

# Written evidence from the Relatives & Residents Association

10 August 2020

## 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 daily insights 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 Government's lack of strategic action in managing and responding to the impact of COVID-19 on the social care system in England. To summarise some of our main points:

- There appears to be a serious and continuing lack of understanding about the care sector at the top of government.
- Action was taken too late to protect those known to be most at risk.
- The basic tools to manage the virus have still not been provided for the sector, for example testing and PPE.
- Guidance has too often been confused, inadequate and late.
- The emphasis on protecting the NHS has produced responses and policies which were and are harmful to those receiving and delivering care elsewhere.
- At times, the response has devalued the lives of older people.
- As a result, COVID-19 has had a disproportionately devastating impact on older people needing care.

## 1. Overall Government strategy

The response of the Government and its agencies to date has demonstrated a basic lack of understanding about the intrinsic vulnerability of the care sector. This includes its role, the size and operational workings of care/nursing homes, care in the wider community, the structure and shortcomings of the workforce, the fragmentation of the system, the fragility of the sector, and the weaknesses of oversight mechanisms.

Key concerns:

- Lack of any reliable system of central government oversight or safeguarding of older people using care services, despite many people living in vulnerable situations, including people with mental capacity issues and those without family/friends.
- This has been exacerbated by the loss of essential central social services intelligence (formerly provided on a continuing basis to the then Department of Health by the Social Services Inspectorate both within the Department and with a presence in each region).
- 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.

- Lack of oversight (including the ceasing of the Care Quality Commission’s routine inspections and the suspension of Local Government and Social Care Ombudsman casework) designed to ensure that care standards do not fall to unsafe or undignified levels.<sup>1</sup>
- Failure of key agencies to step in or speak out to prevent the crisis unfolding in the care sector, including the [Care Quality Commission](#).
- Lack of awareness of the need for professional oversight to ensure appropriate input and expertise on infection control in the average care home.
- Lack of timely guidance on managing staff shortages and on reducing staff movement (between and within care homes as well as in domiciliary care), including agency staff, which led to care staff spreading the virus within and between different settings.

### PPE and testing

- 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 and feverish competition between bidders in the same country.

*“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 R&RA Helpline caller, July*

- R&RA Helpline callers have been extremely concerned about the continuing lack of PPE and regular testing, putting care users and staff at risk and preventing visiting.
- Regular testing of care staff and users, crucial to managing the virus in care settings, is still not taking place.
- An effective test, trace, isolate system, fundamental to controlling future outbreaks, is still lacking more than six months after the outbreak arrived in England.

## 2. Impact of lockdown and isolation

The R&RA Helpline has received an influx of calls from family members concerned about the well-being of their relative receiving care due to the impact of lockdown.

Key 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 where a visitor not being present would cause the person to be distressed.
- 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 impracticable.

*“I’ve only spoken to mum three or four 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 R&RA Helpline caller, July*

- 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.

<sup>1</sup> The Care Quality Commission rated 16% of adult social care settings ‘inadequate’ or ‘requires improvement’ in 2019 (over 3,600 care settings). ‘State of Care’, Care Quality Commission, October 2019.

- Isolation is having a devastating impact on mental well-being. We hear of people who become increasingly depressed and withdrawn: they have stopped eating or drinking, lost speech, think their relatives have ‘abandoned’ them or passed away, and have ‘lost the will to live’. Some care users no longer recognise or remember their family and friends.

*“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 R&RA Helpline caller, May*

- After a month without any guidance from Government on visiting in care homes, new guidance lacks clarity and leadership. It encourages blanket approaches, provides scant practical advice on future management of the virus and is difficult to follow.
- Lack of appropriate guidance has led to fear, rigidity and a huge diversity of practice on visiting, including blanket bans, inflexible time limits (which can be distressing for people affected by dementia), chaperones/monitoring by staff (affecting people’s privacy) as well as residents being prevented from leaving care homes.
- Lack of appropriate oversight of the sector (above) and of a viable, central complaints mechanism has left older people and their families with few routes and little power to challenge poor practice.
- There has been little central dissemination of good practice to encourage individualised approaches and allow care providers to learn from each other.

### 3. Impact on and prioritisation of protected characteristics

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

Key concerns:

- The Government’s initial failure to include known mortality figures of care users in the daily count created a feeling that the lives of people using care services were less valued.
- R&RA Helpline callers reported relatives not being sent to hospital for treatment or 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.
- We hear concerns about people being asked to consider, or re-consider, Do Not Resuscitate Orders.
- Callers have reported problems with inaccurate death certification, including inappropriate terminology like ‘frailty’.

*“[My wife] starved herself to death. Her death was due to the pandemic – but she didn’t die from the virus itself. It wasn’t coronavirus, or the ‘frailty of old age’ [as listed on her death certificate]. It was death due to a refusal to eat.” R&RA Helpline caller Sheikh Rehman*