

Healthwatch in Sussex - Care Home Wellbeing project: Support to Relatives and Family Carers during the COVID-19 Pandemic

January to March 2021

Working with relatives and carers with family and/or friends in care homes to help understand any issues, hear any concerns, and provide advice and information. To find out what support health and care professionals can provide relatives and family carers as the pandemic continues and to make recommendations for care after the pandemic.

Background

A series of webinar events were organised between September 2020 and March 2021 on behalf of informal carers (families and friends) of care home residents. Their purpose was to:

- Share unpaid carers' views and experiences of visiting (or not visiting) their relative or friend in a care home during the pandemic.
- Enable unpaid carers to ask questions and gain answers from health and social care representatives about current and future access to care home residents.
- Have access to timely, accurate information around official and local visiting guidelines.
- Raise any concerns about wider care home service improvement; and
- Influence decisions made by health and care leaders during the pandemic.

Overview of the project

Healthwatch in Sussex (East Sussex, West Sussex and Brighton & Hove) together with [Sussex Partnership NHS Foundation Trust](#) (SPFT), [Carers Support West Sussex](#) and [Care for the Carers](#) hosted six webinars over three months at the beginning of 2021 for relatives and carers with loved ones in Care Homes.

Conversations and connections were established at a pilot Sussex wide webinar event in November 2020 ([Staying Connected with loved ones in Care Homes during the pandemic](#)) and these continued into the 2021 webinars. 100 people registered for the “*Staying Connected Webinar*” and participants included carers, representative bodies,

commissioners and front-line staff from health and care services. In December 2020, Healthwatch was approached by the Sussex Care Home Wellbeing Project lead Dr Padmaprabha Dalby, Consultant Clinical Psychologist at Sussex Partnership NHS Foundation Trust (SPFT). Healthwatch were asked to extend the reach of their project by increasing engagement with relatives, family carers and carers' support organisations.

The project ran to the end of March 2021 to support those possessing relationships with care homes within the context of the Covid-19 pandemic. It worked with staff primarily but was also concerned with the wellbeing of the whole community - staff, residents and their families. The project was delivered by:

1. Dr Padma Dalby Consultant Clinical Psychologist
2. Deborah Becker Care Homes Wellbeing Project

How did our early engagement with carers inform this project?

Healthwatch coordinated three informal online forums during July and August 2020, to provide a space where carers could express their concerns and where we could listen to their views and experiences. During these conversations, and through conversations outside these forums via email and written letter, we heard the following:

- Access to residents varied from care home to care home, some families were allowed to see their loved ones in the garden and others were denied access altogether.
- The negative effects of separation on carers' and residents' wellbeing was significant.
- Communication from care homes varied, with some regularly keeping carers in touch with what was happening in the home, and other carers not hearing anything; and
- Guidance for care homes (especially in relation to visiting) from government and the Clinical Commissioning Groups (CCGs)/public health teams lacked clarity, were inconsistent and sometimes not forthcoming.

In August 2020, Healthwatch East Sussex asked Care for the Carers to carry out a survey with family carers to further explore their experiences. You can read the key findings and recommendations here: [Care Home Families & Friends Support Project](#). Overwhelmingly, we heard from carers the importance of being kept up to date with changes occurring in care homes as the pandemic progressed.

“

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

”

This early insight helped frame our initial webinar delivered in November 2020 but also informed planning for the Care Home Wellbeing webinars in 2021.

The webinars planned for January - March 2021 were co-designed with carers to provide:

- Six place-based webinars over three months (three in West Sussex and three in East Sussex, including Brighton and Hove).
- Topics important to carers to include going forward.
- Access to an open forum where health and care partners could provide up to date information and respond to any questions or concerns from carers (Part1); and
- A safe and confidential platform for carers and carers' support organisations to share any emotional and wellbeing support needs (Part 2).

Three topics were identified as the themes for each month (and these were:

1. The vaccination programme and visiting.
2. The impact that long-term restricted visiting/separation from loved is having on families.
3. What health and care partners could and should be doing to support relatives and family carers?

Dame Philippa Russell, a family carer and vice president of Carers UK assisted in the co-design of this activity and describes the aims of the webinars in this video:

<https://youtu.be/eFsscj9EKwc>

“

Family carers comment from our November webinar... *'apart from this forum no help or advice'*

”

The webinars



January 2021 focus:

The vaccination programme and visiting: ‘Vaccination brings hope, but it doesn’t solve the problem as soon as you receive it!’

News of the [Pfizer BeoNTech Covid-19](#) vaccine being approved was announced prior to our first round of webinars in January 2021, which stimulated lots of discussion and questions from carers.

- Notes from [the West Sussex Webinar](#)
- Notes from the [Brighton and Hove and East Sussex Webinar](#)

Key themes emerged from discussions during Part One of these January webinars:

- Pleased the vaccination roll out in Care Homes is going well and on track.
- Disappointed carers cannot be vaccinated within the same time frame as their relative, cared-for person.
- Unpaid carers have to wait until Priority Group 6 to be vaccinated - causing lots of distress.
- Welcome more communications/updates for relatives/carers.
- Include FAQ’s for Relatives and Carers in local updates.
- Concerns around people living in sheltered accommodation, supported living etc. getting the vaccine and wider care settings.
- Uncertainty around when visiting will resume.

February 2021 Focus:

The impact that long-term restricted visiting/separation from loved ones is having on families! *'Care Homes must be helped to re-open to meaningful visits by March'*

Family carers still had many unanswered questions, and their voices needed to be continually heard and sought by health and care partners to ensure families can reconnect positively and safely by mutual agreement.

- Notes from [West Sussex Webinar](#)
- Notes from [East Sussex and Brighton & Hove webinar](#)
- Watch again the webinar from [East Sussex and Brighton and Hove Webinar](#)

West Sussex also published in early March the following guide for carers after new guidance was published: Supporting a safe return of family and friends to Care Homes

Key themes emerged from discussions in Part One of the February webinar:

These were by far the most emotionally charged of the three webinars (in both East and West Sussex), with often difficult experiences being expressed, highlighting the need for empathetic and sensitive responses from health and care partners as they listened to carers' concerns.

The subject of carers feeling 'disempowered' during the pandemic also came across strongly; initially raised in the first webinar. Other themes raised included:

- Overarching theme was that the sense of loss felt by carers was like that of bereavement. Daily lives and wellbeing had been affected and they had been unable to provide personal care. Losing access to the usual and well understood means of expressing love and support led to feelings of isolation and loneliness for both relative and resident. The importance of human contact and social connection was clear in order to maintain relationships and a sense of community.
- There was 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 had stated could happen from 8 March (unless a home was in an Outbreak situation).
- There was a need for agencies to ensure family carers know about and have access to Healthwatch and the Care Quality Commission ([CQC](#)) so they may raise any concerns arising from the changes being introduced from 8 March 2021 or in general.

March 2021 Focus

What could and should Health and Care Partners be doing to support relatives and carers?

The final March webinar wanted to hear from carers about their views on what should health and care partners be doing as part of an ongoing support to carers around visiting arrangements.

We also asked health and care partners to describe:

- What their organisation had been doing during the pandemic?
- What they would have done differently?
- The difference their work had made; and
- To make a pledge going forward around future support for carers.

Attendance from health and care partners across the two webinars held in East Sussex/Brighton & Hove and West Sussex varied significantly.

In East Sussex we heard from a carer what it was like to reconnect with their loved one in a care home and from other carers via an online poll asking how many of them had been able to visit since 8th March when some restrictions were lifted. This included a pre-webinar poll circulated to 100 carers which asked if felt their local health and care systems were actively enabling and supporting visits. Of those responding:

53.85% said they felt their local health and care systems were actively enabling and supporting visits, and this is an area they will be working on going forward.

There was also a pledge on behalf of Public Health teams in East Sussex to:

- Support family carers in the future.
- Continue to support care homes through the next stages of the pandemic.
- Ensure every effort is made to maximise vaccine uptake and promote it amongst care homes and carers.

The full list of all partner's pledges can be viewed in the notes below from each of the webinars together with watch again options.

- Notes from [Healthwatch West Sussex Webinar](#)

- [Watch again](#)
- Notes from [Brighton and Hove and East Sussex Webinar](#)

Summary

In summarising the learning from across the three webinars, Healthwatch in Sussex would recommend Health and Care organisations

- Share timely National Guidance updates with relatives.
- Follow through pledges made during these webinars.
- Encourage shared learning across Sussex between health and care partners.
- Care Home providers to share good practice.
- Continue with the option for Zoom ‘visiting’ alongside face-to-face visits; and
- Keep the ‘good practices’ identified in these webinars.

What next?

For Healthwatch:

1. A commitment to ‘Keeping the communications going’ Family carers joining the webinars across Sussex wanted to keep the communication channel ‘open’.

How we propose to keep in touch with family carers/relatives:

- Share our overarching report.
- Share updates on changes in visiting guidelines.
- Meet again in 3 months’ time in July 2021.

A commitment to continued engagement with health and care partners and providers to:

- Follow up on any pledges made!
- How partners and providers are maintaining ongoing dialogue with carers and sharing timely updates on changes to visiting guidelines.
- To invite health and care professionals and providers to the ‘meet again’ event in July.

Adding value and achieving influence

Healthwatch has presented this work to the Outstanding Society in May 2021, to demonstrate good practice in engaging with informal carers. The Outstanding Society are a group of providers that have achieved outstanding ratings at their service. They support

care home providers to achieve ‘good’ and ‘outstanding’ ratings with CQC. Zoe Fry, owner and manager at Valerie Manor care home in West Sussex presented at the webinars and Chairs the Outstanding Society meetings. [Watch again](#) as Jo Tuck from Healthwatch West Sussex promotes the learning from our webinar events.

Ongoing feedback on carers and care homes supported Healthwatch England to publish updated guidance: [COVID-19 What you need to know when visiting a care home.](#) This update also included the [guidance for supported living settings.](#) Discussions, across all the webinars made references to advice, information and support being made available to everyone with loved ones in all care settings.

ITV Meridian also ran a feature [Care home visits and lockdown](#)

National research and guidance

The onset of the pandemic prompted many national organisations supporting older people (and more generally people in care settings) to respond to the pandemic. BMC Geriatrics looked at [Care homes, their communities, and resilience in the face of the COVID-19 pandemic](#); an approach, Healthwatch too were keen to promote, looking at and working within the community and building resilience of family carers/relatives. Early findings of this qualitative research concluded:

...how interdependency between care home organisations, the surrounding community, and key statutory and non-statutory organisations beyond their locality, shaped decision making and care delivery during the pandemic. Recognising these interdependencies, and the expertise shown by care home managers and staff as they navigate them, is key to providing effective healthcare in care homes as the pandemic progresses, and as the sector recovers afterwards.

The Alzheimer’s Society also provided tailored guidance [‘Visiting a family member with dementia in a care home during coronavirus.](#) This came about following concerns raised by the Alzheimer’s Society to combat people living with dementia ‘dying from loneliness’.

The following organisations also produced similar information:

Relatives and Residents Association [End Isolation in Care](#)

Carers UK [supporting care home visits to continue](#)

Evaluation of the webinars

Carers were invited to take part in telephone interviews to share their evaluation of the webinars, together with suggestions to improve forthcoming events and inform agenda planning. Interviews were undertaken by Carers' support organisations.

“

I felt listened to and it's good to have the opportunity for carers to talk. Important that these sessions are happening.

”

Dr Padma Dalby, Consultant Clinical Psychologist at Sussex Partnership NHS Trust, remarked that it had been a privilege to work with Healthwatch and carer organisations to meet so many carers and thanked everyone for being so open in sharing their experiences.

Other comments included:

From a family carer

“In relation to the Carers Webinars, I genuinely believe that it was directly due to the co-ordinated working of Healthwatch, Carer's forum, Dementia Groups, Alzheimer's Society and being able to clearly express the impact on people in care homes as well as relatives we achieved a clear direction from Government that the visiting should be introduced as soon as possible, and that 'touch' was so very important for both. Personally, I am delighted to be able to see my mother regularly again and be classed as 'an essential carer' so have regular testing and am treated like staff, meaning I can see her for short periods and assist in her care. This has enabled me to reconnect to her in a way I would never have been able to with weekly visits.”

The care home challenge: building bridges between relatives, residents and care homes in a pandemic

“As a family carer myself (and as Vice-President of Carers UK and a Patron of Carers Support West Sussex), I have warmly welcomed this series of webinars, co-produced by Healthwatch East and West Sussex and Brighton and Hove and offering a 'safe place' in which to explore the challenges in both protecting residents in care homes and enabling them to enjoy a good (and safe) life. Covid-19 has had devastating consequences for care homes and all who live and work in them. Very importantly, many relatives have loved but grieved for their family members who seemed to be living in virtual solitary confinement.”

Human contacts matter for all of us. But for frail older people, the loss of family and friends often has a devastating impact on their wellbeing.

The webinars offered a unique and safe forum where the challenges of safety versus loving long-term relationships could be explored across all interest groups. Relatives were offered extra confidential sessions to share experiences and public health officials could offer necessary updates and advice to all viewers. Care homes themselves shared their issues and we heard of creative and innovative ways in which some were able to support family and residents' contact and relationships. We are now seeing further relaxation of the rules, the category of 'essential caregiver' will allow some relatives to once again share the care of their loved ones. There are still questions to be answered but I am confident that the webinars have opened up an ongoing discussion and showed that co-production is the best way of shared problem solving."

Dame Philippa Russell, family carer, Vice President Carers UK

And finally, from our local carers' support organisations who were critical to the success of these webinars; **Jo Egan from Care for the Carers shared:**

"Care for the Carers was delighted to work in partnership with Healthwatch, Sussex Partnership NHS Foundation Trust and Carers Support West Sussex on this important project. As a result of the project, we heard from a key cohort of hidden carers, those who care for a friend or relative living in a care home, many of whom were struggling to access timely and accurate information and feeling powerless and isolated amidst the restrictions of the COVID-19 pandemic.

The project enabled us to amplify carers' voices to local decision-makers, to provide supportive spaces for these carers to be heard, and to provide timely and accurate information to carers at a crucial time. We were pleased to utilise the project to remind carers in East Sussex that Care for the Carers is here for them, and to encourage all East Sussex carers to get in touch with us for information, advice, guidance and support."

Sonia Mangan from Carers Support West Sussex added:

Like Phillipa and Jo, I and our team valued supporting carers in the webinars. It is a privilege to hear carers voices. However, the pain that carers expressed about visiting restrictions for their relatives or friends living in care homes is something that will continue to stay with me long after this experience of living through a pandemic is, hopefully, a distant memory. As a Charity team we heard it daily as well as part of this process.

I have had nothing but admiration for the manner in which all parties who have tried to navigate the restrictions and the fear we have all had for the very vulnerable in our society. But it was evident that we just need to do it better in the future.

My pledge as a CEO for an independent Charity supporting unpaid carers living in glorious West Sussex is keep on bring the voices of carers to those who are able to learn the lessons from this and ensure that it does not happen for others in the future.

I am leaving the last word to someone who chose not to attend the webinars whose voice, like others, needs to continue to be heard so that we all commit to making a difference and make sure there is not a next time.

...No doubt everyone there (webinars) will be genuinely well intentioned but ultimately, the most interested person in my husband's welfare is me. In other words, I am the keenest one to keep him safe and also not to catch the virus myself. So, why is everyone telling me that the reason for keeping us apart is to protect him? It makes no sense and it hurts every second of every day.

Contact Details

To keep the conversations going as our care homes and the system recover from the pandemic, please contact:

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Making a complaint: [Find out about our complaints process](#) or email ihcas@healthwatchwestsussex.co.uk

Care for the Carers East Sussex

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