



Spring 2022

Funeral Consumers Alliance of Central New York, Inc.

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FROM THE PRESIDENT’S DESK

Jenifer Breyer

Startled awake by a glorious sunrise, a crocus and single clump of daffodils daring to poke out their heads in my side yard, and choosing to ignore snow in the forecast, I venture to say, “Welcome, dear FCA of CNY members and guests. Open up your screens, grab a cup of coffee, and treat yourself to a lively read; we’ve got lots to share.”

This issue starts with a loving nod to our many-years leader and benefactor, [Joyce Homan](#). Her warm and informative autobiographical sketch accompanies a [piece](#) by Josh Slocum, Executive Director of FCA National, who knows and appreciates Joyce as much as we in CNY do. A fund has been established in Joyce’s honor, and contributions are invited.

We have learned to coexist with the pandemic that continues to make itself known. This means most of our meetings and presentations are available increasingly in person but also via Zoom. We are thrilled to be able to announce our annual meeting is coming, on schedule and in both formats, and we very much hope to see many of you in attendance one place or the other.

Please take a look at our website to see what we’ve got going on and/or results of research undertaken by our Board members whose devotion to cause is as energized as ever. One example is Diane Case’s article on [end-of-life](#) choices and dementia on Page 3 of this newsletter but referenced in a larger format, aka greater detail, on the website. Another is the article on [Hospice](#), by Kateri Spinella and Dr. Joel Potash on Page 4.

Finally, Anthony House, providing hospice care in Oswego, is having its annual Masquerade Ball on June 18. Follow this link to learn more: <https://www.anthonynhouseoswego.org/events>.

Annual Meeting

This year’s annual meeting will be held on May 21 at 2:00. You can attend in person at Park Central Presbyterian Church, 504 East Fayette St. in Syracuse. Parking is available directly across the street from the church. The venue is wheel chair accessible.

You can also attend via Zoom. If we have your email address, we will send you the Zoom link to click on an hour before the meeting begins.

If you would like to receive an email link, send us an email with a request for the link: pkmoller@me.com

GUEST SPEAKER: Charles Garland of Garland Funeral Home in Syracuse. Mr. Garland will talk on how to arrange a funeral and answer questions.

At the end of the meeting we will have a workshop in WRITING THE OBITUARY led by Jan Lane.

Details of the meeting will be available soon on the website.

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One Funeral, Then Seven

By Joyce Homan

A big event in an otherwise ordinary childhood stands out in my mind to this day: my grandfather lying so still in a box in his living room surrounded by a suffocating mass of flowers. Puzzled, I watched men crying.

I know there were other family deaths during my young years but I was shielded from attending them.

Fast forward to my mid-twenties when my husband's father died not yet having met his first grandchild. Planning was a blur of confusion and grief in the chaos of that cross-county trip. Just a few years later, funerals began occurring in our family at such a rate that it seemed like trees falling among us. Father, Grandmother, Aunt, Uncle, Brother, Stepfather...

These contrasting services produced such emotion that it led me to investigate the hows and whys of funerals. Even the terminology needed clarity— *GPL*, *basic services*, *cash advances*, *alternative container use of facilities*, *outer burial vault*. Our family's end of life rituals had been in four different states and I found that each state had its own rules. There is little uniformity in the USA.

I learned surprising things like embalming is not required, the cremation fee is not included in Direct Cremation, a casket is not required for a cremation and not all States require a funeral director.

During this upheaval, in 1963 we moved to Syracuse just after the founding of an important organization— The Memorial Society. This activist group started after Jessica Mitford's eye-opening book *The American Way of Death* exposed the excesses of the funeral industry. After joining and attending a few meetings, I raised my hand once too often, which led me on a path of working with wonderful like-minded people locally and nationally. In 1991, when I took the reins here as president from Reverend Norman Keim, my husband Ray, always eager for a good cause, spent hours at the computer as we transferred the paper instructions once stored at cooperating funeral directors' offices into the society's membership files.

I hesitate to cite specific names for fear of omission, but many Syracusans gave time to energizing the organization by writing letters, redoing the bylaws,

building interest by spreading the word about dignified, affordable funerals. After all, why should a family bankrupt itself for a service that in no way reflects the taste of the deceased. Why not go shopping for a funeral? Why not talk about it? Death is not a secret society for the few!

Memorial Societies popped up all over the country but the name caused confusion. After much semantic struggle, the national organization adopted the current name Funeral Consumers Alliance. I was present as a delegate when that happened as by this time, I had been promoted upstairs to the national board. A lover of travel, these meetings around the country were interesting, and my husband and I could always tick off another museum on our way.

Being on the FCA board meant leaving the 19th century and entering the 21st. It required my mastering the computer, making conference calls, attending business meetings and state regulatory sessions by means of air travel—honing the right side of my brain the art teacher part of me had not been using, although designing the funeral planning booklet *Before I Go, You Should Know* with illustrations by Edward Gorey was one substantial contribution that I happily made.

After my husband's death, I found myself active again on the national board and in 2005 agreed to a two-year term as president. I followed three fine gentlemen presidents, two of whom were lawyers. Daunting. I was fortunate that their advice was always kind and relevant. With an excellent board we tackled budget, fundraising, the Federal Trade Commission, legal issues, and tried to demand pricing transparency from the increasingly glamorized services as more corporations took over local funeral homes.

My four children have laughed at "mom's hobby of funerals" but they will be glad when they find my instructions and see what the savings will be. This has been a 50-year saga of working to educate myself and helping others to choose sensible after-death arrangements. The upside has been making great friends all over the country; working, eating, drinking and laughing with terrific conservationists—putting the fun in funerals. There was no downside.

Josh on Joyce Homan

By Josh Slocum, Executive Director, Funeral Consumers Alliance

In the Funeral Consumers Alliance family, there's a core group of volunteers who are in it for the long haul. More than most, they know how necessary our mission is. After all, most Americans don't pass funeral planning information down to their kids.

Joyce Homan is a member of this special group. Her retirement from the board of the FCA of Central New York will leave a big gap to fill. What you may not know is how much Joyce has done nationally for our collective mission. During my almost 20 years as FCA's executive director, I've known Joyce the whole time. She served two terms on the national board, one of them as our president.

I'll never forget her line at our biennial conference many years ago, reminding all the volunteers not to undersell their efforts. We FCA people are often bashful about asking for donations to support the work, but Joyce was having none of it. Ask for more, and ask more often, she said, because the donations go to good work that no one else is doing.

She called it "the Chivas Regal effect." In a word, she advised us to package ourselves as if the work we did was worth it, because it is.

Over these years, Joyce became both a colleague and a personal friend I was delighted to stop over with on holidays for a meal together, or a restful night in the world's most comfortable guest bedroom. I presume that, just because she's retiring, that won't mean she's going to stop eating. So if you're in the mood for India—call Joyce first. Mild spice, please, but a good variety.

And if you don't already know, when it comes to Joyce, looks can be deceiving. Underneath the grandmotherly exterior is a wicked sense of humor. One April 1 about 15 years ago, Joyce sent me a surprising email that had my heart in my throat. She wouldn't be able to continue her service on the FCA board, she related, because of a serendipitous romance she'd struck up with an undertaker from the world's largest funeral and cemetery company. I have to admit that I spent an entire afternoon fretting before I looked at the date.

This should be wrapped up before it begins to look like a premature obituary (gotcha, Joyce!). Mrs. Homan, hats off to you for years of your time, heart, and financial support to our efforts to try to make the worst day in people's lives a little bit easier.

End-of-Life Decisions and Dementia

By Diane Case

Discussing our end of life wishes with family and close friends is generally not easy. Even when couples share their wishes with each other, adult children may not be included. This may lead to hurt and angry feelings, as in my friend's situation. When she followed her husband's adamant wishes, her children were angry that she didn't seek aggressive measures to try to save him.

Adding in cognitive impairment or dementia makes planning more challenging. A person with dementia needs to make these choices while they still have capacity.

The Compassion & Choices organization has a seven page form titled *Dementia Provision Advance Directive Addendum*.

This form lists behaviors (called markers) followed by four care choices.

The first marker is *I have forgotten everything about my past, but still recognize those closest to me.*

- A. I want to live as long as possible.
- B. I want no life saving treatments
- C. I want to be kept comfortable, avoid or stop treatments that may prevent me from dying from other diseases.
- D. I want to be kept comfortable, stop all treatments, and withhold food and fluid so I can die peacefully.

The person selects desired care for each marker. There is additional space for the person to select his or her own marker and desired care. When completed, the form is to be shared with medical providers, family, and caregivers. It can be used when assessing long term care facilities to seek their willingness and assurance that these wishes will be honored and carried out.

A copy of the form is available on our website: fcac-ny.org

For additional information go to Compassion & Choices Dementia Values & Priorities Tool (<https://values-tool.compassionandchoices.org/>), or Compassion & Choices, P.O. Box 101810 Denver, Colorado 80258, (800) 247-7421.

Hospice

By Kateri Spinella

Families are privileged to have hospice services in their communities! What is hospice? My *Harcourt Brace Student Dictionary* (1968) defines “hospice” as a place of rest or shelter for travelers, especially one maintained by a religious group. Also, my dictionary defines “hospitality” as a friendly welcoming of guests or strangers. Combining the two definitions, we see that hospice is a friendly welcoming place for people who have terminal illnesses to provide them with rest, shelter, and services as they travel from this life to the next one.

Hospice services usually take place in the patient’s home but can often take place in Comfort Care Homes which are very popular and important today. Terminally-ill persons want to die at home or in a homelike setting. When supervision and care 24/7 is not available or possible at home, the terminally-ill person appreciates that care can be provided in the homelike setting of a Comfort Care Home.

Hospice Outreach is a model for compassionate and quality care for persons with life-limiting or life-ending illnesses. Their team-oriented approach to the best medical care, symptom management, emotional, and spiritual support is focused on the person’s needs and wishes. Hospice also extends needed support to the person’s family.

Hospice is service when there is a need. The terminally-ill person and the family can determine which of

hospice's services they wish to receive. The Hospice team can manage the person's pain and symptoms; assist the person with emotional, and spiritual aspects of dying; provide needed medications, medical supplies and equipment; and coach the family on how to care for the dying person. Home aides provide personal care needs and other services such as laundry, and volunteers, as part of the team, can provide emotional support or stay with a loved one while the caregiver goes out to grocery shop or keep appointments and deliver special services such as physical and speech therapy, as well as music or art therapy.

A person with a terminal illness qualifies for hospice care if life expectancy is to be six months or less if the disease runs its expected course. Medicare, Medicaid, and most insurance companies will pay for hospice care. Also, the person’s primary physician is encouraged to remain a part of the patient’s care while in hospice.

It is common and ideal for hospice to assist in preserving the person’s quality of life at end of life. It is a stressful and emotional time which is improved by the compassionate care provided by the team.

Life.*

*Available for a limited time only. Limit one (1) per person. Subject to change without notice. Provided "as is" and without any warranties. Nontransferable and is the sole responsibility of the recipient. May incur damages arising from use or misuse. Additional parts sold separately. Your mileage may vary. Subject to all applicable fees and taxes. Terms and conditions apply. Other restrictions apply.

WORD BRAND

The care given includes medicine and medical supplies, emotional support, and spiritual support; in short, whatever the person needs at this time. For hospice, the comfort of the person is primary. Also important is the encouragement and support to the family at the end-of-life moment.

This article is the result of a collaboration between Kateri Spinella, director of Anthony House in Oswego, and Dr. Joel Potash, former medical director of Hospice of Central New York.

Question Corner

Where is medical aid in dying available in the US?

Medical aid in dying is available in Washington, DC (2017). The following lists the ten states where it is legal followed by the year it took effect.

Oregon (1997), Washington (2009), Montana (2010), Vermont (2013), California (2016, reauthorized 2021), Colorado (2016), Hawaii (2019), New Jersey (2019), Maine (2019), New Mexico (2021).

Sharing our support for this bill may be helpful to expedite enactment in NY State.

Resource: Winter 2022 edition of *Compassion & Choices Magazine*

Recent Articles Worth Reading

Federal program offers cash to cover COVID-19 funeral costs:

<https://apnews.com/article/coronavirus-pandemic-business-health-emergency-management-federal-emergency-management-agency-0b63f9fcbf4ea0c5948adddc53e6b1c7?fbclid=IwAR2chUXG1VJIGVXIZ6zQ5U0wkN-n1rA-zCkXDb6EHYG92ypQWrZGE9bl48mY>

What to know about end-of-life planning:

<https://www.medicalnewstoday.com/articles/end-of-life-planning?fbclid=IwAR3hARo9iR4A8K0-zAUuQRnnrLPymHxpk07zZ1kXBz51oQs4-CYRNOrPa-Xg>

Seven keys to a good death:

<https://greatergood.berkeley.edu/article/item/seven-keys-to-good-death?fbclid=IwAR1f->

[Vit1wmdE51- w9BjJSOvAIWaDba9umqm-VT5VInYT9juXbTnlCqL5Pxc](https://www.sciencefriday.com/segments/book-the-grieving-brain/)

An interesting workshop:

<https://transformationalstorytelling.org/journey-into-dying-and-living/> Jim Brule

How grief rewires the brain:

<https://www.sciencefriday.com/segments/book-the-grieving-brain/>

Dealing with your electronic remains:

<https://theamateursguide.com/apple-now-lets-you-pick-someone-to-inherit-your-data-when-you-die/?fbclid=IwAR1rP3iV4o49K589fSMxDx2tb-TQrxGUTH8rGYLxCg3SqU87HrkXUIjBef1g>

The importance of death doula:

<https://apple.news/A2L5t1fGYS5CpqMm0Oap-k7w6>

What to consider before agreeing to be someone's health care proxy:

<https://www.upstate.edu/informed/2022/021822-johnson-expert.php?fbclid=IwAR0M7kXn7-cXFe-Lkq4FAif5uyzdONhr18kubLHAWUHUAx8V6Keb-HGLLGK94>

Shopping for funeral services:

https://consumer.ftc.gov/articles/shopping-funeral-services?fbclid=IwAR1eALXxhvmIFfSxyO8VvP-pvYM511e1gtXHY4UJEIS4qmE_1GnaVnPQM-c9A

End of life planning:

<https://www.medicalnewstoday.com/articles/end-of-life-planning?fbclid=IwAR3hARo9iR4A8K0-zAUuQRnnrLPymHxpk07zZ1kXBz51oQs4-CYRNOrPa-Xg>

Are your end-of-life preferences up to date? This is a good time to check and make sure. If you would like a new Preferences form, send us an email or letter.

As you know, your membership in FCA of CNY is lifetime, although we do appreciate contributions. We have found the cost of printing and mailing our twice-yearly newsletter to be very costly. In the future we will publish our newsletters online only (fcacny.org), **UNLESS YOU REQUEST A HARD COPY OR AS AN ATTACHMENT TO AN EMAIL.** You can let us know your decision by sending us an email (fcacny@gmail.com) or old-fashioned letter/postcard to: PO Box 67, Dewitt, NY.

Please help us conserve money, paper, and energy, and keep our membership fee low. Accept our appreciation.

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**THANK YOU FOR YOUR
CONTRIBUTIONS**

We rely on your donations to continue the work of the organization. We thank these members who made contributions since the last newsletter:

Wendy Bousefield, Jenifer Breyer, Robert Coye, Margaret Diehl, Thomas Evans, Jane Feld, Lanny Freshman, Shannon Galster, Ramesh Gaonkar, Francis Morigi, Wesley Muller, Thomas OConnor, Mark Petite, Robert Pfohl, Shirley Quinn, Vicky Schipper, Scott Shablak, Anita Slagle, Marie Sprayberry (in memory of Jae Evangelisti), David Stam, Steven Tennant, George and Judy Tennant, Ann Tussing, Joyce Ucci, Shaila Wood

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May we honor your gift with your name in our next newsletter? _____

Please use the pre-addressed envelope enclosed in this newsletter to mail your preferences and contribution back to us. Contributions to FCA of CNY are not tax deductible.

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