



Ethical Considerations Relating to Long-Term Residential Care Facilities in the context of COVID-19

The following guidance is for providers of long-term residential care (LTRC) and all staff working in congregated long-term residential care settings (LTRCS) including, but not limited to, healthcare assistants, nurses, clinicians, managers, and visiting GPs. It will also be useful for policy makers.

The guidance is focused on the ethical considerations that arise specifically in the context of the particular impact that Covid-19 has had within LTRCS. LTRC encompasses a broad group of services, including community hospitals, nursing homes, and residential facilities for people with intellectual disabilities or mental health difficulties, as well as a variety of providers (the State, voluntary and private)¹. This document cannot cover all aspects of care given the diversity of settings and populations, and as the most significant burden of COVID-19 has been placed on older persons, in particular on those living in LTRCS, issues discussed are particularly pertinent to the nursing home setting.

However, there are a number of common concerns relating to the consequences of COVID-19 in LTRC that require ethical consideration, acknowledging that each individual has their own specific need and care settings differ. These issues include increased vulnerability to infection and onward transmission within the residential community, difficulties with communication, testing and the implementation of physical distancing, the impact of isolation and restricted contact with family and loved ones, and the proportionate protection of rights.

During the pandemic there is a particular need to retain a holistic view of the wellbeing of residents of LTRCS, be cognisant of their rights as citizens, and to be vigilant that in seeking to shield them from infection, these rights are not infringed upon to an extent, or in a manner,

¹ Many of the key messages in this guidance are also relevant to clients of day care facilities in intellectual disability services, as well as individuals in direct provision centres, homeless emergency accommodation and prisons. While these settings differ from one another in many significant ways; they are similar in the sense that they are places where individuals congregate or reside in ways that make them more vulnerable to acquiring COVID-19 and more vulnerable to the potentially coercive authority of others.

which is disproportionate. The provision of health and social care during a pandemic should continue to be person-centred and follow a rights-based approach. Individuals in LTRC settings have the same human rights as other people and must be treated with dignity and respect. In line with the Convention on the Rights of Persons with Disabilities (CRPD) and the Council of Europe's Recommendation on the Promotion of Human Rights of Older Persons, all persons in LTRC should have equal access to high standards of care and to protection in situations of risk.

VULNERABILITY

As the Ethical Framework for Decision-Making in a Pandemic² makes clear, while we are all vulnerable during a pandemic, some groups are particularly so because of biology, pre-existing medical conditions, social disadvantage or because they live in a congregated setting. Vulnerability is most commonly understood as a diminished ability to protect oneself from harm or promote one's interests. It is not static or global, is a state of being not a categorical distinction; people who are vulnerable in one respect may be resilient in others. As such, it is an integral feature of being human and of human relationships; everyone at some point in their lives must depend on others for help meeting basic human needs³. As is the case in the general population, residents of LTRCS experience different levels of vulnerability at different times. People may sometimes be vulnerable due to their inherent dependence on others for support in meeting their everyday needs, and with support they may be able to live full and meaningful lives. Situational vulnerability refers to environmental and contextual factors that may render groups and individuals particularly susceptible to harm or exploitation because of their circumstances, as a result of their relationships with others, or because of inequalities of power or need⁴.

People living in LTRCS are vulnerable in different ways. We need to be conscious that in responding these vulnerabilities we may exacerbate matters by undermining the person's autonomy or by depriving them of agency and increasing their sense of powerlessness. In accordance with the principles of minimising harm and solidarity, institutions whose purpose is to care for vulnerable people have a special responsibility not to multiply the vulnerabilities of those in their care. Decision-making involving people with intellectual disabilities or diminished capacity must promote inclusion, autonomy and participation to the greatest extent possible.

² Department of Health Ethical Framework for Decision-Making in a Pandemic (March 2020). Available at: <https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/>

³ UNESCO (2013). The Principle of Respect for Human Vulnerability and Personal Integrity. Report of the International Bioethics Committee of UNESCO, 13.

⁴ Mackenzie et al (2014), 7.

VALUES OF HOME

Long-term residential care settings are places of hospitality as well as healthcare. While there can be a tension between the role of LTRCS as a place of residence and provider of healthcare, for many residents the LTRCS is their home, or has become their home. Adults with a disability, for example, who live in a small group home may have little or no personal or healthcare needs but will benefit and flourish in a community context that supports them to live as independently as possible.

Home has powerful emotional and symbolic meanings. It connotes family, security, safety, refuge, familiarity, a sense of belonging, treasured memories, independence and control. Over time, friendships and kinships are often built up between residents and staff, as well as among fellow residents and their family members. Because LTRCS are homes as well as healthcare settings, specific ethical values are at risk and need to be nurtured, namely, protecting and preserving autonomy, dignity and privacy, as well as building and reciprocating trust and mutual respect.

To ensure that these values are protected in the context of COVID-19, and in line with the Ethical Framework's procedural values of openness/transparency and inclusiveness, LTRC providers should ensure that residents and those close to them are consulted to the greatest extent possible in relation to any operational changes that they make in their efforts to address concerns about COVID-19 transmission. This may require using a range of communication tools to reach different populations in LTRCS. It will involve maintaining and strengthening existing relationships between service providers, staff, residents and their families, to ensure the residents' safety, wellbeing, and autonomy is protected during the pandemic. Questions and concerns of residents and their families or those close to them should be responded to in a timely manner. The procedural value of responsiveness requires that care providers offer residents and/or their families the opportunity to challenge decisions which directly affect their own or a loved one's care.

DUTY OF CARE

A particular duty of care exists in relation to those who are disproportionately impacted by COVID-19. Even though the devaluing and marginalisation of care work has been a global concern for many decades, receiving care and, for many, giving care is central to their lives⁵.

⁵ Joan C Tronto (2013) *Caring Democracy*, New York: NYU Press

The COVID-19 pandemic has provided a reminder of the value and centrality of the work of care providers and caring relationships in our communities.

In accordance with the principle of minimising harm, LTRCS should put in place additional measures to support safe, quality care. This may involve enhanced observation of residents to identify early signs and symptoms of illness or deterioration of their current health status. Providers of residential care have a responsibility to ensure that the clinical needs of residents are met and that they have timely access to healthcare providers, either as visitors or through the use of telephone or preferably video consultations.

Quite apart from vital emotional support, family members often perform important care functions for residents in some LTRCS, such as nursing homes, for example, providing assistance with eating, personal hygiene and mobility. Ensuring there are no gaps in care may mean deploying extra personnel to attend to the residents' additional care needs in the absence of family members. Staff with an appropriate skill mix and seniority should be assigned as needed to an LTRCS to support a review of, and enhance, existing controls and support and to monitor their implementation. This will require flexibility from staff in other healthcare settings who may be redeployed to the LTRC sector to perform this function. If there is a requirement to deploy supplementary external staff to a LTRCS, every effort should be made to ensure that individual staff are not working across more than one facility. This will serve to reassure residents and mitigate the risk of transmission of COVID-19 between LTRCS.

Providers of LTRC and staff members of LTRCS have a critical role to play in ensuring the safety and dignity of those in receipt of care and support. As part of their duty to care, those involved in the care of individuals in LTRC should be cognisant of and uphold the obligations placed upon them by their own professional codes of conduct. All staff have an ethical obligation to ensure that appropriate standards of care and patient safety are upheld, and to disclose harm or potential harm to those in their care. Staff should be trained in recognising and reporting abuse or unsafe practices and employers must have policies in place setting out the process to be followed for reporting failures in care. Given the complexity and seriousness of dealing with an outbreak in a LTRCS, there is a requirement for on-site senior leadership to ensure timely, appropriate action is taken to safeguard the health and wellbeing of both residents and staff.

Providers of residential care have an obligation to ensure that all staff are appropriately protected from risk when discharging their duty of care to residents. Many residents in LTRC

may be frail or have multiple care needs and will require closer interaction with staff than is necessary in other healthcare settings. This places staff, not all of whom are healthcare professionals, at greater risk of infection with COVID-19. This duty of care must be balanced against the likelihood and magnitude of the risk faced by the staff, their duties to themselves, their families, their co-workers, and other residents in need of care. All staff working in LTRCS should take all reasonable precautions to ensure that they are able to care for all residents in the LTRCS, but they are under no ethical obligation to accept unreasonable risks in discharging their duty of care.⁶ As part of their duty to care to themselves, their colleagues, and those for whom they care, infection control measures should be adhered to and if a care provider develops symptoms of, or tests positive for, COVID-19 they must self-isolate at home or in accommodation provided to them, and they should not return to work or care for individuals until they have been advised that it is safe to do so.

Staff working in LTRC face unprecedented challenges, both in terms of the scale of the resource demands, and the moral distress which may be experienced if they find themselves unable to provide the high-quality care or support that they would expect of themselves in normal circumstances. Providers of residential care should recognise that staff are themselves vulnerable and must be provided with the support they need to enable them to continue to care for residents during the pandemic. In line with the principle of reciprocity, staff should be provided with appropriate PPE and training in its use, as well as training in infection control measures. Appropriate guidance should be provided to staff being asked to work outside their normal scope of practice. Furthermore, practical supports, such as accommodation, transport and psychosocial mentoring for staff should be put in place by the employer.

PROTECTING LIBERTY IN THE CONTEXT OF PUBLIC HEALTH RESTRICTIONS

The right to liberty is one of the most fundamental human rights. The Ethical Framework for Decision-Making in a Pandemic specifies that restrictions to individual liberty and the measures taken to protect individuals from serious harm should not exceed what is considered necessary to address the actual level of risk to, or critical need of, those whom the restrictions are designed to protect. Protecting residents, staff and members of the public from COVID-19 has required imposing necessary temporary restrictions on the liberty of residents in congregated settings. Given the power asymmetries in LTRCS between residents, their families, and health and social care workers and managers, care must be

⁶ Ethical Considerations for PPE Use by Healthcare Workers in a Pandemic (April 2020). Available at: <https://www.gov.ie/en/publication/58d3de-ethical-considerations-for-ppe-use-by-health-care-workers-in-a-pande/>

taken not to impose disproportionate or coercive measures to achieve the ends of safety, efficiency, or other organisational goals. Practices which limit residents' agency and undermine their autonomy, such as physical restraint or psychotropic medications, must not be used to manage situations which could be resolved by relying on less restrictive measures.

People with cognitive difficulties, intellectual disabilities and those who communicate differently are often at a disadvantage because information is not available to them in an accessible format. Respecting the rights and dignity of individuals involves providing residents themselves or those who assist them with decision-making with clear, timely information about COVID-19 and any implications it may have for their safety and care. The reasons for imposing social distancing measures should be explained clearly. Information about the need for PPE, reduced visitor access, confinement to rooms or wards, postponement of activities, etc., should be presented in a manner which the person can understand and, in so far as possible, which does not cause them additional anxiety. Time and resources need to be dedicated to communication and to building trust in order to promote equity and ensure that the environment and the way it is organised is not an obstacle to understanding.

Communicating with residents and those close to them about visitor restrictions is crucial. It is important that everyone understands why the restrictions have been implemented and what impact they will have on their interactions. Any changes or updates to these arrangements and the basis for them, should be communicated to residents and their families in a timely fashion. Regular updates about the wellbeing of the residents should be provided to families, e.g. organising a regular call from the service to families by a person directly involved in the care of the resident. In certain cases, it may be appropriate and important to the wellbeing of the resident to enable a visit or visits, under prescribed conditions e.g. when a resident is at the end-of-life, or to reduce significant distress or confusion of a resident.

Social restrictions impact negatively on all members of society, but the sense of social isolation can have an especially detrimental effect on the welfare of residents in LTRCS. Physical distancing measures and visitor restrictions, including restriction to rooms/wards are likely to have a particularly negative impact on the wellbeing of residents in nursing homes and community hospitals, on people with intellectual disabilities and on individuals with cognitive disabilities, including dementia. Very often, visitors are not guests in the usual sense, but family members visits are what makes life meaningful for individuals in LTRCS and are a bulwark against loneliness, anxiety and depression. They have a pivotal role in the

ongoing wellbeing and resilience of residents, e.g., providing emotional support, reminiscing, preserving identity and continuity, as well as acting as advocates, communicators and allies.

Every effort should be made to find innovative ways to maintain residents' contact with each other and the outside world and to compensate for the loss of personal pursuits and communal activities within the LTRCS. Individual activities, tailored in so far as possible to the residents' needs and interests, should be provided in place of group activities. Technology-based communication such as video calls can allay the concerns of family members about the mental and physical wellbeing of the residents. For those individuals without family members or loved ones, and with their consent, access should be provided to independent advocacy services so that issues can be raised from the residents' perspective. As soon as deemed safe, providers of LTRC should institute measures to enable social contact for residents.

Providers of residential care have an obligation to be reflective, proportionate and creative in respect of how the overall wellbeing of residents is assessed and maintained. A proportionate response would require that restrictive measures should be justifiable, transparent, flexible and open to review and modification where necessary in individual circumstances and at the point at which the circumstances change for everyone.

TESTING FOR COVID-19

Testing for COVID-19, which has been prioritised by the HSE for residents and staff in LTRCS requires a holistic and person-centred approach. To ensure safety, equity, and consent more time and resources may need to be spent on the communication process, on building trust, and on ensuring that the environment and the way it is organised is not an obstacle to understanding. The need for testing of residents in LTRCS should be explained clearly. Consent to testing should be obtained from the person themselves in line with HSE's National Consent Policy⁷ and the Guiding Principles of the Assisted Decision Making (Capacity) Act 2015⁸. Where necessary, a resident should be supported to make a decision. Where a resident clearly lacks decision-making capacity, and they have no legally-appointed representative, someone with a close ongoing personal relationship with the person should be consulted where possible, not for the purposes of obtaining consent, but in order to ascertain any past expression of the resident's wishes. If the preferences of a resident cannot be ascertained, a decision to test may be made:

⁷ HSE, National Consent Policy (2019). Available at: <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf>

⁸ The Act was signed into law on 30 December 2015 but has yet to be fully commenced.

- if it can be carried out in a way that is not unduly intrusive and burdensome;
- if knowledge of their COVID status will be of benefit to them; and
- if it will promote the wider health interests of all other residents and staff.

If a resident with capacity difficulties refuses testing or becomes distressed during testing e.g. a person with dementia, then testing should not proceed. There may be a requirement for on-going testing which can be both physically and emotionally burdensome for both staff and residents. In that context it is essential that all reasonable measures, including robust infection control, are put in place to minimise the requirement for repeated testing.

In the case an asymptomatic individual who has capacity, be they staff or resident, refuses to be tested their refusal should be respected. In deciding what action should follow e.g. asking someone to restrict their movements, a public health risk assessment should be undertaken, taking into account a number of factors including whether the person has had close contact with an individual who has COVID-19.

Results of COVID-19 testing should be disclosed to the person from whom the test was taken and/or their legal representative⁹. Confidentiality is a vital component of the doctor–patient relationship. Erosion of trust in the therapeutic relationship could lead to individuals omitting important information, which in the context of a pandemic could be especially detrimental, not only to the person themselves but also in broader public health terms.

In facilities where appropriate isolation cannot be achieved between COVID-positive and COVID-negative residents, the question arises as to whether residents who are COVID-positive should be relocated. In essence, this may involve asking an individual to leave their own home at a time when being in their own home might be critical to their mental, psychological, and emotional wellbeing. Consideration should be given to the person's wishes and the capacity of the new facility to provide the level of individualised care and support needed. Communication strategies should be put in place to maintain important caring and familial relationships and to ensure that the person does not become distressed as a result of any move. Providing information and images of the place that they may be asked to go to may assist.

⁹ Public interest considerations can justify a disclosure without consent in certain limited circumstances e.g. where it was necessary to avoid exposing others to a risk of death or serious harm.

TREATMENT DECISIONS

Older people, people with disabilities (intellectual or physical), or those with mental health difficulties have the same rights of access to healthcare as all other members of the population. Residents in LTRCS should not be at any disadvantage relative to others in accessing care or treatment during a pandemic or at any other time. Decision-making in relation to treatment should be made in a manner which is fair and transparent, and which respects the rights of residents. Access to treatment and treatment decisions should be in accordance with the World Medical Association guidance, which states that the allocation of treatment should be based on “[a consideration of] the person’s medical status and predicted response to the treatment, and should exclude any other consideration based on non-medical criteria”¹⁰. As for all other patients with COVID-19, residents of LTRCS should receive the appropriate treatment in the appropriate setting. In line with the procedural values of openness, transparency and accountability, appropriate records must be kept of treatment decisions taken and the basis upon which they were made.

Where advance care planning discussions have not already taken place, and if the person has capacity to participate in the conversation, his or her treatment preferences should be sensitively explored. In the event that there is no other option but to carry out a discussion about advance care planning by telephone, it is especially important that the healthcare worker involved is properly trained to conduct this complex conversation and that the resident has support prior to and following the conversation. Wherever possible, and with the consent of the resident, those close to the resident should be included in the discussion about future treatment, on the understanding that it is the resident’s wishes that are paramount. If an individual lacks capacity to make advance care decisions, and there is no family contact available to provide an indication of what the person might want, support should be sought from an independent advocacy service.

As part of the advance care planning process, the access pathways to and availability of unscheduled acute care (primary/secondary/tertiary), as well as the clinical decision makers required to authorise referral for unscheduled acute care should be clearly identified.

Limiting treatment in situations in which individuals have refused it or in situations where it offers no overall benefit to the person and/or where it may be unduly burdensome is an

¹⁰ World Medical Association (2017). Statement on medical ethics in the event of disasters (S. 8.3.1) Available at: <file:///C:/Users/0109480s/Downloads/wma-statement-on-medical-ethics-in-the-event-of-disasters.pdf>. See also the Statement of the [Council of Europe Committee on Bioethics](https://www.coe.int/en/web/bioethics/-/covid-19-human-rights-principles-must-guide-health-decisio-1) (14 April 2020) available at <https://www.coe.int/en/web/bioethics/-/covid-19-human-rights-principles-must-guide-health-decisio-1>

ethically and legally accepted practice. Blanket policies governing decisions relating to transfer or non-transfer to hospital or Do not Attempt Resuscitation Orders (DNAR) orders, are inequitable and discriminatory. There may be situations where an individual expresses a request for treatment, such as admission to ICU, which may not be clinically appropriate or of benefit to an individual. The reasons why this is the case should be explained to the person in a sensitive manner.

As stated in the Ethical Framework for Decision-Making in a Pandemic, in a situation where resources such as ICU care may be limited due to increased demand, available resources should be distributed fairly, effectively, and in ways that recognise the moral equality of all persons. Even if it is considered that a resident is unlikely to benefit from ICU care, acute hospital care may be appropriate e.g. to allow for better monitoring, treatment and symptom relief, and this should be provided if the person agrees.

Residents who are seriously ill (either as a result of contracting COVID-19 or for another reason) and who express a desire not to have their care escalated, as well as those who would not clinically benefit from, or may be harmed by, an escalation of treatment should receive the best possible palliative or end-of-life care. The question of whether palliative or end-of-life care should take place in a hospital, hospice or the LTRCS depends primarily on the wishes of the individual and should also take into account the severity of the resident's symptoms and the capacity of the LTRCS to deliver appropriate palliative or end-of-life care.

The goals of end-of-life care include the meeting of bodily and spiritual needs (where requested) managing pain, and reducing suffering, as well as accompanying the dying person (not abandoning them to die alone) and supporting them to die well. A compassionate, pragmatic and proportionate approach is required in the care of those who are dying. The presence of a person close to the resident should be encouraged and facilitated (they should be made aware of the potential infection risk and trained in the use of PPE as required).

In the case that palliative or end-of-life care is being delivered in the LTRCS, clear accessible linkages should be made with palliative care specialists and/or local GPs to provide direct care, consultation or provider support. For those individuals who elect to have palliative or end-of-life care *in situ*, there should be advance prescribing of drugs, so that in the event of a rapid deterioration of the resident, the appropriate drug, in the appropriate formulation, together with any equipment needed to administer it, are readily available.

For those who die as a result of contracting COVID-19, death may be unexpected and

relatively sudden. Other residents, their families and staff caring for them may have little time to prepare for or adjust to the news of their dying and it is likely to be experienced as traumatic, disorienting, and emotionally fraught. Restrictions mean that residents may not have the opportunity to mourn in the normal ways for a fellow resident who has died. It is vital that support is put in place, not only for bereaved families, but also for staff and residents who have lost a loved one.