



Attendees at the End of Life Care and Planning kick-off event included from left: LaVonne Douville, Chief Impact Officer, United Way of Tucson and Southern Arizona; Kelly Huber, Director of Strategic Grants and Initiatives, Community Investments, Community Foundation for Southern Arizona; John Amoroso, Executive Director, David and Lura Lovell Foundation; Keynote Speaker Dr. Jessica Nutik Zitter, Critical & Palliative Care Specialist and Author of "Extreme Measures," and Mark Clark, President & CEO, Pima Council on Aging.

Planning for End-of-Life Care Foundations Award Nearly \$3 Million

By Monica Surfaro Spigelman

Some say it's both the best of times and the worst of times for healthcare providers. Here's the dilemma:

As modern medicine ramps up with new technologies that help prolong life, too often these advances subject individuals who have lost the ability to communicate or don't know the true ramifications to complex procedures – without taking into consideration the patient's wishes. This ambiguity can lead to costly and emotion-laden conflicts with long-lasting implications for patients, their loved ones and even employers through lost work time and diminished job focus.

The newly transformed Elder Alliance: End of Life Care Partnership aims to tackle this dilemma. The partners intend to improve end-of-life experience and care across the state. The EOLCP is bringing together healthcare providers, technology stakeholders, policy leadership, nonprofits and community experts in a structure that will increase their collective ability to shape Arizona as a leader in end-of-life care tactics that best serve individual and community needs.

This collaborative approach was significantly advanced several months ago, when the David and Lura Lovell Foundation and the Community Foundation for Southern Arizona's Shaaron Kent Endowment Fund announced their alliance to award almost \$3 million to Arizona nonprofits to cooperatively address issues related to end-of-life care programs. The grants to 10 nonprofits are for programs that intend to engage communities, educate professionals and patients, institute organizational and community standards of practice,

develop the healthcare workforce and impact public policy.


Already recognized by The Chronicle of Philanthropy for its innovative methodology, the EOLCP now is one of the largest funded initiatives of its kind in the nation – a model for local action to best manage resources effectively.

"Our goal is to seed a movement that fundamentally changes the way we talk about and plan for end of life," said John Amoroso, executive director of the Lovell Foundation, where a broader 24-year focus on integrative health and wellness has led the foundation to catalyze community efforts and better equip organizations to alter systems and address the root causes of social issues.

CFSA agrees that a collective plan will best magnify the impact of local resources on this critical issue. Since 2012, CFSA has granted \$850,000 from the Shaaron Kent Endowment for end-of-life programs in Southern Arizona. According to Sandra Nathan, CFSA senior VP of philanthropic services and community investments, studies show that some 70 percent of people over age 60 (in an inpatient setting and needing to make

a decision about treatment during the last week of life) were physically unable to communicate their wishes to family or clinicians. "Yet only 1 in 3 Americans has completed an advance care plan for end of life," she said.

"Our culture has been obsessed with curing disease and extending longevity for a long time," Amoroso said. "We need to learn how to live as well as we can, for as long as we can, but also to include thoughtful consideration and planning for our dying

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END OF LIFE CARE PARTNERSHIP MEETING

Monday, Feb. 12, 9-11 a.m.

TMC Senior Services, 1400 N. Wilmot Road
Featuring Harriet Warshaw, Executive Director, The Conversation Project
Members, prospects and public welcome
No admission charge
www.AZEndofLifeCare.org or (520) 903-3911

PHOTO: COURTESY UNITED WAY OF SOUTHERN ARIZONA

Start the Conversation

days, as part of a well-lived life. We all have a stake in that conversation.”

While the healthcare sector has a prime stake in advance care planning, the EOLCP underscores the imperative to also bring business, nonprofits, the faith community and community organizations to the table to coordinate an approach that addresses this issue.

More than 175 organizations already have signed up to learn more about the EOLCP, with the initial cohort of the 10 grantee organizations agreeing to a set of decision-making principles for implementing their programs. The United Way of Tucson and Southern Arizona is the EOLCP convener and backbone organization, promoting dialogue and building public/private collaborations. “United Way does not provide any health-related direct services, but has years of experience bringing people together for a common purpose and agenda,” said LaVonne Douville, United Way senior VP of community development. Collective impact methods and strategies will be used to guide diverse entities in a planning process that will help grantees achieve measurable outcomes and track success over time, she said.

The EOLCP is beginning its work to ensure that people have quality end-of-life care and receive it in the place of their choosing, Douville said. Sarah Ascher, a local leader in healthcare advocacy and strategy, has been hired as EOLCP’s senior director. The AZEndofLifeCare.org website went live in November, providing resources and education targeted for both providers and individuals in the community.

Grantees meet regularly to share ideas and identify needs. The impact is cumulative and – not surprisingly – the models vary from cultural awareness and youth resilience to healthcare provider training. But the entire value chain has a shared responsibility that extends to all communities across the state, particularly for underserved and vulnerable communities.

Douville said one important early implementation strategy involves the work of the Arizona Connected Care and Arizona Hospital and Healthcare Association to deliver provider education within the healthcare system. In addition, Interfaith Community Services is developing a community-based education system, including a focus on faith communities, to increase community awareness about the importance of end-of-life care plans. AzHHA will provide community education in the balance of the state.

From the physician’s perspective, there is a sense of urgency since Medicare began to reimburse providers for their conversations on Advanced Care Planning as of Jan. 1, 2016. “For most patients today death happens after a chronic illness and at a certain point care needs to shift from a curative to a palliative approach,” said Dr. Evan W. Kligman, a family physician in Tucson and former medical director for Casa de la Luz Hospice inpatient unit. He is a member of the Arizona Medical Association/Arizona Osteopathic Medical Association Task Force on End-of-Life Care and liaison to the EOLCP.

Joint Task Force Chair Dr. Ron Fischler, a pediatrician in Scottsdale, added, “Historically, both patients and their healthcare practitioners have been reluctant to discuss these issues, leading to dissatisfaction. When patient wishes are not clearly articulated, the default action by healthcare practitioners is aggressive care to the end, which is both costly and often futile.”

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What’s a first step toward a positive approach to the end of life? At any age, it means opening up conversations about your wishes, identifying someone to represent you should you no longer be able to express your wishes, and knowing what medical expertise and community support are available to help you complete an advance care directive. The EOLCP suggests these four tips in exploring those first steps in a most personal and critical healthcare decision:

Learn

The first step is to become familiar with the issue of end-of-life care planning and the options involved:

- Watch “Passing On,” Arizona Public Media’s Emmy-award winning documentary on end-of-life-care and planning, as well as other resources.
- The EOLCP September kickoff event featured a leading voice in the interdisciplinary movement to improve end-of-life experiences. Dr. Jessica Zitter’s work includes the Oscar-nominated documentary “Extremis.” Her new book – “Extreme Measures: Finding a Better Path to the End of Life” is both a practical guide to navigating the healthcare system and a powerful argument for re-imagining end-of-life care planning to ensure a fulfilling experience that adheres to our wishes. Read this book to explore your relationship with living and dying.

Discuss

Talking about mortality isn’t the easiest conversation, but it’s an important one. There are resources to help you get started:

- Let’s Talk starter kits are available from The Conversation Project (www.TheConversationProject.org/starter-kits)
- Receive news from EOLCP about speakers and resources or to attend a community education workshop to learn how to approach end-of-life conversations with family or friends (www.AZEndofLifeCare.org)
- Learn about local Death Café meetings (www.DeathCafe.com/deathcafe/4807)

Decide

Advance care plans are written instructions about what kind of care you do and do not want, and who can speak for you if you are unable to communicate your wishes. In Arizona, these documents are recognized:

- The official State of Arizona Life Care Planning Packet. This packet includes a form to designate your healthcare power of attorney (www.Azag.gov/seniors/life-care-planning)
- Five Wishes. This form will be available free of charge at EOLCP community education workshops.

Share

Your Advance Directive should be easy to locate in case of emergency, so that others clearly understand your wishes. Update the document regularly, and give a copy to:

- Your healthcare power of attorney
- Primary care physician or other healthcare provider
- Family members
- The Arizona Advance Directive Registry is a free registry to electronically store and access your medical directives (www.Azsos.gov/services/advance-directives)

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