Ethical Framework for Virtual Care in Long Term Care Facilities

It is imperative to strive for continuity of care within the health system and meet patient needs to the greatest extent possible during the COVID-19 pandemic. This requires collaboration between acute care and long-term care (LTC) institutions to ensure that long-term care residents receive the most appropriate care possible and are able to access acute hospital care when it is appropriate to do so. Decisions about the transfer to acute care during the COVID-19 pandemic should balance the commitment to continuity of care with pressures that may exist to limit access of long term care residents to acute hospital care by reducing or discouraging otherwise appropriate transfers.

Principles to guide decisions:

- **Stewardship:** Available health care resources and services should be used responsibly to provide the most appropriate care to residents/patients. Stewardship requires that resources and services be used according to the best available evidence and in accordance with residents' wishes. Good stewardship, which is a shared responsibility of both the LTC and acute sectors, reflects a commitment to solidarity across the health system to safely and effectively promote the well-being of all Ontarians
- **Beneficence:** Promote resident well-being by maintaining the highest quality of safe and effective care.
- **Non-maleficence:** Minimize harm to residents wherever possible. This may include minimizing risks of harm that may accrue from transferring residents to hospital where their exposure to contagions may be heightened, or when they are not in need of acute care, as well as failing to transfer long-term care residents to hospital when they require acute care.
- **Autonomy:** Respect residents' self-determination to make informed decisions about their care. This requires ensuring that residents' values and wishes about future care are known, and that residents (or their substitute decision-makers) are provided with all information required to provide informed consent to treatment proposals. There may be limits to the extent of residents' autonomy during surge.
- **Proportionality:** Restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual risk. Moreover, individuals from vulnerable groups should not be disproportionately affected by a decision where harm is unavoidable.
- **Equity:** Residents should be treated in such way that similar cases are treated equally, where irrelevant or arbitrary characteristics such as geographic location, age, or home setting do not serve as the sole basis for treatment decisions. Treatment and transfer decisions should account for the interests and needs of the most disadvantaged, and the decisions about allocation are made through fair processes.
- **Solidarity:** Responsibility of leaders and decision-makers to build, preserve and strengthen interprofessional, inter-institutional, and inter-sectoral collaboration.
- **Non-abandonment:** An ethical obligation exists for health care workers and health institutions, including LTC institutions and acute care hospitals, to remain in a continuous caring relationship with their patients/residents. This relationship remains in place during a pandemic. Different levels of care can be provided, but the patient cannot be altogether abandoned.

Principles to guide decision-making processes:

Decision-making processes should be guided by the following principles:

- **Transparency:** Decisions should be communicated to individuals and the public. Justifications, based on the values and principles in this document, should accompany these communications.

Principles are listed in no particular order and are adapted from HHS Ethics Framework, The Ontario Ethics Pandemic Taskforce and Bridgepoint Treat vs Transfer During a COVID-19 Pandemic Surge

- **Consistency:** Decisions should be consistent, so that all persons in the same categories are treated in the same way, unless relevant differences exist.
- **Inclusiveness:** Decisions should be made explicitly with residents' views in mind, and where possible there should be opportunities to engage individuals in the decision-making process.
- **Accountability:** There are mechanisms in place to ensure that decision makers are answerable for their actions and inactions. Defense of decisions should be grounded in evidence and in the ethical values and principles outlined in this document.
- **Trust**: Trust is enhanced by upholding the process values enumerated above. In particular, ongoing communication with stakeholders will be essential to engendering trust.

Each of the above principles ought to be upheld wherever possible, but are expected to conflict with one another. The process by which the above principles are balanced when making decisions should adhere to principles of procedural fairness, including transparency and consistency. Decisions affecting long-term care residents' access to acute hospital care should also be informed by Ontario Residents' Bill of Rights. The relevant rights of residents are indicated below.

Relevant Rights from Residents' Bill of Rights:

Right # 1 - Respect and dignity: "Every resident has the right to be treated with courtesy and respect and in a way that fully recognizes the resident's individuality and respects the resident's dignity."

Right #3 - No neglect: "Every resident has the right not to be neglected by the licensee or staff."

Right #4 - Proper care: "Every resident has the right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs."

Right #6 - Citizens' rights: "Every resident has the right to exercise the rights of a citizen."

Right #7 – Knowing your caregivers: "Every resident has the right to be told who is responsible for and who is providing the resident's direct care."

Right #9 – Participation in decisions: "Every resident has the right to have his or her participation in decision-making respected."

Right #11a – Plan of care: "Every resident has the right to participate fully in the development, implementation, review and revision of his or her plan of care."

Right #11b – Consent to treatment: "Every resident has the right to give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent."

Right #11c – Care decisions: "Every resident has the right to participate fully in making any decision concerning any aspect of his or her care, including any decision concerning

his or her admission, discharge or transfer to or from a long-term care home or a secure unit and to obtain an independent opinion with regard to any of those matters."

Right #16 – Designated contact person: "Every resident has the right to designate a person to receive information concerning any transfer or any hospitalization of the resident and to have that person receive that information immediately."

Right #24 – Written policies: "Every resident has the right to be informed in writing of any law, rule or policy affecting services provided to the resident and of the procedures for initiating complaints."

Residents' Bill of Rights. *Long Term Care Homes Act, 2007.*

Long Term Care Ethical Decision-Making Tool

Ethics involves supporting decision-making processes that ensure we treat people fairly, remove barriers to accessing health services, respect patients' privacy, communicate effectively, and make sure the hospital is a safe place for all. This Decision-Making Tool is primarily intended to assist in making decisions in event of a pandemic. It is to be used in conjunction with the ethical principles outlined ate the beginning of the document. These guiding questions can help you and your team in making difficult decisions. Depending on circumstance or the kind of decision, you may not need to consider all the questions.

Criteria	Things to Consider
Risk to Patient (Treatment/ procedure)	• What length of time can the treatment be delayed before seeing a decline in the resident's condition? • What impact will deferral of treatment have on a successful outcome/prognosis? (Prognosis Calculators – https://eprognosis.ucsf.edu/calculators/#/) • What is the likelihood that delay in treatment will result in increased ER visits and/or need for in-patient admission? • If patient's condition worsens, could they be managed as an outpatient? • Can medical conditions/symptoms be reasonably managed while waiting for treatment/ procedure? • What level of frailty and palliative performance is the resident experiencing? (See Appendix 1: Clinical Frailty Scale (CFS); Appendix 2: Palliative Performance Scale; Appendix 3: CFS-PPS Conversion Chart)
Patient Preferences and Impact on Quality of Life	• What is the patient's capacity? (full, partial, none) • What is the patient asking for? What seems to be important to the patient? (i.e. family presence, pain management, surviving illness) • What are the resident's relevant values/wishes? What is the evidence of these? (i.e. Advance Care Plan, Advance Directive, Living Will, POA form, family conversations) • Can relief of pain and suffering (physical, emotional, spiritual) be reasonably managed? • What is the daily experience of the resident (i.e. ratio between moments of joy and moments of suffering)?
Health Care Provider/ Systems Considerations?	• Will providing treatment/intervention to the patient expose health care providers to more than usual risk, including through the consumption of resources required for providers' safety? • Do you anticipate that the change in the proposed treatment plan will result in moral distress? • Will alteration of standard of care impact patient population or community? • Is there a current outbreak of COVID or other infectious disease currently in the LTC facility? • Does Patient require isolation? • Would Transfer back to LTC facility to be possible once ready for discharge?

Prioritizing Patient Procedures, Treatments and need for Transfer to Acute Care

Reflect upon the questions above. When determining an application to the priorities of a patient population, consider the effect of competing treatment options: *e.g.*, will there be an effect on the ability to resolve the major disease process, will life expectancy be affected, what are the implications for symptom control and quality of life, and what are the broad economic implications and opportunity cost? If these outcomes are to be affected, can these be quantified?

When determining an application to the priority of an individual patient, think about their underlying illness, comorbidities, life expectancy, quality of life and standards of practice. Assign them to one of the priority groups below. In addition, as the pandemic lasts longer you may need to revisit the classification of your patients with your group to determine if their status has changed.

Priority Category	Definition	Examples
Priority A	Patients who: Are critically ill (unstable, suffering unbearably, and/or whose condition is immediately life threatening) **or** Need diagnostic procedures only available in acute care or treatment to sustain life (e.g. nephrostomy tube insertion) **and** For whom there is effective treatment **and** Who are likely to benefit from the treatment	• Acute respiratory illness (*e.g.*, pneumonia, aspiration, • COPD exacerbation • Sepsis requiring intensive management • Trauma resulting in (unstable) fractures • Injury or hemorrhage • Blocked nephrostomy tube • Dislodged G-tube reinsertion • Curative chemotherapy, *etc*.
Priority B	Patients who: • Have a non-life-threatening condition and are stable **and** • For whom treatment can be deferred **or** • Who are less likely to benefit from treatment * *Physicians and the rest of the health care team will monitor these patients to ensure they are not put at undue risk. If their status changes, they will be upgraded to priority A and sent to acute care.*	• Routine feeding tube replacement • PICC line • Nephrostomy tube • Suprapubic catheter change, *etc.*
Priority C	Patients for whom services may be deferred until after the pandemic without significant consequences. * *Physician and the rest of the health care teams will monitor these patients to ensure they are not put at undue risk. If their status changes, they can be upgraded to priority A or B.*	• Routine non-urgent follow-up appointments (many of these will be cancelled by acute care)

Appendix 1: Clinical Frailty Scale[i,ii,iii,iv]

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Principles are listed in no particular order and are adapted from HHS Ethics Framework, The Ontario Ethics Pandemic Taskforce and Bridgepoint Treat vs Transfer During a COVID-19 Pandemic Surge

Appendix 2: Palliative Performance Scale[v,vi]

Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Appendix 3: CFS – PPS Conversion Chart[vii,viii]

CFS	PPS
3	90%
4	80%
	70%
5	60%
6	50%
7	30%
	20%
	10%

Document management:

The final version of the document has been approved on April 14, 2020.

This document has been developed by the *Virtual Care for Long Term Care Core Working Group – Ethical Decision-Making Stream.* The members of the ethics stream included: Sandra Andreychuk (lead), Kelly Drake and Julija Kelecevic (HHS), Patricia Ford (St. Joseph's Healthcare Hamilton) and Portia Machonisa (Shalom Village).

The team has used the following material for creation of the current document:

- Ontario Bioethics Table (2020): Ethics Framework for Ramping Down Elective Surgeries and Other Non-Emergent Activities During the COVID-19 Pandemic
- Sinai Health System BAH Treat *vs.* Transfer During A Covid-19 Pandemic Surge (gratitude to Peter Allatt, the lead author on the document and Sinai Health System Bioethics Department)
- Residents' Bill of Rights. *Long Term Care Homes Act, 2007.*
- HHS Ethics Framework
- Palliative Performance Scale
- Clinical Frailty Scale
- All other references are listed in Endnotes

ENDNOTES
[i] Rockwood K. Clinical Frailty Scale version 1.2. https://www.dal.ca/sites/gmr/our-tools/clinical-frailty-scale.html
[ii] Rockwood K. A global clinical measure of fitness and frailty in elderly people. *CMAJ* August 30, 2005 173 (5) 489-495; DOI: https://doi.org/10.1503/cmaj.050051
[iii] Ibid
[iv] Gregorevic K *et al*. The clinical frailty scale predicts functional decline and mortality when used by junior medical staff: a prospective cohort study. BMC Geriatr 2016; 16: 117. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4890513/
[v] Victoria Hospice Society. Palliative Performance Scale (PPSv2). 2001. http://www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf
[vi] Victoria Hospice Society. Palliative Performance Scale. Website. https://victoriahospice.org/how-we-can-help/clinical-tools/
[vii] Grossman D *et al.* Enhancing communication in end-of-life care: A clinical tool translating between the clinical frailty scale and the palliative performance scale. *JAGS* August 2014; 62(8). https://onlinelibrary.wiley.com/doi/abs/10.1111/jgs.12926
[viii] Grossman D *et al*. Enhancing communication in end-of-life care: A clinical tool translating between the clinical frailty scale and the palliative performance scale. April 18, 2015. http://www.virtualhospice.ca/Assets/CFS-PPS%20Poster%20FORMAT%20APR18_20151120154653.pdf