



Funeral Consumers Alliance of the Finger Lakes

Fall 2009 Newsletter

P.O. Box 134, Ithaca, NY 14851-0134 • (607) 273-8316

E-mail: info@imsfca.org • Website: www.imsfca.org

President's Column

by Barry Adams

A new president usually builds upon contributions of his or her predecessors. My immediate predecessor, Wayne Sinclair, served four years as President of the Alliance. He provided effective leadership as well as informed responses to substantive questions about the funeral industry and issues confronting the Alliance. Wayne continues on the FCAFL Board of Directors, and equally important, he has the new title (though not an altogether new function) of Service Coordinator. All of us who have worked with Wayne are grateful for his contributions to the welfare of the Alliance.

One of those contributions, the price survey, is much in evidence in this issue of the Newsletter. The current survey was conducted by Vice President Milt Zaitlin and Treasurer Dominick Paolillo, with Wayne's advice and support. The topic of funeral pricing is so important and so complex that we have devoted a large portion of this issue to its presentation. The table tells only part of the story; a full understanding of the issues involved requires careful reading of the accompanying narrative. We invite feedback.

We also invite feedback from readers who have had dealings with funeral homes. Although not equipped to do statistically valid customer-satisfaction surveys à la *Consumer Reports*, we can make good use of anecdotal reports of our members' experiences, both the good and the not so good. We are also open to suggestions about how to extend this service and convert it to the benefit of our members. What kind of feedback mechanism or protocol would you recommend? What pitfalls do you perceive, and how can we avoid them?

This issue of the Newsletter also includes an article on anatomical donation and a further comment on the advantages of pre-planning (as distinct from pre-payment) for funeral goods and services. The importance of making plans and of communicating those plans to others is the topic of an article by a local emergency medical technician that raises questions pertinent to medical and funeral needs alike. All of these articles are variations on the importance of advance planning, which remains our dominant take-home message to Alliance members and the public at large.

Body Donation Was Featured Topic at Annual Meeting

Diane Piekut, Ph.D., of the University of Rochester Medical Center was the featured speaker at the Alliance's annual meeting in April. Piekut is Director of the Center's Anatomical Gift Program and an Associate Professor of Neurobiology and Anatomy in the School of Medicine and Dentistry. A teacher of anatomy for over 30 years, she described the Rochester program as well as aspects that are common to most anatomical gift programs. Piekut emphasized both the essentiality of donated bodies in the training of physicians and dentists and the gratitude that teachers and medical students feel toward donors and their families.

Body or anatomical donation and organ donation both fall under the topic of anatomical gifts. If an organ donor who also has a plan for body donation dies in circumstances that permit extraction of viable organs for transplantation, then this procedure has priority and makes the body unacceptable for use in medical instruction. A back-up plan for disposition of the body is then needed.

Some things you may not have known:

- Over 140 members of the FCAFL have plans for donation of their bodies to medical institutions.
- You are never too old to be an acceptable donor, but you must be at least 18 years old.
- Only a few conditions disqualify a donor. These include gross obesity, extreme physical damage such as severe burns or mutilation, and certain communicable diseases that could pose a safety hazard to people working with the body. Asymptomatic carriers of dangerous pathogens such as the AIDs virus, hepatitis viruses or the tuberculosis bacterium are disqualified. Autopsied bodies are not acceptable.
- Donation of eyes to an eye bank does not disqualify the body for donation to a medical institution. Some programs accept bodies from which the brain has been removed for research.
- The availability of bodies to medical institutions varies regionally. Some anatomical gift programs always need more donations, while some others occasionally have more than they need. In the latter case, a fortunate program may send a body to a less fortunate one.
- A donated body is typically used for at least a year and then cremated. The ashes are returned to the donor's family, if the family has requested to receive them, or are disposed of in a respectful way.

The University of Rochester maintains a beautiful rural burial site for the ashes of donors.

- It's a good idea to have a backup plan for disposition of your remains in case your body cannot be accepted by an anatomical donation program.

- If you die without an arrangement for donation of your body, your survivors can make the arrangement. It's best to make arrangements in advance, however.

Donation of a body can be cost-free to the donor's family, provided that a funeral home is not involved. For example, the SUNY Upstate Medical University at Syracuse will send a funeral director anywhere in the region to acquire a donor's body and attend to the necessary permits for transportation and disposition. If a funeral home is utilized, however, the family must pay for transportation and services, which together can cost as much as cremation or burial. The University of Rochester Medical Center currently provides transportation only from locations within Monroe County. Donations from the southern Finger Lakes region to the U of R require employment of a funeral director.

One may ask, "Why is a funeral director required? Can't relatives obtain needed permits and transport their deceased loved one?" No. New York State law requires the involvement of a funeral director in the final disposition of every human body. New York is one of only six states that mandate such costs for survivors.

The FCA of the Finger Lakes has a leaflet, Anatomical Gifts, with contact data for the several organizations that can accept anatomical donations from the Finger Lakes region. It is available at the FCAFL website along with links to the organizations, and is also available from the Alliance as an email attachment or by U.S. Mail.

Friends and Loved Ones Remembered

Donations received since March, 2009, have included those honoring the memories of:

Elizabeth Keppler Ainslie, Barbara Booker, Dora Flash Bourne, Gerald R. Dawson, Stuart deProse, Carol A. Hoff, Helen Gartlein, Marge Loucks, Lee McAdams, Frank B. Miller, Neil A. Poppensiek, Betty

Saul, Robert D. Swank, Michael Talutis, Ruth Drew Wells, Arnold Wilhelm, and David Wyatt.

How Can We Leave Well Enough Alone?

by Michelle Paolillo

"Just leave her alone for chrissakes!" The elderly man was pleading with us as we kneeled on the upstairs bedroom floor around his wife's body. In response to his early morning 911 call, emergency responders raced through the dark chill to his home. Something was wrong with his wife. She wasn't responding, and he'd done the sensible thing by calling us. When we arrived, we found she was warm but was not breathing and had no pulse. The trained EMT's answer to these findings is almost reflexive: begin CPR. It was then that the man began pleading with us to stop.

My EMT training is grounded in two basic tenets. The first is that time is of the essence: when attempting resuscitation, every second counts. The second is the sad fact that training is often not enough: even with a quick response, the chances of trained and disciplined rescuers reviving an elderly person from complete cardiac arrest are still very, very small. The practice of emergency medicine is subject to written protocols that encourage swift response along pre-defined decision trees. We do not have much flexibility to deviate from these set patterns. To "leave her alone" would be an acceptable response under only a very few conditions. One is that the patient has suffered a traumatic injury incompatible with life—clearly not so in the case I am describing. Another is that the signs of death have been present so long that it is clear that resuscitation would be futile—clearly not so in the woman before us. The third is that a patient has a valid, out-of-hospital Do Not Resuscitate (DNR) form. "Does she have a DNR?" we asked. The husband shook his head. We continued to work, which clearly distressed him as he pleaded with us several more times to stop. My heart was with him even as I continued CPR. He had only just begun to grieve, and we were unable to help

The Funeral Consumers Alliance of the Finger Lakes, Inc. is a non-profit, public-service organization, founded in 1958 as the Ithaca Memorial Society, that promotes advance planning of funeral arrangements and consumer education and protection with respect to funeral-related issues, and contracts with funeral homes for simple, dignified, reasonably priced services for its members. Membership is free and open to all. The FCAFL is guided by a volunteer Board of Directors and is a member of the national Funeral Consumers Alliance, Inc., which has more than 100 affiliates. The Newsletter is published twice a year and is freely available.

The Board of Directors, 2009-2010: Barry Adams, President; Milton Zaitlin, Vice President; Catherine Darrow, Secretary; Dominick Paolillo Jr., Treasurer; David Bandler (to 2010); Carol Hardy (to 2012), Robert Cotts (to 2012), Charles Elliott (to 2012), Wayne Sinclair (to 2012). Advisor: Philip S. Winn.

him with his loss as all available hands were needed for resuscitation efforts. When additional responders arrived a few minutes later, we were able to spare a person to steer him out of the bedroom and sit with him apart.

As an EMT, I am an optimist when it comes to resuscitative effort. There is just no other viable position when the default position is to act quickly and try earnestly. So I try to resuscitate anyone who does not fall within one of those three “nonviable” categories described above. However, experience has also taught me that the best help I can give in any situation is an intervention that honors the patient’s choices regarding his or her own care, including the decision to “go gentle into that good night.” In cases where people have clearly expressed their wishes in appropriate legal form, such documents release me from the obligation to attempt resuscitation, so I can help those left behind. An out-of-hospital DNR in hand allows me to direct my efforts instead toward consoling the family and assisting them in contacting funeral directors and emotional supporters. This was something I would have done sooner for the elderly gentleman who called us had I not been constrained by the circumstances.

Death is frequently understood as happening when we cross some mysterious line at the end of life. For those of us involved in emergency medicine, it’s not so much a line as a large gray area through which people can go and return, sometimes several times before either coming back to “our” side or finally slipping beyond our reach. Everyone should consider their feelings about resuscitative efforts carefully and have frank conversations with their medical provider about the interventions used in resuscitative efforts, including specifics relating to their own medical risk factors. They should evaluate these interventions in light of their philosophical or religious positions and decide the course of action for that transition from life. And they should not stop there but should make their wishes known in appropriate legal form. If they do not want responders to attempt resuscitation, they should use either an out-of-hospital DNR or a MOLST (Medical Orders for Life Sustaining Treatment) form, which allows for some modification of resuscitative efforts as well as in-hospital directives for care. If one does not legally express his or her wishes to the contrary, emergency responders are compelled by the standards of their practice to employ full resuscitative measures.

There’s one thing more, which applies to one’s wishes with respect to funerals as well: frank conversations with one’s family and caregivers to let them know one’s wishes, and, more specifically, where the appropriate documents (whether a DNR or a MOLST form or an FCA membership form) are kept. If a patient is alone and unable to communicate, an EMT will look on the refrigerator for the DNR or MOLST form, and look for medical

DNR jewelry on the body. Additionally, if family members understand that someone has strong feelings against certain interventions, they will be less likely to request unwanted intervention from responders, even though insistence on resuscitative intervention from family members can trump a valid DNR. As with funeral planning, candid discussion can help family and healthcare providers alike stay on the same page with a patient’s wishes, whether they be to “rage against the dying of the light” or to “leave well enough alone.”

Ms. Paolillo is an emergency medical technician and a member of the Emergency Medical Service of the Trumansburg Volunteer Fire Company, Inc.

For web links to New York State forms for health care proxy, living will, and non-hospital DNR orders, see the Resources page at the Alliance site: www.imsfca.org.

More on Prepayment

The last two issues of the Newsletter have contained articles on prepayment of funeral expenses, the more recent piece being written by the participating funeral directors. Overall, their article presents an attractive case for prepayment. We are fortunate that New York State regulates prepayment with an eye toward consumer protection, including FDIC or comparable insurance of the deposited funds. But in the interests of clarity and complete disclosure some follow-up comments on the financial aspects of prepayment are merited.

For people spending down resources to qualify for Medicaid, prepayment can assure that survivors remain unencumbered by funeral expenses. However, while the recent article reports that funds are “in all cases refundable subject to the laws governing such deposits,” where Medicaid is concerned prepayment arrangements are irrevocable. This is understandable because Social Services excludes the prepayment amount from countable resources when the application for Medicaid is considered. Unused funds in a prepayment account revert to Medicaid to compensate for medical assistance.

The article goes on to say that there are “no per transaction fees to be paid,” but various alternative fees may be charged to the account. Moreover, whether or not the interest rate earned is “favorable,” it should be compared with rates of inflation in the funeral industry because the prices charged will be those in effect at the time of the funeral. The article correctly states that the earnings are reported to the IRS, because the earnings are taxable income. This may not be an issue for someone about to go on Medicaid. But others should do the arithmetic to determine if, for them, prepayment is the appropriate way to set aside funds for a funeral that may occur in the distant future.

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Bereaved Consumers Bill of Rights

“The Bereaved Consumer’s Bill of Rights Act of 2009,” recently introduced in the U.S. House of Representatives by Rep. Bobby Rush (D-IL), would set national standards for the protection of funeral and cemetery consumers. If enacted into law, it will direct the Federal Trade Commission to strengthen and expand the Funeral Rule, which currently applies only to funeral homes. It will require the FTC to establish regulations compelling cemeteries to give customers the right to buy only the goods and services they want; families will then be able to buy markers, monuments, or grave vaults from less expensive retail vendors rather than be captive to prices set by a cemetery. It will also require cemeteries to keep accurate records of all their burials, including locations of graves, and to make those records available to regulators. Cremation-only businesses that serve the public directly will also be subject to the price disclosures and consumer rights that the Rule currently mandates for funeral homes.

The bill grew out of a hearing before the House Subcommittee on Consumer Protection on July

27 of this year, following the discovery that many graves had been dug up and resold at a Chicago cemetery. Joshua Slocum, executive director of the national Funeral Consumers Alliance, testified before Congressional lawmakers, urging them to take a broader look at an industry riddled with practices that take advantage of consumers when they are most vulnerable. While scandals like that in Chicago grab headlines, he said, many ongoing abuses of funeral and cemetery consumers are underreported or get swept under the rug. The FCA advised Congressional staff on what provisions the bill should include and has expressed satisfaction with the outcome.

As Slocum points out, “When a friend or relative dies, families are in shock, they’re confused about their options, and they’re vulnerable to misinformation and high-pressure sales pitches.” He noted that the FTC Funeral Rule has helped correct some of these problems, but only when families are at a funeral home. Rep. Rush’s bill extends protections through the whole funeral transaction.

For more on this and related topics, visit www.funerals.org, the website of the national Funeral Consumers Alliance.