PCOA

Aging well for life

Supporting Families with Unique Needs Through End-of-Life-Care Planning

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Workshop Objectives

Learn how PCOA, the AAA in Tucson, Arizona built and delivers culturally sensitive, responsive, and person-centered end-of-life care planning by:

- Honoring unique perspectives and values
- Considering capacity and ensuring informed decision-making
- Normalizing regular and open communication
- Tailoring services to specific populations

Consider ways your organization can integrate end-of-life care planning into your service areas

A Little Background...

PCOA's History with End-of-Life Care Planning

- Community Elder Alliance began championing end-of-life care planning 15 years ago
- End-of-Life Care Partnership began in 2014
- Partnership "sunsetted" in 2023
- PCOA remains one of the only end-of-life care planning assistance providers
- Now embedded into standard workflows

PCOA's History with End-of-Life Care Planning...*continued*

- Projects within Dementia Capable Southern Arizona are supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $999,996.00.
  - Funding includes support from ACL/HHS as well as varying contributions from non-government sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.
  - Note that the EOL dementia presentation was developed outside of ACL funding. This is intentional and important – because it was not funded by ACL, PCOA owns the presentation outright.

Understanding Pima County Arizona, including Tucson

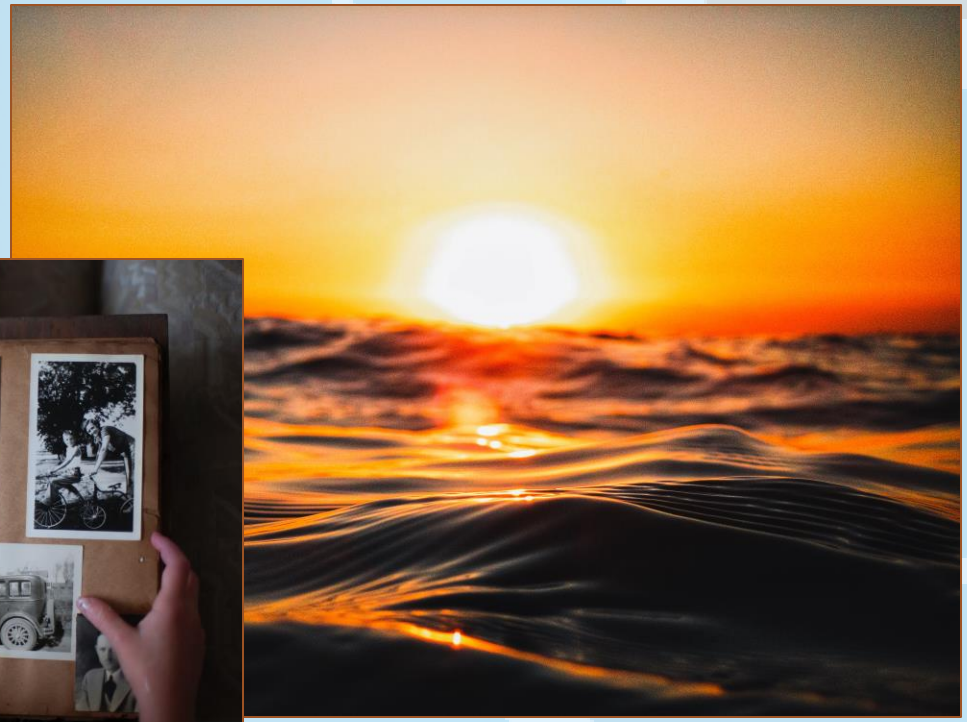
- Over 1 million people
  - 50% White
  - 39% Hispanic or Latino (26% speak Spanish at home)
  - 5% American Indian (Tohono O'odham and Pascua Yaqui)
- Over 13% are foreign born, including refugees
- 91% urban and 9% rural
- Median income of $59, 215
- 22% of population is 65+ compared to 17% nationally
- 12% of older adults have dementia

Begin with Values: Identifying Unique and Personal Perspectives in End-of-Life Care Planning

What is End-of-Life Care Planning?

What Makes Life Worth Living for You?

¿Qué es lo Más Importante para Usted a Medida Que se Acerca el Final?



¿Cómo Quiere ser Recordado?

Strategies for Honoring Perspectives and Values

1. INCLUDE IMPORTANT PEOPLE IN DISCUSSIONS
2. REFLECT PARTICIPANTS' WORDS AND CONTENT
3. ACKNOWLEDGE FAMILIAL, CULTURAL, AND SPIRITUAL VIEWPOINTS
4. EMPHASIZE DAILY INVESTMENT IN LEGACY
5. PROVIDE CLEAR LANGUAGE AND DISTINCTIONS

Capacity and Informed Decision-Making

What is Capacity?

ABILITY TO UNDERSTAND INFORMATION; MAKE INFORMED, REASONED DECISIONS; AND COMMUNICATE THOSE CHOICES

CAPACITY IS DECISION-SPECIFIC

ASSESSED BY PHYSICIANS, PSYCHOLOGISTS, AND OTHER QUALIFIED HEALTHCARE PROFESSIONALS

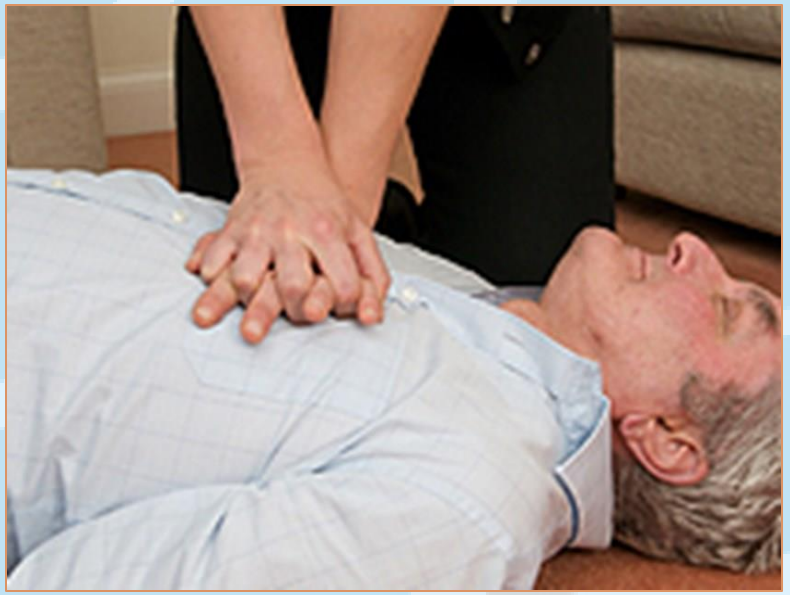
What is Informed Decision-Making?

Refers to a person's ability to:

- Understand a health condition, diagnosis, prognosis
- Comprehend options including treatment benefits and risks
- Weigh options
  - Quality and quantity of life
- Align decisions and documents with personal preferences and values

CPR Facts

- CPR was designed to save troops on the battlefield
- While receiving CPR can double or triple your chances for survival, only about 10% of people who receive CPR in a non-hospital setting live
- Survival chances decline 10% for every minute that CPR is delayed
- Of those who receive CPR:
  - 97% will have broken ribs
  - 59% will have bruising
  - 50% will have irreversible brain damage



Next Steps if Capacity Exists

- Complete Advance Directives as soon as possible
- Choose a trusted person to act as Healthcare Power of Attorney
- Discuss wishes regarding medical care and living arrangements

Strategies for Honoring Capacity and Informed Decision-Making

Right to Choose	Educate important people and loved ones about capacity, and a person's right to choose
Thorough Information	Provide thorough, credible, and unbiased information about life-sustaining treatments * Conversation Project * Honoring Choices * Respecting Choices
Ensure Consistency	Compassionately challenge assumptions or inconsistencies

Normalizing Conversations about Living, Dying, and Death

Develop State Specific Tools for End-of-Life Education and Assistance

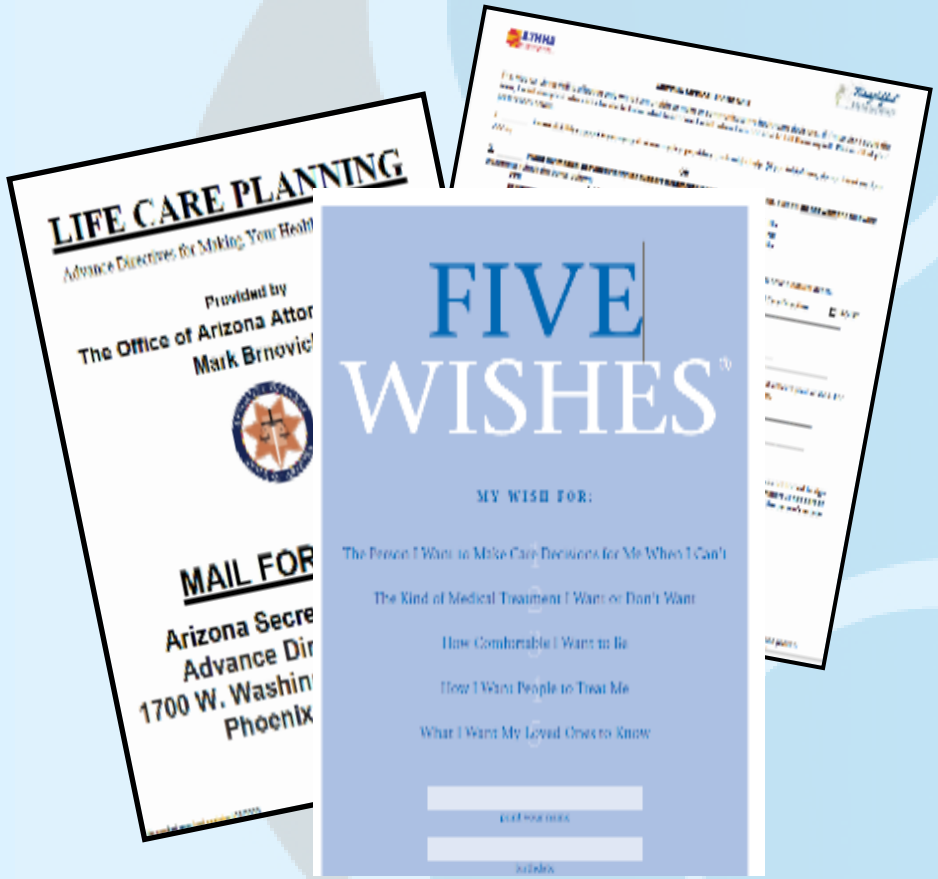
- Acknowledge confusion and provide clarity
- Develop reference resources
  - End-of-Life Glossary
  - Frequently Asked Questions
- Research state statutes
- Identify state-recognized templates

What is an Advance Directive?

A legal document that describes your healthcare wishes should you be unable to communicate them

- Living Will
- Medical Healthcare Power of Attorney (HCPOA)
- Mental Healthcare Power of Attorney (MHCPOA)
- Pre-Hospital Directive (DNR)

Arizona's Templates for End-of-Life Care Planning



Select the Template that Meets Your Needs

Five Wishes

•Wish 1: The Person I Want to Make Health Care Decisions (HCPOA)

•Wish 2: My Wish for the Kind of Medical Treatment (Living Will)

•Wish 3: How Comfortable I Want to Be

•Wish 4: How I Want People to Treat Me
Wish 5: What I Want My Loved Ones to Know

Thoughtful Conversations

- Healthcare Power Of Attorney (HCPOA)
- Mental Healthcare Power of Attorney (MHCPOA)
- Living Will

AG's Life Care Planning Packet

- Healthcare Power Of Attorney (HCPOA)
- Mental Healthcare Power of Attorney (MHCPOA)
- Living Will
- Pre-Hospital Medical Directive (DNR)

Why are Advance Directives Necessary?

- 50% of people become incapacitated and unable to make or express their own medical decisions.

- Without a legal End-of-Life Care Plan, healthcare providers must provide aggressive, and life-sustaining treatment.
- This occurs even if it is not the patient's or their loved one's wishes.

Having a complete and legal End of Life Care Plan empowers healthcare professionals and loved ones to honor your wishes.

Choosing Your Power(s) of Attorney

- Will talk with you about sensitive issues and your end-of-life values *now*
- Will honor and advocate for your values and wishes
- Will make difficult decisions, and separate their feelings from yours
- Comfortable in a medical setting
- Can handle conflicting opinions of family members, friends, and medical staff
- Can be a strong advocate in the face of an unresponsive doctor or institution
- Lives close by, or could travel to be near you

What Happens Without a Power of Attorney?

- Surrogate Decision Makers—by Law
  - A "surrogate" is appointed:
    - Spouse
    - Adult Child(ren)
    - Parent(s)
    - Domestic Partner
    - Sibling(s)
    - Close Friend
  - Your physician, in consultation with Hospital Ethics Committee
  - Two hospital physicians
  - Court-appointed Guardian

The Six "D's" for Review

- You reach a new DECADE
- You experience a DEATH of family member or friend
- You DIVORCE
- You receive a new DIAGNOSIS
- You have a significant DECLINE in your condition
- You experience a DISASTER like a natural disaster or pandemic

Strategies for Normalizing Conversations about Living, Dying, and Death

- Identify and develop simple, straightforward teaching and reference tools specific to your state
- Break down and "chunk" end-of-life terms, documents, and processes into basic, actionable steps
- Explain and assert the "why" reasons for engaging in end-of-life care planning
- Offer genuine options, and patiently empower clients to make informed decisions

Tailoring Services for Specific Populations

Get to Know Your Communities

- Seek to listen and understand
- Identify believes about death, dying, legacy, and afterlife
- Recognize communication styles and decision-making practices
- Address distinct challenges or barriers

Become Part of Your Communities

- Go to your communities
- "Borrow" credibility
- Foster trusted partnerships
- Participate in community events
- Honor a person's "heart language"
- Represent communities in materials

Strategies for Tailoring End-of-Life Services for Specific Populations

Time	Sensitivity	Opportunity	Engagement	Inclusion
Take the time to listen, learn, and develop responsive and culturally-sensitive initiatives	Ensure that presentations are culturally sensitive as well as linguistically accessible	Hold space for any hesitation, resistance, or "pushback" as opportunity to address barriers and identify needed resources	Be part of the community and cultural events as much as possible	Use inclusive terms and images to ensure accessibility

Outcomes and Stories

In the Past Year...

- More than 438 people have received assistance–3% of whom are Spanish-speaking
- More than 137 people have completed advance directives–5% of whom are Spanish-speaking
- We facilitated more than 25 presentations cross-cultural events for approximately 500 people

Meet "Celia" and Her Important People

Integrating End-of-Life Care Planning into Services

Improve Staff Comfort with End-of-Life Care Planning

- Recognize that staff have same hesitations, concerns, and biases as community members
- Provide reference materials
- *Passing Thoughts*... interagency blog
- Special events (*e.g.* Healthcare Decisions Day)
- In-service workshops about end-of-life topics
- Departmental trainings specific to service needs

Embed End-of-Life Care Topics and Strategies into Service Delivery

- Information and Referral
  - Awareness of document and community resources
- Advocacy
  - Support rights and independence
  - Assist with document completion
- HCBS–Case Management
  - Include in assessments and redeterminations
- Long-Term Care Ombudsman
  - Awareness of document and community resources
  - Assist with document completion
- Dementia Initiatives
  - Awareness of document and community resources
  - Assist with document completion

Questions?

The Older Americans Act's mission is to support older Americans to live at home and in the community with dignity, independence, and quality of life for as long as possible.

Providing support for and assistance with end-of-life care planning is a key component of fulfilling this mission!

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Thank You!

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