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Arizona END OF LIFE CARE PARTNERSHIP
Anchored at United Way of Tucson and Southern Arizona

The David and Lura Lovell Foundation
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Glossary of Common End of Life Terms

The terms and definitions listed below represent some of the most significant social, medical, and legal concepts related to End of Life Care Planning. The list is not intended to be comprehensive, and the information provided does not represent medical or legal advice. If you have additional questions, or desire to be connected to resources that can assist you in your End of Life Care Planning needs, please call the PCOA Helpline at (520) 790-7262.

Acute Illness: An acute illness is one which is serious or painful, but anticipated to last for only a brief period of time. There are some acute illnesses that may evolve into chronic health conditions.

Advance Care Planning: Advance Care Planning is the same as End of Life Care Planning. It is the process whereby a person thinks through their values, and documents their preferences for the types of care desired and not desired in the event that they become unable to communicate those wishes due to serious or chronic illness, or incapacitation.

Advance Directives: "Advance directives" is a generic term for a group of documents, typically:

- Living Will
- Healthcare Power of Attorney
- Mental Healthcare Power of Attorney
- Do Not Resuscitate Order (Pre-Hospital Medical Directive)

that are prepared by a person, prior to serious illness or incapacitation, to ensure that their wishes will be honored in the event of their inability to communicate these wishes. In order to be legally valid, the person signing an advance directive must be able to understand the nature of the document being signed. An advance directive can be revoked. Advance directive documents should be copied and shared with family members–especially those named as agents, as well as with physicians, and hospitals.

There are four most typically used templates for advance directives. These include:

- Arizona Life Care Planning Packet (a multi-page document including a Living Will, Healthcare Power of Attorney, and Mental Healthcare Power of Attorney with instructions): https://www.azag.gov/sites/default/files/docs/seniors/life-care/2018/Life-Care-Planning-Packet-Complete.pdf Also available in Spanish: https://www.azag.gov/sites/default/files/docs/seniors/life-care/2018/Spanish_LCP_Updated_5-14-18.pdf
- Arizona Short Forms (a one-page Living Will and one-page Power of Attorney form available in English or Spanish): https://www.thoughtfullifeconversations.org/forms
- Five Wishes (a user-friendly booklet that provides a Living Will and Healthcare Power of Attorney along with prompts to consider values and desired legacy): https://fivewishes.org/
  Also available in other languages: https://fivewishes.org/translations
- Prepare for Your Care (a California form adapted for Arizona by the Arizona Hospital and Healthcare Association; contains large print, colorful illustrations, and worksheet pages that assist in making healthcare decisions; available in English or Spanish): https://www.thoughtfullifeconversations.org/forms

Agent: An agent is someone named by a person and given authority, in an advance directive, to make decisions (e.g. medical healthcare or mental healthcare) on behalf of the person who is not able to make or express decisions on their own. An agent is also known as a proxy, or a Power of Attorney.

Aggressive Treatment: Aggressive treatment is attempting every possible medical intervention to cure disease, or to prolong life. In many cases, aggressive treatment can create side effects or unintended complications.

Arizona Advance Directive Registry: In the future, the Arizona Advance Directive Registry will be hosted and maintained by a healthcare organization called Health Current. A person's end of life care plans will be accessible by healthcare professionals as part of their electronic health record.

Artificial Nutrition and Hydration: Artificial nutrition and hydration is provided to supplement or replace ordinary eating and drinking when a person is unable to consume enough food or water to sustain health, or life. A chemically balanced mix of nutrients and fluids is delivered through a tube inserted directly into the GI tract or a vein.

Capacity: In end of life care planning, capacity is a person's ability to understand their medical condition, treatment options, and the risks and benefits of both pursuing and refusing treatment. The person's ability to remember, process, or understand other

unrelated concepts is not necessary to establish decision-making capacity for healthcare decisions. Capacity may be evaluated by healthcare providers, mental healthcare providers, attorneys, or a judge.

Cardiopulmonary Resuscitation (CPR): CPR is a procedure used to treat someone who has stopped breathing and whose heart has stopped beating. It is used to maintain oxygen in the blood and blood circulation. It may involve just chest compressions, or emergency medical personnel may provide intubation and mechanical ventilation. In some cases, the heart may be stimulated in an attempt to restart it by electric shock (through an AED (Automatic External Defibrillator)) or physician-ordered drugs.

Chronic Illness: A chronic illness is a disease that is expected to last one or more years and requires regular and continuing medical treatment. A chronic illness may also limit a person's ability to participate in life activities or care for one's self. Some people experience more than one chronic illness.

Comfort Care: Comfort care, also known as palliative care, is medical treatment focused on reducing a person's experience of disease symptoms, including pain, rather than emphasizing a cure. Palliative care is a holistic approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the person to ensure the highest quality of life. Over the course of a lifetime, palliative care may or may not be combined with curative treatment. A person can request comfort care at any time—regardless of age or medical situation.

Conservatorship: A conservatorship is the result of a legal court proceeding in which a judge removes financial decision-making authority from an individual who is deemed incapacitated, or unable to make their own financial decisions. The judge transfers decision-making power to another individual who becomes a "conservator." A conservator must meet legal requirements to be appointed and to maintain the conservatorship.

Curative Treatment: Curative treatment is medical care focused on curing a person's disease, or prolonging life. It often includes aggressive treatment and can create side effects or unintended complications. Curative treatment may also be accompanied by comfort, or palliative care.

Do No Harm: Known as non-maleficence, care providers are expected to consider whether continuing curative, or life-sustaining treatments is potentially more harmful than discontinuing those treatments. To "do no harm" is to consider the whole person receiving care (physical, mental, social, and spiritual) and to offer options that provide the greatest benefits with the fewest risks.

Do Not Resuscitate (DNR) Order: A DNR is sometimes called "Pre-Hospital Medical Care Directives" or "orange cards." These forms, which must be signed by a physician and printed on bright orange paper to have legal effect, ask emergency medical personnel to withhold life-saving measures in the event that a person's heart or breathing stop. Presenting this document to medical personnel means that the person understands that death may result from their wish to withhold resuscitation. NOTE: The Pre-Hospital Medical Care Directive is a standardized form that must be printed on bright orange paper and signed by a physician to be valid. A recent photo of the person should be attached to the form.

Durable Financial Power of Attorney: A Durable Financial Power of Attorney allows a person (known as the "principal") to choose another individual (known as an "agent") to make fiancial decisions on their behalf, and in their best interest, if they become too ill to make or communicate decisions. The agent may only make decisions that benefit the person involved, and the agent cannot personally benefit from the Power of Attorney unless there is language in the document that specifically allows it. While templates are commonly available, it is recommended that an attorney is retained to draw up a Durable Financial Power of Attorney to protect the principal against fraud or exploitation. Additionally, attorneys can include legal statements that grant rights to the agent to manage the principal's personal affairs like turning off utilities as needed. A Durable Financial Power of Attorney must be signed by the principal, and a witness, and a notary.

Durable Healthcare Power of Attorney: A Durable Healthcare Power of Attorney allows a person (known as the "principal") to choose another individual (known as an "agent") to make healthcare decisions on their behalf, and in their best interest, if they become too ill to make or communicate decisions. Once the person regains the ability to communicate or make decisions, the agent is no longer authorized to do so. This document can include a person's wishes as to which medical procedures or interventions they do or do not want to receive. A Durable Healthcare Power of Attorney must be signed by the principal, and a witness, or a notary. NOTE: A Medical or Healthcare Power of Attorney gives the agent authority to make all medical care decisions unless specific limitations are included ahead of time.

Durable Mental Healthcare Power of Attorney: A Durable Mental Healthcare Power of Attorney allows a person (known as the "principal") to appoint another individual (known as an "agent") to make mental healthcare decisions on their behalf, and in their best interest, if they become unable to do so. It allows the agent, in consultation with a neurologist or psychiatrist, to have the principal committed to a locked mental health facility for treatment. A Durable Mental Healthcare Power of Attorney must be signed by the principal, and a witness, or a notary. NOTE: This document can be helpful for someone with a mental illness or a disease related dementia where institutional mental health services may be needed in the future. Mental health institutional placements are not covered by a regular Health Care Power of Attorney and require a court proceeding—unless a Mental Healthcare Power of Attorney has been prepared ahead of time.

End of Life Care Planning: End of Life Care Planning is the same as Advance Care Planning. It is the process of thinking through values and documenting preferences for the types of care desired and not desired in the event that a person is unable to communicate those wishes because of illness and incapacitation. Effective End of Life Care Planning typically involves end of life education, conversation with loved ones, discussions with healthcare providers, formalizing documents, and sharing copies of end of life documents with loved ones, agents, healthcare providers, and hospitals.

Fiduciary: A fiduciary is a person who accepts responsibility for taking care of the needs or property of another person for the sole benefit of that person. A public fiduciary is a county official who has statutory responsibility to assume guardianship of incapacitated persons who have no one to assume this role for them. A private fiduciary is a person who has been certified or licensed to serve as a personal guardian or conservator, and has been retained and paid for voluntarily.

Financial Power of Attorney: See Durable Financial Power of Attorney.

Guardianship: Guardianship is the result of a legal court proceeding in which a judge removes decision-making authority from an individual who is deemed incapacitated, or unable to make decisions and transfers it to another individual—known as a "guardian." The judge transfers decision-making power to another individual who becomes a guardian and makes all decisions for the person the same way that a parent makes decisions for a child.

Healthcare Power of Attorney: See Durable Healthcare Power of Attorney.

Hospice: Hospice is comfort care for people facing a life-limiting illness or injury, and who are believed to have less than six months to live. Hospice engages an expert team to provide non-curative medical care, pain management, and emotional and spiritual support tailored to the person's needs and wishes. Hospice services are available to any qualifying patient, regardless of age, race, religion, or illness, and is covered under Medicare, AHCCCS (Arizona's Medicaid program), and most private insurance plans. Support is also provided to the hospice client's loved one(s) or caregivers. Hospice can be provided in a person's home, an assisted-living residence, a skilled nursing facility, a hospital, or an in-patient hospice building.

Incapacitation: Incapacitation is the state of being when a person is mentally and/or psychologically unable to make informed and consensual decisions, or to understand the effect of those decisions, or is unable to communicate their wishes.

Informed Consent: Informed Consent is the process by which a person receives complete information about their treatment options, understands the potential risks and benefits of both the treatment options and the outcome of refusing treatment, and voluntarily agrees to a specific course of action. In many cases, a person is required to

provide a signature as proof of informed consent for healthcare treatments.

Intake: Intake is a term often used for an introductory or assessment interview, and is completed by social service, mental healthcare, healthcare, and other providers. The questions asked can be personal in nature, and are often necessary to determine the person's condition or state, and appropriate interventions or treatments. Professionals who conduct intake interviews are professionally and ethically expected to regard the person with the utmost respect, and the information provided with confidentiality.

Intubation: Intubation is the medical insertion of a tube from a person's nose or mouth into their windpipe. Intubation seeks to create and preserve an open airway so that a person can receive oxygen and to release carbon dioxide.

Legacy: Simply put, legacy is a gift given to a person's self as well as to others. Meaningful end of life care planning includes examining and exploring legacy. A person may create personal legacy by making amends with an offended person, or extending forgiveness to another who caused offense. Creating legacy for others may include gifting loved ones, or the community, with tangible (money, assets, or treasured items) or intangible (memories, well-wishes and blessings, or a call to action) benefits.

Life-Sustaining Treatment: Life-sustaining treatment, also known as "life support," is medical procedures that support, or replace a function essential to the human body for living. Life-sustaining treatment is intended to delay the dying process for a person with a terminal illness. They can also be used temporarily in other situations like trauma or post-surgery to get a person through a period of instability when their body needs extra support to recover. Examples of life-sustaining treatments include dialysis, artificial nutrition and hydration, mechanical ventilation, and CPR.

Living Will: A Living Will allows a person to identify, in advance, which medical procedures or interventions they do or do not wish to receive. A Living Will is intended to guide treatment in the event that the person becomes unable to make, or communicate decisions due to an irreversible coma, persistent vegetative state, or similar type of condition. A Living Will may be a stand-alone document, or included as part of a Durable Healthcare Power of Attorney (see above). The Living Will must be signed by the person, and a witness, or a notary. NOTE: When creating a Living Will, it is important to speak with a healthcare professional about the meaning of all the terms and treatments that are included, as well as the potential implications of the decisions being made.

Mechanical Ventilation: Mechanical ventilation forces air into the lungs with a ventilator machine when the lungs are not functioning at healthy or life-sustaining levels. The ventilator is attached to a tube which is inserted, or intubated, into the windpipe.

Medical Power of Attorney: See Durable Healthcare Power of Attorney.

Mental Health Power of Attorney: See Durable Mental Health Power of Attorney.

Notary: Also known as a Notary Public, or Public Notary, is a state-appointed official whose job it is to deter fraud by verifying a person's identity and their willingness to sign important documents, and then witnesses the signing of those documents. A Notary's seal provides proof of validity for those important documents. While notarization is not required for Advance Directive documents in Arizona, it is recommended (a Notary's signature is required on Financial Power of Attorney documents). Notary services are performed at many banking institutions and mailbox stores.

Palliative Care: Palliative care, also known as comfort care, is medical treatment focused on reducing a person's experience of disease symptoms, including pain, rather than emphasizing a cure. A person can request comfort care at any time—regardless of age or medical situation. Palliative care is a holistic approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best possible quality of life by controlling pain and symptoms. Over the course of a lifetime, palliative care may or may not be combined with curative treatment.

Person-Centered Care: Person-centered care, whether provided by a friend, family caregiver, or healthcare provider, is care that recognizes the whole person—body, heart, mind, and spirit rather than simply the person's illness, disease, or disability. It involves respecting the person's values and priorities, including them in decision-making, honoring their self-determination, and preserving their dignity.

POLST (Physician's Orders for Life-Sustaining Treatment): A POLST is both a legal document and a doctor's order for a patient believed to be at risk for a life-threatening event. A physician completes the POLST form in conversation with a person who has an advanced, progressive, or terminal illness. A POLST defines the end of life care the person wishes and does not wish to receive, and healthcare professionals are obligated to honor the POLST whether the person is at home, or in a hospital, assisted living facility, or skilled nursing facility. A POLST is not considered an advance directive, and if a patient's end of life care plan contradicts a POLST order, the plan takes precedence. POLST order originals are maintained by the person's healthcare provider. Any copies should be made on bright pink paper and should be displayed on the person's refrigerator (or other prominent location). Copies, on bright pink paper, may also be provided to the person's Durable Healthcare Power of Attorney, physicians, and care facilities

Pre-Hospital Medical Care Directive: Pre-Hospital Medical Care Directives are sometimes called "Do Not Resuscitate" forms or "orange cards." These forms, which must be signed by a physician and printed on bright orange paper to have legal effect, ask emergency medical personnel to withhold life-saving measures in the event that a person's

heart or breathing stop. Presenting this document to medical personnel means that the person understands that death may result from their wish to withhold resuscitation. NOTE: The Pre-Hospital Medical Care Directive is a standardized form that must be printed on bright orange paper and signed by a physician to be valid. A recent photo of the person should be attached to the form.

Principal: A principal is the person who expresses their wishes in Powers of Attorney documents, and appoints another person to act as their agent if incapacitated. A principal is the one whose best interest is protected by advance directives.

Prognosis: A prediction about the future course of an illness or disease based on patterns observed in and experienced by other people with the same illness or disease.

Proxy: A proxy is a person named and given authority, in an advance directive, to make decisions (e.g. medical healthcare or mental healthcare) on behalf of someone else who is not able to make or express decisions on their own. A proxy is also known as an agent or Power of Attorney.

Quality of Life: According to Britannica, quality of life is "the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events….Within the arena of healthcare, quality of life is viewed as multidimensional, encompassing emotional, physical, material, [spiritual], and social well-being."

Questions for a Healthcare Provider after a Chronic or Terminal Illness Diagnosis:
- What is my diagnosis?
- What are the physical and emotional effects of this illness?
- How might my life look different in six months, one year, or five years?
- What are some of the "big changes" in how I feel, how I behave/function, and how I relate to others that my family and I should be prepared for?
- What treatment options are available? And what is their intended purpose (to cure my illness, prolong my life, or reduce my symptoms)?
- What are the potential side effects of my treatment options?
- What end of life considerations should I be aware of because of my illness?

Revocation, or to Revoke an Advance Directive: A person has a right to change and/or terminate (revoke) their own advance directive as long as they have cognitive capacity to make such a change. Reasons for revoking an advance directive may include the following:
- You wish to name a new person to serve as a Power of Attorney
- You have changed your mind about desired treatments
- You prefer different arrangements for your remains or memorial service

It is important to communicate the revocation in writing, and to provide written notice to your Power(s) of Attorney, healthcare providers, hospitals, and the Arizona Advance Directive Registry. NOTE: It is highly recommended that when an advance directive is

revoked, an up to date replacement be completed at the same time.

Right to Self-Determination: The right of each adult individual, with capacity, to freely make decisions for themselves, without interference, as long as the decision is in keeping with local, state, and federal laws.

Surrogate: A surrogate is a person named and given authority, in a medical emergency, to make healthcare decisions on behalf of someone else who is not able to make or express decisions on their own. A surrogate is assigned according to state laws for surrogate decision-makers.

Surrogate Decision Makers–Statutory Priority: According to Arizona State Statute 36-3231, if a person becomes unable to make or communicate healthcare treatment decisions and has not prepared an advance directive, a surrogate decision-maker can make healthcare decisions on their behalf. If willing and available, the following individuals can serve as surrogates regarding treatment decisions (in order of priority):

- Spouse (unless legally separated)
- Adult child
- Parent
- Domestic partner
- Sibling
- Close friend, or
- Attending physician

There are some things that a person with a Durable Healthcare Power of Attorney can do that an appointed surrogate cannot do. One such example is to authorize removal of a feeding tube.

Terminal Illness: A terminal illness is a physical disorder, like infection or disease, that will cause death. A terminal illness is called "incurable" if no conservative treatments are available to eliminate, or "cure" the infection or disease.

Values: Values are those standards or principles by which a person lives; those tangible and intangible items of value and importance. Values can also include a person's beliefs about what is right or wrong.

Ventilator: A ventilator, also known as a respirator, is a machine that pushes air into the lungs through a breathing tube placed in the windpipe through the intubation process. A ventilator may be used when a person cannot breathe on their own, or is breathing ineffectively such that there is not enough oxygen or too much carbon dioxide in the cells.

Withholding or Withdrawing Treatment: Withholding or withdrawing treatment is a decision made by a person, or their agent, to forego life-sustaining measures or to

discontinue them after some period of time. This decision can be communicated in an advance directive prior to the situation. Or, this decision may have to be made in an acute illness or injury situation. If the decision is made by a principal's agent, it should always be made in the principal's best interest.

Witness: In end of life matters, a witness is typically the term used for a person who observes a principal sign important documents, including advance directives, and whose signature provides proof of the principal's ability to make reasonable decisions and evidence of the principal's formal end of life decisions. A witness is 18 years of age or older, and must not be a family member (by blood, adoption, or marriage), and must not be providing healthcare to the principal. Possible witnesses may include a neighbor, friend, or acquaintance, but the witness may not represent the principal or receive benefit from serving as the witness.