Thoughtful Life Conversations

Advance Care Planning
for U of A Faculty
July 13, 2022

AzHHA participates in the Arizona End of Life Care Partnership, which is supported by The David and Lura Lovell Foundation and the Community Foundation for Southern Arizona.
Our Objectives

1. Describe the importance of Advance Care Planning for patients and families across the lifespan
2. Review the common Advance Care Planning forms, including Living Will, Durable Medical Power of Attorney, and POLST
3. Explain how to use the Arizona Healthcare Directives Registry (AZHDR)
4. Demonstrate communication strategies to engage patients in a conversation about advance care planning across the continuum of care (e.g., health fair, ambulatory setting)
5. Recognize the role of Public Health professionals as part of an interprofessional team in the care of patients with serious illness and life-limiting illness
6. Describe the role of community resources and services in promoting advance care planning for patients and families across the lifespan
Who Needs to Have the Conversation?

View the above video here:
https://www.youtube.com/watch?v=sp6pSA4ZiLY&feature=youtu.be
The Challenge We Face
Approximately one in three US adults completes any type of advance directive for end-of-life care.¹

39% of Arizonans report they have completed an advance directive. ²


²Arizona Statewide Survey by Public Opinion Survey, August 2018
Barriers to Discussing EOL Wishes

**National**
- Too Many Other Things to Worry About Right Now
- Don’t Want to Think About Dying
- Loved One Does Not Want to Talk About Death or Dying
- Too Young/Long Way Off
- Haven’t Thought About It
- No One to Talk To
- Will trust my healthcare team to make decisions

**Arizona**
- Haven’t gotten around to it (41%)
- Never considered it (22%)
- I’m healthy; I’m young; Don’t think it is necessary (20%)

*Arizona Statewide Survey by Public Opinion Survey, August 2018*
Why and How To Begin Planning
Why Plan for End of Life?

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
Start with Personal Reflection
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):
Conversation Tool: Go Wish

- Briefly ready cards & separate into 3 piles:
  - Very important to me
  - Somewhat important
  - Not important
- Wild card to be used for anything
- Identify top 10
- Rank top 10
- Think about talking to your family & loved ones
- Make time to tell them

Play online at: http://www.gowish.org/gowish/gowish.html
Advance Care Planning Conversations

View the above video here: https://youtu.be/SF4DORv_UYk
The Conversation

View the above video here:
https://www.youtube.com/watch?v=pyMXtVprN74
<table>
<thead>
<tr>
<th>Who Do You Want To Talk To?</th>
<th>When Would Be A Good Time To Talk?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mom</td>
<td>The next holiday</td>
</tr>
<tr>
<td>Dad</td>
<td>Before my child goes to college</td>
</tr>
<tr>
<td>Child/Children</td>
<td>Before my next trip</td>
</tr>
<tr>
<td>Partner/Spouse</td>
<td>Before I get sick again</td>
</tr>
<tr>
<td>Sister/Brother</td>
<td>Before the baby arrives</td>
</tr>
<tr>
<td>Faith Leader (Minister, Priest, Rabbi, etc.)</td>
<td>The next time I visit my parents/adult children</td>
</tr>
<tr>
<td>Friend</td>
<td>At the next family gathering</td>
</tr>
<tr>
<td>Doctor</td>
<td>Other</td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
Conversation Starters

“I know this is difficult, but I would like to talk to you about something that is really important to me.”

“I care about you and want to tell you some things that I hope would make it easier for you if I couldn’t make decisions for myself.”

“It’s OK if you feel uncomfortable with this topic but, please, just listen to me right now.”

“I need to think about the future, will you help me?”

“Please, do this for me.”
**WISH (HOPE) / WORRY / WONDER**

I’m going to beat this/I’m going to live for many years/I think you’re wrong........

I **HOPE** you are right (**validate** patient concerns, goals,) but I am.......  
WORRIED because you are having more pain/losing weight/sleeping more (express **empathy/concern**) so......  
I **WONDER** whether we should make a plan in case things don’t go as well as we would like? (**reframe/plan**)

***Note: These phrases are examples of empathic continuers. Patients may not immediately respond to your first empathic statement. They will often need multiple successive empathic responses to their questions to work through an emotion.***

Goals of Care Conversations training materials were developed and made available for public use through U.S. Department of Veterans Affairs contracts with VitalTalk [Orders VA777-14-P-0400 and VA777-16-C-0015].
### **Empathic Responses**

<table>
<thead>
<tr>
<th><strong>Understanding</strong></th>
<th><strong>Respecting</strong></th>
<th><strong>Supporting</strong></th>
<th><strong>Exploring</strong></th>
<th><strong>“I Wish”</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>This must be...</strong>&lt;br&gt;• Frustrating&lt;br&gt;• Overwhelming&lt;br&gt;• Scary&lt;br&gt;• Difficult&lt;br&gt;• Challenging&lt;br&gt;• Hard</td>
<td>What you just said really helps me understand the situation better.</td>
<td>I really admire your • Faith&lt;br&gt;• Strength&lt;br&gt;• Commitment to your family&lt;br&gt;• Thoughtfulness&lt;br&gt;• Love for your family</td>
<td>We will do our very best to make sure you have what you need.</td>
<td>Could you say more about what you mean when you say...&lt;br&gt;• I don’t want to give up&lt;br&gt;• I am hoping for a miracle</td>
</tr>
<tr>
<td><strong>I’m wondering if you are feeling ...</strong>&lt;br&gt;• Sad&lt;br&gt;• Scared&lt;br&gt;• Frustrated&lt;br&gt;• Overwhelmed&lt;br&gt;• Anxious&lt;br&gt;• Nervous&lt;br&gt;• Angry</td>
<td>This really helps me better understand what you are thinking.</td>
<td>You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.</td>
<td>Our team is here to help you with this.</td>
<td>Help me understand more about.....</td>
</tr>
<tr>
<td><strong>It sounds like you may be feeling ...</strong>&lt;br&gt;• hard on you&lt;br&gt;• frustrating&lt;br&gt;• challenging&lt;br&gt;• scary</td>
<td>I can see how dealing with this might be ...</td>
<td>I can really see how (strong, dedicated, loving, caring, etc.) you are.</td>
<td>We will work hard to get you the support that you need.</td>
<td>Tell me more...</td>
</tr>
<tr>
<td><strong>In this situation some people might feel ...</strong>&lt;br&gt;• important this is to you.</td>
<td>You are such a (strong, caring, dedicated) person.</td>
<td>We are committed to help you in any way we can.</td>
<td>Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you?</td>
<td>I wish that for you too.&lt;br&gt;<em>[In response to what a patient or family members wishes, such as a miracle]</em></td>
</tr>
<tr>
<td><strong>I can’t even imagine how (NAME EMOTION) this must be.</strong>&lt;br&gt;Dealing with this illness has been such a big part of your life and taken so much energy.</td>
<td>I’m really impressed by all that you’ve done to manage your illness (help your loved one deal with their illness).</td>
<td>We will go be here for you.</td>
<td>Can you say more about that?</td>
<td>I wish we weren’t in this spot right now.</td>
</tr>
</tbody>
</table>
Documenting Your Wishes

ADVANCE HEALTH CARE DIRECTIVE

Instructions

If ever I am unable to communicate and have an irreversible condition and die in a matter of days or weeks, or if I am in a coma and not expected to recover in a matter of days or weeks, or if I am in a coma and not expected to recover in a matter of days or weeks, or if I have brain damage of disease that makes me unlikely to recover from the coma, I want treatment to be provided that will enable me to return to my home and get back to the way I was before I became ill or injured.
Why Create a Healthcare Directive?

This is a way to make your health care wishes known if you are unable to communicate when the time comes.

It allows a person to do either or both of the following:

• Appoint a decision-maker, a healthcare representative.
• State your instructions for future health care decisions.
Advance Care Planning Process

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

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

Crisis & Decline
- Condition worsening
- Revisit Serious Illness Conversation (POLST)
- Goals of Care Discussion (If clinical decision)

End of Life
- Poor Prognosis
- Revisit Serious Illness Conversation / Goals of Care Discussion
- Revisit POLST

Advance Directives
- Planning for future care

Serious Illness Care Program, Ariadne Labs

Arizona POLST

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Arizona State Documents

• Living Will
• Healthcare Power of Attorney
• Mental Healthcare Power of Attorney
• Prehospital Medical Care Directive
  (DNR= Do Not Resuscitate)
• POLST
Advance Care Planning Documents
Many Options Available
Living Will

• Legal document
• Outlines in writing your desires for treatment in the event you are unable to make decision
• Can include wishes for autopsy, organ donation and funeral planning
• Sometimes confused with a Will (a will involves the distribution of property and money after someone dies)
Durable Healthcare Power of Attorney

• May be referred to as a Surrogate Decision Maker, Agent or Proxy
• Can make decisions over the phone (does not have to be local)
• Choose someone who
  – Can advocate for you and follow your wishes
  – Talk to the healthcare team and ask questions
  – Is available and willing to accept responsibility
• Discuss your wishes with this person
Who Will Speak For You?

View the above video here:
https://www.youtube.com/watch?v=iTxv-20ULwQ
Who Speaks for You If You Cannot Speak for Yourself?

1) Representative named in Health Care Power of Attorney
2) Surrogate
   a) Spouse
   b) Adult Child
   c) Parent
   d) If unmarried, domestic partner
   e) Sibling
   f) Close Friend
3) Your physician in consultation with hospital ethics committee
4) Physician in consultation with 2\textsuperscript{nd} physician
5) Court appointed guardian
Mental Healthcare Power of Attorney

• Allows you to authorize an agent to make decisions if you are unable to make mental healthcare decisions due to mental or physical illness, injury, disability or incapacity including Alzheimer's and dementia.

• Important with inpatient care for behavioral health services are needed

• Can be a part of a single document that includes the living will and healthcare power of attorney or can be a stand-alone document
Prehospital Medical Care Directive

• AKA “the orange form” because it is printed on orange paper
• Directs EMS to not start CPR
• EMS does not follow a Living Will
• Usually this is for people with advanced or terminal illness or end of life
• Must be signed by the patient and a healthcare provider
• Must be printed on orange paper
• Even if you have a living will stating that you do not want to be resuscitated it will not be followed by EMS because it is not signed by a provider
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

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

Who is least likely to live after CPR?

15% of people who have CPR live through it. Your chances of living through CPR in a hospital is 20%.
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**
The right conversation at the right time... helps ensure the right care at the right time

- Identify Health Care Proxy (HCP)
- Conversation about care preferences

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

- Progression of Serious or Chronic Illness(es)

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

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

Advance Directive
- Planning for future care

POLST
Goals of Care and POLST discussions begin with the progression of serious illness and should be revisited with clinical progression/crisis/poor prognosis

Serious Illness Care Program, Ariadne Labs
POLST Addresses Gaps

### Healthcare Directives

- Can be vague, open to interpretation
- Can be completed...
  - Long ago, before serious illness
  - Without considering goals of care
  - Without discussion with a provider about benefits and burdens of specific treatments
- Many times are not available when needed
- Prehospital medical directives address DNR only

### Surrogates

- Often don’t know patient’s preferences for specific treatments
- May not agree
- Find life sustaining treatment decisions emotionally difficult

### POLST

- Protects people with a DNR so they can get the care they want
Arizona POLST Legislation

**ARS § 36-3209B:** In the event of a conflict between a healthcare directive (or surrogate decision) and a POLST form, the former is presumed to represent patients’ wishes.

- Conflicts between POLST and AD could arise if old directives not invalidated or updated with POLST.
- To reduce chance of conflict, all documents should align and patient, agent/surrogate and loved ones should be in agreement on the patient’s treatment decisions/goals.
Population Intended for POLST

• Patients who are considered to be at risk for a life-threatening clinical event because they have a serious life-limiting medical condition
• Includes frailty
• Patients for whom their provider would not be surprised if they died within 1-2 years
### National POLST Form: A Portable Medical Order

**Patient Information.** Having a POLST form is always voluntary.

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient First Name</td>
<td></td>
</tr>
<tr>
<td>Middle Name/Initial</td>
<td></td>
</tr>
<tr>
<td>Preferred name</td>
<td></td>
</tr>
<tr>
<td>Last Name</td>
<td></td>
</tr>
<tr>
<td>Suffix (Sr. etc.)</td>
<td></td>
</tr>
<tr>
<td>DOB (mm/dd/yyyy)</td>
<td></td>
</tr>
<tr>
<td>State where form was completed</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>M</td>
</tr>
<tr>
<td>Social Security Number’s last 4 digits (optional)</td>
<td></td>
</tr>
</tbody>
</table>

**A. Cardiopulmonary Resuscitation Orders.** Follow these orders if the patient has no pulse and is not breathing.

- **Pick 1**
  - [ ] YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion. (Requires choosing Full Treatments in Section B)
  - [ ] NO CPR: Do Not Attempt Resuscitation. (May choose any option in Section B)

**B. Initial Treatment Orders.** Follow these orders if the patient has a pulse and/or is breathing.

- Reassess and discuss interventions with patient or patient representative regularly to ensure treatments are meeting patient’s care goals.
- Consider a time-trial of interventions based on goals and specific outcomes.

- **Pick 1**
  - [ ] Full Treatments (required if choose CPR in Section A). Goal: Attempt to sustain life by all medically effective means. Provide appropriate medical and surgical treatments as indicated to attempt to prolong life, including intensive care.
  - [ ] Selective Treatments. Goal: Attempt to restore function while avoiding intensive care and resuscitation efforts (ventilator, defibrillation and cardioversion). May use non-invasive positive airway pressure, antibiotics and IV fluids as indicated. Avoid intensive care. Transfer to hospital if treatment needs cannot be met in current location.
  - [ ] Comfort-focused Treatments. Goal: Maximize comfort through symptom management: allow natural death. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Avoid treatments listed in full or select treatments unless consistent with comfort goal. Transfer to hospital only if comfort cannot be achieved in current setting.

**C. Additional Orders or Instructions.** These orders are in addition to those above (e.g., blood products, dialysis).

[X] Protocols may limit emergency responder ability to act on orders in this section.

**D. Medically Assisted Nutrition.** (Offer food by mouth if desired by patient, safe and tolerated)

- **Pick 1**
  - [ ] Provide feeding through new or existing surgically-placed tubes
  - [ ] No artificial means of nutrition desired
  - [ ] Trial period for artificial nutrition but no surgically-placed tubes
  - [ ] Discussed but no decision made (standard of care provided)

**E. SIGNATURE: Patient or Patient Representative (eSigned documents are valid)**

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient’s representative, the treatments are consistent with the patient’s known wishes and in their best interest.

<table>
<thead>
<tr>
<th>Required</th>
<th>Authority</th>
</tr>
</thead>
<tbody>
<tr>
<td>[x]</td>
<td></td>
</tr>
</tbody>
</table>

**F. SIGNATURE: Health Care Provider (eSigned documents are valid)**

Verbal orders are acceptable with follow up signature.

<table>
<thead>
<tr>
<th>Required</th>
<th>Data (mm/dd/yyyy) Required</th>
<th>Phone #</th>
<th>License/Cert. #</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ]</td>
<td></td>
<td></td>
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</tbody>
</table>

**Printed Full Name:**  

**Supervising physician signature:** N/A

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A copied, faxed or electronic version of this form is a legal and valid medical order. This form does not expire.

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2019

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Section A focus is Cardiopulmonary Resuscitation Orders

- Requires informed consent on likelihood of surviving CPR, risks, benefits and alternatives discussion with shared decision making
- If the patient is 1) not breathing and has no pulse, and 2) has chosen “DNR” then no defibrillator (including AED) or chest compressions should be used
Survival Data

- Different articles define survival differently
  - Survival to discharge versus survival to home with good neurologic function

- Overall
  - Survival of inpatient CPR ~15%
  - Survival of out-of-hospital CPR ~8%
  - Survival of CPR in the nursing home ~2%
  - Patients >65 ~10%
  - Cancer patients ~6%
  - GO-FAR estimates ~1-27%

Reisfeld Resuscitation 2006
Ebell JAMA Internal Med 2013
Thompson Resuscitation 2018
Pape Resuscitation 2018
Zahar Am J Hosp Pall Med
Section B: Initial Treatment Orders

- Requires a goals of care conversation with the patient/agent/surrogate to determine their treatment choices
- If comfort care cannot be achieved in the current setting, the patient should be transferred to a setting able to provide comfort
### C. Additional Orders or Instructions

In your goals of care conversation there are specific treatments/interventions the patient has strong wishes on, write them here.

<table>
<thead>
<tr>
<th>EMS protocols may limit emergency responder ability to act on orders in this section.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>
Section D: Medically Assisted Nutrition

- Remember that POLST is for “current care” not future care
- It is normal to have diminished appetite with serious illness
- Harm sometimes outweighs the benefits; may not extend life and may increase suffering (advanced dementia)
Completing the POLST Form

• The healthcare provider:
  – Completes the POLST form after each section is discussed with the patient, agent/surrogate
  – Summarizes the goals of care conversation
  – Reviews the patient’s decision & affirms commitment
  – Signs the POLST form only after the patient has signed it
• The patient:
  – Signs the completed POLST form

Tip: Ensure the Living Will is up to date with POLST
Summary: POLST Key Concepts

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

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).

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

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

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What To Do With Your Healthcare Directive Documents?

• Share your documents widely.
• Give a copy to your health care representative.
• Make copies for your loved ones.
• Discuss with your doctor; get it into your medical record.
• Keep a copy yourself.
• Send a copy to the Arizona Healthcare Directive Registry.
• Take it with you to the hospital.

Note: Photocopies are just as valid as originals.
Registering Advance Directives and POLST

https://healthcurrent.org/azhdr/

• AZ has a new Healthcare Directives Registry
  – Housed at Contexture -- Arizona’s Health Information Exchange
• Use the public facing portal
  – Providers and people can submit advance directive
• POLST will be included IF ATTACHED to the Advance Directives
• In the future, EMS will have access to the registry so they can identify if a person has an Advance Directive/POLST/Pre-Hospital directive prior to arriving on scene
When Should You Review and Update Your Health Care Directive?

- Important life changes
  *Marriage, Birth, Divorce, Deaths*
- Major Illness
- New Diagnosis
- Change in treatment plan
- Change in your wishes
- Transfer from one care setting to another
- On a periodic basis

*Keep Your Wishes Up To Date!*
Interprofessional Team

• A team-based approach is essential with the national shortage of primary care providers
• Multiple conversations with various team members may occur before advance directives are documented
• Any trained ACP facilitators can participate
• Team-based ACP processes, including ACP group visit models can be integrated into primary care and long-term care settings
• ACP can occur in community-based clinics, long-term and subacute care facilities, academic clinics
• ACP education can be shared
• Public awareness campaigns are effective
Community Resources

• Structured evidence-based decision tools improve patient knowledge and preparation for shared decision making for treatment choices, including
  – ACP, palliative care and goals of care communication
  – Feeding options in dementia
  – Lung transplant in cystic fibrosis
  – Truth telling in terminal cancer
• Local resources and assistance are available
  – Classes at libraries, senior centers, and community centers, houses of worship
Resources

- [https://arizonapolst.org](https://arizonapolst.org)
- [www.polst.org](www.polst.org)
- [www.thoughtfullifeconversations.org](www.thoughtfullifeconversations.org)
THANK YOU

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