



CREATIVE CHOICES

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The Newsletter of the Funeral Consumers Alliance of Central Texas

“THE CONVERSATION”

Nancy Walker, FCACTX Executive Director

This newsletter with clickable links is on our website at www.factx.org/newsletters.html

For more than ten years, I have been urging adults over 18 to complete medical advance directives and to have “the conversation” (which often ends up being a series of conversations). Time and again, even people who have not yet had the conversation tell me they appreciate the benefits of discussing their views and decisions with their healthcare agent(s), family, close friends, caregivers, and medical providers.

Month after month, we see COVID-19 sweeping across our nation and the world. Here in Texas, we are being told that emergency rooms, ICUs and funeral homes are overwhelmed. We know that thousands of people have died without the comfort of seeing or speaking with their loved ones. We are advised that only a limited number of people will be permitted to attend funeral services. Every day, newspapers and websites swell with obituaries. Little wonder more of us are preparing or updating our wills and advance directives. In doing so, we often find ourselves giving serious thought to what will matter when we are in the final days or hours of life.

Clearly, the pandemic is reaching into our depths, stirring thoughts and feelings with which most of us are not routinely familiar. Finding words to express and understand those thoughts and feelings is one way to help ourselves through these deeply challenging times.

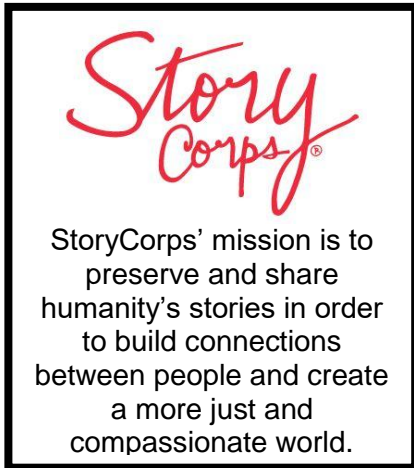
Whether we have the “pandemic conversation” solely within ourselves, or we decide to talk with others, the questions below – created by StoryCorps – may provide a place to begin.

1. What is the biggest way your life has changed because of the pandemic?
2. What has been the most challenging part of this experience?
3. Are you afraid? If so, what frightens you?
4. What has given you comfort and hope during this time?
5. Has this experience changed you? If so, how?
6. Is there someone you can't see right now who you really wish you could?
7. If the quarantine ended tomorrow, what's the first thing you would do?
8. If you could ask anyone from your life, living or dead, for advice on getting through this experience, who would it be, and what would you ask them?
9. Do you or have you had COVID-19? What is/was that experience like for you?
10. What memory of this time do you think will stay with you?

More StoryCorps questions about the pandemic, general topics, and questions for grandparents at <https://storycorpsorg-staging.s3.amazonaws.com/uploads/StoryCorps-Connect-Great-Questions-Final.pdf>.

GOOD NEWS!

STORYCORPS CONNECT IS IN OUR HOMETOWN!



If you listen to NPR, chances are you've heard three-minute StoryCorps snippets. Over the last 15 years, StoryCorps has recorded over half a million 40-minute, two-person conversations. A selection of them is available at <https://storycorps.org/stories/>.

StoryCorps says the purpose of these recordings is to remind all of us of our shared humanity, to strengthen and build the connections between people, to teach the value of listening, and to weave into the fabric of our culture the understanding that everyone's story matters.

In March, 2020, as a response to the COVID-19 pandemic, StoryCorps created **StoryCorps Connect** at <https://storycorps.org/participate/storycorps-connect/>.

[StoryCorps Connect](https://storycorps.org/participate/storycorps-connect/) is a first-of-its kind platform that enables you to record a StoryCorps interview with a loved one remotely using video conference technology.

With your permission, your interview will be stored in StoryCorps' archive at the American Folklife Center at the Library of Congress, an ever-growing archive of the wisdom of humanity.

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SAVE THE DATES!

National FCA's FREE Online Conference

**Tuesday, September 22 through
Thursday, September 24, 2020**

SEPTEMBER 2020						
SUN	MON	TUE	WED	THU	FRI	SAT
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

Keynote Address: African American Undertaking: History, Burial Rights and Deathwork

Presenter: Dr. Kami Fletcher, associate professor of American & African American History at Albright College

Thursday, September 24, 12 noon CST

Specifically discussing her research about the earliest African American undertakers in Baltimore, Dr. Fletcher provides a history of African American undertaking and undertakers. Focusing on the rise of the Reconstruction-Era African American undertaker, Dr. Fletcher will show how race, racism and the autonomous black cemetery led to early 20th-century African American undertaking as a vehicle for wealth building and communal self-help. The talk will put special emphasis on how Black women undertakers used newspapers to subvert patriarchy and gender norms in order to thrive in death work that was dominated by men.



Another presenter at the conference will be our **President Emeritus, Lamar Hankins**.

Lamar's presentation, **Seven Ways to Die with Dementia: Some Thoughts about Advance Planning**, will be scheduled later this month.

FREE Registration and program schedule at www.funerals.org

LEGACY LETTERS

“Immortality is the genius to move others long after you have stopped moving.” (Frank Rooney)

A legacy letter – also known as an ethical will or a heart will – is your opportunity to leave a unique message of affection, inspiration and hope for your loved ones. There is no right or wrong way to express your thoughts. It’s okay to make ‘em laugh. It’s okay to make ‘em cry. The important thing is to share your message in a way that leaves no doubt as to who you are.

Some of many reasons to create legacy letters / ethical wills:

- We all want to remember and be remembered
- We want to share life lessons that led to wisdom and enriched our lives
- If we don’t tell our stories and the stories of earlier generations, they will be lost forever
- We have a context in which to identify and express what we value most and what we stand for
- We have a means to pass our values to future generations
- We wish to bless and express our love for our children and grandchildren
- We have stories to tell about personal or family items we plan to pass to our heirs
- We have a context in which to express regret, ask forgiveness, and seek reconciliation
- We will become more comfortable with our mortality by creating something of meaning that will live on after we are gone
- We will learn a lot about ourselves in the process of writing an ethical will

Although the content may be similar to a memoir or spiritual autobiography, a legacy is written with the specific intention to transmit love and learning to future generations.

Even though it is not a legal document, an ethical will is sometimes used by estate and financial professionals to help clients to articulate values to inform charitable and personal financial decisions and to prepare a last will and testament.

**Writing is not the only way to create your legacy!
Consider also – in any combination – videos,
audiotapes, scrapbooks, photo albums.**

Life Occasions for which a Legacy Letter would be a Special Gift:

- for someone receiving a driver license
- for someone graduating from high school or college
- for betrothed or newly married couples
- for expectant and/or new parents
- for reflection near the end of life
- for divorcing couples
- for children in growing families
- for “empty-nesters”
- for people entering middle age or senior years

QUESTIONS THAT CAN LEAD TO MEANINGFUL ANSWERS

Whether you're planning to have a meaningful conversation or to record your memories and thoughts for those you love, here are some questions to help you get started:

- If you could sum up your life's hopes and dreams, what goal or goals mattered most?
- If you volunteered your time to a cause, what cause did you choose, and why?
- What filled your heart with wonder? What made you feel like singing?
- In what ways did you make a positive difference in someone else's life?
- What principles consistently guided your life?
- What have you always tried to stand for?
- What insights have you gained through the trials of life?
- What lifted you up when you were down?
- What joy or circumstance brought deep meaning to your life?
- What obstacles did you overcome? How did you do it?
- How has your faith shaped your thoughts and actions?
- What did you learn through suffering?
- How did you overcome discouragement?
- How did you deal with lost opportunities?
- If you had serious or long term health problems, how did they affect your life?
- What did you not care at all about?
- How do you define "success"?
- If you have been someone's caretaker, how have you handled it?
- What was your greatest pleasure?
- Did you ever spend a lot of time waiting for something that never happened?
- What is the dearest thing you ever lost? How did you cope?
- What did you once think you knew for sure, but later changed your mind?
- What are your thoughts on forgiveness?
- If you had left only one memory of life, what would it be?
- What, if anything, would you do differently if you could do it over again?
- What did you learn from failure?
- What was your greatest adventure?
- Did you ever completely alter course and start over?
- What did you learn from your parents? From your children?
- How would you spend your time if you knew you had only 6 months to live?
- What would you have said if asked this question in 2015: "Where do you see yourself five years from now?"

Questions modified from Linda S. Parker's e-book, ***Life Legacy Letter: How to Leave a Legacy Letter for Generations to Come***

PATIENTS OVERESTIMATE THE SUCCESS OF CPR

Doctors should discuss CPR to clarify and inform patients before they consent to it, say researchers

Patients and the general public appear to significantly overestimate the success of cardiopulmonary resuscitation (CPR) and underestimate the negative impact it can have on a person's health, suggests research published online in *Emergency Medicine Journal*.

Read the complete report, **Perspectives of emergency department attendees on outcomes of resuscitation efforts: origins and impact on cardiopulmonary resuscitation preference**, at available for free download at <https://emj.bmj.com/content/early/2020/06/11/emj-med-2018-208084>. The six-page report is available for download at no charge.

US researchers have therefore recommended clinicians discuss CPR with patients and their loved ones to clarify the practice's success rate and the real benefits and risks involved before patients or their families are asked to consent to it.

Emergency physicians often talk to patients or their families about end-of-life care and the outcomes of resuscitation efforts. Patient and family preconceptions of CPR can have a significant effect on the tone of discussions and the subsequent medical care provided.

Previous studies have shown that most lay people overestimate the success of CPR and underestimate its morbidity, but no studies on the subject have been carried out amongst patients and visitors in an emergency department.

Patients in previous studies have cited television as a large source of their belief that rates of survival after CPR vary between 19% and 75%, whereas actual rates of survival of CPR range from an average of 12% for out-of-hospital cardiac arrests to 24-40% for in-hospital arrests.

Therefore, a team of researchers from the University of California in the US carried out a survey of 500 emergency department patients and their companions to assess their expectations and examine whether or not variation in information sources, prior exposure to CPR, and healthcare experience would influence peoples' predicted CPR success rates.

The survey was carried out amongst adults in the emergency department waiting area within a tertiary care hospital in Sacramento, California, between June and September 2016.

An "optimism scale" was created to reflect expected likelihood of survival after CPR, or CPR success, under several sets of circumstances.

Results showed that of the 500 respondents, more than half (53%) had performed or witnessed CPR, and/or participated in a CPR course (64%).

Television was the main source of information about CPR for around 95% of respondents.

At least half of the people interviewed estimated the success rate of CPR as being more than 75% in all situations. The estimated CPR success rates were unrelated to age, sex, race, spiritual beliefs or personal healthcare experience.

The vast majority (90%) of people interviewed said they wanted to receive CPR if it was possibly needed.

Comments also revealed that only 28% of respondents had discussed CPR with a physician, but most participants believed that a physician should talk to them about their CPR preference.

The study had some limitations such as the fact that it took place at a single institution and for convenience, the sample only included English speakers, which limits generalizing the findings. Some participants might also have been distracted by illness or the emergency department waiting area environment.

(continued on page 6)

MEMBERS: YOU DID YOURSELVES PROUD!



In mid-March, we sent a flyer to all our members asking you to respond to the Federal Trade Commission's request for public comment on the Funeral Rule. Of the 724 comments published by the FTC, nearly 16% were submitted by our members!

Yes, other FCA affiliates provided input; but none of them came close to the **114** you contributed! Thank you!

When the FTC makes a decision about revising the Funeral Rule, you can be sure we'll let you know.

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Patients overestimate the success of CPR (continued from page 5)

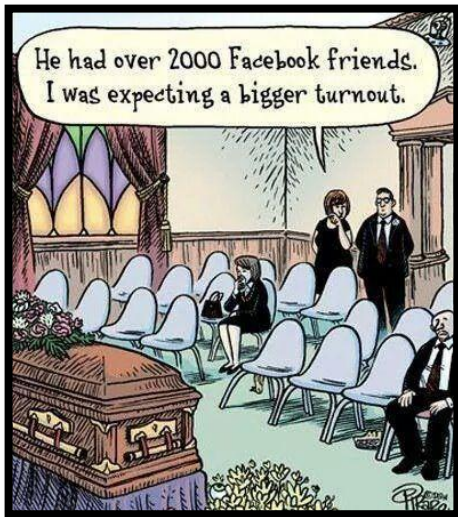
Nevertheless, the researchers conclude: "Patients and visitors to an emergency department, regardless of prior healthcare or CPR experience, overestimate the likelihood of success with CPR.

"These findings should prompt emergency department physicians to initiate discussions about resuscitation with their patients while also providing them with key information to help facilitate informed decision-making.

"When discussing CPR preferences, emergency department providers should focus on true rates of survival and outcomes in any shared decision-making conversation and should not assume that a patient or companion with healthcare experience will have realistic expectations."

Source: <http://theamateursguide.com/patients-overestimate-the-success-of-cpr/>

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Felt uncomfortable driving into the cemetery the other day. The GPS blurted out, "You have reached your final destination."



DO I WANT A VENTILATOR?

Coronavirus prompts more people to consider, or revisit, end-of-life care

By Naomi Martin

The coronavirus pandemic has pushed the fact of human mortality to center stage, prompting scores of people, not just doctors, to consider or revisit their end-of-life wishes. Complicating matters, the pandemic has introduced ventilators — a life-support tool seldom discussed outside hospitals before the outbreak — into mainstream Americans' worries.

Amid talk of hospitals rationing ventilators, some people are updating their living wills or proxies to say that they do want a ventilator to extend their lives, if necessary. Others, largely elderly people and those with serious health conditions, are making it clear that if their odds aren't great, they wouldn't want the machine to keep them alive.

"In the two-and-a-half years we've existed, we've never answered questions on ventilators, but now they're pretty common," said Renee Fry, cofounder of [Gentreo](#), which offers low-cost estate planning.

It's [urgent](#) that people clarify their wishes to family now, doctors say, because the coronavirus can progress quickly, making patients suddenly so sick that to stay alive, they must be put in a medically induced coma and on a ventilator.

In that moment, they may not have a chance — or be able — to fully consider the potential consequences such as brain and organ damage, or needing to live bed-bound with a feeding tube.

Most people who contract the coronavirus don't become seriously ill, and only a small portion require intensive care. However, early data [suggest](#) that perhaps 50 percent to as many as 80 percent of coronavirus patients who are placed on ventilators don't survive.

"The reality is even if we have enough ventilators, that's not going to save most people," Dr. Breanne Jacobs, an emergency room doctor and professor at George Washington University School of Medicine who [wrote about the issue](#).

Most elderly people would prefer to pass away at home with family rather than alone in a hospital, she said, so "if they understand a ventilator is not going to miraculously get them back to where they were, a lot of people would probably change their mind about allowing doctors to do intubation."

The crisis has [prodded](#) many people to take up the oft-deferred task of discussing end-of-life goals. Thousands have downloaded a new coronavirus-related [guide](#) from The Conversation Project, which helps people broach the uncomfortable topic.

Doctors advise against using medical terms, like ventilator, in documents, because that's not helpful to clinicians aiming to follow someone's overarching wishes. Instead, they say, people should focus on big-picture values.

"A lot of people say, 'I don't want to be intubated,' but they mean they don't want to be intubated for the rest of their lives," said Suelin Chen, cofounder of [Cake](#), which offers free end-of-life planning services. "If it were just to recover for a few days, they'd want that."

Specialists say everyone over 18 should, at minimum, record their [health care proxy](#), which in Massachusetts requires two witnesses. If that's impossible during social distancing, people can complete a ["trusted decision-maker" form](#), which is better than nothing.

And they should discuss [key questions](#) with their chosen person before an emergency, such as what makes life worth living, how much suffering are they willing to endure, and for what odds of success. These should be ongoing conversations, as people's wishes change with age and health status, they said.

(continued on page 8)

Do I want a ventilator? (continued from page 7)

“This isn’t just doom and gloom — it’s how do you want to live your life all the way through the end?” said Kate DeBartolo, senior director at [The Conversation Project](#).

The downsides of inaction can be high. Someone may receive procedures they don’t want, as hospitals can be obligated to try to keep someone’s heart beating, regardless of whether their brain is alive. Without clarity, family members may disagree over stopping life support, prompting infighting and guilt. Planning reduces depression in grieving relatives, a [2010 study](#) found.

In some instances, family members may have to go to court to take a loved one off life support.

“With my mom, I always say it was the greatest gift that she gave us,” said Patty Webster, 50, a Conversation Project community engagement leader, whose mother, a hospital chaplain, made her wishes so clear that when she suffered two strokes, her family all agreed when the heart-wrenching time came to stop prolonging her life.

“She had an end-of-life that she wanted,” Webster said. “She had friends and family by her side, laughing and crying, together with her when she took her last breath.”

Amid coronavirus, Webster revisited the topic with her family. She shared an [article](#) by a doctor about the damage that ventilation can cause. Afterward, her in-laws, in their 80s, emailed to say they wanted to live to 110, but only if “cognizant, thinking, and communicative,” and likely wouldn’t want ventilators.

Webster and her husband, meanwhile, would be willing to try temporary ventilator treatment for a chance to remain in the lives of their children, 18 and 20, in an active, meaningful way.

People who have started end-of-life planning during the crisis say it offers a measure of control. That doesn’t mean thinking about death gets any easier.

“It’s terrifying to think about when you flat-line, that’s the end,” said Chris Haynes, 48, a South End restaurant publicist who recently crafted his will, but can’t bring himself to envision his end-of-life care. “It just shakes you to your core.”

Pushing past that discomfort can make a huge difference to families and doctors, said Peter L. Slavin, president of Massachusetts General Hospital. In one recent case, he said, a health care proxy for a critically ill coronavirus patient knew that the patient wanted to try a few days on a ventilator. Then, if her condition didn’t improve, she would switch to hospice care.

“It’s hard whenever a patient is dying,” Slavin said, but “it felt like we were doing right by this patient and her family.”

Lately, Slavin has discussed the coronavirus by phone with his primary care patients who have advanced cancer, dementia, or heart failure. He describes the potential harms and low odds they’d face on a ventilator. He recommends that, if infected, they not pursue intensive care. Most patients agreed, he said.

For Slavin personally, the calculus is different. At 33 and healthy, he faces a good chance of recovery if infected and would want to try every option to survive and build a future with his wife.

“At another point in my life,” he said, “I might say, ‘I want a time-limited trial of intensive care, then shift to making comfort the top priority.’”

Source: <http://theamateursguide.com/do-i-want-a-ventilator/>



Remembering Deceased Member – Volunteers with Gratitude and Affection



Leon Lebowitz



Julia Rector



Jo Schneider

A special tribute to Leon Lebowitz

Lamar Hankins, January 12, 2020

When I read Leon Lebowitz's obituary, I thought back to our first meeting in 1992. It was at an annual meeting of AMBIS, the Austin Memorial & Burial Information Society, now named the Funeral Consumers Alliance of Central Texas (FCACTX). He was the presiding officer and was self-effacing and generous in the time he provided to the organization. Leon served for over 25 years on the board, providing the legal work necessary to incorporate the organization that was created in 1964, and securing nonprofit status for it with the IRS in the 1980s. For the past fifteen years, he was listed as President Emeritus of the organization. I never took a law course from Leon, but I always found his counsel to be wise, caring, and courteous. His loss to the greater Austin community is beyond measure. He truly was a mensch.

**REMINDER:
A LASTING MEMBER BENEFIT**
With permission from next-of-kin, FCACTX posts member
obituaries on our website at no cost.

Especially now, while the pandemic is curtailing funeral services, Mary Kuhlemeyer Clark, who wrote her own obituary, offers timely suggestions for living through these times:

In lieu of a funeral, please pick a day of your choosing every year to remember me and spend the day with those you love. Please consider: Sitting on a porch swing with the one you love. Ride a horse and smile the entire time. Play bridge. Euchre is good, too. Help a student with homework. Do not eat peas, drink milk, or eat gravy on that day, as I never ate those things. Buy tickets for you and one you love for the vacation of your dreams. Smile. Make a card for someone and say a prayer for the person to whom it goes before sealing the envelope. Organize something to look forward to doing with friends. Read. Make someone laugh. Tell your children and grandchildren that you love them. Don't clean today. Or tomorrow, for that matter. Plant a tree. Give someone garden flowers. Get a hairstyle that requires NO time to do each day. Thank a veteran and put a wreath on the grave of a veteran, please. Do it for Christmas if not now. Or both. Vote. Above all, say a prayer to thank God for your life and your loved ones, and for His blessings.

Complete obituary: <https://www.legacy.com/obituaries/journalstandard/obituary.aspx?n=mary-kuhlemeyer-clark&pid=196506535>

WE'RE ALL IN FOR YOU! THANKS FOR BEING ALL IN FOR US!

If you have been a member of our FCA for more than a year, you know that we ask for donations only once a year. Because our volunteers donate to other organizations, we know it can be annoying to have our inboxes and mailboxes crowded with follow-up appeals. Our FCA chooses not to do that. Nor do we raise revenue by selling advertising space on our website or in our newsletters because our consumer activities require that we be beholden to no one but you.

Year after year, you have shown us that you appreciate our efforts to serve all who seek end-of-life information. You shower us with words of thanks and send us donations to keep us going. These gifts, no matter how small or large, are what sustain us.

Because we have no staff and payroll expenses, each dollar you donate goes directly towards our overhead expenses, our training materials, and our memberships in organizations – such as the Aging Services Council – which help us spread the word about our services throughout the five counties that we serve.

Thanks to your generosity, we hired a consultant to create a 9" X 4" rack card, to promote our FCA throughout our community.*

Thank you for cheering us on by donating as generously as you can.

* If you would like to help us distribute our new rack card in your area, please call or email us and we'll send you as many as you like.

* * * * *

A UNIQUE GIFT FOR SOMEONE YOU LOVE



Whenever you donate \$35 or more, you can assign double-duty to your donation by giving a gift membership to someone you love. Just attach a note to your payment and we will contact you to put the gift membership process in motion.

* * * * *

PLANNED GIVING

An easily overlooked way to support FCA of Central Texas is a non-cash gift – such as a car, motorcycle, boat, or mobile home – that can be converted into cash to help us achieve our mission. You may also support our FCA through your estate plans. Some gifts may provide a tax advantage and/or may not require the assistance of an attorney.

For information about planned giving opportunities, strategies, and benefits to you as well as to FCA of Central Texas, please contact volunteer Gary Lichtenstein, CPA, at gary@lichgroup.com; 512-924-8456. A longtime FCACTX member, Gary can answer your questions and provide guidance on your options.

YES! I am making a tax-deductible donation to support FCA of Central Texas.

Name: _____ Donation Amount: \$ _____

**PLEASE
PRINT**

Update, if any, to address on the other side of this coupon:

Phone: (_____) _____ Email: _____

Payment Method:

- Check enclosed (payable to **FCA of Central Texas**)
- Credit Card: 16-digit-number: _____ Donation: \$ _____
(Visa, MC or Discover) Expiration Date: _____ 3-digit Security Code: _____
- I'll use my credit card or PayPal account to donate online at www.fcactx.org

Contact me to discuss volunteer opportunities.

**We do not
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FCA of Central Texas is a 501(c)(3) nonprofit organization.

Our Taxpayer Identification number is 74-6065131.



WE'RE HERE FOR YOU!

Call us at **512-480-0555**

Email us at office@fcactx.org



Send mail to

**FCA of Central Texas
3710 Cedar Street, Mailbox 13
Austin, TX 78705-1449**



Visit us online at www.fcactx.org

- * To join or donate to FCACTX
- * To download advance-planning forms, newsletters, surveys, and other items of interest



Follow us on **Facebook** at
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to read a variety of interesting articles.
(Please LIKE us, too!)

a Heartfelt



TO OUR VOLUNTEERS!

OUR DEDICATED VOLUNTEERS

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- Treasurer: Jan Hanz
- Secretary: Nancy Walker
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Gary Wheat

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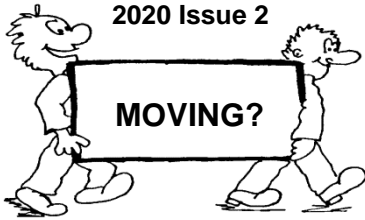
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2020 Issue 2



**Funeral Consumers Alliance
of Central Texas**
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City, State, Zip

Phone

Email address

Help me transfer my membership to an FCA
affiliate outside the Central Texas area.

CREATIVE CHOICES

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



From its inception in 1964 as the Austin Memorial & Burial Information Society (AMBIS), Funeral Consumers Alliance of Central Texas has served, and welcomed as members, all persons wishing to receive information about end-of-life topics. As an affiliate of the national Funeral Consumers Alliance, we are "open to all, regardless of race, creed, religion, gender, sexual orientation, or national origin." With a commitment to equity and social justice, the FCACTX board reaffirms our organization's mission, which is to help people make educated, practical choices that will meet their needs at the end of life.

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