



The Relatives & Residents Association

Unit 6, Aztec Row
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10 January 2023

Reference: M2/R9R/RA/TJS

Dear Tim Suter,

Thank you for your letter dated 4 November 2022 via Leigh Day. As you will know, we were applying for core participant status for module 2 and were awaiting the outcome of that application before replying to your letter. As our application has been rejected, I understand that you need a response to your letter by 10 January 2023. I have put together as much information as I can in the time, but I'd be happy to follow up or provide further information as required.

R&RA and our beneficiaries

The Relatives & Residents Association (R&RA) is the national charity for older people needing care and the relatives and friends who help them cope. R&RA was established in 1992 in recognition that many older people in need of care are unable to advocate for themselves and rely on the support of relatives and friends.

R&RA provides information, advice and support to empower older people and their families/friends across England. We use their unique perspective to raise awareness and to influence policy and practice.

Throughout the pandemic, R&RA's Helpline has been supporting older people and their families at the sharp end of the pandemic, giving us a unique insight into the experiences of families dealing with coronavirus and measures taken to manage it.

Consideration of older people needing care

R&RA were not involved in discussions with the Government about their response to the pandemic until July 2021 when we were invited to join the COVID Adult Social Care Working Group of Stakeholders at the Department of Health and Social Care (DHSC).

Given the poor decision-making by the Government and their mismanagement of the pandemic, we can only conclude that older people needing care were not adequately considered when decisions about the response to Covid-19 were made. During the early stages, the lives and wellbeing of people in care were put at risk by the Government's neglect of the care sector. The Government then swung dramatically to the other extreme, imposing severe restrictions on movements in and out of care settings, with a devastating impact on lives and wellbeing. We expand on these concerns in the next section.

Lessons to be learned

Below we summarise some of the key lessons that can be learned from the Government's management of the pandemic.

A better understanding of the care sector is needed at the top of government

The response of the Government and its agencies demonstrated a basic lack of understanding about the vulnerability of the care sector. This includes its role, the structure and shortcomings of the workforce, the fragmentation of the system, and the fragility of the sector. There was a failure by

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key agencies to step in or speak out to prevent the crisis unfolding in the care sector, including the Care Quality Commission (CQC).

Focus on people, not institutions

In the early stages of the pandemic the Government (and its agencies) failed to recognise the risk of the virus to people using care and staff. For example, Public Health England (PHE) guidance stated, as late as 25 February 2020, that it was “very unlikely” people receiving care would become infected. Government policies to ‘protect the NHS’ put the lives of older people needing care, and those caring for them, at far greater risk, particularly the discharge of patients from hospital without testing. Responses must identify and focus on the people most at risk and where they are/will need to receive support. This would have helped to avoid care services being an afterthought and care staff not receiving the support they needed to protect people most at risk from the virus.

Responses to crises must be compliant with basic legal rights

The Government’s response to the pandemic has put the lives and wellbeing of people in care at risk throughout (from neglect of the sector in the early stages, through to imposition of severe restrictions on movements in and out of care settings). The response demonstrates a lack of understanding about the legal responsibilities on the Government and its agencies (including PHE/UKHSA and CQC) to protect not just wellbeing from the virus but to ensure that measures imposed to manage the virus do not breach other fundamental rights, including to liberty, autonomy, family life and (wider) wellbeing. Policies must recognise that people needing care have the same legal rights as everyone else and should not be discriminated against or left behind during a crisis or the recovery.

We need better systems to protect the rights of people needing care

Legal duties to protect rights have been too easily ignored by the Government and its agencies. We need a better system of alert and accountability when human rights breaches occur, and strategic action to recognise and act upon systemic human rights risks to ensure older people are not discriminated against. Safe access to care settings must be maintained for safeguarding teams, inspectors, social workers, health practitioners, and other professionals, to allow them to spot and raise issues.

Close the oversight gap

There has been an alarming lack of oversight of the impact of Government guidance on visiting in care settings. The CQC ceased routine inspections and have failed to proactively monitor compliance with the visiting guidance. With no such monitoring mechanism in place, the Government simply cannot know whether and how care settings are implementing the guidance, the impact this is having on residents and how many are being unlawfully denied their rights. This gap in oversight must be urgently filled, now and for the future.

People needing care should not be isolated from family carers

Isolation from family and friends has caused serious harm to people’s mental and physical health. Our helpline heard of people who stopped eating or drinking, lost speech, thought their relatives had ‘abandoned’ them or passed away, and ‘lost the will to live’. Never again should people needing care be isolated from the vital support of their family carers. The Government should introduce a new legal right to a Care Supporter to ensure the support of relatives/friends is recognised as a basic component of good care, with the same infection prevention and control precautions in place as staff.

Lives must not be devalued

The response to the pandemic has at times been discriminatory and devalued the lives of older people. This includes the Government’s initial failure to include known mortality figures of care users in the daily count, inappropriate use of Do Not Resuscitate decisions, inaccurate death

certification, and decisions about access to healthcare raising fears that the process of prioritising health services was being based on non-clinical factors such as age or disability.

Ensure services supporting people at risk are adequately protected

Care staff were left without the basic tools to protect those most at risk from the virus. From the outset, central government policy should have arranged for the supply and payment of PPE and regular testing for all care staff, users and visitors as a basic principle of effective infection control. This would have helped avoid problems with quality and distribution, as well as the damaging turf battles over supply.

Close the gap in support for older people needing care

When people living in care face problems with that care, too many are afraid to speak out or report it to the regulator due to fear of reprisals (including, ultimately, eviction). The decision to suspend LGO casework that required action by local authorities or care providers effectively halted the complaints process. The decision to give powers to local authorities to 'ease' some key duties under the Care Act left people uncertain about their legal rights at a critical period. There must be appropriate oversight by the regulator and a viable, central complaints mechanism to ensure the rights of people relying on care services are protected.

Better support for care workers

Whilst COVID-19 has created unprecedented challenges, the pandemic has also exposed or exacerbated many pre-existing problems. It has placed strains on a sector consistently overlooked and neglected by the government. Care workers have not been able to respect the rights of people needing care, without adequate equipment, testing, training and wage security for this already fragile workforce. The status of care workers needs to be aligned with staff within the NHS so that adequate sick pay is provided, the provision of free PPE is protected and they are recognised as keyworkers. Longer-term reform is needed by the Government to ensure care workers have the training, skills, career progression and specialist support to deliver this vital frontline service, and to ensure it is appropriately staffed, regulated and funded.

Articles and reports published

- Written evidence to Joint Committee on Human Rights inquiry on human rights implications of Gov response to COVID, July 2020: <https://www.relres.org/human-rights-covid-inquiry/>
- Written evidence to APPG on Coronavirus on Gov response to pandemic, October 2020: <https://www.relres.org/appg-coronavirus-report/>
- Joint statement on reuniting residents of care homes with their relatives and friends with Age UK, the National Care Forum, the Registered Nursing Homes Association, John's Campaign and Rights For Residents, February 2021: <https://www.relres.org/joint-call-visiting/>
- Visiting and the Law, a guide for care providers to ensure their use of Government guidance was compliant with their legal duties, June 2021 and updated throughout the pandemic: <https://www.relres.org/visiting-guide-providers/>
- Written evidence to the Joint Committee on Human Rights inquiry on human rights in care settings, outlining the harm caused by COVID restrictions, September 2021: <https://www.relres.org/rights-at-risk/>
- Published a call for new right to maintain contact in health and care with John's Campaign and Rights For Residents, April 2022: <https://www.relres.org/care-supporter/>
- Extensive summaries and explainers of Government guidance, supporting families to understand and use legal rights to challenge restrictions, throughout pandemic

Oral evidence to Parliament

R&RA was invited to give oral evidence to:

- the APPG on Coronavirus, August 2020: <https://www.relres.org/evidence-covid-inquiry/>
- the APPG on Coronavirus, October 2020

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- the Joint Committee on Human Rights for their inquiry on visiting in care settings, January 2021: <https://www.parliamentlive.tv/Event/Index/b992425e-7551-47ab-8a25-17c4dfd87e5>
- the APPG on Ageing and Older People about the Government's neglect of the care sector during the pandemic undermining the rights of older people, July 2021: <https://www.relres.org/evidence-appg/>
- the Joint Committee on Human Rights for their inquiry on human rights in care settings during the pandemic and beyond, January 2022: <https://www.parliamentlive.tv/Event/Index/b8f46013-11a6-43e2-99a9-d0e8f6713507>

Correspondence with Government/agencies

- Letter exchange with CQC expressing disappointment with their role during the pandemic and calling for them to take a proactive role in ending the harm caused by COVID restrictions, included an appendix of evidence from our helpline about the harm, May 2020, May 2021, May 2022 and August 2022: <http://www.relres.org/letter-cqc/>; <https://www.relres.org/letter-cqc-2021/> and <https://www.relres.org/letter-cqc-guidance/>
- Joint letter to the Prime Minister urging the roadmap out of lockdown to include reopening of visits by essential caregivers, which led to a change in policy, February 2021: <https://www.relres.org/prime-minister-isolation/>
- Letter to the Prime Minister urging the opening of the public inquiry, which led to a letter exchange with the Care Minister about this, August 2021: <https://www.relres.org/letter-to-pm-inquiry/>
- Joint letter to local health and care leaders on harm caused by COVID restrictions, calling for end to isolation and for legal duties to be met, in collaboration with leading care organisations, January 2022 and September 2022: <https://www.relres.org/letter-isolation/> and <https://www.relres.org/letter-isolation-2/>
- Supported joint letter to Secretary of State for Health and Social Care from over 60 MPs calling for right to maintain contact across health and care settings, May 2022: <https://www.relres.org/mp-letter-care-supporter/>

Lobbying

- Met regularly with CQC to raise concerns about their inaction during the pandemic to ensure the rights of people needing care were protected, including in quarterly I-I meetings and in quarterly meetings of sector leaders
- Invited to join the COVID Adult Social Care Working Group of Stakeholders at DHSC, July 2021. Membership led to regular meetings with DHSC civil servants and other agencies (such as PHE/UKHSA), being consulted on policy changes and updates to the guidance. R&RA played an active and significant role in these meetings, including:
 - Submitting evidence from the R&RA helpline about the impact of Government guidance on visiting, August 2021 and February 2022
 - I-I meetings with DHSC civil servants on the guidance and its impact, July 2021, September 2021 and November 2021
 - Significant improvements achieved to COVID guidance on visiting as a result of R&RA suggested amendments, November 2021, March 2022 and July 2022
 - Drafted and submitted a suggested rewrite of the visiting guidance to DHSC, supported by Care England, NCF, NCA, ARC and the Alzheimer's Society, February 2022 (not taken up by DHSC)
 - Requested DHSC share clinical evidence of the impact of COVID restrictions, in two meetings in February 2022, a meeting in March 2022 and twice by email (which didn't materialise)
- Began a joint campaign for a change in law to end the harm of COVID restrictions, with Rights For Residents and John's Campaign, Jan 2022 to present
- Met with Care Minister to discuss harm of pandemic restrictions, February 2022

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- Tabled Parliamentary Questions about evidence of harm of isolation in care, March 2022
- Organised event in Parliament calling for an end to the harm of COVID restrictions and a new legal right to maintain contact across health and care settings, attended by the Care Minister, with John's Campaign and Rights For Residents, March 2022:
<https://www.relres.org/parliament-care-supporter/>

I hope this information is helpful and has answered the points in your letter. Please let me know if we can be of further assistance at this stage.

Kind regards,
Helen

Helen Wildbore
Director