COMMUNITY ETHICS

FROM THE DIRECTOR

I have just finished reading all of the articles in this newsletter—as a way to gauge how and what I would write in my “Director’s column.” I started off with Gene Hirsch’s “The Intimacy of Dying.” I’ve read this before, several times before in fact. It’s good, I thought, I could skim it. But today, it just stopped me in my tracks! The last time I read it, I hadn’t shared with my dear friend Nancy the death of her mother, nor had I talked with her mother about her cancer, her most recent trip to New Mexico, or about how she loves her grandchildren. I hadn’t yet taken part in the loving vigil in the library of my friend’s home where her mother told me days before she died, “I feel like a queen!” She spent her very last days there, amidst the tender and attentive care of her family.

Instead of talking about “D&D” (“death and dying”), Gene suggests, we should talk about “D in L” (“death in living”)! Of course, I never put it that way. Then I thought of those photos my younger brother Art sent. He had just visited some cousins in Dallas—Leah and Aaron are both dying, we have heard. But there they all were! Out for a great meal with the joy I remember them showing when we were kids! So, I heard something different when I read his words today. Or was I reminded of something I had forgotten? And as I read on, I could hear Gene talking and gently delivering his message with a twinkle in his eye. Consider this phrase:

“...When we lose a loved one or even think about losing a loved one, we are grieving. We actually begin to grieve in very small ways well before a person dies. Have you ever thought about how much you’d miss someone dying or leaving you? Have you sometimes become anxious for a moment at the thought of losing your child? Then you’ve grieved just a bit. And in the process, you may have enriched your own life and that of your loved one by awakening your sensitivity and reminding yourself of your appreciation of that person. For these reasons, you may want to pause a bit the next time you grieve to think about how fortunate you are to be able to do this.”

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I have never been able to explain grief in this way; yet I know it happens this way. Gene Hirsch—friend, poet, "retired" cardiologist. We are fortunate indeed to have you with us as a teacher and it is with pride that we use this article and two poems as the "centerpiece" in our current issue of Community Ethics.

Then I moved on to Rhonda Hartman's two articles, "No Means No," a summary of the Duran case and what it teaches us about advanced directives, and "Dying Young: Cues From the Courts," an exploration into five court cases regarding end-life-issues for adolescents. Once again, I could actually hear Rhonda carefully discussing the terms in the papers. About the Duran case: "For reasons we understand and for reasons we do not understand, health care providers sometimes resist honoring patient's directives to refuse life-sustaining treatment." From Dying Young: "Collectively, these cases provide us with cues about issues that merit closer examination in the clinical environment where young patients are dying—issues that warrant ethical discourse and educational development in order to achieve optimal levels of understanding about how the quality of care may be enhanced for young, dying patients."

Each word deserves its own articulation and attention. Taken together, her words provide a thoughtful, clear, and poignant vision of the status of the courts interpretation of dilemmas that occur in our hospitals—a vision that Professor Hartman is documenting, interpreting, and teaching to all of us. She does it in her unique manner and for that we are deeply appreciative.

Alan Meisel's review of the current state of Physician Assisted Suicide focuses on John Ashcroft's objection to using drugs in doses that would prove to be lethal, and the recent Supreme Court decision to override that objection. In 1989, Alan published his remarkable book, The Right To Die (John Wiley & Sons, Inc. (New York) 1989). The book is now in its second edition and includes annual supplements. When I introduce Alan as a speaker, I always mention that his book won the American Association of Publishers' Most Outstanding Book Award in the Legal and Accounting Practice Category. It certainly deserves the award, for it clearly, concisely, and authoritatively reviews the legal cases—over 100 by now—that have forged our policies on Right to Die issues. This voice is a welcome one for these are complex dilemmas, and the facts are hard to come by. Having Alan take the time to write for our newsletter and lend his perspective on this timely topic is a privilege.

A case report entitled "Finding a Language, Creating a Space," written by David Barnard, adds another dimension to this issue of the newsletter. David observed this case while he was on his sabbatical in Canada. It resembles the types of cases that appear in his remarkable book on Palliative Care, Crossing Over: Narratives of Palliative Care (New York: Oxford University Press, 2000). This particular case points out the international differences in how patient's spiritual needs are or are not attended to at the end of life. These differences can be attributed, in part, to concerns for a "minimal length of stay" and adhering to "restrictive utilization review requirements" that Palliative Care in the U.S. must satisfy. I would like to hear more about this from David and I trust we all will, in the future. David, in addition to his responsibilities at the University, will begin Law School in the Fall. He hopes to learn the skills that will enable his gentle, yet compelling voice to be heard in arenas other than academia. Best of luck, David!

We close this issue with an article by the Reverend Bruce Bryce, who is also "retired." (To all of you who are, in Paul Simon's words "Gettin' Old," you might take note of the contributions of our retired CEP faculty.) Bruce speaks again of the importance of religion and spirituality in caring for patients, but his essay also includes a theme that relates to the costs of that care. He actually told his Board of Directors that his "efforts made friends, not profit." He went on to point out the anxiety that spiritual leaders feel in the cost-conscious healthcare environment. The message that Bruce delivered was to educate all of us, and that included the people on his hospital board who had the power to make decisions about whether this type of care would continue to be provided. We hope this issue extends his message to a wider audience.

All in all, this is a spectacular issue of Community Ethics. My special thanks to Rhonda Gay Hartman, who oversaw this edition's publication. That the CEP can garner the wisdom of each of these contributors as they focus on an issue like "Death in Living," is one of the strengths of the network. From an intimate personal perspective, to a legal, ethical, case-based perspective, to one captured in poetry, religion, and politics, the issue is a microcosm of what our ethics education program is about. Many newsletters come across your desk…and end up either stacked in the center….or filed permanently on the other side! Please take some time to visit with our faculty and staff as you read this issue of Community Ethics. It just might stop you in your tracks as well.

Rosa Lynn Pinkus, Ph.D.
Director, Consortium Ethics Program
Thwarting Assisted Suicide Threatens Palliative Care

by Alan Meisel, J.D.
Director, Center for Bioethics & Health Law

Physician-assisted suicide may have come out of the closet thanks to Jack Kevorkian’s macabre antics, but it is now a topic of serious public discourse. Throughout the 1990s and into the new millennium, various attempts have been made to legalize physician-assisted suicide through legislative and judicial activities. All but one has failed, and now the Bush administration is intent on burying that one too.

The first effort to legalize physician-assisted suicide to come to a vote actually predated Kevorkian’s activities. It was a failed referendum in California in 1988. The second failed referendum was in Washington state in 1991, which led the supporters of legalization to commence a lawsuit to declare unconstitutional the state’s law making assisted suicide a crime. In this lawsuit, several terminally ill individuals and their physicians sued the state claiming that the law making it a crime to aid suicide violated their rights under the United States Constitution’s guarantee of due process of law and the equal protection of the laws. In 1994, a federal trial court judge in Seattle upheld their claims and declared the law unconstitutional as applied to competent, terminally ill patients seeking assistance in ending their lives from a licensed physician. The state of Washington appealed the case to the United States Court of Appeals for the Ninth Circuit, which also held the Washington prohibition on assisted suicide unconstitutional.

At about the same time, a similar lawsuit was brought in the federal courts in New York, making similar claims about a New York statute also making aiding suicide a crime. The result at first, however, was different. The federal trial court judge ruled that the New York statute did not violate the federal constitution. Then the petitioners — again, terminally ill patients and their physicians — appealed the decision, and the United States Court of Appeals for the Second Circuit, reversed the trial court decision. It held that the New York law violated the constitutional guarantee of equal protection because terminally ill patients who were being kept alive by life support could obtain assistance in ending their lives by having a physician, at their request, withdraw life-sustaining treatment, but terminally ill patients who were living without life support — but suffering greatly — were prohibited from obtaining assistance in ending their lives. These two lawsuits (Washington v. Glucksberg and Vacco v. Quill) were appealed to the United States Supreme Court, which decided them both in June 1997.

In the meantime, however, other highly significant events were taking place in Oregon. In 1994, voters in that state were the first to approve a referendum to legalize physician-assisted suicide. A lawsuit to invalidate this new law was quickly filed, and as a result the law did not go into effect. Eventually, the United States Court of Appeals for the Ninth Circuit — the same court that had struck down the Washington law making assisted suicide a crime — reversed this decision, but the reversal was put on hold — and thus the Oregon law legalizing physician-assisted suicide was also on hold — pending appeal to the United States Supreme Court.

Thus, when the Washington and New York cases came before the Supreme Court, physician-assisted suicide had already been legalized in one state. The Supreme Court unanimously ruled that the United States Constitution did not guarantee terminally ill citizens of all states the right to physician-assisted suicide, thereby reversing the decisions of the lower federal courts in Washington and New York. However, the Court’s opinions did not prohibit states from legalizing physician-assisted suicide if they wished to do so. It merely held that the United States Constitution did not guarantee such a right. And when the lawsuit challenging the Oregon referendum legalizing physician-assisted suicide finally reached the United States Supreme Court several months later, the Court refused to consider it. This had the effect, some three years after its initial passage, of finally putting the Oregon law into effect. And it has been in effect ever since, with 70 patients having used it between November 1997 and the end of December 2000.

Shortly after the Oregon law went into effect, the director of the federal Drug Enforcement Administration (DEA) issued a directive ruling that it would be a violation of the federal Controlled Substances Act for any physician, including those in Oregon, to dispense controlled substances for the purpose of aiding a patient in ending his own life. However, the DEA director neglected to consult with his boss, Attorney General Reno, who commenced a study of the action and concluded that the DEA director had not acted in keeping with the Congressional
purpose in enacting the Controlled Substances Act—namely, to prevent trafficking in illegal drugs and abuse of legitimate drugs. Reno concluded that the Controlled Substances Act did not support the ban on the use of legitimate drugs for an approved medical purpose.

During both the Clinton administration and the Bush administration, Congress attempted to overturn Reno's ruling but failed to do so in part because of concerns that such a law would also thwart use of medications needed to relieve pain in the terminally ill. However, now that the Attorney General's office is in the hands of a dyed-in-the-wool opponent of physician-assisted suicide—John Ashcroft—the Bush Administration has taken a new tack in thwarting Oregon's efforts to maintain legal physician-assisted suicide by once again issuing a directive that the prescription by physicians of medications to aid a patient in ending his or her life violates federal law and is grounds for withdrawal of the physician's authorization to prescribe controlled substances.

Where this will all go, no one knows. The Ashcroft directive was challenged in federal court, and in April 2002, a federal judge in Portland, in an opinion that was unusually critical of a high federal official, held that the Attorney General acted without legal authority in issuing this directive. For now, at least, that means that the physician-assisted suicide is alive and well in Oregon. However, the federal government might appeal this ruling, and if it does, it might ultimately wind up before the United States Supreme Court.

There is good reason to believe that the Ashcroft directive violates the Supreme Court decisions about physician-assisted suicide in at least two ways. First, the Supreme Court permitted states to legalize physician-assisted suicide if they chose to do so, and that is exactly what the voters of Oregon chose. Second, a majority of the nine Supreme Court justices made clear that terminally ill patients had a right to adequate palliative care and if it was not made available, they would be inclined to revisit their ruling that there was no constitutional right to physician-assisted suicide.

It is ironic that a "states' rights" administration would attempt to thwart a Supreme Court ruling giving each state the right either to legalize physician-assisted suicide or not legalize it as its citizens wish. It would be tragic if the same administration were permitted to adopt a ruling that imposed suffering on terminally ill patients by restricting access to adequate palliative care thereby making a mockery of the sanctity of life it is ostensibly seeking to promote.

University of Pittsburgh Offers Master of Studies in Law

There is a new academic program at Pitt that might be of interest to participants in the CEP.

The University of Pittsburgh School of Law offers a masters degree in law, intended to provide legal education to people who use law— or will use law—in their careers and who want to learn more about it, but who do not want to become lawyers. The degree requires 30 credits, including an introductory course designed especially for this program, with the remainder of the courses to be chosen from among regular law school courses. The degree is available on a part-time basis over no more than four years, or full-time for a year. In addition to a concentration in health law—which includes bioethics—students may concentrate in a variety of other areas in law, such as business law and intellectual property law, or design their own concentration.

For further information, visit the University of Pittsburgh School of Law at http://www.law.pitt.edu/msl or call 412/648-7120 for descriptive materials.


For reasons we understand and for reasons we do not understand, health care providers sometimes resist honoring patients’ directives to refuse life-sustaining treatment. This resistance is due, in part, to a general uncomfortableness of letting people die in hospitals when the means to prolong their lives are at our disposal. Being uncomfortable in letting people die creates conflict with individual decision-making autonomy, despite recognition for autonomous decision making in law and bioethics. Autonomous decision making is grounded in the ethical value of personal determination and dignity, and in the legal right of liberty for making intimate, personal decisions, especially involving bodily integrity. This ethical value and legal right take center stage in conflicts involving the decision to refuse life-sustaining treatment.

In re Duran is instructive. Maria Duran, 34-years-old, had a diseased liver and needed a liver transplant to survive. Maria decided to be evaluated as a candidate for transplant at the University of Pittsburgh Medical Center because she had been told that surgeons at UPMC could perform transplant surgery without a blood transfusion. This fact was important to Maria, who had deeply-held beliefs in Jehovah’s Witness. During the evaluation, Maria discussed her beliefs with the treating physicians. She also executed a durable power of attorney (DPA) for medical care, which read in pertinent part:

I am one of Jehovah’s Witnesses. On the basis of my firmly held religious convictions, and on the basis of my desire to avoid the numerous hazards and complications of blood, I absolutely, unequivocally and resolutely refuse homologous blood (another person’s blood) and stored autologous blood (my own stored blood) under any and all circumstances, no matter what my medical condition. This means no whole blood, no red cells, no white cells, no platelets, and no blood plasma no matter what the consequences. Even if health care providers (doctors, nurses, etc.) believe that only blood transfusion therapy will preserve my life or health, I do not want it. Family, relatives or friends may disagree with my religious beliefs and with my wishes expressed therein. However, their disagreement is legally and ethically irrelevant because it is my subjective choice that controls. Any such disagreement should in no way be construed as creating ambiguity or doubt about the strength or substance of my wishes.

In her DPA, Maria designated Larry Johnson as her health care agent.

When Maria was informed that she was close to receiving a liver, she traveled from her home in New York to Pittsburgh, where she stayed with Mr. Johnson and his wife. Before leaving New York, Maria discussed her religious beliefs with her family, including her husband Lionel Duran and their two teenage children. Of her immediate family, only Maria held beliefs as a Jehovah’s Witness.

Prior to undergoing surgery, Maria provided her doctors with copies of her DPA, and she reiterated her refusal to accept blood transfusions. Following surgery, Maria’s body rejected the liver, and her physicians determined that a second surgery would be her only chance for survival. When Maria became incapacitated due to her deteriorating physical condition, Mr. Johnson consented to the second surgery. He also consented to a kidney dialysis and biopsy for her. Maria’s condition further deteriorated, causing her to become comatose; her physicians then determined that only a blood transfusion could prolong her life.

Health care provider responsibilities should include talking forthrightly with patients about their values, preferences, and treatment choices...
Lionel Duran petitioned the Pennsylvania Orphan's Court to appoint him as an emergency guardian for the purpose of consenting to the blood transfusion. The court scheduled a hearing on the petition and heard testimony from Mr. Duran, Maria's treating physician, and her sister. Mr. Johnson was not notified about the hearing. At the conclusion of the hearing, the court granted Mr. Duran's petition, authorizing him as Maria's emergency guardian. Despite Mr. Duran's consent to transfuse Maria, she died.

Mr. Johnson filed exceptions to the Orphan Court's order, requesting the court to rule on his exceptions. Instead, the court affirmed its order granting Mr. Duran's petition, and Mr. Johnson appealed to the Pennsylvania Superior Court. The Superior Court responded to the following issues: (1) whether the case should be dismissed because it was moot; (2) whether a patient's common law and constitutional rights of bodily self-determination and religious freedom protect her refusal of medical treatment from being overridden by the appointment of a guardian with authority to consent to the treatment in question; (3) whether a person, whose values conflict with the patient's, should be appointed as her guardian to make health care decisions contrary to her instructions, without any showing that her designated health care agent acted improperly; and (4) whether a patient who has appointed her own health care agent has been deprived of due process of law by the failure of her agent to receive notice of a petition to appoint a guardian to make health care decisions for her contrary to her values and instructions.

As to the issue of mootness, the Superior Court found that the appeal should proceed despite Maria's death, because the points raised: (1) are otherwise apt to evade review (a transfusion ordered by a court in an emergency will be given before the appellate process can be completed); (2) are capable for repetition (given a substantial Jehovah's Witness population, it is likely that medical treatment involving this populace will result in health care providers seeking court orders to authorize transfusions); and (3) entail matters of public importance (privacy, bodily integrity, and religious freedom).

The Superior Court then proceeded to the merits of the case. First, the Court decided the issue of whether individual rights in bodily integrity and in freedom to exercise religious beliefs protects a patient from court appointment of a guardian to override her express wishes. The Court stated that the concept of bodily integrity is "sacred and deeply rooted" in our common law. This concept forms the basis of the informed consent doctrine and, accordingly, the basis for rights to choose and to refuse medical treatment. The Superior Court also identified four countervailing state interests: (1) protection of third parties; (2) protection of the ethical integrity of the health care profession; (3) preservation of life; and (4) prevention of suicide. In Maria's case, the Court assessed that these interests were not compelling enough to override her right to refuse blood transfusions. Specifically, the Court could find no evidence in the record that implicated third party interests. Although Maria had two teenage children, the Court found the record before it devoid of any evidence that these dependents would be left emotionally and financially bereft by Maria's refusal of treatment.

While rights in law are not absolute, state interests generally are not overarching enough to prevent a patient from exercising the right to refuse even life-sustaining medical treatment. As the Superior Court acknowledged, "[o]n balance, the right to self-determination ordinarily outweighs any countervailing state interests, and competent persons generally are permitted to refuse medical treatment, even at the risk of death."

The Court further found that medical ethics is neither offended nor implicated when health care providers abide by a patient's competent, thoughtful, and deliberate refusal of treatment. It is, according to the Court, axiomatic that doctors want to treat patients to the best of their ability and to promote patients' well-being; depriving patients of personal autonomy in decision making is not requisite to this axiom. As to the state's interest in preserving life, the Court determined that this interest is "relatively low" when the patient's decision neither injures others nor impacts the public at large.
And, while the state’s interest in suicide prevention correlates to life preservation, Maria did not harbor an intent to die. Rather, her treatment refusal “merely allow[ed] the disease to take its natural course.” The Court explained that her death resulted from the underlying disease and not from any self-inflicted injury. Thus, state interests in preventing Maria from refusing life-sustaining medical treatment did not outweigh her right to personal autonomy and “must give way to Maria’s liberty and autonomous decision to forego a blood transfusion that might prolong [her life].”

Once the Superior Court established the strength of a patient’s right to personal autonomy in medical decision making, it turned to the issue of whether the Orphan’s Court abused its discretion by appointing Mr. Duran as an emergency guardian. Guardianship appointments are appropriate when a court determines that clear and convincing evidence has shown that a person: (1) lacks capacity; (2) needs a guardian; and (3) the court’s failure to appoint a guardian would cause irreparable harm to the person or to the person’s estate. In Duran, the Superior Court ruled that the Orphan’s Court appointment of Mr. Duran as emergency guardian was error. The Court concluded that to rule otherwise “would devitalize personal health care directives and devalue the common law right to personal autonomy.” Notably, Maria did not need a guardian. She designated Mr. Johnson as her personal representative and no evidence suggested that Mr. Johnson acted contrary to either Maria’s expressed wishes or to her interests. And yes, Mr. Johnson should have been notified about the guardianship hearing. Pennsylvania statutory law requires such notification when it “shall appear to the court to be feasible in the circumstances.” Not only was it “feasible,” but the record revealed that Mr. Duran and the health care team knew about Mr. Johnson and where to contact him. Indeed, they had contacted him to give consent for Maria’s second surgery, kidney dialysis, and biopsy.

In addition to what the Superior Court ruled, several points not fully developed or ruled on by the Court merit consideration. First, there is an issue of standing that can preclude judicial review. Standing means that a person has a legally protected and tangible interest at stake in the controversy. Who has standing in particular disputes is sometimes established by statute. The Superior Court in Duran noted that the case was not a statutory cause of action where the legislature had designated who may bring the action; therefore, Mr. Johnson had standing to proceed with appellate review. Unlike Mr. Johnson who, as Maria’s health care agent, had a stake in the legal proceeding, a person contesting a patient’s medical decision making may be challenged on the ground that he or she lacks a legally protected and tangible interest in the matter. Health care providers are occasionally concerned about the possibility of lawsuit should they honor a patient’s express refusal for medical treatment and “a remote relative comes out of the woodwork.” Although Pennsylvania does not statutorily bar that person from initiating legal action, the person’s standing to proceed may be vulnerable to challenge. Someone may be a ‘relative’ but is estranged from the patient and/or knows little about the patient’s values and desires and, thus, any interest at stake that the person may have is tenuous at best.

Further, although the Superior Court underscored the viability of state interests, it determined that, as applied to the factual record in Duran, these interests were not compelling enough to override Maria’s express desire to exercise personal autonomy in medical decision making. These state interests, of course, must be considered on a case-by-case basis, and the strength of each depends on the facts adduced. While
rights in law are not absolute, state interests generally are not overarching enough to prevent a patient from exercising the right to refuse even life-sustaining medical treatment. As the Superior Court acknowledged, "[o]n balance, the right to self-determination ordinarily outweighs any countervailing state interests, and competent persons generally are permitted to refuse medical treatment, even at the risk of death."

Lastly, the Court emphasized the directness of Maria’s wishes and empathized with those who care about her: "[I]t is a difficult thing to decline potentially life-saving treatment for a loved one, rendered mute by her condition, on the basis of her devotion to religious beliefs. Nonetheless, absent evidence of overarching state interests, the patient’s clear and unequivocal wishes should generally be respected." From an interpretive standpoint, this language may raise questions for clinical practitioners about what constitutes a "clear and unequivocal wish" (other than simply knowing it when one sees or hears it) and how a patient’s wish should be discerned. Yet, the Superior Court did not require the expression of "clear and unequivocal" wishes for recognizing the right to refuse medical treatment—only that the clarity of Maria’s wishes left no question about what she wanted. The best we may be able to discern is that more likely than not the patient would decline a particular medical treatment based on what is known about his or her wishes. Given the legal framework established by the Superior Court in Duran, every effort should be made by health care providers to ascertain, with documentation, the patient’s wishes, and to encourage patients to clearly communicate their desires. These efforts may result in patients wanting to execute and/or revise DPAs and living wills. Health care providers should also be sensitized to how they address patient concerns, expression of values, and desires.

Moreover, while patients’ desires may stem from religious beliefs, as in Maria’s case, religious beliefs are not the only values on which patients base autonomous decisions. Health care provider responsibilities should include talking forthrightly with patients about their values, preferences, and treatment choices, and attempting to persuade them to accept treatment, sometimes on a short-term basis, when patients refuse treatment. As Dan Brock and Steven Wartman have cautioned, however, "even the irrational choices of a competent patient must be respected if the patient cannot be persuaded to change them." There is a limit to persuasion and that limit is when we understand from the patient or through the patient’s health care agent that treatment is unwanted and why, even if the treatment would prolong life.

Any time life hangs in the balance, it is reasonable that health care providers should struggle with issues related to patient treatment decision making, especially decisions that forego life-prolonging measures. But, as the Pennsylvania Superior Court in Duran instructs, when a competent patient has made known her autonomous wish to refuse treatment—regardless of what health care providers and/or family members think would be best for the patient—those wishes should be respected. As Duran counsels, no really does mean no!

References


Drs. Michael A. DeVita and Rhonda Gay Hartman have written a comprehensive presentation (slides or PowerPoint) on the Duran case. The presentation is entitled, "Advance Directives and In re Duran: What Does It Mean?" The presentation covers the Pennsylvania Superior Court’s ruling in Duran, highlighting the importance of the decision and what health care providers should know. To schedule the presentation, please contact Jody Stockdill, Administrator, Consortium Ethics Program at (412) 647-5832.
The Role of Spirituality and Religion in the Process of Dying and Death

By The Rev. Dr. Bruce E. Bryce, Retired

Dr. Bryce is the former Director of Pastoral Care at Sewickley Valley Hospital, D.T. Watson Rehabilitation Hospital, and Valley Care Masonic Center. In retirement he serves as the Interim Pastor of the Presbyterian Church of Coraopolis.

The quality of life in the western world has been significantly improved over the last thirty years because of the impact of people like Dr. Elisabeth Kubler-Ross, Dame Ceciley Sanders, and—yes—possibly even Dr. Jack Kevorkian. If for no other reason, these high profile people have raised the public consciousness of the process of dying, death, bereavement, and other end of life situations. By itself, On Death and Dying has given western culture a more realistic and positive attitude toward this natural process of life. Along with a growing number of medical, social, philosophical, and religious thinkers, these giants have helped create an environment in which the subject of death is no longer feared but actually embraced with a beauty that transcends the provincial folklore and shallow religious rationalization of even a generation ago. The veneer of blind professionalism and misguided paternalism that hindered physicians for a long time has been removed, and more compassionate and understanding doctors have emerged, better able to meet the total needs of their patients. They no longer ignore the whole person when dealing with a diseased body. They have been freed to speak about prognosis as much as about diagnosis. They are better able to concentrate on the quality of life as well as on its quantity.

I remember appearing before the Board of Directors of a hospital on whose staff I served as Director of Pastoral Care. Before I made my presentation concerning what I did to justify the salary they paid me, I was able to observe their deliberations. They gave much thought to how they would spend the millions of dollars they had generated through fees for service, financial development, and governmental grants and subsidies.

Upon being introduced as the individual whose job it was to spiritually usher the sick, the suffering, the dying, and their loved ones through “the process” of living, dying, and grieving, I acknowledged the importance of what they were doing and how it affected the lives of those whom they were committed to serve. I enlightened them to the truth of the matter that my responsibilities in no way generated one single cent toward their efforts. I told them I was aware of what they had expended to fulfill the hospital’s mission, and that my efforts made friends, not profit. I shared with them the anxiety of spiritual health caregivers about job security during these times of economic challenge.

I urged them to respect and support the work of spiritual caregivers with the same understanding they had for physicians and nurses. I wanted them to realize that without the contribution of those who met the spiritual needs of the patients and families, the great work of the medical disciplines would be much less effective. My presentation helped them understand, appreciate, and respect the efforts of social workers, chaplains, and others daily meet the unseen and often difficult-to-define aspects of facing life while dying, and life after the dying is over.

Spiritual health caregivers deserve a place on the team. They are the bridges over the troubled waters of life. They are like “spiritual kayaks” that transport the dying and the bereaved over the “white water of grief.” They are those who help the dying and the bereaved make the decisions they would rather ignore. They are as significant as those who help patients deal with the disease that has attacked the physical body. They are also “catchers” for physicians who choose to “pass the buck” to those who are better able and more willing to deal with that which is beyond the realm of medical science.

The influence of those who guide people through the end of life is as important as the influence of those who walk with them through birth and growth. I made this point in my remarks to the board by saying that while they had spent hundreds of millions of dollars over the years to provide the best medical professionals, equipment, and facilities, these efforts had, at best, only enhanced life for seventy, eighty, ninety, or a hundred years. I then reminded them that they only needed to spend a fraction of a percent of these funds for those in the spiritual sciences—those who deal with eternity.
Thanks be to God for those who have broadened the viewpoint of health care. Care of body and mind is not complete unless the spirit is included. They cannot be separated. There must be a commitment to a wholistic (please accept my spelling of this word) approach.

Too often the role of religion has been to camouflage the significant feelings experienced by the dying and those who walk to valley of the shadow of their death with them. As a clergyman, appreciate the relevance of holy writings, liturgy, and spiritual counseling. They have carried the dying and the bereaved through the pain and turmoil of “the process” and they have deposited them at a place where they must then move on. The importance of the presence of those who share the same spiritual values needs also to be seen as being essential to the restoration of physical, mental, and spiritual health following the devastation of death.

As a hospital delivers medication, therapy, nursing services, social services, surgical services, etc., so the church, the synagogue, or the mosque has the means by which faith is delivered. Faith is an effective medication in the treatment of the spiritual distress that accompanies “end of life” pain. Not all medication is scientifically developed. Within the resilient inner human being resides which often heals in a manner unexplainable to scientific measurements. Faith in a higher power, one’s physician, or one’s self can and does generate great healing power.

Religion is an institution created by human beings to meet the challenges science cannot understand. It is a means to an end—an end that benefits humanity far beyond the realm of physical health and existence. It is justified by spiritual faith. It helps that faith to be seen and developed. It encourages that faith to be used and it offers guidelines by which that faith can be used.

The role of religion is to promote the relevance of human spirituality. Its value is in being a part of the common effort with the physical and social sciences to elevate the wholeness of the human being.

The Christian writer James said, “Faith without works is dead.” Those disciplines that join together to meet the wholistic needs of the sick, suffering, dying, and bereaved are partners in this ministry to unlock the tremendous power of faith that every human being has locked within his or her soul.

TRUE GRIT

by Sally Rogers

My grandmother was 70 when I was born. She died at 96. She had high blood pressure, chronic heart disease and arthritis of the spine, hands and feet. The spinal arthritis bent her double by the time she was 80, and her hands were crippled and painful to use. She nevertheless enjoyed life to its fullest, laughed easily, nurtured as second nature.

She grew her own garden and orchard, canned from their abundance, baked her own bread, cleaned her own house, washed clothes in a big black wash pot, cuddled children, made tea cakes, wiped tears from small faces, and cooked three meals a day until she was 91 and entered a nursing home. In the 26 years my life and hers coincided, I learned more from this small, crippled, aged woman than I could learn from any other in 100 years. That “elderly” wisdom has been passed now to my children, and my grandchildren. If she had “done her duty” and died, four generations would have been deprived of knowledge, wisdom, the ability to be self-sufficient, and all the other of those small but crucial everyday lessons that make life infinitely greater in sum than the whole of its parts would indicate.

In the South, we have a word—”grit.” If plural (“grits”), one eats it. If singular (“grit”), one is eat up with it. My grandmother was plumb eat up with grit, to use the vernacular. Until there is a way to measure the aforementioned grit, leave well enough alone. People come into their dying in their own time and place, just as they do their birthing.

And there’s not a one among we humans qualified to make that call.

Sally Rogers (saltex@interrex.net) is a “semi-re-tired” journalist who writes a trice-monthly column for the 145-year-old Colorado County Citizen in Columbus, Texas. “True Grit” came to our attention via the MCW Bioethics Listserv.
Death and dying are not exactly popular subjects for idle conversation. I do not know anyone, including myself, who is entirely comfortable about examining the subject in public. Yet, so many difficulties arise, not from the subject itself, but from our personal fantasies and fears of those fantasies. If we can never discuss the subject at a time when no one is dying, we can never test our fantasies against reality and never come to grips with one of the most important events of our lives. Even dire realities are seldom as threatening as the fantasies to which we cling.

To begin with, I think "D & D," death and dying, is a poor term. Perhaps "D in L," Dying In Living, may be better. Although dying may lead to death, it is an inseparable part of our lives. Denying dying in order to deny the ominous thought of death could haunt us in ways that "stunt our growth." The two are different. We have the option of carrying our awareness, our strengths, our understanding, our self-regard, into our declining process in ways that can spare us and our loved ones untold anguish.

"Enemy" or "Friend"

It would be wrong to assume that death is a universal enemy at all times to all people. You are not surprised to hear that attitudes to dying may become individually "real" only in our terminal stages of life. For example, most of us are familiar with the ninety year old woman who loses her husband and suddenly reverses her attitude, wishing for her own death because life without her spouse is no life at all. We have seen people with terminal illness who have wanted more than anything else to be relieved of their strife. We have seen mothers stay alive far longer than predicted until their sons arrived home from the battlefields, following which they promptly died in peace. We have seen aged people who have simply grown tired and wish to close the book.

So, death is final. But dying is not. I will not speak of new miracles and breakthroughs. For the foreseeable future our concern is comfort, palliation, reflection, and those things about dying at any age that we can do something about. I will examine dying with you and try to persuade you that it is within your reach to manage its occurrence as you manage other parts of your lives, growing considerably wiser by accepting it and by sharing your questions and discussion with others.

I can think of at least three distinct intimacies related to dying:
1) the intimacy of thinking and sharing your thoughts,
2) the intimacy of making thoughtful decisions about it, and
3) the intimacy of sharing those decisions and the peace and comfort they can bring at the end of a life.

Talking About Dying

Some people deny dying because they have not yet come in contact with their own mortality. Older people, more likely, may feel they would be rejected for speaking their inner thoughts and fears. Perhaps they "should not" have such thoughts. Perhaps they should show a stoic "stiff-upper-lip." "Who would care?" Or, they may imagine that if they think or speak about dying, it becomes more likely to happen. They may not speak to their children or spouses about it because they do not want
frighten them. The wish is kind, but silence, in the end, may not be so kind. Professional guidance is available to help people begin to speak about such matters.

Younger people will usually not initiate a discussion of dying with their elders, possibly because they think that such questions might hurt their feelings or because the discussion might in some mysterious way bring it about. Such a discussion may open up a "can of worms" for all involved. But at this early point the "can of worms" can be far less threatening than if it "opens" under the pressure of impending death. In fact, it might resolve difficult issues and resentments that should have been resolved a long time ago. Professional help is particularly good at helping us put such problems behind us.

Imagine a son or daughter asking, "Mom, Dad, at the end of the line, what do you think you will want or need from us? Let's talk about how we can understand each other better and feel less confused when the time comes." That's hard to imagine. But what if the parent said, "Hey kids. I'm getting older. I'm going to die some day. I know it's tough to talk about, but could we have a few words, anyway?" You will have invited your children into your confidence in perhaps your most vulnerable spot. That's love and trust. And it can invite love and trust in return.

My point here is that we needn't be afraid to speak. Most of us are full of assumptions and frequently imagine that we have powers we simply don't have - in this case, the power to hasten death or bring it into our homes by speaking or even thinking about it. We can become afraid of possessing this imaginary power, dismiss the subject, or become "too busy living life" and unfortunately, become very silent. Some of us could miss opportunities to make important financial decisions, like those that minimize the tax bite to Uncle Sam. We fail to consider "Advance directives," i.e., "living wills" or "Durable Powers of Attorney," to express our wishes and to help make intelligent decisions for us if we lose our own decision-making abilities. At the point of impending death, I have seen uninitiated families panic and tear apart. I have seen families argue among themselves with gaping emotional wounds, and develop or unveil animosities that have brought hurt for many years thereafter. Discussion postponed to the time of death, if it can occur at all, may not have nearly the impact that it otherwise could - something like closing the barn door after the cow has escaped, or at best, while the cow is escaping.

Dying is a Living Process

The word "Dying" brings to mind many things. I’ll speak of it simplistically as a process not too dissimilar to growth and maturation. I mean it starts somewhere, undergoes reasonably predictable steps, and ends somewhere. In growth and maturation there are physical changes, recognition of them, new ways of thinking about one’s self, one’s future, aspirations, spiritualism, responsibilities, rewards, and many other things. In the dying process, there are also physical changes, with recognition of them, new ways of thinking about one’s self, one’s future, aspirations, spiritualism, responsibilities, rewards, and many other things. The details are different, but the recognition and adjustment processes are quite similar. And we who are older have gained experience from our maturation earlier in life. If we think about it, we may perhaps have even gained the wisdom to understand that those who hide their thoughts and feelings in isolation frequently risk going into disabling depression. Depression with aging, as well as with chronic and terminal illness,
is quite common. It can be extremely painful. Isolation is one of its hallmarks.

Our conscious dying process can begin at any time. It can begin when we tell ourselves we are dying. This can be at twenty-five years old or at fifty, or at 100. Or, as in most instances, it begins when the degeneration of our bodies becomes apparent and we begin to see a steady physical decline. When the decline is slow, we don’t, at first, think too much about it. When chronic or terminal illness occurs, we may anticipate possible suffering and hastening of the dying process.

Of course, each person lives and dies in his/her own individual way. There are no rules or stereotypes. But one way or the other, however gradual or rapid our decline, as the end approaches, we may be old and dying, but our functioning minds are hardly dormant. I have seen people with very important concerns asking very important questions. I have seen fears come alive. We may develop ideas of what the instant of death really will be like, about an afterlife, about feelings of loneliness or security, about legacy. In a healthy way, we bring closure to our lives by reviewing and resolving life problems and joys and by thinking of our legacies, what we are leaving behind to help others and to be remembered by. All this and more occur in the process of recognition and new ways of thinking and adjusting. If you are into slogans, you might consider, “No surmises, no surprises,” or “Excitement loses its excitement,” or “Gimme some Peace. I’ve earned it.”

Personal Thoughts

Candidly, my hair has turned gray and left me. I have wrinkles and am frequently sluggish. I am not the person I once was. In some ways, thank God for that. Perhaps I can even learn to like the person I am. But - I’ve begun my dying process. I’ve had to admit that I am going to die! I don’t know when or how or how fast.

Even for me, a physician, there was a long period of ambivalence. Finally, I spoke to my family about my feelings and thoughts. My legacy and my wishes, my perceived failures and guilt are no longer secrets. I feel a certain peace, even though I may not die for another twenty years. In that case, we’ll probably discuss it again when I get further along. Am I frightened? Of course. But only sometimes. I don’t dwell on it. I don’t think about it much. But I’m a lot less anxious now than before, because I feel a sense of relief, able to function better and enjoy my lifetime, unburdened. In fact, I sometimes feel downright rich. And no one else seems sad either! There is plenty of time for that.

I know that I’ll probably die as I’ve lived. I’ll struggle with dying as I do with life or accept it as I accept life. I know I may fear death as it comes close. I know that my dying may not be neat. It may be tortuous. I may feel angry at everyone, sad, exhausted. But I have control now in determining how I will conduct my dying process, to master eventual suffering, maximize my maturity, dignity and happiness along the way, and spare my loved ones the suffering of confusion at my death.

Right now, if you ask me what I would like at that time, I would like two things more than anything else, inner peace and a loving hand to hold. I have sat with many patients who have wanted the same things. And I have a measure of confidence no matter how rough the going gets, because I feel more in touch with myself now.

Thoughts About Hope

We families persist in battling death even when death has already won the battle. And at what cost? This question is constantly debated. I clipped an article from the Pittsburgh Post Gazette (2/3/00) headlined “Kids dying of cancer often suffer needlessly.” Dying people suffer from extreme measures and from pain even when it has been reliably determined that there is no longer any hope of prolonging a tolerable life. In this instance, how much are we fighting for the child’s, or our loved one’s, life which is over? Or, in our tortured state of mind, how much are we really fighting against our own personal difficulty at the thought of losing this loved one and our own personal fear of dying, which we may not have come to grips with?

We know what inevitable impending death looks like. And we cannot successfully wage a last ditch war against it. But we are far from helpless. Instead, in the context of an entire life span, we can treat it as the time in the dying process when we and our loved ones come together and support each other by sharing new ways of thinking, feeling, and behaving: Behaviors like tending to the effective relief of suffering, reaffirming bonds, and participating in peace, intimacy, community and closure. These are extremely powerful instruments of the living. They focus attention on our own caring personal characters, as well. They make us whole in our own lives. Thinking in this way is not always an easy thing to do. But it is realistic. And given the more difficult alternatives, it wins out.

Recently an eleven-year-old boy with a brain tumor was seen on television speaking with ease about his imminent death and his wish to donate his organs. This child had come to live to the fullest to the very end, in an enviably healthy closure to life. Brave, or prepared? Both.
As so many times in the past, we learn once again that “a little child shall lead them” (Isaiah II:6).

When we lose a loved one or even think about losing a loved one, we are grieving. We actually begin to grieve in very small ways well before a person dies. Have you ever thought about how much you’d miss someone dying or leaving you? Have you sometimes become anxious for a moment at the thought of losing your child? Then you’ve grieved just a bit. And in the process, you may have enriched your own life and that of your loved one by waking your sensitivity and reminding yourself of your appreciation of that person. For these reasons, you may want to pause a bit the next time you grieve to think about how fortunate you are to be able to do so.

Caring at End-of-Life

In the old days, medicine had little idea how to relieve suffering and promote enrichment and dignity in the terminal, dying person. In the new days, we know a great deal more. Thoughts and attitudes have begun to change considerably and constructively.

Yet, with current demands, it sometimes feels to me as if we don’t really care or that we think we don’t have the time to care. But I don’t really believe that either are true. Instead, in responding well to the immediacies of our social roles, we—health care workers and patients alike—may lose a bit of our inner sovereignty, that is, the luxury of self-directing our thought as independently as we might like.

One of my very respected mentors once confided his first steps in directing his thoughts toward discussing and considering end-of-life issues. When an exigency comes reflexly to mind, he suggested, simply hesitate long enough before responding to permit wisdom to operate. This can sometimes feel very trying for minutes, many minutes. But it works. I think most of us are wise, if we can only wait long enough to “watch it happen.”

The Hospice Movement

Perhaps the single most important innovation in helping people to cope and maintain dignity at the end of life has been the hospice movement. Hospice has stirred a quiet revolution that many of us doctors still do not fully understand. It is producing subtle, but unmistakable changes in medical care.

Besides offering care with dignity at the end of life, Hospice has changed the way we view chronically and terminally ill people and their loved ones. It has placed dying in a perspective that makes it more difficult for us to “write off” infirmed people who have aged and those who have lost their abilities to be economically productive. It has given us a humane alternative to the frenetic “emergency” mind-set, with its unprepared feelings at the end of a life. It has revived the model of selfless “giving” as standard medical practice.

Hospice brings out the best in all of us: It fosters intimate expressions of love, sympathy, and compassion in those of us who care for dying people. It gives the dying the gift of a healthy closure to life. Many so called “primitive” societies respect (even revere) their elders, caring well for them through the length of their lives. Perhaps in the future we will become less complicated and primitive again, enough to earn the reputation as a society that nests and cares for the least of its own, with the unimaginably satisfying humanistic rewards that follow.

PHYSICIAN *

EZ Hirsch

I saw you weep
as you spoke
with the patient
whom you’ve grown
to love
beyond the vows
that you took
as a child.

As souls join in peril,
you share her illness
though you cannot
suffer her pain
and you will not
die her death.

Still, you anguish
to watch her grow weak
and waste the substance
of her body.

Yet, you feel comfort
as she, silently smiling,
without pleading
or thrashing,
as she gently
holds your hand
as you walk with her
to the edge of life
and bid her goodbye.

* Written during a conference interview between Dr. Robert Arnold and his patient with AIDS
Finding a Language, Creating a Space
by David Barnard, Ph.D.

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Case. Mr. L.O. was an elderly Russian immigrant to Canada, admitted to the Palliative Care Unit of a Canadian hospital with advanced rectal cancer. When L.O. was first presented to the multidisciplinary team, his major problems were identified as persistent rectal pain and anxiety. The initial workup of the pain suggested a neuropathic component, and adjustments were made to L.O.'s medications. His complaints of pain and anxiety persisted over the next several days. L.O. then began to experience terrifying nightmares. Even during the day, when he was awake, he would have what he called "flashes" of frightening imagery, but the nightmares were the worst. L.O. was so fearful of them that he resisted falling asleep as much as he could. The images were horrific, often violent, with L.O. sometimes being the victim of the violence, sometimes the perpetrator. A CT scan was ordered to investigate the possibility of brain metastases as a contributing factor. At the same time, the attending palliative care physician had a long interview with L.O., in which they explored the content of the nightmares in depth. L.O. was an amateur artist, and the physician suggested that he might sketch the images in his dreams, or, if not the exact images, some rendering of how they made him feel. L.O. did this. Subsequent conversations revealed that L.O. was estranged from his children; the main reason that he needed to be in the Palliative Care Unit was that none of his children cared enough about him to support him while he lived at home. L.O.'s sketches showed a small figure—himself—cowering at the bottom of a deep pit, with another figure standing far above, looking down.

The physician suggested that L.O., who had become physically well enough for a weekend pass, bring some of his previous paintings back with him to the Palliative Care Unit. Within a few days, the sound of hammering could be heard from L.O.'s room. He was hanging his pictures, 15 or 20 in all. Most were landscapes, but there were also a portrait of a lovely young woman, and a winter scene, all in black and silvery white, of a snow- and ice-lined brook leading into a dark woods. The next morning L.O. reported that he had dreamed of eating a chicken dinner.

Discussion. Two features of this case are striking. The first is the necessity of combining medical and psychosocial approaches to L.O.'s nightmares and overwhelming anxiety. Both the CT scan and several psychoactive medications were appropriate and helpful. But it was the in-depth exploration of the content of the imagery, and even more, the suggestion that L.O. use his art to capture his emotional state in drawings, that appeared to unlock the insights and emotions that lay beneath the anxiety and terror. The physician succeeded in helping L.O. find a language to express himself more effectively and concretely than he had been able to do at a purely verbal level. The physician found a form of expression that "fit" the patient, even though that form was somewhat unconventional.

The second feature concerns the possibility of creating a living space in the Palliative Care Unit where L.O. could work his way to a feeling of peace and safety, despite his estrangement. This use of the inpatient palliative care service would almost certainly be impossible in the United States, with our minimal lengths of stay and our restrictive utilization review requirements. L.O. died in this Canadian palliative care unit many days after his physical and emotional symptoms had been brought firmly under control. But the inpatient environment remained critical to his spiritual wellbeing. Even though the Canadian health care system faces some of the same economic pressures as that in the U.S., the possibility still exists there for more flexibility to respond to the broadest range of patient or family need, compared to the limits imposed by hospice and palliative care financing in the U.S.

References.
Dying Young: Cues from the Courts

by Rhonda Gay Hartman

In an age where longevity of life is coveted and celebrated, dying young seems antithetical to the extraordinary biomedical achievements that make possible the extension and enhancement of human life. Yet, thousands of children and adolescents die from disease and accident in hospitals or at home each year. Despite extensive law and literature addressing end-of-life issues within the context of adult patient care, there is little information about the particular concerns and challenges confronting dying pediatric patients. This information is desirable not only for improving the quality of care but, to some extent, for providing a mirror that reflects the way we ought to treat any dying patient.

Relatively few state courts have decided end-of-life care for pediatric patients, although the short time span from 1990-1992 witnessed state courts determining the discontinuation of life-prolonging medical care for pediatric patients. This time frame is notable in bioethics and law because the United States Supreme Court decided *Cruzan*, Congress enacted the Patient Self-Determination Act, and states, including Pennsylvania, passed advance directive legislation. The cases are *In re Chad Eric Swan*, *In re Guardianship of Crum*, *Matter of Long Island Jewish Medical Center*, *In re Jane Doe*, *In re Joelle Rosebush*, and *Belcher v. Charleston Area Medical Center*. Each of these cases involved a dying older child or adolescent. Petitioners in these cases were hospitals and health care providers seeking clarification of their role in the decision-making process, and parents seeking declaratory relief from either civil or criminal liability; one case was initiated by a county prosecutor and three cases were appealed by the state following trial court orders to permit de-escalation of medical treatment for the minor patient.

Comprising “pediatric precedent” on which other courts have since relied when deciding issues relating to minors’ medical decision making, the courts in each case responded to the issue of whether life-prolonging treatment should be discontinued. In so doing, the courts employed either an autonomy-based (focusing on a minor patient’s right to refuse unwanted medical care) or a *pa-rens patriae*-based (focusing on an assessment by the court, in its role as *pa-rens patriae*, of the minor’s best interests) approach.

Collectively, these cases provide us with cues about issues that merit closer examination in the clinical environment where young patients are dying – issues that warrant ethical discourse and educational development in order to achieve optimal levels of understanding about how the quality of care may be enhanced for young, dying patients. These issues include: patient decision making and respect for pediatric patient preferences; the dynamic of the physician-pediatric patient relationship; the appropriateness of third party involvement such as a guardian *ad litem* when there is decision-making conflict; and discussions concerning treatment options, including the timely introduction of palliative treatment, hospice, and home care.

Primary decision makers in pediatrics are parents or guardians because minors, who are defined by law as any person under eighteen years of age, are presumed to lack the complement of skills necessary for medical decision making. In *Matter of Long Island Jewish Medical Center*, for example, the New York Supreme Court stated that minors lack the capacity to make decisions concerning their medical treatment and refused to allow Phillip Malcolm, who suffered from bone cancer and was just weeks shy of his eighteenth birthday, to refuse blood transfusion treatment due to his religious beliefs. By contrast, the West Virginia Supreme Court of Appeals in *Belcher* suggested that experience with life-threatening disease escalates maturity levels in minors, asserting that “[i]t is difficult to imagine that a young person who is under the age of majority, yet, who has undergone medical treatment for a permanent or recurring illness over the course of a long period of time, may not be capable of taking part with decisions concerning that treatment.” At issue was muscular dystrophy patient Larry Belcher, who died as a result of a DNR order that was authorized by Larry’s father in an attempt to de-escalate aggressive measures to prolong Larry’s life. The state high court remanded the case to the trial court for a determination
of whether Larry had been mature and capable and, therefore, should have decided whether he would have wanted a DNR order.

Like the West Virginia high court in Belcher, other courts have highlighted the importance of considering the preferences of the pediatric patient. For instance, the Supreme Judicial Court of Maine found 17-year-old Chad Swan's previous expressions that "if I can't be myself...no way...let me go to sleep" and "I would want somebody to let me leave - to go in peace" as clear and convincing evidence that Chad would not have wanted reinsertion of a gastrostomy tube in his vegetative condition to prolong his life. The Ohio Probate Court was similarly persuaded by 12-year-old Dawn Crum's observation about a little boy with spina bifida - notably that she thought it was unfair that he should live like that and that she would not want to live like that — to conclude that "if she were aware of her condition, Dawn would not want to remain in her current state." Dawn had acquired viral encephalitis, which caused her rapid deterioration into a chronic vegetative state that required intubation. And, the Michigan Court of Appeals, when deciding that life-support could be removed from 12-year-old Joelle Rosebush, who was unable to breathe without a respirator following an automobile accident that left her in a persistent vegetative state, emphasized the legitimacy of pediatric patient preference by urging state legislators to consider the legal validity of a minor's advance directive.

Like most states, Pennsylvania's advance directive legislation does not explicitly recognize a living will or power of attorney executed by a minor, although the Advance Directive in Health Care Act includes high school graduation and marriage as criteria for having a legally valid written declaration of wishes. Information is desirable about how an advance directive would potentially impact the dynamic of family relationships, particularly between parent and child, including whether an advance directive could allay parental guilt and grief in decision making about the minor's care and whether an advance directive would impact the interpersonal responsiveness to the pediatric patient during the dying process. Also deserving critical exploration in the clinical setting is whether an advance directive would provide a terminally ill pediatric patient with a sense of empowerment, control, and even relief, including a sense that she can shape the perceptions of others about her dying and achieve depths of personal meaning.

The courts in Swan, Crum, and Rosebush also raise a question concerning the level of evidence for honorary a pediatric patient's wishes to forego life-prolonging care. The Maine Supreme Judicial Court in Swan, for example, ruled that Chad's previously expressed wishes constituted clear and convincing evidence that he would not now agree to reinsertion of the gastrostomy tube to prolong his life, in contrast to the ruling of the Michigan Court of Appeals in Rosebush, which rejected a clear and convincing evidentiary standard of a teenager's prior wishes "because its adoption would preclude the termination of life-support efforts for minors, in direct contradiction of the right to refuse medical treatment." According to the Michigan appellate court, the best approximation of any patient's preferences on the basis of available evidence suffices.

If the preferences of minor patients should be considered and even respected in determining their end-of-life care, the dynamic between health care provider and patient take on heightened importance for the decision-making process. Particularly, decision-making capacity is not monolithic; rather, it requires a set of collaborative skills between patient and physician. Such collaboration entails a dialogical model for physician involvement to facilitate a pediatric patient's skills for imagining the dying process and for fitting it in with who the patient is, to determine how the patient processes the concept of dying, to obviate psychological and emotional barriers that prevent a patient from being able to process his or her own dying, and to optimize the pediatric patient's decision-making capability for determining his or her well-being. Facilitating exercise of these skills by a pediatric patient through dialogue is an altruistic measure of the physician as a steward to parens patriae that ultimately fosters autonomy by enabling the adolescent to achieve both knowledge of self and self-knowledge. In the end, beneficent treatment requires a proactive, rather than inactive, stance of health care providers when caring for pediatric patients, thereby promoting the young patient's sense of autonomous well-being. An omission to engage the patient arguably transforms into harm to pediatric patients confronting their own dying and undercuts the physician's ethical obligation of nonmaleficence – do no harm. Consequently, the contours of beneficence and nonmaleficence for pediatric patient care compel closer consideration and clarification.

Another cue from the courts concerns third party involvement when there is conflict in decision making about the end-of-life care for a pediatric patient. Conflicts that reach the courts usually result in court appointment of a guardian ad litem. Guardians ad litem advance the best interests of the minor following an independent investiga-
tion and evaluation of the facts. Yet, the court in Rosebush stated that a guardian ad litem should only be appointed to exercise legal rights on a minor's behalf when either the parents or surrogate decision makers are incompetent or other family members are unavailable or unwilling to act as surrogates. Insofar as the appointment of a guardian ad litem is contingent on the absence of a surrogate decision maker for the purpose of exercising the minor's decisional autonomy, the Michigan appellate court recasts the role of guardian ad litem akin to a patient advocate that is afforded adults by statute and/or by institutional procedures.

The appellate courts in Swan and Crum, moreover, support conclusions for withdrawal of life-sustaining treatment by referring to the guardian ad litem's agreement concerning withdrawal, raising questions for critical examination about guardian ad litem appointments, the guardian ad litem's role, and the weight afforded the guardian ad litem's recommendations. Stated differently, if the guardians ad litem in Swan and Crum had disagreed about the withdrawal of life-sustaining treatment, it is uncertain whether that disagreement would have been altogether persuasive to these courts' analyses. Would it have mattered at all? Thus, appointments of guardians ad litem in medical decision making concerning pediatric patients present issues worthy of exploration beyond the clinical setting.

Yet another cue from common law concerning the care of dying pediatric patients entails the quality of care. Of the courts that recognized a minor's legal autonomy for refusing life-sustaining treatment, only the Maine Supreme Judicial Court emphasized the quality of life at Chad Swan's end of life. Indeed, the court punctuated its opinion with palliation treatment concerns, stating that, although it was "appropriate to leave to the parents the effectuation of Chad's medical decision," they should "ensure that Chad receives the palliative care necessary to meet his needs for humane treatment." In so doing, the court shifted its focus from medical outcome of cure and/or life prolongation to quality of care while dying. This statement by the Maine high court suggests the importance and timeliness of discussions concerning palliation. Attention to exhausting all curative options in pediatrics prior to considering palliative care arguably delays the timely introduction of palliation or referral to palliation specialists. Other points requiring careful consideration in the clinical environment where medical perceptions and approaches to death and dying continue to evolve include: at what stage should physicians discuss palliative treatment with parents and, when possible, the pediatric patient, who should be involved in the discussion, and what treatment options constitute "humane treatment." Although not squarely addressing "humane treatment," the Ohio Probate Court in Crum underscored the significance of pain management, comfort and dignity for a dying child or adolescent – qualities commonly associated with palliation and hospice. Increasing information about symptom and pain management, as well as how to effectively treat the emotional and spiritual needs of dying pediatric patients, would add richness to the Maine high court's directive of "humane treatment."

Death is inherently individual and solitary – ultimately, one dies alone. However, the process of dying should be inscribed with support and empathy for the emotional and spiritual needs of any patient. Thus, cues from the courts that have confronted the issue of discontinuation of life-prolonging care for pediatric patients provide a starting point for examining the clinical, ethical, and legal issues impacting this specialized area of care and, most importantly, for enhancing the quality of care afforded those patients who are dying young.¹

References

¹ 569 A.2d 1202 (Maine 1990).
⁴ 418 S.E.2d 3 (Georgia 1992).
⁸ For extensive analysis of these and other cues from the courts that have decided end-of-life care for pediatric patients, see Rhonda Gay Hartman, “New Age Evolutionary Epistemology: Reviving Sir Karl Popper's Philosophy of Science for Adolescent Legal Autonomy” (manuscript accepted for publication and on file with the author).
Allow Me to Introduce James Dwyer, Ph.D.,
New Associate Director of the CEP

by Rosa Lynn Pinkus, Ph.D.

The Consortium Ethics Program extends a heartfelt and enthusiastic welcome to James D. Dwyer, Ph.D., who will be joining our faculty as Associate Director on July 1, 2002. Jim has taught philosophy and medical ethics for the past twelve years in both clinical and academic settings at New York University. He was awarded the “Machette Award for Outstanding Teaching” at the University of Irvine, California early in his career, in 1980. In 1994, NYU College of Arts and Science followed suit by presenting him with the “Outstanding Teaching Award.” Jim has been characterized as “exceptional in his grasp of students’ thoughts and in his ability to challenge them.” Even-handed, rational, yet concerned best describes his teaching style. Finally, he is noted for not just teaching facts, but also encouraging students to understand others’ views, to challenge their own beliefs, and to grasp how those positions should and could be assessed and improved.

While at NYU, Jim served as a member of the ethics committee of the N.Y.U. Hospital, Bellevue Hospital, and the New York VA Medical Center. A colleague who chaired these committees during Jim’s tenure offered that Jim “consistently elevated the quality of the discussion at these meetings by his ability to quickly identify and assess the weight of competing ethical principles in the case being considered and by his thoughtful insights and comments on other relevant issues.” In addition to serving on these various committees, he formed an ethics committee for the Student Health Service at NYU.

Much of the education in the CEP takes place in our member institutions. Talks to ethics committees, Nursing Grand Rounds, Ethics Week presentations, and community “fireside chats” anchor the ethics education network to the frontline where caretakers face the day-to-day dilemmas that are at the center of their practice. When Jim interviewed, he studied the map of Western Pennsylvania and Ohio that we have posted on the office wall. We talked about Bradford Hospital in the Allegheny Forest, Butler and Grove City “up north.” Then there was the nexus of hospitals within driving distance from the Center—Braddock, West Penn, St. Margaret, Canterbury Place—and those of the East: Latrobe, Indiana, and Punxsutawny. Jim’s lively sense of humor and his ability to listen, carefully combined with his “quiet, reserved, and dignified manner,” will provide a welcome presence in your hospitals. The fact that in addition to all the basic issues in medical ethics, he has presented talks ranging from ethical issues in Surgery, Neurology, Rehabilitation, Human Genetics, and Human Cloning as well as issues related to “Global Disparities in Health and Moral Duties to Assist,” should start you all thinking about what you would like to ask him to talk about first!

Finally, Jim is an accomplished author. He has recently begun to write short stories based on his clinical experiences and I look forward to reading and hearing more of this creative bent in his work. His published articles thus far are both scholarly clearly written. They speak to the interdisciplinary audience that characterizes the field of bioethics. For those of you curious to learn about Professor Dwyer first hand, we direct you to the following:


So, it is with this brief introduction that I announce our new Associate Director. You can call him after July 1st (412-647-5789) just to say hello, or you will have the chance to meet him in person at the Retreat.
Thank You

Our sincere thanks to

RHONDA GAY HARTMAN, J.D., PH.D.

I would like to personally thank Rhonda Gay Hartman, JD, Ph.D., who served as Interim Assistant Director for the CEP this year, for her enthusiastic, scholarly, and practical contributions to the program. In addition to carrying out her teaching responsibilities with the Duquesne University School of Law and the University of Pittsburgh’s School of Medicine, Rhonda presented more than thirty on-site educational programs this year. An enthusiastic faculty member of the CEP since 1995, Rhonda is well-known in the Consortium for her engaging and knowledgeable presentations at our seminar programs and at our retreats.

Rhonda continued her impressive publication record by completing several manuscripts related to ethical and legal issues in decision making by adolescents, including “Adolescent Decisional Autonomy for Medical Care: Physician Perceptions and Practices” (University of Chicago Law School Roundtable, Fall 2001) and “New Age Evolutionary Epistemology: Reviving Sir Karl Popper’s Philosophy of Science for Adolescent Legal Autonomy,” (submitted and accepted for publication in the coming year). She served as guest editor and author for this newsletter and for the thematic Community Ethics newsletter that focused on adolescent decision making.

Several special programs sponsored by the Consortium Ethics Program have benefited from Rhonda’s involvement. These include the UPMC Ethics Policy Task Force and the UPMC Long Term Care Ethics Committee. She participated in two programs at Canterbury Place, first, as a facilitator for the Canterbury Place Board of Directors Retreat, held on February 8-9, 2002, and second, by helping organize and speaking for the May 15th “Fireside Chat,” a unique opportunity for residents and their families to ask questions and participate in a discussion about advance care planning and medical decision making.

Rhonda was central in organizing the “Community Medical Ethics Project,” a series of community outreach talks on medical ethics, sponsored by UPMC Horizon, Thiel College, and Holy Trinity Lutheran Church of Greenville, PA. The first of these talks, which Rhonda presented on April 25, 2002, focused on informed consent and the importance of on-going dialogue between patients and their physicians. Two more sessions are scheduled for June and September.

I wish to take this time to thank her for these accomplishments and for just being part of our faculty this past year. So, I say again, “Thank you, Rhonda!” I’m sure the entire program joins me in wishing you a productive and happy summer, and we will plan to see you in September! Rhonda will continue to share her valuable insight and experience with us as the Consortium spends its next academic year exploring the relationship between medical ethics and the law.
Congratulations

The CEP extends its heartfelt congratulations to

MARYANNE FELLO, RN, BSN, M.ED.

Who received

The Nancy Bohnet Award for Excellence
A Lifetime Achievement Award

The Nancy Bohnet Award for Excellence has been established in memory of Nancy Bohnet, VNA of Western PA and a founding member as well as one of the early presidents of the Pennsylvania Hospice Network. Through Nancy’s dedication she helped to create the roots of our hospice community. This award serves to honor Nancy’s integrity, as she always focused on what was best for the patient, and her honesty, which was apparent in all of her work.

Maryanne was presented with the Nancy Bohnet Award for Excellence at the Annual Meeting and Conference of the Pennsylvania Hospice Network on April 29, 2002.

Congratulations to

ANDREW E. THURMAN, P.C.

on the establishment of his solo practice in Pittsburgh.

Andy’s practice will focus exclusively on health care and nonprofit corporation law. Andy is also an Adjunct Professor of the Heinz School of Public Policy of Carnegie-Mellon University, where he teaches a graduate course in Health Law and Policy. In addition, Mr. Thurman is one of the founders of The Alliance for Health Care Integrity, a national initiative aimed at integrating the corporate ethics and compliance of health care providers and payers.

Prior to entering private practice, Mr. Thurman was the Assistant General Counsel of the West Penn Allegheny Health System, where he coordinated the legal advice provided to Forbes Regional and Allegheny Valley Hospitals while providing legal services relating to ethics, research and compliance for the entire system. Andy has been involved in planning and teaching with the Consortium Ethics Program since its beginning in 1990.

Congratulations, Andy—We wish you all the best of luck!
CONSORTIUM ETHICS PROGRAM
13TH ANNUAL ETHICS RETREAT

EXPLORING THE RELATIONSHIP BETWEEN LAW AND ETHICS IN HEALTH CARE

September 20-22, 2002
Lakeview Resort & Conference Center
Morgantown, WV

FACULTY:

Beth Chaitin, DHCE
University of Pittsburgh

Jim Dwyer, Ph.D.
University of Pittsburgh

Paul Han, MD
University of Pittsburgh

Rhonda Hartman, JD, Ph.D.
University of Pittsburgh

David Kelly, Ph.D.
Duquesne University

David Korman, Ph.D.
University of Pittsburgh

Alan Meisel, JD
University of Pittsburgh

Ellen Ormond, Ph.D.
UPMC Health System

Rosa Lynn Pukus, Ph.D.
University of Pittsburgh

Stella Smetanka, JD
University of Pittsburgh

Walter Smith, Ph.D.
University of Pittsburgh

Alan Steinberg, JD
Horty, Springer & Mattern, P.C.

Ronald Stiller, MD
UPMC Health System

Andrew E. Thurman, P.C.
Private Practice

RETREAT COSTS:

Registration Fee (paid to University of Pittsburgh):
• $125.00 per person (covers conference break service, supplies, and administrative costs)

Lodging (paid directly to Lakeview): $119.00 per night + tax
• Each room sleeps 1-4 persons (2 double beds)
• There is no additional fee for overnight guests
• Note: There are a limited number of two bedroom condominiums available on a “first come, first serve” basis. Please inquire when you register. Condominium cost: $225.00 per night + tax.

Meal Plan (paid directly to Lakeview):
• $130.08 (incl. tax): Fri. Dinner, Sat. Breakfast, Lunch & Dinner, Sun. Breakfast and Lunch/Brunch

RESERVATION INFORMATION:

• Contact Lakeview Resort & Conference Center at 1-800-624-8300, Mon-Fri, 8am – 5pm, to make reservations and payment arrangements for lodging & meals. A block of rooms has been reserved for the “University of Pittsburgh Consortium Ethics Program.” Reservations must be made by August 20, 2001. After this date any remaining rooms in the block will be released for general sale to the public.
• Reservations must be guaranteed with a major credit card or payment with check or money order.
• When making your reservations, you will need to indicate your choice of either the “Full American Plan” (lodging & meals) or the “Basic European Plan” (lodging only).

If you have questions or need further information, please contact Jody Stockdill at 412-647-5832.
Focus on End-of-Life Care

On November 26, 2001, the Consortium Ethics Program sponsored EPEC (Education for Physicians on End-of-Life Care) at the Wyndham Garden Hotel in Pittsburgh, PA. The EPEC program was developed by the American Medical Association and funded by a grant from the Robert Wood Johnson Foundation. The complete EPEC Curriculum includes material to teach physicians and other members of the health care team skills in end-of-life care.

The CEP's one-day workshop stressed the acquisition of fundamental skills needed to care appropriately for dying patients. Participants in the conference took part in both plenary and interactive small group sessions. Through these sessions, they explored such topics as strategies for pain and symptom management; practical legal issues; communication between physician and patient, and the importance of advance care planning; and suggestions for health care providers who must communicate bad news to patients and/or families. This unique program provided a forum for sharing ideas about how health care providers may enhance the quality of a patient's life at the end of life. Robert Arnold, M.D., David Barnard, Ph.D., and Rosa Lynn Pinkus, Ph.D. were the course directors for the program, and they were joined by Tadao Okada, M.D. and Patricia Klatt, Pharm.D. in presenting the educational modules.

In addition to the EPEC conference, the University of Pittsburgh End-of-Life Providers Task Force is offering an additional, on-site educational session to be scheduled at your hospital. This session is aimed at increasing physicians' ability to encourage and engage in end-of-life conversations with patients and families. A trained facilitator will visit your hospital (regardless of participation in the CEP-sponsored EPEC program) to lead an interactive session specifically designed to enhance physician skills in end-of-life discussions with both patients and families. To schedule this session, please contact Nicole Fowler at 412-692-4884 or fowlernr@msx.upmc.edu.

Summer Seminar in Health Care Ethics

University of Washington
Seattle, Washington
August 5-9, 2002

This annual one-week Seminar, chaired by Dr. Albert R. Jonsen, provides an intensive introduction to the concepts, methods, and literature of health care ethics. It is directed to, and registration is limited to, physicians, nurses, social workers, chaplains, teachers, and others involved in the care of patients or the education of providers. The Seminar is designed to sufficiently familiarize health care professionals with the field of bioethics, and to provide participants with skills and information sufficient to enable them to make competent ethical decisions in clinical situations.

The registration deadline for the Summer Seminar is July 19, 2002, and enrollment is limited to 125 participants. For additional information or to receive a course brochure when available, please contact:

Marilyn J. Barnard, Manager
Continuing Education Program
University of Washington
Department of Medical History & Ethics
Campus Box 357120
Seattle, WA 98195-7120
Phone: (206) 616-1864
Fax: (206) 685-7515
mbarnard@u.washington.edu
As always, we extend special words of thanks to Vira I. Heinz Endowment for contributing the seed money to establish the Consortium Ethics Program. We are also deeply indebted to the Hospital Council of Western Pennsylvania and the University of Pittsburgh Center for Bioethics and Health Law for their continued co-sponsorship.

If you have suggestions or questions regarding the Consortium Ethics Program, wish to submit information for an upcoming edition of Community Ethics, or wish to receive this newsletter, contact Elizabeth Stow, Consortium Ethics Program, 3708 Fifth Avenue, Suite 300, Pittsburgh, PA 15213, phone (412) 647-5734, fax (412) 647-5877, e-mail <cep+@pitt.edu>.