PCOA
Aging well for life

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

The David and Lura Lovell Foundation
Community Foundation for Southern Arizona

The Arizona End of Life Care Partnership is supported by The David and Lura Lovell Foundation and the Community Foundation for Southern Arizona.

# Frequently Asked Questions about End of Life Care Planning

## Advance Directives

End of life care planning is an important part of living and ending life well. Individuals and couples can provide clarity and comfort for family members by completing and formalizing their end of life care plans. And family, or informal caregivers, often have questions about end of life options related to the person for whom they provide care. Following are answers to a number of end of life care planning questions in Arizona (each state has different end of life expectations and laws). The questions and answers are not intended to be comprehensive, and the information provided does not constitute 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.**

You may also wish to consult your attorney. If you do not already have an attorney, you can find a list of attorneys who specialize in Elder Law, or to see if you qualify for a no-cost Legal Clinic appointment ($15 donation requested), by calling PCOA at (520) 790-7262. You can also meet with an attorney for 30 minutes at a minimal cost though the Lawyer Referral Service which can be reached by calling (520) 623-4625.

### Q. What is end of life care planning?

End of life care planning is the process of thinking through and making decisions about the type of care and treatment you do, and do not, wish to receive at the end of your life. End of life considerations include deciding whether you wish to receive life-sustaining treatment, identifying people who matter and to whom you give authority to carry out your wishes, describing the

types of comfort you would like to receive as you die, and sharing the ways you wish for your life to be remembered and celebrated. End of life care planning is a personal process in which you explore your values and priorities, write them down in legally-recognized ways (advance directives), and share the information with important people including loved ones, healthcare providers, and healthcare facilities like hospitals or rehabilitation centers.

### Q. I was just diagnosed with a chronic or terminal illness, and I don't know what I need to know. Are there questions I can ask my healthcare provider?

* 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?

### Q. What is 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. Some types of life-sustaining treatments include:

- 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.
- 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.

- 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.

### Q. What is palliative, or comfort 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. A person can request comfort care at any time—regardless of age or medical situation.

### Q. Where does a caregiver begin when concerned about a care recipient's ability to adequately handle medical decisions and finances?

A caregiver best begins by asking their care recipient if there are any documents that designate another person to assist him or her with medical and financial decisions. If the care recipient has not completed end of life care planning documents, determine if they are willing to discuss their wishes and formalize their plan. Remember that adults have the right to refuse assistance, even if doing so may not be in their best interest.

### Q. Does a family, or informal, caregiver need legal documents (advance directives) to make medical or financial decisions on behalf of the person for whom they care? Or can they just take charge?

A caregiver may **not** make financial or medical decisions for their care recipient, even a family member, without legal authority. A caregiver may provide emotional and physical support in keeping with the care recipient's wishes and healthcare providers' orders, but may not make decisions about changing, starting, or ending treatments, or managing the care recipient's personal affairs or assets. To make these types of decisions, a caregiver must be authorized as the care recipient's Durable Healthcare Power of Attorney, Durable Mental Healthcare Power of Attorney, and/or Durable Financial Power of Attorney, or other legal designation. It is important that the responsibilities and limitations for these powers be fully understood prior to accepting the

legal role. A caregiver is not obligated to assume a role as their care recipient's Power of Attorney agent.

### Q. What is a Power of Attorney?

A Power of Attorney is a legal document that allows one individual to appoint another individual to act on their behalf in medical, mental health, and/or financial situations. The individual granting the authority is called the "principal" and the individual acting at the principal's request is known as the "agent." A Power of Attorney is required, by law, to act solely for the benefit of the principal, and prohibits the agent from benefiting as a result of their role as Power of Attorney. The Power of Attorney does not grant the agent authority to act against the wishes of the principal. Even if the agent disagrees with the principal, the principal's instructions about their expressed wishes must be followed.

For an agent to act on behalf of the principal when the principal is considered incapacitated, the Power of Attorney (created when the principal had capacity) must contain language that makes it "durable." A "Durable Power of Attorney" is one that contains words such as "this Power of Attorney shall not be affected by my disability or lack of mental competence" and the power will remain in effect even if the principal becomes disabled or incapacitated.

### Q. When should I begin my end of life care planning?

Adults, age 18 and older, benefit from end of life care planning at any time—but especially before they "need" a plan. It is important to consider options and formalize wishes before a crisis or emergency situation. Even healthy adults should consider completing their end of life care planning.

### Q. Where do I get end of life care planning forms?

PCOA offers no-cost copies of the Living Will, Healthcare and Mental Healthcare Powers of Attorney, and "Do Not Resuscitate" forms. These forms are also available on our website: End of Life Care Planning – Pima Council on Aging (pcoa.org)

PCOA also has End of Life Specialists who are available to assist you in preparing your end of life care plans, and sharing the information with your loved ones and healthcare providers. Call PCOA at (520) 790-7262 for more information, or to schedule an appointment.

Power of Attorney templates can also be purchased at office supply stores, online, or by retaining an attorney.

### Q. Do I need an attorney to complete my end of life care planning forms?

Most people do not need an attorney to draft or complete their Durable Healthcare Power of Attorney, Durable Mental Healthcare Power of Attorney, Living Will, or "Do Not Resuscitate" Order.

PCOA recommends hiring an attorney to draft Durable Financial Power of Attorney forms because of the potential for abuse and/or mismanagement, and because an attorney can explain the responsibilities and limitations of acting as a person's Power of Attorney agent. Sometimes, banks do not recognize the authority granted by a Durable Financial Power of Attorney, and may require that a person complete additional forms to authorize another person to manage their bank accounts in specific circumstances.

### Q. Does my end of life care plan take effect as soon as I write it down?

No, your end of life care plan takes effect once it is signed and witnessed (or notarized), **and** you are no longer able to make decisions or express your wishes. At that time, your healthcare team will work with your Power of Attorney agent(s) to identify the treatment options that are most consistent with your end of life care plan.

### Q. Does my end of life care plan have to be notarized to be considered legal?

Not in Arizona. In Arizona, an end of life care plan is considered valid and legal if it is signed by a witness. In end of life matters, a witness is typically the term used for a person who observes another person (the principal) sign important documents, including advance directives, whose signature provides proof of the principal's capacity to make reasonable decisions, and evidence of the principal's formal end of life decisions. A witness is 18 years of age or older, must not be a family member (by blood, adoption, or marriage), must not be providing healthcare to the principal, and must not be appointed to represent the principal as an agent. Possible witnesses include a neighbor, friend, or acquaintance, but the witness may not represent the principal in any way, or receive benefit from serving as the witness.

### Q. What do I do with my end of life care plan once it is filled out and signed?

Make copies of your advance directives, and keep the original accessible. Discuss your end of life care plan and provide copies to your agent(s), loved ones, healthcare providers, and healthcare facilities. It is important that a copy be provided (by you or your agent) to the hospital in an emergency situation also. Consider submitting your end of life care documents to the Arizona

Advance Directive Registry (details in a subsequent response).

### Q. What if my care recipient cannot find the previously prepared documents or does not remember if they have any?

Obtain permission from your care recipient to contact family members, friends, physicians, and their attorney to see if anyone can confirm the existence of these documents. If they cannot be located, your loved one would benefit from starting their end of life care plan over again.

### Q. Can my end of life care plan be followed if I am at home?

Advance directives can be followed, but may not be if you are at home. Emergency medical personnel are required to provide care to preserve or revive life unless they immediately find a Do Not Resuscitate (DNR) Order. 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. The DNR Order should be posted in a prominent location (e.g. front door or refrigerator) or given to emergency medical personnel by a caregiver or loved one. You may also wish to speak with your healthcare provider about a medical alert bracelet or necklace that describes your wish to not be resuscitated.

### Q. How will my healthcare provider know that I have an end of life care plan?

Be sure to talk with your healthcare providers and provide them with copies of your end of life care plan for your medical record.

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.

### Q. Will my end of life care plan be honored if I am transported to the Emergency Room?

In some emergency situations, it may be impossible for healthcare providers to know that you have an end of life care plan before they provide you with life-sustaining care. Your valid end of life care plan will only be honored in the Emergency Room if the healthcare providers have access to the plan (by paper copy or electronic health record). It is important that your healthcare agent

know and understand your wishes so that they can advocate on your behalf if you are unable to communicate your wishes in an emergency medical situation.

### Q. Are healthcare providers required to follow my end of life care plan?

End of life care plans are legal documents, but healthcare providers reserve the right to make different treatment decisions for you in some situations. Examples of these situations include when your end of life care wish violates healthcare standards or law, or when the wish goes against the healthcare agency's/facility's policies. In these situations, the healthcare provider is obligated to inform you or your healthcare agent immediately. Because of this, PCOA recommends that you discuss your end of life care wishes with your healthcare providers before finalizing your end of life care plan.

### Q. Will having an end of life care plan affect the quality of healthcare services I receive?

As long as you are able to make and communicate your healthcare wishes and preferences, having an end of life care plan will not affect the type or quality of healthcare services you receive. Your healthcare providers will take guidance from your end of life care plan if, and when, you are unable to make or communicate your healthcare wishes and preferences yourself.

### Q. Can I change my end of life care plan? And if so, when?

Yes! You can change or revoke (terminate) your end of life care plan at any time. And as many times as you would like! 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 agent
- 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 of Attorney agent(s), 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.

### Q. What if my care recipient wants to change their Power(s) of Attorney or Living Will?

A person has a right to change and/or terminate (revoke) their advance directives as long as they have cognitive capacity to make such a change. Reasons for changing a Power of Attorney or Living Will may include the following:

- Your care recipient wishes to name a new person to serve as a Power of Attorney agent
- Your care recipient has changed their mind about desired treatments
- Your care recipient prefers different arrangements for their remains, or memorial service

It is important that your care recipient communicates the revocation in writing, and provides written notice to their Power of Attorney agent(s), 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.

### Q. What happens if I do not have an end of life care plan?

If you do not have an end of life care plan, and you are unable to make or express your healthcare wishes, healthcare providers will seek a surrogate to make those decisions on your behalf. A surrogate is assigned according to state laws for surrogate decision-makers. 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 directives, 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.

### Q. What if my care recipient does not have an end of life care plan?

A person must understand the meaning of the advance directive forms at the time they sign the documents in order for them to be valid. If your care recipient is incapacitated, or unable to appoint a Power of Attorney agent, a surrogate may be identified to make healthcare decisions on your care recipient's behalf. A surrogate is assigned according to state laws for surrogate decision-makers. 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.

In some cases, a Guardianship, which requires court approval, may be necessary if the care recipient is incapacitated. If you have any concerns about your care recipient's capacity, be sure that you keep documentation including healthcare records and letters from your care recipient's healthcare providers, or other witnesses.

### Q. Do I need an end of life care plan for each state if I live in two different states?

Typically, no. Most states will recognize end of life care plans from another state. In some states, however, specific legal requirements must be met (like notarization) though not required by other states. Similarly, end of life wishes must be consistent with the legal statutes, or laws, in that state. For example,

physician-assisted suicide is legal in some states, but not in Arizona. PCOA recommends that you consult an Elder Law Attorney to review your end of life plan and its legality in each state where you live.

### Q. Can I have a Healthcare Power of Attorney and a Living Will at the same time?

Yes. A Healthcare Power of Attorney assigns another person, an agent, who makes healthcare decisions on your behalf if you are unable to make decisions or express your wishes. By contrast, 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. It is important to ensure that your Durable Healthcare Power of Attorney and Living Will documents express the same wishes and preferences so that no conflicts result.

### Q. What is a POLST (Physician's Orders for Life-Sustaining Treatment), and do I need one?

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 end of life care 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 agent, physicians, and care facilities. Discuss your need for a POLST with your healthcare provider.

### Q. If a person has Power of Attorney documents, why would a Guardianship proceeding be necessary?

Power of Attorney documents are very helpful, but only as long as the principal agrees to cooperate, and as long as the person who is appointed the agent agrees to continue to serve in that capacity. If the principal has prepared the directives, but chooses not to comply with the plan or decisions being made by the agent, then it may become necessary for the agent to Petition for

Guardianship. This can also be the case if the agent is no longer serving and an alternate was not provided for in the Power of Attorney documents. A Guardianship is a formal court proceeding. The principal must be notified of the hearing and will have an attorney appointed to present their point of view to the court. If the court finds the principal unable to make or communicate responsible decisions (known as incapacity), a Guardian or Conservator is appointed to manage the principal's decisions and affairs even if they object to those decisions.

**Summary:** We hope these questions and answers have been useful. If you have further questions you may also wish to consult your attorney. If you do not already have an attorney, you can find a list of attorneys who specialize in Elder Law, or to see if you qualify for a no-cost Legal Clinic appointment ($15 donation requested), by calling PCOA at (520) 790-7262. You can also meet with an attorney for 30 minutes at a minimal cost though the Lawyer Referral Service which can be reached by calling (520) 623-4625.