

FCA REPORT

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When a newborn dies: How professionals can help

By Bernadette McDonald, RN, MSN, NNP-BC

The birth of a child is supposed to be one of the most precious and memorable times in a parent's life. Unfortunately, unforeseen complications can occur with a pregnancy, delivery, or with a baby being born sick or prematurely.

As a neonatal nurse practitioner for years in the Kansas City area and now in St. Petersburg, Fla., I have been blessed by God to play a part in caring for the tiniest of patients. There is no greater thing than the gift of life, and watching these babies take their first breath is priceless. Caring for babies of all sizes and races has brought so many joys, and tears, to my life.

One common factor with all babies is the love their parents and families have for them. As a part of the medical team, our main goal is to help these tiny babies grow to be strong and healthy so they can go home with their families.

As hard as we all work to accomplish this, some circumstances are out of our control. We then have the painful job of telling parents that their baby will not survive, that there is nothing more we can do. These are the hardest, most painful moments in my profession, watching the hopes and dreams these parents have for their newborn baby being stripped away, their hearts breaking.

Now, instead of trying to decide what car seat to buy or what color to paint the baby's room, the parents have to decide on funeral plans. This was *never* on their list of things to prepare for before the baby comes. The emotional and financial burdens they now face are beyond comprehension. They have no idea how to make plans like this.

Social workers and chaplains available at most hospitals will offer assistance with plans and spiritual support. Or, if preferred, we offer to contact the family's pastor. Even then, we don't have all the answers. Nobody has them. How could they? □

Bernadette McDonald, a native of Strawberry Hill in Wyandotte County, is a neonatal nurse practitioner at the 90-bed intensive care unit of Johns Hopkins All Children's Hospital in St. Petersburg, Fla. Often, she says, babies too sick to remain at the hospital of their birth are transferred to the more specialized Johns Hopkins facility.

NOTES FROM FCA-GKC

This tragic situation, played out frequently in area neonatal units, raises questions for us at the Funeral Consumers Alliance and for social



Bernadette McDonald

workers, spiritual counselors, and health care teams. How can we ease the burden for these parents?

The FCA's strength is the information we collect about the funeral industry in our region. We cannot be in hospital waiting rooms, but we can help equip social workers, chaplains, doctors, and nurses with information they can pass on. If you are one of these professionals, please familiarize yourself with the rich store of information on our website, funeralskc.org.

Included on the website is our **Funeral Price Survey**. This four-page marvel, refined and distilled over the years, contains prices charged by 114 funeral providers for the three basic types of body disposition: standard funerals, immediate burial, and direct cremation. The list is organized by area of the city, with addresses, phone numbers, and prices for each category. The 10 lowest-cost providers of direct cremation and immediate burial appear on the back page of the survey, along with our phone number, email address, and mailing address (also on the back page of this newsletter). Contact us for hard copies of the handout, free of charge.

Advice to hospital staff members: Do not press families for a quick decision on where to take the baby's body. Several hours may be required for a decision that's right for the family to emerge. Many funeral providers and cemeteries offer free or discounted services for infant deaths. It takes some time to make these calls and arrangements. The gift of a few hours may be the best service you can offer at this time in parents' lives. □

Death in the time of Covid-19

This newsletter holds valuable information related to the Covid-19 virus. Please see 2, 3, and the back page for related stories.

Pandemic motivates creative changes in funeral practices

By Steve Nicely, FCA-GKC Board Member



At Highland Park Funeral Home, mourners may drive up and view their loved one through a window. Such measures have been put in place to facilitate funeral rituals that have been dramatically disrupted by the Covid-19 pandemic. Other innovations include video conferencing and streaming of services and new protections for professionals handling bodies.

Funeral directing during the Covid-19 virus pandemic has required marked adjustments from past routines and practices. Government restrictions, which continue to evolve, have stressed service providers and consumers alike.

Limiting services and visitations to 10 persons has been especially difficult for families.

"It's quite unfortunate," said Rick Wiseman, of Porter Funeral Homes. For example, "Some big families might have 20 grandchildren" who are shut out from the services for a beloved grandparent.

As with other public services, the pandemic has fostered creative innovations for funeral homes. Highland Park Funeral Home, in Kansas City, Kan., initiated drive-through viewing by placing the casket in a window next to a driveway, allowing friends and relatives who may have been excluded to see the body of a loved one. The challenge has been with those who got out of their cars and clustered at the window for a better look. In one instance, Highland Park Funeral Home had to call the police, said Highland's owner, Jeff Bowker.

Expanded video conferencing and streaming is another common innovation that seems likely to continue after the crisis. The 18 funeral homes operated by the McGilley

chain, including Newcomer's and Mount Moriah, are examples.

"We have moved a lot to virtual platforms," said Patrick McGilley, market director for McGilley Memorial Chapels, which uses Cisco WebEx for video conferencing with families in order to make funeral arrangements, and Facebook Live for streaming services.

"It helps families to go through the grief process and experience a final good-bye," he said.

Some of the live-streamed funeral services at Porter's have been recorded on YouTube and placed on the funeral home's website with the obituaries, where they can be viewed after the service by anyone near or far, Wiseman said.

Procedures for the treatment and preparation of bodies also have changed. Most hospitals now use body bags, which have been sprayed inside with disinfectant; the bodies are also sprayed. Those who handle bodies at the funeral home are now wearing personal protective gear for contact with *all* bodies received, because the cause of death often is not certain.

"I'm hazmatted up when embalming," said Thad Rogers of Kansas City Funeral Directors. "It's a whole different arena for an old embalmer like me. I'm not used to all this protective gear." □

This newsletter, past newsletter archives, and a treasure trove of information about funeral options are all available on our website. Take a look today!



www.funeralskc.org

A letter of support to area funeral providers

Dear Funeral Provider,

We at the Funeral Consumers Alliance of Greater Kansas City have never before written just to express supportive thoughts for you and your colleagues. Usually, when we communicate, we have routine questions to ask or we are seeking your help keeping our Funeral Price Survey accurate. In fact, though, as professionals who serve local individuals and families when they struggle with end-of-life issues, our board members and volunteers *do* think of you and your colleagues often.

We are thinking about you now with special empathy. A worldwide emergency brings everyone moments of loneliness and anxiety. In addition, for you there must be unique pressures. We think of you managing families whose needs are complicated by the quarantine's limitations on their grieving rituals and practices; the financial devastation that must be such a trying challenge for your business and for these families and their incomes; and your position having to mediate between the needs of grieving persons and government safety requirements. All these problems, not of your making, put you in line for emotional overflow from the unique pain the limitations cause.

Soon you will hear from one of our volunteers to update our 2018 Funeral Price Survey so the 2020 publication will accurately reflect your business. But that is not our purpose now.

Now we just want to encourage you, your staff, and all in your circle as you provide the last, and arguably least-celebrated, link in the emergency response chain. The Covid-19 pandemic may have exacted the worst possible price for some of the families you are serving, all while families and individuals continue to need you for more predictable deaths. And no one knows how long this all will last.

We will continue to think of you as you choose to do your important work.

Wishing you well,
Kate Sargent, FCA-GKC Board President

A rare chance to affect the FTC Funeral Rule

By Nancy Petersen, FCA-GKC & National FCA Board Member

We need your help!

It has been 21 years since the Federal Trade Commission opened the Funeral Rule for public comments, and *now it is open again*. The Funeral Rule is what regulates funeral practices nationwide, but a lot has happened since 1999, especially with Internet technology.

So far in the open period, only 538 comments have been made, and that's not enough.

We need to be heard! The National Funeral Consumers Alliance, and our board and volunteers in Greater Kansas City, are asking everyone to consider three important changes:

1. *Should the Funeral Rule be changed to require funeral homes with websites to post their general price lists (GPLs) online? We say Yes! Online prices will help consumers plan and make decisions without being pressured. This is the 21st century. We can find the answers to many questions on the Internet, but not the prices charged by many funeral homes.*

2. *Should the Funeral Rule be amended to require that funeral homes include the actual cost of cremation when listing a direct-cremation cost (no services, just cremation and return of ashes)? We say Yes! The current rule does not require this. Some funeral homes include the fee in their stated cremation price. Others don't, then add it as an extra charge of about \$350.*

3. *Should the Funeral Rule be extended to cover cemeteries? Again we say Yes, to give families more protection! The current rule does not regulate cemeteries. Cemeteries are not required to have general price lists, to share those lists, or to allow consumers to pick items directly from such a list. Cemetery owners have no federal oversight; they simply must not break criminal laws.*

Your comments need not be long, just a clear statement in your own words for the benefit of all of us, because we will all need funeral services sooner or later.

Deadline for comments:

EXTENDED UNTIL JUNE 15, 2020

How do I submit a comment? Please

Google "Federal Register Funeral Rule Comments" and click the button on the right side, "Submit a formal comment."

Be succinct. Be practical. Be clear. Be heard.

Thank you for your invaluable help. Please share this information with others. □

The big picture

By Kate Sargent
FCA-GKC President



Hello. Writing to you involves imagining you holding this newsletter. I see you choosing to read about developing and distributing clarity-building information for grieving people when death brings them to urgent decisions. Clearly, you are a person with a special set of interests and we would love to get to know you better.

As last December turned to January, I said to a friend, “2020 is such beautiful round number. Probably a really good year.”

Or not. Instead, beyond imagination, the world caught a virus. In the decision zone that crisis creates, the things that really don’t matter to us just fall away, clear as day.

“Why was I doing *that*?” we think, from our too-quiet corner of social distancing. It’s a useful winnowing of commitments when they no longer match our experience, strengths, and heart choices.

My new view from the president’s chair confirms that the mission of FCA is, more than ever, a “keeper” in my life because the mission is needed by vulnerable grieverers. FCA is a group of talented and committed volunteers that I am so privileged to support as they do this work. I hope for you also to have such confirmations, informed by your wisdom and generosity, as you decide what to take, going forward, and what to leave behind.

2020 finds FCA-GKC deeply engaged:

Substantially widening our key project. We want to expand distribution of our Funeral Price Survey and community education materials by placing them with key professionals who assist people in bereavement crises. The Sisters of Charity of Leavenworth have underwritten this project to create sustainable change, especially in support of the poor. The information for professionals now includes an educational packet developed through the leadership of 2019 president Ginny Farney. The folders, including the price survey, are available on our website, funeralskc.org.

Providing “labeling” opportunities. Community service organizations bring together large groups of people and give them access to service personnel seated at tables, ready to visit. Our volunteers join personnel from many other agencies, explaining our services and how to access them.

Welcoming a social-platform intern. This volunteer will help us expand our online information reach.

The FCA-GKC board and volunteers wish you the best during this difficult year, along with this parting thought about a unique tombstone I once saw in a pioneer cemetery. It named the deceased, gave her dates, and said simply, “She hath done what she could.” As the years passed, I thought about that humble message, respecting it more as time went by. So this is for her and all other strong, brave souls, a blessing to leave with you: Let us do what we can. □

Longtime board member retires from service



Editor’s note: Pam Thomas, PhD, has left the FCA-GKC board after dedicated service spanning a quarter-century. Here she shares some memories of that time.

Twenty-five years! How did that happen? I remember when I joined the Funeral Consumers Alliance of Greater Kansas City in 1995, and being told that my term on the board would be up in the year 2000.

I thought, OK, I can do this! It’s related to my job (then) as gift body director at the University of Health Sciences (now the Kansas City University of Medicine and Biosciences). Being passionate about protocols, science, human and family relations, and student care for donated bodies, I thought I could help with the goal of informing people about what to do at the time of death.

Our FCA-GKC leader then was a very passionate Mercedes Bern-Klug, who was working on an advanced degree at the KU Medical Center. The board met at All Souls Unitarian Universalist Church, and several board members belonged to that church.

What kept me going as a member all of those years? The passion and expertise of the group—social workers and hospice workers, nurses, ministers, academics, engineers, accountants, newspaper writers—all bright, enthusiastic people. We shared information and ideas. The friendships kept me going. Everyone was willing to work hard to help people make the best decisions with their loved ones. We answered phone messages on a regular basis and reported on funeral costs in our newsletters and at our annual meetings.

Over the years I filled the roles of treasurer, secretary, and vice president as we met at All Souls, Community Christian Church, the Midcontinent Public Library, Shepherd’s Center of Kansas City Central, and most recently the Partners in Primary Care, Midtown.

Among my least-favorite tasks was answering phone calls in the instances when I felt I just couldn’t find any way to help those who didn’t know where to turn. I also was not fond of interacting with funeral directors to pick up price lists!

My favorite aspects included board meetings with food, stuffing newsletters, meeting new people, annual meetings, and all the friendships made over the years. □

One board member and volunteers sought

The FCA-GKC board of directors has been in a state of flux lately. Longtime member Lyle Van Vleet died early last year and Frank Cockrell moved to volunteer status after his term as president. Pam Thomas resigned in December after 25 years of board service. Kathleen Foster is working and studying for her master's degree, so she cannot be active. Ginny Farney resigned in January after serving a year as president, and Kate Sargent took over as president. Diane Etzel-Wise and Jon Shafer joined as new board members, and Angie Martinez, a former board member, has rejoined.

Now we have eight talented, capable board members. Our bylaws say we have room for one more. Is this something you would consider? We would also welcome volunteers to help update our Funeral Price Survey and perform other functions. A talent in spreadsheets, communications, social media, or finances, or a passion for service to grieving families, would be helpful. Or perhaps you just have a talent for getting things done. Board members receive no pay for their labors and cannot be involved in the funeral industry. □



Current FCA-GKC board members, from left: Kate Sargent, Jacquie Amweg, David Johnson, Diane Etzel-Wise, Angie Martinez, Steve Nicely, Nancy Petersen, and Jon Shafer.

President Kathryn (Kate) Sargent, Kansas City, Kan., is a retired school social worker. She holds bachelor's degrees in education and psychology with a certificate in death and dying. She facilitated an addiction recovery group for five years. Her graduate studies include course work at the St. Paul School of Theology.

Retirement is freedom to commit to a worthy cause. An invitation to serve as FCA board president allowed me to see our remarkable volunteers and their passion to help their neighbors with end-of-life decisions. I wanted to be part of that.

Secretary Jacquie Amweg, Independence, Mo., is a licensed clinical social worker at Kansas City Hospice and Palliative Care, where she is the Passages Counseling Program coordinator. She holds bachelor's and master's degrees in social work.

I attended a workshop by a former board member and learned about FCA. I wanted to be part of this mission of providing needed resources for the community.

Treasurer David J. Johnson, North Kansas City, Mo., is retired. He holds a bachelor's degree in accounting from Kansas State University.

I was invited to become a volunteer by another FCA board member in 2016. I am a retired accountant and felt I could utilize my skills with numbers for the Funeral Price Survey.

Diane Etzel-Wise, Lenexa, Kan., is the clinical education trainer at Wyandot Behavioral Health Network. She holds a master's in health services administration and has more than 50 hours of studies toward a doctorate in social work.

Steve Nicely and Lyle Van Vleet introduced us to FCA about four years ago. As a social worker and educator, I was drawn to the mission of supporting informed decisions about funerals from the beginning.

Angie Martinez, Independence, Mo., holds associate and bachelor's degrees in psychology. She has worked as a mental health technician involving suicide prevention, trauma, and interpersonal violence. She holds associate's and bachelor's degrees in psychology. She is a former FCA board member who recently rejoined the board.

I have a passion for helping others and serving my community. After years in behavioral health, I have returned to school to become an art therapist specializing in grief and trauma.

Steve Nicely, Mission, Kan., is retired. He holds a bachelor's degree in journalism.

Former FCA President Bev McGill saw an opportunity to recruit a newsletter editor when she learned of my retirement. One of my best jobs in high school and college was as a greeter, maintenance man, and chauffeur at George F. Porter & Sons Funeral Home in Kansas City, Kan. Fifteen years of volunteering with FCA have added meaning and purpose to my life.

Nancy Petersen, Kansas City, Mo., is the community liaison at Ability KC. She holds a master's degree in social work from the University of Illinois–Chicago.

I heard past FCA president Bev McGill speak, and was immediately sold on the concept and the need. Since then I have been involved with the FCA-GKA affiliate and am in my second term on the FCA national board.

Jon Shafer, Kansas City, Mo., joined the board recently after moving from Wisconsin, where he was on the board of Sacred Ceremonies, a nonprofit informing about home funerals and green burials. He has been a community organizer, director of a county council on aging, and chaplain.

*I got interested in end-of-life issues through my Quaker faith and by reading *Dealing Creatively with Death: A Manual of Death Education and Simple Burial*, by Ernest Morgan. □*

'It's so great that someone is researching all this'

By Jacque Amweg, FCA-GKC Board Secretary & Hospice Social Worker

To see the influence of the FCA-GKC Funeral Price Survey, one only has to see what happens when it reaches the hands of social workers in the medical field. They are the ones who are supporting patients and families at times of illness and death. Often family members feel overwhelmed when faced with choosing funeral services.

"I use the list all the time, and it helps a lot of people," said hospice social worker Cathleen Edwards. "Probably half of my patients don't have a plan."

Because we avoid the topic of death as a society, people often come to the end of life unprepared for making funeral arrangements and have no idea where to start. The financial realities of funeral planning can require a delicate balance between what a family can afford and the desire to honor a loved one's memory. After assessing the circumstances, social workers can encourage families with limited means to seek other meaningful ways to honor their loved one without risking financial ruin on a funeral.

"For many of us hospice social workers, the FCA funeral price list is our *only* tool," said Julia Vering, LMSW, LCSW, ACHP-SW. "Families are always appreciative of the unbiased information the Funeral Consumers Alliance puts out that can save people thousands of dollars. I do not go on visits without it."

Hospice social worker Maureen Kennedy, LMSW, said she provides patients and families with the price list on her first visits.

"They are always amazed at the variety of costs, especially for direct cremation," she said. "The comment I hear all the time is that it's so great someone is researching all this. The price survey is especially helpful if the patient is declining quickly—so I hand them the list and it is done!"

Your support of the Funeral Consumers Alliance of Greater Kansas City is making a difference every day. Your

financial support is most appreciated and needed. Thank you! □



Nineteen supporters contributed a total of \$914 to FCA-GKC since October. Your contributions to this not-for-profit organization are tax deductible. Thank you! We cannot function without you.

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Annual meeting date-saver **Friday, Nov. 6, 2020**

We hope that Covid-19 conditions will improve enough by the morning of Nov. 6 for the FCA-GKC board to host its annual meeting. A location and a keynote speaker have been booked.

The topic for the meeting is medical assistance in dying, sometimes known as MAID. Eight states and Washington, D.C., representing 20 percent of the U.S. population, now have laws permitting people with terminal illnesses to take prescribed drugs that end their lives.

FCA-GKC neither favors nor opposes the practice. *Education is our sole purpose.* During the meeting we intend to explore all aspects of this issue being widely discussed in our culture.

Free continuing education credits will be provided to social workers. □

Demand exceeds availability for local natural burials

By Steve Nicely, FCA-GKC Board Member



At the historic Highland Cemetery of Prairie Village, natural burial has become an increasingly appreciated and popular option for families. Left, a shrouded body. Right, family members lower a cardboard coffin.

Editor's note: This article is updated from a talk Nicely delivered at the FCA-GKC annual meeting in November 2019.

We at FCA-GKC spent 10 years searching for a local public cemetery that would allow natural burial, meaning no embalming, metal caskets, or grave liners. Instead, bodies are buried in biodegradable containers of wood, cardboard, or wicker, or in shrouds.

"No demand for it," we were told over and over by cemetery administrators. "Too much maintenance involved." "No money in it."

Then we found a cemetery four years ago: the historic Highland Cemetery of Prairie Village. The aging sexton was ready to give up his responsibilities. And the cemetery allowed natural burial. After all, in the 1860s, when Highland was founded, *all* burials were natural.

But FCA, a consumer protection organization, doesn't offer funeral services. So, three FCA-GKC board members joined two community residents to form a separate nonprofit corporation and assumed management of Highland. There were 150 gravesites left for sale. Today we are sold out, and 10 families are on a waiting list.

It has been easy selling graves at Highland, located at the west end of the 5000 block of West 65th Street in Prairie Village. The availability of natural burial was the driving motive for most sales. Higher maintenance costs and less profit are honest concerns voiced by cemetery operators, but Highland's record seems to prove demand.

Today, cremation accounts for more than half of all body dispositions nationwide, and that trend continues

because cremation is comparatively cheap and considered environmentally friendly. *It is not, though.* One cremation burns as much fossil fuel as a 500-mile road trip, and the carbon of the body harbors atmospheric contamination. Natural burial, on the other hand, does the same thing trees do. It sequesters the carbons of the body in the earth, where it decomposes and nourishes future growth.

In Kansas, Oak Hill Cemetery in Lawrence and Mount Muncie in Lansing have natural burial sections. Near Salina, Heart Land Prairie Cemetery also offers natural burial. In Missouri, Green Acres and Sugar Creek cemeteries near Columbia provide the option.

As the cremation rate rises, cemetery plot sales decline. I keep wondering when cemetery operators will understand that offering natural burial is preferable to no burials at all. If you hear of a cemetery that permits natural burial, maybe a historic one like Highland, please let us know. We'll pass on the details in our next newsletter and to those on Highland's waiting list. □

Preplan, but don't prepay

Funeral homes like to see families arriving ahead of time to plan funerals, and FCA does, too. But the funeral home will try to sell a prepaid plan, and we advise against it. *Preplan*, we say, but don't *prepay*.

We suggest opening a bank or credit union savings account jointly with a trusted friend or relative who knows your wishes. □

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COVID-19: Facts can diminish fears

Editor's note: This is condensed from an article by Josh Slocum, executive director of the national Funeral Consumers Alliance.

When a disaster or a pandemic occurs, people are understandably fearful. But humans are prone to amplifying our fears beyond reality, and one of the first places the human mind goes when in a state of fear is to thoughts of death and dead bodies.

Throughout history, people have believed that illness and plague arise from and are spread by the dead, or by "miasmas" in the air. Though we figured out germ theory more than a century ago, these folk beliefs are still a big part of our mental landscape. Our heightened emotional state also makes it difficult to know when we've left the realm of the rational and are instead ruminating.

Put simply, we have a strong emotional belief that the dead "contaminate" — physically, psychologically, spiritually. This causes undue worry, and it is causing many of us unhelpful stress during the Covid-19 pandemic.

Let's separate fear from fact.

Will I catch Covid-19 from a dead body? This is very unlikely compared to the objective risk to us from those *living* with the illness. It's living, breathing, coughing, sneezing humans who spread disease to each other. The dead do not do these things. Except in the cases of rare and especially virulent diseases comparable to Ebola, disease transmission from the dead to the living is very uncommon. On Covid-19, the CDC says this:

"There is currently no known risk associated with being in the same room at a funeral or visitation service with the body of someone who died of Covid-19."

Do the bodies of those who died from Covid-19 need to be cremated immediately? No. The dead are not the source of transmission of this pandemic. Communicable diseases need a living body for a host environment. (This

means also that we do not have to worry about microbes "contaminating" the ground from burial.)

Will cremation spread the virus? No. The virus cannot even withstand hot water and soap. There is no chance it would survive a crematory.

Won't funeral homes be overrun? On average, no. But in hot spots like New York City and other urban areas, morgues, funeral homes, and crematories are experiencing a temporary spike. We spoke to funeral directors and hospital pathologists in New York City the first week of April, as this was written, who say that they are running out of space or that crematories are backed up. In regions hit hard, there may be a delay of a week or two before a cremation is performed. We know that is not any family's first choice. But perspective matters.

I've seen news stories about refrigerated trucks parked outside hospitals to keep up with the bodies. This is an example of how easy it is to fall into an atmosphere of fright from news coverage. Hospitals and funeral homes made a logical, practical decision to accommodate a temporary and unexpected overrun of bodies. The dead are being kept refrigerated, which is a good thing, giving families time to decide on arrangements.

The staff here at FCA understand these fears. We shared them before we came to work in this field. We don't criticize people for having them, because we know it's human and normal. But we also know that plain-language, direct conversation about facts is the most effective way to help people ease those fears. □

For more details, visit www.cdc.gov/coronavirus/2019-ncov/faq.html. Or visit <https://funerals.org> and see our white paper, *Dead Bodies and Disease: The Danger That Does Not Exist*.