

West Sussex Care Homes Wellbeing Project - Relatives and Carers

Zoom Webinar held on Wednesday, 24 March 2021 from 5:00 to 6:00 pm (Part 1) on

‘What could and should health and care organisations be doing to support relatives and carers?’

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)

Sonia Mangan, CEO, Carer Support West Sussex

Rosemary Pavoni, Care Home Owner and Chair of West Sussex Partners in Care

Daniel McIntyre, Public Health Consultant, West Sussex County Council (WSCC)

Lee Jenner, Adult Social Care Team (WSCC)

Jacqui Nettleton, Head of Integration, West Sussex Clinical Commissioning Group

In attendance

Pam Thomson - Carers Support West Sussex

Cheryl Berry - Healthwatch West Sussex

Liz Mackie - Healthwatch East Sussex, Project Lead

Event Facilitator

Katrina Broadhill Healthwatch West Sussex

Care Homes Wellbeing Project Team

Dr Padma Dalby Consultant Clinical Psychologist

Deborah Becker Care Homes Wellbeing Project

1 Introduction to the Webinar

Katrina Broadhill welcomed attendees to the webinar, noted these webinars are a valuable opportunity for family carers to ask questions and get information. Healthwatch hopes to sustain the connections facilitated by this series of webinars. The work has attracted interest from a university conducting a study, and Katrina will share this information with attendees.

Katrina asked the panel to introduce themselves.

Dr Padma Dalby is a Clinical Psychologist who has been running a Care Home Wellbeing Service for the last few months in response to the Covid pandemic. Rosemary Pavoni is the Chair of West Sussex Partners in Care and owns and manages a care home in Horsham. Daniel McIntyre is a Consultant in Public Health with West Sussex County Council. Lee Jenner is the Interim Commissioning Lead for Supplier Management & Quality Assurance. Jacqui Nettleton is the Head of Integration for West Sussex CCG. Sonia Mangan is the Chief Executive for Carers Support West Sussex.

2 Reflections from the Panel

Katrina asked panellists to describe what their organisation has been doing during the pandemic, what they would have done differently, the difference it has made, and to make a pledge going forward.

Sonia reported that Carers Support West Sussex currently supports around 30,000 carers of an estimated 120,000 in West Sussex. At the start of the pandemic, Carers Support West Sussex attempted to reach out to care homes to remind them that their organisation can support family/friend carers. Sonia also took carers' stories to Public Health to identify the key issues in terms of visiting restrictions. This was done jointly with Public Health, CQC, and Healthwatch.

Carers Support West Sussex also worked to help family/friend carers access iPads. Carers Support West Sussex has made a difference by joining the collective response with Healthwatch, the NHS, and family/friend carers. This has created a movement by bringing people's experiences to make sure things are done differently. Sonia

acknowledged that Carers Support West Sussex could have connected with care homes better, and could have been better connected prior to 2020. Sonia pledged that the organisation would reach out more to care homes in West Sussex to ensure that everyone in those homes knew that organisations like Carers Support West Sussex were available to help.

Padma works within a large mental health and learning disability trust, so it is important to work in partnership with carers. She described the ‘triangle of care’, which has the person receiving care at one point, their family and friend carers at another, and the professional provider of care at the third point. This triangle runs through all her work. Early in the pandemic, Padma tried to get funding to set up the Care Homes Wellbeing Support Service, but was only able to deliver the service from November 2020. This service serves the whole care home community, including residents, family/friend carers, and staff, and tries to support the communication and wellbeing of that community.

Padma stated that the webinars have been a privilege to be involved with. She has been able to directly meet family/friend carers, hear their stories, and see how they have supported each other in the second part of the sessions. Going forward, she is passionate to build on this work. The webinars have been a place where carers’ voices have been heard, listened to, and have been able to hold other organisations to account. Healthwatch has taken away issues raised by carers and lobbied on their behalf. They have created an environment where carers support each other and recognise the way carers’ organisations are there to support the carers of people who live in care homes.

Padma hoped that people attending the webinars have become aware of the support available, and more able to articulate the support they need. She will work across the health and care system to advocate on the behalf of carers and ask for more support and resources to meet their needs. The pilot of the Care Homes Wellbeing Project is ending, but Padma is exploring new ways to support that work going forward.

Deborah noted that coming to the Healthwatch webinars and listening to carers had informed the sessions she had run for care home communities. It has been important to maintain a sense of a connectedness while it has been challenging to do so. DB has worked with colleagues in care homes to manage this. DB thanked all attending family/friend carers for their openness, honesty, and time.

Daniel reported his focus has been on making care home environments as safe as possible so that visiting can take place. He has been working closely with the CCG and social care colleagues to control and manage outbreaks. Between December and February, Daniel was involved in outbreaks in 175 care homes, half of all those in West Sussex. This has improved more recently. The Council’s other role was to interpret and align the guidance from the government.

Daniel has also provided a daily picture of Covid within West Sussex. He acknowledged that the Council could have provided more timely guidance and communication. He commented that it has been difficult for carers and care providers that the guidance has come out so quickly, and with little turnaround time. Going forward, the Council will maintain their commitment to make care settings as safe as possible and enable carers and family members to keep visiting. Katrina commented that the public health team has also been working to open up individual homes that have been reticent about allowing visiting.

Lee stated the Council had issued millions of items of PPE through the Sussex Resilience Forums. They have individually supported care homes, particularly during outbreaks where large numbers of residents have passed away. Lee noted that West Sussex have disseminated government guidance with a local slant. This has hopefully helped make homes more accessible to families and carers. He noted that it would have been useful to have known how and when information would be communicated by the government. The Council has distributed millions in Adult Social Care grants, with almost 5,000 payments to individual care providers across Sussex to support them with additional costs incurred by the pandemic. Lee pledged to continue this work, as the feedback from care providers has been positive, particularly around the new forum for care providers.

Rosemary noted that one thing gained from the last year has been a much better understanding and working relationship between care providers at West Sussex County Council. She emphasised the importance of communication and mutual support to ensure the best outcome for service users, families, and carers. Rosemary noted care homes have a responsibility to staff to ensure they are working in safe environments. She said care home are still afraid of Covid outbreaks, and are not yet out of the woods. There are currently four types of visitors to care homes. The first are essential visitors, who take on the role of carers and are treated as members of staff. They can have PCRs and lateral flow tests. The second are nominated visitors, who are allowed to visit their loved ones. The third are window or screen visitors. The fourth are people visiting their loved ones at the end of their life.

Rosemary stated the guidance received is often conflicting. It is about working within the guidelines to the best interest of the service users, staff, and family. She emphasised this was about communication and partnership, and working through problems. She pledged to continue the good things learned from the last year. Katrina agreed that communication was incredibly important.

Jacqui stated that she had lost her mother to Covid, and had experienced the difficulties around visiting in care homes even at the end of life. She expressed that she felt deeply for everyone going through that experience.

Jacqui noted that the CCG had tried to make the communication between the guidance and care homes clearer. The vaccination programme has been rolled out rapidly, with a 90.6% vaccination rate across residents of West Sussex. 98.9% of care homes have been visited for the first vaccination. This has led to a reduction in the community infection rate. There are now only 11 outbreaks in care homes. Jacqui expressed hope that as the outbreaks continue to decline, this will help care homes have the confidence to facilitate visits.

3 Audience Questions and Discussion

Katrina noted the government's road map proposes things will be more open from (not before) June 21st. She queried whether as restrictions relax, care homes will remain subject to restrictions, and if so, whether these would vary according to each home (this was a question received in advance).

Daniel stated that it was about data, not dates, and that the changes would take place from no earlier than June 21st. He noted that Covid is a rapidly changing landscape. The decline in outbreaks demonstrates the impact that the vaccine has been having on care homes in West Sussex. June 21st remains a long way off. If the decline continues, it is likely that there will be an easing of restrictions, supported by vaccinations and the community testing programme. He emphasised, however, that unexpected events may still occur. It is likely that there will still be an emphasis on hands, face, space, as well as other ongoing guidance.

Katrina stated that the second round of vaccinations is starting to happen. She queried when visitors such as hairdressers will be able to go back into care homes to support residents (again a pre-event question).

Jacqui noted that there is a national date for this. Care homes are private providers, and it depends on how secure they feel about letting these visitors in. They will each interpret the government guidance. She stated that many care homes have been through trauma, having lost residents they care for deeply. She acknowledged that the vaccination programme is bringing down the transmission rate, as well as ensuring those who do catch Covid wouldn't be as ill. This will filter through to visiting. Jacqui noted that as statutory providers, the CCG can only influence this a certain amount. In the end, it is up to the managers and owners of care homes.

Sonia stated that family/friend carers also care very deeply for the care home residents. She referred to Padma's concept of the triangle, noting that family/friend carers want to be part of the solution. They want to be invited to speak with the care home providers about what the solutions are.

Katrina noted that the connections made with family carers are a fantastic asset to help decision-makers. Care home providers should come together with family/friend carers and be open and transparent. Katrina queried whether there is a local communication protocol for homes to communicate when there is an outbreak.

Lee stated that care homes will have their own policy, but are expected to communicate with anyone who may want or need to visit. They report regularly to the Public Health system.

Rosemary noted that, under CQC regulations, care homes are required to be open and transparent in their duty of care. It would be the legal responsibility of care homes to tell families.

Slobodanka Rangelov noted that it was important that both patients and carers were involved in decision-making as equal partners.

Zoe Fry (owner of Valerie Manor) stated that it could be daunting for some managers of homes to work in partnership. Skills of Care are seeking providers who've managed to do this with both health care professionals and relatives. Zoe noted that she makes her decisions and writes policies with relatives. Skills of Care are releasing a video to help providers who are struggling to do that. Katrina asked Zoe to share this when it is available so Healthwatch could forward to family carers (a link to this will also be made available on the website.)

Suzana Sheppard (Carers Support West Sussex, and friend of a carer) noted that the biggest concern for family carers is whether the vaccine will be mandatory for care home staff. The second biggest concern is the frequency of visits, and what a family member must undergo in order to visit. The third biggest is how each care home will interpret the guidance. It is concerning not to know what is the basic acceptable level for care homes.

Rosemary emphasised that no care home goes out of their way to deliberately misinterpret the guidelines to their own advantage. They receive multiple, conflicting guidelines, which means interpretations can vary. She noted that it has not yet been decided whether vaccines will be compulsory. Care home providers are worried that this will mean they lose their staff. Making the vaccine mandatory will raise human rights issues. This will be a difficult problem going forward.

Dame Philippa Russell (Chair of Carers UK, and a family carer) agreed, noting that there is an ongoing debate about whether vaccination should be mandatory for certain occupations. In London, the number of refusers in care home settings is going up, mostly among younger people from particular ethnic minority backgrounds. She also stated that there is a debate about whether those with relatives in supported living can mandate that anyone coming into contact with their relatives must have had a vaccine. Requiring people to have a vaccine may be viewed as discriminatory. Philippa anticipated that there would be a public consultation about this soon.

Katrina thanked the panellists for attending, and closed the first part of the meeting.

(Meeting concluded at 18:00)

You can watch back the webinar by clicking [here](#).