

The human rights of people living in care homes: never again an afterthought

To the Editor — Residents of long-term care homes (LTCHs) in England aged 65 years and older endured disproportionate deaths and suffering during the COVID-19 pandemic. A more robust framework in place before the pandemic to protect their human rights, defined as the rights and freedoms of all humans contained in international and national human rights law, may have saved lives and could potentially have avoided the level of hardship experienced by this marginalized group.

According to the Office of National Statistics, at least 43,256 LTCH residents died with the involvement of COVID-19 between March 2020 and January 2022 in England and Wales¹. Mortality was particularly high during the first wave of the pandemic (until September 2020), with nearly 20,000 deaths of residents of LTCHs involving COVID-19, accounting for around 40% of all COVID-19 deaths. There is evidence to suggest that many of these deaths were preventable². It is astonishing that LTCH residents and their human rights were an afterthought to the English government in the process of pandemic policy making, which especially in the early phases of the pandemic failed to take quick action to protect residents in LTCHs despite knowledge regarding older peoples' vulnerability to the virus³. For example, in March 2020 the government advised the National Health Service to discharge patients without prior testing for COVID-19 from hospitals into LTCHs and without the need to isolate from other residents for 14 days. This policy lasted until mid-April 2020. Although the English High Court recently cleared the government of legally violating the rights to life, privacy and a family life with this policy, it confirmed that the government had acted unlawfully because it disregarded the vulnerability of older people in LTCHs⁴.

The situation of LTCH residents during the COVID-19 pandemic led to public acknowledgment of their precarious human rights situation. The [media printed headlines](#) referring to 'human rights abuses', with a focus on visitor restrictions that were more severe and lasted longer compared to those affecting the rest of society. Amnesty International in October 2020 published a report into the human-rights-related failures of government to protect LTCH residents

from COVID-19, calling for a public inquiry into human rights in care settings⁵. Grassroots human rights advocacy groups emerged, led by families of LTCH residents, demanding access to their relatives, who were dying without them.

But, as many people in England are living with COVID risks relatively reduced in their priorities, and heightened political and financial insecurity, there is danger that the human rights situation of LTCH residents will move into the background of the minds and agendas of change makers, without meaningful improvement. To achieve such improvement, it is important to learn from residents' experiences during the pandemic, which means to analyze and document the reasons for this particularly precarious human rights situation and to address them.

LTCH residents started the pandemic from a situation of weak human rights protection. Some human rights frameworks meant to protect LTCH residents' rights or to offer redress for human rights violations put in place before the pandemic were apparently de-prioritized during the pandemic and were not able to address human rights concerns effectively. For example, the Care Quality Commission (CQC), England's regulator and inspector of care services, in 2014 adopted a 'human rights approach' to regulating and inspecting LTCHs with the aim to hold care providers accountable for protecting basic human rights like dignity and equality of their residents⁶. A key mechanism here is the physical inspection of LTCHs. However, in March 2020 all inspections of LTCHs were suspended, and with them the CQC's 'human rights oversight' in these settings. The CQC is generally unable to investigate individual human rights complaints, thus not offering a viable alternative to raising concerns outside the remit of their inspections. While the CQC's reluctance to enter LTCHs for older people, especially during the early stages of the pandemic, is understandable, the CQC's role in ensuring that human rights are respected and protected was more important than ever before in the light of the heightened vulnerability of residents and stresses on care providers.

There also seems to be a lack of awareness and understanding among public authorities and care professionals

of the various risk factors leading to potential human rights violations and solid frameworks to ensure that rights are continually upheld. For example, we have evidence that in England, LTCH residents, among other groups, were subject to 'do not attempt cardiopulmonary resuscitation' (DNACPR) notices without their consent, often on the basis of blanket decisions because of age, frailty or disability⁷. In the beginning of the pandemic there was no official guidance for care professionals about the use of DNACPR notices in advanced care planning, despite their relevance for LTCH residents, who often live with co-morbidities or are at the end of life. It was reported that during the pandemic individuals were not only denied resuscitation on the basis of such blanket notices, but also [basic medical treatment like antibiotics or fluids](#), potentially in breach of fundamental rights like the right to life, health and freedom from degrading treatment. Two years into the pandemic, after concerted advocacy efforts, the government did finally publish guidance to health and care providers to avoid future failures in applying DNACPR notices and other advanced care planning. It is doubtful that the existence of such guidance alone pre-pandemic, without adequate training and awareness across care providers, would have avoided all instances of illegitimate DNACPR notices and applications thereof. But there would have been a framework for human rights advocates to draw on and highlight the human rights relevance of DNACPR notices for older people in the pandemic.

Another issue is the disregard and at times lack of clear solutions for questions around how care providers are to protect and respect their residents' rights in the face of competing legal duties. This is outlined by considering the human rights clashes during the pandemic around residents' rights to a family life and social participation in the name of protecting their rights to health and life through infection control. Care providers have a duty to protect residents from a COVID-19 outbreak within the setting. External visits were not allowed or limited for large parts of the pandemic because of infection control. An update to official government guidance for LTCH providers on visitation issued in March 2021

Table 1 | Examples of human-rights-relevant practice and actions

Specific human right as contained in the European Convention on Human Rights and Freedoms 1950 (applicable in the UK through the Human Rights Act 1998)	Practice example or exemplary action	Type of good practice or action	Source of good practice or action	Potential benefit to LTCH residents' human right
Article 2: the right to life	Universal Principles of Advanced Care Planning	Principles to support care professionals to uphold good practice in advance care planning, including DNACPR notices	Coalition of partners including the National Health Service	This resource was developed from the experiences of LTCH residents and other care users during the COVID-19 pandemic regarding blanket DNACPR notices and may help to avoid instances of such poor practice in the future, in line with the protection of the right to life
Article 5: the right to liberty and security	Protecting Human Rights in Care Settings ⁸	Academic research to inform policy	The Essex Autonomy Project, University of Essex	This academic research project is one example of human-rights-specific research into the human rights situation of LTCH residents during COVID-19, specifically on the deprivation of liberty. Academic research can benefit residents by analyzing and documenting human rights violations and/or good practice and experiences to improve human rights protection.
Article 8: the right to respect for privacy and family life	Visiting and the Law: A Guide for Care Homes during COVID-19	Practical guidance document for providers of LTCHs	Relatives & Residents Association	This resource could increase the confidence of LTCH providers to navigate visitor guidance during COVID-19 outbreaks in the home and thus help to strengthen residents' right to a family life by ensuring that residents are not cut off again from relatives due to restrictions
	Distribution of free tablet computers to care homes across England	Action to support digital connection of care home residents	National Health Service	The pandemic has shown that access to technological devices and Internet can, with limitations, support LTCH residents' connections to relatives and friends through making available an alternative way to communicate other than physical contact

Examples of human-rights-relevant practices and actions taken by various organizations as a result of LTCH residents' human rights situation during the COVID-19 pandemic in England that could help to strengthen the human rights protection of older LTCH residents. This table outlines what kinds of actions could be taken across different organizations.

said that every resident may appoint one 'essential caregiver', a person able to visit with few limitations to balance out the detrimental effects of residents' isolation from families and friends. However, this guidance was not legally binding, while providers' legal duties to protect LTCHs from COVID-19 outbreaks were not lifted. The guidance was updated more than 30 times between July 2020 and March 2022 and at times contradicted other similar guidance issued to providers. Providers were thus not only faced with the need to balance competing rights of residents but also with confusing and fast-changing guidance, as well as potential legal and regulatory action against them in the case of a COVID-19 outbreak⁸. Lockdowns in LTCHs still are a reality for many residents when COVID-19 infections occur within the home, with the guidance on allowing visitors not rolled out in all instances.

Another factor has been the lack of direct inclusion and voice of residents throughout the pandemic when it comes to policy making and also human

rights advocacy. An example is the Joint Committee on Human Rights' inquiry into human rights in care settings, opened in September 2021. This committee is a group of parliamentarians who are charged with investigating specific human rights issues and offering recommendations to government. [The inquiry](#) invited written and oral evidence from members of the public. This is generally an important initiative to understand the precarious situation of LTCH residents, but it is striking how few of the submissions of evidence directly involved the views of older LTCH residents. While during the pandemic the voices of families of LTCH residents and care professionals were lifted, the voices of residents are still quiet. If the human rights situation of older LTCH residents is to be strengthened, their participation in relevant processes is itself a matter of respecting their right to social and political participation and their right to freedom of expression, among other rights.

The human rights situation of older LTCHs residents has also instigated 'good

practice' or actions that could help to address the points raised above. The charity Relatives & Residents Association has issued practical guidance to providers of LTCHs on how to navigate visitation and infection control and balance their competing legal duties. Advocacy efforts are continuing to enshrine in law a right of every LTCH resident to nominate one or more individuals who can visit in all circumstances. Academic research shed a light on the human rights situation in LTCH during the pandemic⁹. Other practice examples are captured in Table 1. If these kinds of efforts continue, the result could well be a much stronger system of human rights protection. This might ensure that the human rights of older LTCH residents will never be an afterthought again, but instead are at the center of policy making and care provision under any circumstance. □

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Competing interests

The author declares no competing interests.