

Written evidence from Relatives & Residents Association (COV0210)

R&RA

The Relatives & Residents Association (R&RA) champions the rights of older people needing care in England. We provide information, advice and support to empower older people and their families/friends, and use their unique perspective to raise awareness and to influence policy and practice.

The R&RA Helpline has been supporting people 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.

Introduction

We welcome the opportunity to express our concern and disappointment at the extent to which human rights have been undermined by the Government's mismanagement of the pandemic. Action was taken too late to protect those known to be most at risk, the basic tools to manage the virus were not provided for the sector (such as testing and PPE), guidance was inadequate and late, and the focus on protecting the NHS led to policies which were harmful to those receiving and delivering care. As a result, COVID-19 has had a devastating impact in care settings.

What steps need to be taken to ensure that measures taken by the Government to address the COVID-19 pandemic are human rights compliant?

1. Family life and mental well-being

When lockdown measures were introduced, R&RA called for older people to be supported to stay connected to their families. Where people were at the end of life or in distress due to dementia or other conditions, steps should have been taken to facilitate personal contact where possible.

Human rights concerns:

- Government guidance advised against visiting care homes in England except in end of life situations, out of sync with hospital visiting and Scottish Government guidance for care homes which also permitted visits for those with a mental health issue.
- The R&RA Helpline received an influx of calls from family members concerned about how their relative would cope without their regular emotional and practical support.
- Many families are unable to maintain contact via other means (such as phone/video) either due to lack of support to facilitate contact, communication difficulties, or dementia/other conditions making such contact unfeasible.
- Some residents were/remain isolated within care homes (confined to their rooms, communal areas closed), with staff interaction minimised, particularly impacting those without family/friends who lack external contact.
- Isolation is having a devastating impact on mental well-being. We hear of people who have stopped eating or drinking, lost speech, think their relatives have 'abandoned' them or passed away, and have 'lost the will to live'. A high percentage of calls to the R&RA Helpline involved concerns about mental health during this period.

"After four weeks of no contact with dad or the care home, as a family we were extremely worried about his mental and physical well-being" Anonymous helpline caller

- Government guidance on visiting care homes was withdrawn on 19 June and to date hasn't been replaced with revised guidance. A month's absence of guidance so critical to protecting people's human rights is unacceptable and one example of the Government's neglect of the care sector during this pandemic.
- In the absence of guidance, we hear a huge diversity of practice on outdoor/window visits, including blanket bans, time limits (which can be distressing for people affected by

dementia), chaperones/monitoring by staff (interfering with people's right to privacy) and residents prevented from leaving care homes.

"I've only spoken to mum 3 or 4 times since March – the time limit the home put on window visiting makes that too distressing due to her dementia, and communication via telephone has been difficult for her. I worry how she's coping without me." Anonymous helpline caller, July

Action needed:

- The Government urgently needs to produce a strategy for safely unlocking care homes. It should set out where urgent action is needed to protect people whose human rights are at risk, via individual needs and risk assessments.
- A renewed focus on mental health is needed to attempt to reverse the impact of months of isolation, including access to specialist support.
- Sharing of good practice by care homes in helping families stay connected.

2. Safety and physical well-being

As Government polices to manage the pandemic unfolded, R&RA called for adequate resources and staff levels across the sector. We highlighted that care workers would not be able to respect the rights of care users without adequate equipment, testing, better support and wage security for this already fragile workforce.

Human rights concerns:

- Our helpline callers have been extremely concerned about lack of PPE and regular testing, putting care users and staff at risk.
- Lack of sick pay meant care workers were forced to choose between the safety of care users/colleagues and their own financial stability, with resultant increased infection rates.
- Lack of timely guidance on managing staff shortages, on reducing staff movement between and within care homes as well as in domiciliary care, and on use of agency staff led to care staff spreading the virus within and between different settings.

Action needed:

- The public health budget must supply and pay for PPE and regular testing of all care staff, users and visitors as a basic principle of effective infection control.

"We successfully challenged an invoice from the care home for 'additional Covid-19 costs', with the help of R&RA. It is unfair that people have paid the extra charge, who may be elderly and vulnerable, and may not have felt capable of challenging it." Anonymous helpline caller

- An effective test, trace, isolate system is fundamental to controlling future outbreaks.
- All care staff should receive full pay if they have to self-isolate or go off sick.
- Care staff should receive training and share best practice on communication skills from a distance, behind PPE.
- Longer-term reform is needed 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.

What will the impact of specific measures taken by Government to address the COVID-19 pandemic be on human rights in the UK?

3. Safety and dignity: care standards

As lockdown took effect, R&RA called for care services to be supported to ensure care standards do not fall to unsafe or undignified levels.

Human rights concerns:

- Stopping visits from family/friends restricted their ability to provide oversight, voice and advocacy. This coincided with the relaxing of other safeguards and oversight.
- Ceasing CQC routine inspections left our helpline callers concerned about lack of oversight (in contrast, the Scottish Care Inspectorate resumed inspections and began reporting fortnightly to Parliament).
- Suspension of LGO casework that required action by local authorities or care providers effectively halted the complaints process.
- Powers for local authorities to ‘ease’ some key duties under the Care Act left people uncertain about their legal rights at a critical period.

“I am worried that standards of care are slipping even more during this crisis and mum’s human rights are being eroded. Her care home is short staffed and the care workers are burnt out.”
Anonymous helpline caller

Action needed:

- We urged CQC to reconsider its approach, to identify where urgent oversight, intervention or professional support is needed, prioritising settings with a history of serious breaches of the Regulations, without a manager, with a high staff turnover, not inspected for three or more years, and with users with no friends/family to provide oversight.
- A Government strategy on opening care homes should encourage care providers to facilitate private contact between residents and their family/friends/advocates.
- As these vital safeguards are reinstated there is likely to be a backlog of Regulation breaches/casework which may require additional resource to process.

Which groups will be disproportionately affected by measures taken by the Government to address the COVID-19 pandemic?

4. Life and well-being of older people needing care

There have been failures to protect the right to life (Article 2 of the Human Rights Act) and well-being (Articles 3 and 8) of older people needing care.

Human rights concerns:

- 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.
- Care services were an afterthought, with the Government’s social care action plan coming too late (after the peak of the virus).
- Our helpline callers reported relatives not being sent to hospital for treatment or of being asked to agree end of life plans that excluded hospitalisation, raising fears that the process of prioritising health services was being based on non-clinical factors such as age or disability.
- Callers also raised concerns about lack of medical care for care users as GPs and other health practitioners stayed away to prevent cross-contamination, and care staff lacked the expertise or equipment to provide adequate medical and palliative care.

Action needed:

- Older people receiving care, and care staff, must not be an afterthought during the next phase of the pandemic.
- The focus should be on protecting the *people* most at risk, not solely on protecting the NHS.
- Additional NHS support is needed for care users, including district nurses, physios, pharmacists and oversight from specialists.

5. Discrimination: older people needing care

The response to the pandemic has at times been discriminatory and devalued the lives of older people.

Human rights concerns:

- We hear concerns about people being asked to consider, or re-consider, DNR orders.
- Callers have reported problems with death certification, including inappropriate terminology like ‘frailty’.

“My wife’s death wasn’t due to coronavirus or ‘frailty of old age’ as listed on her death certificate. It was due to a refusal to eat.” Helpline caller Sheikh Rehman

- Evidence shows that people from Black, Asian and minority ethnic communities, men and those living in more deprived areas are at higher risk of death from the virus, yet lack of data about care users hampers strategic action, particularly on ethnicity.
- CQC’s failure to produce their mortality figures on care users for public use and the Government’s initial failure to include them in the daily count created a feeling that the lives of people using care services were less valued.

Action needed:

- Leadership from Government is needed to ensure older people’s lives are valued, and health and care services are enhanced and financed to protect the rights of all people.
- Figures on excess deaths may be the only reliable count of the true impact of COVID-19, given continuing unreliability of death certification.
- Data on ethnicity in care settings should be collated to allow appropriate action to be taken to protect those most at risk from any future outbreaks.

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