



Living in a care home during the coronavirus (COVID-19) outbreak

Residents and Relatives Experiences

October 2020



What was the project about?

The coronavirus (COVID-19) outbreak changed the way care was provided to those who live in care homes. We wanted to hear about the experiences of people who lived in Buckinghamshire care homes, and/or their relatives who would normally visit these homes.

What did we do?

Lockdown measures, government guidance and the decisions made by the care homes themselves, changed frequently, particularly during spring 2020. We therefore decided to ask for feedback about the period March 16th to May 31st when care homes made the greatest changes.

Government guidance meant care homes closed to visitors early on during the outbreak. As a result, we developed an online survey to capture people views. We offered to phone anyone unable to access the survey online.

We worked with four residents and two relatives from three different Fremantle Trust care homes to co-design the survey questions. We launched the survey on 23rd June and closed it on 17th August. We asked people about:

- communication
- movement around the home
- meals and snacks
- meaningful activities and visitors
- keeping safe, hygiene and staffing levels.

We publicised our surveys via social media and our newsletter during June and July. We were interviewed on Wycombe Sound and Marlow FM. Mix96 FM published a piece on their website. We also asked local organisations to publicise the survey. The Fremantle Trust also publicised the surveys directly to their residents via activity coordinators and to the relatives of people living in their care homes in Buckinghamshire.

We have summarised the responses by survey question in this report. The total number of responses to each question varied. This is because not everyone answered all the questions. We have also summarised comments by theme. These summaries indicate of how often a theme was mentioned rather than an exact count. Some feedback was about more than one theme so the number of results can exceed the number of responses. More information about our approach and our statistical analysis is in Appendix 1.

Who did we hear from?

We received 292 responses to the survey. Of these, 61 responses did not relate to either the relevant time period or to a Buckinghamshire care home. Another 33 left the survey when asked whether they were a resident or relative. This report reflects the views of the remaining 208 people.

A summary of who we heard from is set out below. A full breakdown of the demographics is in Appendix 2. Of those answering the question:

- + 93% identified as White British.
- + 133 identified as female and 35 as male.
- + 77% of all respondents were over 56. 48% residents were over 86.
- + 170 were relatives. Of those, 109 said their loved one lived with dementia
- + 85 relatives said the care home provided nursing care.

What did we find?

Communication

We asked residents about how staff told them about what was happening in their care home during this time. We heard from 38 residents.

- + 79% said they felt well informed or very well informed.

We asked relatives how the care home communicated with them. We heard from 170 relatives, though not all of them answered these questions.

	Not at all OR not very well informed	Quite well informed	Well OR very well informed
Physical health	35%	17%	43%
Wellbeing and mental health	39%	18%	37%
General care home news	35%	20%	40%

Table A - During the outbreak, how informed and up to date did you feel about....

The responses were evenly split in each area, although relatives felt less well informed about general wellbeing and mental health.

- + We found strong statistical evidence that relatives of those living with dementia felt less well informed about the resident's physical health, compared to all other relatives.

The full results are shown in Appendix 3.

Keeping relatives informed

We asked how the care home communicated with relatives. For comparison, we asked about before and after the outbreak. The results are shown in Figure 1.

- + Both care homes and relatives principally used phone and email to keep in touch, although the care homes phoned relatives noticeably less after March 16th.
- + Nearly 50% (79/165) of respondents said there had been relatives' meetings in the home prior to the outbreak. Some said these had been replaced by virtual ones and / or video calls.

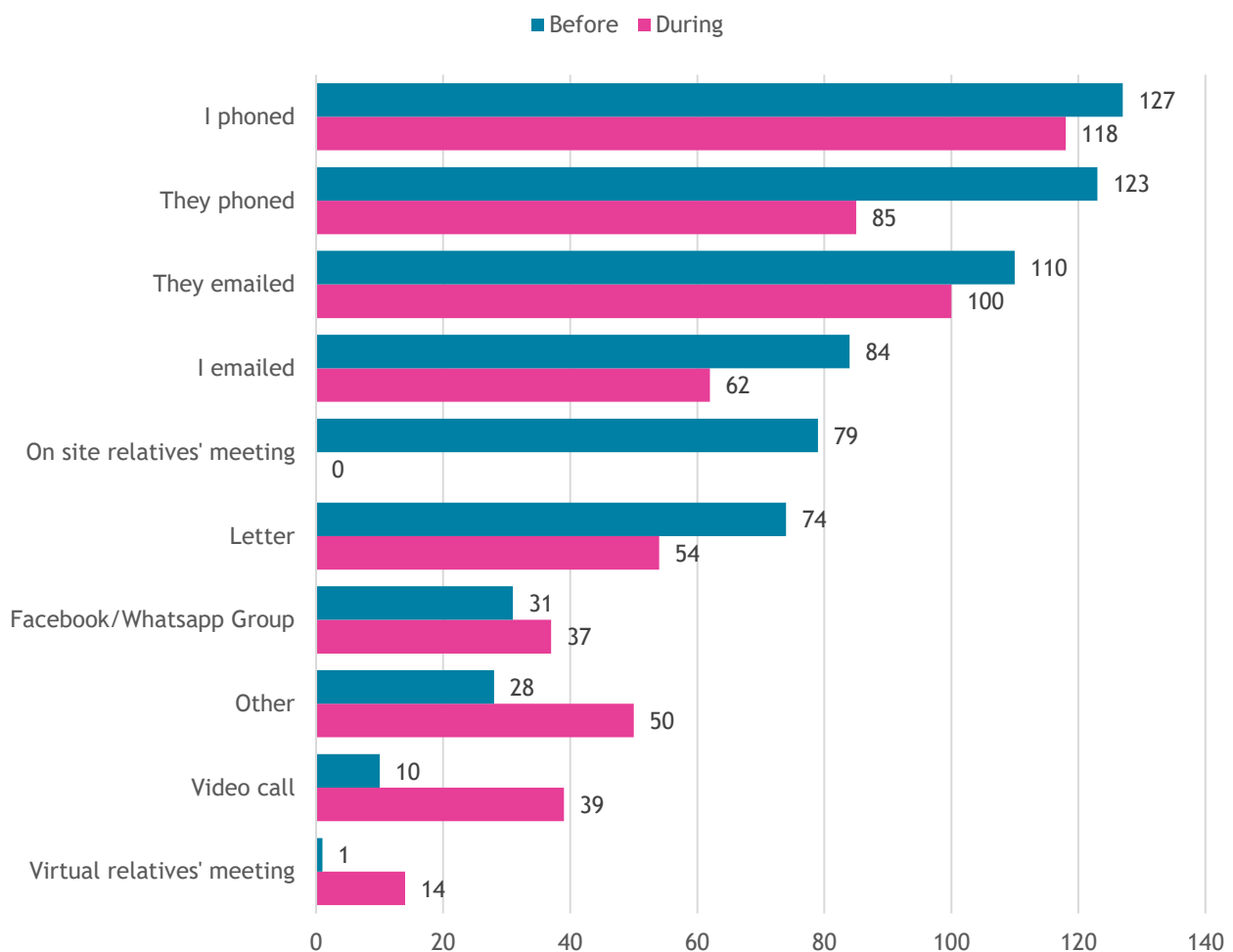


Figure 1 - How did the care home communicate with you (the relative)?

Some relatives also left comments about communication before the outbreak.

- + 8 relatives told us they visited the care home regularly so would talk directly to the manager face to face.
- + 5 people were frustrated by infrequent communication.

We received 50 comments about communication with the care home during the outbreak. These were split evenly between positive, negative, and neutral comments. We found that some relatives have been very happy saying it was exactly as before lockdown.

“We have been kept well informed throughout the outbreak by email (our preferred choice). Staff always available should we wish to phone.”

Others have not wanted to bother the home, trusting they will look after their loved one.

“...contacting the home during a very difficult period should be minimal in order that staff can focus on caring for the residents.”

However, other relatives were not positive. Some told us they had received no, or little communication from the home.

“Communication from the care home has been non-existent. I have complained repeatedly ... with very poor response. They have been negligent in keeping relatives informed.”

Others felt the care home had not been proactive enough in this area.

“... I usually have to phone them because I have picked up on an issue... I have felt frustrated they haven't been more informative.”

Movement around the home

We heard from 205 people who told us about changes to where people could go in the home.

- + 62% told us there were changes.
- + Surprisingly, over a quarter of relatives (30%) answered “Don't know” when asked whether there were changes or not.
- + We found strong statistical evidence that relatives of those living with dementia answered “Don't know” more often, compared to all other relatives.

Any changes to where residents go?

We asked where residents could go in the home during the outbreak. There was a lot of variety in the responses. Some people only told us about a single incident or point in time. Others gave more detailed replies:

“At the beginning I had to stay in my room but later I was allowed to move around the unit on the 2nd floor. I now eat in the dining room but at the start I had to eat in my room too. We can't go into the garden though”

Over half of respondents (72/122) said residents could go to the dining room or lounge and / or into the garden (61/122) at some point.

“As long as symptom free they went where they normally went”

- + 57% of responses indicated residents were confined to their units or specific areas.
- + 34% that people were confined to their own bedroom at some point.
- + 31% that people were confined to their own bedroom with COVID-19 symptoms.

How did you feel about changes to where residents could go in the home?

We had responses from 111 people. Figure 2 shows the responses were similar between residents and relatives. We found that most people said that they were fine about the changes to where they could go in the home (42%) or else these changes made them feel safe (38%).

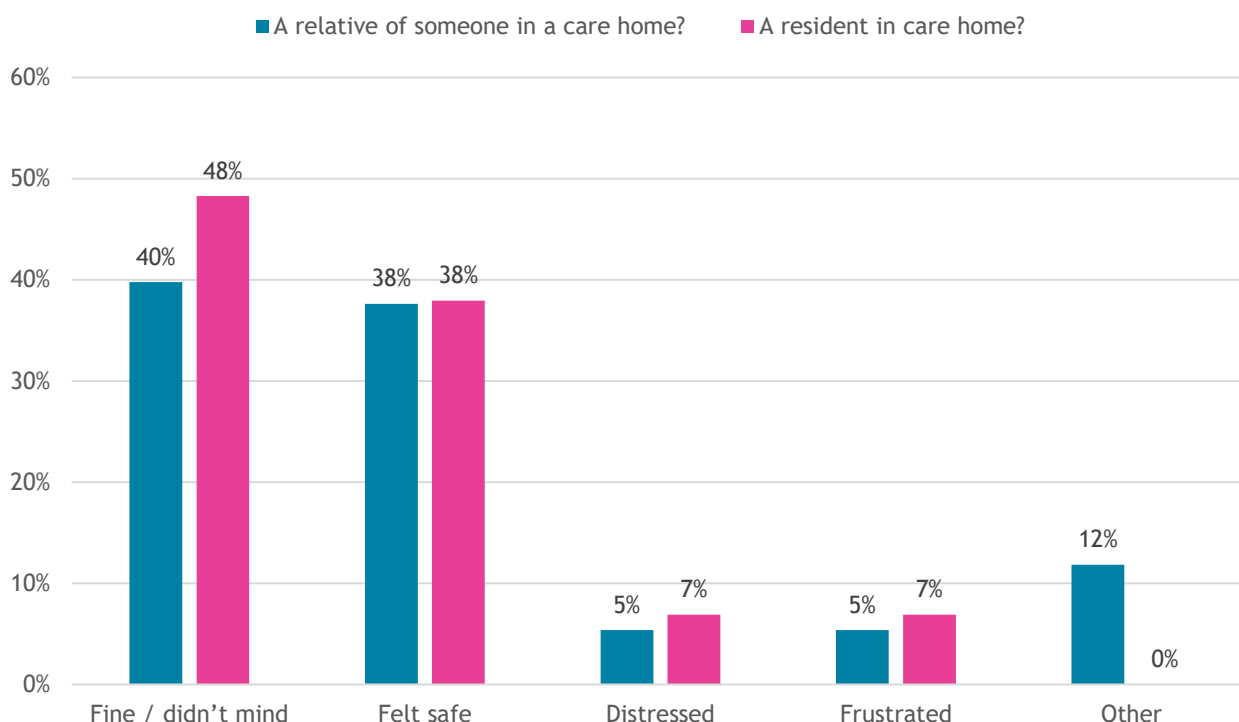


Figure 2 - How did you feel about any changes to where residents could go in the home?

There were six positive comments from relatives. All said they understood the reasoning.

“I was aware that the restrictions were necessary to protect life”

However, we received 16 other comments, all from relatives, that were negative. Some felt that they were not being kept informed and didn't know where their relative was allowed to go.

“Was only aware after things had changed and once things had returned to normal.”

Seven were concerned about the negative impact on residents' mental wellbeing. They believed being confined to one area and / or spending more time alone in a bedroom was detrimental.

“The period of two weeks confinement to her room badly affected my mother's mood and mental function. This was distressing though it was necessary.”

Some relatives were concerned that residents might not have understood why they couldn't move about as they wanted to. Others questioned whether residents had any genuine choice about what was happening in their lives.

“Frustrated but understand why; patient [relative] doesn't.”

Despite many people telling us there was access to the garden, a quarter (4) of the negative comments received were about no outdoor stimulus.

“Relative no longer able to go into the garden which had a serious impact on their physical health not to mention mental health. It was their wish to go into the garden, but this was not actioned despite it being possible in a safe way.”

Meaningful Activities

204 people told us about activities happening in the care home.

- + 69% respondents said some or all activities stopped within the home.
- + Over 30% of relatives said they did not know whether they stopped or carried on, but only 11% of residents said they did not know.

131 people gave at least one answer when asked about which activities stopped. There were some noticeable differences in how residents and relatives answered as shown in Table B. There is no obvious explanation for these differences.

- + Over 33% (43/131) of respondents to this question said everything stopped. This was the most common response from residents (63%).

What stopped?	Relatives	Residents	Total
Trips out	65%	38%	60%
Visiting entertainers	64%	33%	59%
Chiropodist appointments	52%	29%	48%
Everything	26%	63%	33%
Religious services	29%	33%	30%
Group activities	31%	17%	28%
Exercise / Zumba / Oomph	29%	21%	27%
Hairdresser	15%	17%	15%
Going into the garden	14%	0%	11%

Table B - Which activities stopped

A full set of results can be seen in Appendix 3.

How did you feel about these activities stopping?

We found there was a range of feelings. We looked at the 119 comments from this question and identified themes and sentiment. This gave us 150 results, which can be seen in Figure 3.

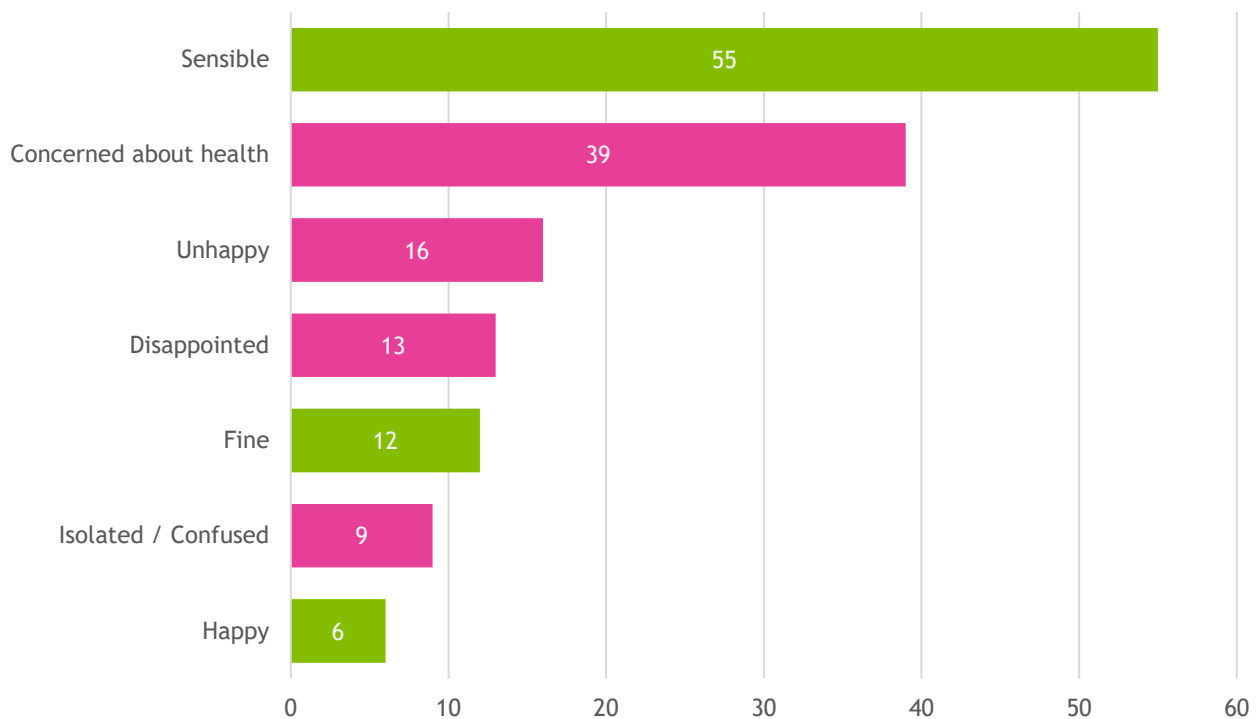


Figure 3 - How did you feel about these activities stopping?

The key theme was that many people believed that stopping activities was a **sensible** measure. They believed it was necessary to protect residents and minimise the risk of infection being brought into the home.

“Fully understood why; kept my daughter safe.”

“It was the right thing to do and followed Government guidelines”

However, 51% (77) of comments were negative. Most were from relatives. They were concerned about the impact on **residents’ mental and physical health**. These comments show the range of concerns.

“Little enough before c19. Boredom obvious and exacerbated isolation feelings”

“Mental well-being deteriorated rapidly. Dementia progressed rapidly.”

“... it has resulted in a severe deterioration in ability to walk”

A more detailed summary can be found in Appendix 3.

New activities

We asked whether there had been any new activities introduced. We heard from 197 people.

- + 28% (55/197) said they or their relatives had experienced new activities. Most were video calls with families, as shown in Figure 4
- + Over 50% (102/197) said they were unsure if there were any new activities.

“Offers of Familigram and Skype calls were really appreciated...The activities team worked really hard in very difficult circumstances. Not really aware of what happened on a daily basis though.”

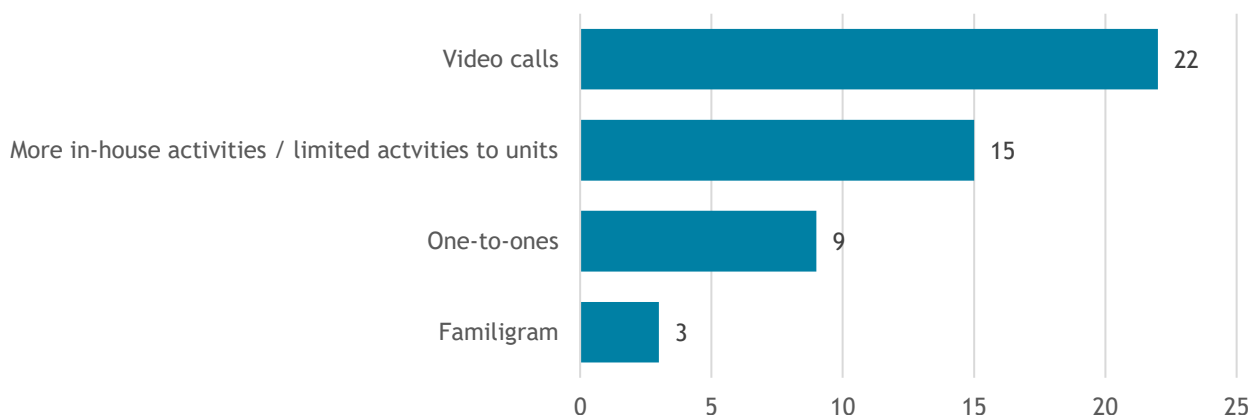


Figure 4 - Were there any new activities/ things to experience?

In their comments, people also told us that staff put on more activities themselves once visitors were no longer permitted and day centres were shut. We received both positive and negative comments about one to one engagement. Some relatives stressed the benefits to both staff and residents of spending more time together, one on one. Although not everyone had these opportunities.

“We asked whether dad would have additional 1-1 engagement with staff. We don't think he has, and they do not have a buddy system which we would greatly appreciate to alleviate loneliness and enable him to engage with one familiar person.”

Meal Changes

200 answered when asked about changes to the daily meal and snack routine.

- + Around 10% said that there were changes.
- + 44% said there had been no changes.
- + Surprisingly, 45% of relatives answered “Don't know” when asked whether there were changes or not.
- + Reassuringly, all the residents did know whether there were changes.
- + We found **very strong** statistical evidence that relatives of those living with dementia answered “Don't know” more often, compared to all other relatives.

23 people told us there had been changes to the daily meal and snack routine. 15 people gave more information about the changes.

- + The most reported change was that they could not eat in the dining room. The additional comments showed that at times they had to eat in their bedrooms.
- + One person also told us that the main meal was moved from early evening to mid-day.

“[there was] a rota so people who eat in dining room could only do so once a week.”

Visitors

“not seen relative since 31 Jan 2020”

199 told us about visiting the care home during this time. The full set of results can be seen in Figure 5.

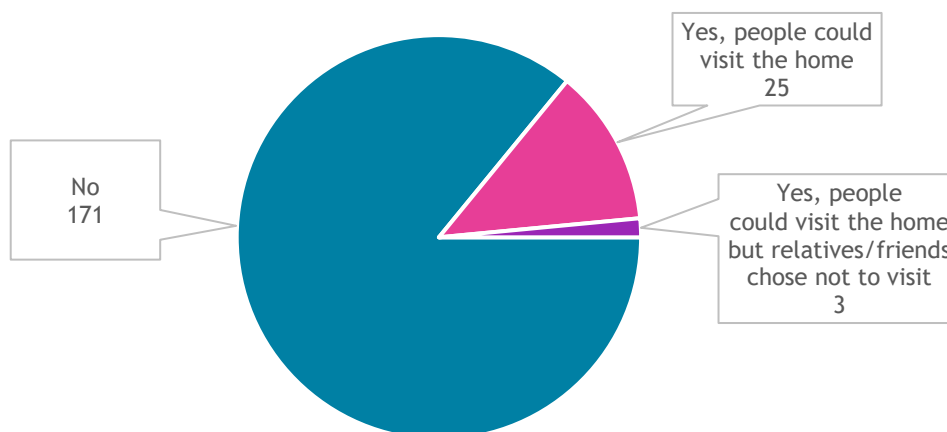


Figure 5 - Did the care home allow visitors?

- + 86% of respondents (171) told us visitors were not permitted from 16 March to 31 May.
- + Of the few respondents who said visitors were permitted, six said residents could have visitors at the end of their lives at any time in the period.
- + For those not at end of life, 23 said visitors were permitted from May.

For those allowed to visit

We had 23 responses giving more information about how/where visits were allowed. Meetings mainly took place in the garden. Some homes did permit residents to sit inside whilst relatives either talked through a closed ground floor window or at a distance through open doors. However, as visits needed to be booked other issues emerged.

“Appointments restricted by the Care Home to 4 slots per day. If the slots were taken, then you had to wait for the next available slot; sometimes 14 days.”

How did these changes make you feel?

For many, being able to visit in the garden or via a window was better than not being able to visit at all.

“Very, very happy to see nearest and dearest.”

However, this was not the case for all. The results can be seen in Figure 6.

Some relatives told us that residents became upset either because they didn't understand the rules around social distancing that still had to be followed, or because they struggled with the PPE worn.

“My Mum did not understand what was happening and became distressed. So much so that I have now stopped visiting.”

“I was glad to be able to see Mum again and the home were very welcoming. The masks have made communication even harder as she doesn't hear well. I think it has made her ability to recognise me and my Dad a little harder.”

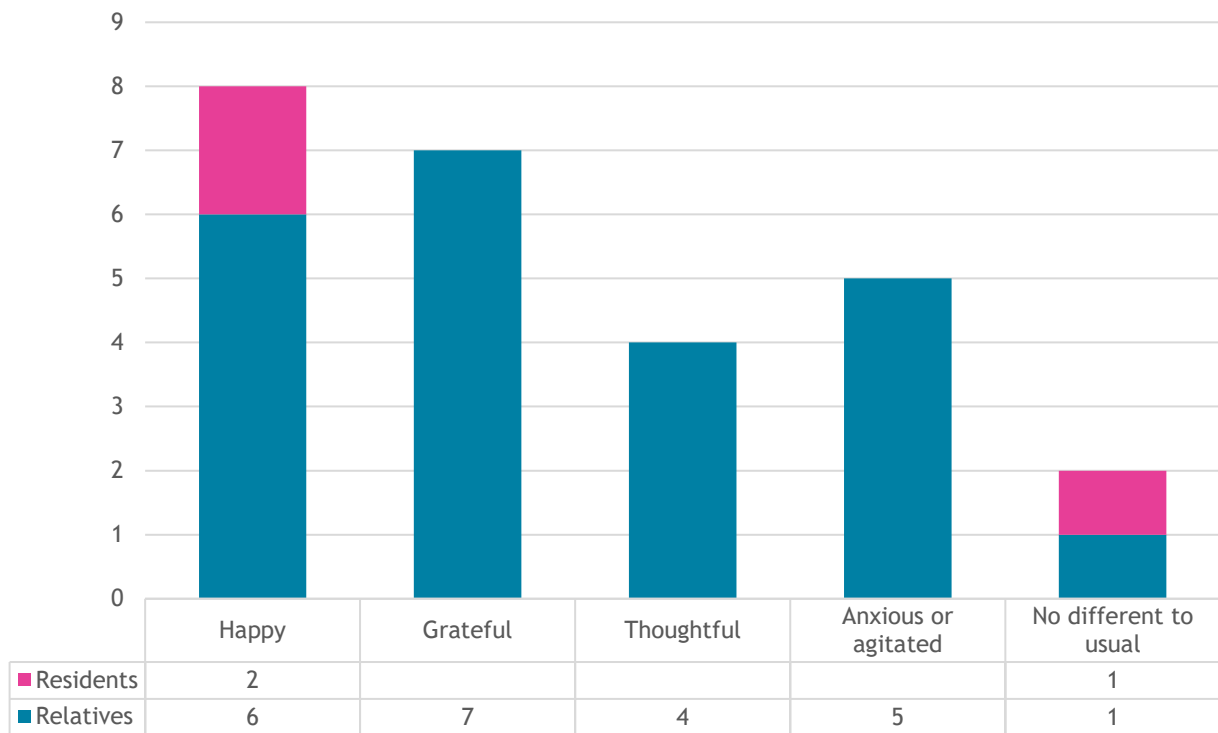


Figure 6 - How did the changes to these visits make you feel?

Keeping in touch

169 people told us how they have kept in touch with their loved ones. People could choose more than one answer. The most common answers were a personal mobile phone, the care home's phone, or video call. The full set of results can be seen in Figure 7.

We found that some residents easily adapted to the new ways of communicating.

“My husband did not seem phased by the changes and appeared calm and content.”

Some relatives took comfort in messages sent with photos of their loved ones.

“The most reassuring communication was the Facebook group which sometimes posted pictures/videos of my Dad enjoying himself.”

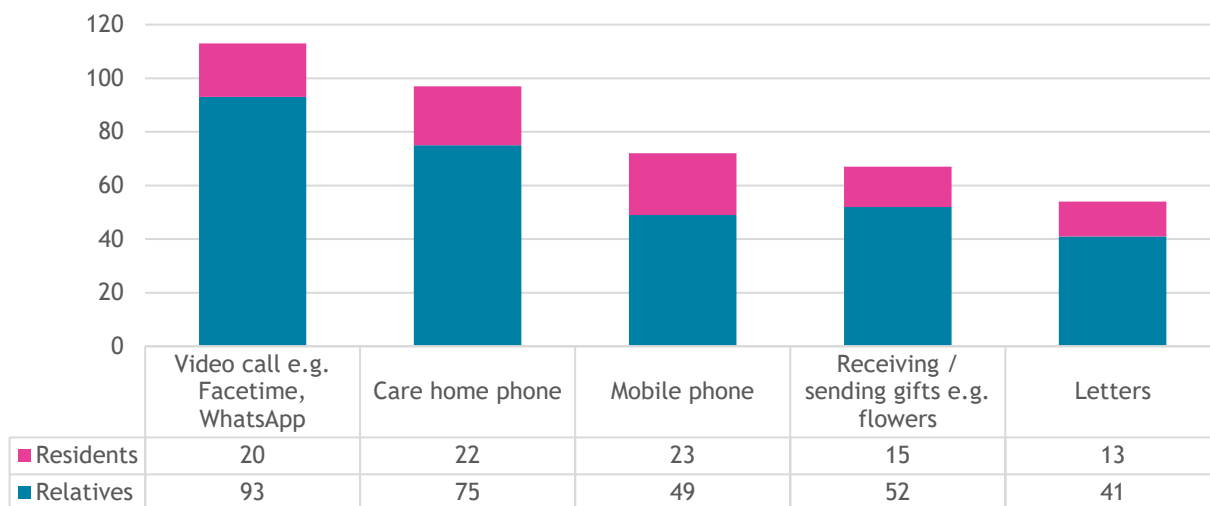


Figure 7 - How have care home residents and relatives / friends kept in touch ?

However, for others, the technology was too difficult, and they lost contact with their loved one.

“Due to the advanced state of my relative’s dementia, it was not possible to keep in touch during the outbreak. We tried telephoning once, but she did not recognise my voice and did not understand what was happening.”

Some accepted that, although there were challenges with technology, any communication was better than none.

“Mum doesn’t understand that with Skype I am actually hearing and seeing her. She usually spoke more to the carer than me and was occasionally frustrated. For me it was worth it though just to see her looking fit and well ...”

Meanwhile some relatives realised that they would have to use different methods to keep in touch and show they still cared. Relatives told us that they sent letters and photos or waved from the car park or outside the railings of the home.

“I sent a card. She was not able to talk or see so other means of communication were not possible or she would not understand, and she would be upset

Although for some their creativity was stopped due to health & safety concerns.

“Care Home asked that flowers and gifts not be sent, to reduce risk of infection. Visits through window were eventually allowed.”

How did you find these changes to keeping in touch?

163 people told us about how they felt using the new ways of keeping in touch. People could choose more than one answer. The results can be seen in Figure 8.

- + Over 46% found the changes “frustrating” and 37% said it was “upsetting”.
- + Some residents found it upsetting but some were more positive or didn’t see any real change.

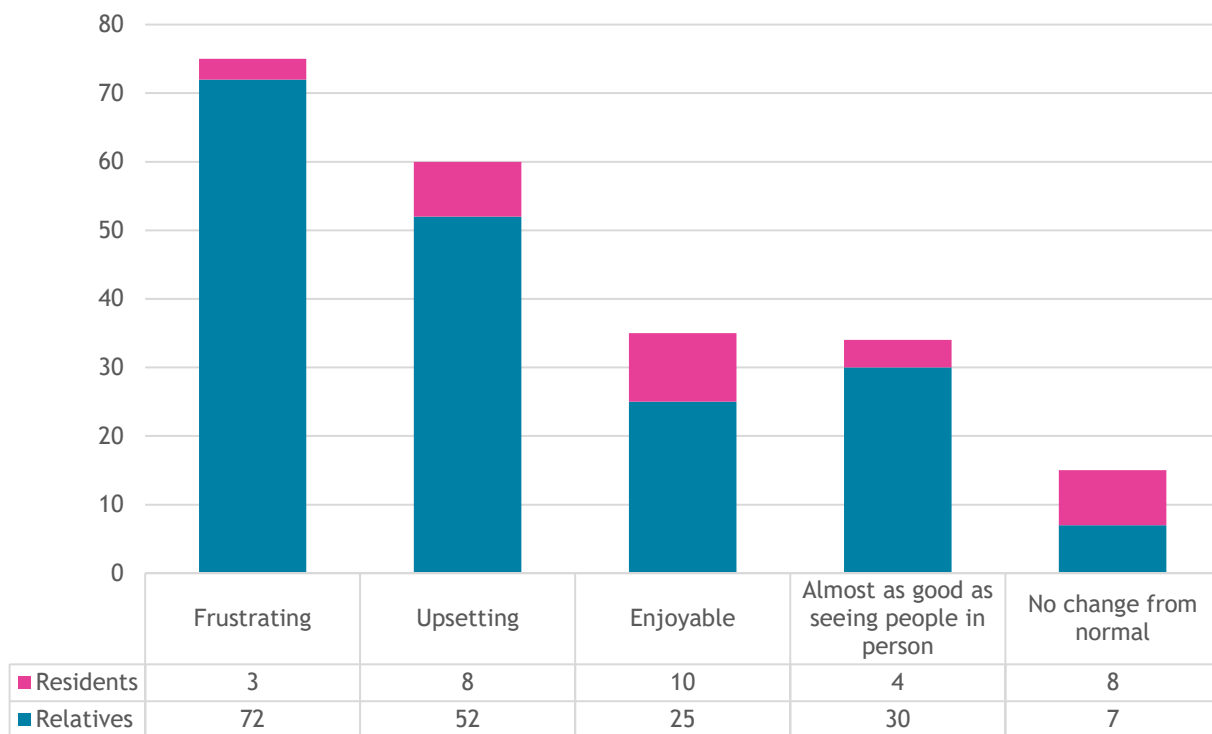


Figure 8 - How have you found these ways of keeping touch?

We looked at the comments from this question and identified themes and sentiment. This gave us 128 results, which can be seen in Figure 9.

- + Nearly 79% (101) of the comments were negative.
- + 20 positive comments were left. These included ones about the benefits of technology that enabled some people to keep in touch.

“It’s a little difficult for my relative to communicate with me via video as he’s seems suspicious of this method. But it was nice for me to see him, reassuring that he still recognised me.”

Nearly a third (25) of the negative comments were about residents often **not understanding** why visiting had changed.

“We have to explain, daily, to my father why we haven't been to see him; it's heart breaking.”

Some were also **confused** by unfamiliar technology.

“My mother doesn't really understand why she can hear us from the iPad but we're not in the room. It's quite distressing.”

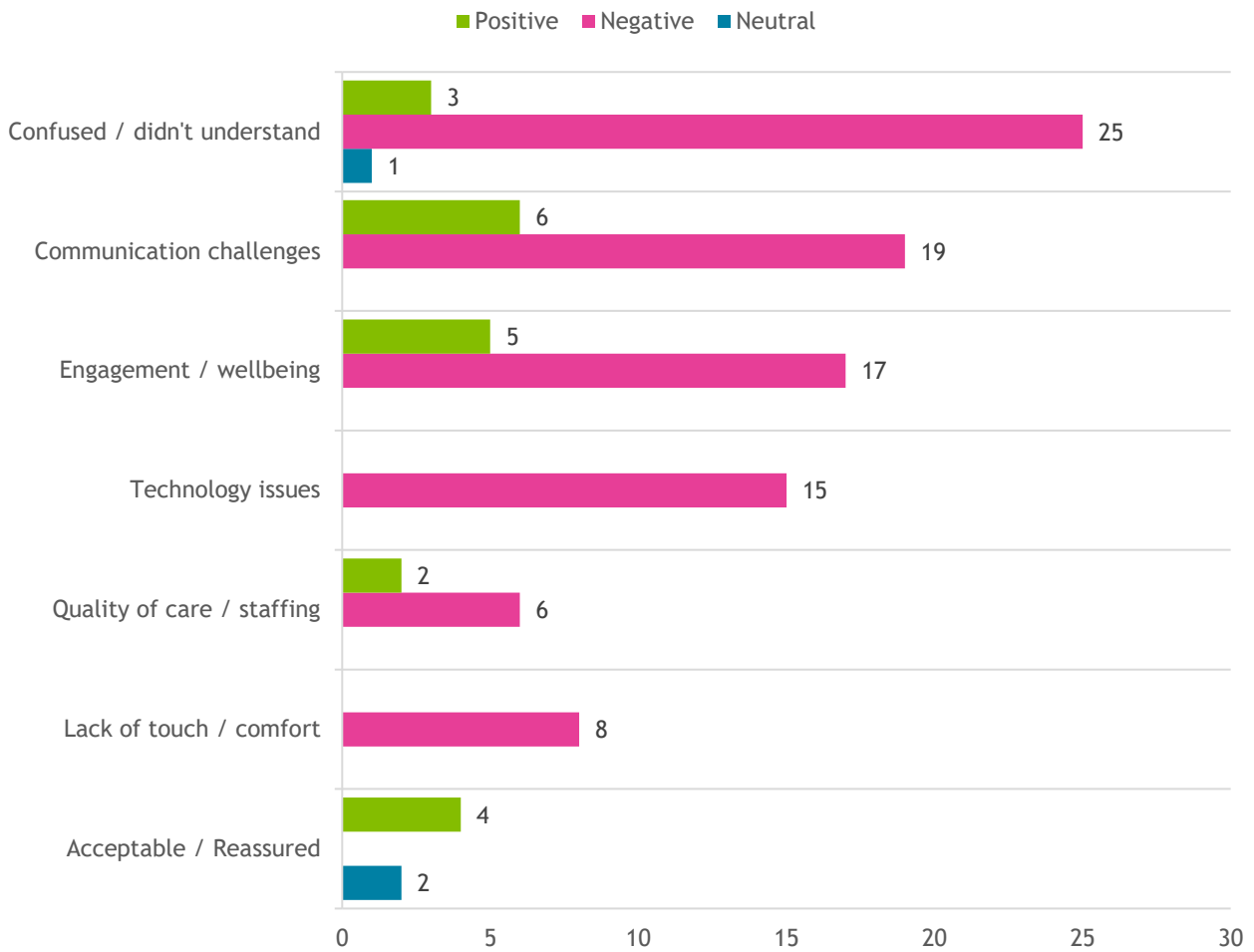


Figure 9 - Most common issues raised (by theme) resulting from the new ways of keeping in touch

19 negative comments highlighted that communication became a challenge. We found that staff did not always know how to use the technology. They did not also always engage with both the relative and resident and could be passive in the communication process.

“System frequently not working. Staff didn’t know how to use technology. Home lost the only iPad one week. Staff talking in the background flicked the sound away from us...”

Staff were a key part of the whole communication process but were often busy elsewhere.

“It seemed difficult to have any predictable routine with phone or video calls - hit and miss. It felt as if everyone was too busy, which is understandable. It was sad to feel out of touch at such a worrying time. At one point all friends and relations were explicitly asked not to contact the home.”

There were 17 negative comments about residents’ wellbeing. We found some relatives were upset because they had no physical contact with their loved ones. They were concerned about the **emotional and physical distress** this was causing.

“Dementia people need affection, hand holding, hugs, see a smile. Lack of those and lack of interaction or relatives’ visits has accelerated their decline. What is there if you can’t see a familiar face or get any affection or able to lip read or see facial expressions. A lonely isolated world and they can’t tell you what they need or feel.”

“As my mother is mostly in bed, window visits were cancelled if she felt too tired to get out of bed. Very upsetting for my dad”

Some relatives were concerned about the **quality of care** being provided to their loved ones. They felt they would have been able to monitor this more closely if they had been able to visit.

“Worrying, e.g. discovered weight loss when finally granted visits, little knowledge of wellbeing, unable to check clothes, laundry etc”

Others were concerned for their own health or that of the staff.

“Upsetting to see staff scared & overworked...”

And for others, their relationship has been changed forever.

“My mum has dementia and is unable to use the phone or write. She has no idea who my sister and I are any longer since the lockdown and we haven't been able to visit or hug her”

These comments show the range of concerns people had. More can be found in Appendix 3.

Treated with Dignity

We asked whether the resident felt they were treated with dignity. We received 170 responses to each of three questions. We had 30 responses from residents and the rest from relatives. We found:

- + 66% of those who answered, told us staff were patient and had time to listen.
- + 56% said staff continued to treat the resident as an equal.
- + 54% said staff asked their opinion and did not assume.

We again found there was strong statistical evidence of a difference in the frequency of “Don't know” answers, between people who said their relative lived with dementia and those that didn't. This difference was only notable in the questions on “time to listen” and “asking opinion”.

We looked at the comments from this question and identified themes and sentiment. We identified 63 results; 35 were positive. What we found, summarised by theme, can be seen in Figure 10.

A third of comments were about the **quality of care** received by residents; half of these were positive.

“The staff have always treated the resident with respect & nothing changed on that front.”

But some relatives had concerns about the care their loved one had received whilst they had not been allowed to visit.

“Dressed in someone else's clothes. No bra. No teeth. No hair washed. No shoes or socks. No music.”

“When I visited my father, he was unkempt.”

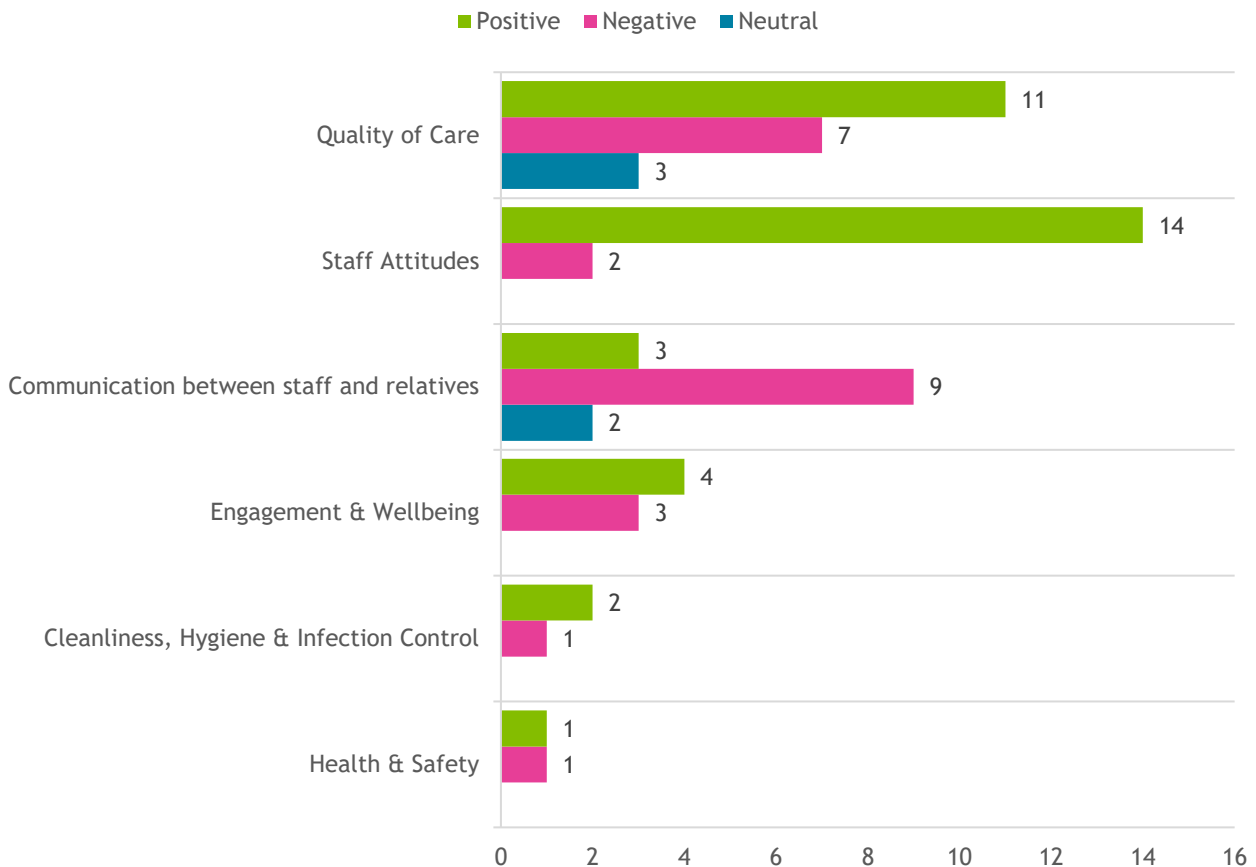


Figure 10 - To what extent did staff continue to treat you with dignity? (analysed by theme)

However, 14 positive comments were about **staff attitudes**. People told us how kind carers were.

“when I have visited and on skype, I have observed how staff have been patient with Mum and she has always looked well-presented and comfortable.”

We did receive two negative comments about how staff treated some residents.

“My father has told us on many occasions that when he has tried to talk to a staff member, they ignore him and walk away. I have heard carers yell at him saying, “we’re too busy for you” and “go and sit down and be quiet”.”

Most criticism was again about **communication**. We found that relatives felt ill-informed often because they were not allowed to visit. For some, this was made worse by their loved one being non-verbal and/or living with dementia.

“I am concerned as I don’t really know how my wife is as she can’t communicate.”

However, there were 4 positive comments. These were about staff helping support resident’s **wellbeing**.

“Always seem to be aware of vulnerability and care well. Made effort to keep mum occupied with her books when in room quarantine.”

These comments show the range of peoples’ views. More can be found in Appendix 3.

Keeping safe and hygiene

Personal Protective Equipment (PPE)

120 people told us about how the resident felt about staff wearing PPE. Figure 11 shows all the results.

- + 75 told us they understood why it had to be worn.
- + 36 found it made communication difficult.

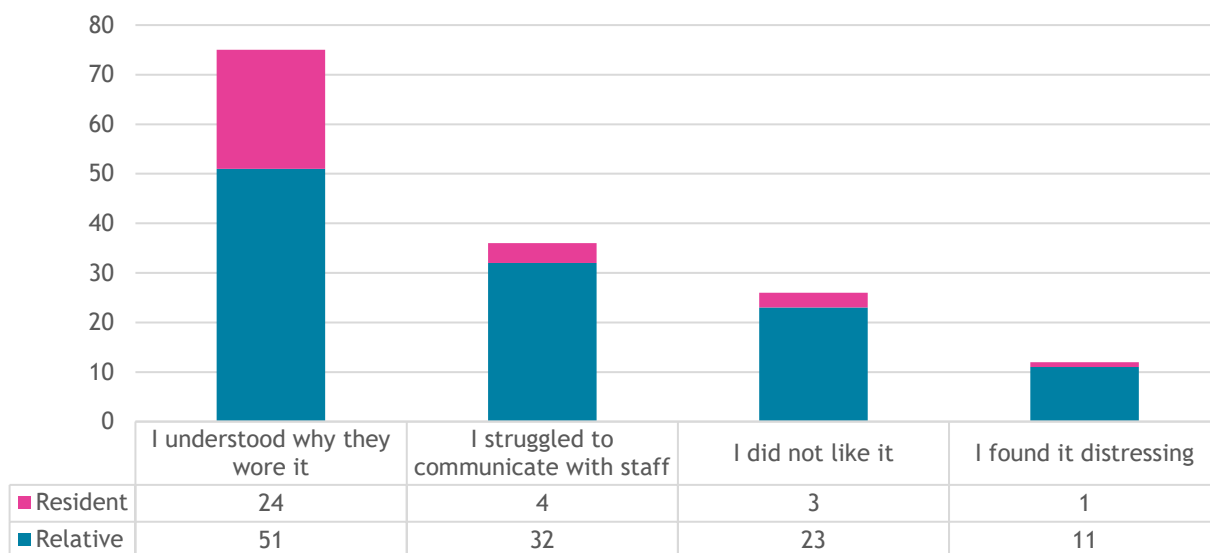


Figure 11 - How did you (the resident) feel about staff wearing masks and other protective clothing?

Over half of the respondents also left a comment. We looked at these to identify themes. Figure shows a summary.

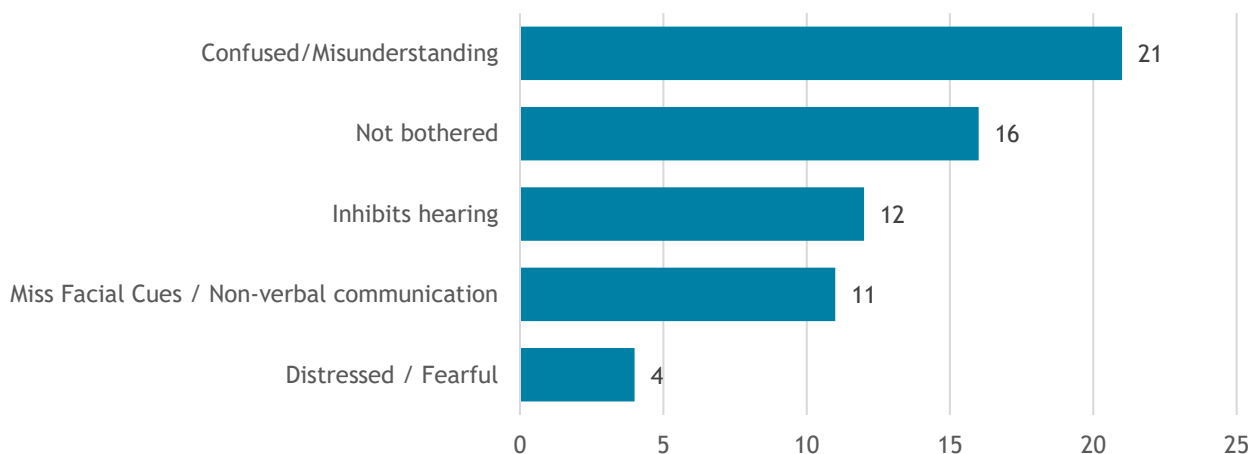


Figure 12 - Most common issues raised (by theme) resulting from staff wearing PPE

Many relatives said that residents, particularly those living with dementia, struggled to **comprehend** why staff were wearing PPE. However, we also found that many became used to the ‘new normal’ and were **not bothered** by the PPE. Some said it made them feel safer.

“My mother has Alzheimer’s. She did not understand the reason for masks but did not seem distressed nor questioned it.”

Some residents were not worried by the sight of staff in PPE. However, we were told that some older residents **struggled to hear** or understand what staff said when the latter wore masks.

Many residents lost the **non-verbal communication cues** they depended on. Some found that they could not recognise carers when their faces were covered by a mask.

“I don't think she would have worried about the masks, but they would have made understanding really difficult because of her hearing difficulties.

“[It's] Isolating; can't see facial expressions to understand what is being spoken or see a smile.”

And one person talked about gloves breaking the bond with residents who already missed hugs from family and friends.

“...it's not just about masks - the wearing of gloves also means that there was no proper human contact - important in my view for someone like my mother.”
(resident has advanced sight and hearing loss)

A few relatives were also concerned that PPE was not being worn or was worn inconsistently.

“No way of knowing how our Mother felt. We were relieved, but photos often posted on Facebook of PPE not been worn properly (noses uncovered or no mask) added to our anxiety.”

Relatives said that some residents, many of whom live with dementia, were **distressed** by staff wearing PPE.

“Mum didn't like the masks as she was scared of the virus which had been all over the news and it frightened her even more.”

These comments show the range of peoples' views. More can be found in Appendix 3.

Feeling safe

We asked whether people felt safe and protected during the pandemic. 167 people responded.

- + Of those, 87% of residents told us they felt safe and protected.
- + Only 53% relatives were of the same view.
- + Only four relatives said they didn't feel their loved one was being kept safe.
- + Another 60 relatives answered “Don't know”; 83% (50) of these were those whose loved ones live with dementia.

Again, we found **very strong** statistical evidence that relatives of those living with dementia answered “Don't know” more often, compared to all other relatives.

27 people left a comment. We looked at these to identify themes and sentiment as shown in Figure 12.

Most comments were about comprehension. All were from relatives. The comments help to show the additional challenges of dementia in such exceptional circumstances.

“As my relative did not understand about the pandemic, she would not have had any sense of her own safety”

“Her dementia is too far advanced for her to even understand that there was a pandemic!”

All positive comments were about keeping residents **healthy and safe**.

“I think my relative felt safe and protected.”

There were concerns about residents having reduced freedoms or choices.

“Felt safe but vulnerable as felt trapped without my family”

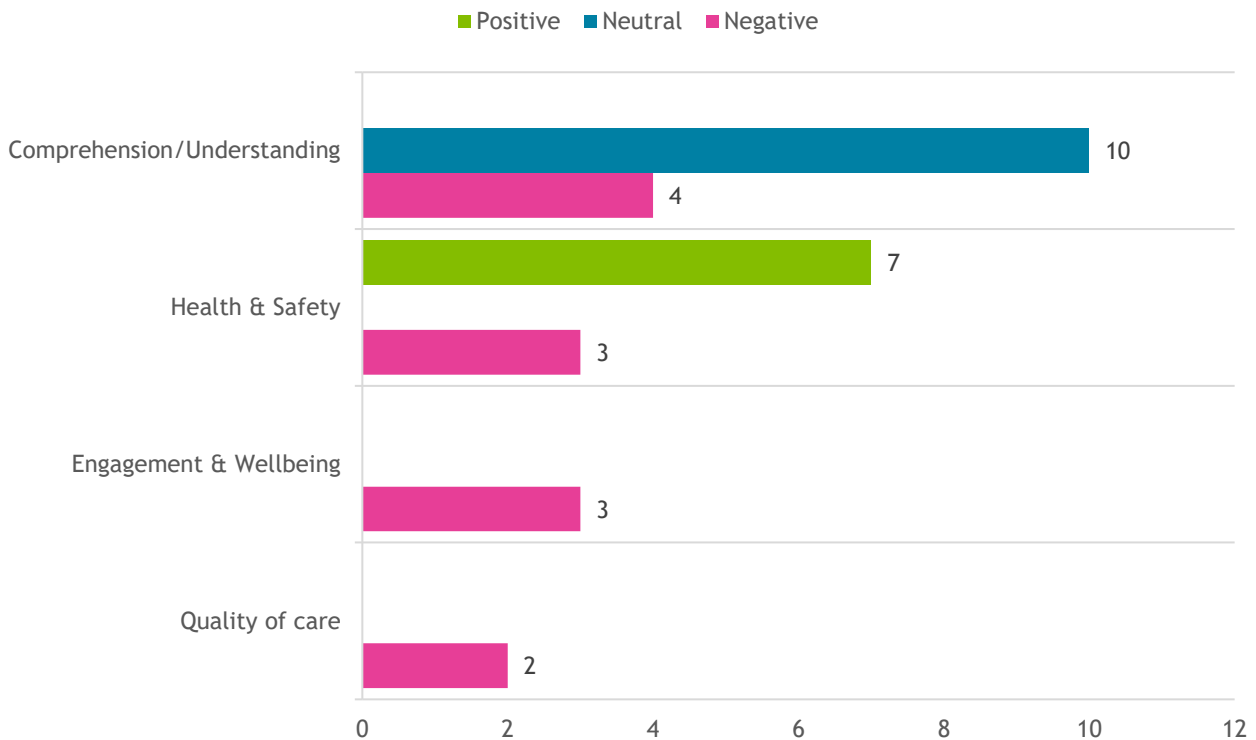


Figure 12 - Did you (the resident) feel safe and protected (analysed by theme)?

COVID-19 diagnoses and suspected cases

We asked about suspected COVID-19 cases and testing in the homes. The findings are shown in Table C. Of those answering the question:

- + 25% said they “[didn’t] know” if the resident had been diagnosed with/suspected of having, - 19 - this included responses from 9 residents
- + 61% didn’t have information about suspected/diagnosed cases in staff

This was another area in which relatives of loved ones living without dementia had more information. In this case, there was strong statistical evidence that people with loved ones living with dementia answered “don’t know” more often when asked about COVID-19 cases amongst staff.

	Yes	No	Don't know
Me (the resident)	11%	64%	25%
Staff	11%	27%	61%
Other residents	35%	25%	41%

Table C - Was anyone living, or working, in your care home diagnosed with, or suspected of having, COVID-19?

Staff Changes

187 people told us about changes in care home staff.

- + 58% (109/187) said that they, or their relatives, were looked after by the same staff as usual.
- + Almost a third of relatives (32% - 50/155) answered “Don’t know” when asked whether there were changes or not.
- + Once again, we found strong statistical evidence that relatives of those living with dementia answered “Don’t know” more often, compared to all other relatives.

20 people told us about how they felt about the changes in staff. Four people, including 3 residents, accepted the changes as unavoidable. We have summarised the remaining comments by theme and sentiment as shown in Figure 13.

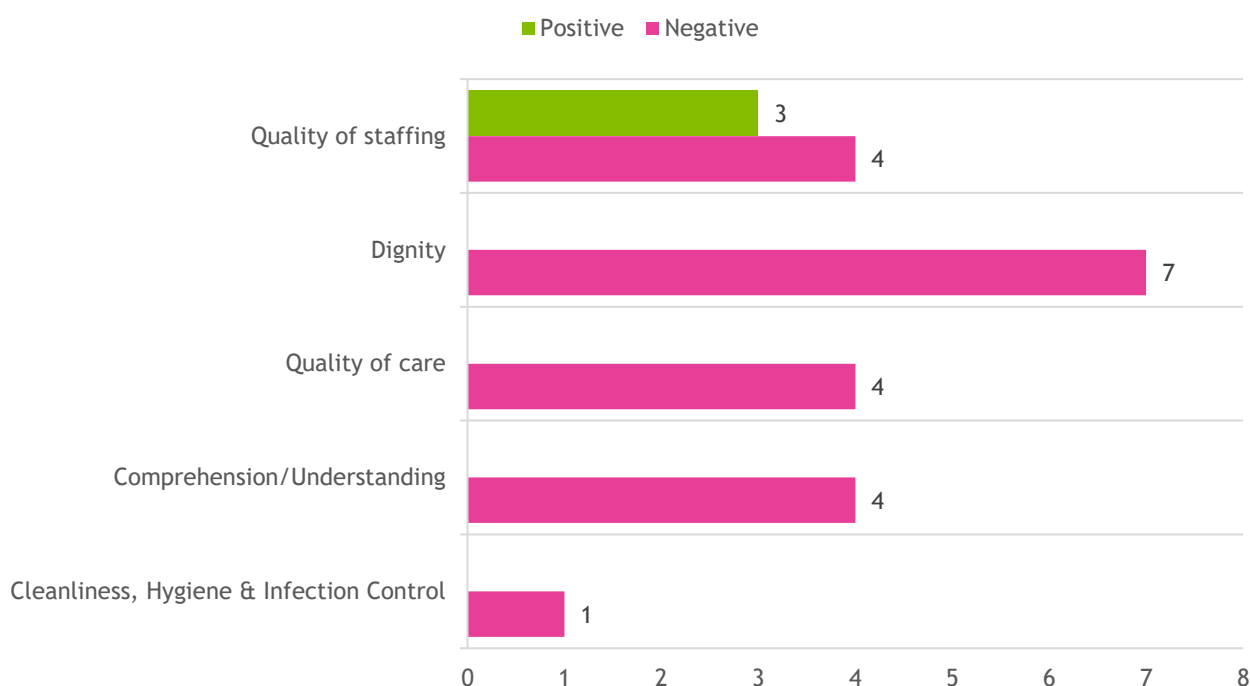


Figure 13 - How did you feel about the changes in staff?

Not everyone found staff changes to be negative.

“I actually enjoyed having fewer changes of faces. They used to mix all the carers up but now we get the same girls.”

However, most of the people did leave negative comments.

One person commented that the new **staff** were extremely nice. However, others were concerned about their loved one’s continuity of care.

“Keyworker left. Senior left. No one to check that things were being done properly.”

“Lots of agency staff. Communication was frustrating due to their poor knowledge of the English language”

Some residents felt confused and unsettled. Many respondents were concerned about the **quality of care** and residents not being treated with **dignity** and as an individual.

“Sometimes difficult with personal care, in that new staff did not know my usual routine/likes and dislikes.”

“Staffing was a huge worry to us. It is often challenging at the best of times. Most difficult was not knowing whether anyone was on duty who knew Mum and whether they had adequate staffing levels. Mum is particularly vulnerable due to her mobility.”

Anything else you would like to tell us?

We asked for any additional comments that people might have. 105 comments were submitted, which we analysed for theme and sentiment, giving 133 separate items of feedback.

Of these, half were negative and half positive. We have summarised these results, by theme, in Figure 14.

Quality of care

This was the top theme for positive results. People told us they were happy with the way some care homes managed during the pandemic.

“The care home has been incredible during the lockdown... My mother was at one point, at end of life, due to her dementia, and the staff were all incredibly respectful and caring.”

“I think the home did a very good job of keeping my husband placid and contented whilst not seeing the family.”

However, not everyone felt this way.

“The deterioration in our relative has in itself been a life sentence.”

“We are deeply concerned about his level of care during the Pandemic. It has not been Person Centred”

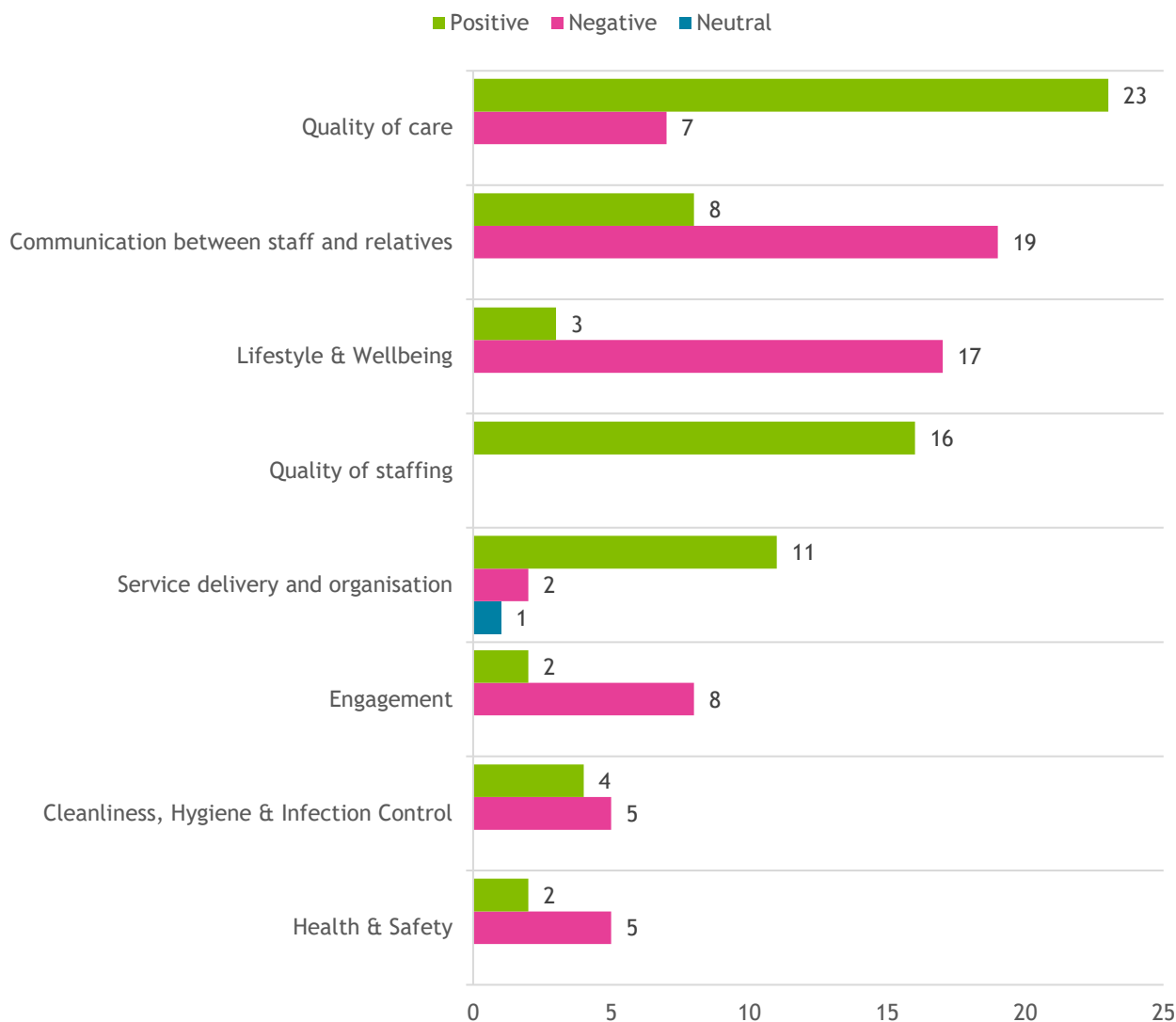


Figure 14 - Is there anything else you'd like to tell us (top 8 themes)?

Communication between staff and relatives

Some of the comments about communication were positive.

“The staff have been amazing kept us informed and our mother safe and happy. We were in contact with her every other day and we were informed in a change in her health. The staff were able to facilitate communication with whenever she wanted to.”

However, 19 were negative. Many reiterated previous comments about either no, or sporadic communication from the care home.

“Communication with relatives was pretty much non-existent. Very frustrating and worrying not knowing what was going on. Was given information only when asked for and it was never volunteered. Never given updates even when resident was extremely unwell.”

“It has all been very random with communication at an all-time low.”

Relatives also found it difficult to get consistent feedback from staff to give them reassurance that their loved one was well and happy.

“At no time during lockdown did we speak to anyone who knew our mother well. The weekly video calls were often facilitated by different (and new) people so there was no weekly comparison. We have found out what limited information we have by accident... “

Some relatives said that an absence of, or inconsistency in, communication reduced their trust in a care home.

“Doctor rang to say mum had all the symptoms and almost certainly she'd got COVID-19. Four days later she died... Staff kept changing their story though after that when I phoned. They said the home didn't have COVID-19, so I asked if the doctor had been lying. They said No of course not but why would they say that? I know there have been deaths from COVID-19 in the home.”

“We didn't receive any updates on what measures the home were making and got different responses depending on who we spoke to on the phone.”

“I would like to have had a lot more information given about what was actually happening in the home as I felt in the dark and pretty helpless at not being able to visit then and now.”

Lifestyle and Wellbeing

Although there were some positive points, relatives again commented on the negative impact of the restrictions on residents' **psychological wellbeing**.

“Sadly, my mother died, not from COVID, but as a bi-product of the situation. They had 2 weeks confined to their rooms. Afterwards she gradually stopped eating and eventually died in June.”

“I do think that mother and probably other residents suffered a mentally downhill trend.”

This included the effects of no longer allowing **visitors** to the home.

“Care home were excellent, but with no contact with family, the resident's dementia got significantly worse. We attempted video calls, but the resident couldn't see/hear us, and we found that very upsetting. After restrictions were lifted, the resident no longer recognised us and has since passed away. We fully understand the restrictions imposed by the house. The fact that they have kept COVID-19 out is testament to the way they did this. But we saw what terrible effect this had on our relative and how it seemed to progress the dementia, without any contact with the family.”

“Whilst we trust the care home and are grateful for the care ... It was never meant to be a place where we left her and never visited. It is scary to think we still have no way of visiting her.”

Some people also commented on visits once they resumed in some locations.

“The whole experience has been very distressing for me and Mum. Supervised weekly visits when we can’t give each other a hug has been horrible. My Mum has no idea what is going on and her ability to communicate has deteriorated markedly. Really awful time!!”

“Only 1 nominated visitor and I am not that person”

Quality of Staffing

All the feedback about this theme was positive.

“The staff have looked after mum exceptionally well during this difficult time and I am very grateful for their care at all times.”

“The staff are remarkable people - so caring although they are extremely busy - they never brush you off.”

“The staff 'on the ground' have been brilliant at a time when they must have been scared themselves.”

Service delivery and organisation

There were a couple of negative comments on this theme, but most were positive.

“We think the care home managed it well but the impact of lockdown on my Mother’s advanced dementia means that she no longer recognises us. We do not know what could have been done differently but it is sad and regrettable.”

Engagement

Most comments were negative. They centred around staff being reactive rather than proactive.

“I didn’t like it; there wasn’t enough activity... If they had thought about it, we might have had more to do and not feel trapped”

“Care homes have been slow to communicate and think of ideas out of the box to mitigate the deterioration of residents. Live-in home care would have been far better as have at least had walks and better stimulation.”

Cleanliness, Hygiene, and Infection Control

Feedback was mixed but all talked about keeping COVID-19 in, out, or under control.

“I think the care home did an amazing job in the circumstances to have just 2/3 cases of COVID-19 which were contained - despite the poor help from Government.”

Two people were concerned about care homes having admitted patients **discharged from hospital** without a COVID-19 test.

“One whole floor of the care home was taken over with patients discharged from hospital. Residents and relatives were not asked opinion beforehand or informed proactively after the fact. Our resident was moved to a new room without consultation. These issues were of great concern in relation to resident’s mental health and additional risk of exposure to COVID-19...”

Health & Safety

Several comments were about the lack of flexibility regarding people not being allowed to visit even if they had a COVID-19 test or correct levels of PPE.

“Think u should b allowed to visit if u have a negative c19 test.”

“For the family, we are finding the way we are treated increasingly difficult and upsetting, given that our relative has late dementia and is non-verbal. We just can’t see an end to it. When can we hold our relatives’ hand or give them a hug? One approach has to suit them all. No individual risk assessments for individual circumstances? What about mental well-being & quality of life? Could we not hold a relative’s hand wearing a mask, with gloves on? Has anyone bothered to consider this as an option?”

This lack of testing for care home residents and staff was also raised.

“COVID 19 was not recorded on my relative’s death certificate as she was never tested. If she was negative, I would have been able to visit before she died and not put myself and family at risk.”

“There should have been testing - at least weekly for all members of staff and residents throughout... I cannot comprehend how anyone could think it anything other than extremely high risk to release NHS patients into care homes without testing before departure and daily thereafter for a period of 14 days so that the home would become aware of an infection at the earliest opportunity...”

Comments were also received about GPs and dentists.

“I wasn’t happy that mums GP rang me beginning of April to talk to her to sign a DNR [do not resuscitate] form.... felt like I was being forced into doing something. The GP said mum was the only [resident] who hadn’t signed one... My mum has full capacity, and I don’t appreciate feeling bullied by someone when it is their care of duty to look after someone. Makes me lose my faith in GPs for care homes.”

“Very concerned that GP not visiting. No contact with social worker during pandemic. No CQC inspections during pandemic is very worrying.”

“My dentist appointment was postponed. I don’t know when I’m going to get one of those again but I’m not in any pain.”

Other

“The excellent continuing care in homes needs to be given a higher profile and recognition given to the commitment of care home managers and staff in terms of better pay, conditions and status. They should not become forgotten workers when things are back to the new 'normal'.”

“I do understand that it was really hard for Care Homes and this just highlighted all of the wider problems in social care. I hope it changes things!”

Conclusions

Several recurring themes arose from the survey.

Communication between Relatives and the Care Home

From those who answered these questions, we found that:

- 79% of residents said they felt well informed or very well informed
- only 40% of relatives felt the same way
- some relatives felt the care home was not proactive enough in keeping them informed
- 30% said residents struggled to communicate with staff wearing PPE.

Relatives of those living with Dementia

We found relatives of loved ones living with dementia felt less informed than other relatives about certain aspects of the resident's life. We found statistically significant differences when compared to relatives of those who do not live with dementia.

The relatives of those living with dementia were more likely to say they:

- didn't feel informed about the physical health of their loved one
- didn't know where their relation could go in the home
- didn't know whether relatives' meals or snacks had changed
- didn't know whether relatives were being treated with dignity in two of the three areas covered
- didn't know whether relatives were being looked after by the same staff
- didn't know whether staff were suspected of, or were diagnosed with, having COVID-19.

This may be because many people living with dementia in a care home are not always able to communicate clearly to others.

We also looked to see if there were differences when loved ones had a different communication issue or lived with disabilities. In almost all cases, **we did not find a difference.**

This strengthens the evidence that communication with relatives of those with dementia is a particular issue.

Meaningful Activities and Life in the Home

Limiting where people could go was one of the measures all care homes took. This differed over the weeks. Care homes tried to control infection and the potential spread of COVID-19. This, when often residents and staff might be asymptomatic, along with limited or no testing, presented huge challenges. We found that:

- some relatives were concerned about the lack of choice residents had over their lives
- 62% of respondents said residents were restricted in where they could go at some point
- many relatives were concerned about residents spending more time alone in bedrooms and receiving less stimulation from activities and the impact this may have on residents' mental health
- others (55) commented that any restrictions to movement around the home, were necessary to protect residents

- 69% of respondents said some or all activities stopped within the home; some care homes stopped all activities rather than continuing them in smaller groups
- 25% of respondents said new activities had been introduced in the absence of visiting entertainers and outside stimulation. These were mostly video calls to families.

Visitors

Care homes were advised, by the government, that only next of kin should be allowed to visit. This was to be "[in exceptional situations such as end of life](#)". It was not changed until 31st July. Some care homes used their discretion to allow visitors earlier. We found that:

- 85% of respondents said they were not permitted to visit/receive visitors, although most people at end of life could have visitors by May
- video calls replaced face to face visits for many residents. However, 46% of respondents found the changes frustrating and 37% said they were upsetting. This method of communication did not suit all residents and some people did not talk to loved ones for several months
- some relatives told us that their loved ones no longer recognised them after several months of not seeing each other in person
- both relatives and residents missed the hugs and reassurance the touch of a loved one brings.

Information Technology (IT)

Technology suddenly became very important when care homes closed to family and professionals. We found that:

- the introduction of new IT, such as iPads, helped to keep some families in touch
- not all homes had a robust IT infrastructure to support the increased use of IT at this time
- not all staff understood how to use the IT available or what support residents needed. Many residents had not used this type of technology, such as Facetime or Zoom, before March
- keeping in touch using IT tools is often confusing and does not work well for some residents, particularly those living with dementia, or a hearing/sight loss.

Quality of Care and Staff Attitudes

Many care homes have faced the challenge of staff self-isolating, shielding or being absent due to fear. We found that:

- people were grateful for the care and kindness shown by staff when working in pressured and uncertain times
- 58% of respondents said they were looked after by the same staff as usual
- some relatives had concerns about whether residents were being treated as individuals, especially where people were not looked after by the usual care staff
- people were worried about the physical health of residents. This might be because they could move around less (some had no access to the garden), because staff had less time or less professionals, e.g. chiropodists, visited
- 66% of those who answered, told us staff were patient and had time to listen. However, only 55% of relatives said their loved one was treated as an equal or asked their opinion
- of those who answered the question, 87% of residents told us they felt safe and protected, although only 53% relatives were of the same view.

Recommendations

Our report gives a snapshot of peoples' experiences and views up until 17th August 2020. We recognise that the way services are delivered in care homes may have changed since people responded to our survey. We would urge providers and commissioners to review all the feedback. The thematic analysis and quotes give helpful insights into a wide range of peoples' experiences.

For Buckinghamshire Council

We recommend that Buckinghamshire Council:

- Make good quality professional mental health support available to all care home staff and residents
- Continue to work with care homes to enable relatives to visit loved ones in a safe way; balancing keeping the home free of infection whilst understanding the rights of the individual to a good quality of life which involves seeing loved ones
- Continue to work with care homes to strengthen their use of IT and their IT infrastructure. The aim would be to improve the:
 - Quality of data stored making it accessible quickly to all who need it
 - Accessibility to healthcare professionals e.g. Medicare which has been increasingly important when they have not undertaken face-to-face visits
 - Range of meaningful activities open to residents via computer tablets, and staff trained to use them
- Continue to work with care homes to support staff to communicate with relatives in the most effective way, keeping everyone informed whilst minimising the time taken to do this
- Continue to support high quality training for staff through a variety of mechanisms.

For Care Homes

Based on the findings we would encourage care homes to build into their day-to-day operational and resilience planning the following recommendations.

- the ICP uses the planned engagement with specific groups to ask how they would like to receive information.
- local providers and commissioners review their Equality Impact Assessments to make sure they identify all the groups who most need to be reached with timely and accessible advice and have the necessary plans in place to communicate with them.

Communication

- Review the range of options available to keep relatives up to date with a resident's physical health and wellbeing as well as what is happening in the home. Some will prefer a phone call or a virtual meeting whilst others may want an email.
- Check email addresses / phone numbers are up to date for relatives etc on a regular basis.
- Train staff in customer expectation management. Relatives need to know how they will be contacted and when they will be contacted in times in any 'crisis' situation such as a pandemic. Staff need to follow this through to reduce the likelihood of relatives contacting

the home more frequently, possibly taking up more of everyone's time. This is particularly important for relatives of those who are not able to communicate easily.

- Look at new ways of communicating: staff with residents and residents with friends and family; build on what worked well (e.g. Familigram) and ensure people are aware of the advantages and disadvantages of each type of communication (especially going forward for new residents/ relatives).
- Ensure everyone's communication needs are met in line with the Accessible Information Standards. For some this will be via lip reading. Look to purchase masks (to the correct standard) with transparent windows over the lips so those who need to lip read may do so and others may see smiles for reassurance and connection.

Meaningful Activities & Life in the Home

- When necessary, limit where people can go within the home or consider creating small 'bubbles' for residents; hopefully eliminating the need to remove access to particular areas e.g. a garden or keeping residents in their rooms.
- Ensure small group activities are continued, with social distancing measures in place, rather than cancelling all activities.
- Continue to embed in all staff that meaningful activities are the responsibility of all. These can be as simple as helping with daily tasks or conversation as well as more structured activities such as craft or quizzes.
- Continue to build on the relationships created or improved, through the pandemic, between staff and residents.
- Ensure one to ones are meaningful and regular for those confined to their rooms to ensure residents still have purpose to their lives.

Visitors

- Risk assess how protecting an individual or keeping a care home safe impacts the quality of life and mental health of individual residents. The benefits of having visitors, in a safe way, for some may outweigh the infection risks.
- Continue to learn from what other homes elsewhere have done. Whilst government guidance needs to be followed, some care homes have been very imaginative about enabling some residents at least to see their loved ones e.g. drive through visiting. It is particularly important to keep those living with dementia in touch with their relatives, so they have some ability to recognise them face to face when any visiting restrictions are lifted.
- When the situation allows and testing is available, treat relatives as key workers to enable them to visit and support residents and maintain their quality of life.
- Ensure relatives feel they can visit their loved one in a safe way, e.g. with PPE, at the end of the resident's life.

IT Development

- Ensure the IT infrastructure is robust.
- Introduce more IT and train staff to (a) use this and fix common issues, and (b) be aware of the support some residents will require when using hand-held IT devices such as iPads.
- Improve resident's familiarity and comfort using any hand-held devices.

- Continue to support those for whom video calls worked well when engaging with friends and family.
- Be aware that IT is not a mechanism that works for everyone and look at other methods of communication with relatives when they cannot visit in person.

Quality of Care & Staff attitudes

- Ensure resident's personal care remains a top priority as this is a fundamental part of treating individuals with dignity.
- Learn from developments in staff using PPE elsewhere e.g. write names on aprons when masks are being worn as this may help some residents identify staff wearing masks.
- Maintain people's physical health by maintaining some gentle exercise for all. This will also help boost mental health (especially in the absence of visitors).

What are we doing to ensure these are achieved?

We have passed our findings to the commissioners of adult social care services and to care home managers in Buckinghamshire. We have also sent our findings to Healthwatch England and the Care Quality Commission.

Acknowledgements

We would like to thank all those who took part in this survey. We would also like to thank the residents, relatives and staff from The Fremantle Trust homes who helped co-design the survey.

Disclaimer

This report sets out the responses received. It does not necessarily reflect the experiences of all service users.

Appendix 1

More information about our approach

Number of responses

The number of responses to each question varied. Some people chose not to answer every question. Others did not complete the survey. In most cases, percentage results were calculated from the total number of people who answered each question.

Analysis of comments

Many of the questions included 'Other' answers with the option of providing additional information. We also invited further feedback for some questions.

To summarise the feedback, we identified the key features of each response and grouped them by theme. We normally use this technique to categorise the feedback we collect from the public as part of our regular Local Healthwatch duties. It is a subjective process. The summaries should be regarded therefore as an indication of how often a theme was mentioned rather than an exact count. Some feedback offered views on more than one theme.

Also, people may have made the similar comment in response to different questions. So, the numbers for each theme reported under each question should not be added together.

For questions where comments were offered, we applied the categories used across the Healthwatch network supplemented with some specific topics.

Quotes and comments have been included as submitted by people. In some cases, we have made minor corrections to spelling and grammar. We have also removed the names of any individuals.

Statistical analysis

The findings from this survey are based on a sample of those who live in or visit a Buckinghamshire care home. This means all findings are subject to sampling tolerances.

To get an overall idea of where variations between groups may occur in the results, we used pivot tables and charts. For example, we looked to see if there were different responses by demographic group. Where we suspected there may be a statistically significant difference, we applied a chi-squared test based on the following assumptions:

- each observation is independent of all the others (i.e. one observation per subject)
- all expected counts should be 5 or greater.

We tested at the 90%, 95% and 99% confidence levels. Only those at the 95% or above level have been reported as significant. This means the difference is likely to be real rather than be due to chance. Where no real difference is indicated there may still be a variation in the responses being compared but the difference is more likely to be due to chance.

All the statistical analysis is shown in full in Appendix 4.

Appendix 2 - Who we heard from

Gender

Gender	Responses
Female	133
Male	35
I'd prefer not to say	5
I'd prefer to self-describe	1
(blank)	34
Total	208

Age Group

Age	Responses
18-25	1
26-35	2
36-45	5
46-55	23
56-65	41
66-75	28
76-85	26
86+	41
Prefer not to say	8
(blank)	33
Total	208

Ethnicity group

Ethnicity	All responses
Black / Black British: Caribbean	1
I'd prefer not to say	8
White: Any other White background	4
White: British / English / Northern Irish / Scottish / Welsh	163
(blank)	32
Total	208

Are you a relative or resident?

	All responses
Relative of someone in a care home	170
Resident of a care home	38
Total	208

Information, given by a relative, about the resident in the care home

The resident:	Responses
Lives with dementia	109
Can communicate with words (verbally)	101
Can communicate without words (non-verbally)	20
Is no longer able to communicate	24
Is bedbound	16
Is at end of life	10
Lives with a learning disability	10
Lives with a physical disability	37

Appendix 3 - Additional Tables and Charts

Communication

How did staff tell you about what was happening in the care home?

Respondent gave at least one answer	All responses
Newsletters	9
Residents Meetings	4
Verbal Updates	31
Other	17

How informed, as a resident, did you feel during the outbreak?

	All responses	
Very well informed	16	42%
Quite well informed	14	37%
Not at all informed	7	18%
(blank)	1	3%
Total	38	100%

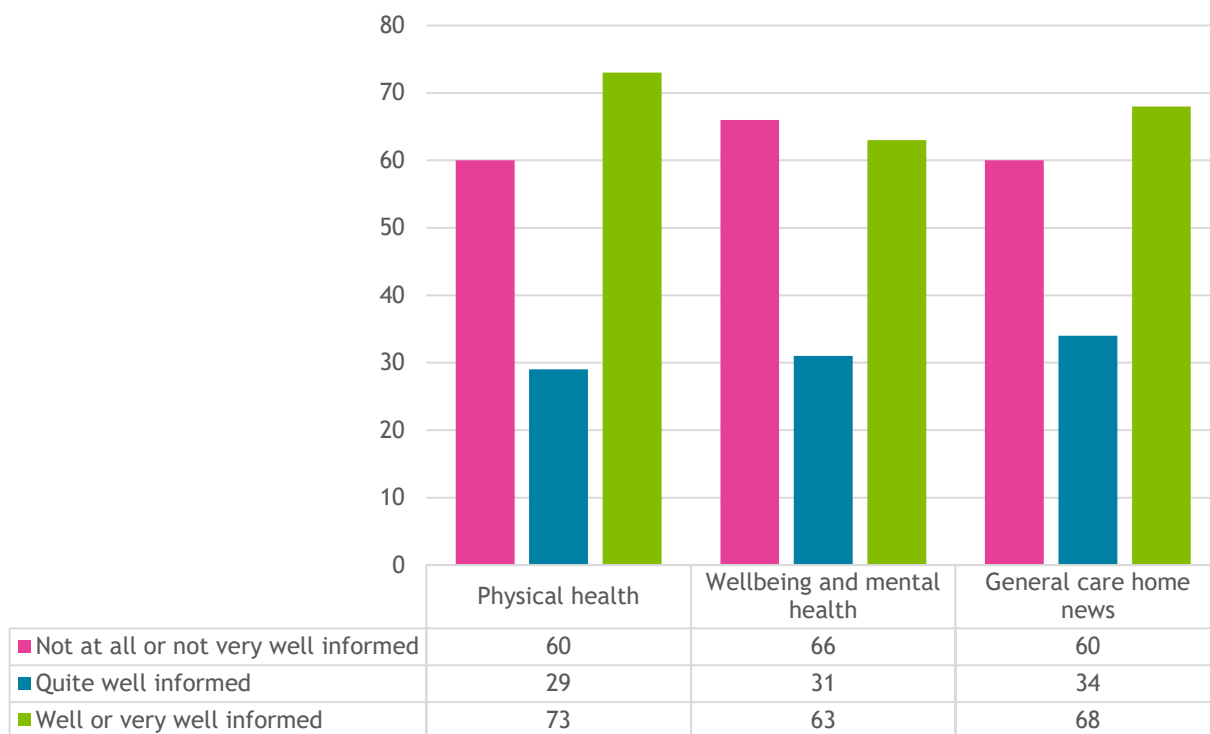
Before the outbreak, how did the care home communicate with you (relatives)?

Respondent gave at least one answer	Yes
I phoned	127
They phoned	123
They emailed	110
I emailed	84
On site relatives' meeting	79
Letter	74
Facebook/Whatsapp Group	31
Video call	10
Virtual relatives' meeting	1
Other	28

During the outbreak, how did care home staff communicate with you and how often (relatives)?

	Daily	Weekly	Fortnightly	Monthly	Never
I phoned	10	67	22	19	11
They emailed	1	26	21	52	34
They phoned	3	25	24	33	29
I emailed	1	18	13	30	39
Letter	2	3	5	44	46
Other					
Video call		28	4	7	57
Facebook/Whatsapp Group	10	22	4	1	49
Virtual relatives' meeting		8	1	5	74
On site relatives' meeting					

How informed, as a relative, did you feel during the outbreak?



Movement within the Home

Were there any changes to where residents could go in the home during the outbreak?

	A relative of someone in a care home?	A resident in care home?	Overall Percentage
Yes	96	31	62%
No	22	3	12%
Don't know	50	3	26%
Total	168	37	100%

Where could residents go in the care home?

Respondent gave at least one answer	All responses
In the lounge / dining room	72
Confined to one unit/ house/part of the home	69
In the garden	61
Confined to own bedroom	41
Confined to own bedroom only with COVID-19 symptoms	38
Don't know	10
Had to change bedrooms	6

Respondent gave at least one answer	All responses
Total (at least one response)	122

How did you feel about any changes to where residents could go in the home?

Response	A relative of someone in a care home?	A resident in care home?	Total
Fine / didn't mind	37	14	51
Felt safe	35	11	46
Distressed	5	2	7
Frustrated	5	2	7
Other	11		11
Total	93	29	122

Meaningful Activities

Did any of the care home's usual activities stop?

	A relative of someone in a care home?	A resident in care home?	Total
Yes	111	29	140
No	5	3	8
Don't know	52	4	56
Total	168	36	204

Tell us which activities stopped

Respondent gave at least one answer	A relative of someone in a care home?	A resident in care home?	All responses
Trips out	70	9	79
Visiting entertainers	69	8	77
Chiropodist appointments	56	7	63
Everything	28	15	43
Religious services	31	8	39
Group activities	33	4	37
Exercise / Zumba / Oomph	31	5	36

Hairdresser	16	4	20
Going into the garden	15		15
Total (at least one response)	107	24	131

Quotes Summary - Some of the 77 negative comments about activities stopping

Respondents were concerned about the impact on residents' mental health. They were worried about a lack of stimulation as residents saw less people daily and had less opportunity to do something meaningful. Relatives were worried for those who live with dementia and how significantly reduced interaction with others was advancing the condition.

“No contact with outside world and no stimulation from outside entertainers”

“Bloody awful coz there was nothing to do”

“My father has dementia and the lack of activities meant that he was just sitting in his room staring into space. I believe it has had a seriously adverse effect on his mental state.”

Some people were unhappy about the impact the lack of/reduction in activities would have had on resident's emotional and physical wellbeing.

“It is not good for her mental health to be isolated in her room 24/7”

“Frustrated as routine stopped and no alternative stimulation. You end up with a relative not able to walk, and bored. They don't comprehend the situation; just their world stopped.”

Some people were also concerned about the impact of medical professionals not visiting.

“Stopping medical, physio and chiropody visits seriously damaged residents”

Other negative comments included resident's lack of choice about the situation and no communication about when some activities would restart.

“It is very hard for the residents as they feel they have been abandoned by their families and they miss their activities and excursions.”

Some relatives also thought the care home should have done more smaller group activities, particularly exercise, rather than stopping activities entirely.

“not enough emphasis on social gains of activities; many could have continued with social distancing”

Were there any new activities?

	A relative of someone in a care home?	A resident in care home?	Total
Yes (please tell us more about these)	37	18	55
No	31	9	40
Don't know	95	7	102
Total	163	34	197

Meal Changes

Did anything about the daily meal and snacks routine change?

	A relative of someone in a care home?	A resident in care home?	Total
Yes	14	9	23
No	62	25	87
Don't know	90		90
Total	166	34	200

In what way did the meals and snacks routine change?

Respondent gave at least one answer	All responses
Couldn't eat in dining room	13
No snacks between meals	2
Meals more repetitive	2
Special dietary needs weren't met	1
Other	10
Total (at least one response)	15

Visitors

Did the care home allow any visitors?

	All responses
No	171
Yes, people could visit the home	25
Yes, people could visit the home, but relatives/friends chose not to visit	3
Total	199

When were relatives / friends allowed to visit the home?

	March	April	May
For any resident	6	5	23
For those at end of life	7	6	6

How have you been able to see people in person?

Respondent gave at least one answer	All responses
Through the window / at a doorway	4
In the garden / outside	22
In a restricted area inside if they wore masks	4
At their bedside at the end of their life	2
Other	11

Quotes summary - Some of the 85 negative comments about how people felt about the new ways on keeping in touch

Some residents were **confused** about why visiting had changed.

“Dad was very upset and confused as he could not understand the changes and felt VERY insecure without regular visits from his daughter ...”

“Confusing. Why can care home staff come in but my Mum cannot. Why can I not visit Mum at her house? “(resident living with a learning disability)

“Resident thought she had been forgotten and abandoned by her family and did not understand about the pandemic.”

For some, just working out who was talking to them and from where was a real challenge.

“WhatsApp video [call] upsetting as father looks sad and withdrawn. Voices are raised as he has hearing problems, but we can tell he is upset by the loud voices...”

“I am concerned my wife doesn't understand why I am not there or why my voice is coming from a phone”

Some people commented that the success, or otherwise, of using technology depended on **staff helping residents communicate with relatives**.

“... they just point the tablet at my relative who has severe dementia and non-verbal... Would have helped if the person making the call actually communicated during the call.”

“phone calls and video calls are difficult because the device is left with the person who has dementia and sometimes, they move it or click it off. It would have helped if someone checked back periodically to ensure all was going...”

Many residents who live with dementia, struggled with the new challenge now they were dependent on audio alone (phone) or else on technology many didn't understand and hadn't used before.

“Because of problems with comprehension, using a phone is difficult I suspect it is more upsetting than useful.”

“Difficult to concentrate on iPad screen so video chats not always successful.”

Several relatives also said the technology often failed or else there were insufficient video call opportunities.

“Most times needed 2 or 3 attempts to get to speak to my relative”

“Supposedly one Zoom call a week, but this doesn't happen.”

“We were only told we could Skype 8 weeks into lock down but only 1 staff member knew how it worked so we've only managed 1 video call ...”

Others were concerned about the **emotional toil a lack of visitors** was having on residents. Concerns extended to residents becoming withdrawn and dis-engaging with life in the absence of the physical touch and mental support residents gain from the physical presence of visitors.

“The period of isolation was very hard. We all felt better once garden visits resumed. Though I desperately want to hug my mother. I believe the loss of that sort of tactile affection has had an impact on her.”

Others struggled because of physical issues such as hearing loss or general ill health.

“My mum finds phone calls more difficult than face to face visits, including having to hold a phone up for a video call and having to get up to answer the phone.”

“... Also, quite difficult with a non-verbal family member and when at a fixed time because often asleep!”

Some relatives were concerned about the **quality of care** being provided to their loved ones. For some, their normal regular, often daily, visits would have involved encouraging their loved one, particularly those living with dementia, to eat and drink. These visits also gave them an opportunity to possibly pick up on issues, after a lifetime together with a loved one, which staff might not have been able to.

“Felt I had little control over what care my relative was getting. Constantly wearing same clothes which I am concerned if they were being washed. She needs help in choosing appropriate clothing and encouragement to wash hair etc.”

“couldn't tell if health/mood was changing”

“I pay £1600 a week and we r unable to see her 😞”

And for others, their relationship has been changed forever.

“Varied from day to day but Mum no longer recognised her grandchildren either on video call or face to face.”

Treated with Dignity

To what extent did staff continue to treat you (the resident) with dignity?

A relative of someone in a care home	Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know	No Answer	Total
They were patient and had time to listen	51	35	6	4	44		140
They asked my opinion and did not assume	34	35	10	8	49	4	140
They treated me as an equal	39	34	11	7	45	4	140

A resident in a care home	Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know	No Answer	Total
They were patient and had time to listen	12	14		1	3		30
They asked my opinion and did not assume	13	10	4	1	2		30
They treated me as an equal	13	10	4	1	1	1	30

Quotes Summary - Some of the 63 comments about being treaty with dignity

A few more examples of the 35 positive comments received.

“When garden visits were permitted in late May it was easy to verify that my relative had been well cared for and was content.”

“The staff are always very kind and caring. At end of life I was allowed free access to my relative in her room, after having my temperature taken as I entered the home daily and wearing gloves, mask, and apron. Staff offered me food and drinks and wanted to give hugs which social distancing prevented.”

“Staff tried to make up for no, and still no, family contact”

A few more examples of the 28 negative comments received.

“Some personal care has declined but I know some people with dementia can refuse. Things like fingernails, shaving for males and haircuts”

“When I visited my father, he was unkempt.”

“Those that knew me best were extremely kind and patient. Those who had not known me prior to lockdown sometimes found my behaviour frustrating.”

Keeping safe and hygiene

Did you (the resident) feel safe and protected?

	A relative	A resident	Total
Yes	72	27	99
No	4	0	4
Don't know	60	4	64
Total	136	31	167

Quotes Summary - Further examples of the 64 comments left about staff wearing PPE

Some, but not all residents, struggled to remember, why staff were wearing PPE.

“Not sure if relative understood due to dementia”

“Confused by the change.”

“Doesn't bother me one bit as long as I don't have to wear them”

As many older people live with a hearing loss, face masks muffling speech can be a real problem.

“resident's dementia is such that he was confused by the masks but his hearing is also poor so he couldn't easily hear their speech”

“Hearing aids were lost and could not see/hear clearly with face coverings.”

“My relative is confused by PPE and cannot always understand people's speech and could not pick up on facial cues etc.”

A few relatives were also concerned that PPE was not being worn or was worn inconsistently.

“Don't think that staff had enough. Staff at my mother's bedside only wore a paper mask and flimsy plastic apron”

COVID-19 diagnoses and suspected cases

Was anyone living, or working, in your care home diagnosed with, or suspected of having, Covid-19?

All responses	Yes	No	Don't know	Total
Me (the resident)	18	101	40	159
Staff	18	44	99	161
Other residents	59	42	70	171

Staff changes

During this time, were you (the resident) looked after by the same care home staff as usual?

	A relative of someone in a care home?	A resident in care home?	Total
Yes	88	21	109
No	17	8	25
Don't know	50	3	53
Total	155	32	187

Appendix 4 - Statistical analysis

During the outbreak, how informed and up to date did you feel about your relative's physical health

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Not well informed or worse	Quite well informed or better	Total
Yes	46	59	105
No	14	43	57
Total	60	102	162

Expected Frequencies			
	Response		
Living with Dementia	Not well informed or worse	Quite well informed or better	Total
Yes	38.8889	66.1111	105
No	21.1111	35.8889	57
Total	60	102	162

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	5.8695	5.8695	5.8695
p-Value	0.0154	0.0154	0.0154
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

Were there any changes to where residents could go in the home during the outbreak?

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	38	70	108
No	12	48	60
Total	50	118	168

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	32.1429	75.8571	108
No	17.8571	42.1429	60
Total	50	118	168

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	4.2547	4.2547	4.2547
p-Value	0.0391	0.0391	0.0391
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

Did anything about the daily meal and snacks routine change?

Null Hypothesis				
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia.				
Observed Frequencies				
	Response			
Living with Dementia	Yes	No	Don't know	Total
Yes	6	33	69	108
No	8	29	21	58
Total	14	62	90	166

Expected Frequencies				
	Response			
Living with Dementia	Yes	No	Don't know	Total
Yes	9.1084	40.3373	58.5542	108
No	4.8916	21.6627	31.4458	58
Total	14	62	90	166

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	3	3	3
Degrees of Freedom	2	2	2



Results			
Critical Value	9.2103	5.9915	4.6052
Chi-Square Test Statistic	12.1894	12.1894	12.1894
p-Value	0.0023	0.0023	0.0023
	Significant difference at 1% level	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Expected Count Check	1	1	1
	0	1	1

Each observation is independent of all the others (i.e., one observation per subject)*

80% of expected counts should be 5 or greater in 2x3 table.

Expected frequency assumption is met.

Did anything about the daily meal and snacks routine change?

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	69	39	108
No	21	37	58
Total	90	76	166

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	58.5542	49.4458	108
No	31.4458	26.5542	58
Total	90	76	166

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	11.6493	11.6493	11.6493
<i>p</i> -Value	0.0006	0.0006	0.0006
	Significant difference at 1% level	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

Did anything about the daily meal and snacks routine change?

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with a communication impairment and a relative of someone in a care home living without a communication impairment.			
Communication impairments include: living with dementia, able to communicate without words (non-verbally) or no longer able to communicate.			
Observed Frequencies			
	Response		
Communication impairment	Don't Know	Other	Total
Yes	73	42	115
No	17	34	51
Total	90	76	166

Expected Frequencies			
	Response		
Communication impairment	Don't Know	Other	Total
Yes	62.3494	52.6506	115
No	27.6506	23.3494	51
Total	90	76	166

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	12.9345	12.9345	12.9345
<i>p</i> -Value	0.0003	0.0003	0.0003
	Significant difference at 1% level	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

To what extent did staff continue to treat you (the resident) with dignity? They were patient and had time to listen

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	36	60	96
No	8	36	44
Total	44	96	140

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	30.1714	65.8286	96
No	13.8286	30.1714	44
Total	44	96	140

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	5.2247	5.2247	5.2247
p-Value	0.0223	0.0223	0.0223
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

To what extent did staff continue to treat you (the resident) with dignity? They asked my opinion and did not assume.

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	39	57	96
No	10	34	44
Total	49	91	140

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	33.6	62.4	96
No	15.4	28.6	44
Total	49	91	140

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	4.2483	4.2483	4.2483
p-Value	0.0393	0.0393	0.0393
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

Did you (the resident) feel safe and protected during the pandemic?

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	43	50	93
No	33	10	43
Total	76	60	136

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	51.9706	41.0294	93
No	24.0294	18.9706	43
Total	76	60	136

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	11.1005	11.1005	11.1005
<i>p</i> -Value	0.0009	0.0009	0.0009
	Significant difference at 1% level	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

Was anyone living, or working, in your care home diagnosed with, or suspected of having, Covid-19? Staff

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	60	41	101
No	19	28	47
Total	79	69	148

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	53.9122	47.0878	101
No	25.0878	21.9122	47
Total	79	69	148

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	4.6432	4.6432	4.6432
p-Value	0.0312	0.0312	0.0312
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

During this time, were you (the resident) looked after by the same care home staff as usual?

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with dementia and a relative of someone in a care home living without dementia			
Observed Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	39	64	103
No	11	41	52
Total	50	105	155

Expected Frequencies			
	Response		
Living with Dementia	Don't Know	Other	Total
Yes	33.2258	69.7742	103
No	16.7742	35.2258	52
Total	50	105	155

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	4.4155	4.4155	4.4155
<i>p</i> -Value	0.0356	0.0356	0.0356
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

During this time, were you (the resident) looked after by the same care home staff as usual?

Null Hypothesis			
There is no difference in response between a relative of someone in a care home living with a communication impairment and a relative of someone in a care home living without a communication impairment.			
Communication impairments include: living with dementia, able to communicate without words (non-verbally) or no longer able to communicate.			
Observed Frequencies			
	Response		
Communication impairment	Don't Know	Other	Total
Yes	41	69	110
No	9	36	45
Total	50	105	155

Expected Frequencies			
	Response		
Communication impairment	Don't Know	Other	Total
Yes	35.4839	74.5161	110
No	14.5161	30.4839	45
Total	50	105	155

Parameters			
Level of Significance	0.01	0.05	0.1
Number of Rows	2	2	2
Number of Columns	2	2	2
Degrees of Freedom	1	1	1



Results			
Critical Value	6.6349	3.8415	2.7055
Chi-Square Test Statistic	4.3601	4.3601	4.3601
p-Value	0.0368	0.0368	0.0368
	No significant difference	Significant difference at 5% level	Significant difference at 10% level

Assumptions

Each observation is independent of all the others (i.e., one observation per subject)*

All expected counts should be 5 or greater in 2x2 table.

Expected frequency assumption is met.

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