46th Annual Arizona Rural Health Conference

Live Well - End Well

How do we create a good death in a death denying society?

Our shared commitment and responsibility to radically improve end-of-life care for Arizonans
Goals

• Discuss the current culture and practice of planning for death in Arizona
• Review Arizona statutes for advance care planning (ACP) & discuss limitations
• Highlight a statewide program that is transforming the “medical death” into one of meaning and purpose
• Discuss innovative evidence based resources to support your communities
Current Culture and Practice
Why Don’t People Want To Talk About Death & Dying?

• Deathaphobic society
  – Keep death at a nice, safe distance
• See Death as a failure
• If we talk about it, it will happen
• FEAR
John McCain has not announced a decision to stop treatment for his brain tumor, but his public actions indicate that he has transitioned from “being sick” and hoping for a cure, to “dying” and hoping for the best possible quality of life in the time remaining.

There are personal barriers to dying well, largely fueled by fear and lack of information, which can be addressed now.
Current Practice

• Little upstream conversation about goals and how they match treatment options

• Focus on procedures, tests, and referrals more than personal priorities

• High-stakes decisions made under stress in times of crisis
The Hard Facts

• Between 12% and 24% of those who lost someone close to them report the patient’s wishes were not carried out

• Between 25% - 38% said that family/friends experienced needless pain rating the quality of end of life care “fair” to “poor”

• By 2020 40% of Americans are expected to die in nursing homes

What Happens without a Plan?

50% of people become incapacitated and thus unable to make their own medical decisions.

The Default is to treat aggressively, even if this is not desired, and even if it is hard for the family to predict the patient’s wishes.

Source: Gundersen Lutheran Medical Foundation, 2002
Did You Know?

That only **10%** of people die suddenly, **90%** of people live with prolonged illness.

Knowing this, if you had a choice... how would you want to die?
CPR was designed to save troops on the battlefield. It was never intended to be used with the frail and elderly or those with end stage disease.

Known complications from CPR that should be part of every informed consent

- People with late stages of cancer (1% survival)
- Elderly, frail
- Those with chronic medical disease

Who is least likely to live after CPR?

50% will have brain damage that will never get better
97% will have broken ribs
59% will have bruising to the chest

15% of people who have CPR live through it. Your chances of living through CPR in a hospital is 20%
Did You Know?

- Only **5%** of nursing home residents live after CPR
- Only **2%** of people with dementia live after CPR
- Only **1%** of late stage cancer patients live after CPR

Do you and your loved ones know this?
What Americans Want

- To die at home
- Freedom from pain
- Time to reflect
- Understanding
- Choices
- Care coordination
- Not to be a burden
- Spiritual well being
- Planning around their wishes
- To be in the presence of loved ones
- Compassion
- Honest dialogue from healthcare providers
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Hope is Not A Plan!
Benefits of Planning

• Increases the likelihood that wishes will be respected at the end of life
• Enables a sense of control
• Strengthens relationships
• Relieves the burdens on loved ones
• Eases sharing of medical information (HIPAA)
• Provides opportunities to address life closure
• Helps to be at peace spiritually
Arizona Landscape
<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Total</th>
<th>Baby Boomers</th>
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</thead>
<tbody>
<tr>
<td>Writing down EOL wishes for medical care is important</td>
<td>86%</td>
<td>92%</td>
</tr>
<tr>
<td>Yes, had conversation</td>
<td>69%</td>
<td>80%</td>
</tr>
<tr>
<td>Yes, completed living will</td>
<td>30%</td>
<td>45%</td>
</tr>
<tr>
<td>Yes, healthcare power of attorney</td>
<td>12%</td>
<td>17%</td>
</tr>
</tbody>
</table>
Feedback From Workshops

- **From community participants:**
  - Why should I complete my Advance Directives (AD), no one looks for them, they just treat aggressively
  - I keep asking my doctor about my future, and he never really answers me
  - I give my forms to my doctor and hospital but they never seem to find them, they go to a black hole

- **From EMS**
  - Forms are rarely available from SNF/LTC
  - Staff never seem to think to pull the AD when they call 911

- **From ICU Docs**
  - In 20 years of working in the ICU I have never looked at a AD; I go by word of mouth
Arizona Advance Directive Registry

Number of Documents in Registry by Age Groups
2005 - 7/2018

- 75+: 15,846
- 65-74: 11,790
- 51-64: 8,115
- 18-50: 3,952
- <18: 104

Total: 39,807

No process to remove documents (e.g., people who are deceased)
Survey of Arizona Physicians

Survey completed by ArMA/AOMA end of 2017
588 Physician Responses

- N= 588
- Just over half of Arizona physicians report having EOL discussions with terminally ill patients
- Less than 40% do this routinely with elderly patients

- Discuss EOL routinely with elderly patients: 37%
- Discuss EOL when death is imminent: 46%
- Report no training on Palliative Care or EOL Conversations: 52%
- Discuss EOL with patients who have a terminal illness: 57%
How to bridge the gap between what people want and what they get?
Advance Care Planning Process

18+, Healthy
- Identify Health Care Proxy (HCP)
- Conversation about care preferences

Diagnosis of Serious or Chronic Illness(es)
- Progression of Serious or Chronic Illness(es)
- Have Serious Illness Conversation
- Begin POLST Conversations

Seriously Ill
- Condition worsening
- Revisit Serious Illness Conversation (POLST)
- Goals of Care Discussion (if clinical decision)

Crises & Decline
- Poor Prognosis
- Revisit Serious Illness Conversation / Goals of Care Discussion
- Revisit POLST

End of Life

Serious Illness Conversations begin - planning in the context of progression of serious illness
Goals of Care Discussion = Decision making in context of clinical progression/crisis/poor prognosis

Advance Directive
- Planning for future care

Serious Illness Care Program, Ariadne Labs
Evidence Based Practice to Support Goal Concordant Care

• Complete Healthcare Directive
  – Copies to HCPOA, loved ones & Arizona Registry
  – Review & Update it periodically
• Have discussions with HC Provider About Prognosis
  – Include HCPOA /loved ones
• Complete POLST if appropriate
• Use Palliative Care and Hospice
• Take steps to ensure all HCD documents are available when needed
Arizona State Documents

In statute:
• Living Will
• Health Care Power of Attorney
• Mental Health Care Power of Attorney
• Prehospital Medical Care Directive (DNR= Do Not Resuscitate) AKA: Orange Form

Not in statute:
• POLST (Provider Orders for Life Sustaining Treatment)
Many Options Available

Arizona Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1: Choose a medical decision maker, Page 3
A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself. They are also called a health care agent, proxy, or surrogate.

Part 2: Make your own health care choices, Page 6
This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3: Sign the form, Page 11
The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3. 1 witness needs to sign on Page 12, or a notary on Page 13.

Life Care Planning Packet
Advance Directives for Health Care Planning

Mail completed forms to:
Arizona Secretary of State
Attn: Advance Directive Unit

Health Care Directive (Living Will)

SECTION 1:
I want my doctor to try treatments that may get me back to an acceptable quality of life. However, if my quality of life becomes unacceptable to me and my condition will not improve, I request that all treatment that extend my life be withdrawn.

Quality of life that is unacceptable by my means: [check all that apply]
- Unconscious (permanent coma or persistent vegetative state)
- Unable to communicate my needs
- Unable to recognize family or friends
- Total or near total dependence on others for care
- Other:

Check only one:
- Even if I lose the quality of life described above, I still wish to be treated with food and water by tube or intravenously (IV).
- If I lose the quality of life described above, I do not wish to be treated with food and water by tube or intravenously (IV).

SECTION 2: You may have this section blank.
Some people do not want certain treatments under any circumstances, even if they might be needed.

Check the treatments below that you do not want under any circumstances.
- Cardiopulmonary Resuscitation (CPR)
- Ventilator (breathing machine)
- Feeding tube
- Diet starts
- Other:

SECTION 3:
When I am near death, it is important to me that:

(Write in or check your preferences)

BE SURE TO SIGN PAGE TWO OF THIS FORM
- If you are not the person who controls your care, have a proxy or attorney sign the form.
- Have a copy of this form with you whenever you go to the hospital or on a trip.
- You should review this form often.
- You can cancel or change this form at any time.

For more information contact Health Care Decisions, 602-222-5220 or www.hcddecisions.org
Some Arizona Resources to Improve EOL Care
Arizona END OF LIFE CARE PARTNERSHIP

Powered by the following Grantee organizations:

United Way of Tucson and Southern Arizona
Arizona Hospital and Healthcare Association
Casa de la Luz Foundation
Interfaith Community Services
Our Family Services
Pima Council on Aging
Southwest Folklife Alliance
Tohono O’Odham Nursing Care Authority Foundation
Tucson Medical Center Foundation
Tu Nidito Children and Family Services
University of Arizona Center on Aging
Thoughtful Life Conversations

- WISHES EXPLORED
- WISHES EXPRESSED
- WISHES HONORED
Key Strategies & Activities

**Professional Education**

Professional Education for Healthcare Providers and Healthcare Systems
Improving provider competencies in advance care planning and end-of-life care

**Policy & Advocacy**

Thoughtful Life Conversations is at the center of policy reform in Arizona for improved payment and legislation supporting needed changes, such as payer reform for advance care planning, and adoption of standardized advance care planning for the seriously ill.

**Communication**

Developing a communication network at the individual, the community and the societal level for knowledge dissemination and innovation diffusion.

**Community Outreach**

Expanding opportunities for Arizonans to have their end-of-life wishes known and honored
## Thoughtful Life Conversations Programs: Community Outreach and Professional Education

<table>
<thead>
<tr>
<th>Program</th>
<th># Short Workshops</th>
<th># Attendees</th>
<th># Train-the-Trainer Workshops</th>
<th># Attendees</th>
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<tr>
<td>Community: Advance Care Planning</td>
<td>45</td>
<td>740</td>
<td>13</td>
<td>153</td>
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<tr>
<td>Professional: Communication in Serious Illness</td>
<td>44</td>
<td>741</td>
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<td>100</td>
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Policy/Advocacy

• POLST State Lead
• AzHHA Healthcare Directive Developed
• Legislation: Healthcare Directive Registry move from Secretary of State to Health Current (Arizona’s health information exchange)
• Coalition to Transform Care
Fundamentals of POLST

• A **process** designed to improve patient care by creating a **system** using a **portable medical order** form that **records** patients’ wishes for treatment

• Starts with a conversation
  – Values, beliefs, goals of care, diagnosis, prognosis, treatment options (benefits and burdens)

• Valid across all settings of care

• Only used for individuals with a serious illness or frailty toward the end of life

• **Always voluntary**
Voluntary
The patient or surrogate decision-maker must agree to having a POLST form.

POLST Form Completed
The POLST form is a portable medical order to support patients transitioning to different care settings.

Discussion
Diagnosis, prognosis, treatment options and goals of care

Shared Decision Making
The discussion results in informed consent and shared decision making for medical treatments.

Not A Healthcare Directive
The POLST form does not take the place of a Healthcare Directive. The health-care directive should be updated to align with the treatment options on the POLST form (patient choice).

Share The POLST Form
Your healthcare provider will keep the original, put a copy in your EMR and it will go into the Health Information Exchange (so other healthcare professionals can access it). Give your agent/surrogate a copy and put a copy on your refrigerator.

For more information: www.azpolst.org and www.nationalpolstparadigm.org
Arizona Provider Orders for Life-Sustaining Treatment (AzPOLST)

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.

**A. Check One**
- [ ] Attempt Resuscitation/CPR
- [ ] Do Not Attempt Resuscitation (DNR/Allow Natural Death) Provide physical comfort, emotional and respectful spiritual support to patient and family.
- [ ] Pre-Hospital Medical Care Directive Form completed (Orange form)

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

**B. Check One**
- [ ] Full Treatment: In addition to treatment described in Comfort Measures Treatment and Selective Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. **Treatment Plan: Full treatment, including life support measures.**
- [ ] Selective Additional Interventions: In addition to treatment described in Comfort Measures Treatment, 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 Treatment (Allow Natural Death): Relieve pain and suffering through the use of any medication by any route, positioning, 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.**

**C. Check One**
- [ ] Medically Assisted Nutrition: Offer food and fluid by mouth if feasible.
- [ ] Medically assisted nutrition Specify type and duration:
- [ ] No medically assisted nutrition

**D. Documentation of Discussion**
- [ ] Patient (Patient has capacity)
- [ ] Parent of minor
- [ ] Court-appointed guardian
- [ ] Surrogate under Healthcare Power of Attorney
- [ ] A legally recognized surrogate under A.R.S. §36-3231.
- [ ] Others in attendance

**E. Signature of Patient/Surrogates and Healthcare Providers**
Signature of Patient or Surrogate required: By signing below, I agree that this form accurately reflects my personal treatment preferences, or if surrogate, the patient’s personal preferences, for medical treatment and life-prolonging measures. This form hereby revokes any prior or inconsistent wishes regarding future treatment and advance directives.

**Patient or Surrogate Signature (signature required):**
- Name (Print):
- Relationship:
- Phone Number:

**Signature of Healthcare Providers:** By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient’s current medical condition and preferences.
- **Physician/NP/PA Signature (required):**
  - Name (Print):
  - Phone Number:
  - Date/Time (required):
- **Physician/NP/PA Name (Print):**
- **Signer License Number:**
- **PA’s Supervising Physician Signature:**
- **Preparer Signature (required if not signing MD/NP/PA):**
  - Name and Title (Print):
  - Phone Number:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED.

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Barriers & Pathways to Implementation

**Barriers**

- **Standard of Care Approach**
  - No legislation
- **Current Law**
  - ARS 36-3209B, Notwithstanding any other law, if there is a conflict between a provision of a valid health care directive, the decision of a patient's agent pursuant to a valid health care power of attorney or the decision of a surrogate decision maker pursuant to section 36-3231 and a health care provider's order, including an order regarding life-sustaining treatment or a similar document, the health care directive, the decision of the patient's agent or the decision of the surrogate decision maker is presumed to represent the decision of the patient.

**Pathways**

- Plans for AzPOLST legislation in 2019 unsuccessful
- Education on AzPOLST across the continuum of care for all healthcare providers
- Updated Healthcare Directive at the same time POLST form completed
  - Added statement requesting AzPOLST form be attached and honored
- AzPOLST Memo providing guidance
Things to Remember about POLST

• AzPOLST Form completion is VOLUNTARY!
• AzPOLST Forms can be changed or revoked at ANY TIME
• AzPOLST Forms are about TREATMENT wishes
  – Comfort Measures are ALWAYS provided
• AzPOLST Forms are signed by health care professionals only after a conversation
TLC Resources

TLC Overview

Thoughtful Life Conversations
Empowering Arizonans to declare their end-of-life wishes

Our Mission
To empower Arizonans to make their life wishes and care directions known and to equip their healthcare teams with resources to honor those decisions.

Our Vision
For Arizonans to have thoughtful life conversations with their loved ones and healthcare providers that result in honored healthcare wishes and improved care towards end of life.

Putting Patients First
For patients with serious illnesses, living longer is not always the top priority. Often, their goals are to:
- Manage their symptoms
- Maintain quality of life
- Experience a sense of control and completion
- Preserve a loving relationship.

Often, there is a gulf between patients' wishes and the care they receive. Thoughtful Life Conversations bridge the gap by providing meaningful discussions between patients and their healthcare providers about their end-of-life preferences.

Transforming Healthcare Delivery for End-of-Life Patients
Thoughtful Life Conversations strives to transform healthcare delivery from sick care to value-based care that advances patient choice and autonomy. We are working to accomplish this through:

1. Professional education for healthcare providers and healthcare systems: Improving provider competencies in advance care planning and end-of-life care.
2. Public education and engagement: Expanding opportunities for Arizonans to know their usual care wishes and how to honor them.
3. Policies and payment systems that support quality end-of-life care: Integrating national quality standards of end-of-life care into Arizona's policies and payment systems.

Learn More about Thoughtful Life Conversations:
602.445.4300 | thoughtfullifeconversations.org

Guide to Advance Care Planning

1. Reflect on what matters most in life.
2. Discuss with your doctor and loved ones.
3. Document your wishes.
4. Communicate your wishes & share your documents.
5. Review & update your documents.

Communication in Serious Illness Overview

Develop the skills to communicate with your seriously ill patients

Maintain control of your care during a medical crisis.

Understanding AzPOLST
Provider Orders for Life-Sustaining Treatment

AzPOLST Overview

AzHA
Arizona Hospital and Healthcare Association

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Thoughtful Life Conversations

“Estate Planning of the Heart”
A gift to family members and a way to ensure our wishes are honored.
Dr. Michael Barton Good Practice (A parody of Green Day’s “Good Riddance”)
The future depends on what we do in the present.

–Mahatma Gandhi

I hope you take the time to get it right!
Questions?

http://www.thoughtfullifeconversations.org/

https://azpolst.org