

ISSUE 1
NOVEMBER 2007

*"If it were possible to heal
sorrow by weeping and to raise
the dead with tears, gold were
less prized than grief."
Sophocles, Scyrii.
Frag. 510*

CONTENTS

A Newsletter Is Born	1
Notes From The President	1
Upcoming Events	1
Book Review	1
Websites of Interest	2
Associate State Director of AARP Speaks at September Meeting	2
Education Committee Update	2
Public Policy Committee Update	2
The Benefits Of Belonging	3

UPCOMING EVENTS

9TH ANNUAL NATIONAL SURVIVORS OF SUICIDE DAY PROGRAM COMING THIS NOVEMBER

On Saturday, November 17 starting at 10:30 am, Delaware will hold it's annual Survivors of Suicide Day Program. For more information and to register go to the DEOLC website at www.deolc.org.

Happy Birthday—A Newsletter Is Born

MARCY RESNICK

You are now reading the premiere issue of the Delaware End Of Life Coalition (DEOLC) Newsletter. It's been a long time in coming (long,

long time!) but it is finally here! Look forward to informative bits of information that touch on end-of-life issues and activities and updates

from the DEOLC. Comments and feedback are welcome. Contact Marcy at 4668officestaff6@bcr-manorcare.com or (302) 463-0006.

Notes from the President

MADELINE LAMBRECHT



The 2007-08 year is off to a great start! At the September 20th meeting, it was my pleasure to present our outgoing

President, Ralph Plumley, with the Presidential Leadership Award for his dedication and commitment to furthering the mission of the Delaware End-of-Life Coalition. A picture of Ralph receiving the award can be found by clicking on the link on the DEOLC web page listing the officers.

As you saw in an earlier e-mail which listed the meeting information for the year, all

meetings will be held at Dover Downs. This site was selected as central for members coming from both the northern and southern parts of the state. There is ample free parking by the hotel, and we are meeting in a room near the Festival Buffet. Mr. John Barnes, Associate State Director, AARP, was the dinner speaker on 9/20/07. I have extra packets of the material he distributed and will bring them to our next meeting on November 29th.

We need your active involvement! Please look at the activities planned for the year (see Committee Reports) and join a committee. Since we hold

committee meetings immediately before the general meetings, you don't have to worry about adding another date to your calendar!

Please note that DEOLC is a co-sponsor of the 9th Annual National Survivors of Suicide Day Program to be held November 27 at the Delaware Biotechnology Institute in Newark. There will be a live morning program, lunch, and the afternoon videoconference. More information plus the registration form is available on the website (www.deolc.org). There is no fee for the program. Please share the information with your colleagues. I hope to see you there!

Book Review

SHEILA GRANT

LAST RIGHTS: Rescuing The End of Life From the Medical System by Stephen P. Kiernan, St. Martin's Press

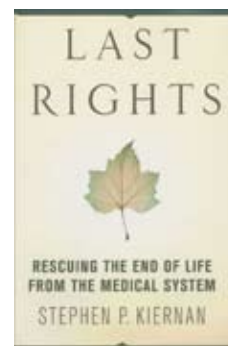
Award-winning journalist Stephen Kiernan, offers a fresh analysis of what's wrong with end-of-life care in the U.S. and a clear prescription for how to improve it. His book, Last Rights: Rescuing The End of Life From the Medical System, has enough solid, detailed information to be useful to health care professionals, but is accessible and valuable to non-professionals as well. He uses both research and real stories to illustrate current dilemmas in end-of-life care. In addition, he offers a thoughtful consideration of public policy questions and a plan for adapting our attitudes and institutions to support a more meaningful way of dying. Readers will appreciate his

approach, which is, at various times, scholarly, intimate, and thoughtful.

Kiernan begins by painting a picture of how dying in America has changed over the last century. In 1900 the average life expectancy was 47 years, and most deaths came suddenly from causes like heart attacks, strokes, and traumatic accidents. Since then, a transformation has taken place. Sudden death rates have fallen sharply, thanks to huge societal and governmental

efforts. These efforts include the development of 911 service and the Emergency Medical System, medical advances in ICU care, CPR classes for the public, the proliferation of automatic external defibrillators, and improved safety devices (like car air bags, child safety seats, bike helmets, and flotation vests).

Due to these advances, average life expectancy jumped to 75 years of age by the year 2000. Today, most people die gradually of causes like cancer, heart failure, lung disease, or dementia. This sort of death requires a different kind of



WEBSITES OF INTEREST

Americans for Better Care of the Dying

<http://www.abcd-caring.org>

Every dying person needs to be able to count on excellent care. Americans for Better Care of the Dying (ABCD) aims to improve end-of-life care by learning which social and political changes will lead to enduring, efficient, and effective programs. They work with the public, clinicians, policymakers, and other end-of-life organizations to make change happen.

Coda Alliance

<http://www.codaalliance.org>

In music, a coda comes at the end of a piece of music, summing up the preceding themes and bringing the piece to a satisfactory close. Coda Alliance is a community-based, not-for-profit organization with a similar purpose, helping individuals and their families plan and prepare for the concluding passages of life. Coda Alliance has a cutting-edge product 'Go Wish Game'. It gives you an easy, entertaining way to think and talk about what's important to you if you become seriously ill.

Growth House, Inc.

<http://www.growthhouse.org>

Growth House, Inc., provides is an award winning international gateway to resources for life-threatening illness and end of life care. Their primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Their search engine gives you access to the Internet's most comprehensive collection of reviewed resources for end-of-life care.

DISCLAIMER: The links above provide additional information that may be useful or interesting and are consistent with the intended purpose of the DEOLC. However, DEOLC cannot attest to the accuracy of information provided by these sites. Publishing these sites does not constitute an endorsement by DEOLC or its members of the sponsors of the site or the information or products presented on the site.

Associate State Director of AARP Speaks at September Meeting MARCY RESNICK

Just as NASCAR rolled into town, so did the DEOLC. We held the first of this year's meetings to be held at Dover Downs in the conference room by the tasty buffet! John Barnes, Associate State Director, AARP Delaware shared insight into AARP and their

focus on education and grassroots activism. He also shared a list of grief and loss literature that AARP publishes. Check out the website: <http://www.aarp.org/families/grief-loss/> for more information. Don't miss our next meeting (breakfast at Dover Downs) on Thursday,

November 29, 2007. Please join in a committee meeting (education, public relations and public policy, membership) at 8:30 am or the main meeting at 9:30 am. For more information (and other meeting dates) visit the website at www.deolc.org.

Education Committee Update

MADELINE LAMBRECHT

The past year has been a busy one! In September 2006, DEOLC presented an all day conference – **"Dying, Death and Bereavement: A Conference for Clergy, Lay Ministers, Members of Religious Orders & Parish Nurses,"** held at the Deerfield Golf & Tennis Club in Newark, DE. Mr. William Colby, author of Unplugged: Reclaiming Our Right to Die in America (2006) and Long Goodbye: The Deaths of Nancy Cruzan gave a presentation titled, **"From Cruzan to Schiavo: What Have We Learned?"** We extend thanks to the other distinguished presenters: Dr. Dan DePietropaolo, Dr. Jeff Kendel, Harriet Bernstein, Alex Tyree, Rev. Tim Rodden, Rev. Tom Ledbetter and Dr. Madeline Lambrecht. The conference was well attended and received very positive evaluations. **"An Evening with Bill Colby"** followed at the same location on 9/13/07. The following day, 9/14/07, we sponsored a **"Public Forum with Bill Colby"** held at the Modern Maturity Center in Dover. Special thanks to Ralph Plumley

for his coordination of these events. All three presentations by Bill Colby were cosponsored by Caring Connections.

In March 2006, DEOLC originated a live webcast from the University of Delaware in conjunction with the 14th Annual Hospice Foundation of America's Teleconference on **"Living with Grief: Before and After the Death."** The keynoters, Dr. Valarie Molaison representing Supporting Kids, Inc., and Sean Hebbel representing the Wellness Center-Delaware, provided foundational information on the topic with additional information presented by panelists Diane Dellinger, Rev. Randall Booth and Dr. Veronica Rempusheski. The AM webcast was transmitted to Bayhealth Medical Center in Dover and Delaware Technical & Community College in Georgetown, DE. Our site coordinators were Terry Towne at Bayhealth and Lori Wescott at DTCC. Bayhealth Medical Center Education Department provided the nursing contact hours – thanks!

In late spring, we collaborated with the DHSS/Division of Services for the Aging and Adults with Disabilities to provide a public presentation, **"Advance Directives: What You Need to Know,"** in all three counties in the state. On May 30, at the New Castle Senior Center, the presenter was Drew Biehl. On June 7, Murt Foos offered the presentation at St. Matthews by the Sea Church on Fenwick Island. Andrea Holecek gave the same presentation as part of the Community Education and Health Fair held at the Modern Maturity Center in Dover on June 21, 2007. We extend special thanks to Victor Orija and Chris Oakes from the Division of Aging for their support of these activities. In closing, I'd like to offer our heartfelt appreciation for all DEOLC members who participated in the many 06-07 education events! We have an even more exciting schedule of events planned for 07-08. Please welcome Michele Lampkin and Terry Towne as the new co-chairs of the Education Committee.

Public Policy Committee Update

MOONYEEN KLOPFENSTIEN

While there are not a lot of specific end-of-life issues being addressed at this time in Delaware, we do have a few tidbits for you—for more comprehensive information contact Kloppey at: MKlopfenstein@Christianacare.org.

- The new edition (2007-2008 Guide to Services for Older Delawareans is now available through the Department of Health and Social Services (DHSS) www.dhss.delaware.gov/dhss/dsaapd/index.html
- House Bill #167 – Sponsor

McWilliams – AN ACT TO AMEND CHAPTER 10, TITLE 16 OF THE DELAWARE CODE RELATING TO POLICIES OF HOSPITALS AND OTHER FACILITIES. This bill allows each adult patient to receive visits in a Hospital from any individual from whom the patient desires to receive visits, subject to certain restrictions contained in the Hospital's visitation policy related to the patient's medical condition, the number of visitors permitted in the patient's room

simultaneously, and the Hospital's visitation hours. In addition, this bill requires the Hospital to honor advance health-care directives and any similar documents, subject to certain limitations set forth in the bill. As of 6/7/07 this bill was sent out of committee.

- CMS proposes an increase in Medicare payments to nursing homes for 2008. <http://www.cms.hhs.gov/apps/media/pressreleases.asp>; <http://www.cms.hhs.gov/snfpps>

THE BENEFITS OF BELONGING

Two great reasons for joining:

- Make your voice heard by participating in DEOLC activities!
- Network with like-minded individuals interested in end-of-life issues.

How do you become a member of the Delaware End Of Life Coalition? Attend a meeting. Join a committee and get involved. Visit our website www.deolc.org for more information!

CONTINUED FROM PAGE 1

care. Rather than resuscitation and ventilators, we should be providing home-based nursing care and psycho-social support for families who take care of loved ones at home.

While Kiernan offers praise to Intensive Care Unit personnel for the lifesaving work they do, he points out that ICU care is problematic for patients when death is “certain and near”. When patients dying of gradual illnesses go to the ICU, they experience poorer quality of life. In the ICU, patients’ living wills are often disregarded. They are subjected to burdensome treatments. They are faced with huge health care expenses (medical bills are the leading cause of bankruptcy in the U.S.). All of this might be worthwhile, if it led to improved outcomes and better quality of care, but studies have shown just the opposite.

Kiernan interviews author, Dr. Ira Byock, who believes medical schools do not adequately prepare

physicians to treat patients at the end of life. He explains that most medical schools require about 300 hours of training in obstetrics, but only about twenty-four hours of training for care of the dying. This seems absurd in light of the fact that only half of the population will ever be at risk for obstetrical complications, and most doctors will never deliver a baby. In contrast, every person alive today will someday die, and virtually every physician will treat dying patients. Our medical schools need to prepare future physicians for this important work.

After describing all the ways in which the system we’ve developed to treat the causes of sudden death are inappropriate and burdensome in treating the causes of gradual death, Kiernan then shows, through personal stories, how people can die well. He gives an inspiring description of hospice care and how it supports patients and families at

the end of life.

Kiernan calls on us to adjust our attitudes, governmental policies, and medical system to the new reality of gradual dying. He holds out hope that the next generation to face death, the baby boomers, will transform our end-of-life culture as they have transformed every other part of our society. He writes “Perhaps this group . . . will recognize the potential for brilliance and brightness in their lives’ final days—and find themselves moved to enact changes into the law to nurture that opportunity, to demand new policies. . . to advocate for themselves and their loved ones . . .”.

Kiernan reminds us that when we live each day mindful of our mortality we add meaning and quality to life. This book provides guidance and inspiration to professional caregivers, families, and all of us who will someday face our own mortality.

