



# HOUSES OF PARLIAMENT

## Joint Committee on Human Rights

Corrected oral evidence: [The Government's response to Covid-19: human rights implications to long lockdown](#), HC 1004

Wednesday 13 January 2021

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Members present: Ms Harriet Harman (Chair); Lord Brabazon of Tara; Ms Karen Buck; Joanna Cherry; Lord Dubs; Baroness Ludford; Dean Russell; Lord Singh of Wimbledon.

Questions 1-20

Witnesses

[I](#): John, husband of a care home resident; Helen Wildbore, Director, Relatives and Residents Association.

[II](#): Alison, mother of young person detained in an assessment and treatment unit; Matt Clifton, Chief Executive, bemix; Alexis Quinn, Rightful Lives.

[III](#): Sarah Burrows, Founder and Director, Children Heard and Seen.

## Examination of witnesses

John and Helen Wildbore.

Q1 **Chair:** Good afternoon, everybody, and welcome to this session of the Joint Committee on Human Rights. We are taking evidence today in our inquiry. As the name implies, half our members are from the House of Lords and half are MPs from the House of Commons. Our concern is basic, fundamental human rights such as freedom of speech, the right not to be detained wrongfully, the right to a fair trial and the right to be in a democracy.

One of the fundamental human rights is the right to family life. In this inquiry we are looking at both the right not to be wrongfully detained and the right to family life. Within those, we will be looking at three aspects in particular.

I am grateful to those of you who have joined us and will give evidence today about the right to family life. It is always difficult to protect it. It is always difficult for those who have been detained for one reason or another, or are in residential care. The restrictions that have been necessary because of Covid have exacerbated the problem of the undermining of people's right to family life.

None of us wants Covid to go on for one more minute than it has to, or for any more people to be infected. Therefore, we completely understand that restrictions are necessary. None the less, the point is to make those restrictions in a way that can still protect and support people's right not to be detained and their right to family life.

We are looking at three settings. One concerns the right to family life of people, mostly older or disabled people, in residential care homes. That is the subject of our first panel. We are grateful to John, whose wife is a care home resident, who will tell us about his experience, and to Helen Wildbore, director of the Relatives and Residents Association.

We will then move to the second panel. This will look at assessment and treatment units for young people with autism and/or learning disabilities who are detained in residential care. We will hear from Alison, whose daughter is currently in an assessment and treatment unit. We will also hear from Matt Clifton, chief executive of bemix, and Alexis Quinn from Rightful Lives. Thank you all for joining us.

The third panel will look at the rights of children whose mothers are in prison and their right to a family life. We are grateful once again to be helped by Sarah Burrows, director of Children Heard and Seen.

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John, have you been able to visit your wife in her care home during the pandemic? If so, what has the experience been like?

**John:** To set the scene, my wife was diagnosed with early-onset dementia in 2012 and she has been in the nursing home since 2014, just over six years now. I used to go in to see her every day, to feed her and to look after her generally until the pandemic came and the home was shut on 9 March last year. She totally lacks capacity. She does not speak and does not move, so she is quite advanced now.

Initially, there were no visits whatever. Then a bit later on into the early summer, the home put a gazebo up just outside the home where I could see her once a week from two metres for half an hour at a time. That did not particularly work out because, with no cognition whatever, there was no response from her. She would sit there and be asleep or just look into space.

Later on, they started to move indoors when the weather got a bit colder in the autumn. They moved into a space near the reception area. Again, we were still two metres away, so there was no touching. We could not get close. We could not communicate particularly. If I spoke, she would not answer.

More recently, about six or eight weeks ago, the home created a pod with a glass partition between the floor and the ceiling. They would bring my wife into one half of that room and I would sit in the other half, having come in from the outside. Again, I was closer to her, but I could not communicate with her because she did not react to anything. I ended up talking to the carer who remained with us for all those events. None of those were particularly satisfactory and I would say they were of no value to my wife, either. Whether she knew I was there or not in those circumstances I do not know, but it was not a great deal of benefit to me. I could see how she looked and that was about it. They were not meaningful visits. The home probably thought they were doing a good job in trying to create a space that was safe for the home and for the residents and for me. It was, and I do not want to take the virus into the home, either. That is the last thing I would want to do. I do miss the personal contact, which was not possible in any of those situations.

That is where we are now. In fact, they have the virus in the home again, so it is closed altogether at the moment. Two of the carers, I believe, have tested positive, so it is closed for 28 days. We cannot even go into the secure area or see her through a window or anything.

**Chair:** John, I am sorry you have had to experience that, and your

wife as well.

**Q2 Lord Brabazon of Tara:** John, thank you very much for coming in. Do you think your right to family life is being adequately protected for you and your wife during this time?

**John:** No, I would say not. We have been married for 45 years and I promised to look after her in sickness and in health and so on. Not only am I her husband but I have the lasting power of attorney under the DoLS application. I have the RPR. I forget what it stands for now. You know what I mean, don't you?

**Helen Wildbore:** It is Relevant Person's Representative.

**John:** Thank you for that. I cannot get close to my wife and therefore I cannot fulfil any of those roles, so I find it quite difficult. I have to speak on her behalf, because she cannot express a view at all. She does not speak. I had to write her best interests for her, which I wrote as though she were writing it—how we did everything together before and how I had visited regularly up to March and now cannot see her. I do not know what she knows. She would not necessarily know that I have not visited, but if I were close to her, that would be beneficial.

In fact, last October, I got a phone call from the home saying that she was not eating, drinking, swallowing and so on. They thought that she was reaching the end of her life, so I went in to see her. I was allowed to sit with her for those three days—not all day but on each of those days. As a result, it seemed to me that she got better on the following day, not right but she started eating and drinking again.

I was then prevented from going in to see her again, which I was pretty upset about. I wondered how she could be at the end of her life one day and then back to normal the following day. Anyway, I have to do what the home tells me to do. If they will not let me in, they will not let me in. It is quite difficult. With a lot of the views I have raised with the home—I do not know if "disregarded" is the right word, but everything is weighted towards keeping the virus out, and nothing about any individual rights seems to be considered, in my view.

**Lord Brabazon of Tara:** Thank you for that answer. Hopefully, she will be vaccinated soon.

**John:** She has been vaccinated. That is one of my questions or points for later on. She was vaccinated on 31 December 2020. They did that fairly early on. All the residents and staff who agreed to be vaccinated were given the first dose then. It has not made any difference to me visiting.

**Lord Brabazon of Tara:** The vaccine should have gone through its two weeks or whatever it is and you should be able to see her, one would have thought.

**John:** I would have thought so, too, but it does not seem to be working quite like that. I do not know if there has been any guidance issued. That was one of my questions or points for later: whether the vaccine would make any difference to visiting arrangements. I was told by the home that they are waiting for government guidance.

**Lord Brabazon of Tara:** Hopefully, it should make a big difference, because if she has been vaccinated and has gone through the required period of time, she should be able to be visited properly.

**John:** Absolutely. I totally agree with you.

Q3 **Lord Brabazon of Tara:** Thank you. Helen Wildbore, does John's experience reflect what your organisation is hearing about the experiences of other care home residents and their families?

**Helen Wildbore:** Yes. We are now in month 11 of these visiting restrictions in care homes across England. My organisation runs a helpline and we hear of the devastating impact that isolation is having on residents, which is why we started a campaign to end isolation in care.

We warned last autumn about a human rights crisis unfolding in care, with many rights at risk. There is the right to family life that you have identified and which John has talked about. Lifelong partners are being separated, parents are being alienated from their children, people are afraid that they will not meet their grandchildren before they pass away with these restrictions still in place, and memories of relationships are fading.

It is also having a profound impact on people's well-being, which is protected by the right to a private life. Isolation is impeding people's mental health, particularly those living with dementia. It is causing distress and increased confusion. People think that they have been abandoned by their families. Too many people are passing away without the support and love of their families. End-of-life visits are only being allowed at the very end of life, as we have just heard. People have the sudden lack of control over their lives, which makes their homes feel more like institutions. For many, contact over video or behind windows and screens exacerbates their distress. It is not working and is not possible for some people.

For some, the impact has been severe. We have heard about people who have stopped eating, stopped drinking, stopped taking medication or have lost speech. We have heard about people losing the will to live. One helpline caller told us that his wife had starved herself to death. For some, this may cross a threshold to be inhuman and degrading treatment, which is prohibited under Article 3 of the Human Rights Act.

People in care are facing a double isolation—isolation not only externally from their family and friends but within the homes, too. Shared areas might be closed, or residents confined to their rooms after going to medical appointments, for example, or being told throughout the pandemic that they cannot leave the grounds of their home, which is interfering with their right to liberty.

For those on the outside, too, like John and other family members and friends, there is the impact on their mental health and their own well-being, watching as their loved one deteriorates, and we hear of their increased distress, anxiety and depression. Family and friends often act as the voice of or the advocate for residents. They might be on hand to spot problems with that care. They may be the only one who a resident tells about health problems, for example.

We are hearing from many helpline callers who are concerned that care standards have dropped during lockdown, which has been exacerbated by the Care Quality Commission ceasing routine inspections and by social workers and health practitioners staying away. Families tell us that they feel bereft and that the systems in place that are there to protect and safeguard rights are letting them down. They feel that the onus is on them to advocate for rights. They feel that they have nowhere to go with their complaints. Too many of our helpline callers are afraid to speak out and use their legal rights for fear of reprisals, including facing threats of eviction from the home. We need to address that power imbalance for those living in care.

**Q4 Joanna Cherry:** Good afternoon. I am Member of Parliament for Edinburgh South West. The rules are a little bit different in Scotland, but we face the same issues. My heart goes out to John. It is the responsibility of all politicians to try to find a solution to this problem.

John, what needs to happen to ensure that visits can take place safely and that the state can fulfil its obligation to protect the right to family life while also protecting the right to life itself? What steps could the state take to improve the situation for you and your wife, to make a visit possible while still understanding that we are in a pandemic and there is a threat to life? What could be done that has not been done so far?

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**John:** One of the main things could be testing, and the vaccine that is on its way now. I have offered to be tested in the past with the home, but they will not do it for me. I also understand that all the staff in the home are being tested three times a week now, once with the PCR test and twice with the lateral flow tests. I am quite prepared to do that.

When I went in October, I wore the mask, the apron and everything else that they wanted. I had my temperature taken and so on. In my case, I am at home on my own, although I have two sons. Their mother has not seen them or our grandchildren for nine or ten months. Unless the vaccine has a positive impact on visits, the testing certainly could be arranged.

I am part of the ZOE report, and because I reported a sore throat I had a test. I have had two tests and they have both been negative, but they are of no value to the home accepting me in, because by the time the test is taken and I get the result, it could be different; I could be positive by then. They are reluctant to accept anything that would allow me to go in.

I would like to know more about the vaccine, if that is possible, because it is rolling out now. I have not had mine yet, because I am not quite old enough, but the time will come when I have mine. My wife has had only one. Maybe family carers could be regarded as key workers and hence have the same rights as the staff. We are all sensible people at the end of the day and we want what is best for our relative who is in the care home, and what is best for us and for everybody else. We are not going to do anything outrageous. The last thing I would want is to be responsible for taking the virus into the care home and infecting other people, let alone my wife. That certainly could be done.

It could be made legislation rather than guidance. The home always tells me that they are following the Government's guidance. However, a lot of the more recent guidance says that the home should start from the point of allowing visits, but they do not seem to want to follow that. They find all the negative things that would prevent visits, like taking the virus into the home. Although we are told that it is a balanced view, it seems heavily weighted to keep the virus out, with little effort made for family life or the isolation in homes or whatever. In my view, it is not balanced.

I believe that the key worker status, the testing and ultimately the vaccine are the ways forward.

- Q5 **Joanna Cherry:** To follow up on your idea about key worker status, in Ontario, Canada, they have passed emergency legislation to designate people like you essential caregivers. Those designated

family members are given the legal right to act as care homes in the same way as the staff, thereby recognising their vital support role.

If we were to pass essential caregiver legislation similar to that in the United Kingdom, giving people like you the right to go into the home like a paid carer, would that work?

**John:** It should do, as long as it is mandatory for the homes to follow the legislation. If they can still make up their own rules despite that, then, in a way, we are no further forward. In fact, I had heard about the Canadian effort. I thought Scotland was looking to do something similar.

**Joanna Cherry:** Yes, there have been some cross-party discussions about it in Scotland. In fact, somebody asked the First Minister a question about it at lunchtime today.

You are right that it would have to be actual legislation, as it is in Ontario, so that there is a legal right for people like you to be designated essential caregivers and to enter the homes. There is also government guidance. It is across the board in Ontario. Presumably, that would address the issue you have and would enable you to go back to doing pretty much what you did before.

**John:** That is right. One would certainly hope so. I do not just visit and say, "How are you?", and come home again. I give her care and attention.

**Joanna Cherry:** Exactly. You were her carer.

**John:** Yes, absolutely, which I did for her first six years in the home and before she went into the home, as a husband would do.

Q6 **Joanna Cherry:** You mentioned, John, that you are a bit young to be prioritised for the vaccine. Should we introduce a law to ensure that relatives who were previously caregivers, like you, get prioritised for the vaccine so that they can go in to see their relatives?

**John:** I understand that I was recently put into group 6, but I would guess that I am in the group 4 range. Yes, it would certainly bring them up the pecking order if having the vaccine allowed people to go. If it makes no difference, what are we gaining from vaccinating people?

Q7 **Joanna Cherry:** Thanks, John. That was helpful. May I direct the same questions to Helen? What needs to happen to ensure that people like John can visit safely and have their right to family life respected, while at the same time balancing that with the need to protect the right to life for everybody in the care home?

**Helen Wildbore:** As we have seen cases rising across England, protecting people living in care and people working in care from the virus is, of course, of the utmost importance. We have seen almost a year of isolation and of those restrictions. It has created, as I have said, another risk to the well-being of older people living in care.

Care homes need to manage both the risk to residents' well-being from isolation and the risk posed by the virus. They can do that by individual assessment and by granting access to essential visitors who are providing crucial practical and emotional support to ensure that residents' rights are respected—those who are helping with eating, drinking and taking medication, relieving distress, and helping with mental health issues. These essential visitors should have the same safety precautions as staff have with testing, appropriate PPE and access to vaccines, so that they are seen as a vital part of the care team.

We also need more human rights training for care staff, including not only their duties under the law but how they apply those in practice so that they can carry out the necessary balancing of risks to ensure that residents' rights are protected.

We need to remove some of the practical barriers in place to facilitate visiting. We have heard about the problems with providers getting insurance, for example. We have joined the calls for the Government to provide indemnity or to unblock restrictive insurance policies.

Time is of the essence now. The average stay in care homes is just over two years. We are now coming up to a year of these restrictions. People go into care to have not just their physical care needs met but their social and emotional needs, and to enjoy a good quality of life during their final years, not simply to just exist.

Q8 **Joanna Cherry:** What do you think about the legislation I mentioned that has been passed in Canada, which enables family members, like John, to be designated essential caregivers? As I understand it, there was emergency legislation in Ontario on that. Given that time is of the essence here, should we be looking at doing something similar? Then we would have a standardised approach both in law and in guidance across the board.

**Helen Wildbore:** We hear lots of confusion through our helpline about what is permissible at the moment in law and, as John said, coming through care homes. There has been guidance on top of guidance, some of it not very clear. Until recently, the Government's guidance on visiting encouraged blanket approaches

rather than the individual assessments that are so crucial to making sure that people's rights can be respected.

We have seen tons of regulations coming from Parliament, with 65 changes to them since the pandemic started. We have the platform there, we have the tool there, to put something like that into law through those regulations, which are already constantly changing. Legislation would help to show real leadership coming from Parliament, to give the direction that these kinds of visits should be facilitated and to support care homes to abide by their duties under law. As John says, the guidance is only guidance. It is only advisory. The onus in the guidance is very much on care providers themselves to come up with a system and their own policies on how to manage those visits. We need a strong direction from Parliament on this to ensure that care providers meet their duties under law to their residents and their family members and friends.

**Chair:** Thank you very much indeed, John and Helen, for what you have told us. If the Government are committed to a particular approach to the extent that they are prepared to put it into guidance, and if, as your evidence has indicated to us, that guidance has not been universally applied in the way intended, the next step is to go to legislation and put it into law, as Joanna said in relation to the Canadian example. At the moment, Parliament is making itself available to change the law to respond to the Covid situation in quick time. That is certainly something that we could propose, and it is certainly realistic that that could happen.

In relation to the vaccine, after the first four initial priority categories have been gone through, in about mid-February the Government will again look at who they will prioritise for the vaccine, including occupational groups. That would be an opportunity for us to argue for those who are effectively caregivers for people in residential care. At that point, we will have an opportunity. You have given us good evidence that can lead to practical proposals, which are steps that the Government could take and which could make a difference.

Of course, Helen, you are absolutely right: a human rights approach requires not just a blanket approach but looking at each individual and requiring each individual's rights to be respected. Thank you very much indeed.