World Hospice and Palliative Care Day was celebrated in October 2006 with a variety of presentations at locations throughout the Salt Lake Valley. Therese Jones, Ph.D., Division of Medical Ethics and Humanities professor, presented an analysis of Margaret Edson's acclaimed “Wit”, a story from the point of view of a woman dying of terminal cancer that chronicles her trials in today’s medical world, and her reevaluations and discoveries through serious illness. Susan Sample, M.F.A., DMEH Program Associate, facilitated poetry workshops, one for child patients, another for health care professionals, using poetry as a window through which to see and express the griefs, wonders, and insights of illness and caregiving. The DMEH sponsored Physician Literature and Medicine Group, a bi-monthly discussion of fine literature chosen for its relevancy to medicine, read and discussed Joan Didion’s The Year of Magical Thinking, a memoir that documents Didion’s first year reflections after the sudden death of her trusted, beloved husband of 41 years, John Dunne, while she kept vigil over her young adult daughter, Quintana, who was facing a prolonged, life-threatening illness. In this article, I present varied perspectives captured at the Physician Literature and Medicine discussion and my own reflections on the lessons and questions about grieving and mourning that arose from the book and from this unique forum for discussion. The Physician Literature and Medicine Group attempts to capture understanding on multiple levels—a blend and balance of literary, personal, universally human, medical, and healthcare perspectives.

Life is fragile. When a loved one unexpectedly dies, we cannot believe it. We grieve, we mourn, but at first, and for a long time afterward, we simply cannot fathom it. Joan Didion writes: “It was in fact the ordinary nature of everything preceding the event that prevented me from truly believing it had happened, absorbing it, incorporating it, getting past it.” Whether death occurs in a mind numbing 9-11 terrorist attack watched worldwide, or in the quiet privacy of one’s own home, loss is loss—and death is overwhelming loss. Those who have recently lost a loved one—a spouse, a child, a close friend, a parent—become fragile and unstable, as they are forced out of the denial in which we all cocoon ourselves, living as if we are “safe” and will live to see tomorrow. But none of us ultimately survives, and the literary skill with which Joan Didion captures the reality of this universal, human eventuality and its grieving process, enriches us all.

The raw, exposed look of “extreme vulnerability, nakedness, (and) openness” in the recently bereaved, Didion explains, is recognizable: the grieving feel invisible, incorporeal, and want the person back. Didion speaks of her need to be alone.
because she was not prepared to accept the finality of the news: it must be reversible. Only when she was alone could her husband “come back.” She even kept his shoes ready for him. Was this craziness? Or was it grief, a response to stress and loss, an alternative way of thinking—magical thinking? Is the magic in this thinking that her beloved will come back and live with her forever—or that she can come to accept that the death has happened at all—and move on with her life? Does grief have a therapeutic, even evolutionary value? And when does magical thinking end? After a year—when memories of last year no longer include the loved one’s presence? Or does it ever really end? After all, magical thinking can get us through a lot in life.

Didion tells us that “grief, when it comes is nothing we expect it to be…(it) has no distance. Grief comes in waves, paroxysms, sudden apprehensions that weaken the knees and blind the eyes and obliterate the dailyness of life.” Grief is a slippage out of rationality, or at least into an alternative rationality, a time of never ending “what-ifs” where we try to alter reality. In grief, we experience a sense of not having sufficiently appreciated things, of needing to relive every mistake. In our culture, at least, we worry about and guard against signs of dwelling in self-pity for even though we feel that our world is empty, we do not think that we have the right to say so. And so in grief we find ourselves comparing our losses to the losses of others and counting ours as small in comparison.

In grief, we seek meaning. The funeral, Didion shares, wraps us in “the care of others and the gravity and meaning of the occasion.” But the reality of grief, she laments, is “the unending absence that follows, the void, the very opposite of meaning, the relentless succession of moments during which we will confront the experience of meaninglessness itself.” If grief is thrust on us, outside of our control, mourning, or dealing with grief, is very much in our control, and requires exhausting attention. Unable to concentrate, we can still “get on top of things”, deal with mundanities—open the mail, straighten the house, and importantly, “read, learn, work it up, go to the literature.”

Joan Didion is clearly a very informed consumer, educated, trained, and capable of intense research into medical journals, historical and academic texts, etiquette protocols on grieving, able to access long-time personal relationships with medical experts. Was she a strong patient advocate or a difficult patient? Some professionals at our discussion group were glad that Didion was not scrutinizing their medical care. She certainly used her clout to try to achieve the best for her family and even pushed boundary limits when she showed up in scrubs at the ICU. Others thought that Didion was doing whatever anyone would do, accessing all of the resources that she possibly could. Still others were bothered by Didion’s exceptionalism as a person of privilege, a wealthy, respected author, an insider among the literary elite. Some even question if Didion’s work has been given special immunity from critique when the New York Times wrote a glowing accolade such as, “I can’t imagine dying without this book.” But judgments aside about a privileged life well-lived versus the lives of the suffering by those who have no health insurance, or about the sudden loss of life due to cardiac arrest as John Dunne suffered versus a prolonged, painful mode of death, or about being young or old when death catches us, the fact remains that privilege did not protect her from loss.

Didion’s account surprised some due to its absence of mention about those around her. Where were the supportive doctors, nurses, and healthcare workers? Was Didion being hard on the medical profession? (After all, in the Terry Schiavo case, it was noted, Didion had argued adamantly that everything should be done to save Terry’s life.) Or is it that although death and grief have been “professionalized” in our modern era to occur in hospital settings rather than at home, the grieving process by nature is intensely personal, a turning inward? Medical personnel were simply a bit tangential to this type of internalizing experience.

Doctors find themselves face-to-face with grieving people often. It may not even be a life that is lost; it may be the loss of some functionality that is being grieved. Grief may be more or less complex and devastating. Joan Didion’s processing of grief may be instructive in helping us to know what to do and say in these circumstances. While some believe that the book offers many minute, unnecessary details, but very little understanding through reflection, I suggest that understanding Didion’s reflection lies in the choice of the details she focused on. The universality of this process amazes. One grief-stricken person may focus on a bird that alighted at the windowsill, “sent by the deceased who loved birds”; another grief-stricken person may emphasize that it rained the day their loved one died, “as though the very heavens were crying.” It may be that in grieving, it is the listener’s or reader’s job to “connect the dots,” understanding with compassion the significance of these grief musings, whatever they may be.

Linda S. Carr-Lee  Research Associate
**November Evening Ethics Discussion Group**

"Dialysis Redux: Insufficient Ventilators for Epidemic Influenza."

The next Evening Ethics Discussion will be on **Wednesday, November 29, 2006 at 7:30 p.m.** We will discuss "Dialysis Redux: Insufficient Ventilators for Epidemic Influenza."

"No one knows whether an avian flu virus that is racing around the world might mutate into a strain that could cause a human pandemic, or whether such a pandemic would cause widespread illness in the United States. But if it did, public health experts and officials agree on one thing: the nation’s hospitals would not have enough ventilators, the machines that pump oxygen into sick patients’ lungs.... To some experts, the ventilator shortage is the most glaring example of the country’s lack of readiness for a pandemic."

Like a recent article from the **New York Times**, which included these quotations, our discussion will focus not so much on global readiness, but rather on the specific problems that are raised by a sudden, enormous and vital need for ventilators and too few ventilators to meet that need. Questions for discussion will include: Should we plan and provide for such a possible but unpredictable need? If we cannot meet the need, how should we allocate the available ventilators? How should the decision to allocate be made and who should participate in that process? Do we prefer a hospital, city, state, or federal response to this problem?

Please call us for the articles, address and more information regarding this event. (801) 408-1135

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**Division Members On the Road and in Print**

"**Should Rapid Tests for HIV Infection Now Be Mandatory During Pregnancy?** Global Differences in Scarcity and a Dilemma of Technological Advance" by Charles B. Smith MD, Margaret P. Battin PhD, Leslie P. Francis PhD JD, and Jay A. Jacobson MD has been accepted by Developing World Bioethics.

Armand Antommaria presented a talk entitled "Bioethics Mediation: A Critique" at the American Society of Bioethics and Humanities annual meeting on October 28th in Denver.

Peggy Battin presented two talks: “Has assisted dying been abused: what the data from Oregon and the Netherlands say.” and “Dying through the lens of past times and cultures: Did the Stoics have it right?” at the American Society of Bioethics and Humanities annual meeting on October 30th in Denver.

Jeff Botkin presented a talk to the Children’s Oncology Group and the American Society of Clinical Oncology on Informed Consent for Genetic Testing in Research on October 3rd in Los Angeles.

He was also involved in a meeting as a member of the CDC committee titled “Evaluation of Genomic Applications for Practice and Prevention (EGAPP),” an organization to provide evidence-based evaluations of new genetic tests.

Leslie Francis has been nominated to become a member of the National Committee on Vital Statistics, which makes recommendations about such issues as the privacy of health records.

Jay Jacobson will participate in a Panel at Westminster College, November 2, 2006, “How education in Humanities prepares one for a career in Medicine.”

He will present Ethics Grand Rounds for the Department of Ophthalmology: “The role of clinical ophthalmologists in surveillance and use of new and potentially dangerous drugs and products.”

He will also speak at Salt Lake City Estate Planning Council, “Helping Clients meet personal needs and goals when they are dying.”

He will also be a speaker at Salt Lake City Rotary Club, “On Gratitude.”

Tess Jones presented "Ending in Wonder: Replacing Technology with Revelation in Margaret Edson's "Wit" at the World Hospice and Palliative Care Day Celebration, Huntsman Cancer Center, on October 7th.
Activities and Programs

Published by the Division of Medical Ethics and Humanities of the Departments of Internal Medicine at LDS Hospital and the University of Utah School of Medicine

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We're on the Web!
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A Physicians Literature and Medicine Discussion Group* will meet in the LDSH Pugh Board Room. We will discuss Never Let Me Go by Kazuo Ishiguro. Our facilitator will be Therese Jones. Dinner will start at 6:15 p.m. Discussion will begin at 6:30 p.m.

The LDS Hospital Ethics Committee will meet in the Pugh Board Room at 7:30 a.m.

The Division of Medical Ethics Resident House Staff Conference* will be held at 12:30 p.m. at the VA Medical Center in the Tsagaris Conference Room. The topic is “Telling the Truth When the News is Bad” The facilitator is Jay Jacobson.

A 2nd Physicians Literature and Medicine Discussion Group* will meet in the UUMC Administrative Large Conference Room 5A275. We will discuss Vigil by Alan Shapiro. Our facilitator will be Susan Sample. Dinner will start at 6:15 p.m. Discussion will begin at 6:30 p.m.

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Mark Danner Lecture—will be held at the Salt Lake City Library. He will speak on: “Into the Light of Day: Torture, Human Rights, and the New State of Exception.” Danner will be signing his two most recent books following a Question and Answer period. The Division of Medical Ethics is among the co-sponsors for this event.

The Division of Medical Ethics Resident House Staff Conference* will be held at 12:30 p.m. in the LDSH classroom D/E/F. The topic is “Telling the Truth When the News is Bad” The facilitators will be Armand Antommaria and Therese Jones.

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This month’s short story Recommendation for your enjoyment from our Medical Humanities Scholar Tess Jones:
“ Fetishes,” by Richard Selzer
...a story about a woman undergoing surgery and the priorities, dignity and kindnesses in her doctor-family relationships. Copies of the piece can be found on our website or picked up at the DMEH, or by calling us at 408-1135.

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