Healthwatch Oxfordshire

Your voice on health and care services

> "We have been married for 58 years and together for more than 60. The crowbar forcing us apart by separation will kill us both."

> "…they are allowed to hold her hand and care for her. My heart is in pieces that I cannot do these things for her. Our biggest fear is that she is taken and we never get to hold her again."

Voices from the loved ones of care home residents during the COVID-19 pandemic

> "Nearly whole year of not hugging/kissing mum is breaking my heart."

> "The Family Support unit has been excellent…Their support has been outstanding, sending me photos of my wife engaged in various activities inside the home or giving me an account of what she has been doing."

Contents

Healthwatch Oxfordshire would like to sincerely thank everyone who responded to this survey, and those who shared their personal stories with us. Their input has helped ensure that the unique experiences and challenges of care home residents and their loved ones throughout the COVID-19 pandemic has been heard.

1. Executive Summary

Between November 2020 and the end of February 2021 59 people told us about their personal experiences of having a family member living in a care home during the COVID-19 pandemic. These stories were powerful, often painful, and intimate. If you read no further than this Executive Summary please find time to read the personal stories found here (page 27 onwards).

It is important to note that leading up to the time of this survey, all agencies involved had worked out some measures to protect all involved: patients, staff and relatives. During the survey period this was "work in progress" however some people we heard from had not been able to visit their relatives at all between April 2020 and February 2021.

Key findings

- Generally relatives are very positive about the carers who are looking after their loved ones but there is a sense of sadness and envy that their close physical and emotional relationships have transferred from relative to carer.
- There is little consistency across care homes to support relatives – either with visiting or communication about their loved one.
- Relatives and residents find visiting often upsetting, challenging, distressing, stressful, very frustrating due to the COVID-19 constraints imposed by Government and applied by care homes.
- Physical barriers to having a good experience include wearing face masks and gloves, windows, 2 metre rule, poor access to wifi and associated technology.
- The impact on families has led to an intense feelings of loss, fear, and distress.
- Some relatives believe that the impact of COVID constraint measures on residents has been detrimental to their physical and mental health.

Relatives want the authorities and care home providers to:

1. Listen to them, and consider relatives part of the "caring team".
2. Be more flexible around the number and frequency of visiting opportunities.
3. Treat Government advice around visiting as just that, and not prescriptive, unless so stated.
4. Establish regular and personal communication between care home and relatives about the wellbeing of the residents.

> "It's heart-breaking not being able to touch or get close to my husband. He doesn't understand why I can't come in and feels abandoned. It's cruel beyond belief."

Healthwatch Oxfordshire has heard in depth from a relatively small number of relatives of people living in care homes. There are strong themes found during this listening process that we believe are reflections of others' experiences as reported by Healthwatch England[1], and in both local and national media.

Reflecting on what we have heard about the negative impact on both residents and families during this research and that COVID-19 will remain in our community these tight restrictions on visiting cannot continue; things need to change to enable more flexibility of visiting.

There is a need to work out ways in which relatives can be treated as part of the "caring team", and hence can come and go within Care Homes in same way as staff and support services. This could include undergoing regular COVID-19 lateral flow tests.

We suggest that the issues raised in the report and summarised above cannot be addressed by a single commissioner, provider or authority.

Care homes are regulated by the Care Quality Commission (CQC), which over the past year has not been carrying out a regular inspection programme. The temporary suspension of CQC inspections, together with the absence of relatives in the homes means, that for many homes and their residents the only outsiders have been staff. A fifth of our respondents did not have any contact with the home over the past year.

This issue of Care Home visitors' absence is well summarised in this quote from "Social Care Institute of Excellence":

> 'Those who are important in people's personal lives – their partners, carers, family members and friends – should remain important when they move into a care home. They are vital to the residents' wellbeing and safety. The sustained and accepted involvement of families and carers is one of their best protections against abuse and neglect.'

Following the publication of this report Healthwatch Oxfordshire will call together the organisations below to hear their responses and initiate work on how Oxfordshire care homes can become exemplars of good practice, in valuing the role of families of loved ones living in a care home.

Organisations include: Care Quality Commission, Oxfordshire County Council, Oxfordshire Adult Safeguarding Board, Oxfordshire Association of Care Providers,

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[1] Healthwatch England Call for better guidance on care home visits https://www.healthwatch.co.uk/response/2020-12-21/call-better-guidance-care-home-visits-read-our-letter-government

Oxfordshire Care Homes Association, Oxford Health NHS Foundation Trust, Oxfordshire Clinical Commissioning Group.

2. Background

In March 2020, Healthwatch Oxfordshire launched a survey listening to the concerns and priorities of care homes during the first few weeks of lockdown, with a follow up in October.

We heard that staff were becoming increasingly concerned about the wellbeing of care home residents regarding the loneliness and separation from their loved ones. On the back of this we launched a project to listen to the experiences of people who have a loved one living in a care home. We focused on what it is like to visit their loved one now, how this has evolved during lockdown, what communication has been like, and the personal impact this has had them and their loved ones.

3. Methodology

We utilized a mixture of online questionnaire, hard copy of questionnaire, a 'letter writing pack' (see Appendix 2) that we printed off and delivered to several care homes across the county. This, along with a pre-paid return envelope gave those residents who were able, as chance to write to us directly. We had two letters in response to this.

We developed an online survey with open and closed questions (see Appendix 1). We promoted the survey through Healthwatch emails, social media, Oxfordshire County Council, community magazines, Parish newsletters, Care Homes in Oxfordshire, and GP practices. We heard from 59 people. We held an on open forum using Zoom Video Conferencing technology and used social media to promote this.

We also conducted telephone or video interviews with eight people who completed the questionnaire and wanted to share their experiences in more detail. One person also kindly sent us a written account of their personal experience.

Survey results were downloaded for cleaning and analysis in Microsoft Excel. The data is presented in graphs and described in the results section. We transcribed interviews and present what we heard as personal stories using a combination of summarized points and verbatim quotes.

We launched the survey at the end of November 2020. At that time, we were in a national lockdown, and Oxfordshire was moved into a Tier 2 'High Alert' when we moved into regional lockdowns on 2nd December 2020.

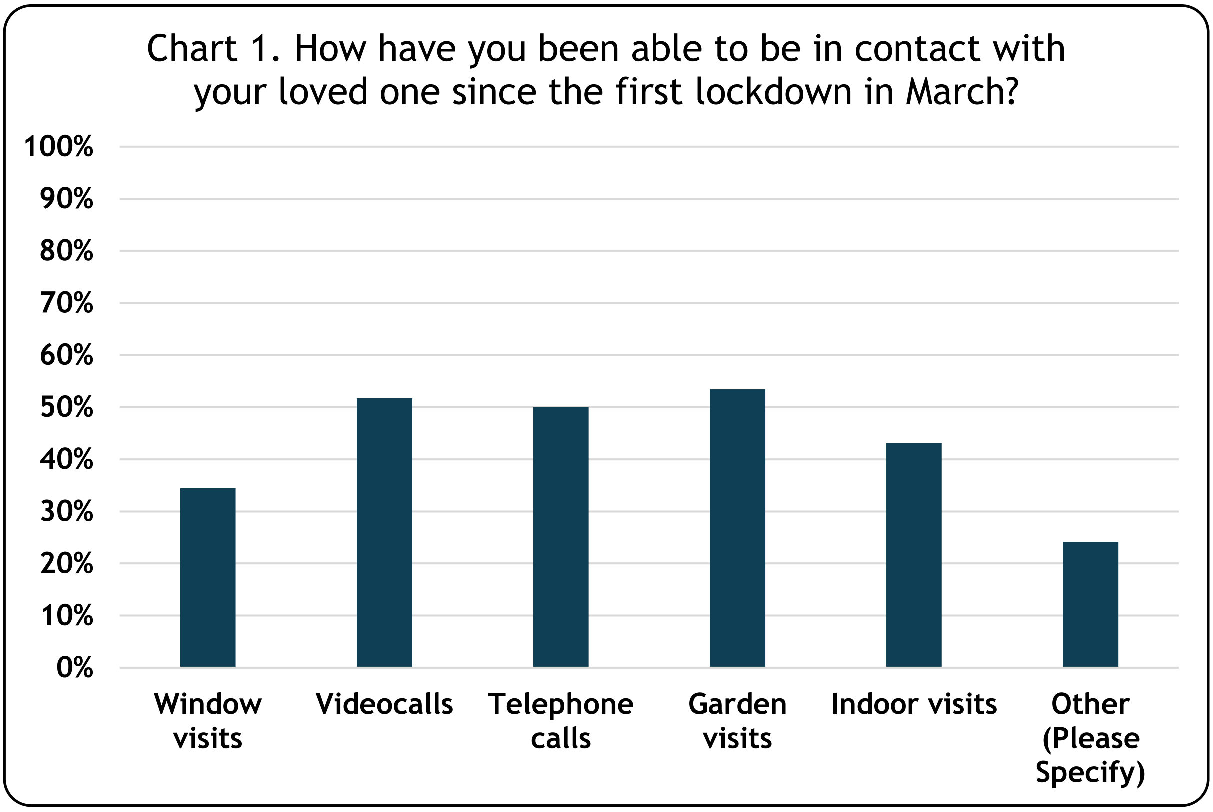
On 26th December, the country moved into a "stay at home" national lockdown.

4. What we heard

As well as the survey responses, the personal experiences and opinions that we heard from people were powerful, often painful, and intimate. To honour and share them as clearly as possible, we will weave standalone stories through the body of this report. All names have been changed to protect the anonymity of those that participated and their family members.

Visiting care homes during COVID-19

We asked how people had been able to keep in contact with their loved ones since the first lockdown in March 2021.



Among the ‘other’ responses, examples given included *“a dedicated, indoor visiting room”,* and *“a visit using a curtain between me and my father,”* as well as *“discussions with family liaison officers”* and *“coming for a walk with us.”*

We asked people to tell us what their experience of visiting under these circumstances has been like.

All 59 respondents answered this question, with the overall message being that the experience had been upsetting and challenging. People used words such *“distressing”*, and *“stressful”*, or *“very frustrating”*. One person described visiting under these circumstances as *“terrible, awful and inhumane”*, while another simply stressed: *“I cannot begin tell you how heart-breaking this is.”*

Read Carly’s* story

I can’t tell you how the lack of meaningful care home visits has affected my mother, because I don’t know. She moved to a care home only days before lockdown in March 2020. I have no idea how her dementia would have progressed if we had been able to visit more, stimulate her and take her out for walks and tea…. [click here to read on or go to page 27]

Outside and window visits:

We asked people to tell us more about this. Issues we raised around the physical barriers that were in place, such as windows, wearing of masks, and having to remain two metres away.

“…having to socially distance is heartrending with a dementia sufferer who expects a hug,” explained one respondent. *“When I started having to wear a plastic apron and gloves my mother became more withdrawn.”*

“Since visits have had to be through a screen (and with plastic apron and gloves for me), it has been almost impossible to engage with my mother...”

We received similar responses that engagement and communication was made harder because of these barriers, with others saying:

“Mum is virtually non-verbal so communication is almost impossible in the room with the window.”

“I'm deaf and my Mother is deaf. Talking through masks is very difficult particularly as I use lip reading to communicate.”

“Two metres away with a mask on. Dad couldn't see us or hear us properly and just talked gibberish. Couldn't share anything with him. He no longer knew who we were. Very upsetting. Before March he knew us all.”

However, ten respondents said that they felt that the new ways of visiting were adequate and that they had had a satisfactory or positive experience:

"The garden visits have been shorter than my normal internal visits, but I have been greatly reassured that my wife is as good as she can be and is well cared for. They also used their imagination and initiative in arranging a visit by our daughter to see her mother. Although the visits are shorter, it really doesn't matter - my wife has lost the context of where she is and while she is always pleased to see me, the staff have stage-managed the visits very well so that they are stress-free and rewarding for both of us."

Video and telephone calls

The use of video call technology to allow continued communication was welcomed, although 19 people said that it presented its own set of challenges and difficulties. Obstacles such as poor connectivity or staffing pressures were highlighted:

"Unfortunately, the broadband at the Home keeps losing connection during the calls, so this is very frustrating," one respondent told us, while another explained that they "*had one call and it was cut off due to the wifi connection in the home.*"

Another told us that their loved one was "*reliant on staff for placing video calls and they are understandably very stretched,"* and a further respondent explained that as "*The home has been very busy, organising video or telephone contact is tricky.*"

For others, the obstacle lay in their loved ones having difficulties using the technology, with one respondent recounting that their experience using video calls was "*very distressing as Mum has dementia and does not know what she's looking at*".

Other similar comments noted that "*I tried video calls with mum but that too was difficult*", "*his eyesight was so poor he could not do FaceTime,*" or "*We don't have the technology to use Facetime.*"

Visiting in general

Some care homes were reported to have gone the extra mile, having enabled visiting in a bespoke, individualised and creative manner.

"The care home have built a Covid Suite where a wall with a large window means we can sit indoors in comfort and speak through an audio system," one respondent told us, while another explained that their experience of visiting "*was organised really well with a pickup on the M1 On Christmas Eve and drop off the other end on Boxing Day.*"

A further answer described a "*special area set out for visitors,*" while one respondent said:

"I have mostly done garden visits so that I can play table tennis on the lawn with my friend who has dementia and is a resident. The home has bought a new outside table specially for him."

Conversely, two respondents told us that they have taken the decision to move their loved one out of residential care and into the family home:

"I took mum home and nursed her back to health - I'm convinced that she would be dead if she was still at the [care home]"

"I decided I had to get Mum out to live with me temporarily… I've been looking after her ever since. She has improved in her mood, she's eating more and engaging with life".

Abigail's story…

Abigail's* mum has dementia and has been living in a care home since February 2020. Abigail told us that the decision for her mother to move into a care home was a very difficult one for her and her siblings. They eventually decided that it would be best for her mother to live in an environment where her physical needs could be met, which would enable the family to focus on her wellbeing… [click here to read on or go to page 29]

5. Personal impact

Jennifer's Story

Jennifer's father suffered from dementia and lived in a residential care home from before lockdown in March, until he was admitted to hospital in December 2020. He was in hospital for ten days before being discharged to a nursing home, where he sadly passed away a few days later….* [click here to read on or go to page 30]

On family members and loved ones

Once again, all 59 respondents answered this question, with all but three describing intense feelings of loss, fear and distress: "*The only word to describe the situation is devastating.*"

"*None of the family have been able to touch my mother since she entered the care home,*" one told us. "*We are concerned she will die without having the warmth of her family around her for months.*"

"*My father died in January, I had seen him once since last March,*" another explained. *"I was incredibly close to my father and the trauma that he spent since last March alone and lonely with strangers who had little time to give him or understanding of his needs will take a long time to come to terms with. I feel incredibly sad how he spent the last year of his life without my support."*

Other responses also touched upon this theme, and the fear of being perceived as having "abandoned" their loved one:

"I've missed visiting my father awfully and the thought of him possibly thinking he's been abandoned haunts me every day."

"It's heart-breaking not being able to touch or get close to my husband. He doesn't understand why I can't come in and feels abandoned. It's cruel beyond belief."

"…our time with her is precious and to lose a whole year without being able to connect with her properly is heart-breaking."

"Nearly whole year of not hugging/kissing mum is breaking my heart."

Another explained that they were struggling with the separation from their loved one compared to those looking after him, saying that it was *"upsetting to see that the carers could touch him and I couldn't - I told them that it was like he was part of your family now not ours."*

In addition, three respondents described the situation as akin to having a relative in prison – "*The closest description is visiting someone in prison", "for all of us this incarceration is torture*" – and elaborated on the resultant feelings of "*Frustration - loss and anger - prisoners would have more visits than care home residents."*

This notion of care homes having become "prison-like" threads throughout the survey and the interviews we carried out.

Rebecca's story…

Rebecca's* mum has been living in a care home since January 2019. Rebecca explained that the move into a care home was a "wrench" for the family, and that in December 2019 her mum had been moved into the care home she is living in now. At the time of interview (February 2021), Rebecca told us that the last time she saw her mum was on her birthday in October 2020. She explained that this visit was upsetting on many levels… [click here to read on or go to page 32]

On care home residents

Of the 58 respondents who answered this question, 44 people said that that the impact of lockdown and related restrictions had had a detrimental impact on their loved one.

Of these 44, 23 people stressed that the mood of their loved one had been affected, describing them as being “*low in mood…*”, “*…depressed, anxious…*”, “*troubled, upset*” and suffering a “*loss of confidence*.”

We also heard comments that loved ones were “*becoming more withdrawn*”, with some going so far as to say that their loved ones had “*lost the will to live*” or were “*giving up*”.

Twenty-two people described a cognitive decline in their loved ones, and felt this was likely to be directly related to lockdown restrictions:

“Dad has become increasingly confused and he finds it difficult to understand why he doesn’t get visitors. By the time this is over, he will not remember who I am.”

“After periods of visiting not being allowed she seems to find conversations difficult as if she has forgotten how to hold one”.

“His ability to verbally communicate had reduced due to increase in confinement.”

“*I think my mother would be happier and would be losing her ability to speak much more slowly if we could have regular contact*,” another respondent commented.

Furthermore, 16 people noted a physical deterioration in their loved ones, which was again linked to the restrictions that arose because of lockdown.

“Yes he has deteriorated rapidly,” one respondent attested. *“He went in semi continent, shuffling and a bit vague. Now he is immobile, fully incontinent and makes no sense in any conversations. Whilst this could be a deterioration as he has Lewy body, it’s a shock. I’d like to think that if we had regular contact we could have kept his brain going and encouraged him, what we have had to do is rely on staff who are stressed and don’t know him.”*

Another respondent explained that their loved one “*hasn't been able to go to hospital for her routine eye treatment for several months causing her eyes to degenerate*,” while a further answer told us:

“Without a doubt our mother has physically and psychologically deteriorated faster than she would have done, due to not being able to be with family physically and interact with us in a meaningful way. There is a sadness in her eyes that was never there previously. It’s very obvious in the photos we take. Heart-breaking for a woman who has so much spirit and was always a happy soul.”

Weight loss was also identified as a consequence of the restrictions, with one respondent explaining that *“My husband frequently breaks down as he is so upset not being able to touch me. He has lost over 10 kilos in 2 months because of the stress,”* and another detailing:

“a severe and steep deterioration of awareness and responsiveness... A disinterest in eating and drinking and attendant weight loss. I feel that these responses are a direct result of her isolation as she is alone in her room, visited only by the care team. Eyes closed as if trying to shut out the agony of her situation.”

However, six people said that they did not feel their loved one had been detrimentally affected, commenting that “*they remain positive overall*” and “*I have no concerns about the wellbeing of my husband as he is extremely well looked after*.”

Additionally, three of those who responded felt it was impossible to ascertain the impact on their loved one, due to the fact they had been unable to visit.

Another issue raised was a perceived deterioration of the relationship respondents had with their loved one, with one stating that:

“I feel that her relationship with us was lessened. She has a lovely relationship with some of the staff which isn't surprising as they are the people she has been closest too. I couldn't help but feel a little envious.”

This feeling of “envy”, and seeing carers as having a “privilege” that is denied to the family, was another common thread throughout the responses to our survey, and echoes comments we received about the impact on relatives, where one respondent described their upset that their loved one felt more part of the carers’ family than theirs.

Claire’s story…

Claire* is mother to David*, who is 22 and is severely physically disabled. He is quadriplegic and unable to communicate verbally; he also suffers with epilepsy. Claire explained that due to the lack of community-based social care, her son now needs to live in a care facility outside of Oxfordshire. She chose this facility carefully, ensuring that it could meet her son’s physical, social and emotional needs, as well as provide all the therapeutic support that has been identified in his care plan…. [click here to read on or go to page 33]

6. Keeping in touch

Next, we asked "Do you have any suggestions that would improve your ability to keep in touch with your loved one?", with 53 people responding.

Seventeen people said they would like face-to-face visits to be facilitated, with one of these stipulating that "*nothing other than close contact is likely to improve my mother's situation*"; however, many people said that there could be more creativity and flexibility in making face-to-face visits safe, with suggestions including "*a return to window visits*", "*longer visits*" and "*more visiting pods.*"

Fourteen people said that despite the impact, they felt that the care homes "*did all they could for us while keeping their staff and residents safe,*" admitting that they "*don't see a way around it that would keep everyone safe.*"

Another of these 14 particularly praised the home's Activities Co-ordinator, who they said, "*has been great at setting up facetime and keeping in contact.*"

Thirteen people said that better use of technology to facilitate remote visits and telephone calls would have helped – particularly in terms of availability resources, or staff having adequate time and training:

"I know they have iPad, but they are not available at weekends."

"Adequate staffing during day and early evening's say till 8.30 pm, so phone calls can be accepted by home."

"Regular face times - it only happens when staff have time."

Eight people observed that regular testing for family members would and could have helped enable safe visits, while seven felt that the situation could have been aided by better communication from care home management and staff to family members, specifically having a named member of staff of family liaison officer.

"*Appoint a carer as a keyworker who could email families once a week to say how he was or what he'd done during the week,*" was one suggestion, with the respondent explaining that "*without this I have a vision of my father stuck in a bed in a room in solitude.*"

A similar voice called for "*regular communication from a named contact at the Care Home*", while another declared: "*The home should have made more effort with regular virtual catch ups. For new residents shown us around so we could get a sense of his room and team around him. A newsletter with staffs faces on would have been nice so you can at least put a face to a name.*"

Elizabeth's story…

Elizabeth's* mum is 96 and had been living independently until late January 2020. The decision to move into a care home was a very difficult one, and only made easier by the idea that the family could visit and could take her out regularly… [click here to read on or go to page 35]

Government guidelines

At the time of launching the survey (November 2020) the Government had announced new guidelines on care homes facilitating visiting that would be introduced in December 2020:

All care homes regardless of tier – and except in the event of an active outbreak – should look to enable:

- outdoor visiting and 'screened' visits (see national guidance for further details)

In tiers 1, 2 and 3 care homes should also seek to enable:

- indoor visits where the visitor has been tested and returned a negative result[2]

When asked about this guidance specifically, 41 of the 55 responses said that this made "*no difference*" or that the "*home was still shut to relatives.*"

Nine people said they had noticed "*marginal*" improvements, but that this did not go far enough, while two people said that they could not comment as their relative had sadly passed away prior to the new guidelines; a further two said that they had since taken their relative out of the care home setting, and so this question was not relevant to their situation.

It is important to say that the survey and most interviews were carried out before the Government announced new guidance that from 8th March 2021:

- Every care home resident will be able to nominate a single named visitor who will be able to enter the care home for regular visits. These visitors should be tested using rapid lateral flow tests before every visit, must wear the appropriate personal protective equipment (PPE) and follow all other infection control measures (which the care home will guide them on) during visits. Visitors and residents are advised to keep physical contact to a minimum. Visitors and residents may wish to hold hands but should bear in

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[2] Source – Reminder letter from Oxfordshire public health team to care home managers dated 24th December 2020.

mind that any contact increases the risk of transmission. There should not be close physical contact such as hugging[3]

James' story…

James'* father suffers from Dementia. Although his family had a difficult experience with the first care home he was in, they have had a much more positive experience since he was moved to the care home he is living in now - a positive experience has continued throughout lockdown…[click here to read on or go to page 37]

7. Communication from Care Homes

When we asked people to tell us more about the communication they had received, 19 respondents described it as poor, feeling that although either general, or COVID-specific, communication had been adequate, "*communication about our individual family member had been poor.*"

One respondent elaborated on this, saying that they were "*very unhappy that if I called or left a voicemail, the call would go unanswered.*" Furthermore, 15 respondents said they felt staff were too busy to communicate with them, and that they felt "*shut out.*"

It was clear that where care homes had dedicated time and energy into communicating personally with family members, this had made a positive and lasting difference in terms of families feeling connected to each other, as well as having a good idea of how their relative was coping:

"We can call whenever, we get regular email updates. We really are very lucky. Everybody at [care home] is lovely and we think of them all as a big family."

"The Family Support unit has been excellent in sending out a weekly bulletin with updates on the health of the residents and staff, and if necessary, they telephone me directly whenever it concerns my wife. Whenever I want more detail, I simply phone or email. Their support has been outstanding, sending me photos of my wife engaged in various activities inside the home or giving me an account of what she has been doing."

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[3] Source: https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes

"The nursing home team are very good and the care regime excellent. I have supported the team as best I can and we are close in communication."

We also asked people how they felt communication from care homes could be improved. Of the 50 people who responded, 22 said they would like care homes to have better capacity and resources to respond to emails and phone calls; 17 people said that a dedicated family liaison service would help, with 8 people saying that the care home viewing the family as part of the care team around a person would help. 12 people said that in their opinion, the care home was already doing a good job.

Eleanor's story…

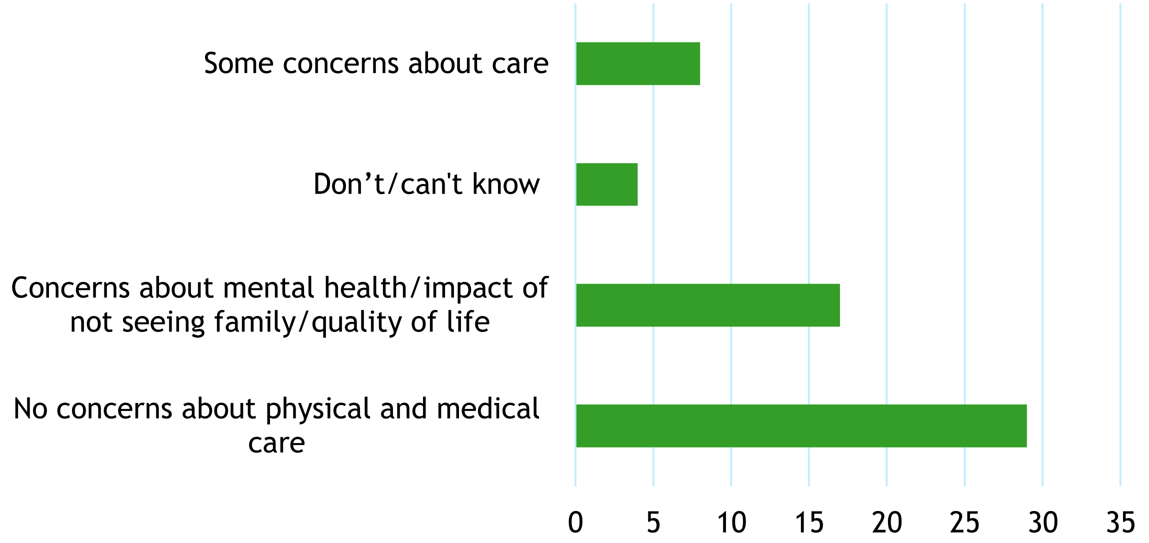
Eleanor's father had been living in a care home since September 2019, due to his diagnoses with Lewy body dementia. Before lockdown, Eleanor visited her father twice a day, and was his main source of support and comfort. After lockdown, however, Eleanor was unable to see her father, except for two visits in the garden, until he reached the end of his life, when she was able to go in three days before, and "*sat with him for his last hour*"….

[click here to read on or go to page 37]

8. Care in the home

We asked people if they had any concerns about the care of their loved one during this time.

Chart 2. Have you had any concerns about the care of your loved one during this time?



As you can see from Chart 2 above, more than half (29 of 55 respondents) said they have no concerns about the physical care and attention their loved ones are receiving in the care home.

Comments such as *"care is phenomenal", "I have full confidence in the standard of medical care"* and *"the staff are kind and lovely and she is well loved and looked after"* reflect this.

Fifteen respondents said that they feel concerned about their loved one's quality of life and mental health in relation to visiting restrictions and isolation in the home.

"She needs her family", "Concerns just relate to the impact on her well-being and functioning of the deprivation of cognitive stimulation and activity" And *"Concerned about her mental health. She is so sad"* illustrate the sentiment shared on this point.

Eight people said they had some concerns about the care their loved on is receiving in the home.

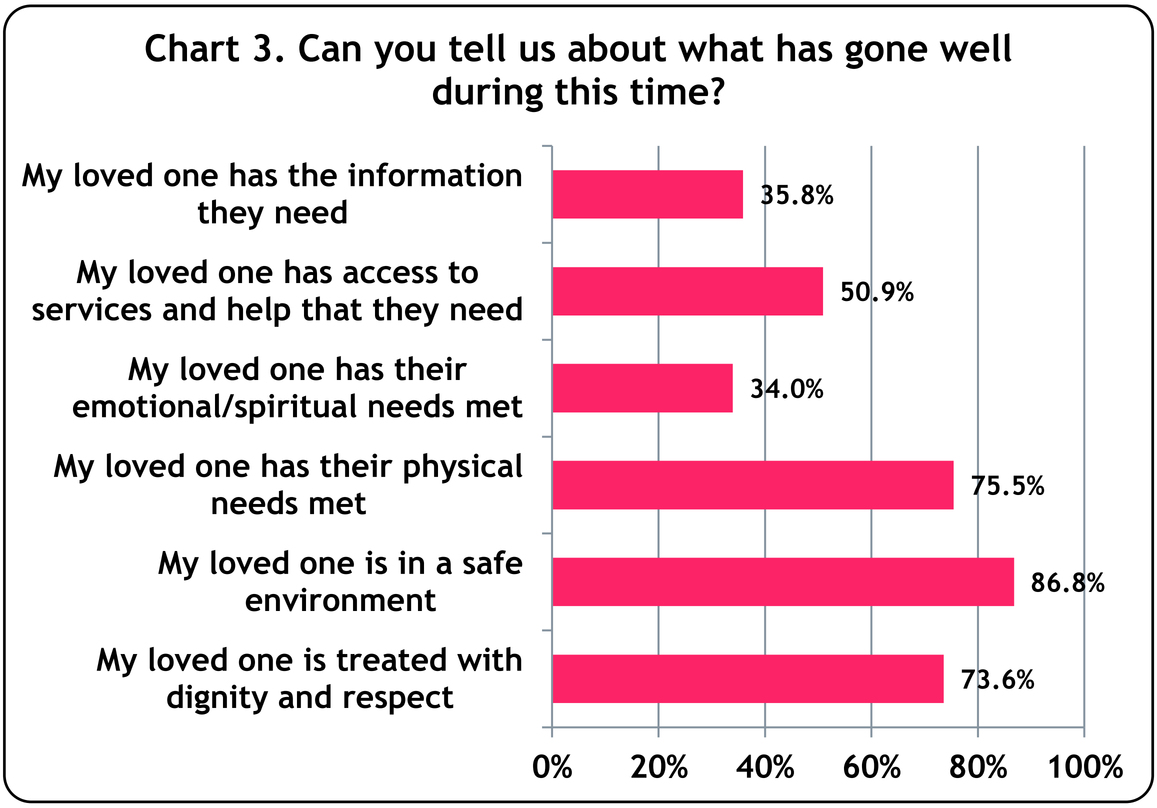
> *"She has had a number of falls (one resulting in a fractured pelvis) and I don't know how long she has been alone before being found."*

Some of these concerns relate to barriers to attending medical appointments due to COVID-19 restrictions:

> *"The worst thing that has happened is that he lost almost all hearing for about 2 weeks because his one working ear was blocked with wax. The management did not take this as seriously as I would have liked, but the delay was not all their fault."*
>
> *"My mother has been ill (which turned out to be two concurrent infections) and the GP refused to visit."*

Four people said they were unable to answer the question because they have been unable to go into the home and therefore cannot know about the quality of care. *"As I have never been inside the home I find it difficult to get a picture of how it is operated".*

9. What went well during lockdown



Fifty-three people responded to this question. Chart 3 above shows that most people (86.8%) believe their loved on is in a safe environment. Around three quarters believe that their loved on has been treated with dignity and respect, and that they have had their physical needs met.

Just over half say that their loved one has had access to the services and help that they need. While just over a third believe that their loved ones have had the information they need and that they have had their emotional and spiritual needs met.

We asked people to tell us what else was going well. Forty people responded to this question. Twenty-one of those said they believe that staff care for their relative well. *"The staff are wonderful. They have a great relationship with my sister. They take very good care of her and I know they feel she is a member of their families", "They do an amazing job of keeping him clean and fed as well as organising activities like painting and gentle exercise, he particularly enjoys the singing when it happens."* And *"As I said couldn't commend the staff more. They are well trained informed diligent caring hard-working".*

Ten people said that they were unable to comment due to not having had any access to the home and not being able to engage with staff or their loved one.

> *"No idea - we can't talk to her properly."*
>
> *"…because we do not go in like we used to we have no real idea about anything other than on Trust and that Mum is healthy physically."*
>
> *"I have no knowledge of how the above is going. I can only assume/hope that the previous high quality of care has continued during the pandemic."*

Five people said that they felt nothing at all had been going well.

Four people said that increase in activities in the care home had been going well *"They are doing everything to support my sister and keep her calm. They keep her busy. They keep her engaged and interested in activities"* and *"Mum is being involved in activities such as art and music."*

Edwards's story…

Edward* has been married to Sylvia* for over 50 years. Edward became Sylvia's carer after her diagnosis of dementia around ten years ago. The lack of community and respite care meant that he was unable to continue caring for her in their home, and decided that she needed full time care. Sylvia has lived in the same care home since the summer of 2018.

Edward's experience during lockdown has been largely positive…[click here to read on or go to page 40]

10. Voices of care home residents

We provided a space in our survey for care home residents to add their thoughts, directly or through their relatives, if and where possible. Most people said that this was not possible due to restrictions, but the following comments were gathered:

"The staff are generally very caring, but they are overworked and there aren't enough of them. It can take a very long time for someone to come to me if I ring my bell for assistance."

"It's made such a difference being able to see my family each week."

"Bloody awful"

"He wants to get out as he cannot see family.

Feeling of abandonment."

"Mum just wants her family around her that's what she always says."

"I have reservations about the CQC assessments. I feel they are carried out by rote according to a manual of procedures and don't always allow for common sense and initiative in assessing the practical quality of the care and emotional support delivered to the residents and their families."

We also sent out letter writing packs into several care homes across Oxfordshire (see appendix 2) along with pre-paid envelopes so residents could write to us free of charge.

We received only two letters back, and one person gave us consent to share their comments:

"It is hard to explain. My health is up and down. I am 100… the carers do their best, but they are very short-staffed, and I feel for them. The staff have very little time to spend doing their jobs.

"At my age I want to see my family. I keep in touch on the telephone. Now my daughters have had the vaccine I hope they will come and see me."

11. Messages to decision makers and authorities

We gave people an opportunity to tell us what they would like decision makers and authorities to hear. We have dedicated this space to share these quotes in full:

“The care home is more like a prison for OAPs and the staff acting like prison warders. Some staff are deliberately obstructive when relatives try to speak with the resident by phone saying they are too busy to make the connection. Outside office hours it is almost impossible to contact the care home”

"Separation is agony for so many. The wellbeing of the residents is synonymous with family visits and every effort to make this a safe and regular event must be foremost in thinking and planning ahead.”

“We have been married for 58 years and together for more than 60. The crowbar forcing us apart by separation will kill us both."

“My mother has a ground floor room with a patio which can be approached from outside in the same way as the current designated room. Because of the problem with the sound in that room, I would like to visit my mother in her own room, even if it means me standing outside with the door slightly ajar”

“Care homes have felt isolated- they have done amazingly well with really difficult circumstances- and maintained community and learnt how to adapt. They seem more comfortable now with risk and understanding that the mental emotional and physical wellbeing of residents and have a system in place to support contact safely.”

“I think this is a very good model of care. The layout of the home allows for various areas to be isolated when necessary. It is a good size for this. Larger homes might find it more difficult, although the more recently purpose-built ones I have visited are probably also set up to enable different areas to be kept separate.”

“If my mum had the choice between staying safe but being a virtual prisoner, she would rather take the risk of seeing her family and having a normal end of life”.

“Receptionist should not be given power. Mental health should be taken care of much more. Residents should be encouraged to sit in lounge together more. Staff should be allowed to sit and chat more to residents.”

“If you mean the Government, I think they should find a better way to fund those needing care and I think they should seek to pay carers better. Brexit will not help

because we will get less carers from the EU. The hostile attitude to foreigners is unhelpful."

"Yes - I'd like them to be aware of residents mental health - and the lack of help in that direction. It's just as important as their physical health."

"I would imagine that physical contact is the one thing that everyone misses during this time. Even just holding a loved one's hand would make a tremendous difference, but because we don't have 2m arms it will never happen."

"I repeat what I said above. The government guidelines have left me with a sense of people in my mother's situation being completely deprioritised. There has been one broken promise after another. We are told in the guidance that testing to enable relatives to enter care homes 'will' be in place 'by Christmas'. Nothing happened on this. I now keep hearing in the media that care home residents are the top priority for vaccination. The staff at my mother's home have had their first jab, and I know elderly people in the community who have received theirs, whereas there is no date for the residents. They are all ""signed up and ready to go"". This promise was not expressed as being conditional on the Oxford vaccine coming on stream. I feel that if people like me don't push, care home residents will be completely side-lined."

"Also, the relevant GP practice appears to have a blanket policy of not entering care homes under any circumstances. They exerted inappropriate pressure in relation to non-resuscitation orders and failed to listen properly to what they have been told about my mother's condition, misrepresenting her symptoms in order to minimise them, and have failed to liaise with other the mental health professionals involved in my mother's care."

"I think it is a Human Right to be able to have access to your family and loved ones. Mum entered the Care Home because we thought it would allow us to concentrate on her mental health support and not worry about her food and medicine. This is the one thing we have not been able to do. We know that at 85 she will die from something; so surely it is better to spend time with us rather than being preserved indefinitely with no contact with her old life and who she was and is! Someone should have put in place a package to allow the elderly in Care Homes to choose to take the risk. Obviously, I want them to prevent this lack of contact from ever happening again but the Authority's performance throughout the Pandemic has always been too late".

"I would like to know if the Government will allow indoor visits to care homes when residents, staff and visitors have all been vaccinated."

"If 2020 was your last 9 months of living how might you choose to spend it; even with early-stage dementia; would you choose isolation from family."

"The massive question based upon fear rather than basic cross infection reality is:

Where is the most likely source of potential cross infection likely to occur? Staff or your loved ones? If visiting a loved one and felt unwell the majority would not visit; relatives may have isolating so have reduced risk. Vs low paid workers with children at school, husbands at work, shopping trips (who may need to work).”

“If we quantify risk over a 15:30 min meeting of relatives with a 2m distance & masked; do we really believe visits by relatives have a higher risk than staff?”

“We need to throw away the legal aspects and look at the quality of life for the elderly rather than mere existence."

“I think it went from covid mad in care homes to making a prison which I understand but felt therefore there needed to be more communication to family members. I used to visit my dad every week and needed the contact.”

"I feel a weekly email or phone call to a relative with an update would be so good.”

“The home calls if my mother is ill or has fallen only."

“More thought about the emotional impact on the family when unable to spend time together. Situations are all very different but it seems unfair that we are now not allowed to visit at all, especially when everyone at the home has been vaccinated”.

“Yes, allow an hours visiting time per week and allow 2 members of the family to visit (not at the same time)”

“More serious for autistic people ...they need special treatment.”

“Restricting visitors to a single person causes a lot of problems and frustration within families. It needs rethinking.”

"You need to be more prescriptive to care homes about finding ways to allow families to see residents in a more appropriate and frequent manner - even if it was only my sister who could see my mother, maybe twice or three times a week, that would help the mental health of both the resident and the family. If the rules say maybe do this, the home says we won't do it.”

“The focus on not catching the virus is making the care home a prison - in fact prisoners have more freedom. There needs to be a more sensible balance between protecting residents from the virus and allowing communication. I believe it is possible without increasing the risk of residents getting the virus - especially as they now have had their first vaccine."

“Due to Mum’s dementia any contact we have with her is valued so much. You never know how long they have.”

“Given the extreme age of my mother, I know she would like to see us all...not just one nominated individual.”

“Please complete the vaccination programme for care home residents & staff asap.”

“The main aim is to get visits up and going as a matter of urgency, for the well-being of the residents, with all vaccinations surely this must easier to arrange, could the visiting family members not receive a vaccine, it’s limited to 1 or 2 people.”

“Test us on arrival and let her children visit.”

“That the staff of xxx are amazing, they are always smiling and always ready to listen. Every spare moment is spent on caring for, amusing and entertaining the residents.”

“I will just be happy when we get to a point in time that I can visit my father in the home and perhaps take him out in my car for things like feeding the ducks or attending small family gatherings.”

“I don’t think anyone realises how hard this has been for families. Yes I fully appreciate staff have not been supported with PPE in some cases and have had to deal with significant loses. However with no one visiting how do we know they are doing appropriate care, if they have enough staff and that they aren’t using agency staff or staff who may not be the best. I think if we had been in a different situation other than new to care it may have been different. I could have spent more time with my dad which is really precious as it’s likely he will continue to deteriorate and it feels like lost time”.

“Just try and make it easier for families to see loved ones so they don’t forget family members.”

“I appreciate they are doing all they can. But as somebody who lives alone, I am less risk to my mum than a lot of the staff who go in and out but they are allowed to hold her hand and care for her. My heart is in pieces that I cannot do these things for her. Our biggest fear is that she is taken and we never get to hold her again”.

"The carer staff in these homes seem to be struggling with their work load and the level of training. My father was in a nursing home I found careers were in most part caring very little basic nursing knowledge and language skills. Authorities should have a far greater presence in these homes. A much higher expectation of best practice. It is not acceptable for a reliance on families to report short comings, they are in a difficult position”.

“These homes have a heavy reliance on agency staff and to stop them working in homes has made matters worse."

“Listen to the family.”

“Please give equal consideration to care homes mental well-being as is given to their physical health.”

“The importance of allowing physical contact with loved ones. They may not have long so every day counts.”

“People like my sister need special dispensations in lockdowns because of their different conditions and inability to understand the rationale behind these lockdowns which causes emotional trauma beyond what can be normally coped with. They need to see family. This is an exceptional situation because there is no explaining and loss of routine and contact is exceptionally debilitating.”

"We have been very lucky that Acacia lodge has taken a positive attitude to risk. We know many others have not facilitated contact to try and keep residents safe.”

“Helpful for decision makers to have given clear and prompt guidance and appropriate PPE and testing to enable people to see their loved ones and access the community where risk is low and or mitigation can take place."

"I do not want anyone to feel my views expressed are too critical, I have no doubt the staff work extremely hard in a very difficult situation and I appreciate how they cope.”

“I have worked in the NHS all my working life and am fully aware of the pressure staff are under."

Nine personal stories

*****All names have been changed to protect to anonymity of the participants and their loved ones.

Carly’s* story

I can’t tell you how the lack of meaningful care home visits has affected my mother, because I don’t know. She moved to a care home only days before lockdown in March 2020. I have no idea how her dementia would have progressed if we had been able to visit more, stimulate her and take her out for walks and tea. All I know is that the woman who in January 2020 was still living independently now slurs when she speaks and can’t find her words (the goldfish in the pond became “carrots” – hey, it worked).

All I can tell you reliably is how hard it is for me, seeing her decline and not being able to give comfort, especially in her first months in the home when her whole life had just changed overnight. It is a wrench when you lose your mother to dementia and a care home becomes the only option. You want to give her lots of hugs and make a big fuss of the remaining little things you know make her happy; listening to a piece of music together or turning the pages of a photo album.

But you can only visit her in the garden, with somebody hovering around listening to these conversations you are just learning to have with your dementia mother, talking about nothing over and over. Then in addition I have to wear a white plastic apron and blue gloves, as well as a mask. It feels even less like two normal people seeing each other. The next stage came when the home enterprisingly built a small summer house for visits. We weren't supposed to shut the door, quite sensibly, so the entire visit would consist of mum telling me we had to go because there was a draught.

Social distancing meant I was trying to have a conversation with somebody who struggles for words with no props to distract us, no cups of tea or "let's have a walk round the garden". My mother's social instincts are still there, so when the conversation flagged, she would insist we went inside, forgetting I was not allowed.

And no hugs. We used to hug a lot. Words didn't always hit the spot between me and mum but there were lots of hugs. Now she holds her arms out and I have to turn my back.

When it got too cold to be in the summer house, we started visits through a Perspex screen.

The first was a bit farcical. After about 10 minutes mum got up and wandered off with her empty teacup. I found myself trapped between the screen and a locked door to outside. Having left my phone in the car, I spent the next half an hour at the window trying to attract someone's attention to let me out. Even in the circumstances you had to see the funny side.

On the next visit mum couldn't stay awake long enough to respond to anything I said.

When I visited on 2 January 2021, the care assistant kindly fetched one of mum's photo albums and we were enjoying looking at it – until we got to the end of the first page. No way could I persuade mum to turn the page however much I mimed doing so. That was the end of that.

10 January 2021. Mum kept trying to duck around the end of the screen to get to me and I kept having to tell her it wasn't allowed.

11 January. Mum's gentleman friend found he can't hear through the screen. He hasn't visited again.

21 January. I rang to book a visit for the weekend but was told that five staff had tested positive so no visits for 28 days. From the coming Monday.

28 January. All staff are now coming in to work again. No one had any symptoms. But still no visits allowed. On the phone this week I made out from mum that a cough is making her miserable and "that woman" keeps nagging her. She probably doesn't have a cough and no one is nagging her but I hate knowing that she is feeling down.

5-6 February. A particularly difficult weekend for telephoning. On the Friday the phone rang and rang and no one picked up. The next day it was engaged a few times but I got through eventually but no one answered and I listened to background noise for a few minutes. Then it was engaged again twice. Then I got through and spoke to someone but mum was too sleepy to talk. They would ring me later today if she woke up. Sunday. No answer. I phone again and a man answered the phone but had never heard of her. I rang another twice and got a staff member this time. Mum was asleep again. They would ring me when she woke up. No one did. I felt so very, very far from my mother.

Mum hasn't appeared in any of the photos on the home's Facebook page for a few weeks now. It looks as though she isn't taking part in activities.

22 February. The 28 days are up today. The home haven't announced the resumption of visiting, but were fine about me booking to go.

Also today, another government announcement about care homes. It is encouraging that this is being given a profile but how do we know the promised access won't go the same way as the visits with lateral flow tests promised "by Christmas" or absolute priority for vaccines which turned out to be absolute priority once the Oxford vaccine was out?

And it is going to be very difficult to choose the one person who can have a meaningful visit. To be honest, if it is a question of holding mum's hand through a latex glove, without being able to hug her, our family's nominated visitor may as well be her gentleman friend. They used to hold hands. You don't hold hands with your mother, you hug her.

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Abigail's story

Abigail's* mum has dementia and has been living in a care home since February 2020.

Abigail told us that the decision for her mother to move into a care home was a very difficult one for her and her siblings. They eventually decided that it would be best for her mother to live in an environment where her physical needs could be met, which would enable the family to focus on her wellbeing.

"It is a human right to be with your nearest and dearest", said Abigail. *"I suppose one could argue that I put my nearest and dearest in a home, so I sort of forego some right to that, but it not my human right I'm worried about, it's hers. We've got power of attorney… and it was never our intention that this should happen… we just wanted them to take care of the medical side and the feeding side… So the whole purpose of putting her there was so we could then concentrate on her mental health and her well-being, and we haven't been able to do that at all."*

Abigail explained how difficult it had been to organise video calls, and that when these were arranged, they were unreliable and susceptible to being cancelled, even on important days such as birthdays. She told us that communication from the care home had been "*appalling*" and that she had not heard the news that there had been a case of COVID in the home from the home itself, but from her own hairdresser. We were also told how difficult it was for the family to ensure that gifts and toiletries they delivered to the home for their mother would ever make it to her, and that the uncertainty of not knowing and not having a sense of trust and connection with the home was having a detrimental personal impact on them.

Abigail further spoke about the importance of connection, and her fears about how visiting restrictions may have impacted on her mother:

"I do think [the dementia] *has been exacerbated. I think if we'd been able to go in, I think she would be still a bit more of the person she was. She'd have a lot more understanding of where she was, and where we all are.... When it first happened, my husband did a map of the UK to sort of put on where we were to help her realise where, but she doesn't even remember she's got that now. Every time we went in we'd say look, this where we are. I went to the window and said look if you were to draw a line from here to there you would see my house. What we can do, because I phone her roughly the same time every day at 4:45, she pretty much knows when she picks up the phone that it's me. I can see the same sunset as her, she will talk about the sunset…"*

Abigail talked us through an example of how COVID-19 restrictions exacerbate, complicate, and intensify already difficult and traumatic family experiences.

"The other thing I should mention - which has been very traumatic in the last two months – is that mum's lost two of her siblings. Not to the Coronavirus. She's 86, she is the last one now, there were 4 of them. I know her younger brother died about 7 or 8 years ago and she struggled, we sort of avoid the issue because she was obviously forgetting that he had died. So when we heard that her older sister had died… We chose after consulting with the nurse, not to tell mum because the nurse had said that what happens is they just absorb it and then later on they feel sad, but they can't remember why and we can't get in to hug her. I'm just literally the other side of the valley from her – if she had been upset, I could have gone in a given her a cuddle, and said it's really sad, let's have a cup of tea. Then just this week I heard that her brother had died."

Abigail stressed that she wanted *"better communication from the care home"* and this would have helped ease the emotional impact of visiting restrictions a great deal.

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Jennifer's story

Jennifer's* father suffered from dementia and lived in a residential care home from before lockdown in March, until he was admitted to hospital in December 2020. He was in hospital for ten days before being discharged to a nursing home, where he sadly passed away a few days later.

Jennifer explained that while her father was in the residential care home, the only visiting opportunity her and her siblings had been short, socially distanced visits in the garden.

"It would be 15 minutes (but they might have extended it to half an hour or something), but it had to be outside in the garden, and you had to be two metres away, and you had to wear a mask and have your temperature taken and everything. My dad had no idea who we were. We tried Skype or iPads, that meant nothing to my dad because he was 92 when he died, nearly 93. He didn't get technology at all, he just got distracted and wandered off. He really didn't get that we weren't just a photograph, he couldn't grasp it at all."

However, Jennifer said that the visiting experience was totally different when her father was on the hospital ward: *"He ended up being on a ward for about 10 days, and we all got to see him at least twice each…. we wore a mask and we sat next to his bed, held his hand, stroked his head, and he kind of knew who we were as well… I was just literally sitting by his bed and he was cold and I was getting him another blanket, and I could take care of him and they didn't mind at all."*

When her father was discharged to the nursing home, Jennifer and her siblings were again unable to visit him. They were not informed that he was reaching the end of his life, and they did not have the opportunity to see him again.

"As soon as he was taken there of course we couldn't visit him. So we have this special sort of week or 10 days, to see him at the hospital. We couldn't go and look at [the new care home] *to check it was alright for him, nothing. We just had to go with this, find out from other people, do they recommend it, is it okay? And then he was only there for four days and died there."*

Jennifer told us that the care home her dad had been living in until he was admitted to hospital contacted her about his belongings, and that they needed collecting or he would get charged for them. When Jennifer went to collect her father's things, they had been bagged up and left at the door. They had no contact from the care home regarding her father's condition.

"They never inquired about dad while he was in hospital - nobody contacted us at all, nobody rang up to explain why they wouldn't have him back or anything at all. Nothing, absolutely nothing."

"We also had the problem with his possessions…. [the care home] *said then "we're going to charge you for storing these" so my husband and I went to collect all his stuff - it was in bags and stuff, so we collected it all so that he wasn't being*

charged so much, to transfer them to [new care home], and I took them to [new care home] and of course only five days later he died and I have to collect it all again. Even when we went through his bags there was tonnes of stuff that wasn't his… It was like they'd stuffed it all in and chucked it out, and it felt really cold…. the carers left all the stuff at the door for us.”

Jennifer also told us about the emotional impact of not knowing how her dad had been coping, or what his condition was like for the last few months of his life, as well as the lack of communication in general from the care home, and the detrimental impact that had had on her and her family.

“I know nothing about what he was like over the last six months. I wrote emails, and I phoned, and I said please can you send us a video or some photographs or tell us what our dad is doing, and they basically didn't have the time. Well they said “we can't send you videos because we don't have the correct resources to send you videos”. *I thought, well they should have the resources to video my dad so we can see where he is and we can imagine what he's doing… Even just talk, and tell me what he's doing right there and then… just five minutes, come on, just five minutes - just to talk to me – something!”*

Jennifer further told us about the impact on her daughter, who never got to see her grandfather again:

“My daughter never got to see him again... On Christmas Day she went to [the nursing home] *and stood outside thinking* “my grandad’s in there,” *and then of course he died the following morning, and then it was like* “I'm so glad I went there.” *She was the nearest to him at the end of his life.”*

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Rebecca’s story

Rebecca’s mum has been living in a care home since January 2019. Rebecca explained that the move into a care home was a *“wrench”* for the family, and that in December 2019 her mum had been moved into the care home she is living in now. At the time of interview (February 2021), Rebecca told us that the last time she saw her mum was on her birthday in October 2020. She explained that this visit was upsetting on many levels.

“They took her birthday presents off me, because they had to be sanitized. The deterioration in mum was unbelievable honestly…[she was] falling asleep. They came and brought her presents to her on the table and I obviously went to help her, and they said no you can't touch them… My sister had given her a birthday card and all she kept doing was fiddling with the envelope, she didn't even open the presents when I was there because I wasn't allowed to help her, and then they said sorry but your time is up.”

"She was so tired she kept nodding off - it was horrible, it broke my heart, it was really, really horrible… She's either ill or they have given her tablets to make her sleep."

Rebecca shared concerns about the medication that her mum may be on, and the fact that she is no longer aware of what this is anymore, as well as that her mum had put on a lot of weight since lockdown in March.

"Mum has put on so much weight. I know you see reports on the news that their loved ones have lost weight, mum has got basically huge. Oh my God so bad, and I remember speaking on the phone, saying I was shocked about mum's weight - could it be a medication? and they said yeah… and I did speak to her GP practice, and basically he said it was one of the medications she's on, and even that upsets me because I used to know exactly what tablets she was on, because I used to sort out the tablets and everything, so now I have no idea."

Rebecca talked about feeling detached from her mum, and how precious time is as a person reaches the end of their life.

"She does not feel like my mum. She does not feel like part of the family anymore. She's got one great grandson who's 5 now, obviously she hasn't seen him at all… She's missed my son's wedding. All these events mum has missed... I think with somebody, anybody that gets elderly, it's hard to get any time back."

Rebecca stressed the importance of physical touch, and how soothing and calming it can be.

"She used to love me painting her nails… I appreciate any touch, I do appreciate any little thing… Yes, I think it's a step forward just to hold her hand. I'm desperate just to touch her, just to literally touch her. I'd like to kiss her, but I know I can't."

Rebecca even offered to become a volunteer in the care home, but this request went unanswered. She also told us about the impact that the lack of personal communication from the care home had had on her.

"When I phone I get "Oh She's fine." *I feel like I'm wasting their time…I feel like I'm being a nuisance… I feel like I'm pressurising them…. If somebody could just ring you, or if even I rang and had a telephone appointment like you have with the doctors, and just had an allocated time, and then they could tell you what was going on…just a little conversation, but there's nothing."*

Rebecca also touched on the damage, in terms of trust, that this lack of communication had on her relationship with the care home. She explained that when she called to organise a visit on the back of the new government guidelines, the carer on the end of the phone had said that the pod was "still available" – which had bothered Rebecca as she had been told that absolutely no visiting was allowed at the time. She has since been wondering if they had just not told her that she could have visited her mum in the pod early this year, but then also feels guilty for questioning this:

“I'm probably reading this wrong but… It has bugged me since…. The way she said it, ‘so you know the pod’s here, you can still visit in the pod’ and I thought could I have done that before?... I'm going to be a bit hurt if I could have gone all of January and February.”

Rebecca further explained how the disconnect has a detrimental impact on her state of mind and creates a lot of anxiety and uncertainty.

“I get these visions, and these thoughts; does mum think that we've just abandoned her, that we've just dumped her, and the whole family has abandoned her? Because like I said we always used to socialise together… but now she has no contact with anybody. She's just sat there wondering where the family is.”

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Claire’s story

Claire* is mother to David*, who is 22 and is severely physically disabled. He is quadriplegic and unable to communicate verbally; he also suffers with epilepsy. Claire explained that due to the lack of community-based social care, her son now needs to live in a care facility outside of Oxfordshire. She chose this facility carefully, ensuring that it could meet her son’s physical, social, and emotional needs, as well as provide all the therapeutic support that has been identified in his care plan.

“My son likes going to the cinema, he likes going bowling, he likes going outside, you know he's a real vibrant outside person,” Claire told us. *“He's physically disabled, and so to get what he needed I had to look for where he could live that provided those things, for his physical support and his occupational support. All those things needed to come into play that I can't get in the community where I live. The community services are non-existent.*

David moved into the care facility in November 2020. The expectation due to COVID-19 was that she would say goodbye to him on the doorstep, and she had to fight to be able to spend a few days with him to assist with the transition and handover to his new carers.

“Transition is hard enough without this immensely difficult transition, because it's all about timing - just because Covid has made the world stand still, the time to leave college doesn't stand still; the time to move into adult services doesn't stand still; you've still got to go - you can't wait for Covid to be over. That hasn't stopped, but the provision is becoming very difficult to navigate, and there's some very scared parents out there who don't know how to manage transition…. It's unbearable it's not being provided for, and that's at care home level, and where they're getting their directive from I'm not sure, but it's across the board that they’re just not being flexible enough to take a common sense approach to any of it”

Claire described the fact that family members have been excluded from a person's care as *"criminal"*, also lamenting that risk assessments are written as a blanket policy, instead of worked out on a case-by-case basis, which she saw as problematic - especially in care homes with young people who are not as at risk to COVID itself.

Claire also described how difficult she found it seeing carers with the *"privilege"* of being physically close to her son while she is denied that opportunity:

"I say to them all of the time, you're so lucky, you're privileged to be able to work with my son, because I can't get to see him, and they fully agree. He's like a little social butterfly, he's the light of my life… he's a wonderful human being, a marvelous young man and they are so lucky to get to work with him everyday"

"I said if I get tested can I come in, I said how is that different? How am I seeing there's anything different than the carers that go in to look after him? They're just people; they're human beings… They're no less or more risk than me but they trot in everyday and have the wonderful privilege of sitting next to my son, but I can't go in. I said I'll have a test… No, it's a blanket policy, no visiting."

Claire also shared her worries that in the long-term, this way of operating will become standard, with infection control "*trumping*" all other aspects of care and family involvement:

"My son and I have a lot of friends and associates with similar children of the same age and we're all lost for words as to how this is being allowed to happen… Whereas we've spent 20 years making them the priority issue and now they've become the side issue in this Covid war where all their rights and benefits have been stripped back to just existing… No aspects of this can be allowed to be kept into our normal because it's detrimental."

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Elizabeth's story

Elizabeth's mum is 96 and had been living independently until late January 2020. The decision to move into a care home was a very difficult one, and only made tolerable by the idea that the family could visit and could take her out regularly.

"She agreed to go but being in a care home was never something she wanted to do, and we appeased her by saying "you know you've got to be safe, we can still come and take you out". I think she thought she was going to be shut in there and that was going to be it…. One of us would go every weekend and take her out and we go to the pub for the lunch, and we do her shopping. The plan was we would still do that, but obviously that came to an end within six weeks. None of that happened ever since, so what we had told her was that we would make that experience better for her, and we were never able to."

Elizabeth explained that before lockdown, "*we would say we were coming and we'd just check in with the staff …and we'd take her out for as long as we wanted. We were made to feel very welcome there. We could either see her in a room or in the lounge. If my children came -there was a whole gaggle of us - we* *take up one of the lounges, and we'd all sit round and have coffee, and there was cake, so it appeared lovely -really nice".*

However, with the onset of lockdown, this all stopped overnight.

"The first two visits I booked, they themselves [the care home] *went back into lockdown because they had two residents with Covid, so I didn't get to visit her. When I saw her in March, I didn't get to see her until October. That's the only visit I had. I went to see her and she was really upset… and it was a difficult visit because I was wearing a mask, and she lip reads a lot and we had to stay a certain distance apart.*

"When I was leaving… she was upset and I said don't worry I'll be back as soon as I can, and as I went out the manager said to me "you do realise… we can only have one designated visitor from the family so unless that's you, you won't be able to visit again"

Elizabeth told us that she did get to spend some time with her mother in December, when the care home called and asked her to take her mum to get some new hearing aids.

"Suddenly the rules were relaxed and I was allowed to go and pick her up and take her to [nearby town] to get her new hearing aids. So that was like the best hour ever…We sat in reception and talked for about 20 minutes, and it was lovely - that was like a little bonus visit because obviously… I can't see her again until I don't know when."

At the time of interview, the Government had announced that from March 9th one family member would be able to visit and hold their loved one's hands. We asked Elizabeth if this would make a difference. She explained that while it was a step forward, it would not make a difference to her experience, as her sister is the designated visitor, and it is restricted to just one person.

"Obviously it's great that my sister can go in and for my mum that's obviously much easier… but I don't understand why that can't be other family members as well. Why does it still have to be just one designated person? Because if they're testing the person when they arrive then surely it could be a different visitor each time?"

Elizabeth stressed that better communication was needed from the care home, particularly in relation to personal updates and family liaison – where the family had only received a "*generic email.*"

"We only get how she is from what she tells us…. When she fell last December she hit her head, she's had dressing on it for the whole year… it wasn't till my sister went last week that she said she has lost the dressing and the wound is healed and things like that. We have no idea that had still been going on.

"I don't know what her mobility is like now… So as well as being important to know how she is, it would also be nice to discuss that with them, because if she was being so reluctant to move I could be encouraging her to make an effort keeping mobility going - those sorts of things, but I don't know."

Elizabeth explained that any face-to-face visits or video calls were always supervised by a member of staff, and that her mum was a very private person and would find it impossible to discuss personal or confidential matters in front of them.

"If you're in a booth why do you need to be supervised? Because it's tying up a member of staff, and it doesn't give my mum the opportunity to say what she wants to say; maybe nothing to do with what's going on in her life but it might be a personal thing that's going on in our family, a confidential thing… About money, and her property, and all those things - she's not going to want to discuss that in front of somebody else."

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James' story

James' father suffers from Dementia. Although his family had a difficult experience with the first care home he was in, they have had a much more positive experience since he was moved to the care home he is living in now - a positive experience that has continued throughout lockdown.

"*I think they're doing a very good job*," James told us, explaining that the staff of the home "*keep us really well informed.*"

James went on to say that he and his father have had window visits, as week as the opportunity to use a "*cuddle curtain*", and that the staff have been on hand to facilitate visiting as best they can.

"*We've had window contact. He can't reach the window to open it. The nurse… answered the phone and they walked down and unlocked it for me. They really are exceptionally accommodating.*

"You get a cuddle curtain between you and your dad… and then my father in sitting on a chair and we can speak to him through this cuddle curtain."

Describing the communication from the care home as "*superb*", James told us he also felt that he could contribute ideas and share concerns with them, and that they would be listened to.

Overall, James said that he was very content with his father's care, and that they were very happy in general, although he did share a concern that the "*recommended optician*" was very expensive, and he felt they were taking advantage of restrictions.

"Luckily we got a copy of the prescription because the optician didn't want to give us a prescription unless he got the glasses, but his glasses were £300-£400 and with the prescription we went to Specsavers and got them for £150"

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Eleanor's story

Eleanor's father had been living in a care home since September 2019, due to his diagnoses with Lewy body dementia. Before lockdown, Eleanor visited her father twice a day, and was his main source of support and comfort. After lockdown, however, Eleanor was unable to see her father, except for two visits in the garden, until he reached the end of his life, when she was able to go in three days before, and "*sat with him for his last hour.*"

Eleanor explained to us that garden visits were too painful for her father, as he had to be hoisted into a wheelchair, and sitting up caused him pain and discomfort. She also explained that video calls were impossible, due both to his condition and the time slot that the home provided. Eleanor's father had a room on the ground floor, but his bed was positioned so he was unable to be seen from the window. Eleanor asked for the bed to be repositioned so that they could see one another, but this was never facilitated.

"They can't provide what a family can provide – "someone concerned about me, loving me." *He still knew me, his face would light up when he saw me. It is part of the care pack if you like. They still need their family; it is working alongside the care home. I've known my father for a lifetime. Nobody was going to know my father like me.*

"Rather than this bog standard "shut the care home down". *part of the care plan should be "what suits this resident best to keep contact with their family."*

"I did see him twice but both those times I could see his was in pain, and he asked to go back to bed. So, the answer for him was move his bed to where he could see me. He was on a ground floor – it was a case of swinging round, it was no big deal."

"I wasn't asking to go in – what would have suited him would have been for them to just move his bed by a window so I could wave at him, tell him I loved him, and occasionally feed a letter to him to tell him I loved him. That would not have put anyone in danger.

When I went in, I used to move it [the bed] so he could look in the garden – it was that easy. It was more to do with very task-driven staff. Even me asking – can we change his video time? Because they gave him a slot which was after his wash, which is quite a traumatic time for somebody who cannot dress themselves… and he was always asleep."

Eleanor talked about the pain of not knowing how her father was or how he coped during lockdown, and that the lack of communication about him from the care home made this impossible to connect with: *"I have no real understanding of what this last 9 months have been like for him. So I have been carrying that around with me.*

I asked for him to be appointed a key worker – for somebody who can't speak or has dementia they should all have key people who can tell a family (I don't mind how they tell me) what sort of week that person has had. There was no contact so I could assess what kind of week my father was having.

The really sad thing about Lewy-Body was that my dad never lost the fact that he was a dad of children, he never lost the fact that he enjoyed seeing his family and he would have missed me… I can't say categorically he understood why I had abandoned him. He would have held that for a few moments and then it would have gone.

I have this vision of a lonely man sat in a room, because nobody has been able to tell me different."

After her father's death, Eleanor said she and her family had no contact from the care home at all.

"Five minutes after he died I left that care home and I have had nothing. My nephew collected his belongings after a conversation my sister had with the housekeeper and they were boxed up outside."

Eleanor talked about the "*creaking system*", and how much care homes relied upon family members to be part of the care package before lockdown, and that when it came into force a void was left, and that the communication and person-centered approach that she felt was needed to help residents and families cope with the separation was absent because staff were under too much pressure. She also raised the cost of care it should have been enough to expect a bespoke approach.

"I would ring the nursing station and I gave up in the end because nobody picked up – I presume because they were busy….I sent emails and I probably had three back – they were quite generic. I'm happy to hear about problems, because I can help them solve them. I would have preferred – 'one thing he had done that week, one thing where I knew at least he had an hour where he was okay.

The lack of communication where you felt a bit of a nuisance – You keep on asking. I accept they were busy…. I didn't think what I was asking was too much"

"Even when it locked down first of all, I found that out by a handwritten notice on the door. My father was paying £6k a month there and I thought – goodness me!

It is an awful lot of money and you can't have a keyworker allocated, or a weekly call?"

Eleanor explained that before lockdown she was part of the care, because she knew her father *"better than anybody"*, but also that she was helping ensure the care he was receiving was good and taking pressure of staff. She felt staff were often inexperienced and that the role of carer needs *"elevating*

"I think it is a creaking system that was exacerbated [by lockdown]…. I was never confident (I felt for them as well as my father) that when a carer walked into his room, that they knew enough about him to give him the care that was adequate… I occasionally had to stop people giving him fluids that weren't thickened….it needs to be job that is well paid that people want to go into."

"Father very often missed breakfast because the time was too early for him."

"That's the bigger picture- the smaller picture is communication and attaching how much value there is with communication with families. It is not just a case of they want to know, but the value that they're adding. It is a 'working alongside' partnership."

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Edwards' story

Edward* has been married to Sylvia* for over 50 years. Edward became Sylvia's carer after her diagnosis of dementia around ten years ago. The lack of community and respite care meant that he was unable to continue caring for her in their home and decided that she needed full time care. Sylvia has lived in the same care home since the summer of 2018.

Edward's experience during lockdown has been largely positive – he feels his wife's needs are being met, and that his own need to see his wife in person as secondary:

"I think they are doing a brilliant job. I mean some of the direct accounts that I read are hair-raising, and I understand that there are some people who are absolutely desperate to see their relatives in care homes. I have a more geeky, pragmatic approach, you know? My wife is gone, but I have a huge moral and ethical obligation to what is left of the person, and provided she is well and is content and free from anxiety, free from pain and is well looked after, then my own need to see her is of secondary importance"

Edward also explained that he feels very connected to Sylvia, and her condition, through the family support unit that the care home provide. This has made a huge difference to his experience of having a loved one in a care home during lockdown.

"[*name of care home] is brilliant. What they do have a family support unit, which is very unusual… They put out a bulletin every Monday afternoon by email to all the relatives, and it sort of says* "hey you know we've got the testing" *or* "everybody is healthy" *or* "we've been testing all the staff", *it is the general update. And one of the other things which they have done recently…. the scope of* *activity has increased during the period of lockdown, and they now have activities 6 days out of 7. For example [name], the activities manager, got Sylvia to make up a Christmas card which she sent me and that was addressed to my daughter when she came home from Germany, and again my son has a birthday coming up... and I'm told by the family support unit that they helped my wife make a birthday card which has been posted off to him... So although I have very little contact with her, I'm assured that she is well and busy.”*

Edward went on to explain how the home’s reporting system works and how much of a benefit it is to him.

“They also have a reporting system and if I ever want to ask specific questions, of course they just bring up the form and talk to me. I was talking to the manager a few weeks ago, and she said “hang on a minute let me just go into the system and call up her notes”*, and this new system she was able to say* “well yesterday she spent an hour and a half engaged in some sort of artistic activity, she was painting” *or* “over Christmas she helped make decorations and she helped decorate the tree” *and then she said* “well the day before that she spent an hour in the music session”*. So, although I can't see her I have lots and lots of evidence, records as to her well-being and what she's actually, what she is doing.”*

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Appendices

Appendix 1. Survey

Family and friends with loved ones living in care homes during COVID-19 questionnaire can be found here **or a paper copy requested by telephone to Healthwatch Oxfordshire 01865 520 520.**

Appendix 2. Letter packs to care homes

VOICES FROM CARE HOMES THIS WINTER

Dear care home resident

Living with Covid has been really challenging for everyone.

We know how hard everyone in care homes has been working to keep everybody safe, and they have done a wonderful job!

We would like to hear from you, as a resident, about what it has been like living in a care home this year - how you have managed to keep in touch with your family, how it has made you feel, and anything else that you would like to tell us.

Please do take the time to give us your thoughts, and return them to us in the pre-paid envelope provided.

Alternatively, you can call us on 01865 520520 or email hello@healthwatchoxfordshire.co.uk to speak to someone in our friendly team

We look forward to hearing from you.

With the very best wishes

Luci

Luci Ashbourne - On behalf of Healthwatch Oxfordshire

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Oxfordshire
Your voice on health and care services

VOICES FROM CARE HOMES THIS WINTER

Dear Healthwatch...

This letter is anonymous. This means you don't have to say who you are. Healthwatch Oxfordshire does make use of people's anonymised comments in reports or on our website.

Please tick one of the boxes below.

☐ Yes, I am happy for my comments to be quoted in reports

☐ No, I do not give permission for my comments to be quoted by Healthwatch Oxfordshire

To find out more about Healthwatch Oxfordshire please see:
www.healthwatchoxfordshire.co.uk

If you would like a paper copy of this report or would like it in a different format or language, please get in touch with us:

☎ **01865 520520**

✉ hello@healthwatchoxfordshire.co.uk

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