NETWORK NEWS

The newsletter of the Florida Bioethics Network

a Health Service Group of the Florida Hospital Association - P.O. Box 531107 - Orlando, Florida 32853-1107 - 407-841-6230

April 1999 **99-2**

President's Message

Jim Wagner, Ph.D.
Patient and Family Resource Counselor
Shands at the University of Florida

The 1999 annual conference of FBN is set for June 24-25, at the Marina Marriott in Fort Lauderdale. You should have received the program brochure already. The content is designed to both inform and instruct, while providing us an opportunity to network. The June date for this year's conference is an effort to avoid the month of October, which is congested with national conferences.

The annual conference is the traditional time for election of new board members and officers. A ballot will soon arrive in your mail. Last year we had exceptional interest among members, and I want to encourage you to consider being a candidate for one of the open positions. The FBN Board meets 3-4 times annually, in Orlando, and one of the meetings is held at the site of the annual conference.

The Board has several important projects underway. Ben Mulvey is coordinating the development of an FBN Website, with the intent to utilize existing resources through FHA. If you have expertise in website design, please contact Ben at 954-262-8214. Cynthia Shimizu and Joel Mattison are focusing on increasing membership by

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In This Issue

FBN 9th Annual Conference

Y2K: *Are We Ethically Ready for the New Millennium?*

As we approach the Millennium, many important ethical issues and decisions must be made. The focus of this conference is to educate the persons facing the ethical dilemmas and situations of the future. Be sure to join your colleagues June 24-25, 1999, at the Ft. Lauderdale Marina Marriott. For a copy of the brochure or further information, please call the meetings department at 407-841-6230, or email sherryg@fha.org.

Florida's Panel for the Study of End-of-Life Care

Cathy Emmett, MSN, CS
Hospice of Southwest Florida

Several members of FBN, including myself, have had the opportunity to participate in the Panel for the Study of End-of-Life Care whose creation was legislated in 1998. This panel had 22 appointed members including representatives from Hospice, Hospitals, Long Term Care, Physicians, Lawyers and Nurses (I am the Florida Nurses Representative to the Panel.) In addition, the panel recognized from the outset, that there were several key individuals and groups missing from the table. Although it was too late to amend the legislation that created the panel, it was not too late to add advisory panel members. Towards that end, FBN was asked to send a representative-both Ken Goodman and Ray Moseley have filled that role earning the widespread respect of all members of the panel. FBN Member Jane E. Hendricks was also invited to participate and lend

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NETWORK NEWS
The newsletter of the Florida Bioethics Network

Network News welcomes letters, comments and articles for inclusion. Please send any correspondence to dmphotos@gte.net or Cathy Emmett, Hospice of Southwest Florida, 5955 Rand Blvd., Sarasota, FL 34238, Fax: 941-921-5813.

President's Message

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targeting Hospice and Nursing Home groups, as well as health care Attorneys.

Ray Moseley, Ken Goodman, Cathy Emmett, and FBN member Jane Hendricks continue to make significant contributions to the "end-of-life" deliberations in Florida. The panel recommendations have been reported out of committee and are now in the legislative process. A portion of this proposed legislation would require the involvement of an institution's ethics process when the patient has a guardian decisionmaker. The role of FBN is also strengthened by calling for FBN to develop a certification process for ethics committees. The life of the panel is proposed to extend to January 31, 2000. The legislative outcomes as well as future goals will be thoroughly discussed at the annual conference.

Other board members and how to contact them are listed in this newsletter. If you have any concerns or issues you wish to identify, please be in touch. We hope to see each of you in Ft. Lauderdale in June!

Florida's Panel for the Study of End-of-Life Care

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her experience as a lawyer working with guardianships and advance directives and Bioethics in Southeast Florida.

This group submitted an Interim Report to the Legislature in February of this year. A copy of that report was sent to all FBN members. Based on that report legislation has been filed in both the House (HB2131) and the Senate (SB2228) which reflects the main recommendations made by the panel. FBN Board member Kathryn Koch and Ken Goodman were asked to testify to legislative committees considering this bill. Their statements are published in this issue of Network News. As we go to press, the bills remain alive, but have not yet been passed by either the House or the Senate. If, after reading the Interim Report of the End-of-Life Panel, you support its recommendations, I would encourage you to contact your representatives and urge them to support the End-of-Life bill (as it has become known). You might also send a letter to Governor Bush regarding your views on these issues. The full text of the bill can be found on the Internet at www.leg.state.fl.us.

At our Annual Meeting in June, we will have a panel discussion regarding the End-of-Life panel and we hope that many of you will be able to attend and discuss lessons learned from this experience and what all of us can do to improve end-of-life care and to enhance ethical decision making at the end of life.

Panel on End of Life Care

The 1998 Florida Legislature created the Panel for the Study of End-of-Life Care. This 22-member panel was directed to study issues related to the care provided to persons as they near the end of their lives. In particular, the group was requested to consider the issues of pain management, advance directives, and regulatory and fiscal barriers and incentives, which impact on end-of-life care. Specifically, the legislative mandates included:

(1) Develop methods to ensure that pain management is a goal in each health care setting;
(2) Identify barriers that hinder health care professionals from providing satisfactory pain management and palliative care;
(3) Determine whether mandatory education in pain management and palliative care should be required as a condition for licensure or relicensure of health care professionals;
(4) Assess the current use of advance directives and determine whether changes are necessary to ensure that, once prepared, advance directives will be honored in any health care setting;
(5) Study the regulatory and financial incentives that influence the site or setting of care and of care providers.

By holding public hearings around the state and encouraging the involvement of advisory groups throughout the state, the Panel has facilitated a comprehensive and integrated approach to the improvement of end-of-life care. All of these interested parties are engaged in a dialogue on end-of-life issues with the shared goal of improving end-of-life care for the people of Florida.

Pain Management and Palliative Care:
Recommendations focus on access to effective pain management, development of standards and guidelines, education for all health care professionals, and public education.

Advance Directives:
Recommendations focus on changing language in F.S. 765 regarding terminal status and number of physicians required for documentation and also creating portability of advance directive forms.

Financial and Regulatory Issues:
Recommendations focus on educational programs for health care professionals and other groups and the establishment of a group to examine reimbursement methods for end of life care.

An interim report was completed January 31. Additional copies can be obtained from:

Frank Maggio
Pepper Institute on Aging and Public Policy
Florida State University
Tallahassee, Florida 32306-1121
850-644-8825 Phone
850-644-2304 Fax

(There is a $20 charge and $5 shipping fee for a total of $25.Checks can be made to the Panel for the Study of End-of-Life Care).

Ethics and the Florida Legislature

By Kenneth W. Goodman, Ph.D.
(kwg@cs.miami.edu)
Immediate Past President of the FBN and
Director, University of Miami Forum for Bioethics

The Florida Legislature is considering some of the most important bioethics legislation in a generation.

House and Senate committees have approved bills that would revise chapter 765 of Florida Statutes, the law that governs living wills. House Bill 2131 and Senate Bill 2228 would, among other things, eliminate the requirement that patients have a "terminal condition" documented by two physicians before a living will could be honored. This requirement has been described as an onerous infringement on the rights of patients to refuse unwanted treatment.

The revision was supported overwhelmingly by the state's Panel for the Study of End-of-Life Care, a group established by the 1998 Legislature. The Panel held "town hall" meetings around the state and recommended the changes after numerous Floridians told stories of loved ones being treated against their will by physicians and nurses who apparently were trying to comply with the law.

The House bill is sponsored by Rep. Nancy Argenziano (R-Crystal River), Rep. Sally Heyman (D-North Miami Beach) and others. Sen. Ron Klein (D-Delray Beach) is sponsor of the Senate bill.

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Ethics and the Florida Legislature

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The Florida Bioethics Network has been represented at the Panel's meetings around the state by a number of members and officers who were appointed as advisors to the Panel. During the 1999 legislative session, FBN members have been active in monitoring the end-of-life legislation and in testifying before legislative committees.

In the House bill, the FBN would be given the role of approving community-based ethics committees that would consult with guardians of patients in persistent vegetative states in cases in which the withdrawal of life-prolonging procedures is contemplated.

Other features of the House and Senate bills call for continuing the work of the end-of-life Panel; make it possible for patients in nursing homes, hospital emergency departments, and other venues to have their advance directives; and make it easier for emergency medical technicians and paramedics to respect advance directives.

The most significant proposed change, though, is the removal of the terminal condition requirement. This change is opposed by a small group whose leaders have suggested that the terminal illness requirement somehow protects patients.

Most noteworthy of all is the very idea that bioethics has moved to center stage in the state Legislature. More than ever before, legislators, staffers and others have had to learn some of the language of bioethics, to attempt to grasp its concepts, and to try to incorporate its insights into laws, regulations and policies.

The bills are available for review on the World Wide Web at http://www.leg.state.fl.us.

Welcome New Members

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Florida House Committee on Elder Affairs and Long-Term Care

March 18, 1999

Statement by Kenneth W. Goodman, Ph.D.

Director, University of Miami Forum for Bioethics
Co-Director, UM Programs in Business, Governmental and Professional Ethics
Immediate Past President, Florida Bioethics Network
Ethics Advisor to the Florida Panel for the Study of End-of-Life Care

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Summary

Two bills before the Committee propose changes to Florida Statute Chapter 765. Foremost among the changes proposed by both measures is the elimination of the requirement that patients be terminally ill before health care professionals may withdraw or withhold treatment.

In my experience, and in that of many others, the terminal illness criterion has proven onerous to patients and health professionals and unworkable in actual clinical contexts. It seems to serve no useful purpose and, indeed, has had the practical effect of infringing on patient rights by subjecting many Floridians to unwanted overtreatment.

It also conflicts with State and Federal case law, and these conflicts have been confusing to health care professionals and to patients.

The terminal condition requirement is not supported by my and others' understanding of any religious philosophy or theology. That is, we cannot identify clear sources of any religious requirement for the criterion.

It has not had the effect of protecting vulnerable patients — in fact, it is too often invoked and used to treat people against their wishes for the gain of others.

Additionally, the Committee has the opportunity to underscore the importance of bioethics education for health professionals; to reduce physician's (unfounded) legal and professional fears of providing adequate pain

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Florida House Committee on Elder Affairs and Long-Term Care

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control; and to simplify mechanisms by which Floridians can refuse cardiopulmonary resuscitation.

1. Background

There is broad agreement that the concept of informed or valid consent is at the core of health care ethics. This concept requires that people be (1) adequately informed, (2) uncoerced and (3) competent before their consent to treatment may be considered valid. The same criteria apply to valid *refusal*, with the following consequence: If an informed, uncoerced and competent patient refuses medical treatment — even life-prolonging interventions — then it is inappropriate and usually unethical to force such treatment on the patient. This is true whether patients are "terminally ill" or not. The concepts of valid consent and refusal are widely established in ethics and law, and are embraced by most religious denominations and authorities. Through the doctrine of substituted judgment, surrogates can also ask that their charge not be overtreated.

There is no "ethical dilemma" or puzzle here. It is just wrong to impose medical interventions on people who have validly refused such interventions — independently of their medical condition. One way to think of valid refusal is as a protection against unwanted touching.

Now, the very point of living wills is in part this: That informed, uncoerced and competent patients can specify their treatment preferences before they lose the capacity to express those preferences. This can also be accomplished through appointment of a surrogate.

But FS 765 requires that two physicians determine that a patient be terminally ill before a living will (or surrogate's decision) that embodies a valid refusal can be honored. This has the following unhappy result: I have a right to refuse treatment if I can *voice* that refusal, but lose my right when I become unable to insist on enjoying it. Let me put this another way: The terminal illness criterion turns Florida living wills into tools that wait until people cannot speak for themselves — and then takes away their right to refuse treatment. This subverts the very point of many living wills and surrogate representation.

Another problem with FS 765 as currently written is that the definition of "terminal condition" is, as a conceptual and practical matter, completely useless: "A condition caused by injury, disease or illness from which there is no reasonable probability of recovery and which, without treatment, can be expected to cause death ..." This has the effect of labeling many diseases (including, for instance, diabetes and hypertension) as terminal conditions. This has served only to confuse many physicians and other health professionals. In fact, it is very difficult to define "terminal condition" in a satisfactory way. This is partly because it is in many cases difficult or impossible to predict the course of illnesses, including whether and when a particular patient will die.

2. Relation to case law

It is important to note that FS 765 also conflicts with key rulings by the U.S. Supreme Court (Cruzan) and the Florida Supreme Court (Browing, Dubreuil). These rulings seem to many to underscore the rights of patients to refuse unwanted treatment, even if they later lose capacity and even if they do not have a terminal condition. Interestingly, the ruling *In re Dubreuil* holds that Jehovah's Witnesses may, by an advance directive, refuse an intervention as simple as a blood transfusion even after they become incapacitated and even if they do not have a terminal condition.

3. Religious issues

To the best of my knowledge, no faith obliges members to endure treatment they do not want. Of course, this is applied in various ways and, within faiths, many reasonable people will disagree about the propriety of certain treatments and certain refusals.

In Catholic teaching, for instance, the following directives, issued by the U.S. Bishops ("Ethical and Religious Directives for Catholic Health Services," *Origins*, Vol. 24, No. 27, Dec. 15, 1994, p. 459) seem apt and representative:

> [57] A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden or impose excessive expense on the family or the community.
>
> [59] The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching [which is intended in part to refer to active euthanasia].

I should add that in consultation with Catholic physicians and philosophers outside of Florida, I have been encouraged in my belief that Florida's terminal condition requirement finds little or no support in Catholic teaching. These authorities, including those at the National Catholic Bioethics Center, have expressed their willingness to confer with Committee members and others about these issues.

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4. Does the terminal condition requirement protect vulnerable patients?

It is occasionally suggested that some sort of "gate" or obstacle to withdrawing or withholding treatment is needed to protect certain classes of patients. It has been proposed that Florida's terminal condition requirement prevents abuse of handicapped, psychiatric or other kinds of patients.

I must admit that I do not fully understand this argument, and can identify no evidence to support it. In my classes with medical, philosophy, nursing and other students, I underscore the importance of both patient rights and the obligation of health professionals to protect and be advocates for vulnerable patients. But I do not see how the terminal condition can help to accomplish this. Here is why:

☐ Recall that living wills that seek to limit treatment are valid only if they are executed by informed, uncoerced and competent patients. Surely it is patronizing to think that such advance directives are somehow not really what the patient wanted — and moreover to wait to act on this view until the patient cannot argue about it.

☐ If a doctor or nurse has reason to believe that a living will was executed under duress, then it is appropriate to defer compliance with the document. I know of no instances in which this is the case.

☐ What seems unfortunately to be more common is that family members insist on overtreatment for their kin. This is usually because they are in denial about their loved one's prognosis, because they can't "let go," or because they realize some financial advantage from their kin's survival (for instance, continued Social Security benefits).

So, in fact, it seems that rather than protect vulnerable patients, the terminal condition requirement is most often invoked to abuse them.

5. Other issues

The committee has a rare opportunity to:

☐ Underscore the importance of bioethics education for health professionals.

☐ Reduce physician's (unfounded) legal and professional fears of providing adequate narcotic and other pain control.

☐ Simplify mechanisms by which Floridians can refuse cardiopulmonary resuscitation.

6. Conclusion

Florida's Panel for the Study of End-of-Life Care was created by the 1998 Legislature to scrutinize FS765 and related chapters. In hearings around the state, this very useful Panel heard from ordinary citizens who protested that their loved ones' advance-care directives were too often ignored by institutions standing on the ceremony of the flawed terminal illness criterion.

The Panel, with representatives of, and advice from, Florida's medical, nursing, legal, religious, bioethics and other communities, voted overwhelmingly to recommend that Chapter 765 be revised to eliminate this burdensome provision.

I think that is a sound recommendation. Of course, the Panel and the legislation before you make other recommendations, and I will be happy to address them. But if the goal here is what I like to call "ethically optimized legislation," then the most noteworthy progress that can be made will be the elimination of that provision. Such a change

☐ Enjoys ecumenical support.
☐ Coheres with State and Federal case law.
☐ Would be the right thing to do.

It has been an honor to have had the opportunity to address you, and I am grateful.

Statement to the Florida House Committee on Elder Affairs & Long Term Care regarding FL St 765 on 3/1/99

Kathryn A. Koch, M.D., Assoc. Prof. Med. Chief/Critical Care, University of Florida Health Science Center

I am Doctor Kathryn Koch. I have been learning, teaching and practicing critical care medicine for more than 20 years. I am currently employed by the State Board of Regents at the University of Florida in Jacksonville, but am not present as a representative of those agencies. I am here because I practice as much medical ethics as I do physiology. I see problems in decision-making at the end of life daily. As a result I have been active in medical ethics in the State of Florida for more than 10 years, particularly in the Florida Bioethics Network.

The problems with what I would call "boiler-plate" living wills, such as the one currently in use in Florida, is that they require the diagnosis of "terminal" in order to be implemented. The definition of "terminal", given our

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Statement to the Florida House Committee on Elder Affairs & Long Term Care

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currently available technology, is one where reasonable and qualified physicians might have valid professional disagreement. Death is no longer commonly an event; it is a fluid process where life leaks away in droplets.

It can be very difficult to determine that point beyond which there is no reasonable hope of future recovery. For many patients, being treated aggressively on an ongoing basis, with hope diminishing every day that they do not respond to treatment, is a fate worse than death. They might not choose ongoing aggressive treatment if it is predicted that another several weeks of ICU care would be required to find out if they are going to be the lucky one to survive (and believe me, I know what that entails). They might not choose to face lengthy rehabilitation if in fact they do survive. A reasonable person might rather face death.

How to word this in an advance directive? "Let my family and caregivers know that if there is little hope for recovery to my prior state of health, or if what hope exists requires prolonged and invasive medical treatments, I would prefer to receive care focused on my comfort rather than care focused on prolonging my life".

I have written my own advance directive based on prediction for recovery to functional independence: if there is a reasonable chance for that type of recovery, I want everything; if there is little chance I can recover to take care of myself, I want supportive measures only; if there is no chance I can so recover I want comfort measures only. If my chances of recovery to full independence are small, I personally would not wish to have my life prolonged by invasive means merely to find out if I might recover the capacity to make my own decisions.

For these reasons I am happy to see the word "terminal" eliminated from this statute, and would encourage even more flexibility than in the current draft.

On the other hand, I have some concerns about the current draft. What if my surrogate has a suspected conflict of interest and/or is not able to represent my wishes with confidence? In that case, I would expect my physician to willfully disregard my surrogate's instruction, expecting that physician not to abuse me nor to terminate my life prematurely. I would expect that physician to clearly state in my medical record why my surrogate's request is not being followed, and to seek additional opinion and mediation to resolve the conflict. I would expect my physician to act in my best interest with the presumption that my interest is defined by what a reasonable person would choose, given my medical circumstances.

What if I, like so many people, had no living will or surrogate, and had never discussed my thoughts with the person elected to be my proxy? I would expect my proxy to make my decisions for me using a "reasonable person" standard; the "clear and convincing" standard is burdensome.

This leads me to the provisions for the person in persistent vegetative state who has no discoverable friends or family willing to serve as proxy.

For individuals with commonly held values, it does appear that continued mere biologic existence in the condition of persistent vegetative state is undesireable (Dagi TF. How much of the brain must die in brain death? J Clin Ethics 1992;3:27-28) My own research has shown that at least 70% of individuals in my practice area would not wish to have their life prolonged in that condition. (Koch KA, DeHaven MJ, Kellogg-Robinson M. Futility: It's Magic. Clin Nlmon Med 1998;5:358-363) I have 4 reservations about this section, however.

1. Persistent vegetative state is not the only medical condition where a patient might be unable to make decisions, and also has no discoverable proxy. The current draft doesn't go far enough.

2. If medical decision-making for incapable patients with no proxy requires a legal guardian, there must be a mechanism throughout the state to provide a legal guardian to adult patients. There are only a few jurisdictions in the state where this is available. Otherwise, medical decisions in such situations will be made even more awkward and difficult than they now are.

3. If decision-making under such circumstances also requires the input of the hospital ethics committee, then standards for decision-making which are uniform across the state must be adopted for the guidance of the committee. Asking hospital ethics committees to participate in actual medical decision-making changes the very nature of those committees in a fundamental and perhaps damaging way.

4. Finally, the approach to decisions under such circumstances should not be a "best interests" approach, for this also is where reasonable people might disagree, and where conflict of interest may affect decisions. I propose rather a "reasonable person" standard, perhaps developed from a series of town meetings around the state, to explore the ethnic, cultural and religious differences in what a reasonable person in this State might choose under different medical circumstances.

Thank you for giving me an opportunity to speak. I will be happy to answer any questions during the discussion session.

American Society on Aging 45th Annual Meeting

Submitted by Cynthia Shimizu, LCSW, Psychosocial Oncology Program, H. Lee Moffitt Cancer Center/ Research Institute

The American Society on Aging held its 45th annual meeting in Orlando on March 4-7, 1999. Cathy Emmett and I facilitated a roundtable discussion entitled "Dealing with Ethical Issues in Long Term Care." Professionals from across the country joined us to discuss some major concerns. What follows is a summary of the main points:

1) There is a lack of ethics leadership in long-term care facilities and programs.

2) There is a lack of ethics education among staff members of long-term care facilities and programs. Personnel do not always recognize an ethical issue or conflict. Approaches for providing care are often based on accepted standards of practice rather than with an open viewpoint and the flexibility needed to facilitate patient preference, choice, and autonomy.

3) There exists a misguided assumption that "to do what is legal" is the best practice, rather than "to do what is ethical." What is "legal" often becomes the default decision made by administrators working in the most highly controlled and regulated institutions that exist is health care today (i.e., nursing homes). What is legal may not be what is morally right for the patient/resident. Several participants agreed that a well thought out decision making process is, in practice, often the most defensible position legally.

4) A distinction was made between "Ethics"- with a capital E - that gets all the national attention, versus "ethics" - with a lowercase e - that represents all the day-to-day decision making that takes place within long-term care facilities. The day-to-day ethical process involves people in relationships dealing with each other in contextual situations.

5) A hierarchy of ethics was described: a) an individual's own personal ethics (Who's life is it?); b) an ethic based on interpersonal relationships (including professional ethics with sanctions for unethical practice); c) an ethic for the common good (life in communities); and d) a social ethic for public policy. An "ethical impact statement" may serve to provide a framework, with the values embedded in that framework, to guide practice and policy making.

6) We need a shared language with agreements on how to talk to one another to be understood. For example, humanistic ethics in the post-modern Western world has politicized the terms "autonomy" and "self-determination." As political terms, what meaning do they have for the individual?

7) Long-term care facilities are where people *live*. Do they feel comfortable? Safe? Protected? Loved? Facility as *home* has implications for contextual ethical decision making.

8) There are certain tensions that exist that are unique to long-term care facilities: "patient" vs. "resident"; resident choice vs. staff accountability; privacy vs. supervision; dignity vs. efficiency; protection vs. independence; individual vs. community; rehabilitation vs. palliation. Long-term care facilities need a mechanism for dealing with these ethical tensions.

A couple of poignant vignettes were shared:

1) Elders in long-term-care facilities don't often get appropriately touched and many experience sensory deprivation. Reportedly, many older women pay to have their fingernails professionally manicured each week, just to have some human touch and physical contact. Is this the result of *politically correct* social policy that has gone overboard in an attempt to protect people from inappropriate (unwanted) physical contact?

2) For many older residents in retirement communities, the highlight of the day is waiting for the mail to arrive. People will begin to gather outside by the mailboxes up to two hours in advance of the mail delivery and the gathering becomes the social event of the day. But, the architectural and site planning doesn't accommodate this gathering. There may be no shade trees, nor park benches on which to sit. The mailboxes may be at a distance from the building, making it impossible for some functionally limited residents to participate (thereby, increasing their sense of isolation). This example sparked a discussion on the ethics of spatial planning and aging in place.

This roundtable discussion was well attended and thought-provoking. It was a pleasant alternative to the more typical formal presentation format.

For further reading on ethical issues in long term care: Hayley DC, Cassel CK, Snyder L, Rudberg MA. Ethical and legal issues in nursing home care. Arch Intern Med. 1996;156:249-256.