

Care Home Families & Friend Support Project

September 2020



Key Findings and Recommendations Report

“The big thing for me has been being kept aware of what’s happening, why it’s happening, and what’s going on.”

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Executive summary

Introduction

The Care Home Families & Friend Support Project, a Pan-Sussex Healthwatch project, sought to explore family and friends' experiences of care homes during the COVID-19 pandemic. Many residents continue to be supported by family or friends after moving to a care home, complementing the care package delivered by the residential setting. In light of Care for the Carers' commissioned role to listen to and amplify unpaid carers' voices Healthwatch East Sussex invited Care for the Carers to co-deliver their input in the delivery of the project.

The project was delivered through a mixed model, comprising of a 'virtual coffee morning', and online and telephone surveys, in August and September 2020. 64 family members/friends and 4 professionals contributed to the project by sharing their views, which are reflected in the key findings and recommendations below.

Key findings

1. Whilst family members/friends recognised the unprecedented challenges care homes have faced as a result of COVID-19, their experiences during the pandemic significantly varied across care homes, with family members' and friends' experiences ranging from poor to excellent.
2. Some family members/friends report having received no communication from care homes or their relatives during the pandemic, and this has caused frustration and distress.
3. Family members/friends and professionals report that the Government failed to provide comprehensive, timely guidance to care homes during COVID-19, and that this has had a negative impact on care home provision and the experiences of residents' family members/friends during the pandemic.
4. There was a significant reduction in contact between family members/friends and their relatives and friends living in care homes during the pandemic, and this has had a substantial impact on the health and wellbeing of family members/friends and their relatives and friends in care homes.
5. Family members/friends greatly valued the efforts many care homes had made to facilitate communication between family members/friends and their relatives or friends during the pandemic.
6. Family members/friends are concerned about how sustainable the already limited visiting arrangements will be during the winter, given the use of outdoor spaces to facilitate visits.
7. Communication via telephone or video call is not possible for all care home residents due to their capacity or health issues, or due to technological issues, and this has posed major barriers to communication during the pandemic.
8. The absence of physical contact between family members/friends and their relatives and friends living in care homes during the pandemic has been particularly difficult.

9. Family members' and friends' experiences of being kept up to date with information on the health of their relative or friend in the care home, and of coronavirus infections within the care setting, varied significantly across care homes.
10. Family members/friends expressed concern about the gaps in support arising from them being unable to visit care homes to provide additional care, and from health services being prevented from visiting care homes.
11. Family members/friends broadly understand and accept the reasons for care homes restricting visiting arrangements during the pandemic.
12. During the pandemic, arranging new care home placements, admission and settling in has been a particular challenge.
13. The period following a friend or relative moving into a care home is a key transition point for family members/friends, during which some family members/friends experience isolation and poor mental wellbeing.

Recommendations

1. Family members/friends of residents must be seen as equal partners in the care and support of each care home resident.
2. Care home providers across East Sussex should communicate effectively and consistently with family members/friends, throughout the pandemic and beyond, including but not limited to:
 - a. Adopting a flexible, holistic response to family members/friends and residents;
 - b. Actively considering and mitigating against any negative impacts of visiting restrictions on care home residents and family and friends who support their care;
 - c. Enabling regular, clear communication with family members/friends regarding planning and decision-making;
 - d. Keeping family members/friends informed about the health of their relative or friend in the care home, involving family members/friends in healthcare decision-making where appropriate;
 - e. Making use of digital communication methods such as emails and Facebook for frequent general updates, for digitally engaged family members/friends;
 - f. Making use of non-digital methods such as telephone calls and letters, for frequent general updates, for digitally excluded family members/friends.
3. Whilst a key priority should continue to be to reduce the risk of COVID-19 transmission, care homes should facilitate in-person visits with infection control measures wherever possible and safe to do so, using dynamic risk assessment measures rather than implementing long-term, blanket bans on visiting which negatively impact on the health and wellbeing of care home residents and their family members/friends.
4. Where in-person visits are not able to take place, alternative communication methods should be utilised and supported by care staff, to ensure that regular contact between family members/friends and their relatives or friends living in care homes is maintained and that individual needs are met.

5. The negative emotional impact on some family members/friends when their relative or friend moves into a care home should be acknowledged, and communication and involvement ensured during this transition period.
6. It is crucial that Government guidance to care homes as the pandemic progresses is clear, timely, and reflects the important role which family members/friends play in supporting the health and wellbeing of care home residents.

Introduction

Background

During the COVID-19 pandemic, significant media attention was given to the impact on care homes and their residents, but the experiences of the family and friends of those living in residential and nursing care were often noticeably absent from the coverage. The Care Home Families & Friend Support Project, a Pan-Sussex Healthwatch project, sought to address this gap, by exploring family and friends' experiences of care homes during the COVID-19 pandemic.

Many residents continue to be supported by family or friends after moving to a care home, complementing the care package delivered by the residential setting. In light of Care for the Carers' commissioned role to listen to and amplify unpaid carers' voices Healthwatch East Sussex invited Care for the Carers to co-deliver their input in the delivery of the project.

Running during August and September 2020, the aims of the co-delivered East Sussex project were to:

- Provide a mechanism for friends and family to safely come together and share personal accounts of what it is like if you have a family member or friend living in a care home during this pandemic
- Understand how care homes are supporting people to stay in touch and to hear where people are struggling to do this
- Understand whether local care/residential home providers are being open and transparent, and how they are keeping family members updated on their relatives' health and wellbeing as a matter of course
- Understand how peoples' expectations and the reality of a move to a care home differ
- Consider what could be done differently in the future
- Explore potential ways for engaging with family and friend carers and seek a sustainable engagement platform for the future.

Building on the learning from Care for the Carers' and Healthwatch East Sussex's previous engagement activities, the project was delivered through a mixed model, comprising of a focus group – delivered online due to COVID-19 restrictions, and marketed as a 'virtual coffee morning' – an online survey, and a number of telephone surveys to ensure that digitally excluded family members/friends had the opportunity to share their views. We also sought to arrange a radio phone-in as alternative method

of engagement but were unsuccessful in securing this opportunity within the project timeframes.

Context

As the COVID-19 pandemic emerged in early 2020, it promptly became apparent that care homes would be significantly impacted for a number of reasons including age and certain health conditions being significant risk factors for dying with the virus. The media was quick to draw attention to this. Media stories focused on a crisis in care homes¹, criticism of the government's response², and the potential impact of the pandemic on future care provision.³ Being published at a time when many were cut off from contact with their relatives, the stories often did little to allay relatives' and friends' fears.

In practice, East Sussex care homes fared relatively well in the early stages of the pandemic, compared with other areas. Between 9th March to 19th July 2020, the period for which Government published data on care homes with a reported COVID-19 outbreak, 34.8% of the care homes in East Sussex reported having experienced an outbreak of COVID-19, compared with 42.6% in the South East region.⁴

Following central Government guidance issued on 22nd July 2020, Local Authorities across the local area issued the *Visiting arrangements in care homes framework: Surrey, East and West Sussex and Brighton and Hove* in August, stating that:

“Each care home / provider is responsible for following the guidance by establishing their own visitor policy based on the use of dynamic risk assessment which takes into account the health and wellbeing needs of individuals.”

Whilst this allowed for flexibility to accommodate the variations in premises and provision across the local care home market, it left already over-stretched care home managers to independently construct individual visiting and communication arrangements during a period of exceptional pressure.

A note about terminology

The term, 'carer', as defined in the Care Act 2014, is used to describe an individual providing unpaid support or care. In the context of residential and nursing care, however, the term 'carer' is more often used to describe Care Workers and Care Staff, rather than unpaid carers. For the purposes of this report, therefore, to make this distinction clear, and to align with the terminology used within the Pan-Sussex project, the term, 'family members/friends', is used to refer family and friends of those living in residential and nursing care, rather than using the term, 'carer'.

¹ www.inews.co.uk/news/politics/coronavirus-care-homes-death-toll-patients-428185

² www.inews.co.uk/news/politics/care-homes-coronavirus-boris-johnson-blames-protective-ring-anger-497852

³ www.theguardian.com/world/2020/aug/27/coronavirus-impact-made-uk-social-care-crisis-even-more-acute

⁴ www.gov.uk/government/statistical-data-sets/covid-19-number-of-outbreaks-in-care-homes-management-information

The terms, 'care home' and 'home', are used generically for the purposes of this report, to refer to residential and nursing care settings.

Methodology in capturing family members' and friends' feedback

Decision-making regarding methodology

With the project approach initially piloted by Healthwatch West Sussex, the broad structure of the project was already established when commencing the work in East Sussex. Whilst minor adaptations were made to communications resources to align with local context, the research questions and methodology of the pilot project were retained, to enable consistency and comparison across the Pan-Sussex project.

Virtual coffee morning

Based on recent positive experience of Care for the Carers engaging unpaid carers with online discussion, an online focus group was arranged for 13th August 2020. The event was marketed as a 'virtual coffee morning' and promoted widely across Care for the Carers' and Healthwatch East Sussex's networks, including promotion to care home providers themselves, and distribution to 2,974 recipients of Care for the Carers' engagement e-newsletter. The session plan for the online event was based around the Pan-Sussex project-wide research questions, detailed in Appendix 1.

Online and telephone surveys

Again reflecting Care for the Carers' recent strong unpaid carer engagement with online surveys, the online survey tool, Smart Survey, was utilised to ask eight questions about the experiences of family and friends of those living in residential and nursing care. Promotion of the survey included the option for family members/friends to complete the questions by telephone, in order to ensure that digitally excluded family members/friends had the opportunity to participate. Like the virtual coffee morning, the survey questions mirrored the Pan-Sussex project-wide research questions in Appendix 1.

Attendance and engagement

The initial Facebook posts by Care for the Carers and Healthwatch East Sussex, promoting the virtual coffee morning and survey, had a combined reach of 2,110 and 49 engagements, and Twitter activity resulted in 1,311 impressions and 41 engagements. Further paid Facebook advertising achieved a reach of 9,438, with 252 clicks and a 1.78% result rate.

The virtual coffee morning was poorly attended, with two family members/friends and four professionals participating. However, the small size of the group enabled a rich insight into participants' experiences, and both family members/friends participating reported having enjoyed taking part in the live sessions, and that they felt listened to and able to share their experiences.

"It was good to be able to talk about my feelings and experience."

The online survey was much more popular, achieving 51 responses, and the telephone survey was completed by 11 family members/friends. **The feedback in this**

report therefore reflects the views of 64 family members/friends and 4 professionals.

What family members and friends said – key findings

Through the online workshop, online survey and telephone discussions, family members/friends shared their personal experiences of care homes during the COVID-19 pandemic. 53% of family members/friends participating in the project reported a positive view of the how the care home their friend or relative lives in has responded during the pandemic, whilst 28% of family members/friends had a negative view.

The following themes arose:

1. Whilst family members/friends recognised the unprecedented challenges care homes have faced as a result of COVID-19, their experiences during the pandemic significantly varied across care homes, with family members' and friends' experiences ranging from poor to excellent.

Positive experiences focused on clear and proactive communication with family members/friends, and timely and person-centred decision making.

“As soon as lockdown happened, my mother's home was brilliant in communicating their stance regarding management of the pandemic but working very hard to recognise the constraints under which we all have to work. As matters have evolved, I have been kept fully informed. I am in touch with the home and with my mother on a regular basis and it is working as well as the circumstances in which we find ourselves allow.”

“Decisions about the management of this pandemic have been appropriate, timely and communicated to me with reasons and I appreciate this. For a relative to be included as part of the team caring for my mother has been very important to me.”

Negative experiences shared by family members/friends included poor or inconsistent communication with family members/friends, poor quality of care provision, and the negative impact of these on the wellbeing of family members/friends and their relatives or friends living in the care homes.

“Homes appear to have a total disregard for sending any communication to family.”

“My wife had mobility problems while at [the care home], due to being left in the bed, she wasn't incontinent, however they made her wear pads as I believe it was too much trouble to put her in a wheelchair and take her to the toilet. The toilet was a distance, including stairs, from her room. I feel let down by so many, I feel my wife was let down and I would like some answers. I now live with the memory of how awful it was for my wife and myself.”

“The home doesn't appear to have been very proactive in trying to help us connect with our Aunt, and it feels like when you do ring up you are a bit of an inconvenience. Our Aunt is not used to using technology, so we are reliant on the staff assisting. We have tried to do skype calls but although the home agreed to helping facilitate these with a tablet, they had it didn't happen.”

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“Spoke to Care Home manager yesterday by telephone, she came across as dismissive of my concerns for my mother. [...] The home manager audibly sighed when I asked if she could refer [to the hospice], she told me NO she couldn't do that [...] I asked the care home to remove back slaps [for choking] from Care Plan as these would break her [...] The Care Home Manager informed me that the back slaps could not be removed [...] I didn't feel listened to and I felt that the Care Home Manager was dismissive of my concerns.”

“I honestly don't believe [my friend] was even out of bed. I was unable to see her, but I feel they had no understanding of her needs. For example, she needed to be reminded to eat and drink fluids, I don't think there was any help given as apparently she had dropped to a size 6, quite a weight/muscle loss, considering she was a size 14 [...] in February.”

2. Some family members/friends report having received no communication from care homes or their relatives during the pandemic, and this has caused frustration and distress.

Some family members/friends described care homes failing to communicate with them effectively during the pandemic and highlighted the significant difficulties they had experienced in trying to obtain information or be supported in having contact with their relatives or friends in the care home.

“There hasn't been any support from the care home about keeping in touch. They simply closed to visitors and that's it. I've found out indirectly how my wife is doing [...] The home has not kept me updated at all. The onus is on me to contact them. I call weekly to try to get an update, but it depends who you speak to as to how much you learn.”

“I've not been allowed to visit and she's not able to use a phone even if I provided one for her. I've sent cards but I'm not sure if she even understands what they are. We're completely cut off from any communication. It's difficult to communicate without being able to visit at all. I used to play music whilst she sang along as another form of communication, but that's not possible whilst I can't visit.”

“Once the home closed for the pandemic it was incredibly difficult to be able to speak to anyone at the home if my mother had any complaints (of which I have many), or to find out how she was doing when she had Covid style symptoms. There was also a point early in the lock-down when she was taken to hospital with a nosebleed that would not stop - I didn't find out about this until after she had been returned to the home.”

“[There's been] limited assistance to either my friend or myself. I was sending postcards but have no idea if they were being passed on as I was unable to speak to [my] friend and during very brief, stilted conversations with staff they did not know and could not help.”

“I phone every day...sometimes it takes an hour to get through. Most staff give very few details. [...] Even on my visits - staff don't want to talk and give as little information on them as possible. I feel very unwelcome.”

Family members/friends noted their disappointment and frustration when care homes have not supported communication between family members/friends and their relatives or friends in care homes.

“The care home did not support me to stay in touch. When I would ring, I was told by I believe the manager who was on a mobile: ‘I am upstairs at the moment but she is fine.’ I was never given the opportunity to talk to her on the phone.”

“I feel the Care Home could have done more to ensure there was a level of contact for us during these last weeks; even if someone could have spared the time to hold the phone for her it would have helped. The whole experience felt as though she had been put away and everyone was just waiting for her to die.”

“[I] do find it a challenge to contact [my father] as there are short windows of time that are best. I also find that there is a lot of demand for people using the phone as they only have one line in.”

“Sometimes cannot get [my partner] by phone as the charger has been put out of his reach and if the weather is not good then no visiting as [we] cannot stand in a wet garden.”

3. Family members/friends and professionals report that the Government failed to provide comprehensive, timely guidance to care homes during COVID-19, and that this has had a negative impact on care home provision and the experiences of residents’ family members/friends during the pandemic.

Family members/friends and professionals described the challenges posed by the gaps and timing of national and local guidance to care homes.

“[The greatest challenge is that] the rules keep changing from the government.”

“The PPE supply and disease testing equipment availability and UK system response has been a continuous issue for the home and not matched by government statements about status.”

“Care homes can only communicate clearly with relatives if they are getting clear guidance – care homes need inbound communication, so they have the time to digest it and disseminate it. Often there were big gaps between what relatives were hearing in the media and what specific guidance care homes were receiving.”

“Taking a flexible, holistic approach to supporting relatives is important, and the government guidance needs to be clear that this is expected. When care homes take a blanket approach, it doesn’t work for relatives.”

Family members/friends report being unclear what they should expect from care homes in relation to communication and quality of care, both during the pandemic and beyond. Some family members/friends reported feeling powerless to speak out when

they have concerns, due to a fear that it would negatively impact on the care their friend or relative receives.

“You're thrown in at the deep end when you place a relative in a care home, and you don't know what your rights are. It would be helpful if they were all working to a common practice, but it seems to be down to the homes to make their own decisions. I don't want to antagonise the home or do anything that would harm my wife, so it limits how much you speak out.”

4. There was a significant reduction in contact between family members/friends and their relatives and friends living in care homes during the pandemic, and this has had a substantial impact on the health and wellbeing of family members/friends and their relatives and friends in care homes.

Many family members/friends cited the emotional pain they and their loved ones have experienced as a result of separation resulting from the pandemic, and some described how it has contributed to a deterioration in the health of those living in the care homes.

“I was devastated to be told I couldn't see [my husband], without any warning 22 weeks ago. After being married for 48 years and never spending more than a few days apart I struggle with the thought I won't be able to say goodbye before lockdown finishes.”

“I miss [my parents] so much. I feel so guilty and frustrated that I have been forced to effectively abandon them at the time when the worst virus in their lifetime is around, which they are most vulnerable to and worse still I've left them in a care home - the most deadly setting for getting the virus. I am so depressed - some days are better than others - I pretend to myself that it was only yesterday I saw them, and I'll be seeing them tomorrow... as I try to block out the pain.”

“My father's mental confusion has increased considerably and he has also had paranoiac/psychotic incidents [...] He told me yesterday that he felt as if he was being kept in a prison camp.”

“The 17 weeks that I didn't see my mother was really, really hard for me. To try and have a Zoom call or phone call with her was impossible; she couldn't understand why I couldn't touch her. The deterioration in those 17 weeks has been horrendous. I can now go in daily again in full PPE, escorted to her room, but it doesn't make up for the time that I wasn't able to see her and the deterioration that's taken place.”

5. Family members/friends greatly valued the efforts many care homes had made to facilitate communication between family members/friends and their relatives or friends during the pandemic.

Many good practice examples were shared of the flexible manner in which some care homes had supported communication between family members/friends and their relatives, despite the barriers posed by COVID-19 restrictions. Efforts to support visits with infection control measures in place were particularly valued.

“The home sees visiting as part of residents' overall wellbeing so they've done as much as they can to support our contact. They realise the impact on residents if they don't have contact with their families. The home has been good at keeping us up to date with changes and providing reassurance.”

“Our aunt has been well looked after during Covid. We have had a dedicated telephone which we can use from early on. Since things have improved, I have had visits with her on decking area attached to home, arranged visits are by appointment.”

“They have tried to set up video calls and garden pods for visits. Due to my father's distress in the garden they have kindly allowed my sister and I to see him in an inside downstairs area which has helped considerably.”

“They've been very good. When we first went into lockdown, they stopped all visitors and we were told we could Skype, but my husband doesn't understand Skype so then they let him call me instead. Then they opened up for visits to take place in the corridor, where I sat behind a Perspex screen, and the care worker sat beside my husband to help him hear what I was saying because he won't wear his hearing aid. After that, they allowed one-to-one visits in the staff coffee lounge and sometimes outside.”

Family members/friends highlighted the importance of care staff actively supporting communication between family members/friends and their relatives or friends during the pandemic, for example, by making good use of technology.

“[The care home is] responsive to ensuring that families can talk either on phone or Apple talk or Skype with their residents. They also have a very active Facebook site on which they show videos of our loved ones and photos and the fun they are having. This is excellent as not only are we able to keep in contact, but we get to know other families and it makes everything seem more bearable. [...] Technology is the key and a can-do proactive team who realise that keeping the family involved makes life happier for the families and residents.”

“We have been able to bring cards, flowers and presents to the front door, these were then 'quarantined' for a day or so and given to Mum with an explanation who they were from. The home has continually sent emails, WhatsApp and Facebook posts showing photos and descriptions of their activities.”

Those care homes which had undertaken regular, proactive communication to family members/friends through newsletters, emails, telephone calls, and private Facebook groups, were strongly praised by family members/friends. Communication was at both a care home-wide level – regarding visiting arrangements, coronavirus infection within the home, activities taking place, and future plans – and at an individual level, regarding residents' health and wellbeing.

“Communication from the care home has been the absolute top, top, top most helpful thing for me during the pandemic.”

“At every significant step, particularly as lockdown stringencies have been relaxed, and throughout recent months in general, I have been kept up-to-date with emails and

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newsletters. During phone calls, I have also talked to management on a regular basis to share experiences. This has worked really well.”

“[The care home] have been amazing with emails, the ability to go on Facebook etc. For those patients who are [able] to understand there have been phone calls to loved ones. Also, in my case they have taken photos of my sister so that I can see all is well. They could not have done any more.”

“The home has made every effort to keep us in touch with mum - they provided an iPad with support from staff to help mum use it - so we were able FaceTime regularly. They emailed us regularly and kept us informed about what's happening. I can't emphasise enough how well they've looked after her - they've really done a good job.”

“[The care home] has been fantastic. They maintain very close links, keep us updated on mum and also are incredibly responsive to requests for FaceTime calls and Skype and just ordinary calls, nothing is too much trouble which means anxiety levels are much reduced. The Facebook pages help us feel part of the action as well even if we are not communicating directly with our loved ones. Our prime concern is our loved ones' welfare and happiness and a short video of them having fun is so reassuring.”

6. Family members/friends are concerned about how sustainable the already limited visiting arrangements will be during the winter, given the use of outdoor spaces to facilitate visits.

Family members/friends were acutely aware that COVID-19 is going to impact on care homes for many months to come and expressed concern about what that will mean for their future contact with their relatives or friends.

“This is long term so we must look to using everything at our disposal to allow for more frequent family visits. We must look to fund winter visiting. At the moment the glorious summer has facilitated outdoor visits, but we need to consider what is required in winter.”

“There is a marquee for the outdoor visits, which isn't ideal in cold and wet weather, and they don't seem to have anything in place for the winter. You have to pre-book the appointments, which is rather restrictive.”

“It's fine for people in wheelchairs to see their family outside, but what about bed ridden people?”

7. Communication via telephone or video call is not possible for all care home residents due to their capacity or health issues, or due to technological issues, and this has posed major barriers to communication during the pandemic.

A marked determinant for family members/friends reporting positive experiences of communication with their relatives or friends during the pandemic was the capacity of care home residents to engage with the alternative communication methods offered.

“We tried talking with her by phone and on a couple of occasions by Zoom. Unfortunately, this was not very successful as Mum really didn’t understand what was happening and would rather sit holding the hand of her support worker.”

“[My father] is deaf in one ear, the other needed syringing before lockdown and this has not been possible since, owing to NHS restrictions, so communication by Skype and on the phone is challenging. He does not understand computer technology and never embraced it before his Alzheimer’s disease took hold.”

“Mum could not understand video calls and window visits were too far from her so I couldn’t hear any of the few words she uttered.”

“Although I can see [my husband on FaceTime], it’s a very poor substitute to be able to be in the same room and he can’t communicate.”

“We understand that the home needs to protect our relatives, but it still didn’t stop the heartbreak for me. Because yes, they’d set up the Zoom, they’d set up the iPad, but my mum got so distressed that I had to stop doing it.”

A range of digital barriers were cited by some family members/friends as impacting on communication with their relatives or friends in care homes.

“The poor broadband at the home has been a problem for FaceTime [...] she can’t understand why she has to do this instead of seeing us in person.”

“Communication via Skype is patchy and the inability to visit him is distressing for him and myself. Phone calls work quite well for limited time (10 minutes before he tires).”

“My husband is confused by Skype and couldn’t understand it, and Skype doesn’t always work on my computer, so it doesn’t really work for us, we prefer phone. The lack of privacy is an issue - having a care worker sitting alongside to help my husband use Skype meant we weren’t alone, and it didn’t feel like a natural conversation.”

8. The absence of physical contact between family members/friends and their relatives and friends living in care homes during the pandemic has been particularly difficult.

Family members/friends highlighted that not being able to comfort their relatives or friends using physical contact has had a negative impact on the emotional wellbeing of themselves and those they care for.

“[The greatest challenge is] being unable to visit on a face to face situation and being able to hold her hand and interact with her.”

“The home have been very good in accommodating our requests for Zoom calls and for arranging visits whilst following the recommendations of the Government but, of course, nothing can compare to being able to hug one’s very elderly, rather confused and upset mother.”

“My parents’ Alzheimer’s is so severe they cannot communicate by phone / FaceTime. Even socially distanced visits once a fortnight in full PPE is of no benefit to them. My mum is totally deaf and tends to stare downwards. Even if she is awake for my visit,

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she either doesn't look at me at all or if she glances up in my direction - I'm just some distance object. My dad may be able to hear me yell his name or the words I love you I call repeatedly for half an hour during my visit from behind my mask and visor, but he doesn't respond as I'm too far away and if he glances over - I don't look like a person behind a mask and visor. For them to receive any communication from me - I need to be able to touch them - even with PPE on."

"Our family member has lost the ability to converse, so phone calls are not possible. Not being able to see her for weeks was difficult. Now we can have a visit at a distance, but we can't engage as we could if we sat next to her and gave her a cuddle. We are not sure she recognises us now."

9. Family members' and friends' experiences of being kept up to date with information on the health of their relative or friend in the care home, and of coronavirus infections within the care setting, varied significantly across care homes.

58% of family members/friends reported that care home staff have kept them up to date with the health of their relative or friend in the home, compared with 22% who reported that they had not been kept informed about health issues. Examples of good and poor practice of communication about health were shared.

"They let me know if there's any problems with mum's health at all. We were asked about our wishes for mum's care in the event that mum gets the virus - where we would want her cared for (in the home or in hospital) - we were really impressed that they were thinking ahead to this."

"I speak to staff every day. Both the manager and deputy manager make me aware of any issues or decisions that need to be made and are always willing to talk these through and give advice."

"I have to ask for updates on my wife's health. The care home doesn't volunteer the information. Some staff are more communicative than others, so it depends who you talk to."

"Staff haven't been good at keeping me updated about my mum's health. Whereas before Covid the home manager might ask to have a quiet word whilst I was visiting, to update me on my mum's health, this has been a gap since the pandemic. It's all on me to actively ask for health updates, which is a worry."

56% of family members/friends reported that care homes had kept them up to date with coronavirus infection in the home, compared with 23% who had not been kept informed about infection levels. Again, examples of good and poor practice regarding this were shared.

"We have been kept up to date by email with any news regarding Covid-19 infection within the home which, thankfully, has not occurred."

"It was reassuring that they kept us updated with regular letters and they were really quick to reduce the risks. They implemented a lockdown straight away, and allowed no

visitors, so they didn't have any cases. They had PPE in place and testing started early. One person with symptoms was quickly isolated whilst waiting for test results and we were told immediately, so it felt like they weren't hiding anything, and it was well-managed.”

“The home has had a very large outbreak but initially their parent company [...] tried to keep it quiet from relatives and getting any information on numbers was impossible. We were told in writing that they would only discuss it with us if our own relative tested positive, and then only their particular case so we were in the dark for a long time. [...] When my father did test positive for corona I was called by the home, abruptly told, and the phone was then thrust in my father's hands so that I could explain it to him before I had even been able to process the information and work out a careful way of doing so. This only served to increase panic and anxiety among relatives. Eventually, due to pressure, [the care provider] started sending regular letters to relatives but these were general to all their homes. In the end we were able to get a figure from our father's Manager during a Relatives Zoom meeting (although we don't imagine she was meant to tell us: it was 70 cases in the home and 10 deaths).”

“The home had one case as far as I know, but I only found out by reading about the death of the resident it in the obituaries column in the local paper [...]. I had assumed they would have told me directly if they had any cases [...].”

10. Family members/friends expressed concern about the gaps in support arising from them being unable to visit care homes to provide additional care, and from health services being prevented from visiting care homes.

Family members/friends echoed concern highlighted nationally by dementia charities that “Family carers are an integral part of the care system and when removed from that, the essential care and wellbeing of the individual suffers.”⁵

“[My parents are] missing out on the extra things I do to make them more comfortable – e.g. moisturise and massage their hands and feet and ensure their TV//DVD player is turned on for them, and that they are sitting or lying comfortably.”

“Before lockdown I was visiting my wife a couple of times a day to help with eating, as it was a way I could help, so it was a big change not to be able to visit at all.”

Barriers to care home residents accessing ear-care services were specifically cited as impacting negatively on communication between family members/friends and those they care for.

“[My mother is] quite deaf and was due to have her impacted wax removed in April but then lockdown prevented any outpatient clinics etc. So, this also hampered any type of communication with her.”

“As a family we are finding it difficult as our mum has gone deaf again and ear suctioning services will not come out at present.”

⁵ One Dementia Voice, *Open Letter to Secretary of State*, 9th July 2020, www.alzheimers.org.uk/news/2020-07-09/open-letter-secretary-state

11. Family members/friends broadly understand and accept the reasons for care homes restricting visiting arrangements during the pandemic.

Family members/friends were often stoic in their reflections about the necessity of visiting arrangements being restricted, and there was a correlation between family members/friends accepting the restrictions where they perceived that their relative or friend was well cared for.

“My heart goes out to the care home staff because they care, and they can see how hard it is for residents and relatives.”

“It's horrible not seeing my mum but it's the way it had to be.”

“Initially when lockdown was introduced, I was very upset thinking that I may never see my mother again but as time went on I am ok in the knowledge that she is being extremely well cared for and she is safe.”

“It's just the way it is - you have to bite the bullet and get on with it. I appreciate that the home doesn't want covid getting into the home and the visits have to be restricted for this reason. The fact that I can see my Dad is well cared for and doesn't seem in distress makes it bearable.”

12. During the pandemic, arranging new care home placements, admission and settling in has been a particular challenge.

Those family members/friends whose relatives or friends had been placed in residential or nursing care during the pandemic described the significant difficulties experienced in either making informed decisions about which care setting to select, or during the settling-in period.

“I wasn't given any information. My wife was in [respite provision] and Adult Social Care advised on the Wednesday that [the care home] could take her on the Friday. I asked if there were any other options and I was told I would have to look for somewhere. I didn't know where to turn.”

“We must absolutely find an acceptable way for families to be able to visit a home before they are placed. Mum was placed temporarily in one sight unseen for us and also with no obvious and easy way of contacting. This was a disastrous episode for my mum and the family.”

“They haven't been ringing us at all. Our Aunt went into the home at the beginning of the pandemic so there was no opportunity to visit the home beforehand or get to know the staff and unless you ring them, when you feel you are a bit of an inconvenience you don't hear from them.”

“It's frustrating not to see how the care home operates so there are lots of little questions I have all the time, e.g. how does Mum provide items for washing, when are organised activities going on. Apparently, an information leaflet does exist for residents. I have asked for a copy but haven't got it yet.”

“Searching for a new care home was [...] traumatic and you were expected in many cases to place your loved one in a home sight unseen, with only CQC reports and a chat outside with the care manager. Maybe a few photos [with] your nose to a windowpane. I would not put my dog in a kennel on such paltry information, let alone an elderly parent. PPE must be provided and maybe a more formal approach to care home visits set up. [...] There must be a better way. Luckily a couple of homes realised you could not make a decision with no facts and were very careful in protecting us and the residents and staff whilst allowing us to get a feel for rhythm of the home, staffing levels, resident engagement, levels of enthusiasm as well as the facilities in the home itself.”

“One of the difficulties in selecting a care home during the pandemic was there didn't seem to be lots of information about the home offered by the home. The onus was on the relative to find the information from other sources like CQC. One of the hardest things was not being able to talk to another relative of someone who was there. Actual verbal contact with fellow carers is important.”

13. The period following a friend or relative moving into a care home is a key transition point for family members/friends, during which some family members/friends experience isolation and poor mental wellbeing.

Where family members/friends had been providing significant amounts of care prior to their relative or friend being admitted to a care home, they cited feelings of loss and isolation arising from their change in role. Some family members/friends asked to be connected to others who were going through the same challenges, and accepted referral to local peer support opportunities.

“Emotionally I'm finding it really difficult. It's such an adjustment and I feel lonely. It feels like a bereavement but you're in limbo. Everything's in a muddle at home. I'm trying to get the house sorted out but it's hard to motivate myself as I feel depressed.”

“It's like someone has passed on but it's not the same as you can't draw a line, so I can't get rid of her things.”

Evaluation

Overall, as a snapshot of family members' and friends' experiences of care homes during the COVID-19 pandemic, the project succeeded in its aims to capture family members' and friends' views and identify key recommendations for practice as the pandemic continues. Whilst the virtual coffee morning had low attendance, both family members/friends participating reported in the post-session evaluation that they had enjoyed taking part in the live sessions, and that they felt listened to and able to share their experiences. The online and telephone surveys achieved a higher volume response and enabled this report to reflect a broader range of family and friend experiences, albeit with the limitations resulting from the short-term nature of project.

There were a number of barriers to engaging with a greater number of family members/friends during this project, including the following:

- The restrictions resulting from the COVID-19 pandemic limited the opportunities to promote the project face-to-face. For example, whilst we sent promotional flyers to care home managers for distribution to relatives, it is likely that the visiting restrictions and infection control measures in place in care homes during the research period would have resulted in few flyers being passed on.
- The consequent reliance on online promotion of the project meant that digitally excluded family members/friends were significantly less likely to learn about the project than those who were engaged with digital platforms.
- A significant characteristic of the cohort the project was seeking to reach is that they are often hidden, not a cohesive or singular group, and not engaged with a specific network that we could have promoted the project through. This created a significant barrier to promotion notwithstanding our best efforts within the project timeframes.
- The term, 'carer', despite being the legal term for unpaid carers set out in the Care Act 2014, is often misused interchangeably to refer to both unpaid carers and paid care workers, yet there is not a snappy alternative which specifically refers to the family members/friends that the project was aimed at. The lack of an appropriate term that better spoke to the target audience may have impacted on promotion reaching the right people.
- These barriers to engagement are likely to be further exacerbated by the additional barriers faced by hard to reach groups such as family members/friends from Black, Asian and minority ethnic (BAME) communities and those from socio-economically deprived backgrounds. The short-term nature of the project, alongside the restrictions on face-to-face engagement imposed by COVID-19, prevented the proactive community development work necessary to undertake targeted reach in these communities.

A further learning point is that the survey questions were already established by the pilot project undertaken by Healthwatch West Sussex, and for consistency and comparison, the survey questions were retained in the same format for the East Sussex surveys. It may have been helpful to include anonymous demographic data such as gender, age, locality, and whether the care home placement is funded by the Local Authority or the care home user, in order to enable further analysis of the responses.

Recommendations

The family members' and friends' feedback gathered through the Care Home Families & Friend Support Project informs the following recommendations:

1. Family members/friends of residents must be seen as equal partners in the care and support of each care home resident.
2. Care home providers across East Sussex should communicate effectively and consistently with family members/friends, throughout the pandemic and beyond, including but not limited to:

- a. Adopting a flexible, holistic response to family members/friends and residents;
 - b. Actively considering and mitigating against any negative impacts of visiting restrictions on care home residents and family and friends who support their care;
 - c. Enabling regular, clear communication with family members/friends regarding planning and decision-making;
 - d. Keeping family members/friends informed about the health of their relative or friend in the care home, involving family members/friends in healthcare decision-making where appropriate;
 - e. Making use of digital communication methods such as emails and Facebook for frequent general updates, for digitally engaged family members/friends;
 - f. Making use of non-digital methods such as telephone calls and letters, for frequent general updates, for digitally excluded family members/friends.
3. Whilst a key priority should continue to be to reduce the risk of COVID-19 transmission, care homes should facilitate in-person visits with infection control measures wherever possible and safe to do so, using dynamic risk assessment measures rather than implementing long-term, blanket bans on visiting which negatively impact on the health and wellbeing of care home residents and their family members/friends.
 4. Where in-person visits are not able to take place, alternative communication methods should be utilised and supported by care staff, to ensure that regular contact between family members/friends and their relatives or friends living in care homes is maintained and that individual needs are met.
 5. The negative emotional impact on some family members/friends when their relative or friend moves into a care home should be acknowledged, and communication and involvement ensured during this transition period.
 6. It is crucial that Government guidance to care homes as the pandemic progresses is clear, timely, and reflects the important role which family members/friends play in supporting the health and wellbeing of care home residents.

Next steps

The key findings and recommendations from this report will be shared with Healthwatch East Sussex and integrated into the wider work and Pan-Sussex activity of the Care Home Families & Friend Support Project.

Healthwatch East Sussex will communicate the findings and recommendations to East Sussex care home providers and other relevant stakeholders. Both Care for the Carers and Healthwatch East Sussex will publicise the report findings through their networks and communication channels.

Where family members/friends cited the specific care setting which their feedback relates to, anonymised feedback will be shared with the relevant care provider by Healthwatch East Sussex. 16 family members/friends cited 11 care home providers in their feedback. The providers which were cited are listed in Appendix 5.

Contact us

For further information on the report findings please contact Jo Egan, Director of Services, Care for the Carers, by email: joe@cftc.org.uk or by telephone: 01323 738390.

The report is part of the Healthwatch Sussex Care Home Families & Friend Support Project. For more information about the Pan-Sussex Project, contact Elizabeth Mackie, Volunteer and Community Liaison Manager, Healthwatch East Sussex, by email: elizabeth.mackie@escv.org.uk or by telephone: 0333 101 4007.

Disclaimer

The findings and recommendations detailed in this report are based on the feedback received through the virtual coffee morning, online surveys and telephone surveys completed during the period of the project set out in the report. Our report is not a representative portrayal of the experiences of all East Sussex family members or friends caring for a relative or friend in a care home, only an account of what was contributed at the time.

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Disclaimer

This report relates to findings during the specific periods as stated in the document and is an account of what was observed at the time. This report will be publicly available in September 2020 by publishing it on our website and circulating it to Healthwatch England, CQC, NHS England, Clinical Commissioning Group/s, Overview and Scrutiny Committee/s, and our local authority.

We confirm that we are using the Healthwatch Trademark (which covers the logo and Healthwatch brand) when undertaking work on our statutory activities as covered by the licence agreement. If you require this report in an alternative format, please contact us at the address above.

Appendix 1 – Online and telephone survey questions

Care Home Families & Friend Support Project

Introduction

As part of a partnership project, Healthwatch East Sussex and Care for the Carers are inviting relatives and friends of care home residents to share their experiences of care homes during the pandemic.

The project will raise awareness of the engagement residents' family and friends would like to have with care homes, such as receiving timely information, and will celebrate what's working well and make recommendations for change where needed.

Please fill out this short survey online, or alternatively if you need help to complete it, call us on 01323 738390 and we can complete it with you over the phone.

Questionnaire

1. How are you and your family/friend in the care home coping? And has this been changing over time?
2. What have been the main challenges for you in staying in touch with your family/friend in the care home?
3. How has the care home supported you in staying in touch?
(We are keen to understand what has worked well, and where people have struggled.)
4. How have staff kept you up-to-date with the health of your family/friend in the home?
5. How have staff kept you up-to-date with coronavirus infection within the home?
6. Who or what has been the most helpful throughout the pandemic? Any top tips we could share?

If your family/friend moved into the care home during lockdown, please tell us about this experience.

7. Did the home match the information you had been given or found out about it before they moved in? If no, please let us know about the difference.
8. Anything else you'd like to tell us?

Appendix 2 – Promotional flyer regarding the virtual coffee morning

Informal carers coffee morning



Do you care for a friend or relative who lives in a care home?

Covid-19 has posed many challenges for care homes. **We want to hear how well homes are supporting unpaid carers.** We want your views on what's working well and what needs to change.



Join our Virtual Coffee Morning online or by phone on Thurs 13th Aug 2020, 10am-12pm, or complete our survey

To book your place at the Virtual Coffee Morning, or complete the survey, visit cftc.org.uk or call 01323 738390

 **No One Left To Care Alone** 

☎ 01323 738390 ✉ info@cftc.org.uk 📞 07860 077300
🌐 careforthecarers 📺 care4thecarers 📺 careforthecarers

Appendix 3 – Promotional flyer regarding the survey

Your views: Care Homes



Does your relative or friend live in a care home?
Covid-19 has posed huge challenges for care homes, residents and their families. We want to hear your experience as a relative or friend. What's working well?



healthwatch
East Sussex

You can complete our online survey at:
www.smartsurvey.co.uk/s/ULS3JS

For more information or to book a call to give your views by phone, visit www.cftc.org.uk or call 01323 738390

 No One Left To Care Alone 

01323 738390 info@cftc.org.uk 07860 077300
careforthecarers care4thecarers careforthecarers

Appendix 4 – Webpage on Care for the Carers’ website promoting the project



Give your views on care homes during the pandemic

by Sonyab | Jul 25, 2020 | Carer News

Does your friend or relative live in a care home? We are delighted to launch a partnership project between Healthwatch East Sussex and Care for the Carers, inviting relatives and friends of care home residents to share their experiences of care homes during the pandemic.

Covid-19 has posed huge challenges for care homes, residents and their families. We want to hear your experience as a relative or friend. What's working well? What should change?

The project will raise awareness of the engagement residents' family and friends would like to have with care homes, such as receiving timely information, and will celebrate what's working well and make recommendations for change where needed.

Care for the Carers and Healthwatch are holding a Virtual Coffee Morning to hear your experiences of care homes during the pandemic on Thursday 13th August 2020, 10am-12pm. Participants can join online or by phone. Register your place by completing the form below and we will contact you with joining details.

Alternatively, if you are not able to attend the Virtual Coffee Morning or would prefer to give your feedback separately, you can complete an [online questionnaire here](#) or let us know if you would like to complete the survey with us by phone and we'll give you a call. For further information about this project and Virtual Coffee Morning, email info@cftc.org.uk or call 01323 738390.

Appendix 5 – Care providers cited in carers' feedback

Avalon
Care UK
Caroline House
Filsham Lodge
Hailsham House
Homelea
Inglewood
Peasmarsh Place
Prideux Lodge
Queensmead
Queen Victoria Cottage Homes