

East Sussex Care Homes Wellbeing Project - Relatives and Carers

Zoom Webinar held on Wednesday 24th February 2021 from 3:00 to 3:45 pm (Part 1) on

The impact of long-term restricted visiting/separation from loved ones is having on families

**‘Care Homes must be helped to re-open to meaningful
visits by 8th March’**

Background

- Sussex wide collaboration between Sussex Partnership NHS Foundation Trust (SPFT), Carers Support Organisations and Healthwatch.
- Part of the Sussex Care Home Wellbeing Project led by Dr Padma Dalby.
- The project running to the end of March to support Care Home Communities in the context of the Covid-19 pandemic.
- Working with staff but are concerned with the wellbeing of the whole community - staff, residents and their families.

Panel

Dr Padma Dalby, Consultant Clinical Psychologist, (SPFT)

Deborah Becker, Occupational Therapist, (SPFT)

Ross B, Public Health Team, East Sussex County Council

Nicola Rosenburg, Public Health, Brighton and Hove

Mike Derrick, Chair of the Registered Care Home Association for East Sussex, Brighton and Hove

In attendance

Jo Egan, Care for the Carers - East Sussex

Michelle Kay, Healthwatch Brighton and Hove

John Routledge, Healthwatch East Sussex

Philippa Russell,

Kate Richmond, Healthwatch East Sussex

Sue Wells, Healthwatch East Sussex

Barbara Hardcastle, Brighton and Hove City Council

Diane Van Eygen, Brighton and Hove City Council

Tazmin Hatcher, Brighton and Hove Council

Leanne Boddy, East Sussex County Council

Ellie Bray, Sussex Partnership NHS

James Wilson, Brighton and Hove Council

Vicky Hickson, Brighton and Hove Council

Event Facilitator

Elizabeth Mackie (EM), Healthwatch East Sussex

Care Homes Wellbeing Project Team

Dr Padmaprabha Dalby (PD), Consultant Clinical Psychologist

Deborah Becker (DB), Care Homes Wellbeing Project

Megan Darbyshire

1 Introduction to the Webinar

Elizabeth Mackie opened the meeting, thanked everyone for attending and reminded the attendees that the meeting was to be recorded and notes taken. Elizabeth explained that this was the second of three webinars in collaboration between Sussex Partnerships Trust, Care for the Carers and Healthwatch. Elizabeth explained that she was from Healthwatch East Sussex, and that there were also people from Brighton and Hove, and people from health and social care teams present.

Elizabeth explained that this was an open meeting and noted that there had been recent national announcements which had given little detail.

2 Setting the scene

Dr Padmaprabha Dalby welcomed the attendees and explained that she was a clinical psychologist working in the Sussex Partnership Foundation Trust, and that together with Deborah Becker and Megan Darbyshire, she ran a care home wellbeing service, a response to trying to support care home communities during the Covid-19 pandemic.

Padma explained that the aim of the webinars had been to provide clear information to family carers and provide a space for carers to get support for particular questions and struggles. Padma noted that the first part of the webinar would consist of hearing from Public Health to get some clarity. Padma expressed her understanding of the difficulty in the long period of separation from people in care homes, and the uncertainty around that, and noted that they wanted to respond to the emotional and practical impact. Padma expressed their desire to provide clarity on new visiting regulations, discuss the approach to care homes accepting more visitors, and provide a space for discussion and support.

Elizabeth explained that Ross Boseley and Nicola Rosenberg were present as members of the Public Health teams in East Sussex, and Brighton and Hove respectively. Ross explained that his team had been supporting the care sector during the emergency response period of Covid-19 and expressed his understanding this period had been difficult on many levels and the measures difficult to adhere to on a human level. Ross noted his recognition of the hard work that had gone on in care homes throughout the crisis, and how effectively they had responded to often changing guidance. Ross explained that he could not yet confirm the details of the new government guidance around care home visitation. Ross explained that he worked for the Director of Public Health in the local authority, whose role had been leading outbreak control plans of Covid-19, including having the power to close care homes if necessary. Ross explained that they had taken a collaborative approach, making sure actions were in line with national guidance, whilst still being able to deviate from guidance based on local data and epidemiology.

3 Questions and Answers

Participants were invited to submit any questions using the 'Chat function' or indicate on screen if they would like to ask a question.

Advance questions not covered in the responses below can be found in **Appendix 2**

Elizabeth presented the questions:

Q. Do Public Health feel confident that care homes would be able to resume visiting as per the new guidance as of 8th March?

A. Nicola said that they would be ready in Brighton and Hove, due to the number of measures that had already been put in place, and that anyone with concerns could address them at their bi-weekly care home meetings. Ross agreed and stated that they needed to see further guidance to set expectations. Ross stated that care homes had coped well previously, and that they had a weekly meeting in East Sussex where organisations could get advice.

One of the attendees explained that her mother's care home had said that visitors would be allowed, but that they were waiting for further guidance to clarify the details, and explained that she would need enough advance notice to be able to organise visits.

Q. Would those visiting be needed to be tested before each visit, and asked how soon people would know that care homes could open?

A. Mike Derrick responded that guidance was expected the following Monday, and that he did not expect any of the guidance to be a big change from previous guidance. Mike noted that the logistics for visiting could be lengthy, which would put a constraint on capacity. Mike gave the example that in his service, with 40 residents and approximately 30 visiting families, they would expect to have the capacity for 6 to 8 visitors a day under new guidance. Mike explained that visitors would have to do a test every time they visited, and that this would take in the region of 45 minutes.

Elizabeth noted that comments were being made in the chat regarding how visits from relatives would affect the capacity and wait-times in care homes for visitors. Other comments noted included disappointments over care programmes failing to be individualised for residents who could not manage technology and asked if there would be support for care homes to carry out guidance. Nicola responded that there would, and that they always went through guidance to see what support was needed.

Q. Elizabeth asked if they published guidance for families and relatives?

A. Nichola responded that they have a webpage that linked to, and explained, guidance, and noted that they had agreed to have similar policies to neighbouring districts provided they did not have high rates of confirmed cases.

Q. Elizabeth asked when more than 1 person could visit?

A. Nicola responded that they did not know, but that it would probably follow the lockdown guidance of people being able to meet indoors from May 17th.

Q. Elizabeth asked if care home staff were helping residents to engage in more video and other connections with relatives?

A. Nicola explained that care homes were doing a lot on this point and that funding supported these initiatives. Ross noted that some care homes were working with creative agencies to find ways to reduce social isolation.

Q. Elizabeth asked why testing could not be done at home?

A. Nicola explained that tests were most effective when administered by a trained individual. A family carer noted that some relatives of those in care homes, like others present on the webinar today, had medical backgrounds, and so asked why they could not administer their own tests and reduce the wait time? **Nicola stated that this was a good question, and that she would formally raise it with Public Health England.**

Q. Elizabeth asked if visitors who had been vaccinated would be given special consideration?

A. Nicola responded that they would not, as there was not yet enough evidence, and vaccines were not mandated. Nicola stated that there was increasing evidence of the efficacy of vaccines, but that she did not know if special consideration would be given in the future to those who had been vaccinated.

Q. Elizabeth asked what the local incidence of the virus was in care homes at that time.
A. Nicola responded that it was extremely low, due to the success of vaccination and the lockdown, and that in East Sussex and Brighton and Hove, the overall rate was 54 per 100,000.

Q. Elizabeth asked Mike how many healthcare visits had been halted during the pandemic.
A. Mike responded that visiting health professionals and social workers had been able to make important visits throughout the pandemic, based on the level of risk.

Q. Elizabeth asked if there was likely to be a requirement for care home staff members to be vaccinated?
A. Nicola responded that they did not legally mandate anyone to have a vaccine, they just provided information and encouraged uptake.

Elizabeth noted that there was a question around residents getting the second dose. Nicola responded that they should be booked in. A delegate commented 'that getting the vaccine did not mean freedom from Covid-19'.

Q. Jo Egan was from Care for Carers asked the panel what recourse there was to challenge care homes which were not doing what was described, other than speaking to the home directly?
A. Nicola stated that they should contact public health teams and the local authority, and that they followed up every query around this, and supported homes and carers that raised issues. Mike noted that where care homes were not doing something, they would have a good reason. Ross stated that this was often a result of pragmatic decision-making when complex decisions presented themselves, such as many residents having symptoms leading to a home being temporarily closed.

Q. Elizabeth asked if visitation length would still be limited?
A. Ross explained that the details on this had not yet been released, and that it would depend on the capacity and situation of each care home.

Q. Elizabeth asked who relatives could contact if a care home seemed to be choosing not to offer visiting options?
A. Ross stated that this would be local authority teams and explained that there may be a genuine reason or complex situation causing a care home to do this.

Ross stated that the visiting pods that had been at some East Sussex care homes in December could be seen as being indoors and stated that this position was held largely due to the exponential rise in cases at that time. Ross stated that their position on these pods had loosened over time, but that they discouraged homes from using them, and recommended risk assessments if they did. Ross noted that there was not a ban on them, and that in December, they had been responding to the situation in Kent.

Elizabeth noted that the time scales for the second vaccine had not been discussed, and asked Isobel Warren from East Sussex County Council to comment on the matter. Isobel stated that the current focus for vaccination teams was to ensure care home residents

had received their first dose, and that second dose plans would then be made. Isobel went on to say that the plans for second doses were made between 9 and 12 weeks from the first, but that the efficacy wouldn't be affected if the second dose were administered 13 or 14 weeks after the first. She stated that, ideally, the same team would administer the second doses as administered the first, and that people would be encouraged to return to wherever they had received their first dose for their second.

Elizabeth shared an example whereby there was a resident who was under a Deprivation of Liberty Safeguards (DoLs) and was not receiving mental health support and asked who the family should contact to raise this? Nicola responded that they should contact the local authority, and that the guidance was to make decisions around best interest. Mike stated that there were two types of visit, firstly the handhold visiting, but also visiting for those involved with providing close contact care, such as dressing, eating and washing, who would be on the same testing and Personal Protective Equipment (PPE) regime as care home staff. Mike stated that care home staff were currently tested three times a week. Mike stated that they would have to wait for guidance to clarify this type of visit, but that it might be a different or better option for relatives in some circumstances. Mike stated that the location of the test was related to guidance that people were not allowed to do tests at home. Mike stated that care home staff were only recently allowed to administer tests at home. Mike stated that it would be good to be able to administer tests at home, to avoid wasted long journeys.

Elizabeth stated that they would get answers to questions regarding big care home organisations and mandating vaccines, and thanked attendees for their questions. The Q&A session was concluded, any questions remaining will be picked up in the closed session (Part 2) due to sensitivities of the content.

4 Sussex Partnership Foundation Trust Overview

Elizabeth introduced Deborah Becker to present slides. **(Please Appendix 1)** Deborah explained that she was an occupational therapist who worked with Padma, and that she wanted to discuss the impact on those living in care homes of the long separation from loved ones, and noted that this would soon be subject to change. Deborah noted that everyone had experienced unprecedented changes to life during the pandemic, and that it had had a distressing impact on carers. Deborah explained that the sense of loss felt by carers was similar to that of bereavement, as their daily lives and wellbeing had been affected and they had been unable to provide personal care. Deborah noted that this lack of love and support had led to feelings of isolation and loneliness, and that the importance of that human contact and social connection was clear in maintaining relationships and a sense of community. Deborah stated that family carers needed a safe space where they could acknowledge their struggles and fears. Deborah noted that relationships were important in determining the quality of life for residents, and that creative solutions would be needed for building these relationships after a sustained period of separation. Deborah stated that relatives would be encouraged to talk to care home staff to find out what to expect, and to consider creative ways to ensure their relatives recognise them, especially in PPE, such as familiar clothing, perfumes, music,

or a lanyard photograph. Deborah stated that she hoped there could be further discussion on this matter with carers in part 2 of the webinar.

Elizabeth thanked Deborah, Ross and Nichola and all the attendees for their contributions to the meeting and stated her hope was that they could have another meeting when they had more detail about the incoming guidelines.

Meeting concluded at 15:47 - Health and Care professionals left the meeting

Conclusion

Healthwatch and partners supporting the Wellbeing project team would like to extend its thanks to Public Health Colleagues from Brighton and Hove, East Sussex and all health and care partners for their empathetic and sensitive manner they listened to carers concerns and shared, often difficult to hear information.

The subject of carers feeling ‘disempowered’ during the pandemic also came across strongly; initially raised in the first webinar, further explanation can be found in **Appendix 3**

Key themes emerged from discussions in Part One:

- Overarching theme was that the sense of loss felt by carers was like that of bereavement, as their daily lives and wellbeing had been affected and they had been unable to provide personal care. This lack of love and support had led to feelings of isolation and loneliness, and that the importance of that human contact and social connection was clear in maintaining relationships and a sense of community.
- There is an urgent need for agencies to work productively together in the coming weeks to achieve a safe and sensible way to enable what the Government has stated can happen from 8 March (unless a home is in an Outbreak situation).
- There is a need for agencies to ensure family carers know and have access to Healthwatch and the CQC to raise any concerns arising from the changes from 8 March 2021 or in general.

Recommendations

- Family carers still have many unanswered questions and their voices need to be continually heard and sought by the system to ensure families can reconnect positively and safely by mutual agreement.
- Healthwatch in Sussex have drafted a Families Carers guide to visiting in Care Homes as described in the Guidance published 4th March 2021 to be shared by Care Support organisations and service providers. (Appendix 3)

Recording

To view the recording or watch again [please click here](#)

**Final East Sussex and Brighton and Hove webinar in series:
Wednesday 24th March - 3:00pm - 4.00pm
(Closed session 4.00 - 4.30pm)**

Timings may vary

Draft

Appendix 1

SLIDES

The impact of prolonged separation from relatives living in a care home on family carers



Deborah Becker
Sussex Partnership NHS Foundation Trust
Care Homes Wellbeing Project



Current visiting options



Pod

Outdoors



Window



The impact of prolonged separation on family carers

- ❖ Family carers of people living in care homes have and will continue to have to cope with visiting restrictions for some time
- ❖ Carers may have common feelings akin to those experienced following a bereavement - grief and loss
- ❖ This separation and loss may have had a significant impact on family carers daily lives, their resilience and wellbeing
- ❖ Loss of being able to provide vital interaction, love and support for relatives may have led to feelings of isolation and loneliness



Promoting a sense of community and maintaining relationships in challenging times

- ❖ Family carers may seek a 'safe space' in which they can feel held so that they can acknowledge that they are not ok at the moment
- ❖ A space where alongside their concerns for their relative, they can share their fears and concerns for their own future
- ❖ Evidence shows that relationships between staff, residents, family, friends and the wider community are the most important factor in determining the quality of life of residents and is a shared commonality in challenging times



Preparing to Meet Again



Talk with care staff about what to expect and how to set up the visit

How will your relative recognise you through PPE? Try -

A photo on a lanyard

Appeal to the senses - a familiar scent, piece of clothing or shared music

Be prepared to talk and be with your relative without them immediately knowing you



Have simple aims – as you build up your visits over time, your regular contact and presence will have an effect

Appendix 2

Pre-webinar questions and answers

Q. How are Public Health/Local Authorities reaching in to help care homes to help the community/families around connecting and visiting going forward? Families are looking to public health to be accountable for ensuring fair practice in all care homes in East Sussex /Sussex. This is based on the need to provide hope to family carers who have tried everything to get a care home to enable safe visiting but have reached dead ends consistently.

Draft

Appendix 3

Relatives: *Impact of separation from care home residents*

Disempowerment

The issue about relatives being unable to visit family members/partners in residential care is not simply to do with aspects of loneliness and lack of social contact. These relationships are more often than not rooted in a long history of essential practical care both in the time prior to residential care and following transfer to it.

Prior to residential care, family carers may have carried sole responsibility, over many years, for all aspects of care to do with that person. The deeper source of distress could be seen as the sudden disempowerment of family carers who, until lockdown were often key partners in the provision of care for that resident, such as:

- Facilitating communication & understanding between the resident and staff members e.g. providing background information and orientation references.
- Provision of personal & daily living care needs e.g. help with eating & drinking (including likes & dislikes), hair & facial grooming, fingernails, washing, dressing care to their relative delivering good quality care to that individual.

Relatives may provide this care as a pleasant way of passing the time when visiting their loved one, but they may also do it because of a concern or realisation that these aspects of care might not be done as well, or at all, if they did not do it themselves.

When relatives provide that kind of support, they are also well positioned to observe, monitor and advocate for, the care and wellbeing of that resident. They are an external witness to the operation of the care setting in relation to someone they know well.

Visiting bans have therefore severed those practical and observational care elements and left carers often completely disempowered from being able to provide or advocate for anything they believe are in the best interests of their relative.

This sense of disempowerment from their caring role can be increased by any sense that the care setting is under stress such as staff capacity, turnover, use of agency staff. For carers, these are all factors which increase the risk of their relative not receiving the attention which carers themselves are now prevented from providing. Likewise, from the resident's point of view, many will, at some level, have experienced that similar change or loss to the practical aspects of their care, as well as social disconnection from their close relatives.