

# NEVER TOO LATE

AREA AGENCY ON AGING, REGION II

National Volunteer Month  
Volunteer Week – April 23-29

April 2017

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## What's New

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## AGING IN OUR COMMUNITY

from W. Mark Clark, President and CEO

### Advance Care Planning: It Always Seems too Early, Until it's too Late

Advance planning for end-of-life care allows you to remain in charge of medical and other decisions, even when you're no longer capable of making them. By making your wishes known in advance, you can protect your loved ones from having to guess at what you would want to happen in a crisis. Yet it's estimated that only 20 percent of people in Arizona and less than 50 percent of those who are terminally ill in our state have executed an advance directive.

National Healthcare Decisions Day/Week (April 16 through April 22, 2017) is a project of The Conversation Project, the renowned national nonprofit dedicated to helping people talk about their wishes for end-of-life care. The national campaign is an effort to highlight the importance of advance healthcare decision-making in the United States, to

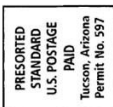
normalize end-of-life conversations and to improve the preparation, documentation and resources available to help citizens make informed choices regarding end-of-life planning and care. Beginning April 16, events across the USA will mark a week-long campaign that facilitates conversations among family, friends and healthcare providers, to talk about end-of-life wishes and to execute written advance directives. Their theme: It Always Seems too Early, Until it's too Late.

Locally, the End of Life Care Coalition (EOLCC) is carrying out the campaign (see page 19 for details). In 2013, Pima Council on Aging began meeting with other concerned parties to organize community efforts around this issue, resulting in the formation of the EOLCC in partnership with University of Arizona Center on Aging and

Passages Consulting Group. The EOLCC is now an action team of the ELDER Alliance of Pima County. PCOA continues to provide staffing for the group, which educates around end-of-life issues, and has spearheaded a campaign to encourage completion of advance care plans. Since mid-2015, PCOA has tracked 968 individuals in Pima County who have completed and documented advance directives as a result of the initiative.

Healthcare directives and advance planning are significant and growing areas of concern for older adults and their families. Every four years, Pima Council on Aging's Community Needs Assessment survey collects input about the needs and concerns of older adults and their caregivers. In 2012, accessing health care legal options such as medical powers of attorney and

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## PCOA information &amp; assistance

**Advance Care Planning***(continued from page 1)*

living wills did not appear in the top 20 issues of concern, but by 2016, the issue had risen to 13th of the 46 issues listed, with more than twice as many older adults indicating concern about the issue of healthcare directives as four years earlier.

Advance directives are written instructions about what kind of care you want and don't want and who can speak for you if you are unable to communicate your wishes. Having difficult conversations, documenting your decisions, and making sure that friends and family understand your wishes and know where to find your documents are critically important to ensuring that you remain in control of choices that can change your life – and death.

To speak with a PCOA staff member who can assist in providing you with and completing advance directive documents, call our Helpline at 790-7262.



W. Mark Clark  
President & CEO

**LGBT Issues in Caregiving**

Did you know there are issues specific to LGBT older adults that shape what challenges caregivers may face?

“Providing long-term care for a friend or loved one can feel overwhelming. And lesbian, gay, bisexual and transgender (LGBT) caregivers may be dealing with a host of additional issues, from healthcare laws and policies that prioritize legal and biological family, to a lack of resources that address their particular issues.” (SAGE, Services and Advocacy for GLBT Elders, Caregiver Resources, 2016).

LGBT older adults may have a long history of facing discrimination and prejudice. This may mean they feel unsafe when receiving or coordinating care from home health staff, in hospitals, in assisted living, rehab, and nursing home settings. The client and/or caregiver may feel the need to remain “in the closet,” i.e., hidden regarding their sexual orientation and/or gender identity. If remaining invisible in this way, their health care providers may not fully understand their medical and other needs, and may not have a picture of the whole person, which is essential to providing optimal care. The caregiver may feel blocked from giving the whole picture, if unsure about the response medical providers will give. (This is why PCOA provides Project Visibility trainings, to improve the culture of care for LGBT elders.)

Same sex couples have relatively recently been given the right to legal marriage. Many health and supportive care settings have begun recognizing the rights of same sex partners to be involved in care planning. Having advance directives

in place (namely a completed Health-care Power of Attorney form and Living Will) can be crucial to confirming who will be making decisions if the client cannot do so themselves. (PCOA can help with this.) This is especially important with same sex partners, since there are many stories of biological family pushing the long-time partner aside, when decisions are needed at times of crisis.

Some LGBT caregivers feel invisible, when dealing with staff that are caring for their partner or spouse, as relegated to the status of “friend,” instead of family. This adds to the stress of already difficult medical care planning, may discourage caregivers from expecting helpful outcomes, and contribute to resulting health disparities for the care recipients.

LGBT caregivers may be caring for family or others who are not LGBT. Finding the support and resources they need may feel impossible. PCOA's Caregiver Support Groups that are LGBT-aware and welcoming are an important tool to reduce the stress of caregiving. We can also help with arranging respite so that the caregiver can have some needed breaks.

PCOA has Caregiver Specialists, well versed in the needs of LGBT caregivers, available for no-cost consultations by phone or in person, on the full range of resources, possible subsidies, and options for support. LGBT caregivers do not have to feel alone and isolated when facing the demands of caregiving.

By Sandy Davenport, LMSW  
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