



**Arizona END OF LIFE
CARE PARTNERSHIP**

Anchored at United Way of Tucson and Southern Arizona

COMMUNITY IMPACT REPORT 2017-2020

AZEndOfLifeCare.org

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Arizona End of Life Care Partnership Anchor Team

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On the Cover: Close up of elements of an ofrenda. (J Mndz/flickr)

Back page: Saguaro Cactus near Tucson, Arizona. (Carol M. Highsmith)

Our Arizona End of Life Care Partnership launched from an idea that originated in a small group of passionate people across social service organizations in Tucson, Arizona to address specific end-of-life care needs in our community.

Three years since its founding, our Partnership has grown to include 18 Grantee Partner organizations, 28 Investing Partners, and more than 350 Stakeholders; and has widened its local, regional, and national sphere of influence, illuminating the Partnership as a model for collaborative efforts to advance quality end-of-life care.

While death, as an experience, is the great human equalizer, the way in which people die relative to age, race, ethnicity, sexuality, circumstance, and quality of care is not equitable. We believe that all people are entitled to receive the care they desire at the end of their lives and know that we must fundamentally change the way we talk about death, bridge resources, and partner across sectors, organizations, and businesses in our community to achieve equity in quality of care.

We must build quickly upon the infrastructure and foundation we have laid in the last three years, continuing to identify gaps for home-based care and to improve quality of end-of-life care in every setting, as defined and communicated by individuals through conversations and advance care planning. We must strategically build upon identified best practices and continually measure progress toward evidence-based outcomes. We must use current national focus on social determinants of health to break down silos and barriers to ensure that people who are underserved and vulnerable have access to quality care and information about available services and tools. We must merge the worlds of healthcare and community to create a common language for all.

As we look to the next phase of our work in the context of the pandemic and its ever-lasting impact, it is more important than ever that we continue to grow our support. An investment in the Arizona End of Life Care Partnership allows our work to continue to expand and address areas of critical need throughout our community.

Thank you for your support!



A handwritten signature in cursive script that reads "Sarah".

Sarah Super Ascher
Associate Vice President
United Way of Tucson and Southern Arizona
Arizona End of Life Care Partnership

OUR STORY

In fall of 2016, a small group of community leaders began to focus on end-of-life care planning in Arizona. With the intention of improving the end-of-life experience and care across Arizona, the Arizona End of Life Care Partnership (EOLCP) was formed to bring together healthcare providers, policy leadership, nonprofit organizations, and community experts to forge an impactful community approach that would become the seed for a movement to fundamentally change our approach to end-of-life care.

The efforts began with a planning grant funded by the David and Lura Lovell Foundation which led to first- and then subsequent second-round grants.

Over the past three-plus years, the EOLCP has built capacity, secured additional support, and has grown in both numbers and diversity.



In just three short years, we've grown from the initial 10 Grantee Partners to **18 current Grantee Partner organizations, 28 Investing Partners, and more than 350 engaged and participating stakeholders.**

We've broadened our focus, recognizing that death affects every age in different ways, and **we secured one of only three Systems Change Grants awarded by the Vitalyst Health Foundation** to convene and lead a project focused on Opportunity Youth and Grief with Metro Goodwill, Tu Nidito, and the Pima County Juvenile Justice Center.



For all of this work, the Arizona End of Life Care Partnership was recognized as a model by the Coalition to Transform Advanced Care (C-TAC) and other regional and national coalitions for a value-based partnership approach with Investing Partners, customized education and outreach, Action Teams, website development and overall Partnership engagement and growth.



MISSION:

To enhance the way we live by fundamentally changing the way we talk about death.

VISION:

To ensure people in our community receive the care they desire at the end of life (aka goal-concordant care).

VALUES:

- Person and Family-Centered Care
- Clear and Compassionate Communication
- Collaboration
- Equity, Inclusivity, Access

TRANSFORMING END-OF-LIFE CARE



Community-
Based
Education

Community
Outreach

Professional
Education

Partner
Development

Workplace
Initiatives

Policy &
Advocacy

Pillars of Our Work

THE ROLE OF UNITED WAY OF TUCSON AND SOUTHERN ARIZONA



As the anchor organization for the Arizona End of Life Care Partnership, United Way of Tucson and Southern Arizona leads this collaborative effort through its mission to build a thriving community by uniting people, ideas and resources.

The Anchor Team provides the connective infrastructure by convening Partners and stakeholders, promoting the work of all Partners, and creating a hub for end-of-life resources. The role of the Anchor

Team is to coordinate community actions toward shared measurable outcomes and social change, to break down silos, and to create a sense of true collaboration





ACTION TEAMS

Our Action Teams work collaboratively toward measurable outcomes with shared vision and ownership. Each Grantee has committed to participate in an Action Team as part of the EOLCP model of shared governance and collaboration.

Community Outreach

Creates and shares consistent messaging about the Partnership and ways to spread the word about our work.

Community-Based Education

Focuses on community workshops on advance care planning and creative ways to tailor the content for specific audiences.

Policy and Advocacy

Brings awareness of relevant policies related to end of life.

Professional Education

Focuses on supporting education and awareness for providers around end-of-life conversations.

Partner Development

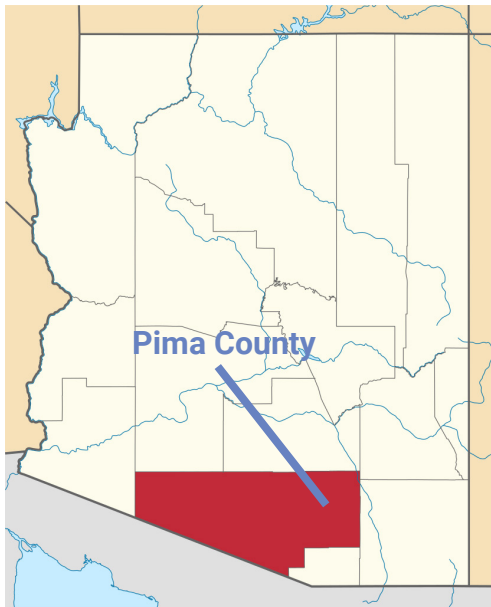
Ensuring collective community impact through Partner education of best practices and programs that exist locally and nationally.

Workplace Initiatives

Focuses on advance care planning as a wellness initiative in businesses and organizations.



OUR COMMUNITY



In 2019, our Partnership commissioned a survey to **gain an understanding of our community's thoughts about death and dying**. This survey of Pima County would provide a benchmark to lead our work for the coming years, providing data on the perception of and experiences surrounding end of life, as well as assess where our community stood regarding end-of-life planning.

75% said they think it's important to discuss their end of life wishes with family/friends.



87% said they are concerned about not being able to communicate wishes to family/friends.



87% said they are concerned about severe mental deterioration or severe memory loss.



However...

39% said they have **not** discussed their wishes with anyone.



53% said they **rarely** or **never** discuss death and dying with family or friends.

68% said they have **not** written down their wishes.

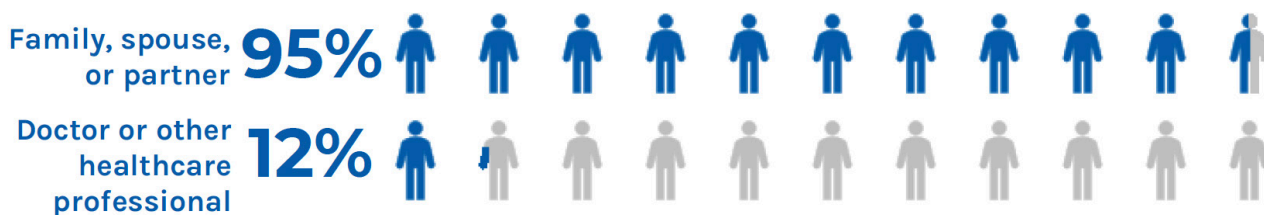


These factors were most often rated as very important:

- Getting honest answers from your doctor
- Understanding your treatment options
- Not being a physical burden to loved ones
- Having good pain management available
- Being physically comfortable
- Being able to balance alertness and pain management



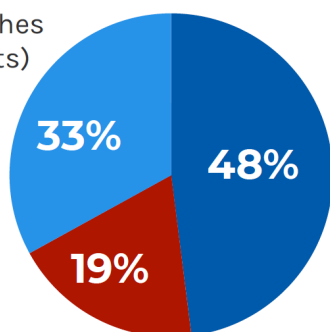
To whom did people speak about their wishes?



69% said they had someone close to them die in the past 5 years. Of those respondents...

How Often Medical Providers Honored the Person's Wishes (According to Respondents)

- All of the time
- Some of the time
- None of the time



- ★ Less than half said the person's wishes were honored **all of the time** by medical providers, and almost one in five said the person's wishes were honored **none of the time**.
- ★ 39% said the person died at home
- ★ 57% said the person died where they wanted to die

The Arizona End of Life Care Partnership, anchored at United Way of Tucson and Southern Arizona, contracted LeCroy & Milligan Associates, Inc., to develop and conduct a survey with a representative sample of adult residents of Pima County, Arizona, about their attitudes and beliefs about death and dying, end-of-life care planning, and their experiences with the death of a loved one. In October 2019, the survey was administered via phone and Internet to a sample of 600 adults that was representative of Pima County with respect to age, gender, and Hispanic ethnicity. Results will inform programming and education efforts related to end-of-life care in Pima County and provide baseline measures with which future survey results can be compared.

OUR IMPACT

In three-plus years, the Arizona End of Life Care Partnership has grown in both size and influence, bringing together Grantee and Investing Partner organizations to address areas across the end-of-life spectrum, including healthcare, hospice, grief, and cultural practices. We have been able to shift social systems and grow our footprint in Southern Arizona and beyond by:

Identifying, evaluating, and continually improving key shared measures, existing and new, to assess the short-term, intermediate, and long-term outcomes and impact toward our vision to ensure that people receive the care they desire at the end of life (goal-concordant care).

Changing the conversations about death and dying through convening, advance care planning community workshops, education of community members and professionals, and support of individuals and their loved ones.

Attracting new and influential Partners and broadening our funding sources, such as Coalition to Transform Advanced Care (CTAC), Dementia Friendly Tucson, University of Arizona, Catholic Community Services, Health Current, and Vitalyst Health Foundation.

Embedding our mission in all Partner organizations' cultures and budgets and, in turn, we are positively impacting the lives of thousands of community members.

Becoming a valued leader in local, state, and national discussions on end-of-life care alongside universities, health insurers, local and state government agencies, national advocacy organizations, and other community-based coalitions. We are regularly sought out by these entities for our input and collaboration.

Receiving national recognition by the Coalition to Transform Advanced Care (C-TAC) and others for creating the largest funded, community-based network for improving end-of-life care.





Active involvement in statewide end-of-life initiatives related to healthcare education and policy, advance directives registry, and person-centered care best practices.

Adding additional Partners focused on areas of need, including Step Up to Justice for low-income legal services, and Catholic Community Services and or faith-based end-of-life services.

Playing a key role in Dementia Friendly Tucson efforts through work with Pima Council on Aging and Elder Alliance to engage community leaders and stakeholders. At this time, Dementia remains a terminal illness with the majority of the person's lifespan spent in the community reliant on social service organizations.

SINCE OUR LAUNCH...

15,922 COMMUNITY MEMBERS
3,728 HEALTHCARE PROFESSIONALS

Have attended community workshops organized by the Arizona End of Life Care Partnership since 2017.

OVER 26,000
 Advance Directives have been distributed to community members in Pima County.

**IN JUST THREE YEARS,
WE'RE ALREADY
CHANGING THE
CONVERSATION AROUND
DEATH AND DYING...**

67% 

Increase in confidence among community members to begin end-of-life planning.

40% 

Increase in knowledge of end-of-life planning among community members.

OUR PARTNER STORIES

The collective impact of our Partnership is measured in the thousands of people we've served, but change is measured through the families and individuals who have benefitted from the work of each of our Partners. These stories shared by some of our Partner organizations illustrate the individual impact that our work has had throughout the community. They represent a nugget of the amazing work being done by our Partner organizations every day with individuals and groups throughout Tucson.

The Dunbar Pavilion in partnership with the Coalition for African American Health & Wellness



One of the participants who had registered for the Honoring a Life workshop called and told us that she had lost her husband approximately 7 days prior to the workshop. We contacted "Thelma" to let her know that her circumstances were completely understandable and offered her the opportunity to attend another workshop. She was adamant about attending the upcoming session because she and her husband had just had the conversation about getting their end-of-life care documents started...they had thought that they would have more time. So, with that in mind, she attended the free community education workshop so that she could at least fulfill what they had wanted to do and honor her husband's wishes. "Thelma" said that recording her wishes and completing her end-of-life documents would be a gift to her children.

El Rio Health

Many of the Advance Directive completions from this year resulted from a clinic that we hosted for people experiencing homelessness. Many of these patients have expressed a desire to complete their Advance Directives. But sadly, many do not have a "person" to speak on their behalf should they become unable to speak for themselves because of a serious illness or injury. Despite this difficult realization, this does not stop them from completing their Living Will or pre-hospital do-not-resuscitate documents. Without a designated agent to communicate a person's end-of-life wishes, the next best alternative is a document indicating the individual's desires. This is important work, and we are proud to provide this additional support to El Rio's patients who are experiencing homelessness.



Interfaith Community Services

A workshop participant, “Sally”, had an aunt who recently moved to Tucson. Upon her arrival, “Sally” quickly noticed that her aunt did not look well. The family had never spoken to her aunt’s doctor or been involved with her care and were unaware of her health condition. “Sally” took it upon herself to call her aunt’s doctor and found out that she had less than 6 months to live. “Sally” immediately contacted the rest of the family to share the news and have the difficult conversation. From this experience as well as the COVID-19 pandemic, “Sally” realized the importance of doing advance care planning. She not only signed up for our workshop for herself but has encouraged her family to do so as well.



Pima Council on Aging

We are proud of the new audience that we were able to reach with our Telenovela Series. The series was aimed at engaging the Latinx community by sharing knowledge and resources about dementia, common barriers to receiving in home services, as well as end-of-life issues. The series was promoted through multiple marketing channels aimed at engaging this audience. We were so pleased with the turnout not only from our Latinx community members, but also members from other diverse backgrounds who attended as well. The participants were engaged, and many commented that they look forward to attending similar future events on end-of-life topics.



Tu Nidito

“Thomas,” a 6-year-old boy, became involved with Tu Nidito in preparation for the impending death of his little sister. He participated in the Tu Nidito Superheroes event before her death. As part of this event, he was excited to meet paramedics, police officers, SWAT team members, police canines, and firefighters. When rescue workers were called and came to the family home immediately following his sister’s death, “Thomas” reported that he was not afraid because he had met these people before, and that they were his “friends.”



OUR GRANTEE PARTNERS

Our current Grantee Partners have received funds to provide specific services that significantly enhance end-of-life care in our community. We are grateful for their ongoing commitment and passion toward our mission.



United Way of Tucson
and Southern Arizona



WHAT'S NEXT?

Our accomplishments in the first three years have ignited tremendous excitement and optimism for the next phases of our End of Life Care Partnership collective impact:

- **Best practices driven by Theories of Change** created respectively for each of our six Action Teams, resulting in specific short, intermediate and long-term desired outcomes and measures.
- **Linking data sources via collaborative initiatives**, including the Arizona Coalition to Transform Serious Illness Care; the Health Current Health Information Exchange Advance Directives Registry, and the Altarum county specific data project.
- **Measuring progress through clearly identified shared measures** of desired outcomes that impact our vision for goal-concordant care, including follow-up community surveys, care experience data, and health care outcome measures.
- **EOLCP Toolkits and website enhancement** for navigation and care coordination within the Partnership and throughout our community.
- **Working with our Partners to empower their work**, including expanding the reach of pro bono end-of-life care legal services via Step Up to Justice; long term care reach through Catholic Community Services; end-of-life resources for dementia via Banner Alzheimer's Institute; and TMC goal concordant care initiatives, all as new Grantee Partner work.
- **Continuing to expand the breadth of our Partnership** to include health care insurers/payers; private businesses; financial planners; mental health and wellness organizations.

We will work across our Six Pillars and associated cross-sector, cross-organizational Action Teams toward three jointly identified long term goals:

1. **The Arizona End of Life Care Partnership will be a model of collaboration and impact**, focused on WHOLE community engagement and WHOLE care coordination across the ecosystem of end-of-life care in Pima County.
2. **Individuals' end-of-life care wishes are honored** across Pima County and Arizona.
3. **Culturally and contextually responsive end of life care conversations** are normalized throughout Pima County and Arizona.



OUR MAJOR INVESTORS



The David and Lura Lovell Foundation

Established in 1994, The David and Lura Lovell Foundation supports work in areas of mental health, integrative health and wellness, including end-of-life care and planning, youth access to the arts, and gender parity.

The Arizona End of Life Care Partnership is of special interest to the Lovell family because of David's own end-of-life experience. The initial grant to the Partnership that was made in 2017 funded ten community organizations, thereby launching this important work focusing on end-of-life care in Southern Arizona. Subsequent grants were awarded in 2019 and 2020 to support additional infrastructure and to address gaps identified in the early phases of Partnership development. Through 2020, The Lovell Foundation has awarded \$3.5 million for end-of-life care and planning projects.

Community Foundation for Southern Arizona

CFSA connects donors to the causes that they care about by serving as a vital link between philanthropy and the needs of the community. The work of CFSA touches every aspect of daily life, including end of life, animal welfare, arts and culture, community development, education, the environment, and health and human services.



Since 2012, through the legacy of the Shaaron Kent Endowment, the Community Foundation has been supporting programs that help ease the transition from life to death. CFSA has granted a total of \$472,550 to these programs. These programs encourage discussion and subsequent action around end-of-life issues and educate individuals, caregivers, medical personnel, family members, and the general community about the needs of the dying and the choices available to them.

Vitalyst Health Foundation



Thanks to a Systems Change Grant in the amount of \$190,000.00 from Vitalyst Health Foundation in 2019, the Arizona End of Life Care Partnership is helping Opportunity Youth in our community, youth ages 16-24 who are not in school or employed. These youth are among the most vulnerable in our community, and throughout their lives have been touched by death, and

often have had to deal with the trauma of these experiences without support.

With the support of the Vitalyst Health Foundation, United Way, Tu Nidito, and Goodwill Metro are working together to promote systems change within the Juvenile Justice Courts in Pima County by the formal inclusion of bereavement support services within probation terms, helping youth to develop healthy grieving strategies, which then promote resiliency. This expansion of their work is core to the mission of changing how we talk about death and acknowledging that our youth are an important part of that conversation

OUR INVESTING PARTNERS PAST AND PRESENT

United Way of Tucson
and Southern Arizona



The David and Lura
Lovell Foundation



Health Current

All Seasons Oro Valley Senior Living
Arizona Hospital and Healthcare
Association
Banner-University Medicine
Casa de la Luz
Casa de la Luz Foundation
Catholic Community Services
Dependable Hospice
Funeral Consumers Alliance of Arizona
Haven Hospice
Health and Wellness Marketing Group
Heartland Hospice
Integrative Touch for Kids
Interfaith Community Services
The Learning Community for Loss,
Grief, and Transition
Legacy Foundation of Southeast
Arizona
Loving Spirit

TMC Healthcare

Pima Council on Aging
Southern Arizona Senior Pride
SouthWest Content
Southwest Folklife Alliance
Step Up to Justice
Tucson Medical Center Foundation
Tucson Medical Center Hospice
Tu Nidito
Valor Health
Viable Insights
Cynthia Buckley/Pastoral Passages
Elizabeth Cozzi
Frank Williams
Hillman Family Foundation
Jill and David Putt
LaVonne Douville and Chet Hedden
Michelle and Charlie Urbina
Patten Family Giving
Sarah Ascher



Supported by



United Way of Tucson
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