Care Coordination Conference

Sandy Severson, BSN, MBA, CPHQ, CPPS, CENP, FACHE
Co-Chair, Thoughtful Life Conversations

September 20, 2016

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Arizona Hospital and Healthcare Association

Thoughtful
Life Conversations

Objectives

- Explore your personal experiences and values about dying
- Review Arizona and national data on end of life care
- Explore healthcare workers views on end of life care
- Discuss advance care planning resources and it's impact on death in America
- Discuss the Thoughtful Life Conversations initiative and resources

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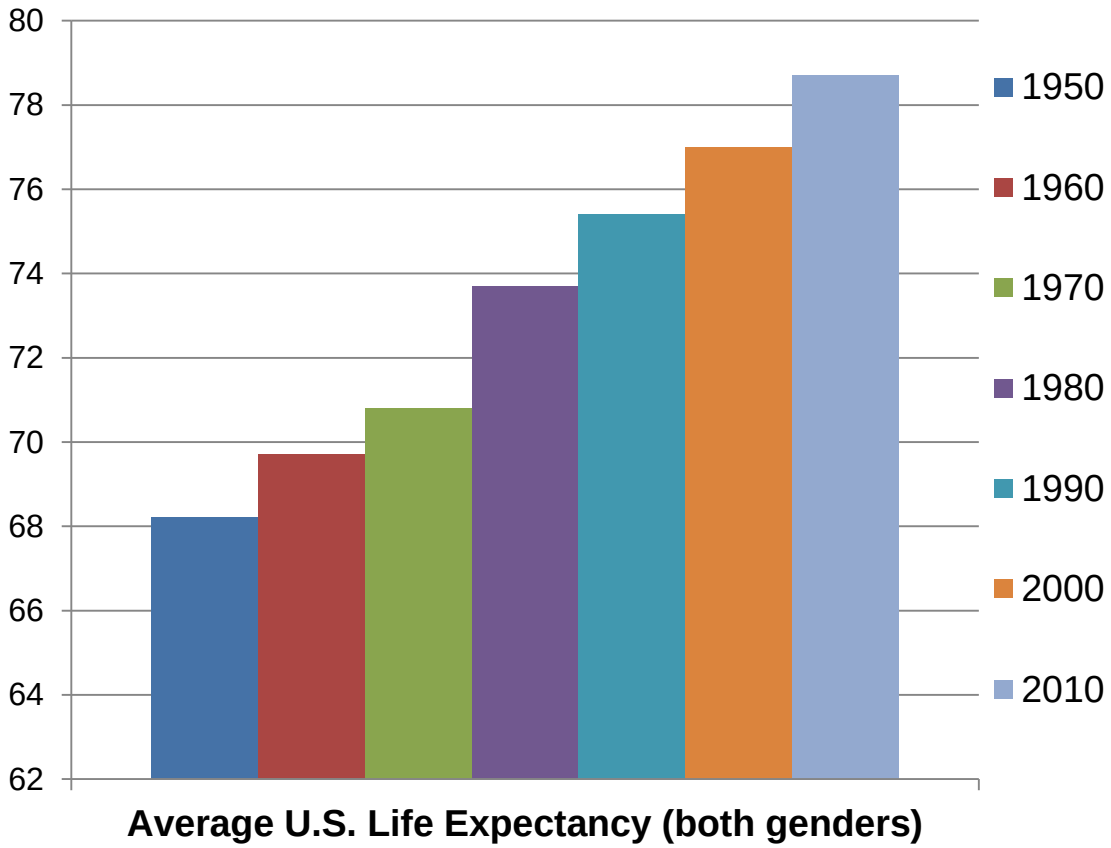
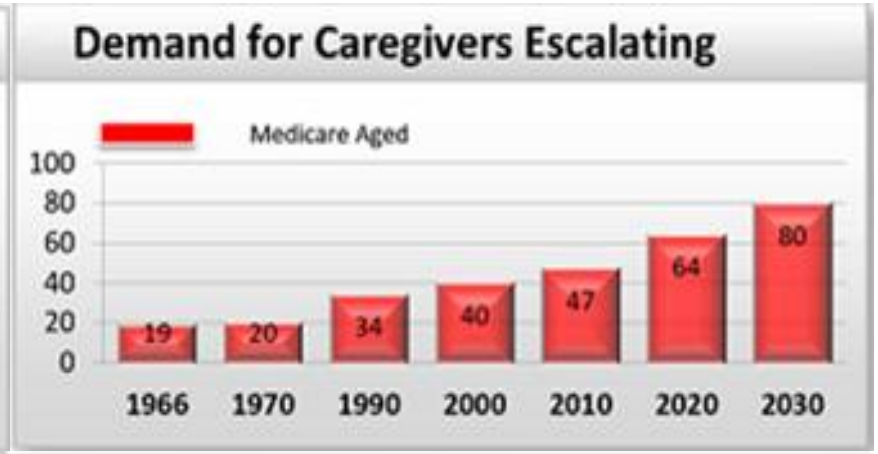
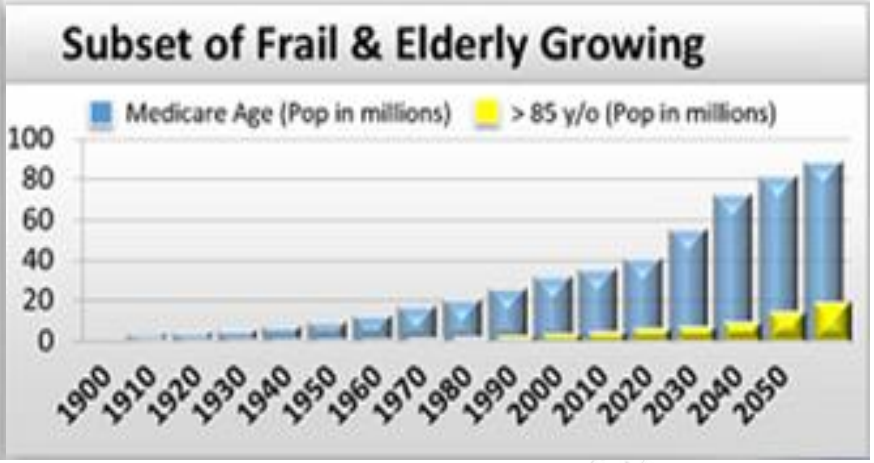
Life Expectancy



Center for Disease Control
Atlanta, GA: National Centers for Health Statistics
http://www.cdc.gov/nchs/

Need for Caregivers Increasing





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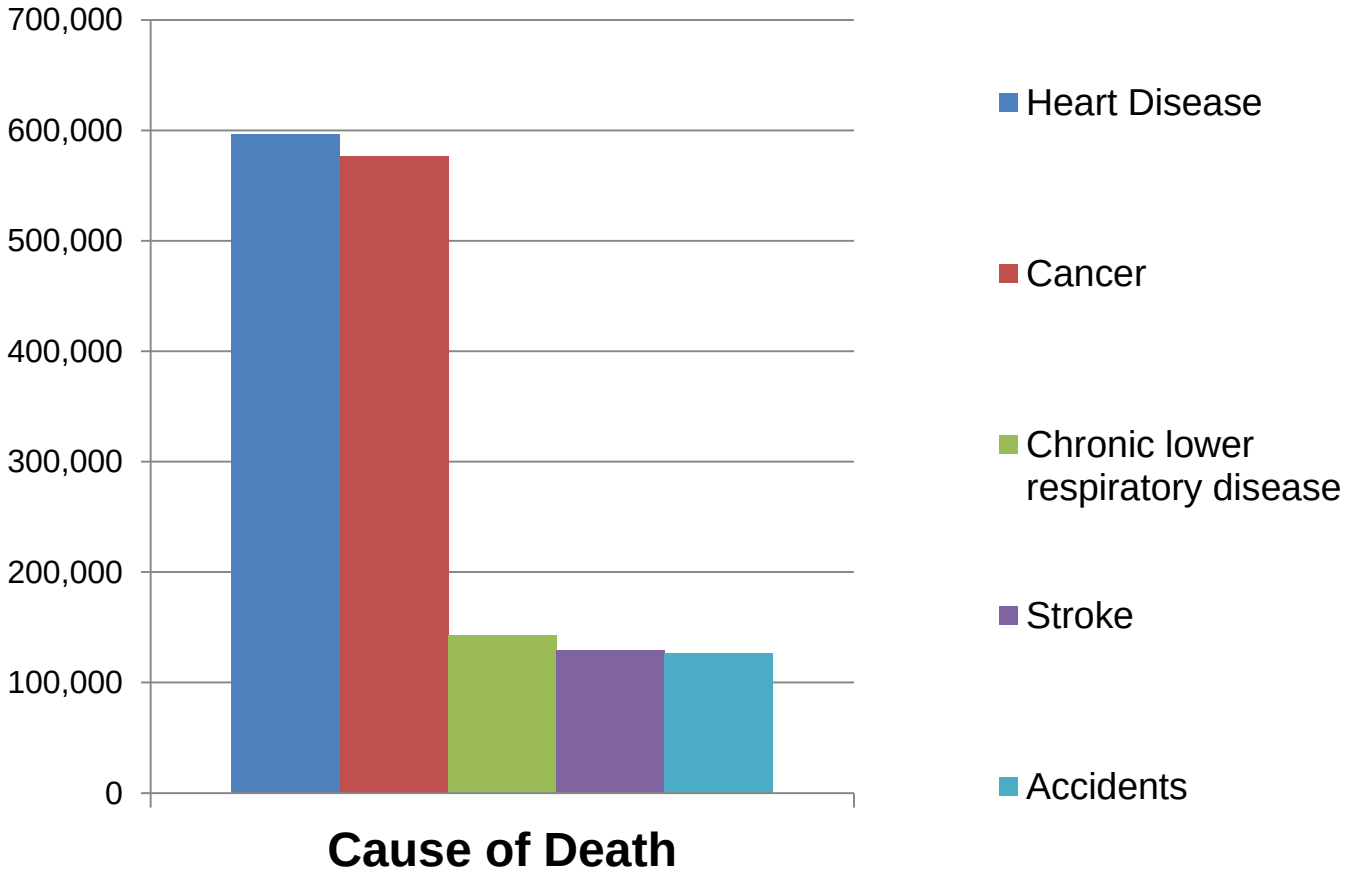
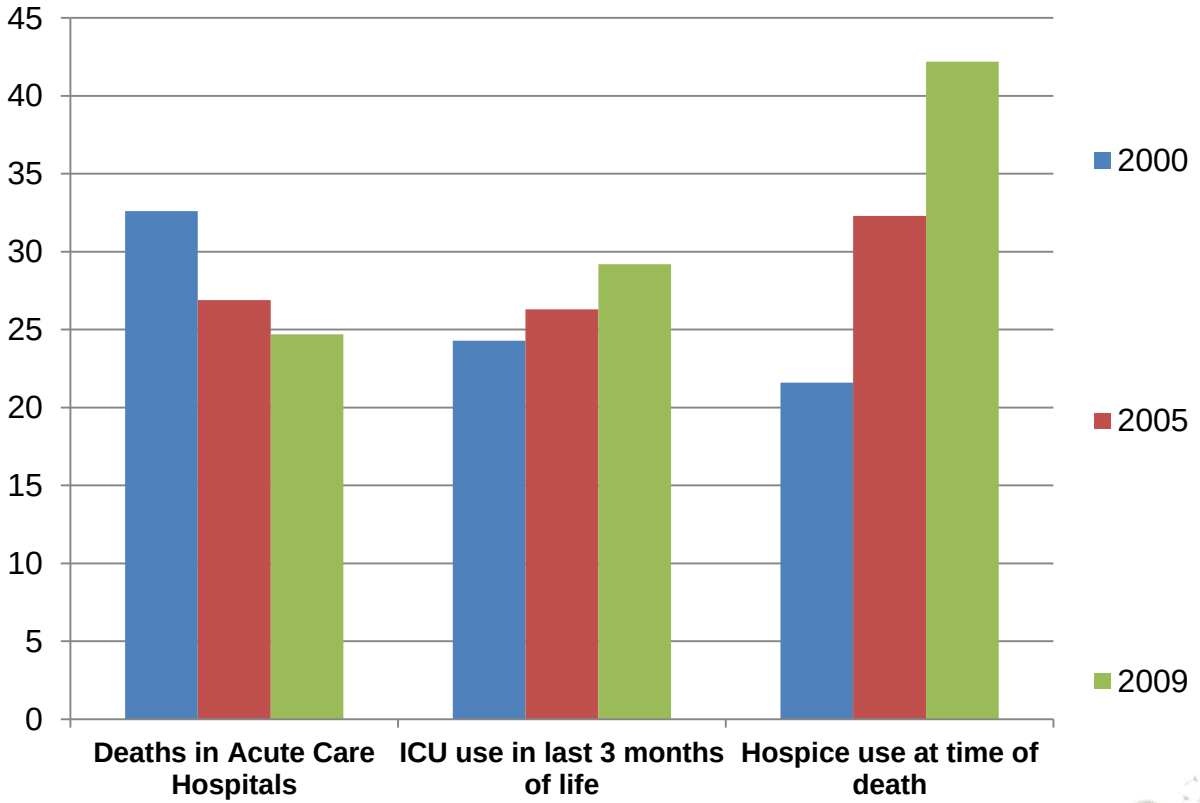
Leading Causes of Death in the U.S.



Centers for Disease Control [Internet].
Hyattsville, MD: Leading Causes of Death; 2010. Available from:
http://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm

Deaths in Acute Care Settings are Down; Intensive Care at the End of Life is Increasing



Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009
Teno, JM JAMA, 2013 February 6

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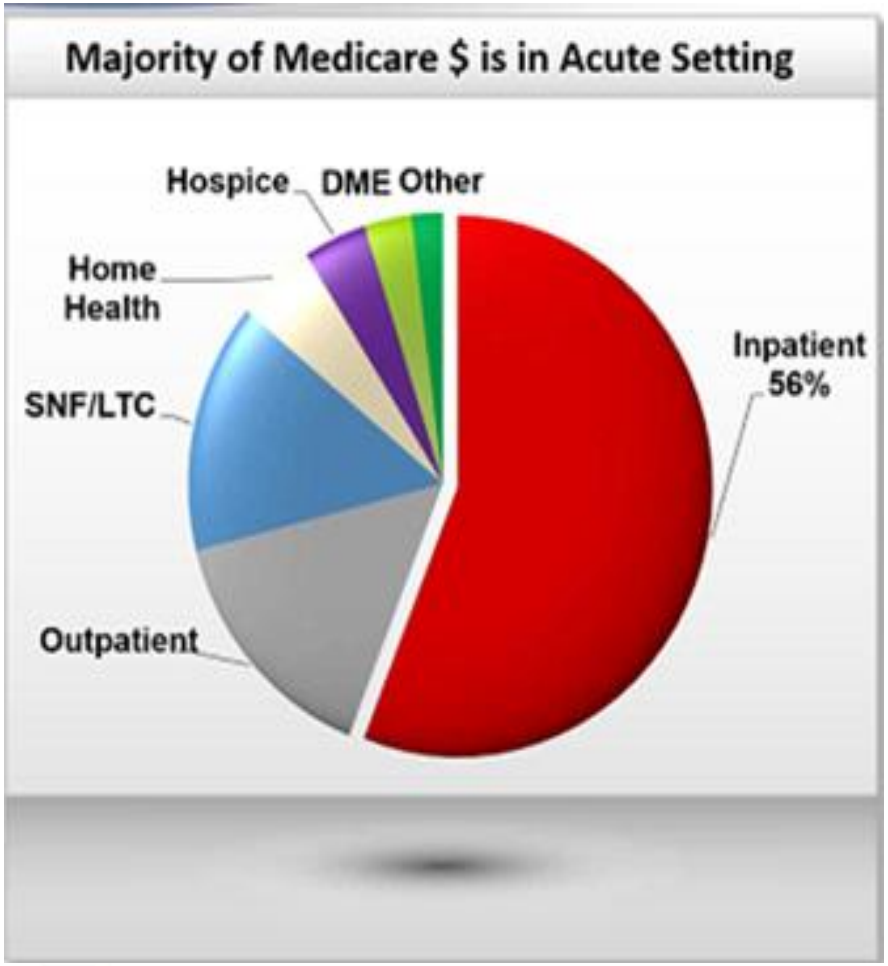
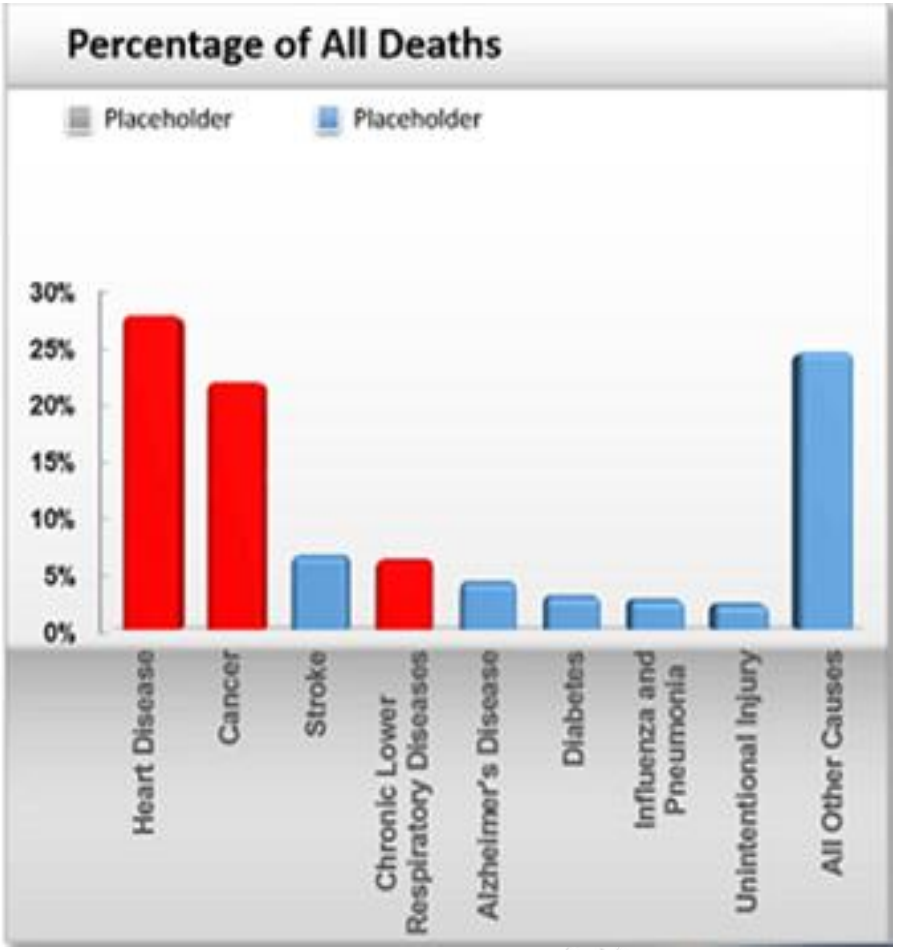
Medicare Expense & Mortality





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Death Dying, and End of Life

"the well-documented finding that health care spending during the last year of life represents a significant amount of health care costs and accounts for a substantial proportion of total Medicare expenditures, **with approximately 60% of spending during the last 6 months of life among Medicare beneficiaries occurring during their final month**."

Bauchner, H., Dr., & Fontanarosa, P. B., Dr. (2016). Jama. *Jama, 315*(4), 270-271. doi:10.1001/jama.2015.14072

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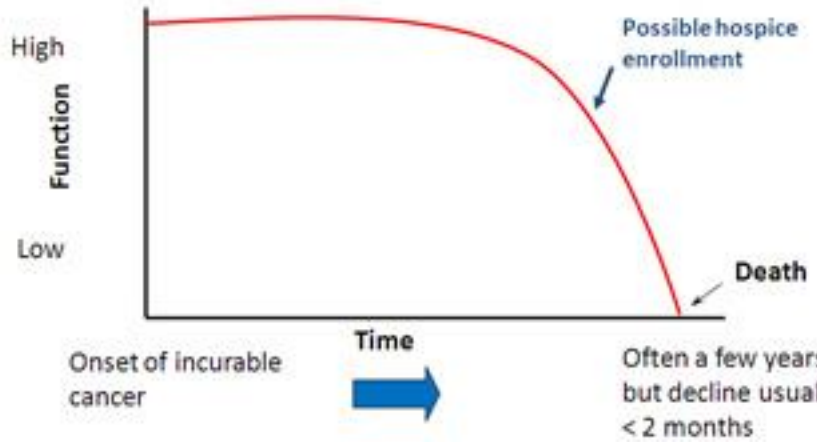
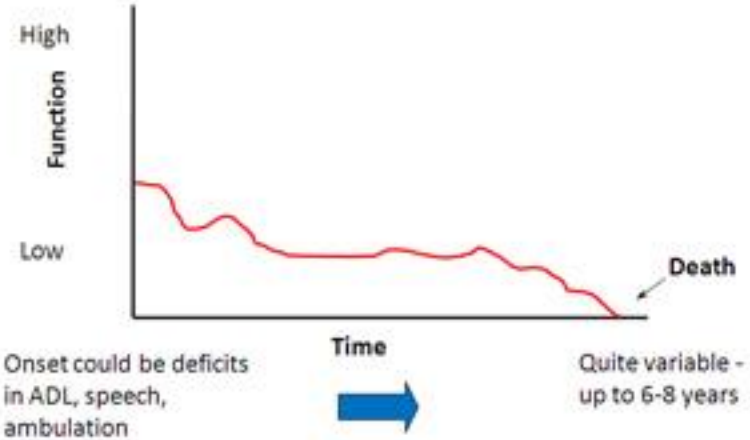
Death Trajectories

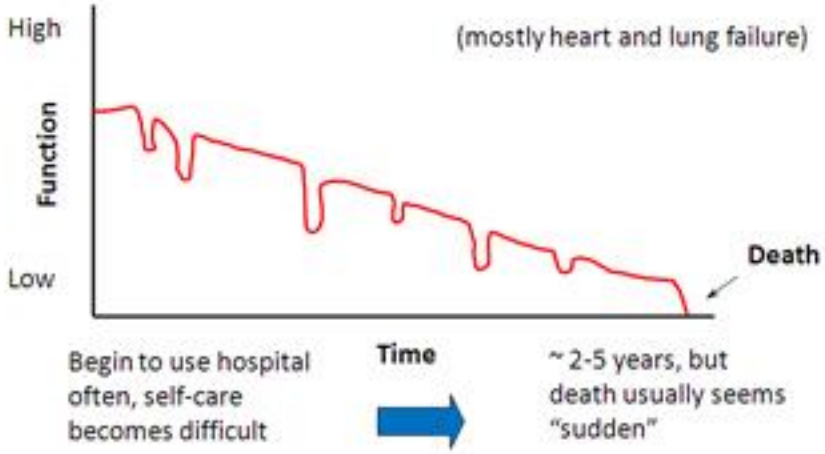
"Cancer" Trajectory, Diagnosis to Death



Dementia/Frailty Trajectory



Organ System Failure Trajectory



9 of 10 deaths in Medicare population are associated with chronic illnesses

7 of 10 Americans die from chronic disease

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HOPE is not a plan *- Atul Gawande*

When the plan is unclear

- **The default is to treat aggressively**

Family & friends are left with

- **Uncertainty**
- **Stress**
- **Guilt or possibly depression**
- **Financial concerns**

Avoid interventions by default

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Dying is not a medical event.

Consider your choices.
Plan for your care.

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IOM Report: Dying in America

- Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.
- The majority of these patients will receive acute hospital care from physicians who do not know them.
- **Therefore, *advance care planning* is *essential to ensure that patients receive care reflecting their values, goals, and preferences.***

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Family Perspectives on End-of-Life Care

Inadequate emotional support	50%
Not enough information	30%
Inadequate physician communication	24%
Inadequate attention to pain	24%
Inadequate attention to dyspnea	22%

Teno, J.M., Claridge, B. R., Casey, V., Weich L.C.; Wetle, T., et al. (2004) Family perspectives on end-of-life care at the last place of care. JAMA, 291, 88-93. Wright AA Associations between end-of-life discussion, patient mental health, medical care near death, caregiver and bereavement adjustment, JAMA 2008; 300(14) 1665-1673

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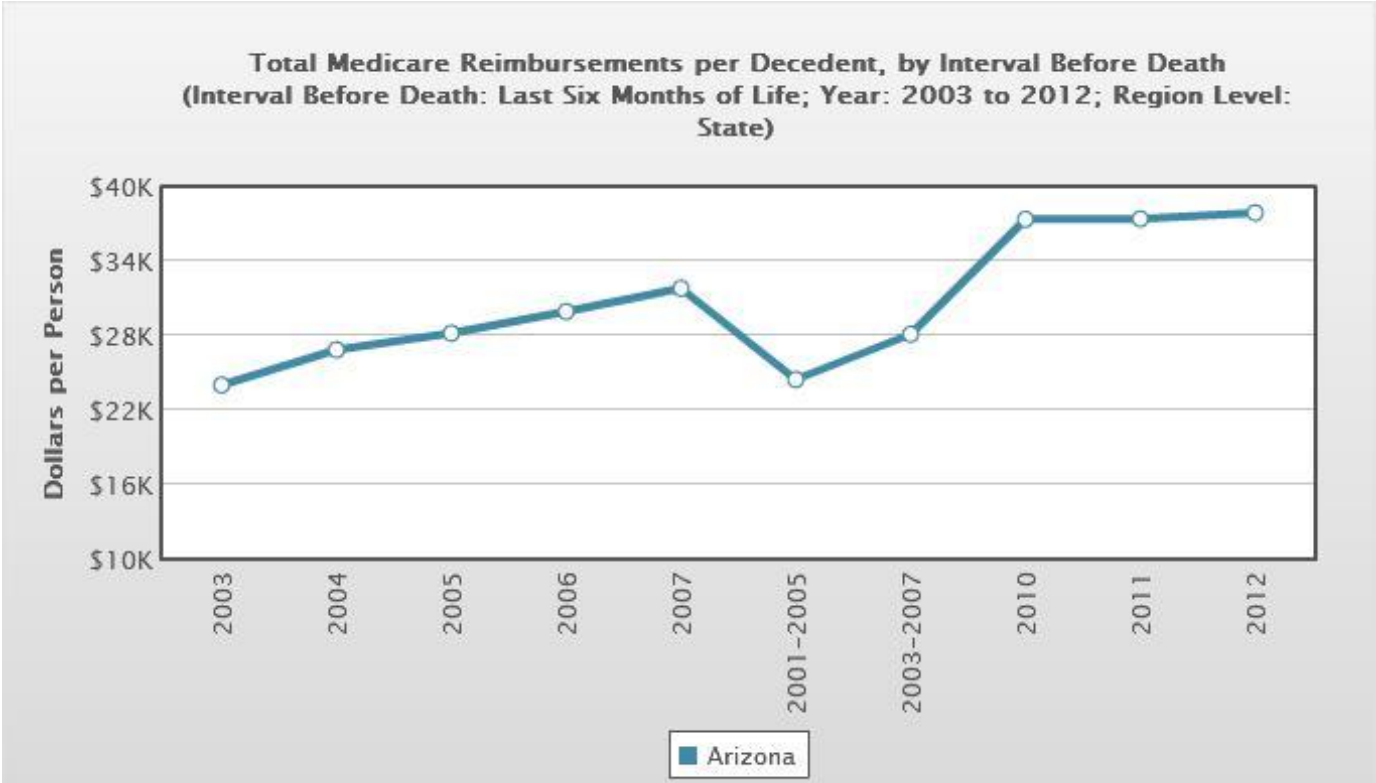
THE DARTMOUTH INSTITUTE
FOR HEALTH POLICY & CLINICAL PRACTICE

Total Medicare reimbursement per decedent in the last 6 months of life

Arizona Compared to National Average



Region (Click a region name to the left to view its profile)	Arizona	National Average	90th Percentile	50th Percentile	10th Percentile
Total Medicare Reimbursements per Decedent, by Interval Before Death (Interval Before Death: Last Six Months of Life; Year: 2012; Region Levels: State)	$37,890	$35,931	$42,927	$31,660	$27,240

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Understanding of the Efficiency and Effectiveness of the Health Care System. (n.d.). Retrieved Dec 1, 2016, from http://www.dartmouthatlas.org/

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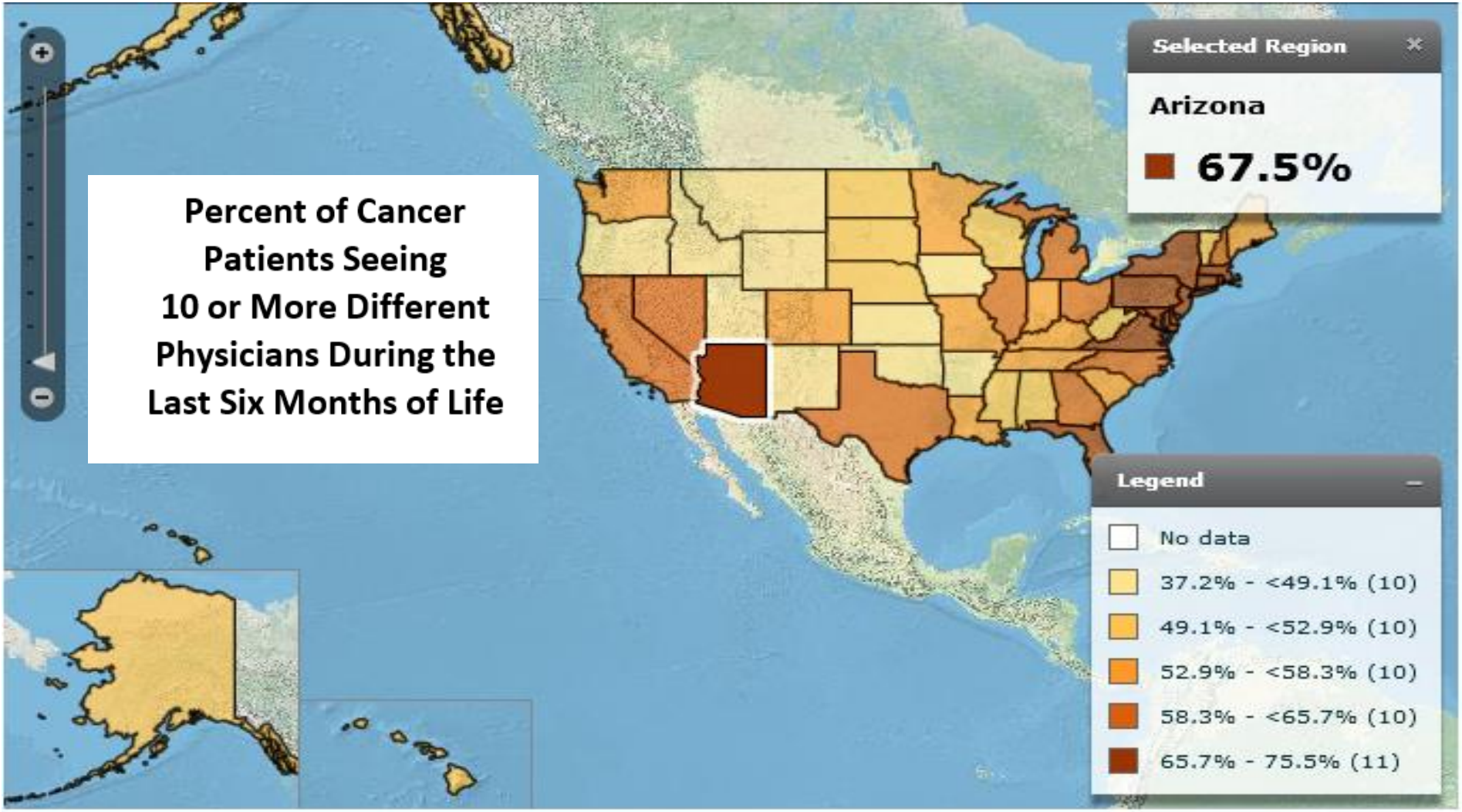

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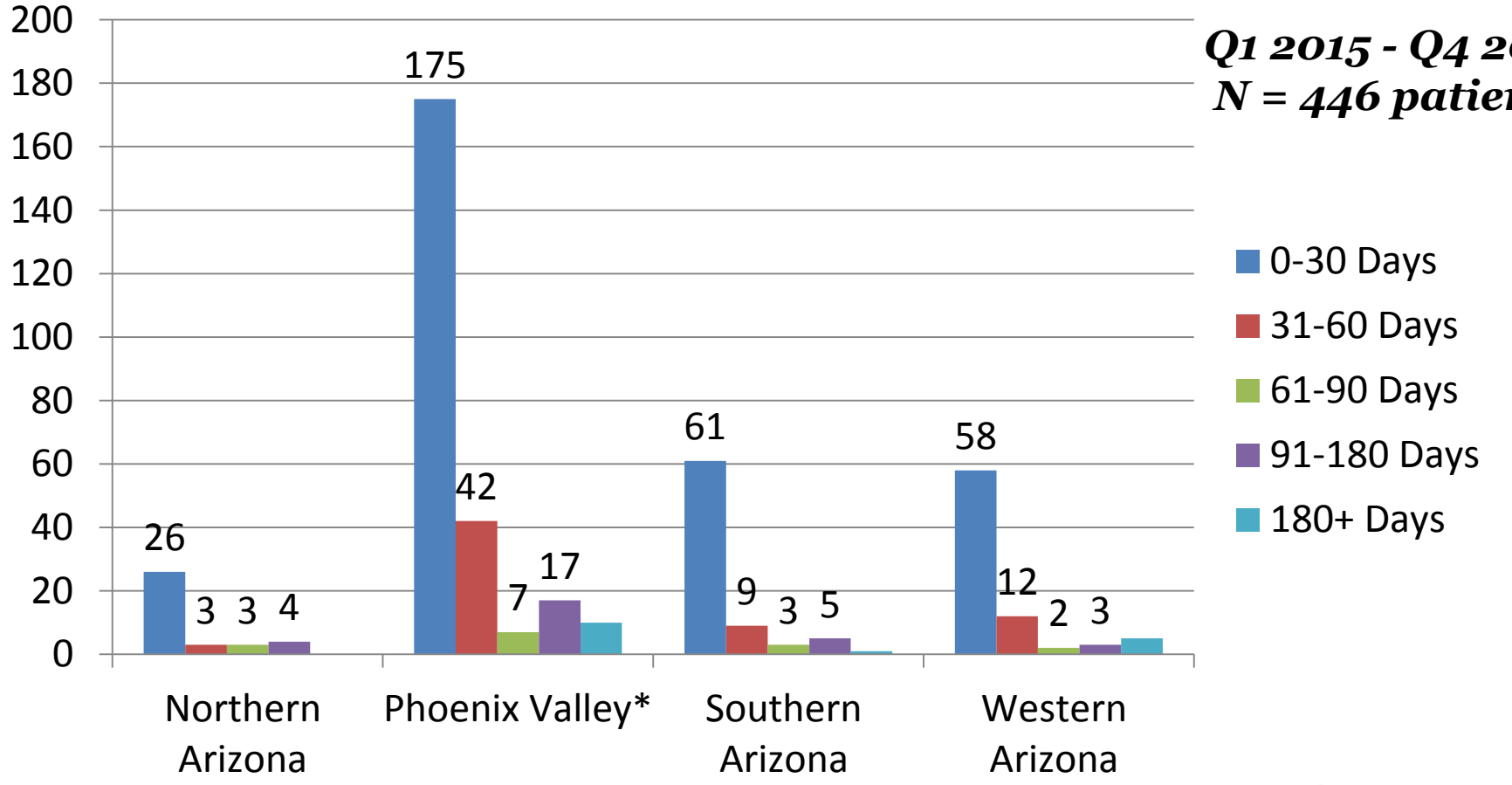
Arizona Medicare Heart Failure Patients

Days to Death from the Last Hospitalization



Q1 2015 - Q4 2015
N = 446 patients

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***Phoenix Valley includes West Valley, Central Valley and East Valley**

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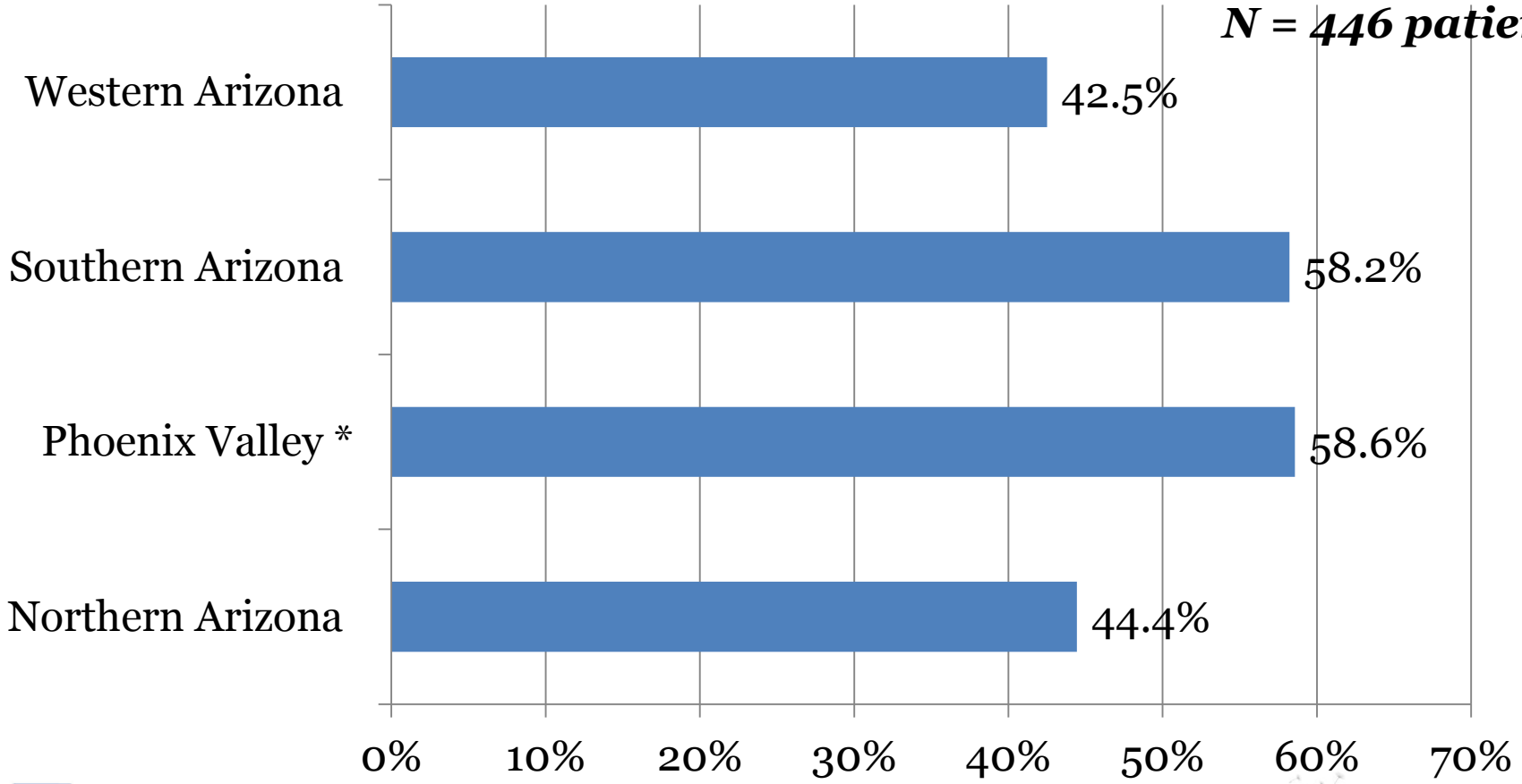
Percent of Arizona Medicare HF Beneficiaries with a Hospice Claim

Q1 2015 - Q4 2015
N = 446 patients



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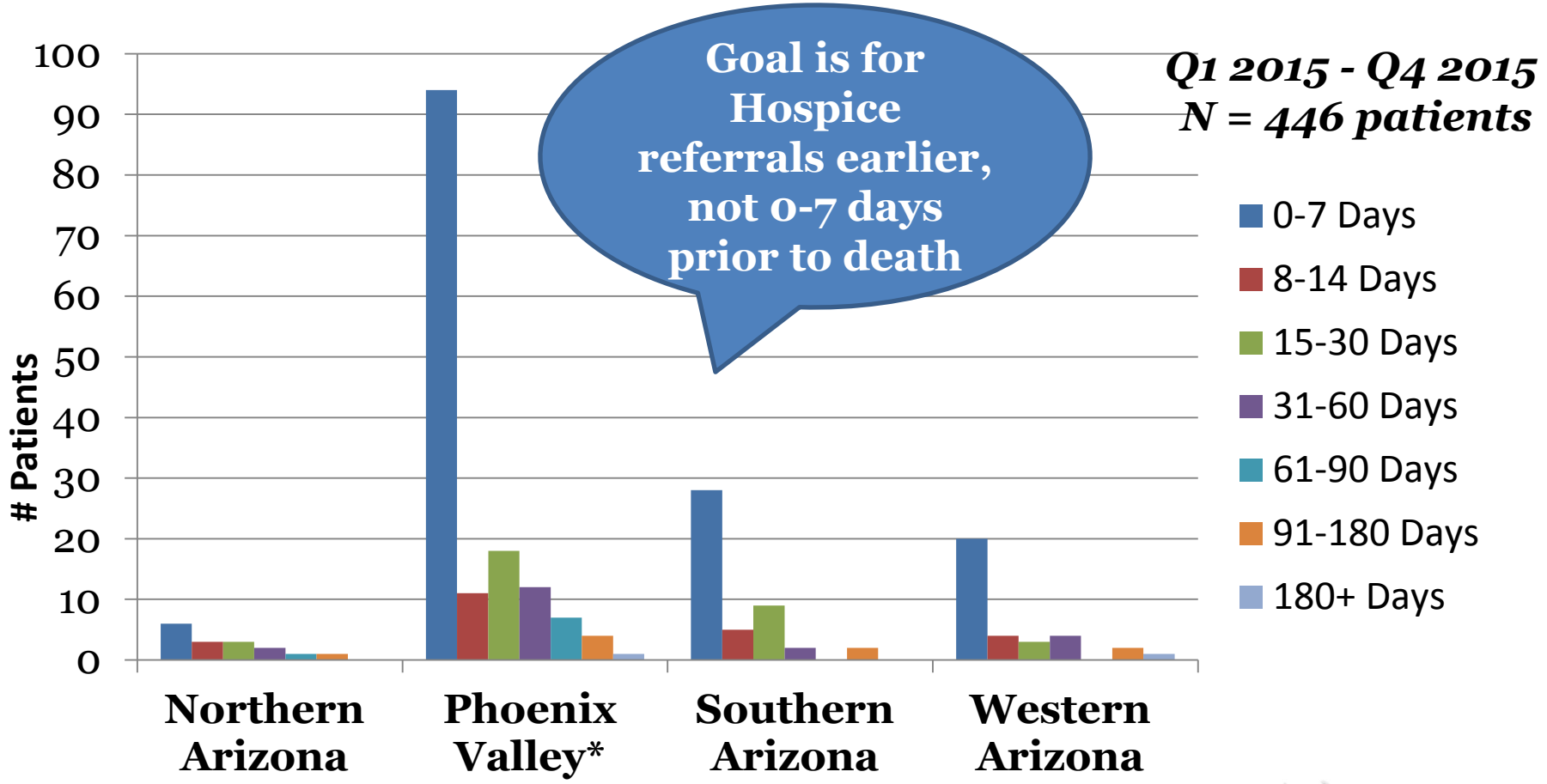
Medicare FFS Heart Failure Beneficiaries Hospice Length of Services



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Personal Reflection

Check all answers that apply

1. Who died in your first personal experience with death?

- ☐ Grandparent/great-grandparent
- ☐ Parent
- ☐ Brother or sister
- ☐ A child
- ☐ Other family member
- ☐ Friend or acquaintance
- ☐ Stranger or a public figure
- ☐ Animal or pet

2. When you were a child, how was death or dying talked about in your family?

- ☐ Openly
- ☐ With some sense of discomfort
- ☐ As though it were a taboo subject
- ☐ Do not recall any discussion

3. What does death mean to you?

- ☐ The end; the final process of life
- ☐ The beginning of a life after death; a transition, a new beginning
- ☐ A kind of endless sleep; rest and peace
- ☐ End of this life, but survival of the spirit
- ☐ Other (specify): _____

4. What about your own death concerns you most?

- ☐ I could no longer have any experiences.
- ☐ I am afraid of what might happen to my body after death.
- ☐ I am uncertain about what might happen to me if there is a life after death.
- ☐ I could no longer provide for my family.
- ☐ It would cause grief to my family and friends.
- ☐ There would be some things left undone.
- ☐ I have no concerns about my death.
- ☐ Other (specify): _____

5. What about the process of dying concerns you most?

- ☐ It would be long and painful.
- ☐ Being a financial burden to my family
- ☐ Causing my family to suffer
- ☐ Being dependent on others to care for me
- ☐ Losing control of my mind and body
- ☐ I am not concerned about the process of dying.
- ☐ Other (specify): _____

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Let's Talk....

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New Netflix Video: Extremis

Extremis

Impossible situations, wrenching emotions, that accompany end of life decisions as doctors, patients and their families in a hospital in the ICU face harrowing choices, impossible situations…

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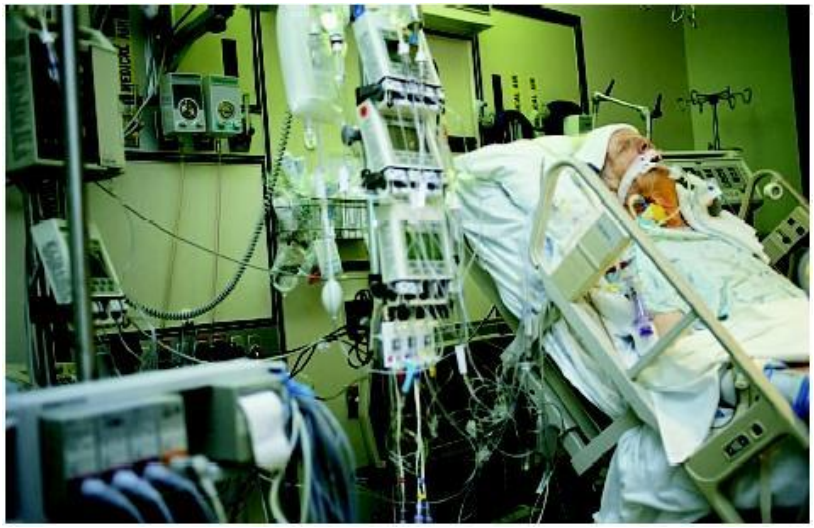
How to bridge the gap between what patients *want* and what they *get*?



At some point in life, the only thing worse than dying is being kept alive.

S Bowron, MD St Paul, MN

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The Problem: "The Big Gap"

What People Want	What They Get
1. Be at home with family, friends	Recycled through the hospital
2. Have pain managed	Often unwanted, ineffective treatment
3. Have spiritual needs addressed	Often die in hospital, in pain and isolation
4. Avoid impoverishing families/being a burden	At great cost to families and the nation.

How Physicians Really Feel

- A recent poll of physicians revealed their personal views:
  - Nearly half (46%) report they frequently feel unsure of what to say
  - Less than 1/3 (29%) report having any formal training on talking to patients and their families on end of life care
    - Of the physicians who have had training on end of life conversations 60% said they rarely feel unsure about what to say
  - 99% of physicians feel it is important for health care providers to have EOL conversations with patients

Poll-"Conversation Stopper: What's Preventing Physicians from Talking with Patients About End-of-Life and Advance Care Planning?" (2016, April 14). Retrieved May 10, 2016, from http://www.jhartfound.org/news-events/news/advance-care-planning-poll

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How Healthcare Providers Really Feel

Ain't The Way To Die

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EOL Conversations Meet the Triple Aims

Earlier conversations about patient goals and priorities for living with serious illness are associated with:

- Enhanced goal-concordant care Mack JCO 2010
- Improved quality of life
- Reduced suffering
- Better patient and family coping
- Higher patient satisfaction Detering BMJ 2010
- Less non-beneficial care and costs Wright 2008, Zhang 2009

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Conversations are too little, too late, and not great

- Multiple studies show patients with serious medical illnesses do not discuss EOL preferences, or first discuss them only in the last days to month of life Wright 2008, Dow 2010, Halpern 2011
- Among patients with ***advanced cancer***:
  - **First EOL discussion occurred median 33 days before death** Mack AIM 2012
  - **55%** of initial EOL discussions occurred in the hospital
  - **Only 25% of these discussions were conducted by the patient's oncologist** Mack AIM 2012
- Many conversations fail to address key elements of quality discussions, especially prognosis

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Advance Care Planning

ACP is a process that unfolds over a life span

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Planning for Future Care
ACP Across the Continuum

Age 18

Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with a Serious or Chronic, Progressive Illness(at any age)

Complete a POLST Form or ACP

End-of-Life Care Planning

CONVERSATIONS

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Treatment Wishes Honored

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Advance Directives vs POLST

Advanced Healthcare Directive (AHCD)	Provider Order for Life Sustaining Treatment (POLST)
Voluntary	Voluntary
General instructions for **FUTURE CARE** Requires interpretation	Specific orders for **CURRENT CARE based on CURRENT CONDITION**
Completed by anyone 18 y.o. or older	Completed only by those who are very ill, elderly and frail
Arizona Registry – must be retrieved or family must provide	Stays with the patient across the continuum of care
Many different forms Signed by patient and witnesses	Single, standardized form Signed by patient (or HC agent) and provider

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POLST vs Pre-Hospital DNR

POLST	Pre-Hospital DNR (Orange Form)
Allows for choosing wishes about resuscitation	Can only use if choosing DNR
Allows for other medical treatments • Nutrition • Ventilation • Others	Only applies to resuscitation
Honored across all heath care settings	Only honored outside the hospital (EMS form)
Not legislated in Arizona currently	Is legislated in Arizona currently
Used only in Pilot form in Arizona currently	Available statewide, used minimally (per EMS)

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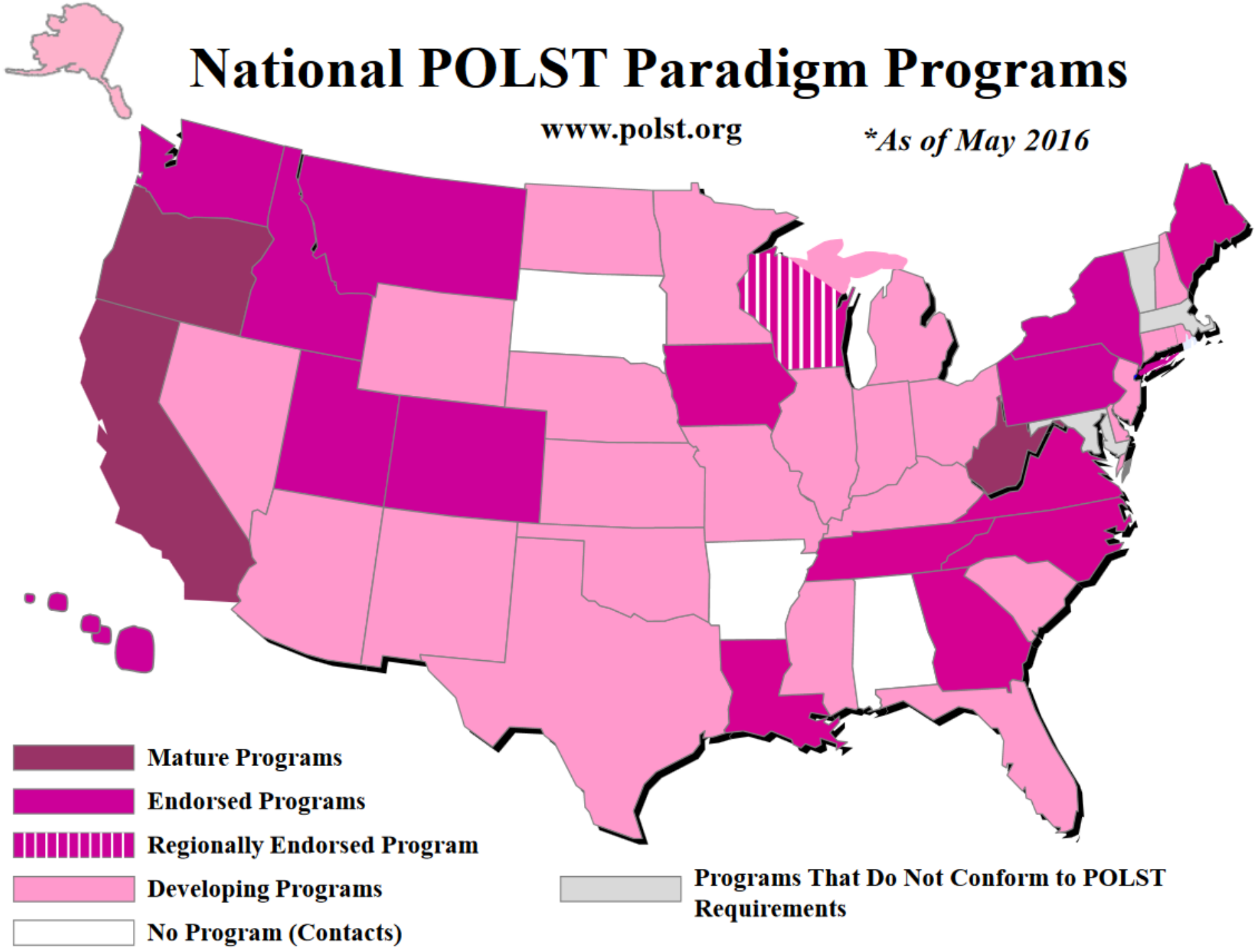
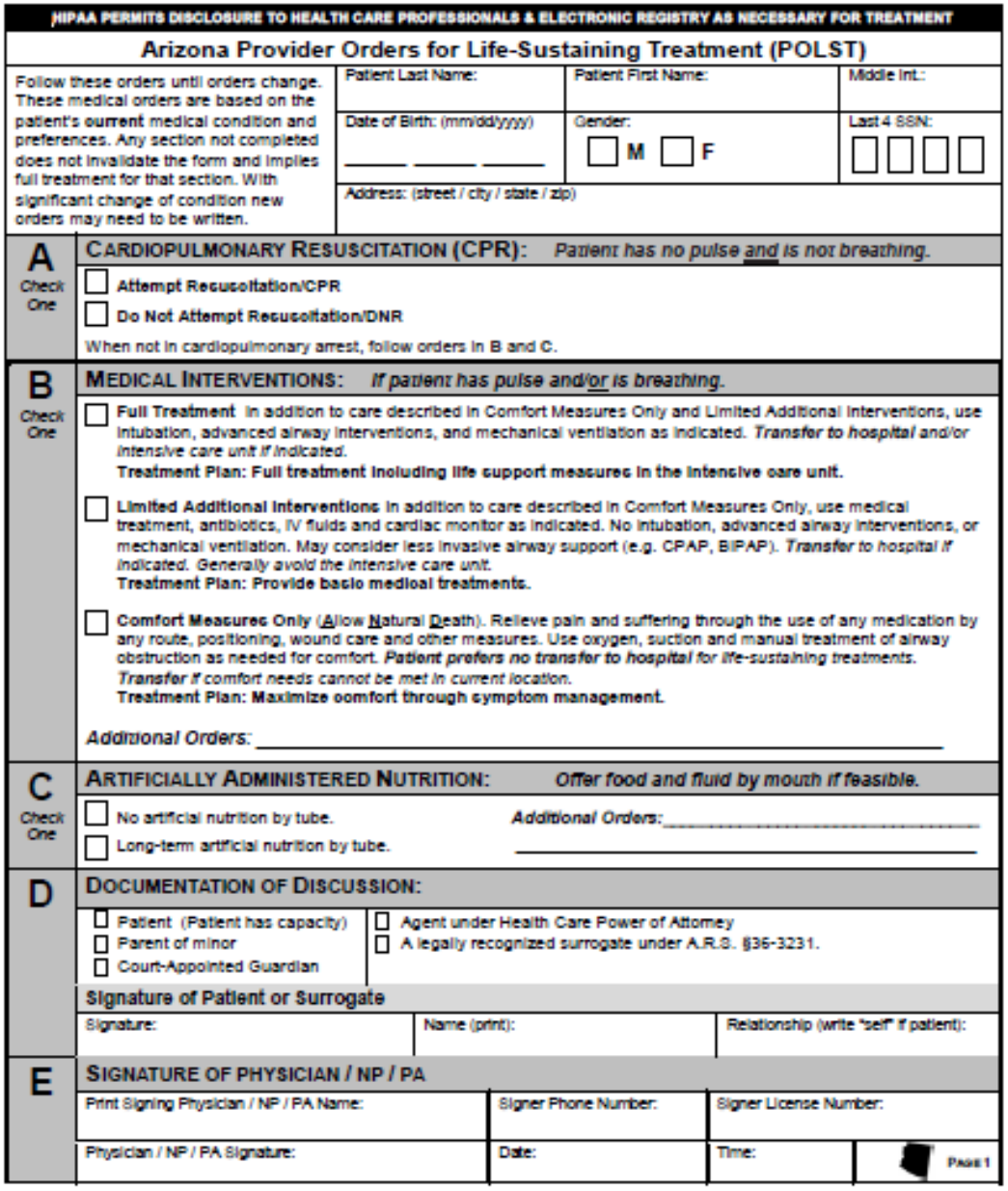
National POLST Paradigm Programs

www.polst.org

**As of May 2016*





HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Arizona Provider Orders for Life-Sustaining Treatment (POLST)

Follow these orders until orders change. These medical orders are based on the patient's **current** medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.

Patient Last Name: | Patient First Name: | Middle Int.:

Date of Birth: (mm/dd/yyyy) _____ _____ _____ | Gender: ☐ M ☐ F | Last 4 SSN: ☐☐☐☐

Address: (street / city / state / zip)

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** *Patient has no pulse and is not breathing.*

☐ **Attempt Resuscitation/CPR**

☐ **Do Not Attempt Resuscitation/DNR**

When not in cardiopulmonary arrest, follow orders in B and C.

B Check One — **MEDICAL INTERVENTIONS:** *If patient has pulse and/or is breathing.*

☐ **Full Treatment** In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. *Transfer to hospital and/or intensive care unit if indicated.*
Treatment Plan: Full treatment including life support measures in the intensive care unit.

☐ **Limited Additional Interventions** In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BIPAP). *Transfer to hospital if indicated. Generally avoid the intensive care unit.*
Treatment Plan: Provide basic medical treatments.

☐ **Comfort Measures Only** (Allow Natural Death). Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.*
Treatment Plan: Maximize comfort through symptom management.

Additional Orders: _____

C Check One — **ARTIFICIALLY ADMINISTERED NUTRITION:** *Offer food and fluid by mouth if feasible.*

☐ No artificial nutrition by tube.

☐ Long-term artificial nutrition by tube.

Additional Orders: _____

D — **DOCUMENTATION OF DISCUSSION:**

☐ Patient (Patient has capacity)
☐ Parent of minor
☐ Court-Appointed Guardian
☐ Agent under Health Care Power of Attorney
☐ A legally recognized surrogate under A.R.S. §36-3231.

Signature of Patient or Surrogate

Signature: | Name (print): | Relationship (write "self" if patient):

E — **SIGNATURE OF PHYSICIAN / NP / PA**

Print Signing Physician / NP / PA Name: | Signer Phone Number: | Signer License Number:

Physician / NP / PA Signature: | Date: | Time:

Page 1

Arizona POLST Form

- Developing state
- In pilot currently
- Undergoing revisions
- Seeking legal review
- Stay tuned

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Palliative Care vs Hospice

Palliative Care	Hospice
For people with serious illness	Care at the end of life (last 6 mos.)
Intra-disciplinary	Team based
Relief from symptoms, pain and stress	Focused on symptoms, comfort, quality of life
Improves quality of life for both patient and family	Supports patient and family
Can be provided along with curative treatment in any setting	Come into your "home" No curative treatment (unless in demonstration project)
Can bill for advance care planning sessions under Medicare as of 1/1/16 (PA, NP or Physician)	Provided as medical benefit under Medicare and some payment models

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Palliative care is a high-value clinical intervention

Provision of early palliative care services—with strong emphasis on communication and patient and family education—to lung cancer patients leads to:

- Improved quality of life
- Less use of aggressive care
- 25% increase in survival
- Reduced costs

Temel et al NEJM 2010

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http://www.thoughtfullifeconversations.org/

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Thoughtful Life Conversations is an affiliation of healthcare leaders, providers and community representatives with a shared commitment and a sense of accountability to improving end of life care for Arizonians.

Our mission is to ***empower Arizonans to make known their life wishes*** *and care directives and to* ***equip their healthcare teams with resources*** *to honor them.*

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What We're Aiming For

WISHES EXPLORED

WISHES EXPRESSED

WISHES HONORED

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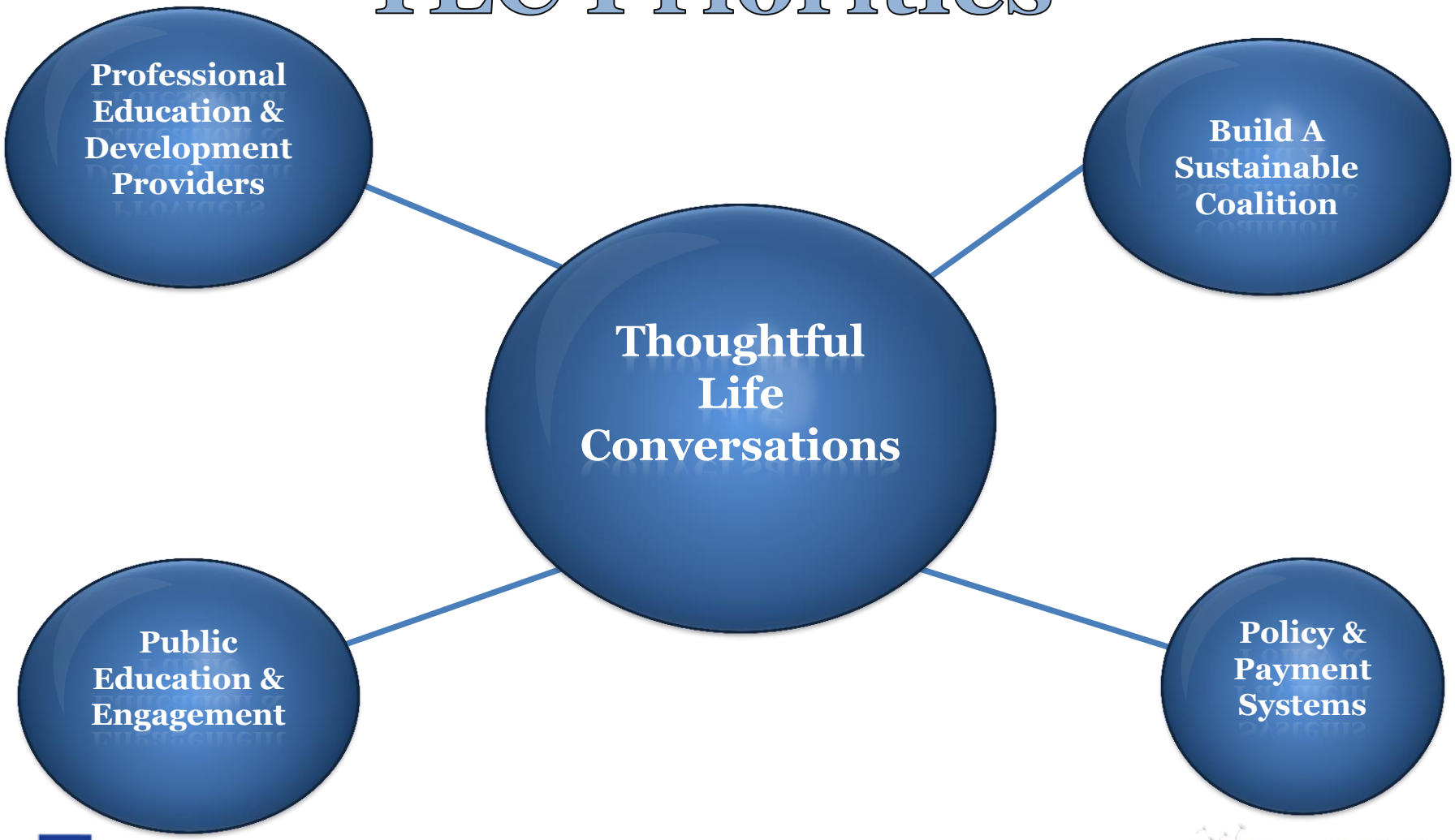
TLC Priorities



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What We Need to Get There

PUBLIC POLICY
& COMMON VISION

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What Will You Do By Next Tuesday?

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Personal Reflection

Check all answers that apply

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2. When you were a child, how was death or dying talked about in your family?

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  _____

4. What about your own death concerns you most?

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- ❑ It would cause grief to my family and friends.
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5. What about the process of dying concerns you most?

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- ❑ Being dependent on others to care for me
- ❑ Losing control of my mind and body
- ❑ I am not concerned about the process of dying.
- ❑ Other (specify):

  _____

6. How large a role has religion played in your attitude toward death?

- ❑ A very significant role
- ❑ Influential, but not a major role
- ❑ A relatively minor role
- ❑ No role at all

7. If you were told that you had a limited time to live, how would you want to spend your time until you died?

- ❑ I would pursue personal pleasures (travel, adventure, chocolate).
- ❑ I would prefer being alone: reading, thinking or praying.
- ❑ I would shift from my own needs to a concern for others (family, friends).
- ❑ I would try to tie up loose ends.
- ❑ I would try to do one important thing.
- ❑ I would make little or no changes.
- ❑ Other (specify):

  _____

8. If or when you are married or have a long-term partner, would you prefer to outlive your spouse/partner?

- ❑ Yes, I would prefer to die second and outlive my spouse/partner.
- ❑ No, I would rather die first and have my spouse/partner outlive me.
- ❑ It doesn't matter to me.
- ❑ This question doesn't apply to me.

9. If you had a choice, what kind of death would you prefer?

- ❑ Sudden, unexpected death
- ❑ Quiet, dignified death
- ❑ Death in the line of duty
- ❑ Death after a great achievement
- ❑ There is no "appropriate" kind of death.
- ❑ Other (specify):

  _____

10. What is one thing you would want to say to someone special before you die?

_____
_____
_____
_____

The Center for Healthcare Decisions developed this questionnaire, based in part on Edwin Schneidman's "You and Death: An Exercise."

For more information, contact the Center for Healthcare Decisions at www.chcd.org.

Life Care Planning Packet

Advance Directives for Health Care Planning

Office of the Attorney General of Arizona
Mark Brnovich

Mail completed forms to:
Arizona Secretary of State
Attn: Advance Directive Dept.
1700 W. Washington Street
Phoenix, AZ 85007

OFFICE OF THE ARIZONA ATTORNEY GENERAL
Mark Brnovich

LIFE CARE PLANNING INFORMATION AND DOCUMENTS

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ARIZONA ADVANCE DIRECTIVE REGISTRY

The Arizona Advance Directive Registry was created in May 2004 by the Arizona State Legislature. The Registry is a database for the storage of advance directives (Living Will, Medical Power of Attorney, and Mental Health Power of Attorney). The Arizona Secretary of State oversees Registry filings, its security, and its operations. Health care providers may use the Registry to look up registered directives using the information provided to them by the registrant or the registrant's loved ones. Further information and access to the Registry is available on the Secretary of State's Web site at www.azsos.gov or by calling 602.542.6187 or toll free 800.458.5842. Please request information at the following:

Office of the Attorney General of Arizona
Mark Brnovich

1275 West Washington St
Phoenix, Arizona 85007

Direct Line: 602.542.2123
Toll Free: 800.352.8431
Fax: 602.364.1970
www.azag.gov

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:

1. **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, and 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.

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 faithgroups.

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. You also have the option of whole body donation for research purposes. 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? Whole body? 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 AREDYING:**

  - 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 aredying?
  - Do you want certain music, poetry, or religious readings? Do you want silence? Radio? Television?

- **REMEMBRANCES TO LOVED ONES, AND FUNERAL OR OTHERARRANGEMENTS:**

  - 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 orcremated?
  - 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 PLANNINGFORMS

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, 7^{the} 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 seq.*
- **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)
- o Durable Health Care Power of Attorney
- o Living Will
- o Prehospital Medical Directive (Do Not Resuscitate)
- o Durable Mental Health Care Power of Attorney
- o Durable General Power of Attorney (Financial)

Please contact the following for a copy:

Name:
Telephone:

FREQUENTLY ASKED QUESTIONS

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FREQUENTLY ASKED QUESTIONS

1. What can I do to make sure that the Schiavo situation does not happen to me and to my family?

Terri Schiavo was in her 20s when she had her catastrophic collapse. Unfortunately, she did not leave written instructions (an "advance directive") expressing how she would like to be cared for if something happened to her. Because she did not leave instructions, the courts had to intervene to determine what she would want. Further complicating matters, her family did not agree on what her wishes would be, causing an incredibly painful situation for all involved. By taking the proper steps now, you can ensure that your wishes are known. Those steps include completing advanced directives, such as a Living Will and/or a Health Care Power of Attorney, and then discussing your choices with your loved ones so they can understand and support your wishes if you are unable to communicate for yourself.

2. Where can I find these documents?

The Attorney General's Office is just one of several sources from which to obtain forms and information on life care planning and advance directives. The forms made available by the Attorney General's Office are free of charge and comply with Arizona law. These forms and information can be found on the Attorney General's website, www.azag.gov. However, please note that advance directives do not require any particular form, and information and forms are also available from medical, religious, aging assistance, and legal organizations.

3. What are the different documents?

For example, let's look at a Durable Health Care Power of Attorney? The Durable Health Care Power of Attorney is a document lets you choose another person, called an "agent," to make health care decisions if you can no longer make those decisions for yourself. Unless the document includes specific limits, the agent will have broad authority to make any health care decision you could normally make for yourself. This could include a decision about whether or not to continue tube feeding. In this packet you will also find a Durable Mental Health Care Power of Attorney, a Living Will, a Letter to My Agent, and a Pre-Hospital Medical Directive.

4. What is a Living Will?

A Living Will is a written statement that expresses your wishes about medical treatment that would delay death from a terminal condition. It also applies to situations of persistent vegetative state or irreversible coma. A Living Will would speak for you in the event that you were unable to communicate. It gives direction and guidance to others, but is not as broadly applicable as a Durable Health Care Power of Attorney. For example, a Living Will does not permit health care providers to stop tube feeding - only an agent appointed by a Durable Health Care Power of Attorney or a court-

appointed guardian may make such a decision.

5. Can I sign both a Living Will and a Durable Health Care Power of Attorney?

Yes, but if you sign both you must attach a copy of your Living Will to the Durable Health Care Power of Attorney.

6. What if I don't sign anything? Who will make decisions for me if I am unable to communicate?

Health care providers (for example, doctors and nurses) will first try to find out if a you appointed an agent pursuant to a Durable Health Care Power of Attorney. It is also possible that a court will appoint a guardian to act as your surrogate. If you did not leave a Durable Health Care Power of Attorney and there is no court appointed guardian, the health care providers will contact the following people, in this order, who will have the authority to make health care decisions for the you (following the your wishes, if known). These people are called "surrogates."

1. Your spouse, unless you and your spouse are legally separated.
2. Your adult child. If there is more than one adult child, the health care providers will seek the consent of a majority of the children who are available for consultation.
3. Your parent.
4. Your domestic partner if no other person has assumed any financial responsibility for you.
5. Your brother or sister.
6. Your close friend.

If none of the above persons can be located, health care providers may make decisions on your behalf with the input of an ethics committee or a second physician. Again, only agents and guardians may make the decision to withdraw the artificial administration of food or fluid once it has begun. A surrogate decision-maker may not make such a decision under Arizona law.

7. Should I complete a Do Not Resuscitate "DNR" Form?

If you are healthy and strong, you may not wish to complete a DNR. You can express your wishes about how you wish to be cared for should you become seriously ill without completing a DNR. DNRs are most appropriate for people who would probably not do well with CPR (cardiopulmonary resuscitation) because they are very sick, terminally ill or otherwise extremely weak. In any case, you will need to discuss the DNR with your doctor, who will also need to sign the form.

8. At what age should I think about filling out these documents?

Now, so long as you are at least 18 years of age. It is never too early to think about these things and make preparations.

9. What should I do once I've filled out the documents?

First, it is important that you talk about the documents and your wishes with your family, your agent and your physician. An agent needs to know what your feelings are in order to act on your behalf. You also need to make sure that the appropriate people have copies of the documents. To register a copy of your documents, please send them to the Secretary of State. Information on how to register your Advance Directive and other Life Care Planning materials can be found on the Secretary of State's Web site at http://www.azsos.gov/

10. Do I have to use a lawyer to complete these forms?

No. You do not have to have a lawyer's help to fill out these documents, but you may wish to consult with a lawyer if you have questions. If you do not know an attorney in your area, the State Bar of Arizona provides information on attorney referral services for persons of varying income levels. Additionally, these legal services can help provide free

legal services to those in need:

Arizona State Bar	Community Legal Services
602.252.4804	602.258.3434
www.azbar.org	www.vlparizona.org

11. Do I have to use a notary or have a witness to complete these forms?

Yes. The Durable Health Care Power of Attorney, Living Will and Durable Mental Health Care Power of Attorney must be signed by EITHER a witness OR a notary. Please note that the witness must be at least 18, cannot be family (related by blood, adoption or marriage), cannot be in your will to receive part of your estate, cannot be appointed as your representative, and cannot be a health care giver. A witness CAN be a neighbor, a friend, or an acquaintance who is an adult, but a witness cannot be provided for in your will and cannot not be caring for you or representing you.

12. How does HIPAA apply to my Life Care Planning forms?

There is a difference of opinion as to whether HIPAA (Health Insurance Portability and Accountability Act of 1996) applies to life care planning documents, such as those provided here by the Attorney General's Office.

In an abundance of caution, we have placed a HIPAA release under the "Signature and Verification" section of both the Health Care and Mental Health Power of Attorney forms, just above the space for your signature. This release should reassure anyone concerned about HIPAA issues, especially medical personnel, that they may provide information about your care to your representative(s).

13. What else should I know?

These documents are meant for you to express your wishes, whatever they may be, so you receive the treatment you want if you can no longer communicate. The Attorney General's Office is not recommending any particular choices but does urge you to think about these choices, discuss them with your loved ones, and complete the appropriate documents for your situation. Hopefully, having your wishes clearly expressed to your loved ones and in these documents will help those close to you avoid the anguish suffered by the Schiavo family.

The primary role of the Attorney General's Office is to provide legal representation to the State of Arizona, its agencies, and State officials acting in their official capacities. The Office is not authorized to advise or represent private citizens on personal legal matters. If you need help with a personal legal matter—such as filing a lawsuit, creating a will, or defending against a criminal charge—you may want to contact a private attorney.

OFFICE OF THE ARIZONA ATTORNEY GENERAL
Mark Brnovich

STATE OF ARIZONA
DURABLE HEALTH CARE POWER OF ATTORNEY

Instructions and Form

GENERAL INSTRUCTIONS: Use this Durable Health Care Power of Attorney form if you want to select a person to make future health care decisions for you so that if you become too ill or cannot make those decisions for yourself the person you choose and trust can make medical decisions for you. Talk to your family, friends, and others you trust about your choices. Also, it is a good idea to talk with professionals such as your doctor, clergyperson and a lawyer before you sign this form.

Be sure you understand the importance of this document. If you decide this is the form you want to use, complete the form. **Do not sign this form until** your witness or a Notary Public is present to witness the signing. There are further instructions for you about signing this form on page three.

1. Information about me (the Principal):

My Name: _____ My Age: _____
My Address: _____ My Date of Birth: _____
_____ My Telephone: _____

2. Selection of my health care representative and alternate ("agent" or "surrogate")

I choose the following person to act as my representative to make health care decisions for me:

Name: _____ Home Phone: _____
Address: _____ Work Phone: _____
_____ Cell Phone: _____

I choose the following person to act as an alternate representative to make health care decisions on my behalf if the first representative is unavailable, unwilling, or unable to make decisions for me:

Name: _____ Home Phone: _____
Address: _____ Work Phone: _____
_____ Cell Phone: _____

3. I AUTHORIZE if I am unable to make medical care decisions for myself:

I authorize my health care representative to make health care decisions for me when I cannot make or communicate my own health care decisions due to mental or physical illness, injury, disability, or incapacity. I want my

representative to make all such decisions for me except those decisions that I have expressly stated in Part 4 below that I do not authorize him/her to make. If I am able to communicate in any manner, my representative should discuss my health care options with me. My representative should explain to me any choices he or she made if I am able to understand. I further authorize my representative to have all access to and copies of my "personal protected health care information and medical records". This appointment is effective unless and until it is revoked by me or by an order of a court.

The types of health care decisions I authorize to be made on my behalf include but are not limited to the following:

- To consent or to refuse medical care, including diagnostic, surgical, or therapeutic procedures;
- To authorize the physicians, nurses, therapists, and other health care providers of his/her choice to provide care for me, and to obligate my resources or my estate to pay reasonable compensation for these services;
- To approve or deny my admittance to health care institutions, nursing homes, assisted living facilities, or other facilities or programs. By signing this form I understand that I allow my representative to make decisions about my mental health care except that he or she cannot have me admitted to a structured treatment setting with 24-hour-a-day supervision and an intensive treatment program – called a "level one" behavioral health facility – using just this grant of authority;
- To have access to and control over my medical records and to have the authority to discuss those records with health care providers.

4. DECISIONS I EXPRESSLY DO NOT AUTHORIZE my Representative to make for me:

I do not want my representative to make the following health care decisions for me (describe or write in "not applicable"):

5. My specific desires about autopsy:

NOTE: Under Arizona law, an autopsy is not required unless the county medical examiner, the county attorney, or a superior court judge orders it to be performed. See the General Information document for more information about this topic. Initial or put a check mark by one of the following choices.

_____Upon my death I DO NOT consent to a voluntary autopsy.
_____Upon my death I DO consent to a voluntary autopsy.
_____My representative may give or refuse consent for an autopsy.

6. My specific desires about organ donation ("anatomical gift"):

NOTE: Under Arizona law, you may donate all or part of your body. If you do not make a choice, your representative or family can make the decision when you die. You may indicate which organs or tissues you want to donate and where you want them donated. Initial or put a check mark by A or B below. If you select B, continue with your choices.

____ **A.** I DO NOT WANT to make an organ or tissue donation, and I do not want this donation authorized on my behalf by my representative or my family.

____ **B.** I DO WANT to make an organ or tissue donation when I die. Here are my directions:

1. What organs/tissues I choose to donate: (Select a or b below)

○ **a.** Whole body
○ **b.** Any needed parts or organs:
○ **c.** These parts or organs only:

1) _____
2) _____
3) _____

2. What purposes I donate organs/tissue for: (Select a, b, or c below)

○ **a. Any** legally authorized purpose (transplantation, therapy, medical and dental evaluation, education or research, and/or advancement of medical and dental science).
○ **b.** Transplant or therapeutic purposes only.
○ **c.** Research Only
d. Other: _____

3. Which organization or person I want my parts or organs to go to:

○ **a.** I have already signed a written agreement or donor card regarding organ and tissue donation with the following individual or institution:(name) _____
_____

○ **b.** I would like my tissues or organs to go to the following individual or institution:
_____

○ **c.** I authorize my representative to make this decision.

7. Funeral and Burial Disposition (Optional):

My agent has authority to carry out all matters relating to my funeral and burial disposition wishes in accordance with this power of attorney, which is effective upon my death. My wishes are reflected below:

NOTE: If you choose whole body donation, cremation is the only burial disposition available.

Place your initials by those choices you wish to select.

_____ Upon my death, I direct my body to be buried. (As opposed to cremated)
_____ Upon my death, I direct my body to be buried in _____
_____. (Optional directive)
_____ Upon my death, I direct my body to be cremated.
_____ Upon my death, I direct my body to be cremated with my ashes to be _____
_____. (Optional directive)
_____ My agent will make all funeral and burial disposition decisions. (Optional directive)

8. About a Living Will

NOTE: If you have a Living Will and a Durable Health Care Power of Attorney, **you must attach** the Living Will to this form. A Living Will form is available on the Attorney General (AG) web site. Initial or put a check mark by box A or B.

_____ **A.** I have SIGNED AND ATTACHED a completed Living Will in addition to this Durable Health Care Power of Attorney to state decisions I have made about end of life health care if I am unable to communicate or make my own decisions at that time.
_____ **B.** I have NOT SIGNED a Living Will.

9. About a Prehospital Medical Care Directive or Do Not Resuscitate Directive:

NOTE: A form for the Prehospital Medical Care Directive or Do Not Resuscitate Directive is available on the AG Web site. Initial or put a check mark by box A or B.

____ A. I and my doctor or health care provider HAVE SIGNED a Prehospital Medical Care Directive or a Do Not Resuscitate Directive on Paper with ORANGE background in the event that 911 of Emergency Medical Technicians or hospital emergency personnel are called and my heart or breathing has stopped.

____ B. I have NOT SIGNED a Prehospital Medical Care Directive or Do Not Resuscitate Directive.

10. HIPAA WAIVER OF CONFIDENTIALITY FOR MYAGENT/REPRESENTATIVE

_____ (Initial) I intend for my agent to be treated as I would with respect to my rights regarding the use and disclosure of my individually identifiable health information or medical records. This release authority applies to information governed by the Health Insurance Portability and Accountability Act (HIPAA) of 1996, 42 USC 1320d, 45 CFR 160-164.

SIGNATURE OR VERIFICATION

A. I am signing this Durable Health Care Power of Attorney as follows:

My Signature:_____ Date: _____

B. I am physically unable to sign this document, so a witness is verifying my desires as follows:

Witness Verification: I believe that this Durable Health Care Power of Attorney accurately expresses the wishes communicated to me by the principal of this document. He/she intends to adopt this Durable Health Care Power of Attorney at this time. He/she is physically unable to sign or mark this document at this time, and I verify that he/she directly indicated to me that the Durable Health Care Power of Attorney expresses his/her wishes and that he/she intends to adopt the Durable Health Care Power of Attorney at this time.

Witness Name (printed):_____

Signature:_____Date:_____

SIGNATURE OF WITNESS OR NOTARY PUBLIC:

NOTE: At least one adult witness OR a Notary Public must witness the signing of this document and then sign it. The witness or Notary Public CANNOT be anyone who is: (a) under the age of 18; (b) related to you by blood, adoption, or marriage; (c) entitled to any part of your estate; (d) appointed as your representative; or (e) involved in providing your health care at the time this form is signed.

A. Witness: I certify that I witnessed the signing of this document by the Principal. The person who signed this Durable Health Care Power of Attorney appeared to be of sound mind and under no pressure to make specific choices or sign the document. I understand the requirements of being a witness and I confirm the following:

- I am not currently designated to make medical decisions for this person.
- I am not directly involved in administering health care to this person.
- I am not entitled to any portion of this person's estate upon his or her death under a will or by operation of law.
- I am not related to this person by blood, marriage or adoption.

Witness Name (printed): _____

Signature:_____Date:_____

Address: _____

_____

Notary Public (NOTE: If a witness signs your form, you DO NOT need a notary to sign):

STATE OF ARIZONA) ss
COUNTY OF _____)

The undersigned, being a Notary Public certified in Arizona, declares that the person making this Durable Health Care Power of Attorney has dated and signed or marked it in my presence and appears to me to be of sound mind and free from duress. I further declare I am not related to the person signing above by blood, marriage or adoption, or a person designated to make medical decisions on his/her behalf. I am not directly involved in providing health care to the person signing. I am not entitled to any part of his/her estate under a will now existing or by operation of law. In the event the person acknowledging this Durable Health Care Power of Attorney is physically unable to sign or mark this document, I verify that he/she directly indicated to me that this Durable Health Care Power of Attorney expresses his/her wishes and that he/she intends to adopt the Durable Health Care Power of Attorney at this time.

WITNESS MY HAND AND SEAL this_____day of_____, 20_____

Notary Public_____My Commission Expires: _____

OPTIONAL:
STATEMENT THAT YOU HAVE DISCUSSED YOUR HEALTH CARE CHOICES FOR THE FUTURE WITHYOUR PHYSICIAN

NOTE: Before deciding what health care you want for yourself, you may wish to ask your physician questions regarding treatment alternatives. This statement from your physician is not required by Arizona law. If you do speak with your physician, it is a good idea to have him or her complete this section. Ask your doctor to keep a copy of this form with your medical records.

On this date I reviewed this document with the Principal and discussed any questions regarding the probable medical consequences of the treatment choices provided above. I agree to comply with the provisions of this directive, and I will comply with the health care decisions made by the representative unless a decision violates my conscience. In such case I will promptly disclose my unwillingness to comply and will transfer or try to transfer patient care to another provider who is willing to act in accordance with the representative's direction.

Doctor Name (printed):_____

Signature:_____Date:_____

Address:_____

_____

OFFICE OF THE ARIZONA ATTORNEY GENERAL
Mark Brnovich

STATE OF ARIZONA
DURABLE MENTAL HEALTH CARE POWER OF ATTORNEY

Instructions and Form

GENERAL INSTRUCTIONS: Use this Durable Mental Health Care Power of Attorney form if you want to appoint a person to make future mental health care decisions for you if you become incapable of making those decisions for yourself. The decision about whether you are incapable can only be made by a specialist in neurology or an Arizona licensed psychiatrist or psychologist who will evaluate whether you can give informed consent. Be sure you understand the importance of this document. Talk to your family members, friends, and others you trust about your choices. Also, it is a good idea to talk with professionals such as your doctor, clergyperson, and a lawyer before you sign this form. If you decide this is the form you want to use, complete the form. Do not sign this form until your witness or a Notary Public is present to witness the signing. There are more instructions about signing this form on page 3.

1. Information about me: (I am called the "Principal")

My Name:_____ My Age: _____
My Address:_____ My Date of Birth: _____
_____ My Telephone: _____

2. Selection of my health care representative and alternate: (Also called an "agent" or "surrogate")

I choose the following person to act as my representative to make mental health care decisions for me:

Name: _____ Home Phone:_____
Address: _____ Work Phone:_____
_____ Cell Phone:_____

I choose the following person to act as an alternate representative to make mental health care decisions for me if my first representative is unavailable, unwilling, or unable to make decisions for me:

Name: _____ Home Phone:_____
Address: _____ Work Phone:_____
_____ Cell Phone:_____

3. Mental health treatments that I AUTHORIZE if I am unable to make decisions for myself:

Here are the mental health treatments I authorize my mental health care representative to make on my behalf if I become incapable of making my own mental health care decisions due to mental or physical illness, injury, disability, or incapacity. If my wishes are not clear from this Durable Mental Health Care Power of Attorney or are not otherwise known to my representative, my representative will, in good faith, act in accordance with my best interests. This appointment is effective unless and until it is revoked by me or by an order of a court. My representative is authorized to do the following which I have initialed or marked:

DURABLE MENTAL HEALTH CARE POWER OF ATTORNEY (Cont'd)

☐ **A. About my records:** To receive information regarding mental health treatment that is proposed for me and to receive, review, and consent to disclosure of any of my medical records related to that treatment.

☐ **B. About medications:** To consent to the administration of any medications recommended by my treating physician.

☐ **C. About a structured treatment setting:** To admit me to a structured treatment setting with 24hour-a-day supervision and an intensive treatment program licensed by the Department of Health Services, which is called an inpatient psychiatric facility.

☐ **D. Other:** .

4. Durable Mental health treatments that I expressly DO NOT AUTHORIZE if I am unable to make decisions for myself: (Explain or write in "None") _____

5. Revocability of this Durable Mental Health Care Power of Attorney: This mental health care power of attorney or any portion of it may not be revoked and any designated agent may not be disqualified by me during times that I am found to be unable to give informed consent. However, at all other times I retain the right to revoke all or any portion of this mental health care power of attorney or to disqualify any agent designated by me in this document.

6. Additional information about my mental health care treatment needs (consider including mental or physical health history, dietary requirements, religious concerns, people to notify and any other matters that you feel are important):

HIPPA WAIVER OF CONFIDENTIALITY FOR MY AGENT/REPRESENTATIVE

_____ **(Initial)** I intend for my agent to be treated as I would be with respect to my rights regarding the use and disclosure of my individually identifiable health information or other medical records. This release authority applies to any information governed by the Health Insurance Portability and Accountability Act of 1996 (aka HIPAA), 42 USC 1320d and 45 CFR 160-164.

SIGNATURE OR VERIFICATION

A. I am signing this Durable Mental Health Care Power of Attorney as follows:

My Signature:_____ Date: _____

DURABLE MENTAL HEALTH CARE POWER OF ATTORNEY (Last Page)

B. I am physically unable to sign this document, so a witness is verifying my desires as follows:

Witness Verification: I believe that this Durable Mental Health Care Power of Attorney accurately expresses the wishes communicated to me by the Principal of this document. He/she intends to adopt this Durable Mental Health Care Power of Attorney at this time. He/she is physically unable to sign or mark this document at this time. I verify that he/she directly indicated to me that the Durable Mental Health Care Power of Attorney expresses his/her wishes and that he/she intends to adopt the Durable Mental Health Care Power of Attorney at this time.

Witness Name (printed): _____

Signature: _____ Date: _____

SIGNATURE OF WITNESS OR NOTARY PUBLIC

NOTE: At least one adult witness OR a Notary Public must witness the signing of this document and then sign it. The witness or Notary Public CANNOT be anyone who is: (a) under the age of 18; (b) related to you by blood, adoption, or marriage; (c) entitled to any part of your estate; (d) appointed as your representative; or (e) involved in providing your health care at the time this document is signed.

A. Witness: I affirm that I personally know the person signing this Durable Mental Health Care Power of Attorney and that I witnessed the person sign or acknowledge the person's signature on this document in my presence. I further affirm that he/she appears to be of sound mind and not under duress, fraud, or undue influence. He/she is not related to me by blood, marriage, or adoption and is not a person for whom I directly provide care in a professional capacity. I have not been appointed to make medical decisions on his/her behalf.

Witness Name (printed): _____

Signature: _____ Date: _____

Address: _____

_____

B. Notary Public: (NOTE: If a witness signs your form, you DO NOT need a notary to sign)

STATE OF ARIZONA) ss
COUNTY OF _____)

The undersigned, being a Notary Public certified in Arizona, declares that the person making this Durable Mental Health Care Power of Attorney has dated and signed or marked it in my presence and appears to me to be of sound mind and free from duress. I further declare I am not related to the person signing above, by blood, marriage or adoption, or a person designated to make medical decisions on his/her behalf. I am not directly involved in providing care as a professional to the person signing. I am not entitled to any part of his/her estate under a will now existing or by operation of law. In the event the person acknowledging this Durable Mental Health Care Power of Attorney is physically unable to sign or mark this document, I verify that he/she directly indicated to me that the Durable Mental Health Care Power of Attorney expresses his/her wishes and that he/she intends to adopt the Durable Mental Health Care Power of Attorney at this time

WITNESS MY HAND AND SEAL this_____ day of_____, 20___

Notary Public: _____ My commission expires: _____

OPTIONAL: REPRESENTATIVE'S ACCEPTANCE OF APPOINTMENT

I accept this appointment and agree to serve as agent to make mental health treatment decisions for the Principal. I understand that I must act consistently with the wishes of the person I represent as expressed in this Durable Mental Health Care Power of Attorney or, if not expressed, as otherwise known by me. If I do not know the Principal's wishes, I have a duty to act in what I, in good faith, believe to be that person's best interests. I understand that this document gives me the authority to make decisions about mental health treatment only while that person has been determined to be incapacitated which means under Arizona law that a specialist in neurology or a licensed psychiatrist or psychologist has the opinion that the Principal is unable to give informed consent.

Representative Name(printed):_____

Signature:_____Date:_____

OFFICE OF THE ARIZONA ATTORNEY GENERAL
Mark Brnovich

LIVING WILL (End of Life Care)
Instructions and Form

GENERAL INSTRUCTIONS: Use this Living Will form to make decisions now about your medical care if you are ever in a terminal condition, a persistent vegetative state or an irreversible coma. You should talk to your doctor about what these terms mean. The Living Will states what choices you would have made for yourself if you were able to communicate. It is your written directions to your health care representative if you have one, your family, your physician, and any other person who might be in a position to make medical care decisions for you. Talk to your family members, friends, and others you trust about your choices. Also, it is a good idea to talk with professionals such as your doctor, clergyperson and a lawyer before you complete and sign this Living Will.

If you decide this is the form you want to use, complete the form. **Do not sign the Living Will until** your witness or a Notary Public is present to watch you sign it. There are further instructions for you about signing on page 2.

IMPORTANT: If you have a Living Will and a Durable Health Care Power of Attorney, you must attach the Living Will to the Durable Health Care Power of Attorney.

1. **My information:** (the "Principal")
   Name:_____ Age:_____
   Address: _____ Date of birth: _____
   _____ Phone: _____

2. **My decisions about end of life care:**

NOTE: Here are some general statements about choices you have as to health care you want at the end of your life. They are listed in the order provided by Arizona law. You can initial any combination of paragraphs A, B, C, and D. **If you initial Paragraph E, do not initial any other paragraphs.** Read all of the statements carefully before initialing to indicate your choice. You can also write your own statement concerning life-sustaining treatments and other matters relating to your health care at Heading 3 of this form.

_____ **A. Comfort Care Only:** If I have a terminal condition I do not want my life to be prolonged, and I do not want life- sustaining treatment, beyond comfort care, that would serve only to artificially delay the moment of my death. (NOTE: "Comfort care" means treatment in an attempt to protect and enhance the quality of life without artificially prolonging life.)

_____ **B. Specific Limitations on Medical Treatments I Want:** (NOTE: Initial or mark one or more choices, talk to your doctor about your choices.) If I have a terminal condition, or am in an irreversible coma or a persistent vegetative state that my doctors reasonably believe to be irreversible or incurable, I do want the medical treatment necessary to provide care that would keep me comfortable, but **I do not want the following:**

_____1.) Cardiopulmonary resuscitation, for example, the use of drugs, electric shock, and artificial breathing.
_____ 2.) Artificially administered food and fluids.
_____ 3.) To be taken to a hospital if it is at all avoidable.

_____ **C. Pregnancy:** Regardless of any other directions I have given in this Living Will, if I am known to be pregnant I do not want life-sustaining treatment withheld or withdrawn if it is possible that the embryo/fetus will develop to the point of live birth with the continued application of life-sustaining treatment.

_____ **D. Treatment Until My Medical Condition is Reasonably Known:** Regardless of the directions I have made in this Living Will, I do want the use of all medical care necessary to treat my condition until my doctors reasonably conclude that my condition is terminal or is irreversible and incurable, or I am in a persistent vegetative state.

____ **E. Direction to Prolong My Life:** I want my life to be prolonged to the greatest extent possible.

3. Other Statements Or Wishes I Want Followed For End of Life Care:

NOTE: You can attach additional provisions or limitations on medical care that have not been included in this Living Will form. Initial or put a check mark by box A or B below. Be sure to include the attachment if you check B.

___**A.** I have not attached additional special provisions or limitations about End of Life Care I want.
___**B.** I have attached additional special provisions or limitations about End of Life Care I want.

SIGNATURE VERIFICATION

A. I am signing this Living Will as follows:

Signature:_____ Date:_____

B. I am physically unable to sign this Living Will, so a witness is verifying my desires as follows:

Witness Verification: I believe that this Living Will accurately expresses the wishes communicated to me by the principal of this document. He/she intends to adopt this Living Will at this time. He/she is physically unable to sign or mark this document at this time. I verify that he/she directly indicated to me that the Living Will expresses his/her wishes and that he/she intends to adopt the Living Will at this time.

Witness Name (printed):_____

Signature: _____Date:_____

SIGNATURE OF WITNESS OR NOTARY PUBLIC

NOTE: At least one adult witness OR a Notary Public must witness you signing this document. The witness or Notary Public CANNOT be anyone who is: (a) under the age of 18; (b) related to you by blood, adoption, or marriage; (c) entitled to any part of your estate; (d) appointed as your representative; or (e) involved in providing your health care at the time this document is signed.

A. Witness: I certify that I witnessed the signing of this document by the Principal. The person who signed this Living Will appeared to be of sound mind and under no pressure to make specific choices or sign the document. I understand the requirements of being a witness. I confirm the following:

- I am not currently designated to make medical decisions for this person.
- I am not directly involved in administering health care to this person.
- I am not entitled to any portion of this person's estate upon his or her death under a will or by operation of law.
- I am not related to this person by blood, marriage, or adoption.

Witness Name (printed):_____

Signature:_____Date: _____

Address:_____

B. Notary Public: (NOTE: a Notary Public is only required if no witness signed above)

STATE OF ARIZONA) ss
COUNTY OF_____)

The undersigned, being a Notary Public certified in Arizona, declares that the person making this Living Will has dated and signed or marked it in my presence and appears to me to be of sound mind and free from duress. I further declare I am not related to the person signing above, by blood, marriage or adoption, or a person designated to make medical decisions on his/her behalf. I am not directly involved in providing care as a professional to the person signing. I am not entitled to any part of his/her estate under a will now existing or by operation of law. In the event the person acknowledging this Durable Mental Health Care Power of Attorney is physically unable to sign or mark this document, I verify that he/she directly indicated to me that the Durable Mental Health Care Power of Attorney expresses his/her wishes and that he/she intends to adopt the Durable Mental Health Care Power of Attorney at this time

WITNESS MY HAND AND SEAL this _ day of_____, 20 _

Notary Public:_____My commission expires: _____

OFFICE OF THE ARIZONA ATTORNEY GENERAL
Mark Brnovich

LETTER TO MY REPRESENTATIVE(S)
About Powers of Attorney Forms and Responsibilities

To My Representative:
Name:_____
Address: _____
_____

To My AlternateRepresentative:
Name:_____
Address: _____
_____

A. What I Ask You to Do For Me: Arizona law allows me to make certain medical and financial decisions as to what I want in the future if I become unable or incapable of making certain decisions for myself. I have completed the following document(s), and I want you to be my representative or alternate representative for the following purposes. (Initial or check one or more of the following):

____1. Durable Health Care Power ofAttorney
____2. Durable Mental Health Care Power ofAttorney

B. Why I Named an Alternate Representative: I chose two representatives in case one of you is unable to act for me when the time arises. I ask that you accept my selection of you as my representative or alternate. If you do not return the Power of Attorney form(s) and this letter to me or inform me differently, I will assume that you have agreed to be my representative.

C. Your Responsibilities as My Representative: By selecting you, I want you to make some very important decisions for me about my future health care needs if I become unable to make these decisions for myself. I might need you to carry out my medical choices as indicated in the enclosed Powers of Attorney, even if you do not agree with them. Please read the copies of the Powers of Attorney I am giving you. You will be my voice and will make medical decisions on my behalf. Other than what I have indicated in the Powers of Attorney as to my specific directions on certain issues, I am trusting your judgment to make decisions that you believe to be in my best interests. If at any time you do not feel that you can undertake this responsibility for any reason, please let me know. If you are unsure about any of my directions, please discuss them with me. If you are not willing to serve as my representative, please tell me so I can choose someone else to helpme.

As to Health Care: You are not financially responsible for paying my health care costs merely by accepting this responsibility. Under Arizona law, you are not liable for complying with my decisions as stated in the Powers of Attorney or in making other health care decisions for me if you act in good faith.

D. What Else You Should Do: Please keep a copy of my Powers of Attorney and other documents in a safe place. Please read these documents carefully and discuss my choices with me at any time. I will give copies of my health care Powers of Attorney to my physician, and I will give copies of any or all of these Powers of Attorney to my family and any other representative I may choose. I authorize you to discuss with them the Powers of Attorney, including, as applicable, my medical situation, or any medical concerns about me. Please work with them and help them to act in accordance with my desires and in my best interests. I appreciate your support, and I thank you for your willingness to help me in thisway.

Signature:_____Date: _____

Printed Name:_____

PREHOSPITAL MEDICAL CARE DIRECTIVE (DO NOT RESUSCITATE)

(IMPORTANT—THIS DOCUMENT MUST BE ON PAPER WITH ORANGE BACKGROUND)

GENERAL INFORMATION AND INSTRUCTIONS: A Prehospital Medical Care Directive is a document signed by you and your doctor that informs emergency medical technicians (EMTs) or hospital emergency personnel not to resuscitate you. Sometimes this is called a DNR – Do Not Resuscitate. If you have this form, EMTs and other emergency personnel will not use equipment, drugs, or devices to restart your heart or breathing, but they will not withhold medical interventions that are necessary to provide comfort care or to alleviate pain. **IMPORTANT**: Under Arizona law a Prehospital Medical Care Directive or DNR must be on letter sized paper or wallet sized paper on an orange background to bevalid.

You can either attach a picture to this form, or complete the personal information. You must also complete the form and sign it in front of a witness. Your health care provider and your witness must sign this form.

1. My Directive and MySignature:

In the event of cardiac or respiratory arrest, I refuse any resuscitation measures including cardiac compression, endotracheal intubation and other advanced airway management, artificial ventilation, defibrillation, administration of advanced cardiac life support drugs and related emergency medical procedures.

Patient Signature:_____ Date: _____

PROVIDE THE FOLLOWING INFORMATION: **OR** **ATTACH RECENT PHOTOGRAPH HERE:**

My Date of Birth _

My Sex _

My Race _

My Eye Color _

My Hair Color _

2. Information About My Doctor and Hospice (if I am in Hospice)**:**

Physician:_____ Telephone: _____

Hospice Program, if applicable (name):_____

PREHOSPITAL MEDICAL CARE DIRECTIVE (DO NOT RESUSCITATE) (Last Page)

3. Signature of Doctor or Other Health Care Provider:

I have explained this form and its consequences to the signer and obtained assurance that the signer understands that death may result from any refused care listed above.

Signature of a Licensed Health Care Provider:_____ Date: _____

4. Signature of Witness to MyDirective:

NOTE: At least one adult witness OR a Notary Public must witness the signing of this document. The witness or Notary Public CANNOT be anyone who is: (a) under the age of 18; (b) related to you by blood, adoption, or marriage; (c) entitled to any part of your estate; (d) appointed as your representative; or (e) involved in providing your health care at the time this form is signed.

I was present when this form was signed (or marked). The patient then appeared to be of sound mind and free from duress.

Signature:_____ Date:_____

PREHOSPITAL MEDICAL CARE DIRECTIVE (DO NOT RESUSCITATE)

(IMPORTANT—THIS DOCUMENT MUST BE ON PAPER WITH ORANGE BACKGROUND)

GENERAL INFORMATION AND INSTRUCTIONS: A Prehospital Medical Care Directive is a document signed by you and your doctor that informs emergency medical technicians (EMTs) or hospital emergency personnel not to resuscitate you. Sometimes this is called a DNR – Do Not Resuscitate. If you have this form, EMTs and other emergency personnel will not use equipment, drugs, or devices to restart your heart or breathing, but they will not withhold medical interventions that are necessary to provide comfort care or to alleviate pain. **IMPORTANT**: Under Arizona law a Prehospital Medical Care Directive or DNR must be on letter sized paper or wallet sized paper on an orange background to bevalid.

You can either attach a picture to this form, or complete the personal information. You must also complete the form and sign it in front of a witness. Your health care provider and your witness must sign this form.

1. My Directive and MySignature:

In the event of cardiac or respiratory arrest, I refuse any resuscitation measures including cardiac compression, endotracheal intubation and other advanced airway management, artificial ventilation, defibrillation, administration of advanced cardiac life support drugs and related emergency medical procedures.

Patient Signature:_____ Date: _____

PROVIDE THE FOLLOWING INFORMATION: **OR** **ATTACH RECENT PHOTOGRAPH HERE:**

My Date of Birth _

My Sex _

My Race _

My Eye Color _

My Hair Color _

2. Information About My Doctor and Hospice (if I am in Hospice)**:**

Physician:_____ Telephone: _____

Hospice Program, if applicable (name):_____

PREHOSPITAL MEDICAL CARE DIRECTIVE (DO NOT RESUSCITATE) (Last Page)

3. Signature of Doctor or Other Health Care Provider:

I have explained this form and its consequences to the signer and obtained assurance that the signer understands that death may result from any refused care listed above.

Signature of a Licensed Health Care Provider:_____ Date: _____

4. Signature of Witness to MyDirective:

NOTE: At least one adult witness OR a Notary Public must witness the signing of this document. The witness or Notary Public CANNOT be anyone who is: (a) under the age of 18; (b) related to you by blood, adoption, or marriage; (c) entitled to any part of your estate; (d) appointed as your representative; or (e) involved in providing your health care at the time this form is signed.

I was present when this form was signed (or marked). The patient then appeared to be of sound mind and free from duress.

Signature:_____ Date:_____

Your Conversation Starter Kit

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

Name: _____

Date: _____

Thoughtful Life Conversations

the conversation project

Institute for Healthcare Improvement

Created by The Conversation Project and the Institute for Healthcare Improvement

This Starter Kit doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It's meant to be completed as you need it, throughout many conversations.

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Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it's critically important. And you can do it.

Consider the facts.

More than **90%** of the people think it's important to talk about their loved ones' and their own wishes for end-of-life care.

Less than **30%** of people have discussed what they or their family wants when it comes to end-of-life care. Source: National Survey by The Conversation Project 2013.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)

70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

One conversation can make all the difference.

Remember:

- You don't need to talk about it just yet. Just think about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- Think about having a practice conversation with a friend.
- These conversations may reveal that you and your loved ones disagree. **That's okay.** It's important to simply know this, and to continue talking about it now—not during a medical crisis.

What do you need to think about or do before you feel ready to have the conversation?

Step 2: Get Set

Now, think about what you want for end-of-life care.

Start by thinking about what's most important to you. What do you value most? What can you not imagine living without?

Now finish this sentence:

What matters to me at the end of life is

Sharing your "What matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

Where I Stand scales

Use the scales below to figure out how you want your end-of-life care to be.

Select the number that best represents your feelings on the given scenario.

As a patient...

1	2	3	4	5
I only want to know the basics				I want to know as much as I can

1	2	3	4	5
Ignorance is bliss				I want to know how long I have to live

1	2	3	4	5
I want my doctors to do what they think is best				I want to have a say in every decision

Look at your answers.

What kind of role do you want to play in the decision-making process?

How long do you want to receive medical care?

1	2	3	4	5
I want to live as long as possible, no matter what				Quality of life is more important to me than quantity

1	2	3	4	5
I'm worried that I won't get enough care				I'm worried that I'll get overly aggressive care

1	2	3	4	5
I wouldn't mind being cared for in a nursing facility				Living independently is a huge priority for me

Look at your answers.

What do you notice about the kind of care you want to receive?

How involved do you want your loved ones to be?

1	2	3	4	5
I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable at first				I want my loved ones to do what brings them peace, even if it goes against what I've said

1	2	3	4	5
When the time comes, I want to be alone				I want to be surrounded by my loved ones

1	2	3	4	5
I don't want my loved ones to know everything about my health				I am comfortable with those close to me knowing everything about my health

What role do you want your loved ones to play? Do you think that your loved ones know what you want or do you think they have no idea?

What do you feel are the three most important things that you want your friends, family and/or doctors to understand about your wishes for end-of-life care?

1. _____

2. _____

3. _____

Step 3: Go

When you're ready to have the conversation, think about the basics.

Mark all that apply:

Who do you want to talk to? Who do you trust to speak for you?

- ☐ Mom
- ☐ Dad
- ☐ Sibling
- ☐ Child/Children
- ☐ Partner/Spouse
- ☐ Minister/Priest/Rabbi
- ☐ Friend
- ☐ Doctor/Caregiver
- ☐ Other: _____

When would be a good time to talk?

- ☐ The next big holiday
- ☐ At Sunday dinner
- ☐ Before my kid goes to college
- ☐ Before my next big trip
- ☐ Before I get sick again
- ☐ Before the baby arrives
- ☐ Other: _____

Where would you feel comfortable talking?

- ☐ At the kitchen table
- ☐ At a cozy café or restaurant
- ☐ On a long drive
- ☐ On a walk or hike
- ☐ Sitting in a garden or park
- ☐ At my place of worship
- ☐ Other: _____

What do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

How to start

Here are some ways you could break the ice:

- "I need your help with something."
- Remember how someone in the family died—was it a "good" death or a "hard" death? How will yours be different?
- "I was thinking about what happened to (Uncle Joe), and it made me realize…"
- "Even though I'm okay right now, I'm worried that (I'll get sick), and I want to be prepared."
- "I need to think about the future. Will you help me?"
- "I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."

What to talk about

- ☐ When you think about the last phase of your life, what's most important to you? How would you like this phase to be?
- ☐ Do you have any particular concerns about your health? About the last phase of your life?
- ☐ Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you're not able to? *(This person is your health care proxy.)*
- ☐ Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- ☐ Are there any disagreements or family tensions that you're concerned about?
- ☐ Are there circumstances that you would consider worse than death? *(Long-term need of a breathing machine or feeding tube, not being able to recognize your loved ones)*
- ☐ Are there important milestones you'd like to meet if possible? *(The birth of your grandchild, your 80th birthday)*

- ☐ Where do you want (or not want) to receive care? *(Home, nursing facility, hospital)*
- ☐ What kinds of aggressive treatment would you want (or not want)? *(Resuscitation if your heart stops, breathing machine, feeding tube)*
- ☐ When would it be okay to shift from a focus on curative care to a focus on comfort care alone?
- ☐ What affairs do you need to get in order, or talk to your loved ones about? *(Personal finances, property, relationships)*

This list doesn't cover everything you may need to think about, but it's a good place to start.
Talk to your doctor or nurse if you're looking for more end-of-life care questions.

Remember:

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances shift.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

Now, just go for it!

Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

Step 4: Keep Going

Congratulations!

Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

- **Advance Care Planning (ACP):** the process of thinking about your wishes—exactly what you have been working on here.
- **Advance Directive (AD):** a document that describes your wishes.
- **Health Care Proxy (HCP):** identifies your health care agent (often called a "proxy"), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.
- **Living Will:** specifies which medical treatments you want or don't want at the end of your life, or if you are no longer able to make decisions on your own (e.g. in a coma).

You can find more information about these documents from the link in the "Keep Going" section of the website Starter Kit at **www.TheConversationProject.org.**

Remember, this was the first of many conversations.

You can use the questions below to collect your thoughts about how your first talk went, and then look back to them when you prepare for future conversations.

Is there something you need to clarify that you feel was misunderstood or misinterpreted?

Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who disagree about everything)?

How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?

What do you want to make sure to ask or talk about next time?

We hope you will share this Starter Kit with others. You have helped us get one conversation closer to our goal: that everyone's end-of-life wishes are expressed and respected.