



**FAO: Gillian Keegan**

**Minister for Care**

**Department of Health and Social Care**

Your Ref: DE-1363182 / Response to the Rights for Residents petition delivery

As you are aware, the Rights for Residents campaign delivered a petition to Downing Street in September with over 270,000 signatures. We have now received a response from your Department stating that you do not intend to ensure residents have the legal right to visits from their loved ones.

The answers to our concerns do not address the actuality of what is happening on the ground. We have outlined in detail below, our objections to the statements made in your response and we trust you will grant the 400,000 residents living in care and their families the courtesy of responding with more empathy, given that many continue to end their lives in isolation.

**DHSC: The care home visiting guidance enables all residents to have visits from essential care givers – loved ones who are able to provide personal support and companionship – in all circumstances, regardless of outbreaks.**

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"*

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. This is not an isolated example, we can provide many more.

The threat of eviction is real and your failure to address issues around visiting rights and access, allows this appalling behaviour to continue. Residents and their families are living with this constant threat, simply for challenging the refusal of a care home to “allow” them to act as an essential part of their loved one’s care.

The CQC are not monitoring ECG compliance, but Rights for Residents are. We can confirm there is widespread flouting of this aspect of the guidance, which continues to have catastrophic effects on the lives of those living in care settings. After being locked away since March 2020, it’s little wonder many are experiencing severe trauma, due to the prolonged separation and isolation.

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 role and we support them in their attempts to achieve this status. However, they often report that they are 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. The CQC recently informed the Daily Express that the DHSC are responsible for collating official data on Essential Care Givers. Could you please make this data available to Rights for Residents, to share with our members?

Our survey also found that of those homes accepting Essential Care Givers, 12% are halting visits during an outbreak – again a breach of Government guidance that deprives residents of the family support and contact that the DHSC has deemed “essential” to their health and well being. During this time, residents are not just isolated from their family members but from each other too. Many are confined to their own small rooms for a minimum of 14 days. Where rolling outbreaks occur, this can extend to 42 days. This is simply unacceptable.

It’s been widely reported that care homes are short staffed and paid carers don’t have time to spend providing companionship, leaving many residents lonely and confused. This is just one of the reasons why it is crucial for the Government to ensure all residents are **guaranteed** the support of an ECG.

Residents continue to tell their families they would rather die than carry on “existing”. Relatives are also plagued by feelings of guilt. They find themselves wishing their loved one would pass away, rather than continue to decline, often in a state of anxiety and distress, while they’re unable to comfort them. Many residents are living the last years, months and weeks of their lives – how can this be acceptable?

Our petition now has 271,000 signatures calling for “Gloria’s Law” and residents, families and their supporters expected a more thoughtful and empathetic response from the DHSC. In your own official care home visiting guidance, you stress the importance of complying with the Human Rights and Equality Acts. Currently, decisions are not always being taken in light of these legal obligations. There is a mass of evidence from Rights for Residents, the Joint Parliamentary Committee on Human Rights and other charities and groups to demonstrate this. Residents and their families deserve an explanation of what steps are being taken to ensure care companies operate within the legal framework.

Such defiance of official Government guidance would not be tolerated within any other industry. The only way to ensure compliance, prevent evictions and further deaths from loneliness and isolation is to enshrine in law their right to have the support to an essential family visitor.

**DHSC: The DHSC does not currently plan to legislate visiting. There are 15,000 care homes across England and each is different in terms of how it can safely facilitate visiting due to size, layout and the individuality of its residents.**

The statement above fails to take account of the fact that in order to protect the human rights of residents, adjustments can and should be made. For example, hospital settings also vary widely and are full of clinically vulnerable patients. Yet, they have managed visiting throughout the pandemic. Limited visiting is enabled - even for patients on communal wards. How is it that care homes are unable to use infection prevention and control procedures in a similar way to ensure every resident has an ECG? Relatives are not asking to go into communal areas, they simply want to spend time in the room of their own loved one, making the risks minimal.

Visitors are subject to LFT tests, PCR tests and follow infection control measures. In addition, the majority of residents and relatives have been fully vaccinated. There is no risk-free solution, nor are there any further mitigating measures anyone can take. The DHSC Guidelines stipulate that care providers should balance a variety of risks but that's not happening across the board. The Government are allowing holiday makers to rely on LFT tests, when returning from abroad, which comes with huge risks for all of us. How can the freedom of holiday makers be given priority over the freedoms and human rights of the most vulnerable in our society?

The Health Minister, Sajid Javid, has announced there could be up to 100,000 Covid cases per day as Winter approaches. Care home staff are free to go on holiday, to pubs, clubs, cinemas, festivals, large events, football matches, family celebrations etc and then provide personal care to our loved ones. These are all high-risk activities but as ever, relatives are seen as the only potential source of infection. Married couples are still prevented from spending time together alone in their own room and mothers and fathers continue to be separated from their children etc. Why should those living in care pay the price for everyone else's freedom?

Many residents are at the end of their life or have life limiting conditions and the pandemic has already robbed them of precious time they don't have. The Government must intervene to end the postcode lottery, in which some care companies follow official guidance while others choose to disregard this. If you fail to support the call for legal change, thousands more vulnerable residents will spend their final months alone. While those in the community enjoy the festive celebrations with their families, many care home residents will once again spend Christmas without any of the joy this special time of year should bring.

**DHSC: The DHSC are regularly reviewing care home visiting data to ensure that care providers are facilitating visiting according to guidance.**

The Care Minister claims the latest statistics show 92.6% of care homes were enabling visits at the end of September. Can you confirm that these figures are based on care homes own responses to the DHSC Capacity Tracker? If so, how can these results reflect a true picture, when care homes can choose not to provide a response?

When care homes reply that they are enabling 'visits', what mechanism is being used 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 harsh visiting restrictions. The DHSC and the CQC have a responsibility to provide more accurate data that includes these experiences.

Even your own figures show that 7.4% **of those care homes responding** are not enabling visits. That figure, as a proportion of the 15,000 care homes is truly shocking.

Given clear evidence that in many cases, visits are not happening in line with Government Guidelines, your ongoing public statements that they “should” be happening offers no reassurance to the residents or their families who are being denied visits:

*“Our message is clear, all care home residents should be supported to get the care and companionship they need, as this is essential to their health and well being”.*

(DHSC statement to Granada TV News 02/11/21)

Instead of making statements that residents “**should** be supported to get the care and companionship they need” you should be taking urgent action to ensure residents **are** getting this vital support.

**DHSC: Throughout the pandemic DHSC has balanced the need to keep care home residents safe from infection, whilst extending visiting opportunities.**

Protecting people’s “right to life” has been almost solely focused 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, during periods of separation, has not been deemed a priority and yet many residents have simply given up the will to live. In response to the prolonged loneliness and isolation, residents have stopped eating and drinking, speaking, walking and are in a constant state of distress, wondering why they have been abandoned by those they love. Many residents lack the capacity to understand why their family members have stopped supporting them.

Public Health England and the DHSC continue to ignore these risks. Increasingly, we are getting reports that Local Public Health Directors are once again advising care homes to stop all visits, including ECG visits, both during an outbreak and also when cases rise in the community. This advice is completely at odds with the official visiting guidance and is going unchallenged.

As care homes continue to ignore your guidance, how can the DHSC ensure that the physical and mental well-being of residents is protected?

**DHSC: The CQC has provided mechanisms for people to feedback on visiting concerns and responds to all complaints made, as long as the name of the service is provided.**

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.

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. No outcome has been forthcoming.

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

If visiting was being facilitated in line with Government guidelines there would be no need for relatives to make an official complaint to the CQC. Citizens in our country should not have to make an official complaint simply to visit a loved one.

**DHSC: The CQC continues to seek assurances from care home providers about how they are supporting visiting to happen and it verifies this when it goes out and inspects. It has a mandatory question on each of our care home inspections which looks at how visiting is being supported to happen in a safe way.**

According to the CQC's website "routine inspections" are still "suspended". In the absence of such scrutiny how can the DHSC confidently claim that the regulator is monitoring how visiting is being supported to happen?

The CQC say they are taking action to ensure compliance with guidance, while failing to produce robust data to support this. It is essential that the CQC verify the information they receive from care providers with residents and relatives to provide some accurate statistics.

**DHSC: The success of the vaccine roll-out controlling infection levels in care homes has meant that residents can now undertake more visits out and receive more visitors in the care home. Visits out could include all of the things that are available to the broader population, subject to an individual risk assessment.**

The notion that residents can currently participate in all of the things that are available to the broader population is ludicrous.

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 between services. 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 disparity is significant and the inequality is staggering.

During the Summer, many of the increased visiting opportunities you refer to, took place outdoors – in the gardens of care homes. Inexplicably some of these were even supervised by care staff. In many cases, these were a substitute for indoor visits, which were not permitted at all. In any case, the opportunity for visits outside will now stop as it is too risky for vulnerable residents to be outside in bad weather.

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 have also been ignored. Being prioritised for the vaccine has not brought about the same easing of restrictions or return of lost freedoms currently being enjoyed by the wider population.

Care providers are still being allowed to control familial relationships, even between husbands and wives. Some 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 prevented from having a personal conversation.

**DHSC: Individuals living in care homes are typically more vulnerable to severe illness as a result of Covid 19. Whilst vaccination is proving very effective at reducing the risk of severe illness and hospitalisation, DHSC is still seeing some cases of the virus and severe illness as a result, among care home residents who have been vaccinated.**

The DHSC are also still seeing some cases of the virus and severe illness among vulnerable people living in the community, who have been fully vaccinated, but their freedoms have not been restricted in the same way. Either we accept a level of risk for everyone, or we take a zero tolerance approach that should apply equally across society.

Why doesn’t the Government’s message, that we have to learn to live with Covid, extend to those living in care settings? Clinically vulnerable people living in society are not subject to harsh restrictions and are not reduced to pleading and protesting in order to see those they hold most dear. This is blatant discrimination and is impossible to justify.

Not only have residents been fully vaccinated, they’re now being prioritised for booster jabs. Most relatives have also been fully vaccinated and take LFT or PCR tests. As there are no further precautions we can take and the virus shows no sign of abating, are Ministers and the DHSC suggesting that care providers be allowed to continue controlling the level of contact between residents and their families forever?

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 stakeholders to speak on behalf of those directly affected by the care home visiting issue. 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 as stakeholders in this process and yet they are the largest group directly impacted by decisions made about visiting access. Including the views of the large corporate care groups, while dismissing the voices of those in their care, has created a huge power imbalance. It has also opened up a divide between residents and their families and care home managers.

No wonder there is a growing reluctance to place loved ones in care, as currently many residents are paying a handsome fee for their own confinement.

Residents and their families expect to be included in the process of policy making around visiting and access but feel their views have been ignored. Going forward, we urge you to make the process of drafting guidance inclusive and fair. All stakeholders should be fully involved in this process. Currently we have a Samson and Goliath situation, with residents and relatives at the mercy of the arbitrary decisions of care operators.

In order to demonstrate the extreme visiting policies being imposed on some residents we have attached a letter that was sent to one of our members, who asked to be nominated as an Essential Care Giver. In the official guidance, the only requirement for a relative wanting to become an ECG is the ability 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 DHSC guidance to care homes.

In the first instance, we would be grateful if you could respond to each of the points we have raised above, in full, as opposed to sending a stock response that would fail to address people's genuine concerns.

In addition, we would welcome the opportunity to meet with you to discuss the issues in more detail.

We hope to hear from you very soon, in order to arrange a convenient meeting time.

Your sincerely

Diane Mayhew and Jenny Morrison

Co founders of the Rights for Residents Campaign

