



Behind the headlines: why in-person care home visiting must get going again

December 2020

Introduction

Over the course of the pandemic Age UK has been contacted by thousands of people parted from their loved ones as a result of the disruption to visiting in care homes. We have heard from partners, husbands and wives, brothers and sisters, sons and daughters, grandchildren, life-long friends all greatly distressed by their sudden separation, and deeply anxious about how their friends and family are coping on the other side of the divide. The stories they have told us are distressing and shine a light on the extraordinary heartbreak experienced by so many families.

The impact of severely restricted visiting, or stopping visits altogether, for such a prolonged period has been clear all over the country. Many have watched helplessly as their loved one's physical and mental health has gone downhill fast. They have seen them giving up hope, losing purpose in life and ultimately, for some, dying sooner than would otherwise be the case. People describe being acutely aware of how much precious time together they have lost. Too many have been unable to say their last goodbyes.

Families and friends talk about how it has left them barely managing to cope themselves. They describe feeling lonely, anxious and overwhelmed with guilt and a sense of hopelessness that they can't care for and support their loved one. In some cases they fear, or indeed know, their friends and relatives living with dementia no longer recognise them or believe themselves to have been abandoned.

This short report explains what residents, their friends and relatives have told us about their experiences over the last nine months, the realities of what it means to 'stop visiting' and why we must make every conceivable effort to restore these personal connections. They are sadly typical of the stories we have heard throughout the course of the pandemic.

These stories have been collected through a recent Age UK survey of 2732 people, 81% of whom had a loved one living in a residential or nursing care home. The other 19% were residents of care homes, nursing homes or those who live or have a loved one who lives in supported living.

Why visiting is so important

1. People have not seen or spoken to their loved ones since the pandemic

70% of family, friends and residents who responded to our survey told us that they had not been able to visit or see their loved one since the start of the pandemic.

One in three family, friends and residents who responded to our survey told us that they had been offered no alternative to in person visiting, such as a video-call.

Lots of family and friends have told us that because their loved one is bed bound; this has stopped them from being able to visit.

It has been nearly ten months now since care homes began restricting visits in response to an unknown virus capable of causing catastrophic loss of life. As a result of this, a significant

proportion of care home residents and their relatives have not seen or spoken to one another in this time. This has been devastating for people to come to terms with.

- *“My mother is bed bound and totally dependent on others for all needs. The staff are busy so don't have time for anything other than basic needs. My mother had daily visits from me and my father prior to lock-down.”*
- *“He is my husband of 42 years and we have never been apart. He is upset and that is upsetting to watch.”*
- *“I feel so very sad [and] tearful. I miss my hubby so very much, we've been married 49 years. I want to see him and be with him, I used to visit daily and this is torture for me and him!! He has Huntington's disease and at the end of his life I'm sure this will be his last year.”*

We asked people to tell us how not being able to see a loved one has made them feel, these were the most common words they used:



2. People told us that they are *deeply concerned about the deterioration of their loved ones*

22% of family, friends and residents unable to visit or use digital options as an alternative, told us seeing their loved one in person meant they could support them to eat.

20% of family, friends and residents unable to visit or use digital options as an alternative told us seeing their loved one in person meant they could support them to be more mobile.

16% of family, friends and residents who'd been able to see each other in person during the pandemic told us seeing their loved one meant they could support them to eat

13% of family, friends and residents who'd been able to see each other in person during the pandemic told us seeing their loved one meant they could help them to be more mobile.

Friends and family of care home residents have told us that they are extremely concerned about significant, quite probably, irreversible deterioration in their loved ones' health over this period. Prior to the pandemic, friends and family played a key role in supporting a loved one to eat, be more mobile and have a good quality of life. It is clear that many people feel their loved ones have suffered greatly, both physically and mentally, where they have been unable to help.

- *"I had a mother in residential care, but sadly she died on 9th September. She had mild dementia, and I think she just gave up. She stopped eating and drinking. From March until she died we only saw her the final 2 weeks."*
- *"[Mum] has lost so much weight which I feel is an effect of no visits. I had a short visit in July and she clung to me and made me promise I would go back soon. I don't know how much longer mum will be with us."*
- *"My mum has dementia and I'm worried about her deteriorating without family contact and stimulation. I'm worried about her feeling as bereft as we do, but that she won't understand the reasons. She is also not eating well and losing weight."*

3. Being unable to visit means that relatives feel *unable to protect their loved ones*

87% of family, friends and residents who'd been able to see each other during the pandemic told us seeing their loved ones in person meant they were reassured about their loved one's wellbeing.

81% of family, friends and residents unable to visit or use digital options as an alternative told us seeing their loved ones in person meant they could be reassured about their loved ones wellbeing.

Friends and family of care home residents told us, that as part of their role in caring for their loved one, it is critical that they are able to act as a guardian of, and advocate for their loved one's safety and wellbeing. It is very clear many are struggling with an immense sense of personal guilt that they have not been able to 'do more' or have 'let down' the person they love. This is taking its toll on their own mental health.

- *"I feel very depressed; from time to time I have considered hatching a plan to assist my wife in escaping from the Care Home. I fear that my heart will be broken when I go and see her, her first words will be, "What's your name?"*
- *"It is bad enough having to have had the need to put a loved one in a home. With [a] lack of contact and unable to take them out for visits home and contact with family, especially grandchildren it is even more guilt to contend with. Life is passing us by, time that can never be retrieved. I don't want mum to die away from family, a thing she has always dreaded, and I promised would not happen."*
- *"I feel as though I have locked my parents away and thrown the key away."*
- *"I feel terrible, like I have deserted my mum."*

4. Both residents and relatives are *experiencing severe loneliness*

66% of family, friends and residents unable to visit or use digital options as an alternative told us that seeing their loved one in person allowed them to provide company.

67% of family, friends and residents who had been able to visit during the pandemic told us that seeing their loved one in person allowed them to provide company.

The separation that families have faced over this time has also left many experiencing severe levels of loneliness, often for the first time. Many of the respondents to our survey, generally the partners or adult children of a resident, have never been separated from their loved one for such an extended period of time at any point. Regular, even daily, visiting had meant that even though families no longer lived together, they were able to maintain a shared life. The effect of separation has been shattering.

- *"Although we speak on the phone [my husband] is confused about why I'm not there and tells me all the time he just needs to see me.... he went into care during lockdown, so I feel lonely and almost as though I am a widow grieving even though I am not. The pain of it all has been unbearable."*
- *"I know we miss each other greatly as I used to care for her in her own home until she fell downstairs. I live alone so am finding my life very limited as seeing my mother and helping her eat gave my life a purpose. I am lonely and at 72 years old I am trying to keep away from infection. I feel depressed and often unhappy as I cannot see my mother or hold or kiss her."*
- *"Two people who have been together for 50 years have been ripped apart at the end of their lives. Neither care whether they live or die. They just want to see each other before the end of their lives."*

5. The impact of separation is seriously affecting *people's mental health*

People told us that they were deeply concerned that their loved one has become depressed or their mental health deteriorated because of the prolonged separation they have faced over this time. For people living with dementia, this is exacerbated by the change in routine and lack of contact being extremely confusing too. This has also taken its toll on the mental health of friends and family.

- *"I feel very depressed; from time to time I have considered hatching a plan to assist my wife in escaping from the Care Home. I fear that my heart will be broken when I go and see her, her first words will be, "What's your name?"*
- *"It's cruel and unfair to keep me apart from my 94yr old blind mum when I don't know how long she's got left. She's extremely lonely and depressed and is definitely losing the will to live."*
- *"[My Son] began to feel confused and sad when this started, but now he is showing signs of depression, not just from lockdown from the effects of long Covid."*

6. People have *lost loved ones* in the most difficult circumstances

People have shared with us the heart-breaking stories of losing a loved one during the course of the pandemic and how restrictions meant many were unable to spend any time or see their loved one before they died. Where saying goodbye had been possible, contact in those last precious days or hours has often been virtual, over a video call and facilitated by the care staff. The pain of these experiences is hard to put into words. Those left behind describe feeling completely devastated by both their loss and the manner in which it happened, fearful their loved one died feeling abandoned and alone. These stories are very distressing and it is clear that people have been severely affected by this situation.

- *"I was his support for 60 years and was not able to say goodbye at the end - I know in my heart that no one else is to blame but still feel as though I had no closure. Lots of people must feel the way I do and I am deeply sorry for them all."*
- *"My grandad was going to die; we knew that it was only a matter of time. But the fact that he might have died thinking we abandoned him kills all of my family. And it probably will do for the rest of our lives. I'm only 23 and I would hope I have many years before me. But this will always be a sad thing for me."*
- *"My husband was in residential care when lockdown was suddenly implemented. The last time I saw him, we high fived and said see you soon. He died 7 weeks later. We never saw each other again."*

7. When *visits* have happened, they *have not been the same*

85% of family, friends and residents who had been allowed to visit during the pandemic, but didn't feel the visit was handled well, told us they weren't able to interact with their loved one like they needed to.

Around 49% of family, friends and residents told us their experience of visiting a loved one during the pandemic had been only slightly fulfilling or very unfulfilling.

78% of family, friends and residents who had been allowed to visit since the pandemic told us they weren't allowed physical contact with their loved one.

28% of family, friends and residents who had been allowed a visit since the pandemic told us their visit was supervised.

65% of family, friends and residents who had been allowed a visit since the pandemic told us that the visit was shorter than before.

While the majority of people have had no in person contact since the start of the pandemic, we know that some care homes have been able to facilitate alternative arrangements such as use of phones and digital devices, or through windows and plastic screens. For those who have been able to benefit from alternative forms of visiting, it has certainly been an important way to maintain some form of contact. It has gone some way to alleviate their anxiety about their loved one's wellbeing as well. However, nearly all would say it is a 'poor relation', neither particularly fulfilling nor allowing residents and relatives to interact in the way they felt they needed.

- *"[Our visit] was outside and cancelled in bad weather and no shade in heatwave. It was once every 10 days, at a 2 metre distance, supervised, with masks and no longer than 30 minutes. It was very basic-no offer of a cup of tea etc. Now it is through locked doors as there is no winter visiting in place."*
- *"[Visiting means] .. I can see if mum is happy, I can see the interaction between mum and the staff. I can check that she is well e.g no bumps and bruises, although the care home has been great."*
- *"[Although I could visit my loved one], because I wasn't able to enter her room, I was unable to do things for her. Because she cannot see I usually sort her clothes, check her phone balance and charge it. I also check her stock of personal goods and put things where she can find them. The care home staff are too busy or just not helpful with this."*

8. People found *window visits and other alternative arrangements very difficult*

Many people told us how window visits were difficult, often because they were unable to make conversation or even properly see their loved one.

Some told us that because their loved one lived on the first floor of a care home or above, window visits had not been possible.

Nearly 70% of family, friends and resident who responded to our survey and told us they had not been able to visit their loved one since the start of the pandemic, also told us that digital and phone communication was not a good alternative to in person visits.

45% of family, friends and residents who had been able to visit each other during the pandemic, told us seeing their loved ones in person was vital because their loved one could not use digital options.

People have told us that due to specific conditions such as sensory loss, dementia, or poor health leading to people being bed-bound that communicating by phone, video or through glass and plastic is impossible, Furthermore, these methods of communication are often distressing and confusing for people. Many respondents say that for them communicating with their relative is done through touch and eye contact – both of which are irreplaceable. This means that there are a large proportion of older people living in care homes who have been unable to use the limited alternative options to in person visiting. It also means many feel they have completely lost touch with their loved ones, with no suitable alternatives to in person contact available.

- *“As a much loved Aunt who has no children of her own, we are her direct family. She also has a very wide circle of friends who would also like to visit. She has vascular dementia and does not understand the process of a video call. Every time she turned her head from the screen she thought I'd left her and she became very anxious. I've asked family and friends to send me photos so I can send them to her. She doesn't understand the photos the way I had hoped she might.”*
- *“Mum is deaf-blind. She is giving up and has said she just wants to die rather than live. I used to be able to take mum in food she likes and to engage her in activities, she likes to touch/stroke things or feel different textiles... she can no longer do this.”*
- *“My dad is totally deaf and I have to use a white board to communicate due to his hearing aids being lost! It's so difficult communicating with him and not being able to give him a cuddle or hold his hand is difficult. He's 95yrs old with dementia and prostate cancer. The care home do give us our privacy by keeping the door of the dining room closed which is good. They are very approachable and help out when needed.”*

What needs to happen now

This survey has revealed a depth of suffering among both care home residents and their families and friends that is upsetting to read about, let alone experience. It shows how vital it is that older people living in care homes who usually receive visitors are able to do so in person, and in as near normal a situation as is safe, once again. Many of these older people do not have time on their side so it is imperative that everyone acts as quickly as humanly possible. For some it is already too late; let's do everything we can to avoid adding to their numbers.

Any person entering a care home carries with them a risk in terms of infection, but with lateral flow tests now becoming available, it is a risk judged manageable by the experts. These tests are not the only weapon in the armoury of care homes in seeking to keep visiting safe: they also have the use of appropriate PPE; regular, thorough cleaning; hand washing; and good ventilation. When all these things are deployed professionally and well,

in a care home which does not currently have an outbreak of COVID-19, then visiting can and should go ahead, especially in the light of our survey findings which demonstrate just how incredibly damaging stopping contact has been and continues to be for everyone concerned.

It is also important to remember that some care homes have managed to keep safe visiting going throughout the pandemic, even without access to lateral flow tests. They have done this through being creative and by adhering religiously to excellent infection control practices. If they can do it surely others can too, and the fact is that now they must; the health and wellbeing, in some cases even the survival, of many care home residents, depends on it. It's time to reunite.

In due course, possibly within the next couple of months, vaccination should completely change the debate about care home visiting, making it considerably safer and giving staff a lot more confidence. However, we cannot wait that long to resume visiting because for many older people and their families and friends it is obvious from our survey that every day counts. The Government has pledged that everyone will be able to see a loved one living in a care home by Christmas: this is extremely ambitious, but our survey shows how important it is that the promise is fulfilled. It's the right target to aim for and at Age UK we will continue to hold the Government, and care home providers, accountable for meeting it.