CREATIVE CHOICES

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This newsletter, with live links, is on our website at www.fcactx.org/newsletters.html

The Newsletter of the Funeral Consumers Alliance of Central Texas

In this season of Thanksgiving, what could be more appropriate or heartfelt than to say to everyone who responded to our annual fundraising appeal

With so much on your mind and ours – month after month after month – we FCA volunteers are especially grateful for your encouraging words and generous donations.

What IS an End-of-Life Doula?

"End-of-life doulas provide non-medical, holistic support and comfort to the dying person and their family, which may include education and guidance as well as emotional, spiritual or practical care, from as early as initial diagnosis through bereavement."

~The National End-of-Life Doula Alliance, 2020

What is the "Doula Model of Care"?

By Patty Brennan, https://www.nedalliance.org/the-doula-model-of-care.html

Doulas are coming into the cultural mainstream and they are not just for birthing and postpartum mothers and their families. The emerging role of the end-of-life doula is gaining traction and helping transform how we approach end-of-life care in the United States and beyond.

Since current evidence for birth doulas is well established and based on a model of care that is gaining widespread recognition and acceptance by both consumers and medical care providers, it behooves the doula profession to unite in our understanding of the doula model of care, especially as it evolves to serve diverse needs of families throughout the lifespan.

There is plenty of room for creative visionaries to adapt the doula model of care for a target demographic or specialized care setting. Furthermore, how each doula manifests the doula model of care and delivers services to families will be uniquely her or his own. (continued on page 2)

What is the "Doula Model of Care"? *(continued from page 1)*

This freedom, entrepreneurship and diversity benefit the variety of individuals and families with needs that are unmet in existing systems of care delivery. At the same time, we must acknowledge what unites doulas and define the core, non-negotiable elements of the doula model of care.

A ***Model of Care*** broadly defines the way services are delivered. It outlines best practices for a person, population group or patient cohort as they progress through the stages of a condition or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

Core Components of the Doula Model of Care: 6 Guiding Principles

- **Non-medical support.** Doulas refrain from performing any clinical or medicalized tasks.
- **Non-judgmental support.** The doula does not impose her/his values on the client such as acting on biases in favor of one method.
- **Family-centered approach.** The individual and their family form the unit of care. Doulas do not take the place of partners, family members or other care providers.
- **Holistic care.** Doulas recognize the biopsychosocial and spiritual aspects of the whole person and provide services in the context of this understanding.
- **Empowerment.** Doulas promote informed decision-making and foster maximum self-determination for the individual and family.
- **Team members.** Doulas are team players with a special role.

Types of Support Provided by Doulas

- **Presence.** Good listener, witness, calming influence, nurturing, support for troubleshooting challenges.
- **Emotional support.** *Always* part of the doula's role.
- **Information sharing.** Education as needed and desired, non-biased and evidence-based.
- **Proactive guidance.** Anticipating needs and making a plan.
- **Resources and referrals.** Making referrals to appropriate community resources and care providers, thereby increasing access to all available services.
- **Comfort measures and physical support.** Can include hands-on comfort techniques, help with positioning, visualization, use of the breath, and so on.
- **Logistical support.** Can include household help, running errands, transportation to medical appointments and so on.

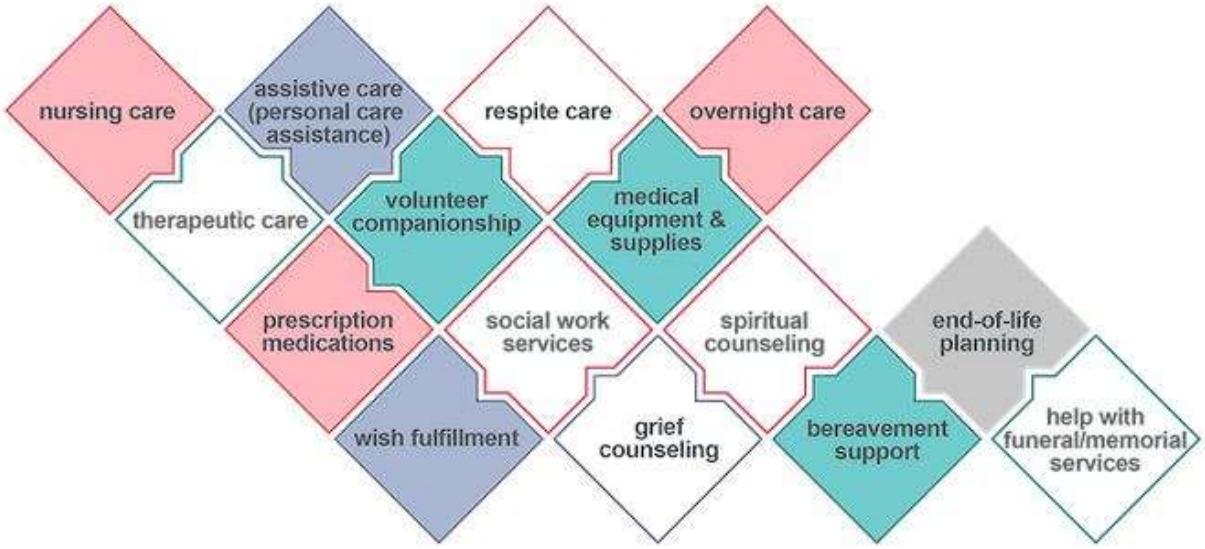
More about the "Doula Model of Care" at https://lifespandoulas.com/doula-model-of-care/.

More about death doulas, doula training, and doulas in our area:

- International End-of-Life Doula Association (INELDA) https://www.inelda.org/find-doula/
- National End-of-Life Doula Alliance (NEDA) https://www.nedalliance.org/
- Quality of Care, Deanna Cochran, RN, End-Of-Life Doula, home-based in Austin area; Doula Trainer, author of **Accompanying the Dying** https://www.qualityoflifecare.com/

Hospice: An Option at the End of Life

There were no needles, no tubes, no catheters and no machines. My father-in-law's death from cancer was as peaceful, as possible.



By Maria Otero

Rather than spend his last days in a cold hospital room surrounded by strangers, Pablo died March 8, 2018, at home in hospice. He was surrounded by his children, grandchildren listening to *rancheras* (folk songs) and corridos (ballads) by Mexican singers Vicente Fernandez, Rocio Durcal, including his favorite tune by Jose Alfredo Jimenez's *ranchera La Mano de Dios* (God's Hand) as he held my husband Jorge's hand in prayer.

Pablo was a former migrant worker, a Catholic, grounded to his faith to the very end. He was going through excruciating pain in his back and bones. In less than four weeks, we went from celebrating his 79th birthday to mourning his painful death from cancer.

My *suegro* (father-in-law) had been dealing with some other kind of unrelated health issues for probably a year. He had endured agonizing test after test, and he was a trooper. We found out that he had cancer, and it was shocking. Some of us were in disbelief, maybe denial, so we couldn't really grasp that we have limited time with him.

Doctors gave us two options: A biopsy to determine where the cancer was located or hospice.

We chose hospice.

November is National Hospice and Palliative Care Month and an opportune time to bring to light this option at the end of life. It is also a good time to clear out some of the misconceptions among the Latino/Hispanic community of this service that provides compassionate medical care at the end of life.

Hospice is not a physical location. It is an interdisciplinary team approach to treatment that includes expert medical care, comprehensive pain management, and emotional and spiritual support. This service enables patients and families to focus on living as fully as possible despite a life-limiting illness. Caring for the whole person allows the hospice team to address each patient's *(continued on page 4)*

Hospice: An Option at End of Life *(continued from page 3)*

unique needs and challenges. This includes understanding and respecting each patient's culture, family traditions and beliefs.

Hospice is almost always provided in the patient's home, but arrangements can be made for it to be provided wherever the patient is most comfortable, such as in the home of a family member or friend. Hospice services are also provided in hospice facilities, skilled nursing facilities, assisted living facilities, hospitals and long-term care facilities.

As a native New Mexican, I'm well aware how hard it is for my Hispanic/Latinos to talk about death. Preparing for death is more critical than ever, especially because Hispanics and people of color are dying at a disproportionate rate from the coronavirus compared to other Americans.

Compassion & Choices created a free **online bilingual COVID-19 toolkit** available at CompassionAndChoices.org to help people understand their end-of-life care options.

Creating an advance directive is something every person should do.

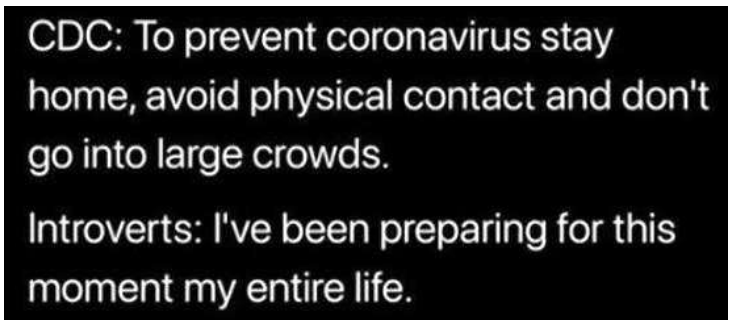
And there is–literally–not a more critical time to do it.

It has been almost two years since *Grandpa* Pablo closed his eyes forever. Just this month, we honored my *suegro's* memory with a beautiful altar during our annual Day of Dead celebration. I hugged my husband and reminded him of those last precious and blessed moments we spent at home with his dad.

Hospice was the best choice we made for my *suegro*. They made sure we got the emotional and calming support needed during those very tough last five weeks. Our family cried in silence as my husband hugged and kissed his father's forehead for the last time.

My *suegro* took his last breath that Thursday night at 10:12 p.m. He knew he was loved. And we were at peace.

http://theamateursguide.com/hospice-an-option-at-the-end-of-life/



A fascinating factoid for our friends born in 1933

Artificial Nutrition (Food) and Hydration (Fluids) at the End of Life

It is very common for doctors to provide fluids and food to people who are very sick or recovering from surgery. This is called “artificial nutrition and hydration” and, like all medical treatments, it can be helpful or harmful depending on the situation.

The information below explains the medical facts about artificial nutrition and hydration at the end of life so that you can make informed decisions for yourself or a loved one.

What is artificial nutrition and hydration? When is it used? How is it given?
Artificial nutrition and hydration is a medical treatment that allows a person to receive nutrition (food) and hydration (fluids) when they are no longer able to take them by mouth. Artificial nutrition and hydration is given to a person who for some reason cannot eat or drink enough to sustain life or health. Doctors can provide nutrition and hydration through intravenous (IV) administration or by putting a tube in the stomach.

Is artificial nutrition and hydration different from ordinary eating and drinking?
Yes, providing artificial nutrition and hydration requires technical skill and has many serious risks. Professional skill and training are necessary to insert the tube, to make decisions about how much and what type of nutrition to give, and to monitor for side effects.

Artificial nutrition and hydration do not offer the comforts that come from the taste and texture of food and liquids. Rather than the recipient, doctors and nurses control when and how much will be given.

What happens when artificial nutrition and hydration is given to patients who are at the end of life?
When someone with a serious, life-limiting illness is no longer able to eat or drink it usually means that the body is beginning to stop functioning. Artificial nutrition and hydration will not bring the person back to a healthy state.

Most doctors agree that artificial nutrition and hydration can increase suffering in patients who are dying and no longer have the ability or interest to eat food and drink liquids themselves. Artificial nutrition and hydration can add more discomfort to a dying person’s physical symptoms such as: bloating, swelling, cramps, diarrhea, and shortness or breath.

It is important to remember that the person’s body is beginning to shut down because of the disease and dying process, not because of the absence of food and liquid. There are ways to ensure a person’s comfort at the end of life by treating dry lips and mouth. Hospice and palliative care professionals are experts in providing comfort treatments.

Is it considered suicide to refuse artificial nutrition and hydration?
No. Everyone has the right to refuse or discontinue a medical treatment. A person at the end of life is dying, not by choice, but because of a particular disease. It is not considered suicide to refuse or stop a medical treatment that cannot bring back health.

What does the law say about artificial nutrition and hydration?
Legally, artificial nutrition and hydration is considered a medical treatment that may be refused at the end of life. If the patient is able to make decisions, the patient can tell his/her physician what he or she wants. For patients who can no longer talk about their wishes, some states demand strong evidence to show what the patient’s wishes are. When there is uncertainty or conflict about whether or not a person would want the medical treatment, treatment will usually be continued.

This is why completing and talking about your advance directive are important – so that there will be no doubt about what kind of medical treatments you would want or not want at the end of life.

Source: National Hospice and Palliative Care Organization (NHPCO) **CaringInfo** publication at https://www.nhpco.org/wp-content/uploads/2019/04/ArtificialNutritionAndHydration.pdf

After you complete or update a healthcare directive, you may find it helpful to keep a record of copies you've given to others.

We invite you to call us at 512-480-0555, or email us at office@fcactx.org, if you would like us to mail or email this Distribution Log page to you. Just let us know how many you need.

Distribution of My Healthcare Directives

Name: ____________________

On ____________ (date), I or my healthcare agent gave the following document(s)

○ Directive to Physicians (Living Will) ○ Medical Power of Attorney ○ Out-of-Hospital DNR

to ____________________ name of person or institution

On ____________ (date), I or my healthcare agent gave the following document(s)

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Distribution Chart developed by Funeral Consumers Alliance of Central Texas www.fcactx.org

Our FCA's End-of-Life Options Class

Because of the pandemic, it is not yet certain that Lifetime Learning Institute will offer spring semester classes in 2021.

If they do, details will be posted on our website, www.fcactx.org, under the Events tab and on the LLI website, www.lliaustin.org.

Details in our next newsletter

WE'RE HERE TO SERVE YOU

Leave us a message at **512-480-0555** (**Our office is currently closed due to the pandemic**, but we check voice mail at least once a day. **We will return your call.**

Email us at office@fcactx.org

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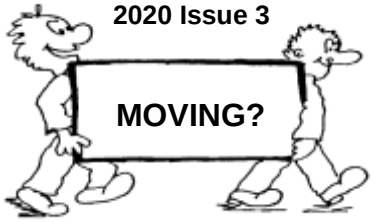

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The Newsletter of the Funeral Consumers Alliance of Central Texas (formerly AMBIS)

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