

Sheffcare: #SpeakUp project report

Exploring the impact of Covid-19 and continued lockdowns on care home residents and their families



#SpeakUp: Sheffcare

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of £2000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care. By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.



Sheffcare

Sheffcare is a Sheffield-based charity, providing care for more than 500 older people across the city. Across nine different homes in Sheffield, we offer residential care, home care, day, respite care and specialist care for people living with dementia. We are strongly committed to providing high quality, compassionate care which enhances quality of life.



Healthwatch Sheffield

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.



Introduction

Why did we carry out a #SpeakUp project?

In the early stages of the Covid-19 pandemic, the virus spread rapidly through many care homes in England, and many residents sadly passed away.

Many measures were then brought in to reduce the spread of Covid-19 within care homes – such as stopping or restricting family visits, regular testing, and higher levels of Personal Protective Equipment (PPE).

As restrictions in many other settings eased, this wasn't always the case for care homes. Strict visiting rules remained in place for some time, and UKHSA policies meant care homes had to return to lockdown whenever Covid-19 cases occurred.

All of this means that, in care homes, the impacts of the pandemic are far from over. We wanted to explore how this has affected our residents and their families and friends.

What did we do?

We planned a talking session in each of our homes so that residents could tell us about their experiences, using picture and word prompts to help people in the discussions. We also created an online survey for friends and relatives to share their own perspective.

Two of the nine homes were in lockdown due to Covid-19 outbreaks during this time period, so sessions were held in the remaining seven homes.

We spoke with:

- **24 residents**
- **32 relatives and friends**
- **8 staff members/volunteers**

Not all the residents we spoke to were able to share their experiences of the pandemic, due to the symptoms of their Dementia. We also found that some residents did not wish to take part in the sessions and didn't want to revisit what happened throughout Covid. At one home, we didn't have any residents who wanted to take part in the session and so we only spoke to staff.

8 of the relatives and friends we spoke with were through interviews, while 24 took part in the online survey.

Findings

How care homes handled the pandemic

Relationships with the care homes were generally positive.

Most of the people we spoke to shared positive reflections on the way that their care home responded to the pandemic, and the relationships they built with staff.

In the survey, most of the people whose relatives had lived in a care home since before the pandemic spoke positively of their relationships with the care home staff and management:

“The care home kept me informed and up to date [...] my relationship with the home has remained strong and positive”.

“It has improved my relationship as I got to know individual carers more and came to understand the problems and pressures they faced”.

There was a strong perception of staff working hard in difficult circumstances:

“It was very upsetting, but staff were excellent [considering] the massive problem of covid”

“The care home did everything possible”.



Care homes generally implemented policies well.

All of the survey respondents were content or happy with how Sheffcare homes communicated their policies, via regular phone calls and letters. Most had no suggestions as to how this could have been better. A few did say that speed of contact could have improved, but there was acknowledgement that it was difficult for care homes to get the right information in a timely way too:

“Email or some other direct electronic method of communication [would have been better]. The rules changed so quickly the letters we received were often long out of date when we read them!”

This is not to say that there wasn't frustration about initial covid procedures – many survey respondents were very worried or frustrated about how covid was handled – but from survey respondents as well as participants in the group sessions, most of this was directed at government/public health decisions:

“All my negative feelings are directed at the government and its crazy lockdown policy”.

“The government handled the [pandemic] very badly – they were risk averse and the guidance was unrealistic”.

People generally felt more positively about the way that the care homes had implemented policies. Some said “Sheffcare took the guidance as the letter of the law and kept rigid rules which were disappointing” – but most people expressed sympathy that “everyone was dealing with a new situation and were unsure of how best to handle it” and that they “understand that Sheffcare did what they had to do”.

How do you feel lockdowns were handled by...	The government/ public health?	Sheffcare?
Perfectly	1	8
Very well	8	7
Could have been improved in some ways	13	7
Very badly	1	1
Terribly – nothing was right	1	1
Unsure	0	0

Experiences of visiting during Covid

Experiences of visiting varied across Sheffield

Visiting policies and procedures were an important part of people's reflections about Covid. Residents and their friends and relatives all felt the importance of being able to keep contact throughout the pandemic, but many had very different experiences. Some of this was due to changing guidelines throughout the pandemic, while other differences were due to policies and procedures being implemented differently in different homes.

Use of technology was one key area where we heard a lot of variability – some survey respondents said their relative's care home used technology to help them keep in touch, while others said there was nothing like this, or it came and went:

"The care home was excellent [...] arranging FaceTime calls with mum"

"Maybe WhatsApp group with photos of residents and what they were doing [...] for a short time there was communication via WhatsApp, but I believe no one is now in this post"

"Despite buying an ipad for independent use and was promised a phone call each week this didn't happen – occasional photos no dialogue – could have been done better. If this ever happens again then this technology for communication must be a priority"

We also heard about different ways of visiting the home, for instance window visits. Sometimes care homes were limited by their layout – eg residents with a room on the ground floor could have window visits, while residents on other floors were isolated for longer. When residents spoke to us about window visits, they often didn't feel this worked well.

"Window visits were hard – weather wasn't good – not being able to see your family was terrible"



Relatives told us that there wasn't always the necessary staff support available to help someone make the most of window visits:

"It would have been good if a carer could have always been with him to help him get to the window and to tell dad what I was saying"

The most common visiting type relatives told us about was the use of visiting pods, which worked well at some homes. Some residents shared positive feedback – "Pod much better and safer", "I had visits in the pod, much better out of the cold". However, others said the pod set up didn't work that well, and "a room with a screen would have been better than a small pod", or "having a warm room inside the home rather than the cold outside pod".

The way people could use the pods also varied across homes – one relative we interviewed said "some members of staff were unreasonable in their actions – you can only have half an hour even if there wasn't anyone after you [...] the rules were followed rigorously and in some cases no common sense was applied".

Some people spoke about variation across care homes more widely – not just Sheffcare homes. They said some care homes did allow visitors to "visit the room but in full PPE" while this was not allowed at all elsewhere. Most people were not allowed physical contact for some time, even when wearing PPE, while other care homes were more flexible in this approach.

Becoming an essential caregiver

Later in the pandemic, one friend or relative was able to become an essential caregiver, allowing them to visit a resident more freely. We heard that this was important to many families, but it was not taken up by many others. There appear to be several reasons for this – some people weren't sure what would be expected of them when they took on this role, and it does not seem to have been promoted equally among care homes, so some families did not manage to take up this opportunity.

The essential caregiver role could also only be taken on by one family member. For some families it was clear who would become an essential caregiver because of their circumstances – "I live the nearest" – while in others there had to be some potentially difficult discussions and it did cause problems – "I wasn't prepared to do this at all".

Other relatives felt that too many hoops had to be jumped through in order to utilise this opportunity – "training and DBS required to visit your own relatives – ridiculous".

The impact of lockdowns

Lockdowns are extremely challenging for residents and their families

In the survey, we asked various questions about lockdowns and the impact they had on residents and their friends and family. Most of the responses we received were very emotional – lockdowns have had a profound impact on people.

One key finding here came from the relatives of people who moved into care homes during the pandemic – it made the process of moving and settling in much more difficult:

“It was difficult as when Nanna [moved in] she had to isolate for 2 weeks so we couldn’t visit which was very hard”

“The care home only had window visits so [...] I was not able to help with arranging dad’s room or to see him in context of being in his new environment”

We also asked how many isolation periods residents had faced, and how this had affected them. Most people found it hard to put a definite number to this question – but people spoke about the national lockdowns, periods of personal isolation when moving into a care home or returning from hospital, and lockdowns due to cases of Covid within the home.

It is clear that people in different care homes have had very different experiences. Some only experienced the national lockdowns, and while this was still difficult, their relatives didn’t express significant concern:



“Only those associated with the pandemic which didn’t bother either of us as I knew she was being well care for and I couldn’t change the situation so was acceptable”

A couple of people said their relative faced more isolation periods but managed it quite well:

“I really can’t remember how many but even though my mum is well into her 90s the isolation did not seem to affect her too much”

Most people, however, said their relative faced many periods of isolation, and expressed significant concern about the impact this had on their wellbeing:

“Affected mental health badly”

“Confused, tearful & lonely [...] Homesick, having recently left her own home to reside in a Care Facility. Separation anxiety further exacerbated as she had recently been widowed”

We also heard about a decline in physical health and mobility for some people – this may have happened anyway, but families felt lack of stimulation during lockdown, and physiotherapists not being able to come into the homes, would not have helped:



“Mum lost her mobility and now has to be hoisted. Bad for mental health and physical health – concentrated on Covid health only – not looking at the whole picture [...] GPs weren’t coming in so staff had to make decisions that they shouldn’t have to make”

Lockdowns had a significant impact on relatives and friends too. Responses to questions about this held a lot of emotion – expressing sadness: “heartbreaking”, “concerned and sad because I missed my mother”, frustration: “frustration that there was nothing I could do”, and guilt: “I felt I had abandoned her though I visited as much as I could”.

Lockdowns have additional impacts on people living with dementia and their families

The families of those living with dementia told us about similar concerns and worries as other families, but these were exacerbated by dementia symptoms. In many cases, people felt that their relative’s dementia had gotten worse more rapidly due to lack of contact, and it was more distressing for all involved:

“6 [lockdowns] and with dementia it affected mum a lot as she needs stimulation”

“Lost count of the isolation periods. All I know is that the isolation led to a clear deterioration in my mum’s cognitive ability – it made her dementia worse”

“Very distressing for my dad as initially he simply didn’t understand why nobody was visiting”

Through the survey and our interviews with relatives, it seemed clear that lockdowns have had a lasting impact on the families of those living with dementia, and for those residents who experienced more rapid cognitive decline.

We also spoke to the relative of one resident who has a learning disability, who had similar concerns about them not understanding what was happening. They told us that visits to day centres and other trips had to stop suddenly, and they worried how their relative would cope with this change to routine. They felt there was a risk of losing the trusted relationships with these services.

We did speak to several residents with dementia as part of our sessions in the homes, but these conversations could be difficult and it was hard for them to express their thoughts. Many of them didn’t remember the pandemic at all and had to have it explained to them several times. Some people knew some words – like “lockdown” – but not others, like “covid” and “pandemic”. Some of the residents we spoke with believed it was a good thing that they didn’t remember, however this was not always a comfort to their relatives who had seen their distress at the time, and their symptoms worsening.

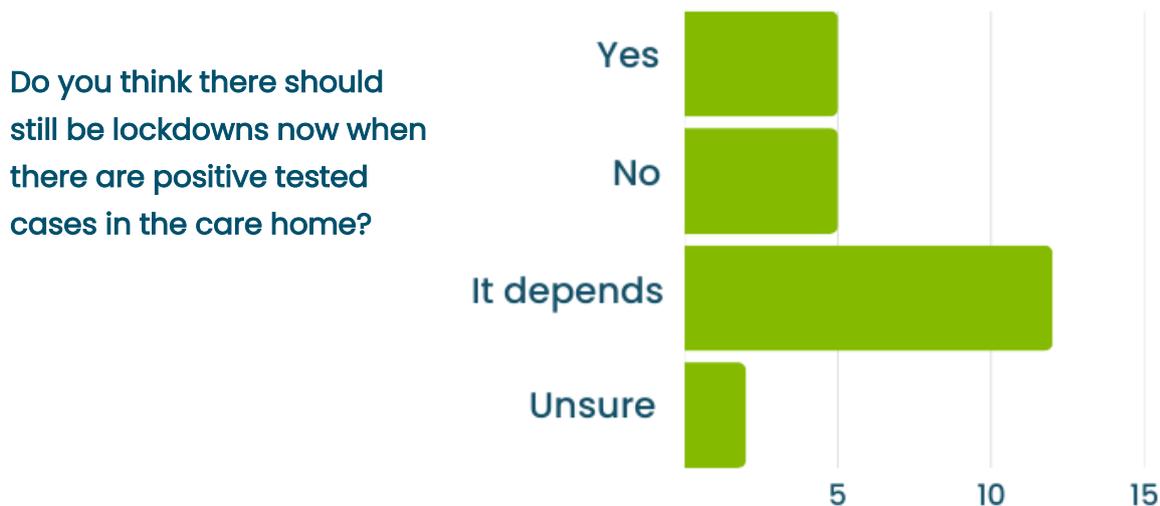


The ongoing impact of covid in care homes

People would like to see more flexible policies moving forward

Care homes must follow national policies designed to prevent the spread of Covid. In practice, this means care homes are entering a lockdown period if two cases of Covid are reported among residents and/or staff.

We asked relatives their thoughts about this policy as part of the survey:



Most people said it depended on the amount of cases, or who is infected. There are clearly a range of perspectives on this issue, but many people would welcome an approach which looks at the circumstances of each case, rather than blanket policies. For instance, 2 Covid cases in a home where 15 people live might feel very different to 2 cases in a home where 100 people live, and people may feel differently at a residential home compared to a specialist nursing home.

During interviews, some relatives expanded further on their thoughts:

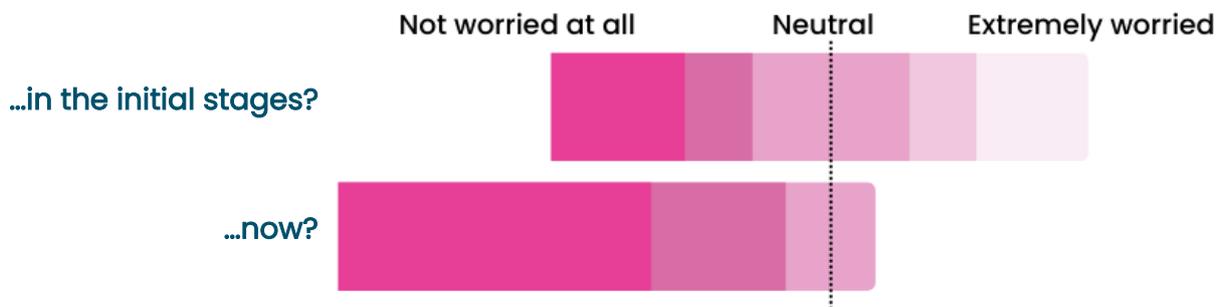
“Testing staff and residents – if 2 tested positive then went into lockdowns and this dragged on and on. Went on and on – far too long. This shouldn’t happen now”

“I believe this is unnecessary and very damaging to people’s wellbeing – if my father dies of covid he dies of covid. If he died of a broken heart that would make me very angry”

People’s feelings about how care homes should manage covid incidents or outbreaks moving forward are likely to be influenced by the serious impact on wellbeing they saw during previous lockdowns, which was of great concern to those we spoke to.

Feelings may also be influenced by how worried they are about residents' general safety now, compared to previous pandemic stages. We asked about this in the survey – no one told us they were worried or extremely worried about their relative now, compared to a much wider picture during earlier stages.

On a scale of 1-5, how worried were/are you for the safety of your relative/friend...



This may also be influenced by the vaccine rollout/booster programme – all the survey respondents said their friend/relative had received the vaccine. They all felt positively about this, with most feeling less worried now they had some level of protection.

When we spoke with residents about the ongoing risk of Covid, many of them felt similarly. While they acknowledged that lockdowns were “being done to keep them safe”, most were “pleased to get visits back and be able to touch their relatives and friends”. None of the residents expressed much anxiety about catching Covid and were keen to see a return to normalcy.

Lockdowns have had a long-term impact on the care home environment

Several residents, relatives, and staff told us that they think the care home environment has not recovered from the impact of Covid. One resident had noticed higher levels of anxiety within the home and further afield:

“[It] changed many things on the outside world and in the care homes – it has spoilt things inside and outside the home – for many people it has left a level of anxiousness”.

Some relatives commented on how it feels now to visit the home – with fewer people engaging in activities and socialising:

“People had got used to being in their own rooms and because of that, now things were better, still kept themselves to themselves. The community element of the home hasn’t yet recovered.”

Recommendations

For care homes

Communication is vitally important – this needs to be maintained (and supported, where necessary) through periods of isolation.

This includes information the home shares with families, as well as supporting residents to maintain contact with family and friends. It might mean using a range of technologies like emails, message groups, and voice and video calls. Staff should be trained and supported to feel confident using these technologies.

Visiting needs to be considered carefully, and feedback sought from residents and families during an ever-evolving situation.

This could include the location of visits (e.g. visiting pods, window visits, or socially distanced indoor visits) and other practicalities like PPE or heaters.

Increased clarity and support should be provided for families around the ‘essential caregiver’ role, or other comparative roles which are created.

Homes could encourage more families to take up this opportunity through wider promotion, explanation, and support to apply.

For policy makers

Blanket rules are not always appropriate, and the needs and preferences of different homes and residents should be considered while setting guidance.

Increased flexibility might consider the number of residents living in a home, its layout, or the needs of the residents (eg in a residential or nursing home).

