stress and discomfort in joints and legs due to reduced physical activity and not having the support to exercise or eat properly.
- Loneliness and isolation effecting physical health.
- Worsening symptoms of lung disease due to increase time spent indoors with heating on.
- Difficulties in being able to speak to a Doctor about their health conditions.
- Poor sleep.

- Not being able to get a Chiropodist or dentist appointment when needed.

Q5. Has your experience of health and social care services been affected by the pandemic?

Thirteen carers have said that their experiences of health and social care services have been affected by the pandemic. Responses include not being able to access community support services when they have been needed, changes to the way medical appointments are being carried out and changes to how their pre-existing health conditions are being managed.

'I think sometimes you feel yourself abandoned by Doctors and Hospitals. My existing health conditions are not being monitored.'

'I've found it very difficult to get through on the phone to the memory clinic. I resorted to email but it was a slow response.'

'I've found it difficult getting appointments for doctors and dentists.'

'Virtual appointments work fairly well but they're not as good as face-to-face appointments.'

'I don't feel that I'm getting what I need through phone call appointments.'

'Feeling down and not being able to speak to my own doctor.'

Carers have also told us about care home restrictions and the effect that they feel this has had on themselves and those that they care for. Carers have expressed helplessness in relation to confusing and conflicting care home restrictions and worry that their loved ones are **'suffering'** and **'declining'** as a result of these restrictions. Carers have reported that part of this confusion has come from the cancelation of window and outside visits at some of the care homes within the Stockton-on-Tees area.

'I was told by Willow View that I couldn't go to see my Dad through the window as they didn't want people traveling to the care home. But I live in the same area?'

Carers have told us that they feel a **'loss of control'**, **'disempowered'**, **'disconnected'** and **'emotionally debilitated'** in relation to the wellbeing of the person they care for and the confusing visiting restrictions of their care home. Carers felt that not enough had been done by the care home to facilitate contact with their loved ones.

'Not so good care received from social worker and care home - felt this was very sad. My husband ended up back in hospital where he sadly died.'

'Missing my partner and not being able to support him makes me stressed in case he isn't ok.'

Carers have also shared positive experiences of health and social care services during the pandemic:

'The receptionists at Arrival Practice have been exceptional. They've made regular contact with me during the week to see if my wife is ok which has been a big help.'

'My Mam lives at Teesdale Lodge Nursing home. The staff there are professional, friendly, kind and caring and we know that they have mam's best interest at the forefront of her care. We have regular outside window visits, and we sleep peacefully knowing that our mam is in safe and good hands.'

'In the earlier days, the social worker from the adult mental health team was phenomenal, she went above and beyond to help my mum and to support us.'

'My Grandad has been seriously ill with Covid in North Tees Hospital for 3 months, now recuperating at home. Staff in hospital were absolutely fantastic, they really worked hard, couldn't fault them and couldn't thank them enough.'

'My husband had dementia, if it hadn't been for the support from Teesside Dementia Link Services, especially Gail Walker, I don't know what I would have done. I thank them from the bottom of my heart.'

Q6. Has there been anything that has helped you cope day-to-day?

Eighteen carers answered 'yes'. The following responses were provided:

- The support and help from staff at Lustrum Vale, the Dementia Hub (including online contact), the Citizens Advice Team, the online 'Finding Me' group, and the Intensive Community Liaison Team.
- Regular support and contact with Gail and Mark from TDLS - including the delivery of carer packs and activity packs, delicious goodies and their Facebook chat page.
- Supportive family, friends and neighbours.
- Exercise and being able to go out for walks when the weather is nice.
- TV, puzzle books, crafts and making things for charity.
- Talking to loved ones on the telephone and via video call.
- Support bubbles

Q7. Is there any other way that you feel that your health care or wellbeing has been affected by the coronavirus?

Fifteen carers answered 'yes'. Carers told us that this was due to:

- The stress of not being able to see a loved one in nursing home and not knowing if they are ok.

- The stress of caring for a family member under government guidelines for keeping safe.
- Not feeling as though they are allowed to contact doctors due to pandemic.
- Grieving the death of a loved one and not being able to see family and friends.
- A lack of contact and support.

Q8. Is there any other support, information and/or self-help resources that you feel you may need to help keep yourself well and health in the future?

Thirteen carers answered 'yes'. Carers have told us that that it is important to them that they have regular contact with health and social care services and to know that there is a range support out there for themselves and the person that they are caring for when they need it. Carers have told us that they need to feel valued, and it is important that they have someone to talk to.

'I do understand that we have never been in this position before, but please don't shut us out, no help, no support, no services, no one to talk to. Thank god for Teesside Dementia Link.'

'Don't leave as all behind.'

'Any support would be gratefully received'.

Carers have also reported feeling stressed and anxious due to those that they are caring for not getting the mental health support they need:

'My son was referred to Impact in June/July 2020 - we still haven't heard anything. My son thinks that they have not bothered and forgotten him. It would have been helpful to have regular phone calls or just someone to say what is happening.'

Summary of Findings:

Mental Health and Wellbeing

Over three-quarters of carers have told us that their mental health and wellbeing has been affected by the pandemic with an increase in feelings of depression and low mood, stress and anxiety, panic, exhaustion, loneliness, loss, abandonment, crying, lack of confidence and emotional difficulties.

Carers have told us that the changes to the support and contact from health and social care services and the demands of the caring role have left them feeling under pressure and exhausted. Carers have also reported that attempts to navigate the social care system and concerns about the welfare of the person that they are caring for has had a negative impact on their mental health and wellbeing.

Additional factors impacting on the health and wellbeing of carers:

- The stress of not being able to see their loved one in their care home and not knowing if they are ok.
- Lack of communication with others.
- Isolation.
- Feeling that no one cares.
- Not being able to receive the usual support from family and friends.
- Difficulties in being able to speak to a Doctor about their health conditions/not feeling that they are allowed to see a Doctor due to the pandemic.
- Changes to the way medical appointments are being carried out and changes to how their pre-existing health conditions are being managed.
- Not being able to access Dentists/Chiropractors when needed.
- Not having the time or resources to be able to look after themselves.
- Lack of sleep.

Communication and contact with Health and Social Care Services:

Carers who have shared positive experiences value the regular phone contact with health and social care services. Carers value the facilitation of contact and communication with those that they care for in their nursing home. Carers have also been able to see those that they care for receive good quality care from health and social care staff.

Carers have spoken about the difficulties of care home restrictions and how this has had a negative impact on their mental health and wellbeing. Carers have told us that some care home restrictions have been confusing and conflicting. Carers have reported a lack of clarity in relation to the cancellation of window visits by some care homes within the Stockton-on-Tees area. Carers have felt that not enough has been done by some care homes to facilitate contact with their loved ones and that they do not know if their loved one is ok and receiving quality care.

Carers have told us that it is important that they have regular contact with health and social care services to help support those that they are caring for. Carers have told us that they need to feel valued, and it is important that they have someone to talk to.

Guidance and Support

Half of carers have told us that receiving support and information from local services has helped them cope-day-today. However, half of carers have also told us that they are not receiving the support they need. Carers have reported that they need guidance and information that is easy and clear to understand and to know that there are a range of support services (especially mental health services) available to them and the person that they are caring for.

Recommendations:

Recommendation Number	Recommendation	Responsible body	Comments
1	Ensure that carers are able to take breaks and that the return of essential services are prioritised.	<ul style="list-style-type: none"> • Stockton-on-Tees Borough Council 	
2	Place high priority on guidance, information and advice for carers that is adapted to their needs.	<ul style="list-style-type: none"> • Stockton-on-Tees Borough Council • NHS Tees Valleys CCG • North Tees and Hartlepool NHS Foundation Trust 	
3	Prioritise carers health and wellbeing and deliver targeted mental health for carers and those that they care for.	<ul style="list-style-type: none"> • North Tees and Hartlepool NHS Foundation Trust • NHS Tees Valleys CCG • Tees Esk & Wear Valleys Foundation Trust 	
4	Provide more guidance to care homes in relation to visiting policies, and to ensure priority in facilitating contact and communication	<ul style="list-style-type: none"> • Stockton-on-Tees Borough Council 	

	between carers and those that they care for.		
5	Delivery of healthcare appointments that take into account the different communication needs of carers.	<ul style="list-style-type: none"> • North Tees and Hartlepool NHS Foundation Trust • NHS Tees Valleys CCG • Hartlepool & Stockton Health Ltd 	
6	Health and Social Care Services to provide appropriate and regular contact and communication with carers to support them in their caring role.	<ul style="list-style-type: none"> • Stockton-on-Tees Borough Council • North Tees and Hartlepool NHS Foundation Trust 	

Responses to The Impact on Unpaid Carers Report

[Tees Valley Clinical Commissioning Group response to The Impact on Unpaid Carer Report](#)

[Stockton Borough Council response to The Impact on Unpaid Carers Report](#)

[North Tees & Hartlepool NHS Foundation Trust response to The Impact on Unpaid Carers Report](#)

[Impact on Teesside response to The Impact on Unpaid Carers Report](#)