



Call for evidence Joint Committee on Human Rights 01/11/21

This submission has been made by Jenny Morrison and Diane Mayhew – the Co founders of the Rights for Residents Campaign Group.

Our campaign was set up in September 2020, in response to the cruel and inhumane visiting policies placed on care home residents as part of the Government's response to the Covid 19 pandemic.

Our members are directly affected by the issue and continue to speak on behalf of those in care who's voices cannot be heard.

Nineteen months into the pandemic, many care homes continue to deny residents their human right to a family life. Our petition with over 270,000 signatures is calling on the Government to take urgent action, before more lives are lost through loneliness and isolation:

- Pass legislation "Gloria's Law" that gives every care home resident the legal right to nominate an essential care giver/visitor that can visit in all circumstances, regardless of outbreaks, tier restrictions, lock downs or variants.
- Produce official care home visiting guidance that brings those living in care settings in line with the rest of society who are no longer subject to ANY Covid restrictions.
- Mandate the Government visiting guidance to care homes and introduce clear penalties for those that refuse to implement them.

The evidence submitted is based on feedback from our membership of 11,000 which is made up of those directly affected by policies and decisions made by care providers, Government Ministers and advisors. Our membership consists mainly of relatives of those living in care settings but includes a minority of residents, care managers and care home staff.

How effective are providers at respecting the human rights of people in their care?

Some providers are very effective at respecting the human rights of people in their care. However, far too many treat their residents as if they have no voice or right to make even the most basic choices.

During the pandemic, issues that were already of concern have been magnified.

Contact and relationships

The fundamental right to a family life has been consistently denied by care providers and the Government has failed to provide adequate guidance to safeguard this right. The liberty and freedoms of residents has also been ignored.

Family members are not “just” visitors. No matter how wonderful care staff are, they cannot provide the emotional support that can only come from a family member. From children separated from their parents to young adults and the elderly, their distress has been unimaginable. Care providers are being allowed to control familial relationships, even between husbands and wives.

There has been large scale disregard for the mental health and well being of those living in care settings. We have witnessed the deterioration of our loved ones through windows, screens and pods, powerless to help ease their distress. It’s hard to comprehend that in some instances this is still happening.

Appeals to the Government to force care providers to take a more balanced approach to risk was ignored for too long and many lives were lost as residents gave up the will to live. Although the Government have produced improved guidance that advises care providers to enable visits – rather than restrict – there remains widespread refusal to follow it. The only people facing the consequences of these actions are the residents and their families.

In March 2020, the majority of the public supported extreme lock down measures, as there was insufficient knowledge about - or protection - from the virus. The restrictions were considered an emergency response to an unprecedented situation. Limits to freedoms and the curtailment of rights were then applied to all members of society. Since then, a huge disparity has developed between the way in which restrictions are applied to those living in care and the rest of the population.

In the Summer of 2020, the Government recognised the detrimental effect that lockdown was having on people’s mental health and well being. As a result, restrictions began to ease for those living in the community, while inexplicably, those in care were left behind. This gradual easing continued while the vaccine was rolled out, culminating in the removal of all restrictions in July 2021.

On so called “Freedom Day” the Government rammed home the point that we must ALL learn to live with the virus if we are to enjoy meaningful lives:

“there comes a point when restrictions no longer prevent hospitalisations and deaths, but simply delay the inevitable. And so we have to ask ourselves the question: if not now, when?” (Boris Johnson 19th July 2021)

Despite care home residents being prioritised for the vaccine, it did not bring about the same easing of restrictions or return of lost freedoms for them. We can provide many examples of how the rights and freedoms of residents were and continue to be denied. Like everyone else they should be free to manage their own risks. It’s a question of equality and fairness.

The DHSC have issued clear instructions that care homes must now enable .meaningful visits, yet many continue to impose blanket policies that limit their residents to one 20 or 30 minute visit, by appointment only, every two or three weeks. The Government refuse to make the Guidance legally enforceable and there are no penalties for care homes that refuse to implement it.

When drafting the various editions of the visiting guidance the DHSC and Ministers have consulted with organisations, large charities, the large corporate care groups and their representatives.

Charities such as Age UK and the Alzheimer's Society are deemed the most appropriate stakeholders to speak on behalf of those directly affected by the care home visiting issue. However, their work is focused on supporting those still living in the community and not on those living in residential care.

Residents and their families are not seen by the Government as stakeholders in this process and yet they are the largest group directly impacted by decisions made about visiting access and other aspects of their loved ones care. Including the views of the large corporate care groups, while dismissing the voices of those in their care, has created a power imbalance. This has had a huge detrimental effect on the human rights of those living in care. It has also opened up a divide between residents and their families and care home managers.

Limits to freedom and liberty

Visits inside or outside of the care setting are subject to individual risk assessments. These risk assessments are subjective and conducted solely at the discretion of individual managers and service providers. The concept of risk varies wildly. Some "allow" residents to be taken to family gatherings, indoor venues etc while others flatly deny this. It is left to an individual manager to decide how risky an activity is, and "permission" needs to be sought for any outing, unlike the broader population who can choose where to go, who with and how frequently. The inequality is staggering.

The DHSC Visiting Guidelines have failed to bring those living in care settings in line with the rest of society who are no longer subject to ANY covid restrictions.

Relatives, who are normally the main advocate and champion of the rights of their loved one, in a residential setting, have largely been locked out of their care throughout the pandemic. This has resulted in an erosion of the rights of residents in ways that extend beyond the vital issue of contact:

Dignity

In the absence of regular visits and support from family members or friends, the personal dignity of care home residents has been greatly compromised. Prior to the pandemic, families were the safeguard that ensured issues around dignity were raised and addressed.

In their absence, there has been a decline in the standards of care and in the areas of personal appearance and hygiene etc. Recurring themes reported to Rights for Residents include things such as:

- Residents not being showered or bathed.
- Dirty nails
- Unkempt hair and clothing
- People wearing the clothes of other residents
- Residents not being dressed appropriately for the weather conditions
- An increase in residents being placed on bed rest
- Resident's hair being cut or shaved without consent
- Residents left from morning till night in front of a TV screen. Those without capacity have no way of communicating whether or not they want to watch endless TV or choose what they would like to view.
- Many are left without their false teeth and expected to eat meals.

etc.

Relatives understand their loved one's preferences, likes and dislikes and tolerance of different experiences. They play a vital role in communicating these to the care staff. Where a person lacks capacity, it's crucial that someone with a unique personal relationship and shared history is able to advocate for them within the care setting. This is essential to providing person centred holistic care.

Privacy

Many care providers still refuse to allow a visit to take place in the resident's room, denying them the right to privacy. In some cases, married couples are denied having a personal and private conversation.

We've still hearing instances where visits are supervised by carers, including instances of outdoor garden visits.

How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

Our focus is on visiting rights and the importance of residents having access to family support. As outlined above, this is the key to ensuring many other rights are respected, including the right to a family life.

Rights for Residents have met with the CQC on several occasions and have supplied evidence to highlight the ongoing abuse of the human rights of residents in care settings, with particular regard to the widespread flouting of the Government Visiting Guidance to care Homes.

According to the CQC's website "routine inspections" are still "suspended". In the absence of such scrutiny how can the regulator assess standards of care or monitor how visiting is being supported to happen?

We have provided them with a raft of information that demonstrates shocking disregard of the Government's advice - that care homes must make enabling visits the default position. Some of the largest corporate care companies, that dominate the sector, have consistently been among the worst offenders.

The CQC will only act if the person making the complaint agrees to be named. Yet relatives are often too nervous to name the service when raising issues as they fear the threat of eviction and the CQC is fully aware of this.

The visiting guidance is not enabling all residents to have visits from Essential Care Givers, as many care providers are ignoring it completely. In some cases, when relatives/residents persistently challenge a care home's refusal to allow this, they are threatened with eviction. This is a typical response from a care home to a relative challenging the refusal of ECG:

"Regrettably, as you will be aware from the numerous conversations you have had with our Manager and staff, we have for some time now, struggled to gain your confidence and build a good relationship with you. This issue has been raised with us again recently by a conversation with your Mother's GP.

It is of the utmost importance to us that families are happy with their loved ones being in our care. I have spoken with the manager of our home, who has now informed the social worker,

that in our opinion the time has come for your mother to find an alternative placement as the relationship between us lacks the necessary trust.

We will do everything possible to assist your mother's move and will not require the normal notice period"

This is not an isolated example, we can provide many more. Moving a resident can be extremely damaging, particularly if they have Dementia, learning disabilities or other cognitive impairments. The change in routine or environment can have devastating effects on their mental health and well being – as we know from our own personal experience.

If visiting was being facilitated in line with Government guidelines – it would be unnecessary for relatives to make an official complaint to the CQC. Citizens in our country should not have to make an official complaint before “permission” may be granted to visit a vulnerable child, spouse, elderly parent or sibling.

The regulator claims it is taking action to ensure compliance with guidance while failing to produce data to support this.

The CQC refer to figures published by the DHSC that show 92.6% of care homes were enabling visits at the end of September. However, these figures are based on care homes own responses to the DHSC Capacity Tracker.

As care homes can choose whether or not to respond to this request for information, it seems a completely unreliable way to establish an accurate picture.

When care homes reply that they are enabling ‘visits’, there is no way to establish the quality of those visits. The Rights for Residents survey, which was also undertaken in September, showed that residents are still subject to inhumane visiting restrictions:

- 24% of non ECG visits are Monday to Friday and daytime only. These restrictions prevent those working from visiting their loved one unless they take annual leave.
- 31% of visits are still restricted to 30minutes and 28% to an hour only.
- 12% of residents were limited to outside visits only
- 4% were still subject to visiting behind a window

The only way to gather accurate data is by speaking to the residents and relatives who are still subject to these harsh visiting restrictions. Without this, the extent of the restrictions on the freedoms, rights and liberties of residents will remain unclear.

In a recent survey of 750 of our 11,000 members, 22% of requests for residents to have an Essential Care Giver were refused. The Government must take urgent action to address the fact that approximately a quarter of residents are being denied what their own guidance stipulates as “essential”.

It's worth noting that the true figures of those being denied ECG status will be much higher - as respondents to the survey were limited to our own group. The vast majority of our members are well informed about the Essential Care Giver but report that they are often the only ECG in their care home. Residents and relatives are largely unaware that they can nominate themselves and there is no requirement for care operators to proactively offer this “essential” opportunity to all of their residents.

What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in the future?

Existing equality and human rights legislation has failed to protect the most vulnerable in our society during the pandemic. This has led to a shocking erosion of their rights and freedoms.

The Government must identify more robust mechanisms to ensure that care providers operate within the legal framework and bring forth new legislation to protect those whose voices are currently not being heard.

The right to life has been focused almost solely on protecting people from the risks posed by the virus, to the exclusion of other risks to life. The damage to people's mental health and well being has caused many to give up the will to live. In response to the prolonged loneliness and isolation, residents have stopped eating and drinking, speaking, walking etc, and yet Ministers and their advisors from Public Health England, continue to ignore these risks.

We must find more balanced solutions to protecting residents from harm, while recognising that the quality of life is just as important as the quantity. This is even more salient as many residents are at the end of life.

The Government need to end the disparity that currently exists between the rights of those living in care and the wider population. Why should care home residents pay the price for everyone else's freedom?

Ministers need to include residents and their families, as stakeholders during the process of drafting legislation, policies and guidance that directly affects them. Currently some residents are paying handsome fees for the privilege of their own imprisonment, while their voices go unheard.

In order to demonstrate the extreme visiting policies being imposed on some residents we've shared below an extract, from a letter that was sent to one of our members, who asked to be nominated as an Essential Care Giver. The only requirement of an ECG is to provide well being support and "companionship". Yet, we are hearing of more unreasonable and unnecessary requirements being placed on relatives which are not outlined in the Government guidance to care homes:

How do I become an Essential Caregiver?

*"While the process is simple, it does involve some ongoing work. You'll need to take part in our regular testing scheme, which includes weekly PCR testing and twice-weekly lateral flow testing, carried out across our homes. **We need an up to date DBS check** and we can arrange this for you if you bring in copies of your ID documents. All essential care givers must be able to show evidence of being double vaccinated.*

*There'll be some infection prevention and control education, including the watching of our 'donning and doffing of PPE' videos, which will be made available to you when you come to visit. **There's some other essential training that we need you to complete on fire safety, health and safety, coronavirus and moving and handling.** It is also necessary to agree the days and times for your support visit to help us manage the amount of people within the home. Together we can ensure that all our residents have an equal opportunity to see their loved ones".*