Arizona END OF LIFE CARE PARTNERSHIP

Anchored at United Way of Tucson and Southern Arizona

Glossary of End-of-Life Terms

Including Medical and Legal Terminology

Table of Contents

Acute Illness

- Any illness that develops quickly, is intense or severe, and lasts only a short period of time and usually responds to therapy.
- Examples: Infection, trauma, fracture.
- May lead to chronic health conditions.

Advance Care Planning

- Also called end-of-life care planning.
- Process whereby a person thinks through their values and documents their preferences for the types of care desired and not desired in the event they were unable to communicate due to serious or chronic illness or incapacitation.
- Decisions based on personal values, preferences, and discussions with loved ones and healthcare providers.

Advance Care Planning Documents/Resources

- **Arizona End of Life Care Partnership**
  https://www.azendoflifecare.org/resources
- **Health Current**
  Arizona Resources on Advance Care Planning
- **Arizona Hospital and Healthcare Association (AzHHA)**
  https://www.azhha.org/tlc_forms
  - Pre-hospital Medical Care Directive – Do Not Resuscitate (DNR-orange form)
  - POLST
  - Living Will (English & Spanish)
  - AZ Health Care Power of Attorney with Optional Mental Health Authority Short Form (English & Spanish)
- **Arizona Attorney General Life Care Planning Packet**
  https://www.azag.gov/seniors/life-care-planning
  - Pre-hospital Medical Care Directive – Do Not Resuscitate (DNR-orange form)
  - POLST
  - Living Will (English & Spanish)
  - AZ Health Care Power of Attorney (English & Spanish)
  - AZ Mental Care Power of Attorney (English & Spanish)
- **Five Wishes**

- https://fivewishes.org/

Advance Directives

- A document drafted according to Arizona law that outlines wishes regarding healthcare and treatment.
- These documents go into effect when a person is no longer capable of making or communicating their own decisions.
- There are several documents that are listed as Advance Directives according to A.R.S. §36-32 in the state of Arizona, including:

  1. Living Will
  2. Health Care Power of Attorney

3. Mental Health Care Power of Attorney
4. Pre-hospital Medical Care Directive – Do Not Resuscitate (DNR-orange form)

Agent (person)

- An individual (over the age of 18) who has been chosen to make healthcare treatment decisions for a person.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- Also called appointed decision-maker, healthcare power of attorney, representative, attorney-in-fact, or proxy.

Aggressive Treatment

- Attempting every possible medical intervention to cure disease or to prolong life.
- Might result in unintended complications.

Appointed Decision-Maker (person)

- An individual (over the age of 18) who has been chosen to make healthcare treatment decisions for a person.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- Also called healthcare power of attorney, representative, attorney-in-fact, or proxy.

Arizona Healthcare Directives Registry (AzHDR)

https://azhdr.org/

- The Arizona Healthcare Directives Registry (AzHDR) is managed by Health Current.
- Designed to help honor patients' end-of-life healthcare wishes by providing seamless access to Advance Directives across the continuum of care.
- The AzHDR provides a reliable and safe place to upload and make accessible Arizonans' Advance Directive documents so end-of-life care will be guided by one's wishes.
- Secure and confidential.
- Registering Healthcare Advance Directives with the Arizona Healthcare Directives Registry will ensure wishes registered are wishes honored.
- The AzHDR will accept healthcare directives submitted in compliance with Arizona Healthcare Directives Law (ARS 36-2301-3287), including:
  1. Living Will
  2. Health Care Power of Attorney
  3. Mental Health Care Power of Attorney
  4. Prehospital Medical Care Directives (DNR-orange form)

Artificial Nutrition and Hydration

- A medical treatment when a patient is no longer able to take in nutrition (food) or hydration (fluids) by mouth.
- Can be done through a tube either through the nose into the stomach (short term) or through surgical placement of a tube through the skin into the stomach (long term).

Attending Provider

- A physician (doctor). Physician's Assistant (P.A.), or Nurse Practitioner who has the primary responsibility for a patient's healthcare.

Attorney-in-fact (person)

- An individual (over the age of 18) who has been chosen to make healthcare treatment decisions for a person.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- Also called appointed decision-maker, healthcare power of attorney, representative, agent, or proxy.

Capacity

- A person's ability to understand their medical condition, treatment options, and the risks and benefits of pursuing or refusing treatment.
- Person's ability to remember, process, or understand other unrelated concepts is not necessary to establish decision-making capacity for healthcare decisions.
- May be evaluated by healthcare providers, mental health care providers, attorneys, or a judge.

Cardiopulmonary Resuscitation (CPR)

- A group of treatments used when someone's heart and/or breathing stops.
- Performed to restart the heart and breathing.
- May consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate.
- Electric shock and drugs also are used frequently to stimulate the heart.

Chronic Illness

- Disease or disease process that is expected to last one or more years and requires regular and continuing medical treatment.
- May also limit a person's ability to participate in life activities or care for oneself.
- More than one chronic illness can be experienced at the same time.

Comfort Care

- Includes physical, emotional, social, and spiritual support for patients and their families.
- The goal of comfort care is to control pain and other symptoms so the patient can be as comfortable as possible.
- May include palliative care, supportive care, and hospice care.

Conservatorship

- 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."
- Conservator must meet legal requirements to be appointed and to maintain the conservatorship.

Curative Treatment

- Medical care focused on curing a person's disease or prolonging life.
- Often includes aggressive treatment.
- Curative treatment may also be accompanied by comfort or palliative care.

Decision-Making Capacity

- A patient has medical decision-making capacity if they can understand the medical problem and the risks and benefits of the available treatment options.
- The patient's ability to understand other unrelated concepts is not relevant.
- The term is frequently used interchangeably with "competency" but is not the same; competency is a legal status imposed by the court.

Do No Harm

- Known as non-maleficence.
- Providers are expected to consider whether continuing curative or life-sustaining treatments is potentially more harmful than discontinuing those treatments.
- Considers the whole person (physical, mental, social, and spiritual).
- Offers options that provide the greatest benefits with the fewest risks.

Do Not Resuscitate (DNR) Order (orange form)

- In Arizona, this is called a Pre-hospital Medical Care Directive.
- Also referred to as a No Code or Allow Natural Death.
- A written order instructing healthcare providers and first responders not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest.
- A person with a valid DNR order will not be given CPR under these circumstances.
- Although the DNR order is written at the request of a person or their family, it must be signed by a licensed health care provider to be valid.
- In Arizona, a non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.
- It must be on orange paper.
- Patients **can** receive all comfort measures, including medications for pain or infection, with a DNR order in effect.

Durable Financial Power of Attorney (document)

- A legal document that allows a person (known as the "principal") to choose another individual (known as an "agent") to make financial 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.
- 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.
- A Durable Financial Power of Attorney must be signed by the principal, and a witness, **and a notary**.

Durable Healthcare Power of Attorney (document)

- A legal document that 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.
- Unless the document includes specific limits, the agent will have broad authority to make any healthcare decision you could normally make for yourself.
- Healthcare Power of Attorney documents do not provide for any financial decision-making powers.

- The person appointed may be called a healthcare agent, representative, surrogate, attorney-in-fact, or proxy.
- A Durable Healthcare Power of Attorney must be signed by the principal, and a witness, **and a notary**.

Durable Mental Healthcare Power of Attorney (document)

- 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. This can occur because of dementia or medication interactions or a mental health diagnosis.
- It allows the agent, in consultation with a neurologist or psychiatrist, to make decisions regarding behavioral health placement and treatment.
- 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.
- The person appointed may be called a healthcare agent, representative, surrogate, attorney-in-fact, or proxy.
- A Durable Mental Healthcare Power of Attorney must be signed by the principal, and a witness, **and a notary**.

Emergency Medical Services (EMS)

- A group of governmental and private agencies that provide emergency care usually to persons outside of healthcare facilities.
- EMS personnel generally include paramedics, first responders, and other ambulance crew.

End-of-Life Care Planning – See Advance Care Planning

- Process whereby a person thinks through their values and documents their preferences for the types of care desired and not desired in the event they were unable to communicate those wishes due to serious or chronic illness or incapacitation.
- Decisions based on personal values, preferences, and discussions with loved ones and healthcare providers.

Fiduciary

- A person who accepts responsibility for taking care of the needs or property of another person for the sole benefit of that person.
- A government official who has statutory responsibility to assume guardianship of incapacitated persons who have no one to assume this role for them.
- A private fiduciary 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 (person)

- A person designated in the Durable Financial Power of Attorney document to carry out the conditions in the document.

First Responder

- A law enforcement officer, a firefighter or an ambulance attendant as defined in section A.R.S. 36-2201.

Guardianship (Adult)

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

Healthcare Power of Attorney (person)

- An individual (over the age of 18) who has been chosen to make healthcare treatment decisions for a person.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- Also called appointed decision-maker, agent, representative, attorney-in-fact, or proxy.

HIPAA (Health Insurance Portability and Accountability Act)

- A federal law that created national standards to protect personally identifiable patient health information from being disclosed without the patient's consent or knowledge.
- Appointed Healthcare Powers of Attorney can access patient's health information.

Hospice

- Non-curative care for people facing a life-limiting illness or injury and who are believed to have less than six months to live.
- 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.
- Services are available to any qualifying patient, regardless of age, race, religion, or illness, and is covered under Medicare, AHCCCS (Medicaid program in Arizona), and most private insurance plans.
- Support is also provided to the patient's loved ones/caregivers.
- Can be provided in a person's home, an assisted-living residence, a skilled nursing facility, a hospital, or an inpatient hospice setting.
- NOTE: Hospice is not a place; it is a type of care.

Hospitalist

- A physician whose practice focuses on patients who are admitted into the hospital and does not follow them back into the community or clinic setting.

Incapacitation

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

Informed Consent

- 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 prior to receiving healthcare treatments.

Intake

- An introductory or assessment/evaluation interview or appointment that is completed by a social worker, mental health worker, or healthcare provider.
- 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.
- During the assessment process, the intake professional may ask if Advance Directives have been completed and request copies.

Intubation

- The medical insertion of a tube from a person's nose or mouth into their windpipe to create an airway and assist breathing.
- Seeks to create and preserve an open airway so that a person can receive oxygen and to release carbon dioxide.

Legacy

- A meaningful end-of-life gift.
- May include gifting loved ones or the community with tangible items (money, assets, or treasured items) or intangible mementos (memories, favorite recipes, well-wishes, and blessings or a call to action).

Life-Sustaining Treatment

- Medical treatment that is meant to sustain or prolong one's life.
- May provide life-lengthening but often is not curative.
- Examples may include, but are not limited to, dialysis, CPR, mechanical ventilation, surgery, and artificial nutrition and hydration.

Living Will (document)

- Legal document that allows a person to identify, in advance, which medical procedures or interventions they do or do not wish to receive.
- Intended to guide treatment if the person becomes unable to make or communicate decisions due to an irreversible coma, persistent vegetative state, or similar type of condition.
- May be a stand-alone document or be included as part of a Durable Healthcare Power of Attorney (see above).
- 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 to learn common medical terminology and treatments as well as the potential implications of the decisions being made.

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
- 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 witnessing the signing of important documents.
- A Notary seal provides proof of validity for those important documents.
- 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

- Specialized medical care for people living with a serious illness.
- Focused on providing relief from the symptoms and stress of the illness.
- Goal is to improve quality of life for both the patient and the family.
- Provided by a specially trained team of doctors, nurses, and other providers who work together to provide an extra layer of support.
- Based on the needs of the patient, not on the patient's prognosis.
- Appropriate at any age and at any stage in a serious illness.
- Can be provided along with curative treatment.

Persistent Vegetative State

- A condition in which a patient is completely unresponsive to psychological and physical stimuli and displays no sign of higher brain function.
- Person is not expected to improve and is being kept alive by medical intervention.

Person-Centered Care

- Care that recognizes the whole person—body, heart, mind, and spirit rather than simply the person's illness, disease, or disability.
- Involves respecting the person's values and priorities, including them in decision-making, honoring their self-determination, and preserving their dignity.

Portable Medical Orders (POLST)

- A portable medical order that helps people who are seriously ill or frail to receive treatments that they want and avoid treatments that they do not want to receive.
- Part of Advance Care Planning but is different than an Advance Directive.
- Only for people who are at risk for a life-threatening clinical event because they have a serious life-limiting medical condition which may include advanced frailty.
- Before the healthcare provider can complete the POLST form, they must have a conversation with the person about their medical condition, what is likely to happen in the future, their goals of care, and the treatment options they want or don't want.
- POLST forms inform other providers about care and treatments that the person wants.

- During a medical emergency, if the person can talk, healthcare providers will talk to them about the care they want. POLST forms are used only when the person **cannot** communicate and need medical care.
- Always voluntary, and the seriously ill person must sign the POLST form with the healthcare provider for it to be valid. https://www.azhha.org/arizona_polst

Pre-Hospital Medical Care Directive – See Do Not Resuscitate Order (DNR-orange form)

Principal

- The person who expresses their wishes in Advance Directives, appoints another person to act as their agent, if incapacitated, and signs the documents.
- The one whose best interest is protected by Advance Directives.

Prognosis

- A prediction made by a medical professional 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

- An individual (over the age of 18) who has been chosen to make healthcare treatment decisions for a person.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- Also called appointed decision-maker, power of attorney, representative, attorney-in-fact, or agent.

Quality of Life

- The degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events.
- Multi-dimensional 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" that I might feel, behave/function and 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- considerations should I be aware of because of my illness?

Representative (person)

- An individual (over the age of 18) who has been chosen to make healthcare treatment decisions for a person.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- Also called appointed decision-maker, power of attorney, representative, attorney-in-fact, or agent.

Respiratory Arrest

- An event in which an individual stops breathing.
- If breathing is not restored, an individual's heart eventually will stop beating resulting in cardiac arrest.

Revocation of an Advance Directive

- A person has a right to change and/or terminate (revoke) their own Advance Directive if they have cognitive capacity to make such a change*.
- A formal way to cancel Advance Directives.
- 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 AzHDR. NOTE: It is highly recommended that when an Advance Directive is revoked, an updated 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, if the decision is in keeping with local, state, and federal laws.

Solo Senior

- An older adult who lives alone or does not have family or friends nearby or a close relationship with someone who could serve as their representative.
- This can be challenging for Advance Care Planning.
- An attorney can assist with identifying/appointing an agent or power of attorney.

Substituted Judgment

- In the event of a medical situation or a decision that **has not been** addressed in a signed Advance Care Directive, the appointed decision-maker must attempt to carry out the wishes that they believe the patient would want if they were able to participate in the decision.
- If there is no Advance Directive and with only limited acquaintance with the patient, the decision-maker must endeavor to act in the "best interests" of the patient.

Surrogate or Surrogate Decision Maker—Statutory Priority (person)

- 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 or representative can make healthcare decisions on their behalf.
- Makes decisions if person unable to do so due to incapacity or inability to communicate.
- If willing and available, the following individuals can serve as surrogates regarding treatment decisions (in order of priority in Arizona):
  - Spouse (unless legally separated)
  - Adult child
  - Parent
  - Domestic partner
  - Sibling
  - Close friend, or
  - Attending physician
- There are some decisions 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/Condition

- An infection or disease that is life-limiting, incurable, and ultimately fatal.
- It is possible for people to live several years with a terminal condition.

Values

- Standards or principles by which a person lives both tangible and intangible.
- Can also include a person's beliefs about what is right or wrong.

Ventilator

- A machine that provides mechanical ventilation by moving breathable air into and out of the lungs to deliver breaths to a patient who is physically unable to breathe or is breathing insufficiently.

Withholding or Withdrawing Treatment

- A decision made by a person or their agent to forego life-sustaining measures or to discontinue them after a designated period.
- Can be communicated in an Advance Directive prior to a medical crisis or may have to be made in an acute illness or injury situation.
- The patient's communicated desires and best interest must be considered when the decision to withdraw treatment is made by the patient's representative.

Witness

- Sometimes required when end-of-life documents are being signed.
- Must be 18 years of age or older.
- Must not be a family member (by blood, adoption, or marriage).
- May be a neighbor, friend, or acquaintance.
- Must not be named in the document as a beneficiary or agent.
- Must not be providing healthcare to the principal (signer).
- The witness may not represent the principal or receive benefit from serving as the witness.