

## **Written evidence from The Relatives and Residents Association (HCS0048)**

### **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.

### **Introduction**

R&RA welcome this inquiry and the opportunity to outline how the rights of older people using care are at risk. Older people in care are facing the most catastrophic and sustained attack on their human rights we've ever seen. Their fundamental rights to life and wellbeing were neglected at the outset of the pandemic. Twenty months later rights continue to be breached and people in care face discrimination as the only group still living under stringent Government restrictions whilst the rest of the country gets back to normal. Older people have been failed by the very systems designed to protect their rights. Too many are afraid to speak out and use their legal rights due to the power imbalances built into the system. This has to change.

R&RA's campaign to End Isolation In Care has been calling for urgent action to end this human rights crisis, including an overhaul of Government guidance on visiting and for CQC to take action to monitor compliance. Our helpline hears the devastating impact measures to manage the pandemic have had on the lives of older people. Families tell us they can't face another winter of these restrictions, and that they worry how long their loved ones have left. Key concerns coming through our helpline are of closed cultures taking hold, and of legal rights being overlooked in favour of non-statutory guidance.

Whilst COVID-19 has created unprecedented challenges and the sector is facing its most difficult period, the pandemic has also exposed or exacerbated many pre-existing problems. It has placed strains on a sector consistently overlooked and neglected. Staffing problems are not new, but have now reached crisis point. We are extremely concerned that a 'perfect storm' is brewing which is putting people's safety, dignity and other rights at risk and that this is going unnoticed, behind closed doors.

Urgent action is now needed to end the human rights crisis in care and build in stronger protections to the system to ensure that older people can enjoy not only the minimum safeguards human rights laws offer but also a good quality of life.

### **Human rights issues**

Inquiry Question: What human rights issues need to be addressed in care settings in England, beyond the immediate concerns arising from the Covid-19 pandemic?

We have set out below some issues under key rights protected by the Human Rights Act (HRA). Many of these issues have been made worse by the pandemic and measures taken to manage it – particularly the lack of access to relatives/friends. Our helpline hears daily from families being refused essential caregiver status as set out in Government guidance, facing illogical, nonsensical rules, cycles of perpetual lockdown, even struggling to get access at the end of life. Given the scope of this inquiry we have not addressed this issue in detail and have focused on the wider picture of human rights at risk, prior to the pandemic too. Our

submission builds on the previous evidence sent to the Committee during its inquiry into the Government's response to the pandemic.

### **Right to life**

- Lack of training on human rights and on end of life care puts older people at risk of discriminatory use of DNAR orders and of inappropriate withdrawal of care
- Older people having their health needs ignored or overlooked due to discriminatory attitudes or assumptions about their wishes/needs

When a woman's health significantly declined after moving into a care home, her social worker refused to review the care or discuss the visiting restrictions with care staff. Instead, the social worker said 'that's what happens with dementia'. [Example from anonymous helpline client]

### **Right to be free from inhuman/degrading treatment**

- Lack of food or fluids leading to malnutrition/dehydration
- Neglect or lack of care leading to harm/suffering

A son became concerned about his father's care after noticing he was not always getting his medication or appropriate diet, was becoming depressed and had a poor quality of life. R&RA supported the son to secure a review of his father's needs and he was moved to a more appropriate setting. [Example from anonymous helpline client]

- Physical or mental abuse
- Leaving people in their own bodily waste

A care home resident was found in distress by their relative, left unchanged with faeces also over the bedding and on the walls. [Example from anonymous helpline client]

- Unacceptable levels of cleanliness impacting on people's dignity

A care home resident's toothbrush was found to have faeces on by their relative. [Example from anonymous helpline client]

### **Right to liberty**

- Restraint/restrictions placed on movement
- Residents being unable to leave a care setting

A care home resident was placed in care without their consent and has been unable to return home, despite saying for months they wish to do so. [Example from anonymous helpline client]

### **Right to private life (privacy, wellbeing, autonomy)**

- Care users being unable to have private contact with relatives/friends, health practitioners/others – this also raises concerns about people's wellbeing and safety if they are unable to privately discuss any concerns about their care
- Access to health practitioners not being facilitated, including mental health teams, therapists, dentists, opticians etc. – families are often expected to arrange and support with these appointments

A care user was found by a relative to have missing teeth and others in a bad state of repair which staff had not noticed. [Example from anonymous helpline client]

- Risk of harm from other care users not identified and acted upon
- Lack of dignity resulting from personal items going missing, being dressed in other people's clothes etc.

A care home resident was found by a relative to be dressed in another resident's clothes and other items of clothing were missing, despite being labelled. [Example from anonymous helpline client]

- Decisions about care and treatment being made without the person's involvement or consent, or that of their chosen representatives

A care user's medication was changed without consultation with their relative and they were placed on medication they had previously had a bad reaction to. [Example from anonymous helpline client]

- Older people being unable to participate in their community due to assumptions about their capacity and living in closed settings/restrictions on movement

### **Right to family life**

- Care users being unable to maintain (or develop) relationships with partners/relatives/friends due to restrictive visiting practices. Whilst this was happening prior to the pandemic it has now become the main issue reported to our helpline, including:
  - Care settings only allowing strictly timed visits in designated visiting rooms even if the resident is too distressed by this
  - Refusing residents an essential caregiver, or stopping the role during lockdowns
  - Only allowing end of life visits at the very end, which are stopped if the resident recuperates
  - Care settings going into lockdown after one positive case

*"I am quite sure that preventing relatives from entering for so long has led to a serious drop in standards. Since April 2020 I have made numerous complaints to my wife's care provider over issues I detected in Facetime calls including poor diet, no oral care whatsoever, being left in bed until lunchtime, and so on."* Robert, whose wife is affected by dementia

- Relatives/friends being unable to advocate on behalf of care users and being excluded from discussions even where they are a Relevant Person's Representative or Power of Attorney

*"My knowledge of mom's wishes has been removed from consideration. The effect of current practices makes my role as her guardian of her needs, desires and wants impossible. My ability to monitor mom's rights has been eroded in favour of ease and lack of scrutiny."* Son who can only visit 30mins in a visiting room which is distressing for his

mum.

- Banning relatives/friends from care settings, impacting on care user's wellbeing too

A man was accused of verbally abusing staff for raising concerns about his mother-in-law's care and banned for over a year until able to access the LGO to successfully challenge the accusations. [Example from anonymous helpline client]

- People being placed in care settings miles from their family

Mr Baker was discharged from hospital into a different care home miles from his wife, without consultation with her. R&RA supported Mr and Mrs Baker to successfully challenge the placement. [Example from helpline client]

- Couples being separated when placed in different care settings

A local authority decided to place a woman in a different care home to her husband, seemingly oblivious to the great distress this was causing. [Example from anonymous helpline client]

### **Right to respect for home**

- People being removed from their home and placed into care without their consent
- Evictions from care settings
- Closure of care settings, also impacting on people's wellbeing

*"I shall never quite recover from the shock of being told my home was to be taken away. This was the place where, at 92, I had expected to spend the rest of my life. I was in shock for many days, even weeks, not sleeping, feeling unsteady and as if a pit had opened at my feet. My friends are scattered and my feeling of security gone. I still cannot absorb the fact that such an action against us was allowed to happen."* Resident whose care home was closed

*"During the eight months since the eviction notice my mother has markedly deteriorated, both mentally and physically. She went into a depression after her eviction. She has become very frail and forgetful and is prone to falling. I do not want to live in a society where the vulnerable can be treated in this way."* Daughter of evicted care home resident

- Residents being threatened with eviction as the home is 'no longer able to meet their needs' when they raise concerns or issues with care

A relative who complained to the care home about her mother being refused an essential caregiver (in line with Government guidance) was told the home may no longer be able to meet her mother's needs and to find a new home. [Example from anonymous helpline client]

### **Right to be free from discrimination**

- Assumptions made about access to care and treatment based on age
- Lack of training on hearing and sight loss and how to support care users

- Lack of support for care users with hearing aids, glasses, dentures etc. to ensure they are working/clean/not missing

The loss of a resident's hearing aids was left unreported and not acted upon by staff until raised by a relative. [Example from anonymous helpline client]

### Service providers

Inquiry Question: How effective are providers at respecting the human rights of people under their care?

#### **Lack of knowledge of rights**

There is a widespread lack of knowledge of human rights amongst care providers. This is due to a lack of training on human rights, the HRA and other laws which protect rights (including the Mental Capacity Act and Equality Act). This leads to care users' rights not being respected or protected. It also means **one of the stated aims of the HRA, to create a culture of respect for rights, has not taken place in care settings**. The Government seem unaware of this knowledge gap, making references to the HRA and Equality Act in guidance for providers during the pandemic with little recognition of the lack of knowledge of these laws amongst care workers.

#### **Strains on the sector**

Providers' ability to respect the rights of care users is further hampered by long-standing strains on the sector, which have now reached crisis point. The high turnover of staff has long been a problem and leads to lack of consistency and relationship-building between staff and care users. Both are crucial to delivering a rights-respecting service, which at its heart is about knowing the person's needs and wishes. Our helpline hears that staff shortages are preventing delivery of dignified care – helpline clients are being told that providers can only do the bare minimum. This is very far from the culture of respect for human rights older people should be able to expect from care services. **We are concerned that the staffing crisis in care is putting people's safety, dignity and other rights at risk and that this is going unnoticed, behind closed doors.**

### The regulator

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

#### **Failure to protect the rights of residents**

When older people needed their regulator the most during the pandemic, CQC retreated to the side-lines. **CQC have borne witness to a human rights crisis unfolding in care and their lack of action has left older people at risk**. Stopping routine inspections left people without protection when they needed it most. Their voice has been lacking throughout the pandemic as decisions which had catastrophic consequences for older people in care were left unchallenged and mistakes repeated, including:

- In the early stages when the Government and its agencies failed to recognise the risk of the virus to people using care and staff (such as PHE guidance stating it was “very unlikely” care users would become infected)

- When care staff were left without the basic tools to protect those most at risk from the virus (including lack of testing and PPE)
- In failing to produce data on deaths in care during the first stages of the pandemic
- As measures to manage the pandemic caused harm to people in care, including the devastating impact on mental and physical health of isolation created by visiting restrictions
- With barriers to safe care persisting (such as the ongoing failure to ensure adequate sick pay for care workers)
- As closed cultures took hold across some care settings

R&RA wrote two letters to CQC, in May 2020 and May 2021, expressing our disappointment with the role they have taken during the pandemic, urging them to act to protect the rights of people using care. We called on them to take a proactive role in monitoring compliance with the visiting guidance. Their response was an unacceptable abdication of responsibility. **It is deeply troubling that we simply do not know how many people's rights are at risk or being breached by lack of compliance with visiting guidance.** It was, therefore, of enormous concern and distress to our beneficiaries for the CQC to have reported to this Committee earlier this year that they see no problem with the implementation of the guidance whilst admitting that they do not collect data to justify this assertion. It is unacceptable that it should fall to families to fill this gap, pushing the responsibility to them to monitor compliance and raise issues. Not least because of the power imbalance in care settings.

### **Failure to support residents to make complaints**

We know from our helpline that when people face barriers or problems with gaining access to loved ones, too many are afraid to speak out to challenge this with care staff, use their legal rights or report it to the regulator due to fear of reprisals (including, ultimately, eviction). **The power imbalance is so vast and people using services are placed in such a vulnerable position, they are afraid to rock the boat.** They can even be subject to other professionals reinforcing this power imbalance.

A wife who has been trying to get better access to her husband has been warned by the social worker to stop rocking the boat with the care home for fear that they will lose the placement. [Example from anonymous helpline client]

Despite CQC's assurances that issues can be raised anonymously and people's identities protected wherever possible, many remain afraid that the care setting will be able to identify them.

CQC do not accept complaints, unlike their Scottish counterpart. Instead they ask people using care/their families to give feedback on care which they 'look at alongside other information'. **CQC's model of relying on problems being reported to them simply doesn't work when so many people are afraid to speak up and have so much to lose.** Our helpline also hears of the lack of consistency in approach by inspectors. Some helpline clients report not hearing back from the regulator when they have fed back concerns and uncertainty about what happens to the information. This erodes trust in the regulator.

Tony contacted the CQC about the impact cuts in night staff were having on his mother but felt no-one was listening. R&RA supported him to raise this with the safeguarding team and local authority. As a result CQC inspected the home and found staff levels too low at

night. [Example from anonymous helpline client]

We are concerned that the CQC's new model of regulation will mean fewer inspections and result in them being even more ineffective in protecting the rights of care users.

### **Lessons from pandemic**

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

There are many, critical lessons to be learned from the pandemic. R&RA have written to the Prime Minister calling for urgent moves to be made to set up the public inquiry into the handling of the pandemic. We requested an urgent meeting with the Government to share insights from our helpline work, to ensure lessons could be learned now, to prevent mistakes being repeated. They have not responded to this request. A summary of some of the lessons to be learned is below.

### **There needs to be a better understanding of the care sector and the needs of people using care by the Government and its agencies**

- The response to date demonstrates a lack of understanding about the vulnerabilities of the sector, how care services operate and the reality of living in care settings
- We are concerned about the lack of any reliable system of central government oversight of older people using care services

### **The focus must be on people, not institutions**

- Policies should focus on the people most at risk and in need, not on protecting institutions
- 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
- Having put the lives of people in care at risk in the early stages of the pandemic, the Government then swung dramatically to the other extreme, imposing severe restrictions on movements in and out of care settings for residents and their families
- 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 in care have the same legal rights as everyone else and should not be discriminated against or left behind during a crisis or the recovery
- People in care must never again be an afterthought

### **Systems to protect the human rights of care users are more important in times of crisis, not less**

- Older people in care have been failed by the very systems designed to protect their rights
- Legal duties to protect rights have been too easily ignored by the Government and its agencies – both the duty to protect the right to life at the beginning of the pandemic

and the duty to protect rights to liberty, family life, autonomy and wellbeing throughout

- We need a better system of alert and accountability when human rights breaches occur
- We need strategic action by the Government and its agencies to recognise and act upon systemic human rights risks to ensure older people are not discriminated against and left behind
- Older people (and their families) should be able to rely on robust, effective safeguarding systems to protect their fundamental rights to safety and dignity, especially in times of crisis – instead our helpline hears that safeguarding teams have been too slow to return to on-site investigations and have too often been ineffective at protecting rights, including prior to the pandemic

A resident was found by her relative with blackened lips and days old food in her room. The relative raised this with the safeguarding team but they failed to respond. The resident later died in hospital of severe dehydration. [Example from anonymous helpline client]

- Open cultures in care settings are crucial to protecting human rights; safe access must be maintained for safeguarding teams, inspectors, social workers, health practitioners, and other professionals, to allow them to spot and raise issues – even more crucial for residents with no family or friends

### **The sector needs a robust regulator to safeguard rights and act as a voice for people using care services**

- Older people have been neglected by their regulator; a fundamental part of the system designed to protect their rights
- The sector needs a regulator who:
  - will act as a voice for people using care services as a respected, authoritative body
  - has the will and confidence to represent those using care services when decisions and policies are being formulated by Government and its agencies which impact on their rights
- The CQC must step up to perform this role, and earn the trust and respect of people using care and their families
- They must begin to monitor compliance with the visiting guidance to measure the extent that older people's rights are at risk in care settings, as we have been calling for them to do for many months
- The care sector needs better, more robust and accountable oversight, with more frequent inspections by the CQC

### **The care system must have the rights of people using care at its heart**

- The current situation is in great danger of becoming the 'new normal' in care settings
- Urgent action is needed to ensure older people do not face continued isolation from family and friends, health practitioners and others, and they/their representatives are no longer excluded from discussions and decisions about their care
- Government guidance on visiting needs an urgent overhaul to ensure legal rights are not undermined and leadership is given on how to fulfil human rights duties
- Providers must ensure they are complying with their legal duties under the HRA and other laws (including the Mental Capacity Act and Care Act)

- People using care should expect to have their rights under the HRA respected, protected and fulfilled to ensure a bare minimum standard of care
- Reform of social care needs to ensure that power is transferred to people that receive care and support, and their families
- Care must be built around the person's needs and wishes

#### **Support from relatives/friends must be recognised as essential to care user's lives**

- When people move into a care setting, their right to maintain contact with their relatives and friends becomes all the more important, yet as a group they have been subject to far more stringent restrictions on contact and movement during the pandemic, for far longer than the rest of the population
- The vital role relatives and friends play must be recognised and respected – not only in terms of love, companionship and emotional support but also the many other roles they might provide for the person in care, including carer, advocate, voice, confidant, advisor, mediator, protector of rights
- Care users' right to family life must be respected, protected and fulfilled by all those with duties under the HRA
- This must include a recognition of the importance of maintaining contact with relatives and friends for the emotional, mental and physical health, and quality of life, of people using care
- This must also include promoting cultures where relatives and friends are seen as partners in care, not a 'problem' or 'barrier' for providers
- The role of Essential Caregiver has been vital for protecting care user's rights to wellbeing and family life – it should be enshrined in law

#### **There must be improved legal protections and support for people needing care**

- Everyone needing care should be able to access independent, impartial advice, information and advocacy to get the help they need
- There should be a central complaints procedure with the powers to bring about meaningful change
- People living in care must be legally protected from unfair evictions (security of tenure)
- Evictions from care homes should be subject to appeal

#### **The care sector needs support to use human rights in practice**

- Human rights were born out of crisis and could have helped the care sector to find a way out of this one
- Leadership was needed to promote this message and show the sector how human rights laws could have assisted with some of the most difficult challenges they have ever faced
- Instead there was a lack of leadership from Government and its agencies, with their own policies and guidance breaching older people's human rights – such as discharge from hospital into care without testing, and blanket isolation periods after visits out of care homes
- Clear, timely, relevant guidance, based on an understanding of the sector and the rights and needs of people using care, is crucial
- Such guidance should help care providers to understand and fulfil their legal human rights duties, not undermine the rights of people using services

### **The knowledge gap on human rights in the care sector must be closed**

- Providers, care staff and Commissioners need accessible, practical tools to help them understand their human rights duties and how to meet them
- Such tools would help to ensure human rights and other laws are not overlooked in favour of non-statutory, advisory guidance – R&RA produced a guide for providers on Visiting and the Law to try to fill this gap
- Care staff must undergo mandatory training on the HRA and other laws protecting rights – not just on understanding the rights and their legal duties to avoid breaches, but also on how to use those laws in practice to improve services
- Training on the HRA should also be mandatory for others working in social care, including social workers, inspectors, health practitioners, Commissioners etc.

### **The social care sector should be as highly valued as the NHS**

- Care is a crucial public service – care staff should be valued as highly as NHS staff for their vital work
- Social care workers must be:
  - properly trained, with accredited, transferable training
  - registered, have mandatory qualifications and a nationally recognised career structure
  - adequately rewarded for providing care which is a crucial public service
- 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
- Reform needs to build a sustainable social care workforce which recognises and values the professional contribution they make
- Leadership is needed from the Government to ensure this becomes a reality

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