

END-OF-LIFE LEARNING SERIES

END-OF-LIFE, DEATH AND DYING GLOSSARY AND TERMINOLOGY FOR LGBTQ+ COMMUNITY

GENERAL TERMS:

ADVANCE HEALTH CARE PLANNING: Regardless of age or health conditions, every LGBTQ+ individual can benefit from engaging in advance health care planning. The process includes reflecting on, understanding and ultimately sharing your personalized values, beliefs, decisions, goals, and preferences regarding your medical care. These legal arrangements outline an individual's specific healthcare choices. This can be completed either by designating a family member, friend or appointee (also known as an agent, proxy or surrogate) or by completing an advance care directive. This is particularly of importance for members of the LGBTQ+ community who may have chosen family or partners in lieu of biological family members. Additional directives can be put into place to protect transgender individuals from "de-transitioning" after death, language to ensure that deadnaming after death is avoided in obituaries and any funeral arrangements.

ADVANCED HEALTH CARE DIRECTIVE: This includes two legal documents: 1. living will and 2. durable power of attorney (also known as medical power of attorney, health care proxy or health care agent). These documents include legally binding instructions detailing medical care in the event an individual is unable to communicate or make such decisions for themselves due to illness or incapacity. These are considered what is called "living documents", meaning that they are meant to shift and change as our life circumstances evolve.

CAPACITY: An individual has medical decision-making capacity if they have the ability to understand the medical problem as well as the risks and benefits of the available treatment options. The term is frequently used interchangeably with competency but is not the same.

COMPETENCY: A legal status of an individual imposed by the court.

DURABLE POWER OF ATTORNEY: A legal document that allows an individual to designate a person, known as an agent, surrogate or proxy, to make health care decisions on an individual's behalf in the event an individual is unable to communicate or make such decisions for themselves due to illness or incapacity; also known as medical power of attorney, healthcare proxy, or appointment of a healthcare agent.

DURABLE POWER OF ATTORNEY FINANCIAL: A legal document that allows an individual to designate a person, known as an agent to act in matters on another's behalf regarding financial or real estate transactions.

EXECUTOR: The legal term referring to the individual designated to carry out the directions of a will. The executor, the durable power of attorney may be different individuals. This is of particular importance for the LGBTQ+ community so that estranged family members or court appointed persons are not designated following death of the LGBTQ+ individual.

GUARDIAN: A court appointed individual who has been granted the legal authority and the duty to care for the personal and property interests of another person. The guardian and the health care proxy may be different individuals.

INCAPACITY: A lack of physical or mental abilities that results in an individual's inability to manage their own care, property or finances; a lack of ability to understand one's actions when making a will or other legal document.

LIVING WILL: A document that outlines an individual's wishes about medical treatment should they be at the end of life and unable to communicate or make decisions for themselves. Also known as "directive to physicians", "healthcare declaration," or "medical directive."

MEDICAL or PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT: MOLST/POLST is a binding physician's order intended for acutely ill patients outlining which life-sustaining treatments are desired. These orders help to translate an individual's advance directives into a clear set of medical orders to ensure that an individual's preferences are honored no matter where they receive care. MOLST document becomes effective immediately upon signing and is not dependent upon an individual's loss of capacity. It does not take the place of a health care proxy. These are legally binding documents and are typically printed on bright colored cardstock and displayed prominently near the individual's bed or door.

PROXY: A designated individual legally empowered to make decisions related to the health care in the event that they are unable to communicate or make such decisions for themselves due to illness or incapacity.

END OF LIFE TERMS:

ANTICIPATORY GRIEF: This refers to the complex range of emotions that can come up when an individual has a life-threatening illness. Anticipatory grief can oftentimes feel as painful as those felt at the time of the death of an individual.

BEREAVEMENT: The process of grieving and mourning the death of a spouse, partner, loved one, friend or pet; oftentimes characterized by sadness and a deep sense of grief.

COMFORT CARE: An essential component of end-of-life care that aims to prevent pain and/or relieve suffering, soothing an individual who is at the end of their life or dying. The goal is to center the quality of life while respecting the dying person's wishes.

DEATH CARE PLAN: This includes a detailed outline of preferences that an individual has for the end of their life and dying. It can include specifics on everything from music they would want playing, gentle touch or massage, aromatherapy, lighting in the room, to detailing specific visitors who are welcome, or not.

DEATH CAFÉ: Community gathering where folks can get together and talk openly about what death and dying looks like, ask questions, share concerns or fears in a safe group setting.

END OF LIFE: Refers to the period leading up to dying and death; typically referring to a life expectancy of 6 months or less to live.

HOLISTIC CARE: Treatment of the whole person including emotional, social, spiritual, intellectual and physical care for both the individual and their loved ones.

HOSPICE: A team-oriented approach to quality, compassionate care for individuals expected to live six months or less. Hospice is voluntary and relies on the participation of the individual's family and/or loved ones. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness. Palliative treatments can continue during hospice care.

Hospice provides medical care, pain management, and emotional and spiritual support expressly tailored to the individual's changing needs and wishes. Care is extended to the dying persons loved ones as well.

LONG TERM CARE: A facility that provides 24-hour professional care and supervision for individuals with complex health needs. Staff administer medications and assist individuals who require help with daily activities such as eating, bathing and dressing.

PALLIATIVE CARE: A comprehensive approach to treating illness that focuses on the physical, psychological, spiritual, and existential needs of the individual. The goal is to achieve the best quality of life available for the individual by controlling pain, relieving suffering and emotional and spiritual distress, and symptoms. Palliative care can begin at diagnosis and at the same time as treatment; palliative care can be given at any stage of an illness, including when an individual is pursuing potentially life-extending treatments.

RESPITE CARE/RESPITE STAY: Relief provided to a primary caregiver, oftentimes by a hospice volunteer, who stays with the dying person so the primary caregiver can take a break. Arrangements can be made by hospice to provide care for an individual (up to five days) to provide a longer period of rest for the primary caregiver.

TERMINAL LUCIDITY: The unexpected return of mental clarity, memory or a sudden consciousness that occurs sometimes shortly before death. Also known as paradoxical lucidity or the rally.

MEMBERS OF INTERDISCIPLINARY CARE TEAMS:

CAREGIVER: An individual (typically not considered a medical professional) who provides physical and emotional assistance to a loved one, family member or friend.

DEATH DOULA: An individual who assists and guides through the dying process, like a midwife or doula does with the birthing process. It is often a community-based role, aiming to help families cope with death through recognizing it as a natural and important part of life. Components of a doula's work can include education, support before, during and post-mortem, and celebrant. A doula is always, first and foremost, in service of the dying person's wishes.

HOME AND COMMUNITY CARE: Covers a range of supportive services provided in the home and other settings. Staff work closely with medical providers, palliative care services and hospice. Other services or providers may include:

- nursing
- physiotherapy and occupational therapy
- nutrition
- social work
- case management
- home support
- end-of-life care
- death doulas
- adult day programs
- community clinics
- assisted living
- access to residential care facilities short term residential care for caregiver relief

INTERDISCIPLINARY TEAM: The hospice care team typically includes a medical director, nurse, social worker, certified nurse's assistant or home health aide, chaplain, volunteers, and grief specialist.

OCCUPATIONAL THERAPIST: A trained provider who helps to manage daily living activities: eating, drinking, dressing, toileting, etc. following injury, surgery, or during illness.

PHYSICAL THERAPIST: A trained provider who helps individuals regain mobility following surgery, disease or injury or assists with maximizing diminished physical strength and mobility to maintain as much independence as possible. Also known as a physiotherapist.

MEDICAL TERMS:

AGGRESSIVE TREATMENT: This can include medications, procedures or any treatment intended to cure or slow the progress of an illness.

APNEA: The cessation of breath for a short period of time, typically lasting less than 20 seconds but sometimes for as long as a minute.

ARTIFICIAL NUTRITION & HYDRATION: Replaces eating and drinking by mouth and provides nutrients and/or fluids through a tube or IV (into the stomach, upper intestine or a vein).

BRAIN DEATH: The irreversible loss of all brain function.

CARDIAC ARREST: When the heart stops beating.

CARDIOPULMONARY RESUSCITATION: CPR is an attempt to restarting an individual's heart and/or breathing through mouth-to-mouth breathing, chest compressions and/or electric shock; medications can also be used to stimulate the heart.

CHRONIC ILLNESS: An ongoing condition or illness that doesn't respond completely to treatment.

COMA: A deep state of unconsciousness where the individual is alive but not able to respond.

DEMENTIA: A decline in mental functioning more significant than would be expected due to aging.

DIALYSIS: The process of filtering blood through a machine in order to remove waste from the body in lieu of normal kidney functioning. Dialysis can be done temporarily to allow the kidneys time to heal or it can be done on a long-term basis to prolong life.

DO NOT HOSPITALIZE: DNH are medical orders signed by a medical professional that instruct health care providers to NOT transfer an individual from a nursing facility or one's home to the hospital, unless specifically required for comfort.

DO NOT INTUBATE: DNI are medical orders signed by a medical professional that instruct health care providers to NOT attempt intubation or artificial ventilation in the event of respiratory distress.

DO NOT RESUSCITATE: DNR are medical orders from a physician instructing healthcare providers to NOT attempt to revive the person through CPR in case of cardiac or respiratory arrest. While a DNR order is written at the request of an individual or their designee, it must be signed by a physician to be valid.

An out of hospital non-hospital DNR are medical orders from a physician for individuals with a terminal illness (not elderly or frail persons) who are at home and do not want to receive CPR.

DYSPHAGIA: Difficulty in swallowing.

DYSPNEA: Difficulty breathing, especially during exertion or when lying down.

END-STAGE DISEASE: The last phase of a disease. It has largely replaced the term "terminal."

FAILURE TO THRIVE: In the elderly, a diagnosis based on weight loss, decreased appetite, poor nutrition, and inactivity.

FATAL DISEASE: The natural course of illness will be fatal (i.e. Cancer, Heart Attack, Pneumonia) but with treatment, often is not fatal.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT: HIPPA is the federal law that requires the protection of sensitive patient health information from being disclosed without an individual's expressed consent. HIPPA also allows individuals to get copies of their medical records from their medical providers.

INTUBATION: Refers to the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

LIFE SUPPORT OR LIFE-SUSTAINING MEASURES: All medical treatments used to prolong life. These can include medical procedures that replace or support essential bodily functions for example CPR, mechanical ventilation, artificial nutrition and hydration, dialysis, and other treatments.

MECHANICAL VENTILATION: A machine that supports or replaces the function of the lungs. Ventilators (or respirators) force air into the lungs.

MEDICAL AID IN DYING: MAID is the process by which a terminally ill individual gets a prescription for a lethal dose of medication, prescribed by a medical professional, that the individual intends to administer themselves to end their own life.

PALLIATIVE SEDATION: The administration of sedating medications intended to decrease an individual's consciousness, alleviating suffering, but not to hasten the end of life. Oftentimes this results in an individual being in a deeply sedated state throughout the remainder of the dying process and death.

PROGNOSIS: An estimate, given by a doctor, based on the experience with the same disease and how the disease will progress. A prognosis may or may not include life expectancy, depending on the severity of the disease and the likeliness of the cure.

TERMINAL PROGNOSIS/TERMINAL ILLNESS: A disease or illness that has advanced beyond the point of reasonable hope for a cure and typically means less than 6 months to live.

TERMINAL RESTLESSNESS: This occurs within the last few days of life or just before death where some individuals become restless, agitated or confused.

VEGETATIVE STATE: When an individual loses all cognitive functioning, any awareness of their environment but may retain non-cognitive functioning i.e. wake-sleep cycles.

VOLUNTARY STOPPING EATING AND DRINKING: VSED is when an individual voluntarily refuses all nutrition and fluids, including through a feeding tube, with the understanding that doing so will allow the dying to happen. VSED is a legal right available to anyone who wishes to shorten their dying process. Oftentimes VSED is a offers a more gentle end of life sometimes referred to as a "dry death."

WITHHOLDING TREATMENT: Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.