Joint Committee on Human Rights

Oral evidence: Protection of human rights in care settings, HC 714

Wednesday 12 January 2022

Watch the meeting

Members present: Joanna Cherry MP (in the Chair); Lord Brabazon of Tara; Lord Dubs; Lord Henley; Baroness Ludford; Baroness Massey of Darwen; Angela Richardson MP; Dean Russell MP; David Simmonds MP; Lord Singh of Wimbledon.

Questions 1 - 7

Witnesses

I: Ruthie Henshall, Ambassador, Rights for Residents; Sharon Clay.

Examination of Witnesses

Ruthie Henshall and Sharon Clay.

Q1 **Chair:** This is the first public evidence session for the Joint Committee on Human Rights inquiry into human rights in care settings. My name is Joanna Cherry, the Member of Parliament for Edinburgh South West, and I am the deputy chair of the committee.

Before we proceed, I want to acknowledge the very sad circumstances in which the committee is meeting today. I am chairing in the absence of our chair, Harriet Harman, who, last Friday, suffered the sudden and tragic loss of her husband, Jack Dromey. On behalf of the committee and staff, I want to extend our sincere condolences to Harriet and her family. Her husband was an accomplished trade unionist and parliamentarian, and greatly loved and respected. I know that he will be very sadly missed.

Moving on to our business this afternoon, today is the first session of the inquiry into protecting human rights in care settings. The committee will take evidence from two witnesses with close relatives in the care system, and then from campaign groups and experts in the field. The purpose of this session is to identify the range of human rights issues in the sector and the quality of complaints mechanisms when failings particularly pertaining to human rights issues come to light.

The Joint Committee on Human Rights published a report in May last year calling on the Government and care home providers to do more to uphold the right to family life of care home residents. We also noted concerns about blanket bans on visiting in care settings, and the committee reiterated its call on the Government to legislate to require that individualised risk assessments are always undertaken for each resident. We provided a draft statutory instrument for the Government to consider. Our inquiry into care settings will look again at visiting during the pandemic, but it will look at other human rights concerns regarding care settings more broadly.

On our first panel this afternoon, we are joined by people who can tell us directly about some of the issues they and their families have experienced while caring for people in care settings. Our first witness is Ruthie Henshall, an English actor and performer, who is also an ambassador at Rights for Residents. Ruthie’s mother was in a care home when visits were suspended during the pandemic in 2020, and she has been campaigning ever since for the right to nominate essential caregivers and to have them continue visiting, even during outbreaks. That is under the campaign for Gloria’s law.

Our second witness on the first panel is Sharon Clay. Sharon has a family member in care, her mother, and has a number of concerns relating to visiting restrictions and, more generally, the mistreatment and potential neglect of people in care.

I will start off with a general question for both of you before I hand over to some of my colleagues to ask more particular questions. As I said, we are

looking at whether the human rights of people in care are adequately protected and what needs to be done to address any of the problems we hear about. For example, we are thinking about the right to life, protection against torture and inhuman or degrading treatment or punishment, the right to liberty, the right to family and private life, the right to the highest attainable standard of health, and protection against discrimination.

I want to ask you both whether you think that the human rights of your family members in care have been adequately protected. If not and you have concerns, can you elaborate on those concerns?

Sharon Clay: I need to admit to this up front: Ruthie and I belong to the same campaign group, Rights for Residents. We are strong advocates for the essential caregiver and visiting rights. I know that Ruthie will concentrate more on that, but a lot of the human rights issues of people in care have to do with a lack of visiting and end of life. This has been made much more serious by the pandemic and the control that care homes now have over the movement and care of relatives, by keeping family members out, so that we can police the care of our loved ones no further.

I do not know whether there are any specific questions that I could just vaguely go on to, because Ruthie will probably cover much more about the essential care. We are not there to police anyone. We are not there to police what is not happening, or not happening as well as it should be, for our loved ones. Maybe they are not being fed or cleaned properly. They are forced to stay in bed or to get up when they do not want to, fitting the timetable from the care home. There needs to be some routine but not as rigid that our loved ones have no control or say over their care at all.

Chair: Ruthie, just to reiterate the question, do you think the human rights of your family members in care have been adequately protected?

Ruthie Henshall: No, not at all. What became very apparent to me was that the care home had all the power and that, as a relative, a daughter of my mother, I had no say in what was happening to her in that home. The fact that I could not get in there was really worrying to me. I was doing window visits, but it was very obvious to me that my mother was spending gargantuan amounts of time, 24 hours, on her own, locked in her room, unable to move and unable even to switch over a channel.

I was able to be with my mother when she died only because I became an essential caregiver, because I knew about that status. I went in the day before she died. I had been in for the five weeks prior to her dying and knew something was wrong that day, so I went back the following day. I phoned them and I asked, “What’s happening with Mum?” They said, “We’ve put her to bed. She just seems quite tired”. I went in, because I was worried about her, and realised she was dying. She would have died without us being there. We would have been informed in the morning, because the carers do not have enough time to deal with everybody in this setting.

Please do stop me. I have so much to say on this subject, but I watched a huge decline in my mother over four months. Their human rights have been completely handed over to a business instead of to the people who really matter and care.

Chair: You mentioned that your mother was locked in her room. Why was that?

Ruthie Henshall: In dementia, there are often lots of people who wander, and they need to wander. Everybody was locked in their room. In care home settings, one of the most wonderful things is the fact that the front room is there for everybody to be in together—families, all sorts. That has stopped and has continued to stop. They are not even allowing priests in sometimes. They are not allowing any kind of entertainment whatsoever, so they are staring at four walls.

Chair: So your mum was locked in her room because of the Covid restrictions in the care home. It was not for her own safety in relation to the dementia, but because of the procedures in place because of the pandemic. Is that right?

Ruthie Henshall: Yes, that is absolutely right.

Chair: Before we move on to some more particular questions, forgive me if this is insensitive, but you said that you realised, on the last day of your mother's life, that she was not just tired but that she was going to die, when the carers had not realised that. What made you realise that, if I may ask?

Ruthie Henshall: She was not very alert. When I went in to visit her, I touched her. I had the same rights as a carer, so I was able to touch her and she was clammy. I was able to hold her, and her breathing was not right. I called the paramedics, who then said, "We can take her to hospital". I realised she was dying, and they told me she was dying. They said, "We don't think she's got very long", and I said, "I'd rather leave her here and be with her than send her to hospital and not be able to be with her". It was very obvious to me, but it would not have been to carers who were literally trying to pop their heads into 50 different rooms.

Chair: Am I right in understanding that it was a combination of the fact that you knew your mother well and that you were able to spend more time with her, because you were not responsible for anyone else, just for her? Is that right?

Ruthie Henshall: That is absolutely right. I read to her. I sang to her. I touched her, to which she would moan with delight, like a child. She would bury herself in me, because that is all she had left. In the four months from the first lockdown, she went from walking, talking and feeding herself to not walking, not talking and not being able to feed herself. She just went downhill so quickly.

Oxford scientists have shown that, in the latter part of the pandemic, more excess deaths can be attributed to loneliness and isolation than to Covid. This is why it is such a breach of their human rights and it was absolutely devastating watching my mother decline like that and having no say over her care. I could ring the home. An awful lot of people are finding that if they make complaints to the home, they are in danger of the home excluding their loved one because they are making a fuss about something. The homes have all the power, and nobody is monitoring them. The CQC just does not have that kind of power. It can say, "This is what we want you to do", but the homes can say, "No, we're not letting people in".

Chair: I am sure we are all very grateful to you for sharing what must be deeply personal and distressing memories, but they are very useful to us in understanding what we need to understand here.

Q2 **Lord Henley:** I declare an interest in that, like Ruthie, my mother has only recently died in a care home. In that particular case, one of my sisters was the regular visitor and essential caregiver, but, for the rest of us, it was that much harder to make visits.

Ruthie, in your recent interview with the *Daily Mail*, you described family members as being the eyes, ears and memories of some residents and patients. You have talked about your own experiences, but I just wanted you to expand on the experiences of other relatives of yours and your mother's, the restrictions they faced, and how you feel your mother's care was affected by your and their inability to visit.

Ruthie Henshall: As I said, my mother declined very rapidly. The biggest problem is that I am one of three daughters of my mother. My father had died two weeks into lockdown. Of course, we understood that we needed to keep them safe at the beginning and batten down the hatches. That is fine, but in the end I was the only person allowed to go in. There were blanket bans. If I tried to call her on FaceTime, she just did not understand at all what this machine was that was in front of her. As she got to the stage where she could not talk, I could not understand and ask her questions, and have her reply.

There are some wonderful carers, but they do not have my mother's memories. They do not love my mother the way I loved her. I would read to her. I would paint her nails. I would hug her. I would stroke her face. I would be there for hours, rather than five minutes to feed and do what they needed to do.

I find it quite shocking that the relatives are almost being seen as the carriers. The carers can come and go as they like. They can go round Asda, do their shop, pick up their kids from school, all of that, and most people who are visiting relatives in a home are being so careful, so what is the difference between the carers and having a relative visit?

The change in my mother was unbelievable. When I got in, the light came back on in her eyes. The care manager said that to me. She said, "I never would've believed this, but I've seen such a difference". It was almost like, in the end, my mother said, "Okay, I've hung on long enough".

With my other sister, we would put the window up as far as it would go, which was about that much, and my sister would try to put her hand in to hold my mother's hand, to give her some kind of comfort. This is what is very difficult, knowing what is going on with parties, and people snogging in alleyways and driving to see how their sight is going. At one point last Christmas, I was standing at a window and my mother was crying, because she did not understand why I would not come in. You have to explain to dementia patients again and again and again what is going on, because they will not remember.

It was so distressing as a family to watch the decline from behind a window. We understood it at the time, but now we have the vaccination, the lateral flows and the PPE. We do not pose a risk. Everything has opened up. Society has opened up for everybody else. Freedom day was unbelievable for everybody: "Yay, it's freedom". What happened to the people in the care homes? Nothing happened.

Q3 **Chair:** Perhaps I could come in there and ask you this, looking at the position we are in now. Last week, I and Liz Saville Roberts MP, the leader of the Plaid Cymru group, raised questions about visiting restrictions in care homes with the Prime Minister on the Floor of the House. The Prime Minister said that there is a need "to strike a balance and to keep home care residents safe and to do what we can to prevent the epidemic from taking hold in care homes". He said that he wanted to "continue with a balanced and proportionate approach that does not allow the disease to get back into care homes in the way that it did". I presume that he means at the start of the pandemic.

That was said to me and another MP last week, so it is about the contemporary situation. Do you both think that the Government's guidance on visiting at present strikes the right balance between safety on the one hand and, on the other hand, guaranteeing the right to family and private life. If not, is the problem the guidance or the way care homes are implementing it?

Ruthie Henshall: I believe it is the way it is being implemented. Because it is not law, it has become interpreted by each care home, and it is a postcode lottery as to where you live and whether you get even a half-hour visit every two or three weeks. This is why I am campaigning for Gloria's law. As human beings, we all think that the rules do not apply. At some stage in our lives, we have all done that: "Well, it doesn't matter for me". If it is not law, it will not be followed by some people, and this is the big problem.

I have not understood why people are not listening. It makes me quite upset, because I do not understand why we are not looking after people in care. I am talking from the point of view of old people with dementia, who have been there for us. They have fought for us. They have built this place

for us, and we have completely taken away their voice.

Chair: So you think it is the implementation of the guidance that is at fault, and that is why you want to see it in law rather than just guidance.

Ruthie Henshall: That is absolutely right, because if you give guidance, it is open to interpretation.

Chair: Sharon, what is your view? Do you think the balance is right and, if not, do you think it is a problem with the guidance or the implementation of the guidance?

Sharon Clay: It is a mixture of both, to be honest. I do not think that the guidance is strong enough. It has passed everything back to the care homes because it is guidance. The power has gone back to the care homes. The guidance is not strong enough. It is just a suggestion: "Let people in if you feel like it", or words to that effect. That is how certain care homes are regarding it: "It's our choice. It's guidance. We can ignore it if we want to".

Like Ruthie, I have struggled. My mum's care home is one of the good ones and has allowed in essential caregivers. Currently, my mum's home is in lockdown for the second month in a row because of Covid, mainly with carers testing positive and not so much with the home. Unfortunately, on Friday, similar to Ruthie, I noticed that my mum was not well. I raised the issue of whether she was coming to the end of life—blank look. On Saturday morning, I woke her up and she had had a massive stroke overnight.

Because of lockdown and because she was transferred back to the home yesterday, essential caregiver status is now on the edge. Mum is in isolation because of coming back from the hospital, even though she had a PCR test before she left hospital, which was negative. She went into the care home from hospital negative.

Because I wanted and desperately needed to be on this meeting today, because I am so passionate about what is happening, or not happening, in care homes now, I rang the care home and said, "Would you allow my brother to go in to visit my mum today?" It is most definitely about end of life. End of life care says that it does not have to be the last 10 or 15 minutes of somebody's life. It can be up to a year if they are a resident. The care home said no. Any visiting my mum going forward will be on a day-to-day basis.

The Government say that essential caregivers can go in regardless of the lockdown situation, although it is not necessarily unlimited access. With my mum's care home, this is the second month the home has had cases of Covid among carers. Given the isolation from the hospital, my brother cannot go in. As for Lord Henley, one person is the essential caregiver, regardless of any other circumstances around whether you can visit.

My mum has not seen her grandchildren for two years and has barely seen my brother because of the constant lockdowns. There are 90 staff in my mum's home. They are not all on duty at the same time. They are tested regularly, which is fine, as are visitors. There will hardly ever to be a time when at least one carer does not test positive. Seventy-two residents get locked down for 14 to 28 days, whereas if members of the public or even carers test positive in their personal life, they are allowed freedom after seven days if they receive a negative test.

Q4 **David Simmonds:** What both witnesses have said very much resonates with me, because it was a situation that seemed common to quite a few constituents I engaged with. One thing that was common to those situations was that often a relatively junior member of staff in a care home, perhaps the care home manager, was making decisions about what the rules would be, which were not in line with the government guidance, the advice of the local authority or, indeed, the policy of the company of which it was a part. The relatives were really struggling to get past that and to enforce the rights that they and their relatives should have had.

Would it be helpful if there was clarity, in an update of the law or the guidance, that a senior person in a position of control, either of the care home itself or of the company or the local authority of which it is part, had to be accountable for the rules and was clearly identifiable, so that anybody who needed to challenge those rules could identify who made the decisions and go back to them? It seemed to me, from my experience of writing to umpteen different people, trying to help an individual, that having a single point of control who was accountable would have helped at least to do that more quickly for some people.

Ruthie Henshall: Yes, that would help, but what became very obvious to me was that I had no say even over my mother's well-being. Do you know what? I will go second.

Sharon Clay: Thanks, Ruthie.

Ruthie Henshall: Sorry, I will go after you, because I have a couple of things that I am ruminating on.

Sharon Clay: I have been very lucky with my mum's care home. The manager has been open to discussion, as has the overall executive team, partly because they admit that they are scared of me. I am a very strong supporter of Rights for Residents. We bang on doors. We handed in a 270,000-signature petition to government, which was pretty much ignored, but we were there. We have had press coverage in the newspapers. My mum's care home knows that I am not going to go away.

I have often found, when you are raising a complaint or trying to do something, that if you ask somebody to put it in writing with a name that is accountable—mainly by email because we all communicate better on email these days, especially with people working from home—asking for their reasons for not complying with something and explaining to them that you plan to circulate it to your MP and to the health authority, it is surprising how quickly they change their mind on something or become more open to negotiation.

Sometimes having somebody who is accountable in writing enables it to be pursued, but whom do you pursue it with? We go round in circles. Report to CQC, and the CQC says that it cannot do anything. Report to the health authority, and the health authority passes you back to the care home, because all these things are only guidance. The interpretation, again, is the responsibility of the care home. We just keep going round and round in circles, and nobody grabs the case and moves on with it.

Ruthie Henshall: When we went through freedom of information to find out what was going on and how the CQC was overseeing things, we were absolutely shocked when we realised that the CQC was not overseeing things. It had not been sending out people to monitor the homes at all and had no idea how many of these homes were allowing essential caregivers. When you look into it, it is amazing how many people can say, "That's their problem" or "We'll do this". Something is really not being done. Something is so amiss when these beautiful people are dying of loneliness and isolation, because there does not seem to be any one person who is saying, "Right, this is how it has to be done. These are the rules, regardless".

Chair: We move on to the question of mistreatment and neglect in care homes.

Q5 **Baroness Massey of Darwen:** Thank you, Ruthie and Sharon, for your very passionate and moving contributions today. I want to talk specifically about some human rights issues. Several things struck me. We are supposed to have the right to health and life, and to be free from torture and inhuman and degrading treatment. Sharon and Ruthie seem to be saying that the guidance is just a suggestion of what might happen, and that monitoring is scarce or does not seem to exist.

Do you think this is a matter of a lack of time for the people working on the ground? Is it about systems that are not properly imposed or not properly understood? Is it a lack of monitoring? I am curious to know how that impinges on people's human rights. Clearly, some things are amiss and I would like to know what some of the answers might seem to be to you.

Sharon Clay: It is a mixture of everything. Care home staff have not had the time to do a lot of the duties that they have. The CQC goes in and monitors once every two to three years, unless there is a big issue. I do not think that anybody has full capability for anything. It is just a muddle. The carers lack the time. They are hardworking individuals. A lot of the mistreatment, misuse and lack of care is not because they do not care. Most of these carers are the most amazing people. They have been working their socks off, especially during the pandemic, and generally anyway. The shortage of carers is not just because of pay. It is hard work; it is stressful. I know that some of the carers have been shocked at just how badly they are doing their job in one way because they do not have time, and they are leaving the care system because of the stress. They feel as though they are letting the residents down.

I do not want to be rude to the CQC, because I do not know its full remit, but it does not seem to have a handle on things that go wrong either. It cannot investigate individual complaints or issues. It can raise them on its two to three-year visit. I am lucky that, with Mum's nursing home, the CQC inspector is open to having a discussion. Even so, its remit is just too small. Sorry, I have rambled and probably not answered the direct question.

Baroness Massey of Darwen: What do you think the answer is, or is there no answer at the moment?

Ruthie Henshall: The care homes have too much power and are not being monitored properly. This, for me, is one of the huge problems. We seem to have very little say over our loved ones' care. It comes down to the same thing, but I feel that there is no one person. I got passed around an awful lot to different people—the manager, the CQC—who were saying, "Sorry, we can't do anything about that because that's not our job". It seems to me that, when things are not in law, it is all open to interpretation and nobody really knows what we are supposed to be doing. I just wish I knew who had the power, because I thought it was the Government. I thought it was what they said.

Chair: You have both talked about the CQC and the effectiveness or otherwise of complaints mechanism in relation to the care and treatment of people in care homes. Lord Brabazon has a specific question about that.

Q6 **Lord Brabazon of Tara:** Good afternoon. You have referred already to the question of making complaints. Has either of you ever made a complaint to the care home, for example, or to the Care Quality Commission about the issues you have encountered? What are the main barriers to making human rights complaints about care providers, and how could these be overcome?

Sharon Clay: I have made two complaints. Like I said, I have been lucky with mum's care home. They are open to discussion. We lock horns over many things. We generally come to some sort of understanding or satisfactory conclusion. I also complained to the CQC pre pandemic with issues that were raised at a regular family meeting held at the nursing home. A number of issues are raised time and time again, which are normally about showering and bathing, hair washing, quality of food, missed meals—general, everyday things. I complained to the CQC that, "These issues get raised time and time again". I got the response to the effect that it cannot take individual complaints forward and that it would review these issues on its next visit, which is sometimes two to three years away.

As Ruthie and I know from being Rights for Residents campaign members, one particular large care provider is a bigger problem. With many care providers, if you start raising issues or making complaints that they do not like, the next thing is that your loved one has an eviction order or, all of a sudden, the home cannot meet your relative's needs and they have to move. Other Rights for Residents members have noted that this has been an issue with one particular care provider, so they are now frightened to make complaints.

Again, the power has gone back to care homes, because people are too scared to make complaints or they will be evicted. This is where the care disappears from care homes, because it becomes a power struggle and a financial issue. They should not be evicting somebody because you had an issue with your loved one's care. They should be finding a solution, not deciding, "This is too much hassle. We've got somebody else in the queue. Let's get rid of this person".

Ruthie Henshall: In the first year of Covid, the manager in my mother's home changed three times, so it was absolutely impossible to form any kind of relationship with a manager. Whatever I raised, I often heard, "I'll have to get back to you on that". Nobody was in control. They are all individual homes with individual managers. I have found that money will always talk the loudest. They lost a lot of residents in the first wave, so they have literally battened down the hatches and said, "That's it. We have to protect what we have".

We are paying for a service. My mother paid £90,000 in the end, because she had savings, so that all went and then we had to top up in the end. You are paying for a service, but you cannot even get in to check on them. It is absolutely crazy, what is going on.

Q7 **David Simmonds:** This question probably covers a lot of points that have been made, but it is a good opportunity for the committee to consider whether there are any specific final changes that you would like us to look at that would make a difference to human rights in a care setting.

Ruthie Henshall: Where do I start? Most importantly, for me and for people from Rights for Residents, with all the information that we have seen, everything that has been going on and the circumstances, it is essential that a law is passed. We are asking for Gloria's law to be passed. That would mean that every person in care would have an essential caregiver who can come and go, no matter what. We can all see, like when omicron reared its head, that we could just go into lockdown again. Everybody in a care setting suddenly gets their human rights removed: their human right to be touched, to be spoken to, to be loved—just family life. That is completely taken away and the rug is pulled. This will keep happening.

Let us put Covid aside and go down the lane a bit. Who knows what will come along? Are they still going to have no rights? They have no voice. We are their voice, so I will just keep shouting as loudly as I can. This is why, having lost my mother, I am so devastated to still be having this conversation nearly two years on about the rights for residents. Please, I beg you, get this passed in law, so that they can have some rights.

Sharon Clay: If you do not mind, I will only reiterate what Ruthie said, but we are both so passionate about this. The Chair said that she had mentioned visiting rights to the Prime Minister, and he said that he wanted not to have the disease in the homes as it was before by controlling the visiting. The disease should never get back to how it was, because, before, we were sending Covid-ridden patients into care homes. My mum was one of those. She went like a petri dish into a care home, because her own care home would not take her back. She was evicted from the hospital into a care home that was opening its doors for funds. I hope to goodness she did not infect other people. She went into another care home with Covid.

I know that, recently, the Minister for Care said that they have been thinking about essential caregivers. I quote: "I support the spirit of the proposed legislation", which is our call for Gloria's Law, but we must ensure that meaningful visits are facilitated by the providers. However, I do not think the legislation would achieve the intended aim". The intended aim is that we have an essential caregiver, or ideally two, who can visit a loved one. They say that it will not achieve its intended aims. If it is legislated, it would, because the care homes would have to allow the essential caregiver to go in and give care, love, affection and touch. Sorry, but, like I said, Ruthie and I are so passionate about this.

Chair: I hear you, and I suppose what you are saying, Sharon, is that, if it was legislated for and the legislation was not observed by a particular care home, the family, loved ones or friends of a resident would have a legal remedy.

Sharon Clay: Yes, exactly.

Chair: That is what both of you are looking for.

Ruthie Henshall: Yes.

Chair: I and the members of the committee are immensely grateful to you both for coming along this afternoon, giving your time and, in particular, talking about issues that are so close to your hearts and so difficult, I am sure, to talk about. What you have described this afternoon touches on the experience of so many people across the United Kingdom in the last couple of years. Those people will also be very grateful to you for having the courage to share your experiences with us, so I am really grateful for that. I cannot thank you enough.