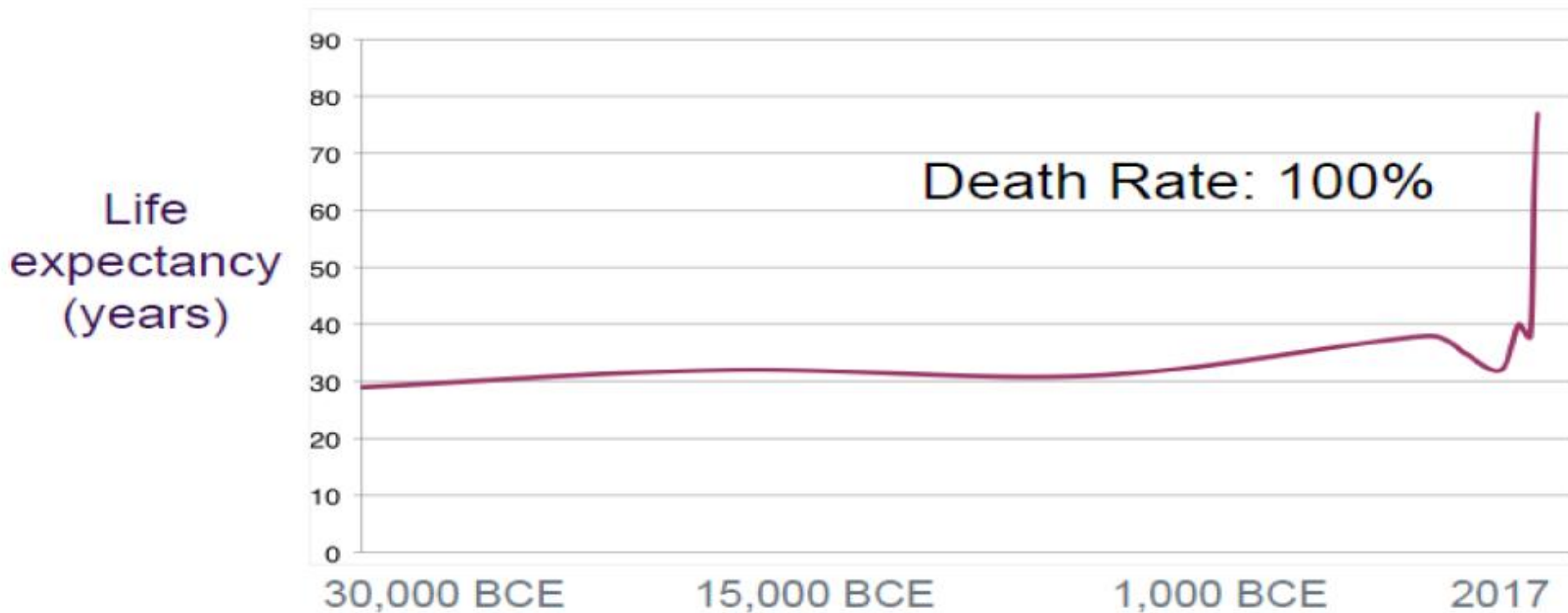


Conference on Aging 2018

End-of-Life Planning

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

Good News, Bad News



UCSF Palliative Care Program

Life Expectancy

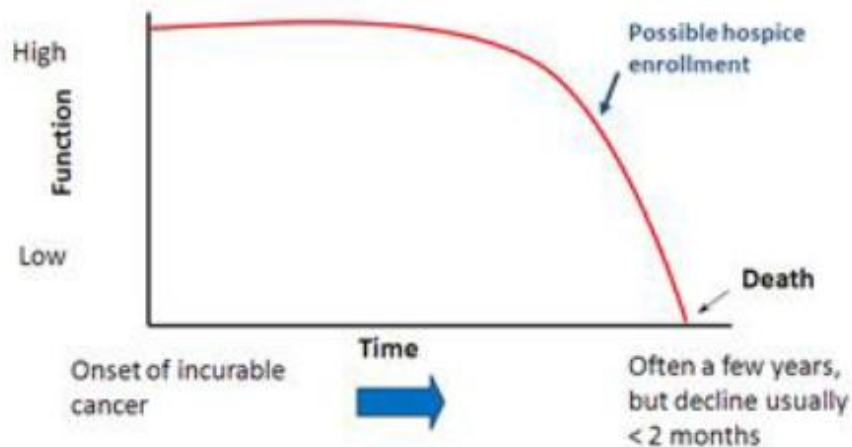
	Arizona	US
Male	77.17	76.3
Female	82.12	81.3
Both	78.86	79.64

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

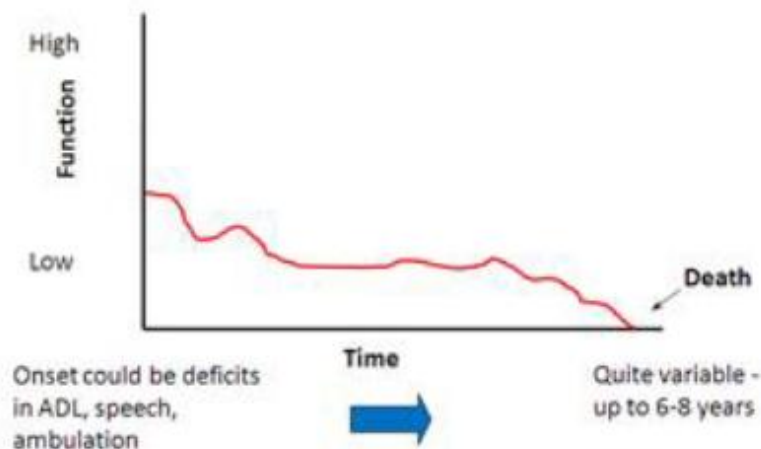
Causes of Death by Rank Order

Death Trajectories

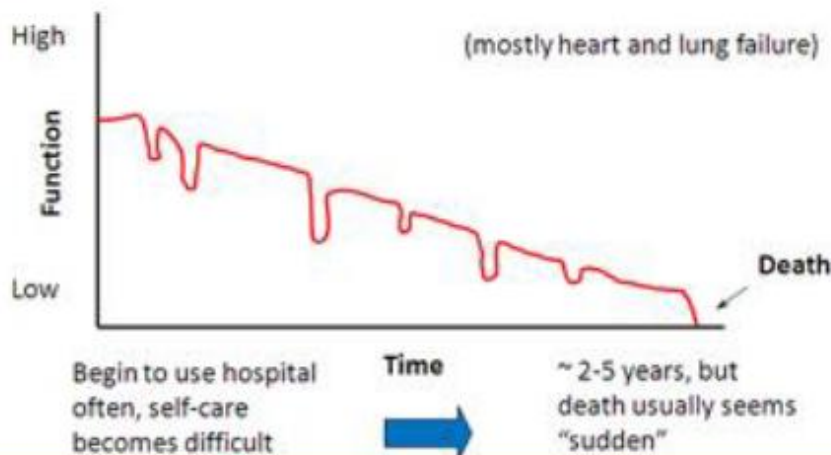
“Cancer” Trajectory, Diagnosis to Death



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

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**

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

Did
You Know?

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 actual
done so**

Source: The Conversation Project National Survey 2013.

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 not communicated their EOL wishes

Source: The Conversation Project National Survey 2013.

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)

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.

National Physician Survey 2016

**Physicians
Personal
Views on
Talking To
Their Patients
on End-of-life
care**

**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**

Arizona Physician Survey Late 2017

**How often
are doctors
talking to
their
patients
about EOL?**

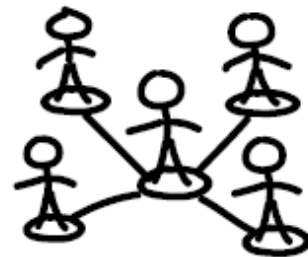
**37% routinely
discuss EOL
with elderly
patients.**

**57% discuss with
terminal
diagnosis
ONLY 46% discuss
when death is
imminent.**

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 Facts?



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.

15% of people who have CPR live through it.

Your chances of living through CPR in a hospital is **20%**

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

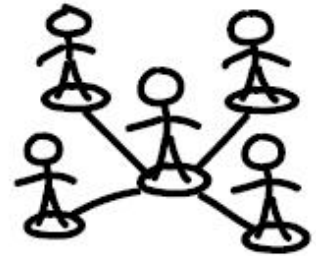
50% will have brain damage that will never get better
97% will have broken ribs
59% will have bruising to the chest

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

Who is least likely to live after **CPR**?

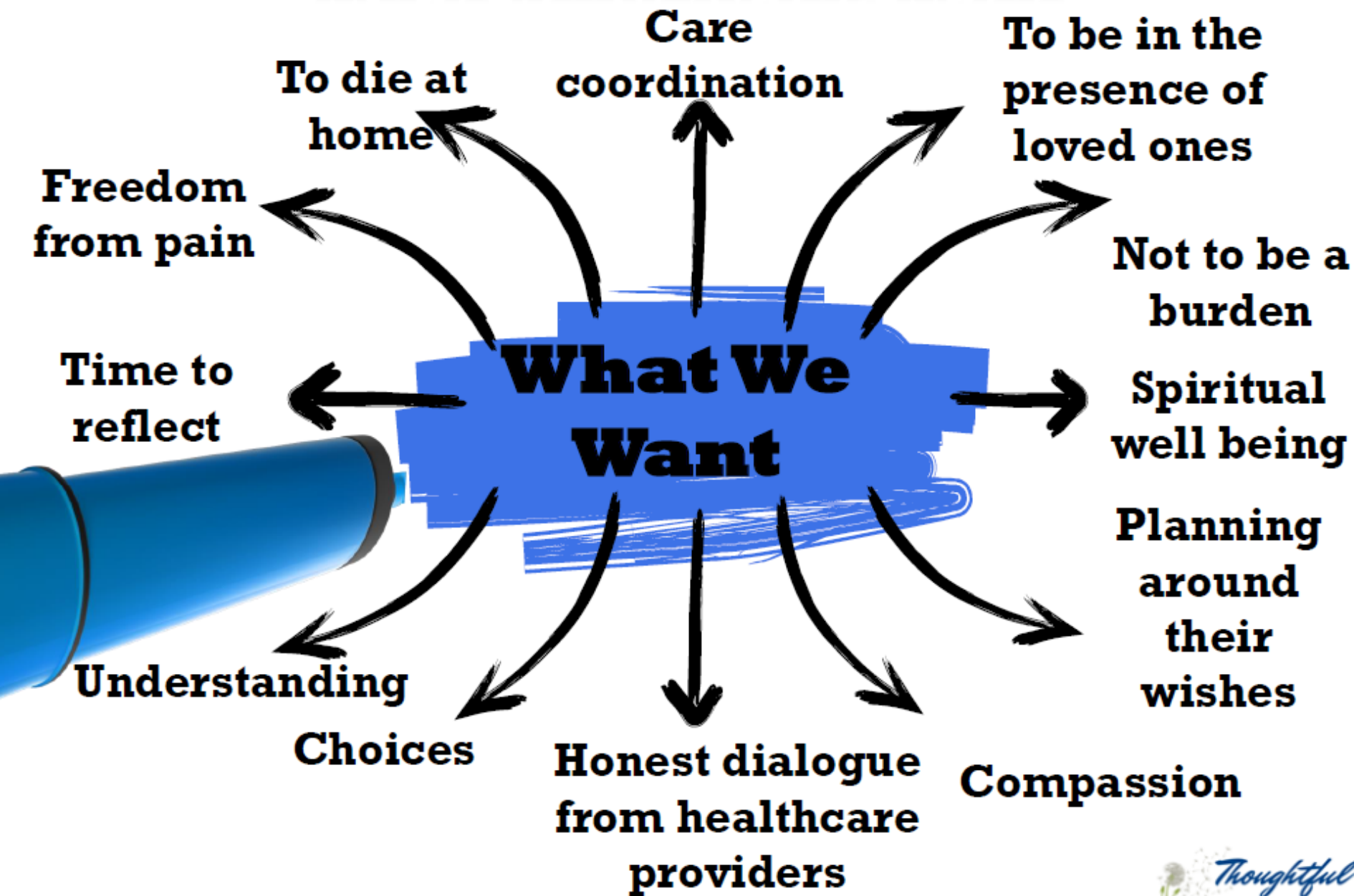
Did You Know?

- 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



About End Of Life....

**Why Don't
We Get
What We
Want?**

**We don't plan
for it!**

**Hope
is Not
A Plan!**

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

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 Problem: “The Big Gap”

What People Want

1. Be at home with family, friends
2. Have pain managed
3. Have spiritual needs addressed
4. Avoid impoverishing families/being a burden

What They Get

Recycled through the hospital

Often unwanted, ineffective treatment

Often die in hospital, in pain and isolation

At great cost to families and the nation.



**The deep 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



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.

*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.



Thoughtful Life Conversations



**WISHES
EXPLORED**



**WISHES
EXPRESSED**



**WISHES
HONORED**



Thoughtful

Life Conversations



Values



Preferences



Priorities

Key Strategies & Activities



Thoughtful Life Conversations

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.



PROFESSIONAL EDUCATION

Communication in Serious Illness

This 2.5-hour didactic session 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.

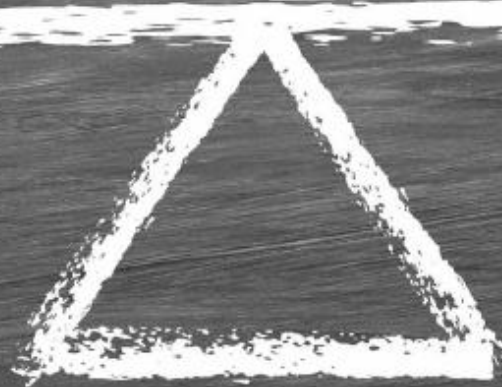
A 5-hour train the trainer class is available.



Policy & Advocacy

RIGHTS

DUTIES



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*



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.



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

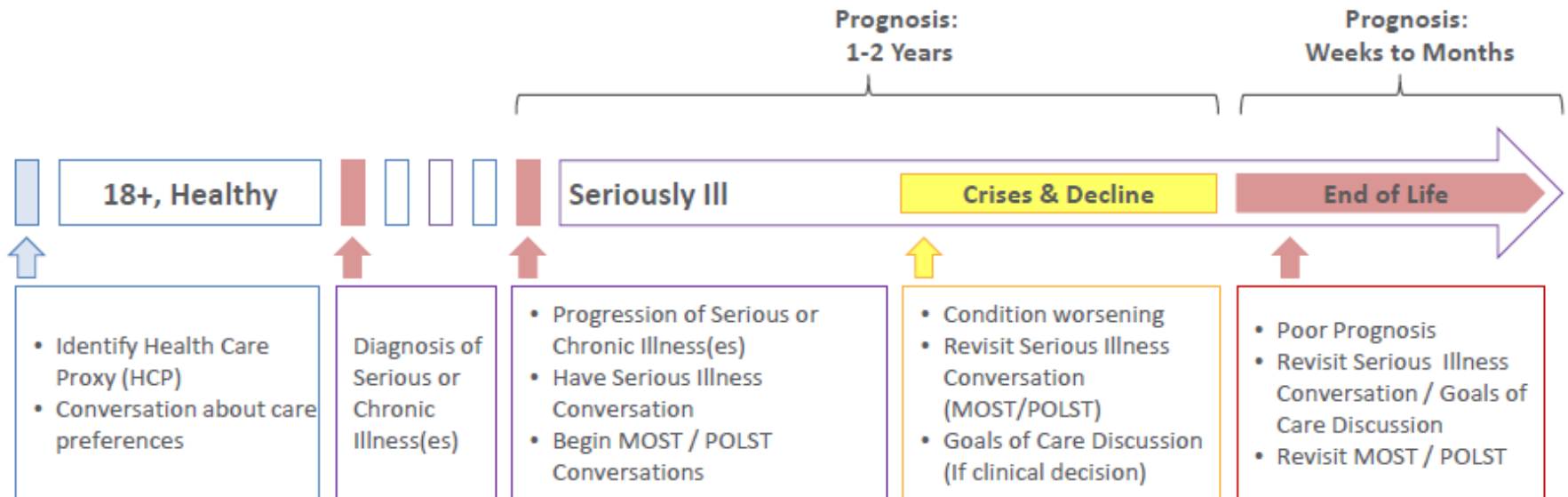


Advance Care Planning

ACP is a process that unfolds over a life span



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

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 – **61%**
- Making sure my family is not burdened by tough decisions about my care – **60%**
- Living as long as possible – **36%**

“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.”



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/>

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.



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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:

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

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 circumstances, 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, (800) 593-9259 OR WWW.HEALTHCAREDECISIONS.ORG

Page 1 of 2

SW 3225 / 11.18



Professional Education Progress To Date

Core Curriculum Developed & Adopted



Train the Trainer Classes Deployed



Medical Director Hired

Communication in Serious Illness



Trainers are training their stakeholders

Spreading to targeted entities and specialties



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

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?

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?

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 Init.:
Date of Birth: (mm/dd/yyyy)	Gender: <input type="checkbox"/> M <input type="checkbox"/> 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 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

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:

<input type="checkbox"/> Patient (Patient has capacity)	<input type="checkbox"/> Surrogate under Healthcare Power of Attorney
<input type="checkbox"/> Parent of minor	<input type="checkbox"/> A legally recognized surrogate under A.R.S. §36-3231.
<input type="checkbox"/> Court-appointed guardian	<input type="checkbox"/> 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



Thoughtful Life Conversations



“Estate Planning of the Heart”

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

**The future depends on what
we do in the present.**

–Mahatma Gandhi



Questions?

<http://www.thoughtfullifeconversations.org/>

