



Staying Connected Webinar Report

December 2020



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1. Executive Summary

During the COVID-19 pandemic there have been considerable challenges across Sussex care homes, including how to keep families in touch with their relatives.

On the 10th November Healthwatch in Sussex¹ hosted an online webinar for families and friends of care home residents. It explored the impact and potential solutions to the separation of care home residents and their loved ones in a pandemic.

This event was attended by 90 people, made up of members of the public, representative bodies, commissioners and front-line staff from health and care services.

We heard emotional accounts from family carers, how care homes were going that extra mile to keep families connected and from support organisations and the impact on many families when support is reduced, including:

- From family members whose visiting had reduced from 5 or 6 times a week to nothing for 17 weeks, and the devastating impact on not being recognised by their relatives when visiting again for the first time.
- The excellent initiatives some care homes were developing to ensure families and friends could stay connected; and
- From support organisations, about the deterioration of mental and physical health of care home residents as a result of reduced family interaction and support.

The webinar provided lots of opportunities for questions and discussion, many questions covering a wide range of topics were forwarded to Healthwatch in advance and others were stimulated by the presentations; a sample included:

- Personal Protected Equipment (PPE) - and why relatives wearing PPE can't interact with residents in the same way the staff wearing PPE can? i.e. scope for identifying relatives as 'key workers' to facilitate access.
- Why councils and the NHS pressured care homes to take back residents without safeguards to ensure that they were not COVID-19 positive.
- What support Public Health teams can and are offering to care homes; and
- What arrangement will be in place for Christmas? (New guidance issued 1st December 2020 Arrangements for visiting out of the care home (new): <https://www.gov.uk/government/publications/arrangements-for-visiting-out-of-the-care-home>)

The webinar received positive feedback from relatives, those representing support organisations and key health and care partners. Healthwatch in Sussex is continuing to work with all parts of the system to ensure the voices of relatives and residents continue to be sought and heard. All parties welcome the

¹ Healthwatch East Sussex, Healthwatch West Sussex, Healthwatch Brighton & Hove

announcement of a vaccine roll out, albeit cautiously, however with winter approaching and high infection rates; there are still many difficult months ahead.

The report will be shared with all participants, key decision makers locally and nationally via Healthwatch England and the Care Quality Commission (CQC).

Next steps, Healthwatch in Sussex (HWiS) will:

- explore with Care Home providers the possibility of engaging with residents to gather their experiences using virtual resources following enter & view protocols.
- invite interested relatives to a discussion group to develop and progress the recommendations, provide detailed feedback to health and care partners and commence planning for a Sussex-wide learning event in January 2021.

Recommendations

1. The webinar presentations were recorded and should be viewed by health and care partners.
2. HWiS to build upon the connections established during the planning and delivery of the webinar and to continue to amplify the voices of families and residents.
3. HWiS to establish an informal ‘discussion group’ to sustain conversations with relatives, take forward recommendations and progress ongoing discussions as new guidelines in relation to Care Homes and visiting are announced.
4. HWiS and partners to share this Webinar report widely in order to influence the decision makers in planning for the future of residential care across Sussex.
5. HWiS and partners to continue to push for greater clarity on guidance for families around visiting arrangements.
6. HWiS and partners to encourage providers to adopt best practice examples of staying connected with families during the pandemic, considering the impact on both residents and relatives.
7. HWiS and partners to explore the suggestion that relatives be awarded key worker status to facilitate continued visiting of their loved ones in care homes.

This report captures the experiences of relatives and family carers, up to and including the 10th November. Responses to questions raised at the event

represented the guidance available to health and care partners and providers at the time of hosting. [Guidance Visiting Care Homes During COVID-19 Updated](#) 1st December and supersedes previous guidance on visiting policies.

2. Background

Healthwatch in Sussex (HWiS) is made up of Brighton and Hove, East Sussex and West Sussex work collaboratively to gather and generate intelligence on priority

health and care themes across Sussex to help inform plans to support the ‘restore and recovery’ of local health and care services.

One of our priority themes is capturing the views and experiences of families and friends with loved ones in Care Homes during the pandemic.

On 10th November 2020 Healthwatch in Sussex hosted a webinar for care home residents and carers together with health and care professionals and voluntary organisations. This event was part of a commissioned piece of work funded by Sussex NHS Clinical Commissioning Groups (CCGs).

The Covid-19 pandemic continues to have significant impact on residents, families, friends and staff connected to care homes Sussex-wide. There are around 800 care homes across Sussex and each local Healthwatch has a shared priority to review the impact of the pandemic on family carers and residents in their respective areas.

As independent organisations, Healthwatch offered care homes, their residents and families an opportunity to share their experiences and have their voices heard by decision makers and commissioners within the local and wider health and care system.

This report summarises the views and experiences captured through this process and provides a set of recommendations to influence and inform future planning, both in the short-term and when the pandemic subsides.

A multi-agency collaboration event on the theme of Care Home visits is being planned for January 2021 where all of our learning can be shared with participants and other stakeholders.

We know...

The arrival of COVID-19 resulted in many rapid changes across health and social care services, with one of them being the suspension of visits to care homes to protect residents, their loved ones and staff.

However, despite care home visits being permitted from July 2020, the sad reality for many has been that visits have continued to be restricted, resulting in detrimental effects on people’s health, welfare and wellbeing.

There are also many examples where care homes have gone that extra mile to accommodate visitors during the pandemic, as you will read about in this report, to help families stay connected.

3. Engagement Activity leading up to the webinar

During June, July and August each Healthwatch designed early-stage engagement activity to gather the views and experiences of relatives with friends or family in a Care Home, each applying different approaches to align with their local circumstances.

Healthwatch Brighton and Hove

Undertook in-depth interviews with family carers to capture their qualitative experiences - you can read the findings in Appendix 4.

Healthwatch East Sussex

Worked with [‘Care for the Carers’](#) to bring together a small number of family carers at a virtual ‘Coffee Morning’ to share their experiences and offer mutual support, and also conducted a survey which captured feedback from 62 family carer.

Through this online workshop, online survey and telephone discussions, family members and friends shared their personal experiences of care homes during the COVID19 pandemic.

Over half (53%) of family members and friends participating in the project reported a positive view of the how the care home of their friend or relative has responded during the pandemic, whilst over a quarter (28%) of family members/friends had a negative view.

The full survey report can be viewed [here](#)

Healthwatch West Sussex

Explored how care homes were supporting families to stay connected using social media. Read their findings [here](#)

Whilst this engagement undertaken by the three Healthwatch generated very rich feedback, a collective decision was made to ‘expand the reach’ of the engagement. This offered an opportunity for experiences of families and friends of those in Care Homes to be relayed directly to health and care services and wider support organisations.

It was clear from the initial engagement that a lack of clarity on visiting guidelines was a concern, so too was the percentage of families and carers support groups indicating negative experiences.

This was set within the context of a second wave of the pandemic and the likely ongoing restrictions placed on Care Home visiting, as well as coming into cool weather, resulting in some losing access to external visiting.

Healthwatch in Sussex agreed to host a Sussex-wide online webinar to bring together care home providers, support organisations and key health and care partners. The aim was to hear from family carers about their experiences, respond to their many questions and draw upon the learning. We wanted to identify any 'quick wins' and inform longer-term learning.

4. Developing the Programme

Healthwatch in Sussex (HWiS) worked with multiple health, care and voluntary sector partners in the months leading up to the webinar. An existing Sussex-wide group set up to oversee the care home crisis in Sussex agreed temporarily to act in an 'Advisory Capacity' to support the development of the programme and ensure adequate representation from across the sector would be available at the event. Their participation would help provide detailed responses to any queries or questions which arose during the event.

It was important during this planning process for HWiS to ensure our independence was not compromised and that the rationale for this event remained firmly embedded in amplifying the voices of relatives and friends of residents in care homes. Critical to its success was having the right balance of attendance between health and care partners and relatives, friends and interested members of the public.

Further assurances were sought and obtained from voluntary sector organisations and charities who could contribute to the webinar could also offer vital support to family carers attending the event in a safe environment.

HWiS extends huge thanks and gratitude to everyone involved in making the programme engaging, informative and of value to families who gave up their time to attend.

To retain our independence and neutrality, Healthwatch approached organisations and individuals with the skills and expertise in the field of residential services for older people and nursing care. However, we recognise the issues surrounding visiting any loved one in a residential setting extends beyond the remit for this activity. No family member was turned away.

Final Webinar Programme can be viewed in Appendix 3

5. Notes from the webinar and links to the recording

Amplifying the voices of Relatives with loved ones in Care Homes across Sussex

The impact of the Covid-19 pandemic on care homes, carers and care home residents has received considerable coverage in recent months. Concerns about infection among vulnerable people has led to many care home residents having little or no contact with their loved ones. This remains a significant issue across Sussex.

One Healthwatch in Sussex response to Care Home issues was the hosting of a [webinar](#) on the 10th November. This event was attended by 90 people, made up of members of the public, representative bodies, commissioners and front-line staff from health and care services. It explored the impact and potential solutions to the separation of care home residents and their loved ones in a pandemic.



Tuesday 10th November 2020 from 5pm - 7pm

Attendance List can be found in Appendix 1

Timetable for the event.

- Welcome
- Presentations
- Relative's Story
- What is the national picture like, what is the Relatives & Residents Helpline hearing and what could be done differently in the event of a second/third spike?
- Life at Valerie Manor during COVID-19
- Q & A /Discussion
- Summing Up
- Breakout rooms
- Next Steps - Reporting timeframes, Evaluation and follow up

1. Welcome

Alastair Hignell, The Chair, opened the webinar and noted the timing of the event given the recent announcement of a Covid-19 vaccine and the likelihood that care home residents and workers will be the first priority in receiving it. Alastair commented that while he has no recent experience of care homes, he is on the extremely vulnerable list due to having multiple sclerosis and myelodysplasia. Alistair explained that he understood the frustration of all those connected with care homes and that there is a shared philosophy to persevere and be positive.

Alistair highlighted that the purpose of the webinar was to look back at the first lockdown and look ahead to the second by listening to experiences from healthcare partners.

Working together will help achieve positive results. The recent media attention on care homes will help them shine a light on what has worked, the lessons learned, as well as highlight the support available to residents, relatives and care staff. Alistair noted the positive impact technology has in helping people stay in contact and allowing greater engagement for those in care homes.

Alistair noted that Healthwatch have engaged locally and with the government. This has ensured that they are included in considerations around the plight of those in care homes, commenting on the importance of patients, relatives and care staff being regarded in what happens next.

A poll was then held with attendees, asking:

Should a family member be given key worker status to enable them to continue to safely visit their loved ones in a care home?

The results were as follows:

- Yes: 85%
- No: 7%
- I don't know what this means for us: 8%

It should be noted the term 'key worker' was not defined but taken as the commonly recognised term implying those that we now realise we rely on, such as NHS and care staff, bus drivers, shop workers, etc.

Presentations STOP

2. Dr Mathew Thomas (MT)

Dr Thomas introduced himself as having been a GP for 30 years in East Sussex involved in looking after a care home with approximately 60 residents. Dr Thomas noted the emotional impact experienced by residents, relatives and care staff.

Looking at the updated government guidance received last week, MT looked at the levels of care around a person, from their family, to care staff, and then the NHS, adult social care, the [Care Quality Commission](#) (CQC) and others. The regulations recognise the importance of opportunities for visiting to take place, which is critical for the wellbeing of residents, and they set out measures that can be put in place to ensure Covid-19 secure opportunities to allow for a balance between the benefits of receiving visitors and the risk of transmission of Covid-19 to care staff and vulnerable residents.

MT next looked at the different issues that residents, relatives and care staff have had to contend with during the pandemic, including the loss of freedom, PPE, mental health and the hope for all wishes to be taken into account when caring for patients. The importance of IT was noted and how it has enabled residents and relatives to connect but has also allowed for care homes to connect with providers outside of their setting, such as other care staff and GPs.

3. Michael Derrick (MD)

Mike remarked that while care homes recognise the vital importance of visits, they are faced with the balancing act of protecting the most vulnerable people within the community.

Looking to the challenges faced by care homes, MD noted that they contended with numerous outbreaks in spring, increasing prevalence of Covid-19 locally in recent weeks and the additional winter pressures that are experienced every year. This huge, sustained pressure is alongside additional workload, changes in guidance and ongoing staffing challenges. MD explained that the National Care Forum has

put out a joint call to action with more than 60 organisations to ask for testing to be made available to regular visitors, provide more support for Covid-19 secure spaces, and provide insurance indemnity.

MD looked to the new government guidance provided last week (now superseded as of 1st December) to be used for the duration of lockdown. The use of separate visitor pods inside the care home that use full-height screens, separate entrances for visitors, no more than two constant visitors per resident, continued use of PPE and social distancing, booked visits only, and continued use of window visits where possible were all noted.

MD added that the guidance also makes clear that care homes regularly communicate with families, and while care homes are facing numerous challenges, he felt most care homes were managing to do this.

4. Lesley Meech (LM)

Lesley provided her experience as a relative, explaining that her mother had moved into a care home in 2015 suffering with Alzheimer's.

She soon felt part of the care home family and that her mother had always said she was well cared for and it was decided that short, frequent visits were more beneficial than long, occasional visits.

Lesley explained that lockdown saw her going from visiting her mother 5-6 times a week to not at all for 17 weeks, adding that the use of phones and iPads only confused her mother and therefore her becoming more distressed.

She noted that while the care home continued to communicate, she felt guilty and witnessed a deterioration in her mother's health where she no longer recognised her daughter. As her mother is now bed-bound, the care home manager has allowed LM to return to frequent visits providing she wears full PPE, stays in her mother's room and socially distances where possible.

Lesley commented on the time the care home spent on allowing her to visit but felt that this should mean that other care homes can find a way to allow relatives to see their loved ones during this difficult time.

5. Zoë Fry (ZF)

Zoe introduced herself as having worked at Valerie Manor care home for 15 years (she is also the owner) and explained that they started very early planning with staff, residents and relatives to prepare for the impact of Covid-19. There was an over-recruitment of staff and a spreadsheet was developed for recording the review of all residents and the effect on them if they didn't receive visitors.

Valerie Manor hold regular relative meetings to allow them to help with writing policies and procedures and to keep them informed of guidance changes. Looking

at the poll conducted earlier in the webinar, Zoe noted that her manager and deputy are attending the webinar with residents, who stated they are unsure if they want to allow visitors into the home, commenting that we all need to consider the anxieties of residents.

Zoe explained that they have introduced a wellbeing plan for each resident to look at their visiting requirements and a wellbeing coordinator role has been created. A call out to the local community was made recently for a 'DIY SOS' for a visitor pod, which will be opened on Thursday to allow for relatives to visit residents safely. Guidance has also been provided by relatives regarding audiology equipment.

Relative's meetings are also a time for sharing and a buddy system has been set up to put existing relatives in touch with new relatives. ZF added that they have also experienced issues regarding litigation, the change in legislation and finances. The care home chose to not take any new admissions for two months to allow for more space, but finances dictate that they reopen. They are now seeing empty beds for the first time and also paying for staff counselling.

6. Helen Wildbore (HW)

Helen provided an overview of the Relatives and Residents Association, explaining that they work for better quality of life for older people needing care, they look to raise awareness, influence policy and practice, and run a helpline.

Looking at concerns around keeping families in contact and the impact isolation has on older people, HW noted that some care homes are showing good practice, other families have little or no contact with loved ones. For many friends and family who visit regularly, practical as well as emotional support is provided, which helps relieve stress and supports communication. The helpline is now hearing about a deterioration of mental and physical health as a result of the reduced support, with some residents stopping eating, drinking, losing their speech, and giving up on life.

Some residents with dementia may be struggling to understand why relatives have stopped visiting and feel they've been abandoned or think that family members have passed away. Many residents are also seeing double isolation, both from friends and family as well as from other residents.

With the average length of stay in a care home being just over two years, many residents have passed away without the support and comfort of their loved ones. When relatives are allowed to visit, it is often very close to the end of life when residents may no longer realise, they are there. HW added that there has been a lot of anxiety experienced due to the sense of loss around the time that has been lost that can't be replaced.

Helen acknowledged the recent vaccine breakthrough as a medium and long-term plan, with the fear being that the situation won't change in time for a lot of

residents. Relatives are experiencing a huge impact on their mental health where they feel powerless as they watch their relative deteriorate. Staff are working through a particularly challenging time where they are attempting to fill the void left by friends and family while also coping with the loss of residents and colleagues.

Looking at what needs to change, Helen explained that in June they called for a strategy from the government on opening up care homes to help prevent a mental health crisis, but this still hasn't happened. HW commented that there has been inadequate guidance from the government regarding visits, and they have therefore set up the '[End Isolation in Care](#)' campaign to ask for better guidance and for the government to provide support and leadership to care homes to manage the virus safely.

130 organisations have also grouped together to call on the government to grant relatives key worker status regarding testing with the only commitment so far being to pilot the scheme. So far, no details or timeframes have been provided.

Q&A session - moderated by Lynne Phair - Independent Consultant Nurse and Expert Witness

Submitted question about key workers wearing PPE and why relatives wearing PPE can't interact with residents in the same way?

- Dr Thomas remarked that this was a difficult question to answer; they need to consider further how to practically put the latest guidance in place, however, he agreed it was reasonable for relatives to be able to interact in the same way.
- Lesley Meech (LM) added; that she has had some contact with her mother when going into the care home, which no one has objected to, but she ensures she has cleaned her hands well and her gloves are changed.
- Lynne Phair (LP) (Moderating) commented that the challenge is ensuring relatives use PPE correctly.
- Lesley responded that she has a clinical background but that the care home manager ensured she was using it correctly.

LP asked Mike Derrick (MD) what the financial and logistical issues are when looking at awarding key worker status to family members.

- MD noted the additional work in having visitors as they have had to open up a booking system, staff have to meet visitors, there's now cleaning in between visits, PPE is offered, and residents are supported when moving around the home.
- MD added that while they have had some funding support from government, it's not enough, but the main challenge is around the capacity for weekly testing.

LP asked Zoe Fry (ZF) if they would need additional financial support from the government to allow for family members having key worker status.

- ZF explained that they spent £30k on PPE before guidance was brought in and they have 28 days of PPE in place.
- ZF added that they currently go through 304 masks over 24 hours to keep 23 residents safe, with the allocation from government being 300 masks a week, although they currently only receive 200. Due to the number of empty beds they now have, staff will need to be furloughed due to previously over-recruiting, and while the NHS has suggested they contract the beds to them, their beds are quite expensive.

LP noted a question regarding local authorities and having designated homes for those with Covid-19.

- ZF commented that if a resident came out of hospital with it then she would want to support bringing them back to the home.

LP highlighted a question on councils and the NHS pressurising care homes to take back residents who are Covid-19 positive.

- MT responded that he was unaware of this and noted that Bexhill Care Centre has been set up to take positive patients.
- Debbie Young (DY) from West Sussex County Council added that there is a dedicated team dealing with designated accommodation as it's a requirement from government guidance, and while there is currently no designated accommodation in West Sussex, they are going out to the market this week.
- Samantha Williams (SW) from East Sussex County Council remarked that the designated care settings were an instruction to local authorities to identify care settings that could take Covid-19 positive patients. Some local care homes put themselves forward and they are now going through CQC assurance testing, but no additional national guidance has been provided on how to operationalise this. SW added that patients can be referred to Bexhill Care Centre but that they don't directly refer positive individuals as a council into designated care settings.
- Nicola Rosenberg (NR), a public health consultant for Brighton and Hove, added that they have not yet filled the instruction around designated settings and that this is still in progress.

LP asked what support public health professionals are offering care homes at this time.

- Nicola Rosenberg explained that they are working closely with care homes and huddles have been set up to allow homes to discuss carrying out risk assessments, address any concerns and for guidance to be shared.

LP questioned if someone with a lasting power of attorney has the legal right to take a resident out of a care home for a visit.

- Nicola Rosenberg responded that this is based on an individual risk assessment and would depend on the cases in the home, cases related to the individual and the rate of cases within the community. She added that the change in guidance last week superseded the previous guidance and means they are required to adhere to all legal frameworks in place and use a [dynamic risk assessment](#) approach.
- HW added that they have also published an explainer on the Relatives and Residents Association website on the law around [moving someone from a care home setting](#).
- LP noted that guidance on the [Mental Capacity Act](#) has also been provided.

Summing Up

Alastair thanked all contributors, noting that while this was a particularly difficult situation, they have to bear the legal aspects in mind, but they are all pushing in the same direction and could work it out by supporting each other.

AH closed the webinar session before attendees went into breakout groups to address further questions.

Breakout sessions:

1. NHS Colleagues Pan Sussex
2. Public Health Team
3. Local Authority & Care Home Representatives
4. Emotional and Mental Well-being Support

6. Themed Q & A Breakout Sessions

HWIS Care Home Seminar: NHS Colleagues Pan Sussex Q & A Session 1

Panel members: Mandy Catchpole, Clinical Programme Lead for Mass Vaccination, Testing and Infection Prevention and Katie Chipping, NHS Sussex Commissioners and Dr Tim Caroe (joined later).

Moderator: Elizabeth Mackie (HWES), **Notetaker:** Kate Richmond (HWES).

For questions relating to: **Infection, Prevention and Control, Testing in Care Homes and Personal Protective Equipment (PPE).**

Comments & Observations:

- a. “Guidance” differs to law or regulations in that it can be interpreted in different ways by each care home; which contributes to inconsistency among them in the access and visiting arrangements they provide.
- b. Guidance on procedures continues to change very rapidly, resulting in severe challenges for all services to keep abreast of it.
- c. The challenge of staying connected is further complicated by the conflict between general “guidance” and how to apply these to the needs of individual residents and staff. There are therefore significant problems for each care provider in interpreting and applying guidance.
- d. Challenges are faced by each care home on how to create a designated space; e.g. Many care homes have no garden or suitable outdoor space.
- e. Care homes have found creative ways of dealing with visits e.g.: some beautiful pods, but these are still physical distancing barriers which are very distressing to many individuals.
- f. The feelings expressed by family and friends of being “shut out” could be reduced by greater transparency of providers about the components of risk assessments.
- g. Care home residents are more at risk of catching Covid-19 and more at risk of dying from it. The most effective way of prevention is distance, handwashing, good ventilation, and staying in a “bubble”.
- h. Family and friends need to be made aware of any available support to help them manage the difficulties and distress resulting from enforced separation from their loved ones in residential care.

Questions:

- What exactly is meant by the term “key worker status”?

- What exactly could this status allow designated family & friends to do regarding visiting?
- Is “key worker” an appropriate term to use or should it be called something else?

Answers & updates:

- “Key worker status” is not at present specifically defined in a list of permissions. The term may have different interpretations according to individual care homes, or in different areas of the country.
- New guidelines are due out regarding dedicated visiting environments, but testing will be dependent of the application of [these](#).

Agreed Action:

- NHS & Social Care systems work to clearly define (and possibly re-name) the status and permissions of a family member or friend designated as having key worker status.

HWIS Care Home Seminar; Public Health Q & A

Session 2

Panel Members: Nicola Rosenburg (NR), Public Health Consultant, Soline Jerram (SJ), West Sussex County Council.

Moderator: John Routledge, (HWES) **Notetaker:** Vanessa Taylor (HWES)

Please find below answers to the questions posed before and during the breakout session. Also included are the chat comments from the breakout session.

When mother had Covid-19 she could not go to a home (from hospital) until she tested negative for Covid-19 yet we are told that after 10 days (or is it 14?) people can go out and about again and are told they are not infected. Again, I feel very confused as this is not consistent behaviour?

Question not answered

Q. If immunity does not persist after the infection why should a vaccine work? I was under the belief that vaccinations work by causing the same immunity response as you see with a real infection. Again, very confusing

A: (NR): Too early to say - NR to attend a Mass Vaccination Programme meeting this week to understand the programme etc.

Could my mother be tested for antibodies so that we can see if she is currently still immune which will reduce a bit of pressure/stress for all concerned and then maybe she can be visited after all. (I presume if she has antibodies, she can't catch it or pass it on).

A: (NR): Science not sufficient for the use of antibody testing only used for research purposes.

Questions on night:

Q. I would like to understand how Public Health can help care homes - some care homes struggling re Personal Protective Equipment (PPE) etc.

A: SJ (W SX) Answer: Guidance available to care homes. Risk assessments.

West Sussex Home has cases; Public Health (PH) notified - W Sx instant management meeting including care home representative, PH, Local Authority (LA) review nature and level of outbreak. Contact tracing secondary testing undertaken. Negative test retested after 7-days. If numbers rising and issues with key staff and care etc. management planning meeting to look at logistics and support for care home. e.g. assistance with Laundry when care staff off.

Other element gaining knowledge about best practice locally and updating and interpreting the guidance pick out key points to clarify to support Care Homes.

Comment: I was interested that Power of Attorney (PoW) is trumped by public health legislation?

Response: The local instant management team will make a decision -Team consists of representatives from all interested parties Local Authorities (LAs), Public Health (PH), Care Home Councils all at the table. It is too simplistic to say one piece of legislation takes precedence.

Q: If we are told to keep 2-meters away, wear masks (Positives and Negatives) and protected by a Perspex screen; why is visiting such a risk? I feel like a passive recipient of rules.

A: It is not mandatory in the guidance. A risk assessment needs to be undertaken. Use guidance in the best interests of all parties. A very wide range of practical problems with interpretation of the guidance including fear of litigation hence care homes erring on the side of caution. Is there a sharing of good practices? It appears that there may be flexibility - however what about the Perspex screen it would seem that they may not be mandatory.

Answer (NR)

<https://www.brighton-hove.gov.uk/care-homes/visiting-care-homes> (link now superseded)

Certain risk levels mean visiting was cut. Risk Assessment is very important really good practice is shared with the care homes active WhatsApp group.

LM Answer: fear of litigation examples of litigation against care homes where a resident test's positive.

As Brighton & Hove City Council (BHCC):

A: Much more joined up decision making within the new guidance.

Q: If immunity does not last after infection why will vaccine work as they work the same way?

A: Too early to say - NR will be attending a mass Vaccination roll out programme to discuss this issue.

Q: My husband is in care home in West Sussex. I signed up to clinical trials for Covid-19 testing I have regular weekly testing which are negative; this has made no difference to the access I have to visiting my husband. Why is this?

A: NR Speak to home and West Sussex Public Health to work together details at PublicHealth@westsussex.gov.uk

Q: What is the difference between me visiting my relative one week and my brother the next week. We are allowed one visit a week?

A: (NR): Need to look at the guidance and undertake a risk assessment on each individual and their contact with other individuals. One main visitor or a maximum of two in previous guidance. Go back to Care home and discuss guidance and ask for support from Public Health at West Sussex PublicHealth@westsussex.gov.uk

Comments from the 'Chat function' included:

- Was interested that POA is trumped by public health legislation.
- My brother went into a Care Home in August, so this is new to me. I voted against 'key worker' status for relatives as I am not familiar with wearing PPE and I am concerned that I would possibly bring infection into the home.
- PPE really is just a plastic apron and pair of gloves and a mask, nothing to be afraid of.
- Will the questions sent in prior to today be answered? (YES)
- The relatives need a WhatsApp group so not isolated.
- Relatives have an important role in monitoring the care given and safeguarding and advocating for the residents which is ignored with the current visiting arrangements.
- Absolutely!
- Yes, this guidance now is much better, and the precautions taken is much better now.
- So how do they know if the vaccine makes them immune?
- PublicHealth@westsussex.gov.uk West Sussex.
- publichealth@brighton-hove.gov.uk Brighton and Hove.
- PublicHealthEnquiries@eastsussex.gov.uk East Sussex.
- Thank you I will contact public health to help the home my brother is in open up for visitors.
- The visits are not close contact, 2m apart in the garden is a very low risk. Close contact is used for personal care.
- Lot of work in West Sussex interpreting the guidance.

**HWIS Care Home Seminar; Local Authority and Care Home
Representative Q & A**

Session 3

Panel Members: Debbie Young ((DY) West Sussex County Council (WSCC), Mike Derrick (MD), Rosemary Pavoni (RP) (Sussex Care Homes Representatives, Samantha Williams (SW) East Sussex County Council (ESCC), Adult Social Care (ASC) teams, Dr Khalid Ali (KA) and Lynne Phair (LP).

Moderator: Katrina Broadhill, (HWWSx) **Notetaker:** Sue Wells (HWES)

Q. Safeguarding - with no outside visitors how are any safeguarding issues being checked?

A. This is difficult, CQC are still visiting, a lot of homes have IT in place. There are still 'window' visits to enable families to check on relatives. There are weekly meetings with the Local Authority and the CQC to support homes, with things like staffing, visiting, infection control etc.

Q. Does a lasting power of attorney override the homes power to take the person out?

A. This is a not a one size fits all, each case has to be judged on the person, and the decision needs to be in the best interest of the person. The homes should have a dynamic risk assessment that has been done with that person (if possible) and their families.

Q. What can be done to keep families involved in the care of their family members?

A. Use of IT, i.e. regular Zoom meetings between manager and family. Dedicated email address/phone number. Regular newsletters etc.

Q. Why are people being discharged into homes that have been judged as 'poor' or 'needing improvement' by the CQC

A. This was down to capacity, a lot of homes were not accepting patients back from hospital unless they had a clear COVID-19 test, which was not always possible as they had to self-isolate for 14 days after the test.

Q. IT issues, there is a lot of talk of use of IT, but how we are dealing with things like not being able to get a signal (especially in rural areas), training and support for staff/families on how to use, the fact that some people simply cannot use IT, due to health (poor hearing/eyesight, dementia etc)

A. We acknowledge there are issues with staff time/knowledge/provision of IT. The care homes association are offering support, and is also being looked at national level by the [NHSX](#), who are a diverse team with a range of skills and expertise, including clinicians, technologists, policy experts, developers, data

scientists and project managers. They report directly to the Secretary of State and the Chief Executive of NHS England and NHS Improvement, and are funded through existing budgets.

Q. What is likely to happen at Christmas? Can I bring my relative home?

- A. At the moment no-one knows. It will depend on where we are in regard to lockdown, if we have gone back to tiers, and where that home is in the tier rating.

Whatever happens, if that person goes to their family, they will have to self-isolate for 14 days afterwards, and this may not be possible.

Homes are making plans to do what they can to make Christmas as 'normal' as possible, i.e. having Carol Singers come in via Zoom.

Families are asked to remember that the decisions are made at a National level and not by the individual homes, the homes want to do all they can to keep families together and involved, and the homes have got to think of the safety of all the people living in the home.

HWiS Care Home Seminar; Emotional & Mental Wellbeing Q&A Session 4

Panel members: Dr Padma Dalby (PD) - Consultant Clinical Psychologist/Clinical Director, Sussex Partnership NHS Foundation Trust (SPFT), Deborah Becker (DB) - training lead, SPFT, Helen Wildbore (HW), Director Residents and Relatives Association, Steve Castellari (SC) - Engagement and Working Carers Lead, The Carers Centre for Brighton and Hove and Jo Egan, Care for the Carers, East Sussex.

Moderator: Michelle Kay (MK) - Moderator, Project Coordinator, Healthwatch Brighton and Hove. **Notetaker:** Ed Peasgood (EP) - Non-Exec Director - Youth Voice, Healthwatch East Sussex.

Question and Answers

Q. How can I manage my husband's and my own privacy and express my emotions via an intercom that a carer has to hold for my husband who has Alzheimer's?

All can hear in the reception area. Dignity and the right to a private life has been removed? Difficulties in communications with different care homes interpreting the guidance differently - time slot systems don't always work for relatives nor residents, becomes a barrier to seeing residents. Technology isn't always the solution particularly when coupled with timing differences in appointments just doesn't create the same realism of an appointment. Loss of connection and discussion with staff, residents and families Residents not wanting to follow restrictions - finding it difficult to follow as they aren't used to it and it is a big change. Could there be one designated visitor per resident? - there should be an agreement between individual care homes and their relatives. Opportunities for projects to support connections. Creative support (especially for dementia), arts, music, memory recall, etc.

Are there opportunities to find creative ways to support communication and connection between families and loved ones in care homes? in the first session we heard a lot about how hard it is for many people to use new technology (online chat) and for some old technology (phones) to stay connected. And also lack of privacy. Wondering whether other solutions feasible for this cohort? Also listening to Helen's talk whether options for creative activities /arts to support residents who feel isolated from other residents?

A: (DP) Importance of residents having a care 'keep-in-touch' plan and understanding what both the resident and their families' needs are.

Michelle HWBH: Also, down to their friend's needs, working with care home staff and managers to strengthen their relationships.

Care for the Carers: computer left facing care home resident to organise online communications, staff put in earphones/play music to help maintain dignity and confidentiality. Technology isn't always the solution.

Old fashion communication methods - e.g. letter writing Edward HWES: technical support, if the resident doesn't know enough about the software and the staff don't, it just doesn't happen, and it could also provide stress sorting out log ins, zoom links, etc, can also create another level of stress, so I think an emphasis on trying to facilitate face to face appointments would be better for wellbeing. Priority for those with dementia in particular, not to lose family and friend contact.

Q. Without a Covid-19 case should visitors be allowed?

A: Helen Wildbore from Residents and Relatives association referred to their helpline and their website on which there is (or will be tomorrow) info on the understanding the guidance at the moment around visiting rights during lockdown and also on how to ensure your care home communicates with you and of course their helpline can offer individual advice.

Guidance read as laws - laws around human rights and legal rights around human rights are ignored. The guidance has to be read in context with legal rights.

Q. How do we encourage a care home reluctant to talk to relatives to engage with us?

Member of staff tested positive, home didn't want us to have that info, what is the duty of candour to share that info with us? Do they have to? care homes need to be transparent. Shouldn't find out from another source as this adds to the anxiety - Covid-19 status should be announced but not sharing personal information - area manager thought it wasn't in the best interest. Due to follow up.

Several organisations spoke about different support they could provide family and friends, including hospices offering counselling and emotional support, and the Residents and Relatives Association with up-to-date info and guidance on their websites. We would recommend that the organisations everyone belonged to in this meeting become part of any follow-up admin around wellbeing.

Details on how to contact all the support organisations can be found in **Appendix 1**

There was no formal plenary session. To close the webinar Alastair Hignell, thank everyone for attending and for their valued contributions. A report including the presentations, discussions and questions and answers will be circulated by the end of November / early December. Message from the chat that we didn't get time to discuss: My father has advanced Parkinson's and is

a very independent and social man who would come out of the care home in a flash if he could. He has deteriorated physically and emotionally. With the new guidance should care homes now allow a nominated individual who can visit inside the home, if they don't have an outbreak? SPFT panel response - staff should use risk assessments to make that decision, risk assessments should be updated regularly,

To support his emotional wellbeing even if his care home could get someone to take him out for a drive that would be lovely - but they will say they don't have enough staff.

7. Reflections from participants

Dr Mathew Thomas, GP who gave a presentation at the webinar, shared his impression of the whole event:

'It was a privilege to be asked to engage with the families of Care Home residents on the Healthwatch Webinar. They gave powerful, insightful and touching stories of the trauma and upset that COVID19 has caused them and their loved ones. I also heard about some wonderfully caring Homes and staff who have gone the extra mile. It gave me a lot to think about and will help shape some of the support I give to the Care Homes going forward'

The speaker presentations are available to download on our [website](#).

Dame Phillipa Russell, DBE Family Carer

'It was a really important contribution to the wider debate about care homes and the importance of recognising, celebrating and sustaining relationships with families and friends, pandemic or not. I was so pleased that there were plenty of 'can do' illustrations of visiting in action'

8. Recommendations

HWiS to build upon the connections established during the planning and delivery of the webinar and to continue to amplify the voices of families and residents.

HWiS to establish an informal 'discussion group' to sustain conversations with relatives, take forward recommendations and progress ongoing discussions as new directives in relation to Care Homes and visiting are announced.

HWiS and partners to share this Webinar report widely in order to influence the decision makers in planning for the future of residential care across Sussex.

HWiS and partners to continue to push for greater clarity on guidance for families around visiting arrangements.

HWiS and partners to encourage providers to adopt best practice examples of staying connected with families during the pandemic, considering the impact on both residents and relatives.

HWiS and partners to explore the suggestion that relatives be awarded key worker status to facilitate continued visiting of their loved ones in care homes.

9. Next Steps

The report will be shared with all participants, key decision makers locally and nationally via Healthwatch England and the Care Quality Commission (CQC).

Healthwatch in Sussex will:

- explore with Care Home providers the possibility of engaging with residents to gather their experiences using virtual resources following enter & view protocols (Phase 3).
- invite interested relatives to a discussion group to develop progress the recommendations; and
- provide detailed feedback to health and care partners.

This insight, together with a comprehensive review of all the literature/guidance issued since the start of the pandemic, and key messages from the webinar will be shared at a learning event in January 2021.

END

Talk to us

If you have questions about the content of this report and would like to speak to Healthwatch, please either call or email the local Healthwatch for your area.

Healthwatch East Sussex

Call: 0333 101 4007

Email: enquiries@healthwatcheastSussex.co.uk

Web: www.healthwatcheastSussex.co.uk



0333 101 4007



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[@healthwatcheastSussex](https://www.instagram.com/healthwatcheastSussex)

Healthwatch West Sussex 0300 012 0122 or
helpdesk@healthwatchwestSussex.co.uk

Please also follow West Sussex as below



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[@NHSadvocacy](https://twitter.com/NHSadvocacy)



[@healthwatchws](https://www.instagram.com/healthwatchws)

Healthwatch Brighton and Hove

Call: 01273 234 040

Email: info@healthwatchbrightonandhove.co.uk

Web: www.healthwatchbrightonandhove.co.uk

Appendix 1: Supporting the Webinar

Health and Care Partners included:

Angela Colosi	East Sussex Healthcare NHS Trust
Mandy Catchpole	Infection, Prevention & Control Lead
	NHS Brighton & Hove
Nicola Rosenburg	Public Health
	Brighton & Hove City Council (BHCC)
Dr Mathew Thomas	GP, NHS East Sussex
Katie Chipping	NHS Brighton & Hove
Dr Tim Caroe	GP, NHS East Sussex
Soline Jerram	BHCC
Isobel Warren, Adult Social Care	East Sussex County Council (ESCC)
Samantha Williams, Adult Social Care	East Sussex County Council (ESCC)
Debbie Young	West Sussex County Council WSCC)
Zoe Fry, Owner/Director Valerie	Manor Care Home West Sussex
Dr Padmaprabha Dalby	Sussex Partnership NHS Foundation Trust (SPFT)
	SPFT
Deborah Becker	NHS Brighton & Hove
Renee Dickenson,	NHS Sussex Commissioners
Jane Lodge,	West Sussex County Council (WSCC)
Emma Radley	Brighton & Hove and East Sussex
Mike Derrick	Registered Care Home Association
	West Sussex Registered Care Home Association
Rosemary Pavoni	
	East Sussex Registered Care Association
Debbie Corti-Young	
	Healthwatch England
Paul Callaghan	Age UK East Sussex
Charles Sheldon	Carers Support West Sussex
Sonia Mangan	Care for the Carers, East Sussex
Jo Egan	Brighton & Hove Carers Centre
Steve Castellari	Independent Consultant Nurse and Expert Witness
Lynne Phair	
	Relatives and Residents Association
Helen Wildbore	

Contact Details of Support Organisations

Age UK East Sussex



<https://www.ageuk.org.uk/eastsussex/>

Call us on 01273 476704

Email us at: customerservices@ageukeastsussex.org.

Care for the Carers, East Sussex



<https://www.cftc.org.uk/>

Call us on 01323 738390

Text us on 07860 077300

Email us on info@cftc.org.uk

Carers Support, West Sussex



<https://www.carerssupport.org.uk/>

Carer Response Line: [0300 028 8888](tel:03000288888)

The Carers Centre for Brighton

www.thecarerscentre.org

18 Bedford Place

Brighton

BN1 2PT

01273 746222

info@thecarerscentre.org

Relatives and Residents Association

<https://www.relres.org/>

Helpline: 020 7359 8136

Open Monday to Friday 9.30am to 1pm.

Email: info@relres.org

Cruse Bereavement Care (Southeast)



<https://www.cruse.org.uk/get-help/local-services/south-east/east-sussex>

Eastbourne & Surrounding Area

Telephone: 01323 642942 Email: EastbourneBranch@cruse.org.uk

Brighton & Hove

Telephone: 01273 234007 Email: Brighton@cruse.org.uk

Links to resources shared in presentations / opening remarks

Sporting Memories - Care Settings Package

<https://www.sportingmemoriesnetwork.com/care-settings-package>

Here is a link to the freely accessible resources we have created during COVID as part of our response under the #TalkAboutSport

campaign <https://www.sportingmemoriesnetwork.com/Listing/Category/lets-talk-sport>

And specifically, if anyone wanted to subscribe to our Sporting Pink, they can do so here <https://www.sportingmemoriesnetwork.com/digital-sporting-pink>

Link to a short video about our pre-COVID, face-to-face Clubs, there is our 'Join the Squad' video <https://vimeo.com/209375059>

Appendix 2 - Advanced Questions and Responses

Q: “What are the rights of residents to leave a care home and be cared for by their relatives/friends?”

This answer does not constitute legal advice.

A: The legislation that covers this question is the Human Rights Act and the [Mental Capacity Act](#). The Human Rights Act requires that the starting point is that anyone is free to leave the care home and go and live wherever they want to. The starting point of the Mental Capacity Act is to presume a person has capacity to make a decision about where they want to live.

This means that a person has the right to make wise or unwise decisions, unless it has been determined that they lack the mental capacity to make that decision. If the person has a condition that might affect their mind or brain (dementia, a stroke, alcohol abuse for example). There should be a capacity assessment, to determine if the person has the capacity to make the decision to live in a certain place. (Decision specific).

This assessment requires the person to be helped to understand, weigh up the risks and benefits, retain and communicate their decision. If they cannot do one or more of these things, they are assessed as lacking capacity to make the decision.

If it is found that the person lacks capacity to decide if they want to leave the care home and live with a family member, the decision should be made in their best interest. This is done by a person referred to as the decision maker. This might be a Social Worker or the LPA.

The Decision Maker must consult with those who have a view on what might be in the person’s best interest. This will include the person themselves and family members. It might be decided that it is in their best interest to go and live with a family member.

If it is decided that it is not in the person best interest, and the decision is disputed, the matter must be referred to the Court of Protection.

If the person has been assessed as being at risk of harm if they leave the care home, because they lack the capacity to understand the risks and make the decisions, a Deprivation of Liberty Safeguard (DoLS) will probably be in place. This sets out the least restrictive way a person can live and may state they are not free to leave the care home. The person named in the DoLS as their representative can request a review of the authorisation. The named representative could also be the person’s LPA but not necessarily. The person can also have an IMCA (Independent Mental Capacity Advocate) appointed by the local authority in cases where there may be dispute between parties.

When a review of the DoLS authorisation is requested the Supervisory body (the local authority) will appoint a Best Interest Assessor (BIA) and psychiatrist to review the authorisation, associated restrictions and speak to the person and those who are relevant to them (relatives, friends and care staff). The DoLS representative also has the right to request a review by the court of protection on behalf of the person, if the person is or is believed to be disagreeing with the DoLS authorisation.

If the person lacks capacity and has an LPA, the LPA has the legal right to act in the person's best interest and this might be to take them home. However, simply because a family member is the LPA, they cannot lawfully remove a person from a care home. If there is a dispute that leaving the care home is not in their best interest, again the matter must be referred to the Court of Protection.

Q: How are Power of Attorneys involved in important decision making e.g. not to treat? This did not happen when my mother was in the Princess Royal Hospital.

This answer does not constitute legal advice.

A: The first matter is to ensure the Lasting Power of Attorney (LPA) is for health & welfare and not for property and finance. Also, the Enduring Power of Attorney (pre 2007) that might be is still valid but only covers finance.

There are occasions when a family member is an LPA or an EPA for property and finance and they mistakenly believe this is for health and welfare too. If the LPA is for health and welfare, they have the legal right to be involved in decisions about a person. The LPA effectively is the person in respect of giving consent. So, if the clinical decision is that the person needs a blood transfusion (for example) the LPA will give consent on behalf of the person.

Decisions about “not to treat”, will have the same considerations made by the clinical team whether the person is giving their views directly (because they have capacity) or if an LPA is giving them (because they lack capacity). The decision whether to treat or not, is a clinical one, and cannot be forced by an LPA, in the same way that a person who has capacity cannot force a Doctor to do something they believe to be wrong.

However, an LPA must be included in these discussions. If the LPA believes the decision not to treat, is not in the person's best interest they can make an urgent application to the Court of Protection.

Equally, if the LPA refused treatment that the Dr felt was in the person's best interest, the hospital would have to make an urgent application to the Court of Protection.

Answers drafted by:

- Lynne Phair
- Soline Jerram
- Rosemary Pavoni

Q: “What are the rights of residents to leave a care home and be cared for by their relatives/friends?”

A: It depends on their capacity, if they have mental capacity then they can leave whenever they want, there would potentially be a notice period. If they don't have capacity then all interested parties would need to make a best interest decision, taking into account the various options and risks.

If there is a dispute about what is in a person's best interest, the matter must be referred to the Court of Protection.

Q: Why do hospitals discharge our most vulnerable people to a care home that is rated by Care Quality Commission as Requiring Improvements and poor reviews.

A: There are many factors that determine which care home a person should be transferred to. The CQC rating is one of them, but also the nature of the shortcomings that CQC identified. Some shortcomings, that mean the rating is requires improvement relate to systems and policies that have the potential to cause harm, if not rectified. Other concerns may be considered as causing actual harm. If this is the case, the local authority would review the impact on potential residents. There are also occasions when a care home receives a poor CQC rating, and the matters are resolved quickly, but there is a delay in a review by CQC.

Other factors that are considered by the hospital social worker would be the location of the care home to the person's family, what their care needs are and whether a care home can support the person, whether they have vacancies and, if funded by the LA, whether the fees are affordable for the public purse. All of these risks and benefits must be considered in totality and must be done in consultation with the person and/or their next of kin.

From Mike Derrick:

The CQC rating is a snapshot of the day of inspection and should be only one of the considerations when choosing a care home. It is always important to visit a home where possible to judge for yourself. A "Requires Improvement" rating can cover a very wide range of issues, from fairly minor to more urgent, these will usually be addressed quickly by the provider who may then have to wait several months or even years before their rating is reviewed. It is always worth asking a provider for information on what had changed or improved since their most recent rating.

Q: My Brother lives in a care home for people with learning disabilities and dementia in mid-July and we haven't seen him in person since. My mother has seen him briefly three times in the garden, but it was only by persisting that was granted. And this last time was told that it was "as a one off"

- We also were told that no other resident has seen their family since March. We have been told there is a visitor's pod being built but could be some time off.
- To us it feels like he is in prison where he can't go out anymore, be visited, and doesn't have the capacity to understand why.
- What effects will this have on my brother? Will he be feeling he is abandoned by us?
- Will he become so institutionalised that when we can see him in hopefully months to come that that will upset him more?
- Who is supporting these homes and checking that there are measures in place to allow visiting as per the government guidelines as it feels in my brother's home that there is no support?

How can we move this forward? Discussed but not responded to

The welcome news announced on 1st December will allow for visits to care homes. The guidance states that:

All care homes - regardless of Tier - and except in the event of an active outbreak - should seek to enable:

- *indoor visits where the visitor has been tested and returned a negative result*
- *outdoor visiting and 'screened' visits*

Visits in exceptional circumstances including end of life should always be enabled.

- *In all cases it is essential that visiting happens within a wider care home environment of robust Infection Prevention and Control (IPC) measures, including ensuring that visitors follow (and are supported to follow) good practice with social distancing, hand hygiene and Personal Protective Equipment (PPE) use.*
In the event of an outbreak in a care home, the home should immediately stop visiting (except in exceptional circumstances such as end of life) to protect vulnerable residents, staff and visitors.

The responsibility for deciding upon visits remains with care homes; [39 Essex Chambers](#) have produced some excellent guidance about the new rules about care home visiting.

<https://www.mentalcapacitylawandpolicy.org.uk/dhsc-visiting-guidance-from-2-december-and-the-court-of-protection-weighs-in/>

It is not possible to respond to how the pandemic and the care home restrictions will impact in individual cases. This will depend on numerous factors which include not only the care home and how they have managed to support the individual, but the person medical condition and care needs as well as their character and personality and how they respond to changing situations in normal times .

CQC have been monitoring care homes to ensure they are complying with the rules. If there is a concern about a care home, CQC should be contacted or the local authority, if they fund the placement.

All providers should now be trying to facilitate safe visiting following updated government guidance on 1st December. Part of this process involves completing a dynamic risk assessment, where the provider has to consider risks to the residents, the physical layout of the building, compliance with PPE and social distancing, staff availability and cleaning availability. Visiting inside of the building is still restricted to the use of pods with substantial screens, this may change with the introduction of Lateral Flow Tests later in December.

This is a complex decision-making process unique to each care home. The CQC are in regular contact with care homes to discuss a range of issues, including infection control management and safe visiting. If you have ongoing concerns, you should initially contact the care home for a formal response. If this response is not adequate, then you may need to contact the CQC to make a complaint. Both the local authority and public health teams are also available to provide advice to care homes if needed. If visiting is difficult then the home should be able to facilitate either window visits or use technology to support remote contact.

Q: What commitments are being made to allow: "normal family interactions by stopping restrictions".

<https://www.nursingtimes.net/opinion/open-letter-infection-prevention-and-control-should-never-be-at-the-expense-of-compassionate-care-16-10-2020/>

A: There has been a challenge of the need to balance the safety of very vulnerable people against the risk of suffering due to the lack of direct contact with family members. As time has gone by, and routine testing has been introduced it has become more evidence how many a symptomatic people have COVID 19, placing vulnerable people at very high risk. Although enabling one visitor for 1 resident may be compassionate care, this must be done against a backdrop of multiplying the risk by every resident. If a care home has 50 residents, they will have around 50-70 staff. If each resident is then allowed routine visits of just 1 person, it increases the risk by 100%

Thankfully, the introduction of family visiting (2 people) across care homes in England is being rolled out as testing kits are delivered. This, together with government commitment that care homes and care home staff will be the first

to receive the vaccine, give hope that normal visiting may be able to occur with a gradual relaxation of the restrictions over the next few months.

The updated visiting guidance issued on 1st December plans for the rollout of lateral flow tests to all care homes, enabling test results within 30 minutes. If this rollout is successful then visits into the buildings, with PPE, would enable physical touch during visits. There are a number of issues, not least the training of staff to support visitor testing, to resolve.

Q: Why if I am having weekly and regular COVID testing can I not visit my husband freely and regularly. This appears to me to make my status the same as the staff. I am a healthcare professional and understand about PPE?

A: Visiting if a person is distressed or at the end of life has been allowed throughout the pandemic. However, care homes must follow the laws set out by the government and follow the public health instructions regarding visiting. Every additional person who comes into a care home, brings a risk to the residents. Testing is only as good as the day it was done, which is why the new system of immediate testing to ensure there is no shedding of the virus is considered the safest approach. Also, the cost of PPE and ensuring everyone is using PPE in accordance with the requirements in that care setting need monitoring. Sadly, community living requires a community response.

Current guidance does not support this approach to visiting. The guidance is intended to reduce risks in a number of ways including reducing the overall number of contacts. Hopefully the introduction of the Lateral Flow test will support more visiting within the building, however providers will still need to carefully manage the overall number of visitors in the building at any time.

Q: Why is outside visiting now at the discretion of the home manager when last week it was permitted? It is within the government guidelines that outside visiting is permitted.

A: Care home managers are legally responsible for their residents and staff and could be criminally liable if something goes wrong due to their failing. A manager must use a dynamic risk assessment process as things change constantly. Also, if there is an outbreak in a home (a minimum of 2 people) the home must close to all types of visiting. This the law and is enforced by Public Health England. Thus, things have constantly changed and will continue to do so, until everyone is vaccinated.

The final decision for any type of visiting rests with the care home manager. When making this decision they must take into account a number of factors. As these factors change, for instance; government guidance, tier level, staff availability, PPE availability, outbreak status, PH advice, then the visiting policy too may need to change.

Q: When mother had Covid she could not go to a home (from hospital) until she tested negative for Covid-19 yet we are told that after 10 days (or is it 14?) people can go out and about again and are told they are not infective. Again, I feel very confused as this is not consistent behaviour.

A: When a person tests positive, the rules for everyone (wherever they live) is to self-isolate for 10 days from the day of the test. If a person is in close proximity, they must self-isolate for 14 days. This is to allow for the 3-5 days incubation period.

If a person is in their own home, there are few people put at risk. However, a person going to a care home is moving into a community living setting.

The government updated their guidance in the early summer to state that a person cannot leave hospital until they have had 2 negative tests (unless going to a special care home that will take positive people). This is to reduce the risk of spread in the home.

If a person is moving to a care home, they will have to stay in their room for 14 days, regardless of whether they have tested positive previously. A care home can be a large community of very vulnerable people and protection as far as possible, is the priority. This is the government guidance and care homes must follow it.

Current discharge guidance for hospitals in the COVID Winter plan makes clear how discharges should take place. If people have tested positive, then they may need to be discharged into a specially registered service - a designated care setting. Care homes are understandably reluctant to take any new residents who might be positive, so normally need a confirmed negative test result prior to discharge. This is to minimise the risk of transmission within the care home. Current guidance requires all new admissions to be isolated in their rooms for 14 days on admission, again to further reduce the risk. The rules applied to care homes are in many areas stricter than those for the general public.

Q: If immunity does not persist after the infection why should a vaccine work? I was under the belief that vaccinations work by causing the same immunity response as you see with a real infection. Again, very confusing?

A: The vaccines have been made in a way to teach the body to challenge and prevent the virus “getting into the body”.

The BBC bitesize website gives very helpful information about the vaccine and how it works. <https://www.bbc.co.uk/bitesize>

Q: Could my mother be tested for antibodies so that we can see if she is currently still immune which will reduce a bit of pressure/stress for all concerned and then maybe she can be visited after all? (I presume if she has antibodies she can't catch it or pass it on?)

A: Antibody tests are not widely available and studies on how long a person has antibodies to the virus are in their infancy and the amount of time a person remains immune is not well understood.

The new testing regime for visitors introduced on 1st December, will enable face to face visiting (with PPE) to resume.

Q: Will nursing, care and residential home managers, governments/local authorities and health care leaders, commit to using infection prevention and control as an enabler that will protect staff, residents and families, instead of restricting visits as a shortcut for inadequate infection prevention measures?

A: All care homes have been legally obliged to follow Public Health England rules and guidance about infection prevention and control throughout the pandemic. Restricting visiting has not been used as a short cut for poor infection control. CQC have been monitoring care homes along with Public Health England to ensure good infection control has been in place. If a care home has not followed good infection control procedures, this should be reported to CQC. Visiting restrictions were put in place in addition to infection prevention precautions.

The importance of continued infection, prevention and control procedures is demonstrated with the new rapid testing regime. PPE is still required along with strict cleaning and will be for some months to come.

Providers are under an obligation to follow government guidance. Visiting does introduce additional risks into the care home, so it is important that these risks are managed as safely as possible.

Restrictions to visits are not a shortcut for inadequate infection prevention measures, they are a carefully considered attempt to balance the risks that all providers are trying to reduce. Whilst recognising the vital importance of visiting, we also have a very clear duty to protect our residents.

Topics recommended for future Discussion Groups:

Looking ahead future suggestions for areas of discussion and to gather further information on include:

- a) **Good working examples of visiting arrangements** (in different types and sizes of care homes for older people);
- b) **Good working examples of visiting arrangements in care homes for younger people with learning and other disabilities**

We now know that the death rate from Covid-19 has been at least 40% higher for people with learning disabilities than for people of similar age without a learning disability.

There are widely varying arrangements for visits, but they have been little discussed.

What do we know and what are the key issues?

- c) **What about supported living?**

Many people living in supported living arrangements have complex needs; they may receive support from multiple carers

Department for Health and Social Care (DHSC) is updating the guidance and there is discussion going on about visiting arrangements. Many of these people are clinically very vulnerable and they may not fully understand all the protection measures needed to keep them safe.

- d) **What is good practice for visits *out of* the care home?**

Before the pandemic, many residents went home regularly - can they do this now?

If so, with what safeguards? And what about visits out of the care home for medical, dental or similar appointments?

There is evidence that some people have been missing important diagnostic or treatment appointments because of ambivalence about any external visits from the home.

Also, some residents who have gone out for a planned visit have subsequently been told that they cannot return, or - if they do - they must have 14 days quarantine.

- e) **What is happening with regard to the Government's request for local authorities to 'designate' places in care homes or elsewhere to which people with Covid-19 can be safely discharged when leaving hospital having tested positive for Covid-19.**

This is proving hugely controversial as relatives and staff are nervous about designated separate spaces for covid-19 in care or nursing homes where there are other non-covid people in the same building.

Some areas have identified separate buildings that can be used (because clearly people must be discharged from hospital as soon as possible for the sake of their own health and also to unblock acute hospital beds). We heard at the webinar that West Sussex has not yet identified any beds, but it will need to do so and in this context the role of the local Director of Public Health will be crucial. It would be interesting to find out what local arrangements are being made for these designated places, where they are and how they manage contact with relatives.

I think your webinar could be a wonderful catalyst for many discussions and some new thinking about how and why we must support relationships and connections.

Appendix 3 - Final Programme

Families and Friends of Care Home Residents - staying connected during the Coronavirus crisis

Are you a family carer trying to stay connected to your relative or friend living in a care home?

We know lots of care homes have gone that extra mile to keep families connected over the last few months...What have been your experiences?

What can we learn from the past seven months?

Join us to find out more at our Zoom online event on

Tuesday 10th November 2020 from 5pm - 7pm

Hosted by Healthwatch in Sussex

You will hear from other families about their experiences, from care home managers, there will be lots of opportunities to ask questions relevant to your experiences as well as have your voice heard. Also joining the event will be NHS staff, representatives from local Adult Social Care and Public Health Teams and support available from Carers groups and charities



A scene some of you may have experienced recently visiting your family member or friend living in a care home; but with the colder weather and winter approaching as well as the increasing uncertainty with Coronavirus cases rising, what does this mean for families in the coming months...

You can forward your questions in advance to:

enquiries@healthwatcheastsussex.co.uk

The full Programme is enclosed below...

If you would like to join this event but do not feel confident in using the Zoom platform, please contact us as soon as possible, and we may be able to arrange some support around this: enquiries@healthwatcheastsussex.co.uk or Telephone 0333 101 4007

BSL Sign Interpreters will be available for this event.

Programme

Session 1 (Prompt Start)

5pm - 6.25 pm

Welcome! Opening the webinar, introductions and setting out the protocols for the virtual event - **Chair; Alastair Hignell**

(5.05) Dr Mathew Thomas (GP) and Mike Derrick, Chair Brighton & Hove and East Sussex Residential Care Home Association

Setting the Scene - As the second wave takes hold...responding to the local situation as a system and the challenges around visiting arrangements for Care Home providers.

Risk vs the Human touch



(5.15) A Relative's Story - Lesley Meech

(5.30) Trevor Greenidge, The Relatives & Residents Association for Quality of Life of Older People in Care - What is the national picture like, what is the Relatives & Residents Helpline hearing and what could be done differently as the second wave takes hold?

(5.40) Valerie Manor West Sussex - Zoe Fry, Director; Life at Valerie Manor during COVID-19

(5.50) Q & A /Discussion - Panellist include: Dr Mathew Thomas, Mike Derrick, Trevor Greenidge, Lesley Meech and Zoe Fry

Relatives will be able to **forward questions in advance** of the webinar, **ask 'live'** at the event, or via the **'Chat' facility**

Moderating this session: Lynn Phair, **Expert Witness and Independent Nurse Adviser** in the **Care of Older People**

(18.20) Summing Up by the Chair and move in to **'Breakout Spaces'** for focussed **Q & A** session with key partners.

Short Break whilst people move into their Breakout Spaces (5 Mins)

Session 2

Breakout Spaces 6.30 - 7pm

Attendees will be digitally transferred to their chosen breakout space (already booked at time of registering).

Q & A with Health and Care Partners

A range of health and care professionals will be available in each of the four Breakout Spaces to respond to your questions including:

1. NHS Colleagues Pan Sussex

For questions relating to: Infection, Prevention and Control, Testing in Care Homes and Personal Protective Equipment (PPE).

Panel Members: Mandy Catchpole, Clinical Programme Lead for Mass Vaccination, Testing and Infection Prevention and Dr Mathew Thomas GP.

2. Public Health Teams

For questions relating to: Public Health Teams role in supporting care homes, including Visiting Guidelines, Testing, managing outbreaks and preventing further spread of Coronavirus.

Panel Members: Nicola Rosenburg, Public Health Consultant (Brighton & Hove) and Soline Jerram (West Sussex County Council).

3. Local Authority & Care Home Representatives

For questions relating to: Care Home residents general well-being, on-going communication with families and what local plans are in place to respond to outbreaks.

Panel Members: Mike Derrick, Rosemary Pavoni, Adult Social Care (ASC) teams, Dr Khalid Ali and Lynne Phair.

4. Emotional and Mental Well-being Support

For questions relating to: Residents or family carers emotional and mental well-being, the impact of missing face to face contact and End Of Life (EOL).

Panel Members: Dr Padma Dalby, Consultant Clinical Psychologist, Sussex Partnership NHS Foundation Trust Teams, Trevor Greenidge.

Carers Support Groups and Bereavement Support will also be available in this Breakout Space).

Main Presenters

Alastair Hignell, CBE, Chair



Ex-England rugby player, Professional cricketer, BBC commentator, author, charity trustee and public speaker. Volunteer; Healthwatch Brighton and Hove, Brighton Dome and Festival. Wheelchair user, dealing with MS and MDS. Brighton resident since 2011.
<https://www.alastairhignell.com/>

Trevor Greenidge, Helpline Officer at the Relatives & Residents Association



Trevor provides individualised support to older people, their relatives and friends who have queries about the provision of care. Previous roles included a generalist adviser for the Citizens Advice Bureau and as an adviser for Counsel and Care, which was a charity focused on care for older people.
<https://www.relres.org/>

Zoe Fry, Director, Valerie Manor Care Home



Zoë Fry, Director at Valerie Manor is a qualified nurse with extensive experience in the health industry both as a nurse and as a manager in providing care and managing large numbers of staff.
<https://valeriemanager.co.uk/>

Lynn Phair, Moderator, Expert Witness and Independent Nurse Adviser in the Care of Older People



My nursing career started in 1977 and I have worked in hospitals, the community, and long-term care settings, provider services and commissioning organisations, always specialising in the care of older people in both physically frail and mental health settings.
<https://lynnphair.co.uk/>

**Dr Mathew Thomas GP, East Sussex CCG
Care Home GP Support.**



Dr Thomas has been a GP for 30 years and has been the East Sussex CCG Clinical Cancer and End Of Life Care Lead for over 15 years. Since the start of the pandemic he has also been asked to provide medical input to Care Home communication and oversight, liaising with Care Homes, the CCG, local Public Health and Adult Social Care departments.

**Dr Khalid Ali, Consultant Geriatrician at
Princess Royal Hospital (PRH) Haywards
Heath**



Dr Khalid Ali is senior lecturer in Geriatrics and stroke medicine and a consultant geriatrician at Princess Royal Hospital (PRH) in Haywards Heath. Dr Ali is the Ageing speciality research lead in Kent, Surrey and Sussex, Clinical Research Network (KSS-CRN)

In attendance /invited

- Cruse, East Sussex Bereavement Services
- Age UK East Sussex (Invited)
- South East England Forum on Aging (SEEFA)
- East Sussex Seniors Association (ESSA)
- East Sussex Dementia Forums
- Sussex Carers Organisations - Brighton & Hove and West Sussex
- Care for the Carers East Sussex

Appendix 4 - Healthwatch Brighton and Hove early engagement findings

Care home Family and Friends Support Forums:

Themes drawn from conversations with family members.

Praise for care homes:

- Impressed with Care Homes - No help from government - no test kits - no PPE
- Testing staff every week/resident's every month
- Imbalance between staff and residents - are not enough
- Staff/overworked/stressed staff
- Felt abandoned - care homes treatment has been awful - care sector left alone
- Care Managers need to produce more advice and information
- Family and friends need different types of support. They need to know that they are not being left out
- Care homes have done an amazing job despite the government!

Access to residents:

- One person has been able to see the residents since June can sit in the garden with them
- The other person can only spend limited time with resident
- Technology not helping - they are trying but people are struggling
- "Don't care if I get it. I would rather take the risk"
- One lady has been getting regular email updates
- We have to communicate with family and friends and give them more information and facts

- Family of residents feel like they are ‘the enemy’ - they carry the risk of bringing the virus into the care homes
- One has COVID and one did not
- Fear of their relatives dying and being alone, without being able to hold their hand
- Each Day Matters
- No one should die alone

Affect on mental well-being (for both resident and family member)

- Guilt around sending relatives to care homes - only felt ok because they could see them before COVID
- Residents gone downhill mentally because they are not seeing residents
- Worried about second wave
- Quality of life and mental health is really affected
- Short term memory loss of residents which does not help Lack of information from authority (CCG, government etc)
- Not heard anything from CCG, social care, CQC over this period
- In terms of immunisation and being immune. How long does that last, will care home residents, staff and families be given priority for immunisation?
- Apart from this forum no help or advice
- Need more information regarding the second wave
- Vaccines are the biggest wish
- Need clearer and more consistent information
- The rolling out of the vaccine really needs to be thought about
- Liked the idea of getting important people in a room to have a webinar/discussion, would like to be able to ask the local politicians and decision makers questions and raise issues face to face August 2020