GENERAL INFORMATION AND INSTRUCTIONS

INTRODUCTION

WHAT IS LIFE PLANNING CARE?

All states have laws that allow us to **make future health care treatment decisions now** so that if we become incapacitated and unable to make these decisions later, our family and doctors will know what medical care we want or do not want. State laws also allow us to **appoint a representative to make future health care treatment decisions** for us if we become incapacitated, since we cannot predict what future decisions might be necessary. These laws are called "advance directives" or "health care directives." Because these laws are somewhat different from state to state, the federal Medicare/Medicaid agency suggests that citizens contact the state's Attorney General's Office about the laws of that state. The Life Care Planning program developed by the Office of the Attorney General follows Arizona law as to "health care directives."

Most people communicate their health care directives by completing forms, such as the Life Care Planning forms, that are tailored to prompt decisions about treatment choices that might be needed. Before you complete these or other health care forms, you should learn and think about what medical treatments you want and/or do not want in the future. Discuss your choices with your family, loved ones, physician, clergyperson, etc. Also consider who you want to appoint to make treatment decisions for you if you become incapacitated. Although you cannot anticipate all the medical situations that might arise, you can give guidance to your decision-maker, doctor, and family as to your values and choices, so they can respect your wishes if a time comes when you cannot make or express decisions for yourself.

So take a few moments to read about and then follow these easy steps to complete the Life Care Planning forms. This is a gift you can give to yourself and your family. Don't delay!

STEP ONE

UNDERSTANDING THE LAW-OUR LEGAL RIGHT TO MAKE HEALTH CARE DECISIONS

Our constitutional rights to privacy and liberty include the right to make our own medical treatment decisions. The government also has interests in some of our medical treatment decisions, which include preserving life, safeguarding the integrity of the medical profession, preventing suicide, and protecting innocent third parties (Arizona, for example, does not approve or authorize suicide or assisted suicide). Choices within the bounds of law as to which medical treatments will be applied or denied are ordinarily made by the person receiving the treatment, through the process of informed consent.

If someone becomes unable to understand, reason or make judgments, his/her constitutional rights to make medical treatment decisions remain. A health care representative appointed by the person in writing or, if no one has been appointed, a representative appointed according to the law, will make treatment decisions as follows:

- Following Expressed Wishes: The representative and physicians will be guided or controlled by medical treatment decisions that were made in writing by the person before he/she became incapacitated.
- 2. **Using Substitute Judgment:** The representative will make choices about treatment decisions based on what he/she believes the incapacitated person would choose; if those choices are unknown, then the representative
 - will decide based on what he/she knows about the incapacitated person's values and wishes.
- 3. **Using Good Faith to Decide Best Interests:** If the representative does not know the decisions, preferences or values of the incapacitated person as to medical treatment decisions, then he/she must decide in good faith what would be in the best interests of that person, considering (a) relief from suffering, (b) whether functioning will be preserved or restored, and (c) the quality and extent of sustained life.

STEP TWO

UNDERSTANDING SOME OF THE MEDICAL CHOICES RELATED TO LIFE CARE PLANNING

You might want to become familiar with some of the medical subjects that relate to future medical care, especially medical treatment choices specifically mentioned in Arizona law. There are many places you can get information to help you -- from your physician, at your local library or bookstore, on the Internet, by sharing experiences of friends and family, etc. -- so this is only a beginning to get you started thinking about these important matters. At the end of this General Information section is a list of resources where you can find more information about Life Care Planning.

Comfort Care

Under Arizona law, comfort care is an effort to protect or enhance quality of life without artificially prolonging life. Comfort care often means pain medication. For example, morphine and other medications may be administered to alleviate pain, and dosages can be increased as pain increases. Medications may or may not cause sleepiness, sedation, or other side effects. Talk with your doctor about your concerns as to pain relief, and what is best in a given circumstance for a suffering person.

Comfort care can also include oxygen and perhaps stopping certain medical interventions. It may involve offering but not forcing food or fluids, keeping the patient clean, cooling or warming the patient, humidifying the room, turning lights on or off, holding the patient's hand, and comforting him/her with soothing words and music.

• Cardiopulmonary Resuscitation ("CPR") and Artificial Breathing

CPR was developed to assist victims facing sudden death, such as heart attack or trauma, and increases the likelihood of long-term survival. Unless a doctor or other licensed health care provider authorizes a Do Not Resuscitate ("DNR") or you have a valid Prehospital Medical Care Directive, CPR is administered virtually every time a person's heart stops. Talk to your doctor to learn more about why you might choose to accept or reject CPR, and the methods of CPR you want or do not want.

Ventilators put air and therefore oxygen into the lungs, and thus can save lives. Oxygen is administered for a short term by a tube through the nose or mouth and for a longer term via a tracheotomy (a hole in the throat). Talk with your doctor about the use of a ventilator.

Artificially Administered Food and Fluids

Food and fluids can be artificially administered by medical procedures, including intravenous treatment or by various types of tubes inserted into the body (if food and fluid can be taken by spoon, drink, or other natural means, it is not artificially administered). Talk with your doctor about artificially administered food and fluids when a person is close to death, as compared to the use of these devices when a person is expected to recover. Also, discuss the comfort or discomfort of these procedures.

STEP THREE

TALKING WITH OTHERS ABOUT YOUR LIFE CARE PLANNING

Now that you are familiar with a few of the issues you might need to think about, you should consider the people with whom you can begin your life care planning conversations. Your medical care is about you – so you should start the conversations with those who can help you consider what medical treatments you might want or not want if you become incapacitated, or as you approach the end of your life. Perhaps they are waiting for you to begin the discussions – so start now!

Your Health Care Representative

Think about who you might want as your representative to make decisions for you if you become unable to do so for yourself. This should be a person you trust to have your interests at heart – someone who can make decisions for you in a manner that is consistent with your preferences, even if he/she disagrees.

Office of the Attorney General of Arizona, Mark Brnovich

Life Care Planning Packet: General Information and instructions

Be sure that you speak with your representative about your choices, so that he/she can make medical decisions on your behalf in the way you would want. This is the only way you will get the benefit of having your "substituted judgment" used rather than your representative or physician's evaluation of what is in your "best interests." Remember, your representative may be asked to make many medical decisions for you if you are no longer competent to or cannot communicate your wishes. These are not only ultimate "life and death, turn-off-the-machine decisions," but also decisions about day-to-day medical care, placement in a nursing facility or hospital, administration of certain medication, etc.

Your Spouse, Children, Other Relatives, and Close Friends

Consider sharing your thoughts about some or all of the above issues with your spouse and children and whoever is closest to you and most likely to be affected emotionally or otherwise by your medical condition and the decisions that must be made. Sometimes problems arise because family members do not understand what the patient would want in a given situation, or they disagree about what treatment is best for the patient. Although the designated representative is legally empowered to make decisions on behalf of the patient, uncertainties can raise concerns for the treating physicians and can result in problems, delays, misunderstandings, and even court proceedings.

This is why it is important that you discuss your beliefs, values and preferences about medical care not only with the person you choose as your health care representative but also with family, relatives, and close friends. This will give them an opportunity to learn from you what medical care you want and will make decisions easier for your representative and your physicians should the time come when you cannot make medical decisions for yourself.

Your Doctor, Clergyperson and Others

You can get medical information about many issues related to the Life Care Planning forms, but only your doctor can give you the personal medical advice you need to make the best choices for you. Do not hesitate to talk with your doctor about these forms and ask for your doctor's opinion about what is best for you.

You may have religious beliefs that influence your choices. Discuss your choices with your clergyperson. You can also learn more about the positions of different faiths from religious magazines, newspapers, or Internet web pages published by various faith groups.

Finally, a lawyer, accountant, banker, or others with whom you have a relationship may also have advice for you about life care planning and choices that are best for you.

STEP FOUR

SOME QUESTIONS AND TOPICS TO CONSIDER AND DISCUSS

Now that you have a general idea of some of the topics that are important in Life Care Planning and you have identified some of the people with whom you should have these conversations, there are some questions you should consider. You do not have to discuss all these topics with everyone, and you may choose to discuss only some of these topics, or none of them. We are all different and we approach questions about disability and end of life medical care differently. There is no right or wrong way, so do what is best for you.

- QUALITY OF LIFE AND PROLONGING LIFE: Consider your values, beliefs, and preferences as to the length of your life in relation to the quality of your life, and whether you would or would not choose to prolong your life regardless of the quality.
 - What "quality of life" means to you: Which of the following or other factors are important to you in considering the quality of your life: The ability to think for yourself? Consciousness? The ability to communicate? The ability to take care of your personal needs? Your privacy and dignity? Mobility, independence, and/or self-sufficiency? The ability to recognize family and friends?

- Your responsibilities: Are there certain people or duties that you feel you have an obligation to live for?
- > Who/what? Do your choices change if your obligations to those persons or duties are resolved? How? When?
- Your age: Does your age play a factor in any or all of your choices? Do your preferences change depending on how old you might be if these decisions must be made?
- Your religious or other beliefs: What is the importance of your religious beliefs or other values in making these determinations? Who can you talk to about this?
- ➤ Where you might be medically treated or "placed": Is your future living environment an important consideration for you? How do you feel about living in a nursing facility or other medical care facility for ongoing medical treatment?
- Finances: Is financial cost a consideration for you when you think about disability or end of life matters? What aspects of finances are you considering?
- **LIFE SUPPORT**: Consider the following common life support measures: food and/or fluids (nutrition/hydration); cardiopulmonary resuscitation (CPR) by equipment, devices, or drugs; and breathing devices such as a ventilator.
 - ➤ Under what circumstances do you want some, all, or no life support to be administered? To be withheld? To be removed or stopped? Why and which ones?
 - What about withholding or withdrawing life-sustaining treatment if you are known to be pregnant and there is the possibility that with treatment the embryo/fetus will develop to the point of a live birth?
 - What about medical care necessary to treat your condition until your doctors reasonably conclude that your condition is terminal or is irreversible and incurable or you are in a persistent vegetative state?
- ORGAN DONATION: You can determine if you want to donate organs or tissues, and if you do, then what organs or tissues do you want to donate, for what purposes, and to what organizations. Or, you can leave the choice to your representative.
 - Who decides: Do you want to decide about organ/tissue donation, or do you want your representative to do so? What tissues/organs: Do you have preferences about what tissues or organs to donate -- Heart? Liver? Lungs? Kidneys? Pancreas? Some or all of the above?
 - What purposes: Do you have preferences as to what uses might be made under Arizona law of your tissues or organs -- Transplantation? Therapy? Medical or dental education? Research or advancement of medical or dental science? Some or all of these uses?
 - What organization: Do you have preferences as to what organization should receive your tissues/organs?
- AUTOPSY: Under Arizona law an autopsy may be required when a person dies who was not under the current care
 of a physician for a potentially fatal illness, and/or the physician is unavailable or unwilling to sign a death certificate.
 This might happen if a person dies at home. However, if the person's doctor is willing to sign a death certificate or if
 the person is under the care of a hospice and its physician will sign the death certificate, an autopsy will probably not
 be required.

If there is no legal reason to require an autopsy, you can decide whether upon your death you want an autopsy or not, or whether you want your representative to choose for you. There is usually a charge for voluntary autopsy. After the autopsy is completed the body is transported to the mortuary for burial or cremation. This can be a sensitive topic at the time of death, and you can help your family and loved ones by making your preferences clear.

- > Who decides: Do you want to decide about an autopsy if it is optional at the time of your death, or do you want your representative to decide?
- Autopsy: If an autopsy is not required by law when you die, do you want or not want an autopsy performed?

COMFORT CARE AND OTHER SUPPORT WHEN YOU ARE DYING:

- What are your preferences and directions about pain and pain medication?
- > Do you want a comfort care medication or procedure even if it might make you drowsy, sedated, or have other effects?
- > Do you want certain people to be with you when you are dying if they can do so? Who?
- Do you have a preference about where you want to die? At home? In a hospital? Somewhere else?
- > Do you want your church, synagogue, mosque, or place of worship advised if you are dying?
- Do you want certain music, poetry, or religious readings? Do you want silence? Radio? Television?

• REMEMBRANCES TO LOVED ONES, AND FUNERAL OR OTHER ARRANGEMENTS:

- Do you have anything you want to be remembered for, or any special words to share with anyone that you would like to write down?
- > Do you want to be buried or cremated?
- > Do you have preferences about a memorial service? What? Where?
- > Are there certain people you would like in attendance? Are there songs, readings, or rituals you want performed?

STEP FIVE

COMPLETING THE LIFE CARE PLANNING FORMS

Now that you have thought about Life Care Planning and discussed certain topics with those who can help you complete the forms, decide which forms you want to sign, and what you want to say in each form. Then read the instructions on each form and follow all instructions exactly, especially as to signing and witnesses. Each form has different requirements for completion under Arizona law, so be sure you follow all the individual instructions on each form.

STEP SIX

KEEPING THE ORIGINALS, MAKING COPIES, AND CHANGING YOUR FORMS

You should keep the originals in a safe place that is also readily accessible, so you can review them from time to time. Give copies to your representative(s) and your doctor(s). You might also want to give copies to family members and close friends. Keep a few extra copies and be sure to take one with you if you go to a hospital or other facility for health care.

The Arizona Secretary of State maintains the Arizona Advance Directive Registry, which is a confidential database that will store a copy of your completed Life Care Planning Forms. The purpose of registering Life Care Planning forms is to create a centralized location where your relatives or the hospital or other health care facility caring for you can access the form if it is not readily available. Access to the Life Care Planning Forms in the registry is password protected.

If you wish to register your Life Care Planning Forms in the Arizona Advance Directive Registry, you should contact the Office of the Arizona Secretary of State:

Arizona Advance Directive Registry
Arizona Secretary of State
1700 West Washington, 7th Floor
Phoenix, AZ 85007-2888
602-542-6187 or 800-458-5842
www.azsos.gov/adv_dir/

You may change or cancel any of these forms whenever you wish. Review your forms every year or so and consider whether to make changes based on your life circumstances. Remember to discuss changes with your representative(s), and/or doctor(s), and perhaps your family, clergyperson, etc.

- If you want to change what you said on a form, complete a new form, following all instructions. Be sure to put a date on the new form, since the most recent form will be the valid form. Try to collect and destroy the original and copies of the old form. Give copies of the new form to your representatives, doctors, and any others you want to know about your wishes.
- If you want to cancel a form entirely, try to collect and destroy the original and all copies of the form. In Arizona, you can also revoke the Durable Health Care Power of Attorney and the Durable Mental Health Care Power of Attorney verbally by telling your representative(s) and/or health care provider. Cancellation in writing is always best if you are able to do so, since writing makes your wishes clearer.

CONCLUSION

SOME FINAL INFORMATION

CITATIONS TO RELEVANT ARIZONA LAWS: You can find the relevant Arizona statutes addressing these issues as follows:

- About Living Wills and Health Care Directives: Arizona Revised Statutes §§ 36-3201 et seq.
- About Representatives or Surrogate Decision-Makers: Arizona Revised Statutes §§ 36-3231 et seq.
- Durable Health Care Power of Attorney: Arizona Revised Statutes §§ 36-3221 et seq.
- Living Will: Arizona Revised Statutes §§ 36-3261 et seq.
- Durable Mental Health Care Power of Attorney: Arizona Revised Statutes §§ 36-3281 et seq.
- Prehospital Medical Care Directives (Do Not Resuscitate): Arizona Revised Statutes § 36-3251.
- Durable General Power of Attorney: Arizona Revised Statutes §§ 14-5501 et seq.
- Autopsy: Arizona Revised Statutes §§ 11-591 et seg.
- Anatomical Gifts ("Organ Donations"): Arizona Revised Statutes §§ 36-841 et seq.

DIFFERENT STATES:

Even though all states have laws for "advance directives" or Life Care Planning, the laws may be somewhat different. Normally the law of the state where treatment occurs controls, not the law of the state where medical forms were signed. If you spend time in more than one state and reasonably conclude you may need medical treatment in more than one state, you might want to have your forms comply with the laws of the states where you might be treated, to the extent possible. Consider asking an attorney for help with this.

RESOURCES THAT MIGHT BE OF HELP:

- 24-hour Senior HELP LINE (within Maricopa County) (602) 264-HELP ((602) 264-4357), (toll-free outside Maricopa County) 1-888-264-2258. A project of Region 1, Maricopa County Area Agency on Aging. There are also regional offices located in or designated to serve each Arizona county at the local level. See your local telephone book for the closest regional office.
- Elder Law Hotline 1-800-231-5441: Free legal advice, information, and referrals to Arizona residents 60 years of age or older; family members can call on behalf of a senior. Attorneys do not provide services in criminal matters, nor do they represent clients in court proceedings. They do give advice, information, and referrals on a wide variety of legal matters important to seniors. Funded by the Arizona Supreme Court and operated by Southern Arizona Legal Aid, Inc.
- Adult Protective Services: 24-hour toll-free hotline, 1-877-SOS-ADULT (1-877-767-2385), TDD: 1-877-815-8390 (Department of Economic Security, Aging and Adult Administration)

■ Hospice: Hospice is for patients who have a terminal illness and have decided to shift the focus of care from cure to comfort. (The word "hospice" is derived from a medieval word meaning a place of shelter for travelers on difficult journeys.) For information and referrals call the Arizona Hospice and Palliative Care Organization at (480) 967-9424, check www.Arizonahospice.org.

WALLET-SIZED NOTICE:

Complete the wallet-sized "Notice In Case of Accident or Other Emergency," cut it out, and keep it in your wallet with your driver's license and insurance cards so that law enforcement and medical personnel will know that you have completed health care forms.

NOTICE IN CASE OF ACCIDENT OR OTHER EMERGENCY: Name:

Date:

I have signed the following forms: (check)

- Durable Health Care Power of Attorney
- o Living Will
- o Prehospital Medical Directive (Do Not Resuscitate)
- Durable Mental Health Care Power of Attorney
- o Durable General Power of Attorney (Financial)

Please contact the following for a copy:

Name:

Telephone: