WEST SUSSEX CARE HOME INSIGHT

July - September 2020

Healthwatch West Sussex have collated a range of stories that show people's experiences of care home living during and after the Lockdown.

We hope these case studies and insight will help our Health and Care System and care home businesses to recognise the impact of the changes arising from the pandemic and seek ways to address these to support residents and their families to stay in connect going forward.

Fiona's Story (July 2020)

Fiona's mother is her 80s and has been living in a Care Home along the coast of West Sussex for the last two years following an operation that left her hospitalised for quarter of the year and no longer able to live independently in the community.

For two years Fiona has been visited her mother daily (unless she was away) and this has been part of her routine. The home locked down about a week before the country locked down in March. Fiona had an answerphone message to tell her of the need to lockdown.

Use of phone

Fiona's mum has a phone in her room, so this has made it more possible to stay in touch with her, but this is dependent on whether her mum is feeling up to talking. When Fiona has been unable to get through on the phone, she then has to call the home. Sometimes the phone isn't answered.

The lockdown has had an impact on her mum, as *her world has narrowed, as all ours have, and it makes it challenging to talk to her*. She has lost a lot of weight and her appetite is not good. Her mobility has declined, and her mood is low (which was previously an issue but is more frequent now.)

Use of online platforms

In the beginning, staff supported the use of Skype and together they have had 3 or 4 attempts at using this. Sadly, this has only worked once. Therefore, they have not tried doing this for a while, but yesterday the home sent out an email to encourage people to use this. The problem is that there has to be a member of staff there and *this inhibits the conversation, as someone is hovering over* her mother.

Continued …

Social Media The home has a Facebook account, but it is not active.

In-person visiting
Fiona has been asking the home when they will be offering some form of face-to-face contact. The response lately has been that *matron is looking at it, we've had so many calls about this.*

It was mum's birthday recently and Fiona had asked to see her. A special allowance was made. She was told that one family member could see her in the home's carpark, for half an hour. The carpark is very noisy as it backs on to the main road, and her mum speaks very quietly, so the situation was not great.

How home has been staying in contact?
The communication sent from the home is not frequent and Fiona has had to chase, and for example, it took 2.5 weeks for an email update to come. *It is frustrating. We don't need a long, fancy email. It could be four lines.*

Fiona suggests homes, like her mother's, needs to make the small investment in regular emails or have a nominated person to call once a week at a specific time. This would be much more effective than what happens in some homes. Fiona has to call for a weekly update. The right member of staff is often busy, for example in the middle of the drug round, so gets disturbed or has to call back.

COVID status updating
The home carried out blanket testing of all the residents four weeks ago. Fiona got a call from a staff member who started the conversation with *are you the Next of Kin*. She was told her mother had tested positive when they had tested all the residents. Her mother only had mild symptoms and has recovered. Fiona said she feels she had to put pressure on them to get an understanding of whether it was just her mum who was positive or others. Initially, she was told it was one other resident, but she happened to be talking to the matron and asked about the number of positive people. She was first told it was confidential and then they did disclose how many had tested positive.

It is not reassuring, not to be told. It creates mistrust.

Before homes could get more than 5 tests, there had been an outbreak in early on with some positive test results and potentially more people (who couldn't be tested). Residents were isolated in their rooms. The dining room has since reopened for lunch and dinner. They are also now running small group activities, including using the garden (which is lovely).

The home has not kept families informed about the staffing levels, as they did not want to cause concern. However, Fiona is aware that in early on during Lockdown the home had 50% of its staff off sick. She feels it is important to know the status and as a family she has thought through alternative arrangements should the home not have adequate staffing. *Knowing the scary truth is better.*

Story #2

(Carer Support West Sussex staff – with the carers permission to a CEO Q&A on 20th August)

Christina looked after her husband for 9 years before putting him in a care home for the past 3 years. Christina has seen the survey on our Dementia Newsletter asking people to tell of the impact of the Covid-19 situation and has completed it. Christina felt the impact even more acutely once she had done that and decided to call in to speak to Carers Support West Sussex.

Christina describes the past 5 months as *distressing to say the least*. However, her current experience is proving even more harrowing in that the impact of not being able to see her husband in a "normal way" is proving more distressing than anything else. Christina says that the government guidelines are open to interpretation for each care home. Christina cannot fault the care home and has *no qualms with the care*. What makes no sense is that the rules that apply to the paid care workers cannot be applied to unpaid carers visiting their loved ones. Christina asks, *Why can't next of kin be treated the same as paid carers? Why are we not recognised as key workers in this situation too? I would like to have as normal a life as is possible with my husband before he goes."* At the moment they are able to have a two meters socially distanced and time limited visit in the garden. When visiting a few days ago, Christina's husband got up to come to her. A paid care worker supervising, told him off and said, *If you go over to your wife she will not be able to visit you again.* The carer has put in a formal complaint, but obviously this adds to an already distressing situation. Christina has to already cope with what has been a "dramatic" change in her husband in the past five months. Christina admits, *This, is so distressing. I cannot sleep at night and am being treated for depression.* Christina says that prior to the Lockdown she would help with care for her husband wearing PPE if necessary, particularly if he was uncooperative with staff. She asks, *What's the difference? I live alone. Am very careful where I go. I would take the same precautions. The paid care workers are going home to families and going out and about. They can also test negative one day and positive the next.*

This story is now becoming the norm and Carers Support are hearing it and reading about it in the press.

Story #3

(Carer Support West Sussex own wellbeing worker)

I would like to ask for support to change the cruel guidelines for the care homes residents and families especially regarding my mum who is 94 years old and has advanced dementia and is in full time residential care in West Sussex.

Since the beginning of COVID-19 I tried to have regular calls, which although not great for my mum as she does not recognise my voice and struggles with her eyesight due to cataracts, it was something at the beginning.

However, since the social distancing visiting started, which at first was open to all family members, making calls has become difficult due to staff needed for visits. Visiting has now been restricted to only one constant visitor which has caused distress for my family as there are many of us.

Also, my mum had a fall at the start of July and was sent to hospital. The paramedics said no one could attend with my mother, but I called the hospital and was admitted.

This was just as well as the doctor did not even bother to look at my mum's hospital book and made no considerations to allow for my mum to try and respond. I stayed the night at A & E with her as she could not be admitted as once she had her stitches in her forehead she was deemed as having no medical needs however, as she is unable to walk no transport was available to take her home until the following lunchtime. On her return I was not allowed to enter the care home and my mum was placed in isolation.

The decline in my mum was obvious but throughout my night and morning with her she improved due to being cuddled and having her hand held and became quite animated.

Although I feel the care home are managing my mother's care, as best they can, even they have stated that the residents have declined. This is prominent in my mother who I feel is showing her frustration by sometimes refusing to eat and refusing her medication, which has now been removed and she is on morphine patches for the severe pain she has in her arthritic knees. I appreciate due to the constant fluctuation of mood and ability with dementia it could be put down to that but knowing my mum as well as I do, I would argue not.

I would also say it has caused a lot of tension in my family, as there are six children, as to who should be the appointed one. Added to this the care home was open to all family members for three weeks and then changed its stance due to the ever-changing government guidelines. The care manager said to me that she wished they would just tell them what they are to do and stick to it. The whole situation is causing family distress and tension with the care home from other members of my family. It seems ridiculous that I can go shopping, to the pub and see friends but not my own mother.

I live alone and am very careful who I see and where I go. I have been very involved in my mum's care from day one. I have always regularly visited, accessing the community when mum felt up to it, attending the hospital when required, assisted when mum was not compliant with eating, drinking, personal care etc. When my mum was very unwell last December/January I was visiting daily and encouraging her to eat, drink and putting her to bed as this was a particularly challenging time.

My mums greatest fear was to end up in a home and be forgotten and abandoned and this is exactly, through no fault of her own or ours, what has happened. The powers that be, need to reconsider urgently the mental health damage to the residents and their families. I have been told that I will only have 15 minutes in full PPE at the end of my mother's life. I refuse to adhere to this and when the time comes will refuse to leave my mother's bedside as no one deserves to die alone.

Story #4

(Relative's experience at Worthing Hospital's A&E, shared on Care Opinion)

My 86 year old mother, who has dementia and frailty was sent as an emergency from her care home to A+E at Worthing hospital in August 2020 with symptoms of a stroke. I followed the ambulance and expected that I would be able to be with her in the hospital. I explained to the receptionist who I was, that my mother has dementia and asked to be allowed to join her. I was told that as my mother lives in a Nursing Home I am not a carer and wouldn't be allowed to join her. They said that they had all the information from the care home, and they would *"get in touch with me if they needed to*". I challenged this and was told to come back in 30 minutes.

When I returned a nurse told me that my mother had had a scan and that they were trying to get a cannula into her vein. She said she would come back in a short time and take me through. I was taken through after about five minutes and was able to spend the next five hours with my mother until she was transferred back to the nursing home.

During that time, I talked to her, reassured her when there was loud screaming from a child nearby, fetched several blankets as she was very cold, helped her drink some tea and eat a sandwich. She was unable to ask for a blanket or drink/eat without help.

The staff were very patient, polite and communicated well with me and my mother. I was able to discuss the details with the doctor. The wait for transport back was only about two hours.

Initially, when I was barred from being with my mother I felt angry, scared and very upset. I feared that my mother might die or become severely affected by a stroke before I could see her. I was fearful that she was on her own, feeling unwell in an unfamiliar place and might be feeling very distressed. I was angry that I was dismissed as *'not being a carer'* as prior to Lockdown I visited my mother for an average of two hours a day, providing her with emotional support and also checking up on various bits of care. Since lockdown she has deteriorated both physically and cognitively. Visiting has been very restrictive and it was a joy to be able to spend the time with her in A+E.

Social Media Stories – July 2020

- I've been impressed with the way steps were taken to safeguard the residents and staff during the coronavirus pandemic. In the last few weeks mum and I have been able to visit my brother in Bay Trees by sitting outside the conservatory with him inside. He was pleased to see us and looked well. I thank al the staff doing a difficult job at the present time, keeping the residents entertained and engaged.

- I've just done a 36 mile round-trip to deliver new slippers to my partner's mother in her care home. She is 91 next week, and we're still not able to see her. It makes me so sad when I drive past pubs full of people, and the crowds along Littlehampton seafront. She has Alzheimer's and every passing day is one less when she'll still know who we are.

- My mum is in a care home and not seen her since March and she gets so upset when I ring her – asking why I don't go to see her. How do you explain to them why it's heart breaking and so not fair.

- Its awful, my Mum is 92 on end-of-life care for over two years, withering away with Alzheimer's and vascular dementia and I just want to give her a big hug in the care home. Hope it won't be much longer before we can give them some love, they are on borrowed time and don't fully understand what's going on.

- I manage a home and it is heart-breaking for all of us in the home. I am seeing significant decline in the mental health of my residents and although we allow window visits, some time I think that is worse, as I think the residents fell they have done something terrible to be shut behind a window or a patio door. I was going to think abut doing social distance visits but feel after this weekend with the pubs that I need to wait a big longer.

- I have a sister in a care home with dementia and no one can see her only through the glass windows. She obviously doesn't understand.

- My dad has just gone into a home and his memory isn't very good, so trying to get him to remember we can't go and see him yet, and that we haven't abandoned him. Though I'm sure they told my mum that after 10 days of his admission he'd be allowed a visit. I think it varies from home to home.