Memorial Society

Newsletter October 2000

Annual Meeting

Saturday, November 18, 2000, 1:30 p.m.
Story Chapel, Mount Auburn Cemetery,
580 Mount Auburn St.
Cambridge, MA

After a brief business meeting there will be two talks. John Van Dusen will report on the activities of our national federation, Funeral Consumers Alliance (FCA). Byron Blanchard will report on recent developments in state regulation of preneed funeral contracts.

Following the formal program John Hynes will host a tour of the Crematory for those interested.

Directions by car: From the west take Rte. 2, which becomes Fresh Pond Parkway, to Brattle St. Turn right. The cemetery is on your left just after Brattle St. joins Mt. Auburn St.

From the Mass. Pike or downtown Boston: Take Storrow Drive west. After crossing the Eliot Bridge to Cambridge, bear right, then left onto Fresh Pond Parkway. Then bear left onto Mt. Auburn St.

Public Transportation: The 71 bus from Harvard Square runs about every 12 minutes and the ride is about 10 minutes. It has a stop opposite the cemetery

Help Us

If you have a preneed funeral contract, please give us a photocopy. We wish to check whether it follows the rules, particularly for contracts funded by insurance rather than by a funeral trust.

It is time for another funeral price survey. Members can help us collect price lists while at the same time becoming familiar with their local funeral establishments.

The Board of Registration which regulates the funeral industry meets twice a month on Tuesday afternoons in a building near North Station in Boston. Your treasurer tries to attend all the meetings, but sometimes can't do so. Can someone help out by attending meetings when he can't do so?

Carlson and Buhrman Speak

Lisa Carlson, Executive Director of FCA, was guest speaker at the Unitarian Church of Martha's Vineyard on March 11, 2000. In an introductory talk, Jan Buhrman, Vice President of the Memorial Society, spoke of how she came to know the Memorial Society and Lisa Carlson:

"The third act, the final act, the final scene in one's life. How we choose to handle death can have a huge impact on our family, community and loved ones. We in our final episode.

We live in a time in which the cultural norm is to have a hired professional bring us through our last rite of passage. Death has become big business. We also live in a period where time and convenience are very valuable. If someone else can perform a service more efficiently and we can afford it, we will pay to have it done. The *Boston Globe* recently ran an article on the long-lost Irish wake, stating that folks are just too busy to take more than a few hours to pay their last respects. One may call a funeral home and have them make the arrangements for a loved one. This is certainly convenient when family members are dispersed around the country or world. But this path, especially, may be one that diminishes the healing experience -- a quality healing process that cannot be guaranteed by paying the the prevailing rate.

We at the Memorial Society support people who do choose to bury a loved one themselves. We hear about their emotional rewards that aid in the healing process, of the letting go of the body after it has been washed and cared for by family or friends. We hear of an inner peace in the middle of profound grief. It allows families to say their goodbyes in their own way and on their own time. This is the completion of the cycle of life and no one should feel that is not an option for them, because residents of Massachusetts have a choice.

I find the time we live in to be an interesting one, when hospice has a huge role in the lives of the dying, but it's also the time of mass-production funerals and one-stop shopping and there is still this very dramatic contrast.

Often we make choices without knowing why, sometimes it's just because that is the way it is done. Sometimes we are just following a gut feeling, or maybe it's something that we read about and then left hidden in our memory until the time when we needed it most. I believe the choices we make about handling death can have a profound effect on one's life and, for me, the meaning of life.

When my family and I decided to care for my mother ourselves in her dying days, it seemed natural to care for her body in her death, which occurred peacefully and in our home. To us it didn't make sense to have someone else care for her in death after we had cared for her in sickness. We also had the time and the resources. I had taken some time to be with her in her death and my husband was a carpenter and able to build a coffin.

Recently I was cleaning out my closets and came across an old *Utne Reader*. I can't remember the date now, but it was written several years before my mother died in 1993. The article was about the possibility of caring for your own dead. It was about Lisa Carlson and her work. I had forgotten that I had ever read the article, but when I found it I realized instantly that this article was what inspired me to take care of my mother when she died.

I have come to know Lisa Carlson as an incredible resource, someone who is passionate about what she does. She's fierce and relentless when it comes to the funeral industry. And she's someone who takes the time. I am so very glad that I read that article in the *Utne Reader* so many years ago, because without knowing there were other options I might have allowed a funeral home to care for my mother and thus would not have gone on to be a board member of the Memorial Society, telling you of your choices in Massachusetts.

The third act, the final act, the final scene in the epic of one's life: it's your choice in how it plays out."

After Jan's talk the Rev. Dr. Arthur Kimber, president of the Memorial Society of Cape Cod, introduced Lisa Carlson as an energetic, humorous leader who has a passion for her work. He provides support to all members of the Cape Cod Society, including those on Martha's Vineyard. Lisa's message was "A Dying Person's Bill of Rights."

She began by saying that only 20% of the folks who have thought about getting a health care proxy together have actually filled out the paperwork. Even if you do have the paperwork all certified, she said, you had better "have a witch on wheels" to see to your wishes, as the medical profession is hard pressed to comply with the directive.

Dying Person's Bill of Rights

* I have the right to be treated as a living human being until I die.
* I have the right to maintain a sense of hopefulness however changing its focus.
* I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this may be.
* I have the right to express my feelings and emotions about my approaching death in my own way.
* I have the right to participate in decisions concerning my care.
* I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.
* I have the right to be free from pain.
* I have the right not to be deceived.
* I have the right to have my questions answered honestly.
* I have the right to have help from and for my family in accepting my death.
* I have the right to die in peace and dignity.
* I have the right to retain my individuality and not be judged for my decisions, which may be contrary to those of others.
* I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever this may mean to others.
* I have the right to expect the sanctity of the human body will be respected after death.
* I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.
* I have the right not to die alone.

Lisa made the point that most of us will be dealing with a loved one's wishes before making our own wishes known, and it is important to change the "I" to "You."

Finally, Lisa spoke of the packet that every adult American should have: the 20-page booklet, "Before You Go, You Should Know." This packet is designed to go in the freezer (why the freezer? so your family and you remember where those directives are!), complete with freezer pouch and refrigerator magnet! In addition to setting out your funeral and final plans, there are

reminders for survivors to cancel your weekly hairdresser and internet account. But more importantly, the pouch comes with your state-specific Living Will and Health Care Proxy.

This packet, $10 postpaid, can be ordered from Funeral Consumers Alliance, preferably by mail to POBox 10, Hinesburg, VT 05461, or on the web site www.funerals.org or, as a last resort (due to limited staff), by calling 1-800-765-0107. The new-member package from this Memorial Society now includes the packet.

Autopsies and Medical Research

Many of our members have decided to donate their bodies to medical schools for use in medical education. Another need, recently explored in issues of the Journal of the American Medical Association (JAMA), is for autopsies to be performed to determine what pathologies existed in a deceased patient, and whether the illness diagnosed by the physician is the one that actually caused death.

In the October 14, 1998 issue of JAMA two articles and an editorial called attention to the need for more postmortem examinations. A ten-year study at the Medical Center of Louisiana found a 44% discrepancy between autopsy and clinical diagnoses of malignant neoplasms (cancer). That is, in 44% of the patients who had been diagnosed with cancer, physicians had either misdiagnosed the disease or not detected it at all. Two earlier studies, conducted in the 1920s and the 1970s, found similar rates of discordance. Taken together, the findings suggest that, despite vast improvements in medical technology, the rate of misdiagnosis has remained more or less constant over the last eight decades. Autopsies are the best way to identify misdiagnosis; yet the number of autopsies has declined sharply in the last thirty years. Autopsy rates at nonteaching hospitals now average below 9%, and some hospitals do none at all.

Identifying misdiagnosis is not the only reason more autopsies are needed. In an editorial in the same issue, Dr. George D. Lundberg lists several reasons for performing autopsies besides determining the cause of death. Among them are:

Produce accurate vital statistics on the incidence of various illnesses;

Monitor the public health:

Assess the quality of medical practice;

Instruct medical students and physicians:

Identify new and changing diseases:

Evaluate the effectiveness of therapies:

Reassure family members who may have questions about the cause of death;

Protect against false liability claims and settle such claims quickly.

Perhaps the major disincentive to performing autopsies is financing. Private insurance does not cover the cost of autopsy, which can run as high as $4,000. However, increasing the autopsy rate would be cost-effective over the long run. In his editorial Dr. Lundberg points out that the cost of high-tech medicine inappropriately used far outweighs the cost of autopsies. The staggering increase in medical costs in recent decades may have been driven by an overuse and misuse of technology that we do not yet entirely understand. He also says that the AMA, which has long advocated increasing the autopsy rate, is renewing its efforts to gain political support for increased funding.

One important existing funding source for autopsies is Medicare. A Medicare patient who dies in a hospital can receive an autopsy under Medicare A coverage. The family of such a patient has a right to request an autopsy and know its results. However, some hospitals may not be able to comply because they do not have a morgue; many have closed their morgues in recent years. Or there may be some other contravening reason. It is worthwhile to make the request, since it is a chance to contribute some extremely useful medical data.

As individuals, we should be aware that body donation is not the only alternative for those who want to help further medical research after death.

Anatomical Gifts, The Law

In Massachusetts and almost all other states the law governing organ and body donation is based on the Uniform Anatomical Gift Act (UAGA). The original UAGA was issued in 1968 and its language was adopted into Chapter 113 of the Massachusetts General Laws by the 1971 legislature. A slightly revised UAGA published in 1987 has been adopted by many states but not by Massachusetts.

Here is what Massachusetts law says about gifts by a person that become effective upon a persons death:

- A person of sound mind and who is eighteen years of age or older may make a gift of all or any part of his body for any purposes specified in section nine, said gift to take effect upon his death. . .
- A gift ... may be made by will. . .

- A gift ... may also be made by a document other than a will. ...the document may be a card designed to be carried on the person which shall be signed by the donor in the presence of two competent witnesses who shall attest to and subscribe the document in said donor's presence
- ...the donor my amend or revoke the gift ... [in a number of different ways]
- The donee may accept or reject the gift.
- A person who acts in good faith in accordance with the terms of sections seven to thirteen inclusive, or under the anatomical gift laws of another state or a foreign country shall not be liable for damages in any civil action or be subject to prosecution in any criminal proceeding for his act.

Massachusetts law *also* provides that the next of kin may authorize a gift:

- On or before the occurence of death in an acute hospital, the director ... shall inform any of the persons listed below ... of the opportunity of authorizing a gift of all or part of the decedent's body ...
- The order of priority of such persons shall be:
  1)the spouse
  2)the adult son or daughter
  3)either parent
  4)an adult brother or sister
  5)a guardian ...
  6)any other person authorized or under obligation to dispose of the body
- If the donee has actual notice of contrary indications by the decedent, or that a gift authorized by a member of a class is opposed by a member of the same or a prior class, the donee shall not accept the gift. [This means that if you don't want to be a donor but you fear your next of kin might disregard your wishes, you must formally notify the donee, NEOB]

The law *doesn't* give the next of kin the right to veto the decedent's decision to donate. In the comments of the drafters of the UAGA(1968) which was enacted into Ch. 113, they say:

> "Subsection (e) recognizes and gives legal effect to the right of the individual to dispose of his own body without subsequent veto by others."

Organ Donation Update

At the 1999 annual meeting in November members were addressed by guest speaker Dr. Francis Delmonico, visiting surgeon at Massachusetts General Hospital and Medical Director of the New England Organ Bank. Dr. Delmonico gave us a brief description of the needs and procedures involved in organ donation.

There is a critical need for donated organs and tissues. According to a New England Organ Bank fact sheet there are more than 66,000 patients waiting for organ transplants nationally. In New England there are more than 3,000 waiting for organs, and many more needing donated tissues.

Not everyone can be a donor. Donors must die in hospital because of the need for two medical teams to be instantly ready to perform the transplantation. The typical donor will be brain-dead but still on artificial life support so that the blood is kept circulating. This is necessary because as soon as the organs cease being oxygenated by the blood they begin to deteriorate. The ideal donor is a trauma victim, but trauma victims account for only about 30% of donors.

An alternative to this type of transplantation is transplantation from a living donor. This method is not suitable for all organs, but it can be used for transplanting kidneys as well as parts of the lung and liver. (It is possible to survive very well with only one kidney; lungs and liver are both capable of regeneration.) Because of recent advances in immunosuppressants, the living donor need not be genetically related to the recipient.

In order to be an organ donor at death, one must meet some criteria based on age and health. Cancer patients as well as people suffering from certain other illnesses are not accepted as donors. The NEOB age restrictions for various organs are as follows:

Heart: Newborn to 60 years
Lung: Newborn to 70 years
Pancreas: 10 to 60 years
Liver: Newborn to 80 years
Kidney: Newborn to 80 years

For tissue:

Bone: 17 to 60 (Males); 17 to 50 (Females)
Heart Valves: Newborn (over 8 lbs.) to 55 years
Intestine: Newborn through 60 years

Corneas, veins, skin and soft tissues can be donated at any age.

In accordance with regulations promulgated by the Health Care Financing Administration and the Department of Health and Human Services, hospitals must report all

impending deaths to their local organ procurement organization. In New England, this means that when an inpatient is nearing death, the hospital notifies the New England Organ Bank. They send a representative to approach the family and request organ donation. If the family consents and the donor is suitable, the organs are removed after brain-death occurs but while the patient is still on life support. The life support is then withdrawn and the body released to the family. The body is not disfigured, and a funeral with embalming and viewing is possible if the family wishes it.

Organ donation involves no cost to the donor family, but the recipient's family may be billed many thousands of dollars if the patient is not covered by Medicare, Medicaid or private insurance.

A legally-correct gift of organs and/or tissues can be made using a Donor Card, but NEOB will reject *any* gift by the decedent. NEOB will *only* accept gifts made by the next of kin. If you wish to be a donor it is very important that you discuss your wishes with your family and make sure they have no objection and will make the gift.

One troubling issue that was raised by our treasurer, Byron Blanchard and by others in the meeting is that the NEOB consent form that is presented to families in the hospital is not available for examination beforehand. Most families see it for the first time only when their loved one is dying and they are under considerable stress. Dr. Delmonico explained that the NEOB wishes the form to be seen only in the presence of its own trained counselors, so that they can answer questions and alleviate fears. Some of our members argued that this is an unnecessary and intrusive restriction. As one member put it, "What is so terrible about that form that an intelligent person cannot be allowed to read it?" Dr. Delmonico replied that "there is nothing terrible about it" -- but neither he nor NEOB would send one although requested to do so by phone and by certified letter. Dr. Delmonico wrote down the name and address of one of our members at the meeting, saying he would send her a copy of the consent form, but he did not send it. There is clearly something about the form that NEOB feels will not survive careful scrutiny; perhaps it has to do with disclosure (or lack thereof) of what happens to donated tissue. (See related article)

The headquarters of the New England Organ Bank is at One Gateway Center, Newton, MA 02458. Phone 800-446-NEOB.

The FAMSA brochure "Body Donation and Medical Education," which we have available for our members, lists three other organ donation organizations: the New England Eye & Tissue Transplant Bank in Boston; the NorthEast Organ Procurement Organization and Tissue Bank in Springfield; and the NIDCD National Temporal Bone, Hearing and Balance Registry at the Massachusetts Eye and Ear Infirmary. We contacted them to find out what their relationship is to the NEOB.

The New England Eye & Tissue Transplant Bank has some different criteria than the NEOB, but the NEOB does refer corneas to New England Eye & Tissue when appropriate. The NorthEast Organ Procurement Organization and Tissue Bank covers a geographically different group of hospitals from the NEOB. Again, there is some degree of cooperation.

The NIDCD National Temporal Bone, Hearing and Balance Registry is rather different from the others. They are concerned with scientific research rather than donation to living patients. They ask for donations of the temporal bone -- that part of the skull that contains the organs of hearing and balance -- especially from people who have any type of ear problem, such as deafness, dizziness, facial palsy, infection, tumor or injury. As with autopsies (see our article in this issue), the study of the temporal bone can contribute significantly to medical research. If you would like to receive a donor packet, call (800) 822-1327.

Body Brokers

The Orange County Register in California recently ran a special investigative report on a $500 million industry using body parts as its raw materials. The full text is available on the internet at www.ocregister.com. The report is concerned with the sale of *tissue* as distinct from *organs*, the distribution of which is federally regulated.

The series reports that New England Organ Bank (which is also a tissue bank) "Recovers skin for LifeCell Corp., a publicly traded New Jersey firm, for use in the proprietary plastic surgery product AlloDerm. Recovers heart valves for CryoLife Inc., a publicly traded Georgia company."

The revelations are troubling. California has since enacted legislation regulating the trade in body parts, and a number of tissue banks have severed their relationships with for-profit companies. Federal Health and Human Services secretary Shalala has setup a panel to study the situation. Stay tuned

Body Donation to Medical School

We don't know of any problems similar to those mentioned in the Body Brokers story connected with body donation to local medical schools. That remains both a way of assisting in medical education and as the very least expensive method of disposing of one's body.

All four medical schools have quite similar policies, but there are some differences that could result in unexpected expenses. Those differences are in how the body is transported to the medical school. Harvard and Boston Univ. expect the family to contract with a funeral establishment for transportation. Harvard will pay $400 or $4/mile while BU will pay a "reasonable" amount. A high-priced funeral establishment may charge *much* more than what the medical school pays, with the family paying the difference. Tufts and U. Mass. will both arrange and pay for transportation of the body and registration of the death, sparing the family the trouble (and financial risk) of contracting with a funeral establishment.

Another difference between schools is in the final disposition of the body. The schools share a cemetery in Tewksbury which is running out of space. Tufts and Boston U. will still bury the whole body, but Harvard and U. Mass. will cremate it first and bury the cremated remains

How High?

How high can the charges go for a direct cremation with a later memorial service? Here is the highest we have yet seen:

Transaction	Amount
Original Charges & Credits	
Basic Services of Director & Staff	1,795.00
Refrigeration	495.00
Carrying Assistants	200.00
Memorial Service	795.00
Transfer of Remains	295.00
Hearse	295.00
Service/Utility Vehicle	185.00
Sanitary Pouch	75.00
Crematory Charges	225.00
Clergy Honorarium	200.00
Paid Death Notices	135.00
Certified Copies	30.00
Burial Permit Fees	10.00
Medical Examiner Fees	50.00
Additional Charges & Credits:	
Alternative Container	445.00
Adjustment to Paid Death Notices	-75.60
Gratuities	20.00
Flowers	126.00
Balance Due:	**5,300.40**

The $795 memorial service was arranged by the social worker and held at the nursing home. The only role for the funeral director was to arrange for the minister and to attend the memorial service, without bringing the cremated remains.

The mortuary was J.S. Waterman & Sons in Boston. The decision to use Waterman was made by the decedent's guardian, Family Service of Greater Boston, which entered into a price-guaranteed irrevocable preneed contract for $6.000. The contract didn't specify the goods and services to be provided for the guaranteed price.

The cremation could have been purchased for $750 to $1,100 complete from several other establishments. The costs for paid death notices, certified copies of death certificate, and flowers would be extra. A memorial service not using a mortuary's rooms needs no payment to the mortuary.

PROXY

(Please vote by proxy if you do not plan to attend the Annual Meeting. Complete this form and send it to: The Memorial Society, 66 Marlborough Street, Boston. MA 02116.)

PROXY VOTE: (Fill in only if you will not attend the Annual Meeting.)

I hereby authorize the Clerk of the Society to vote for:

(1) The Slate of Officers as proposed Yes No

(2) Such matters as may lawfully come before the meeting. Yes No

Signature: Date:

VOLUNTARY CONTRIBUTION FORM

Yes, I would like to support The Memorial Society. The one-time membership fee covers only a portion of the Society's expenses. Your inclusion of a tax-deductible contribution is greatly appreciated.

Contributions: ( ) $5; ( ) $15; ( ) $25: ( ) $40: ( ) $60; ( ) $100: ( ) Other_____

Thank you very much for your consideration.

Keep the portion below for names, address. and phone numbers.

NOMINATING REPORT

President - John Van Dusen (Lawyer, Marblehead)

Vice President - Jan Buhrman Osnoss (Librarian, Martha's Vineyard)

Treasurer - Byron Blanchard (Engineer, Lexington)

Clerk - Paula Blanchard, (Writer, Lexington)

Board members in addition to above:

Harry L. Jacobs (Retired psychologist/physiologist, Wayland)

George S. Richardson (Physician, Nahant)

Larry O'Brien (Woburn)

The Memorial Society, Inc.

66 Marlborough St.

Boston, MA 02116

617-859-7990 or toll-free 888-666-7990 will reach our answering machine. A volunteer will return your non-emergency call within 48 hours. Emergency contact phone numbers are provided.

The Memorial Society, Inc.
66 Marlborough St.
Boston, MA 02116

Annual Meeting Notice

Saturday, November 18, 2000, 1:30 P.M
Story Chapel, Mount Auburn Cemetery
Cambridge, MA