Conference on Aging 2018

End-of-Life Planning

Our shared commitment and responsibility

to radically improve end-of-life care for Arizonans

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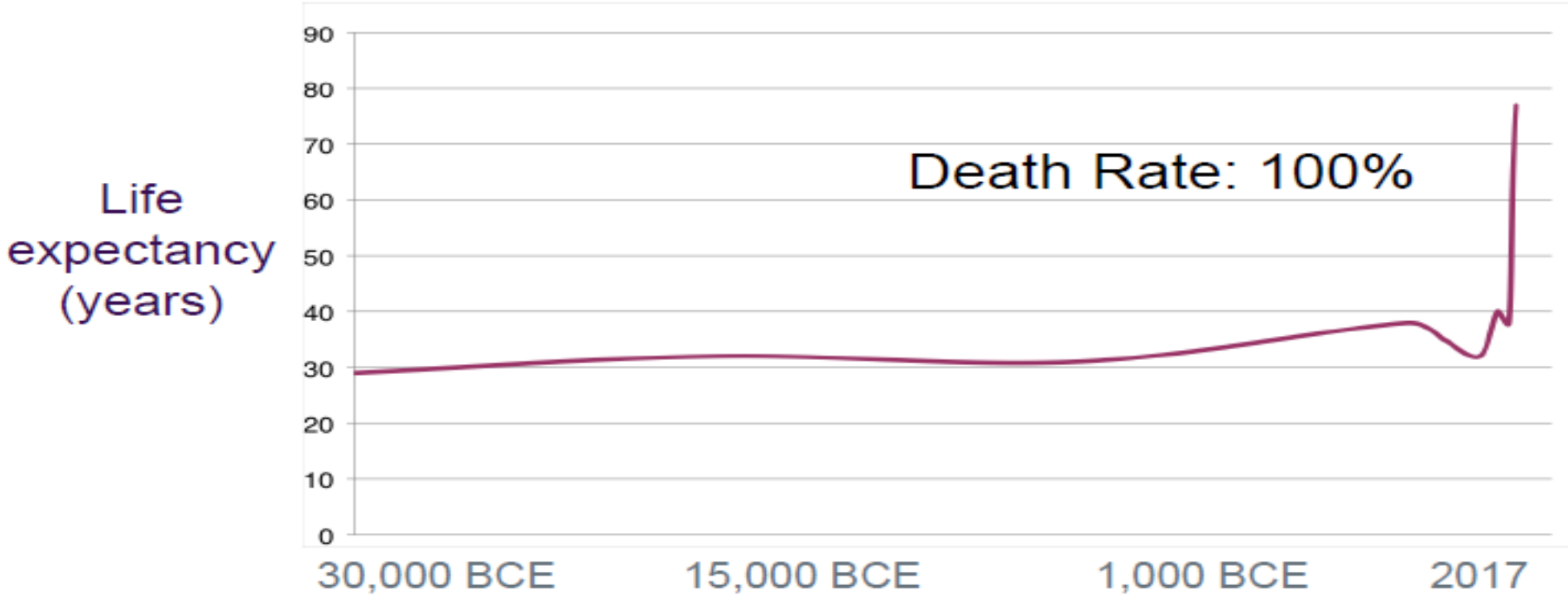
Thoughtful
Life Conversations

Good News, Bad News



UCSF Palliative Care Program

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Life Expectancy

	Arizona	US
Male	77.17	76.3
Female	82.12	81.3
Both	79.86	79.64

Causes of Death by Rank Order

Arizona	US
1. Heart Disease	1. Heart Disease
2. Alzheimer's	2. Stroke
3. Lung Disease	3. Alzheimer's
4. Stroke	4. Lung Disease
5. Lung Cancers	5. Lung Cancers

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

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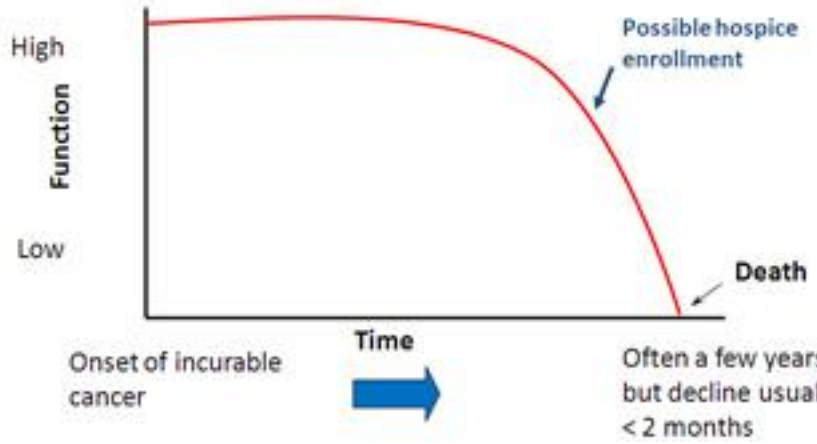
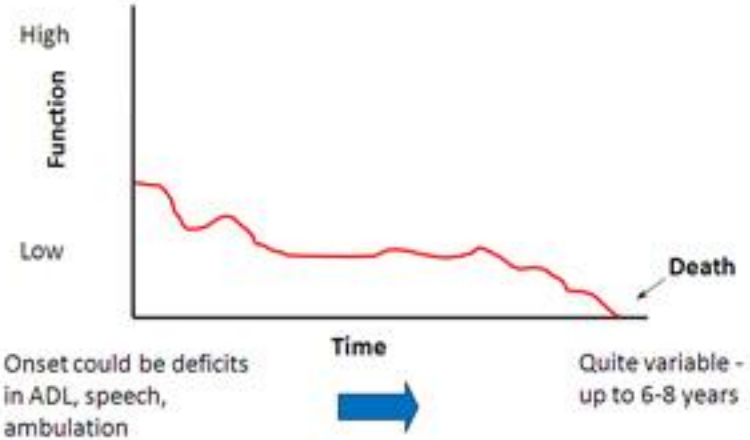
Death Trajectories

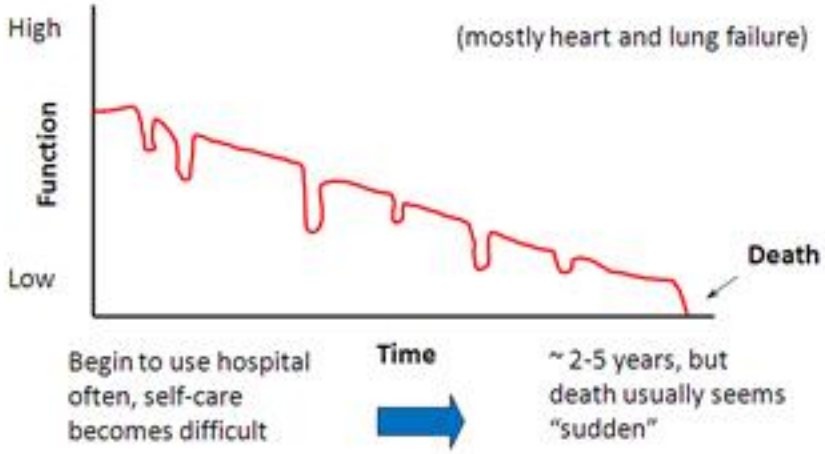
"Cancer" Trajectory, Diagnosis to Death



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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The Hard Facts

- Nearly 20 million baby boomers are expected to die in the next 15 years
  - An average of 1.3 million annually
  - Most suffering from multiple chronic conditions
  - **Must find balance between quality and quantity of life**
- **We need to make more informed choices about living longer and living well**
  - **WGYLM**
  - **Balance longevity with dignity**
  - **Not "What's the matter with Dad" but "What matters to Dad"**
  - **The "right care" at the end of life is what a well-informed patient genuinely wants**

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Vizient, 2017

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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 alone in nursing homes

Thibault, S. (2017, May 10). A better way to care for the dying . Retrieved May 10, 2017, from http://www.economist.com/news/international/21721375

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Evidence About End Of Life

Do you think talking with your loved ones about end of life care is important?

90% of people say that talking with their loved ones about end of life care is important.

Only 27% have actually done so

Source: The Conversation Project National Survey 2013.

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Evidence About End Of Life

What's Important to People at End of Life?

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

But 56% have <u>not</u> communicated their EOL wishes

Source: The Conversation Project National Survey 2013.

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What's Important?

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

Only 7% report having an end of life conversation with their doctor.

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

Thoughtful Life Conversations

What's Important?

70% of people say they prefer to die at home…

76% die in an institution (hospital, nursing home or LTX), and receive more aggressive, invasive, poorer quality of care than they would at home..

Source: National Center for Health Statistics 2010, www.cdc.gov/nchs/data/hus/hus10.pdf

Teno JM, Clarridge BR, Casey V et al. Family perspectives on end-of-life care at the last place of care. JAMA 2016;291:88-93.

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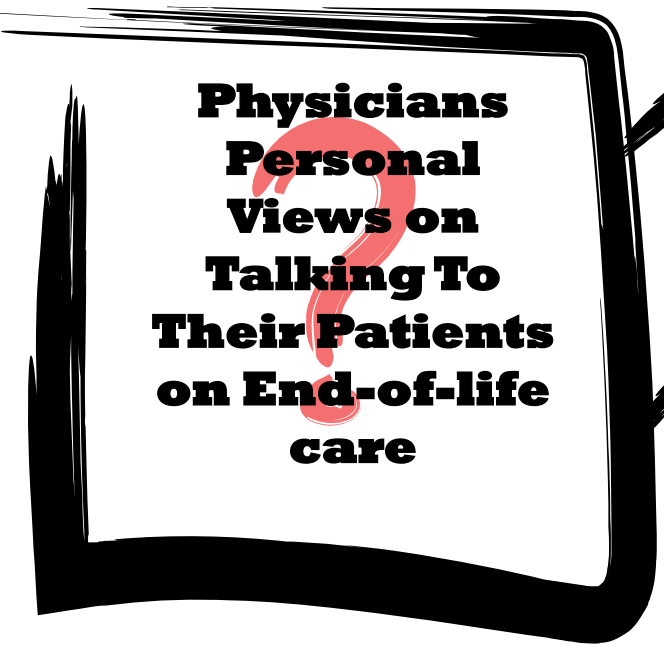
National Physician Survey 2016



46% report they feel unsure of what to say.

Less than 1/3 (29%) report having any formal education on talking to their patients and their families on EOL care

Source: Poll- The Conversation Stopper 2016

Thoughtful Life Conversations

Arizona Physician Survey Late 2017

How often are doctors talking to their patients about EOL?

37% routinely discuss EOL with elderly patients.

57% discuss with terminal diagnosis

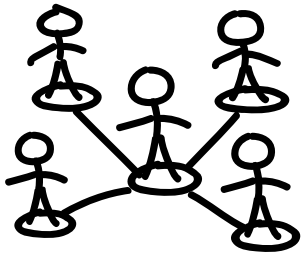
ONLY 46% discuss when death is imminent.

Source: Survey by ArMA/AOMA Joint Physician Task Force on End of Life Care 2017

Thoughtful Life Conversations

Did You Know?

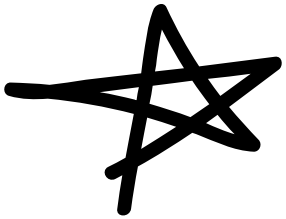
That only 10% of people die suddenly,
90% of people live with prolonged illness



Knowing this, if you had a choice…how would you want to die?

Thoughtful Life Conversations

CPR Facts?



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

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

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

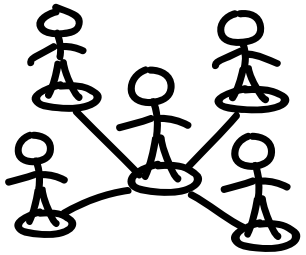
- People with late stages of cancer (1% survival)
- Elderly, frail
- Those with chronic medical disease

Who is <u>least likely</u> to live after CPR?

Thoughtful Life Conversations

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?

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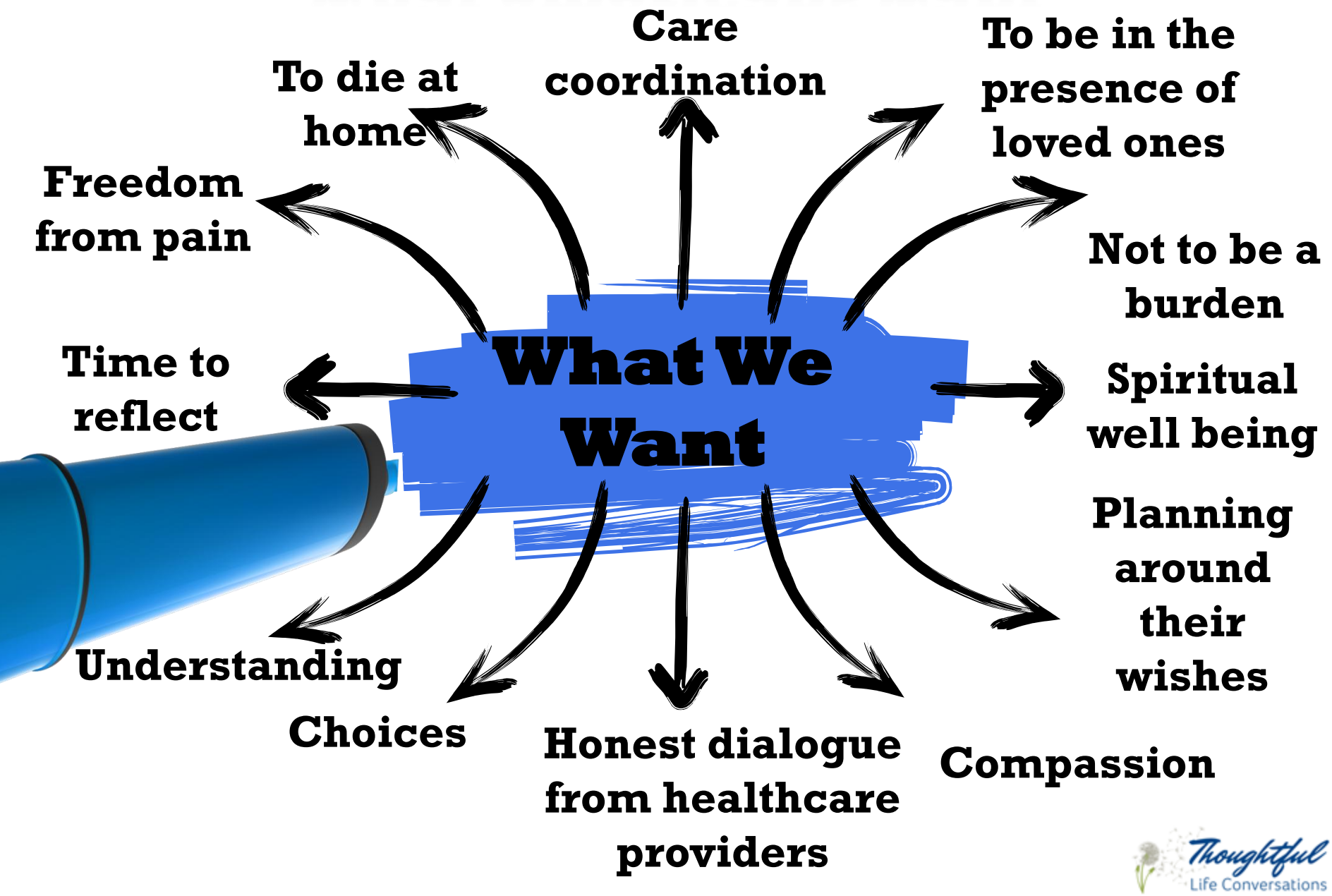
What Americans Want



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About End Of Life….

Why Don't We Get What We Want?

We don't plan for it!

Hope is Not A Plan!

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Advance Care Planning: A Process That Includes

Reflect: What's Important to Me?

Discuss Options – Doctor & Loved Ones

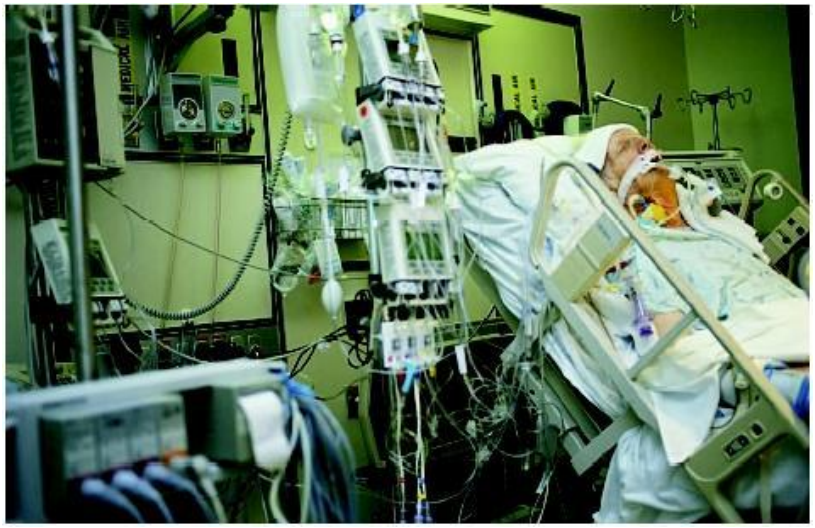
Complete your Documents

Share copies & talk to your loved ones

Review & Update Periodically

Thoughtful Life Conversations

How to bridge the gap between what people *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


The question is
do you want to have a say in how you die?

Too many Americans fail to plan for end-of-life care

Originally published May 28, 2018 at 12:01 pm | *Updated May 29, 2018 at 4:04 pm*

This March 18 photo shows Meghan McCain with her dad, U.S. Sen. John McCain, in Sedona, Arizona. (Meghan McCain via AP)

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

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.

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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.

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WISHES EXPLORED

WISHES EXPRESSED

WISHES HONORED

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Values

Preferences

Priorities

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Key Strategies & Activities

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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.

Community Outreach

Expanding opportunities for Arizonans to have their end-of-life wishes known and honored

Communication

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

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PROFESSIONAL EDUCATION

Communication in Serious Illness

This 2.5-hour didactic sessions reviews the need for a systematic approach to having more, better and earlier conversations about patient values and priorities in serious illness, defines a population with serious illness who may benefit from the serious illness conversation, and teaches how to improve communication in patients with serious illness with a structured communication tool.
A 5 hour train the trainer class is available.

Community Outreach

This 2-hour workshop helps people begin the conversation and outlines a clear process for them to ensure that their priorities and preferences for end-of-life care are known, documented and honored. Objectives are to reduce fear and stigma around talking about dying and to allow people to consider what's important to them; learn how to talk to others about their wishes; review healthcare planning decisions, resources and documents; learn with whom to share their healthcare planning documents; and discuss when to review and update these documents.
A 5 hour train the trainer class is available.

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Policy & Advocacy

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 system

Arizona END OF LIFE CARE PARTNERSHIP

YOUR JOURNEY. YOUR CHOICES. YOUR DECISIONS.

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
Tucson Medical Center Foundation
Tu Nidito Children and Family Services
University of Arizona Center on Aging

As the backbone organization for EOLCP, the United Way of Tucson and Southern Arizona (UWTSA) leads this effort to create a collective impact model for End of Life Care through its mission to build a thriving community by uniting people, ideas, and resources.

www.azendoflifecare.org | 520.903.3911 | *eolcp@unitedwaytucson.org*

Funded by the following foundations.

Legacy Foundation of Southeast Arizona
Promoting Population Health and Community Wellness

The David and Lura Lovell Foundation

COMMUNITY FOUNDATION for SOUTHERN ARIZONA

Community Engagement

Core Curriculum Developed & Adopted

Train the Trainer Classes Deployed

Hired Program Director

Honoring A Life: Advance Care Planning Conversations

Trainers are holding community ACP sessions

Spreading to targeted communities & stakeholders

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Advance Care Planning

ACP is a process that unfolds over a life span

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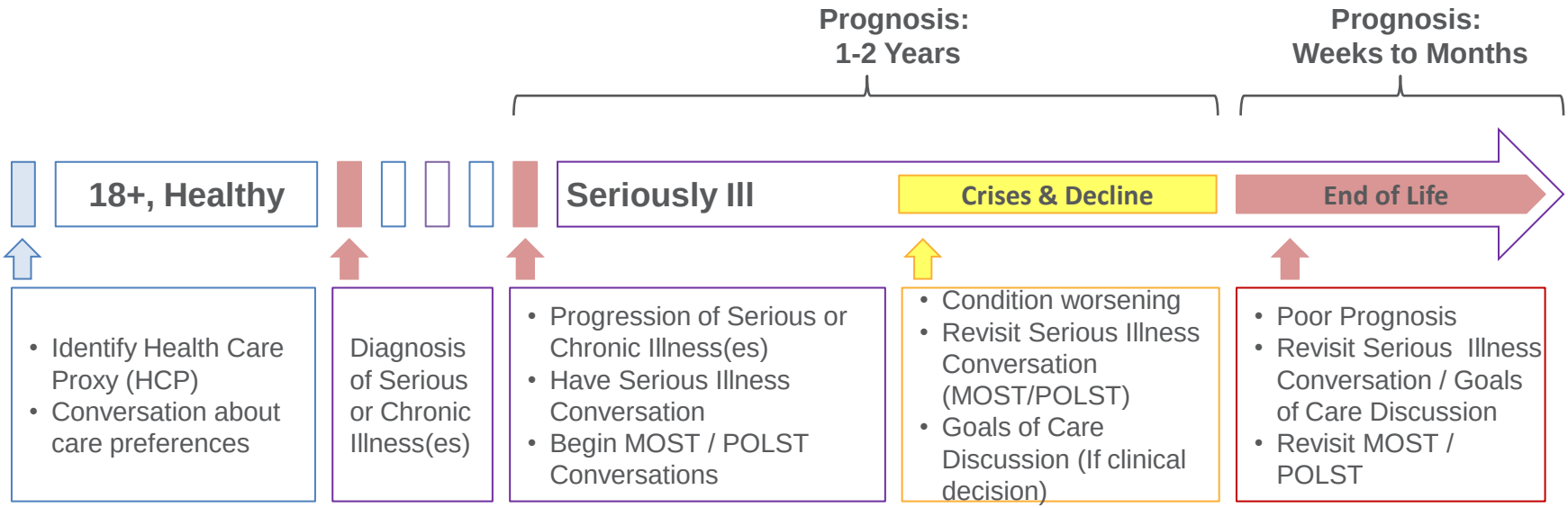
Advance Care Planning



Advance Directive

- Planning for future care

MOST / POLST

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

Where To Start?

- Reflect: What's Important To Me
- Discuss Options & Wishes with your Doctors & Loved Ones
- Complete your Healthcare Directive documents
- Communicate Your Wishes & Give Copies to Your Representative, Loved Ones, and Providers
- Review and Update Periodically

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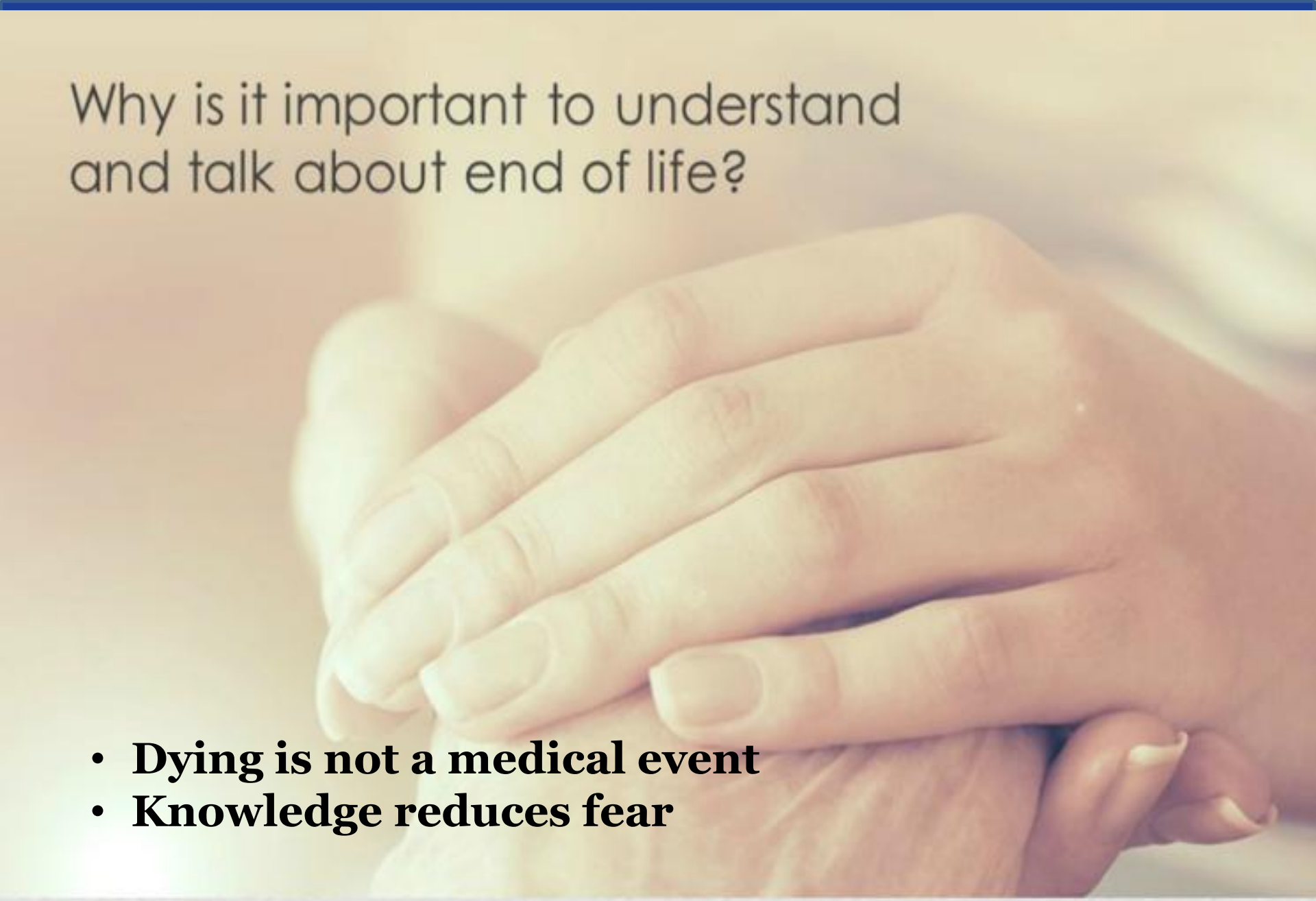
Why is it important to understand and talk about end of life?

LET'S TALK ABOUT IT

Why is it important to understand and talk about end of life?



- **Dying is not a medical event**
- **Knowledge reduces fear**

LET'S TALK ABOUT IT

What is dying?

- Everything between birth & death is LIVING.

Arizona State Documents

- Living Will
- Health Care Power of Attorney
- Mental Health Care Power of Attorney
- Prehospital Medical Care Directive (DNR= Do Not Resuscitate)

Most Important Issues at End of Life

- Making sure family is not burdened financially by my care – **67%**
- Being comfortable and without pain – **66%**
- Being at peace spiritually – 6**1%**
- Making sure my family is not burdened by tough decisions about my care – **60%**
- Living as long as possible – **36%**

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"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."

"Please, do this for me."

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What Matters to Me….

Finish the sentence, "***What matters to me at the end of my life is_____***"

You'll see that this isn't really about dying—it's about figuring out how you want to live, till the very end.

The Conversation Project

Institute of Healthcare Improvement (IHI)

http://theconversationproject.org/

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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.

Your Name

Developed by PREPARE for your care

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

FIVE WISHES®

MY WISH FOR:

1. The Person I Want to Make Care Decisions for Me When I Can't
2. The Kind of Medical Treatment I Want or Don't Want
3. How Comfortable I Want to Be
4. How I Want People to Treat Me
5. What I Want My Loved Ones to Know

HEALTH CARE DIRECTIVE (LIVING WILL)

I, _____ want everyone who cares for me to know what health care I want, when I cannot let others know what I want.

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 (is irreversible), I direct that all treatments that extend my life be withdrawn.

A quality of life that is unacceptable to me means (check all that apply):

- ☐ Unconscious (chronic 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 have the quality of life described above, I still wish to be treated with food and water by tube or intravenously (IV).
- ☐ If I have 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 leave this section blank.)

Some people do not want certain treatments under any circumstance, even if they might recover.

Check the treatments below that you do not want under any circumstances:

- ☐ Cardiopulmonary Resuscitation (CPR)
- ☐ Ventilation (breathing machine)
- ☐ Feeding tube
- ☐ Dialysis
- ☐ Other: _____

SECTION 3:

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

(Such as hospice care, place of death, funeral arrangements, cremation or burial preferences.)

BE SURE TO SIGN PAGE TWO OF THIS FORM

If you only want a Health Care (Medical) Power of Attorney, draw a large X through this page.
Talk about this form with the person you have chosen to make decisions for you, your doctor(s), your family and friends. Give each of them a copy of this form.
Take a copy of this 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) 222-2228 OR WWW.HCDECISIONS.ORG

SW 0229 | JUL 05

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Professional Education Progress To Date

Core Curriculum Developed & Adopted

ARIADNE LABS
BRIGHAM AND WOMEN'S HOSPITAL | HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH

Train the Trainer Classes Deployed

Medical Director Hired

Communication in Serious Illness

Trainers are training their stakeholders

Spreading to targeted entities and specialties

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Sponsored by Arizona Hospital and Healthcare Association

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Thoughtful Life Conversations

Communications in Serious Illness

- Education and resources to help your healthcare team talk to you about what's important to you if you are seriously ill or frail
- The healthcare team includes:
  - Physicians, Physician Assistants, Nurse Practitioners, Nurses, Social Workers, Clergy, others in their offices

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The Golden Questions

- What's your understanding of where you are with your illness?
- When you think about the future, what do you hope for?
- When you think about what lies ahead, what worries you the most?
- What are your most important goals if your health situation worsens?

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The Golden Questions

- What gives you strength as you think about the future with your illness?
- What abilities are so critical to your life that you can't imagine living without them?
- If you become sicker how much are you willing to go through for the possibility of having more time?
- How much does your family know about your priorities and wishes?

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HIPAA PERMITS DISCLOSURE TO HEALTHCARE PROFESSIONALS AS NECESSARY FOR TREATMENT

Arizona Medical Orders for Scope of Treatment (AzMOST)

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 of SS#
Address: (street / city / state / zip)		

A *Check One*

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

☐ **Attempt Resuscitation/CPR**

☐ **Do Not Attempt Resuscitation (DNR/Allow Natural Death)** Provide physical comfort, emotional nd 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*

MEDICAL INTERVENTIONS: ***Patient is breathing and has a pulse.***

☐ **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. ***Transfer to hospital*** *and/or intensive care unit if 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.**

Additional Orders: _____

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 *Check All That Apply*

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):	Phone Number:	Date/Time *(required)*:
Physician/NP/PA Name (Print)		Signer License Number:
PA's Supervising Physician Signature:(if applicable)		
Preparer Signature *(required if not signing MD/NP/PA)*:	Preparer Name and Title (Print):	Phone Number:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED.

Policy Focus:

Arizona Medical Orders for Scope of Treatment

AzMOST
Arizona Medical Orders for Scope of Treatment

Thoughtful Life Conversations

"Estate Planning of the Heart"

They are a gift to family members and a way to ensure our wishes are honored.

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Thoughtful
Life Conversations

The future depends on what we do in the present.

–Mahatma Gandhi

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Thoughtful Life Conversations

Thoughtful Life Conversations

Questions?

http://www.thoughtfullifeconversations.org/

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