

CENTER NOTES

This issue of **Midwest Medical Ethics** is devoted to an issue of wide interest—living wills. A living will law became effective in Missouri in September, 1985. Kansas has a similar law, as do more than thirty other states. We are also reprinting a sample living will from the Missouri law. While there are some parts of the law which present some problems, we believe that the law is a positive step.

The Center is very pleased to have a new Executive Director, Myra Christopher. Myra has recently graduated from the University of Missouri/Kansas City with a degree in philosophy, specializing in bioethics. She also has experience with not-for-profit organizations. We are delighted to have Myra with us.

The Board of Directors has approved new categories of memberships. We now have a category of institutional memberships available.

Institutional members receive fifteen copies of **Midwest Medical Ethics**. Each institution would be entitled to send five people to the Center journal club, and all employees would receive the membership discount to Center educational events. Institutional memberships are \$100, \$250 or \$500 per year depending on the size of the institution.

Founding memberships (\$500 per year) are available to individuals who wish to further support the Center.

Individual memberships are now \$30 for one year.

Please call us if you have any questions about membership categories.

Karen Ritchie M.D.
President

LIVING WILLS

Robert M. Veatch

Decisions about medical care always involve choices based on ethical and other values. As biomedical technology has made it possible to prolong life for longer and longer periods, the values underlying choices about continuing life-prolonging care become more and more important. People standing in different ethical and religious traditions have different views about what kinds of care are appropriate. Everyone wants certain interventions that will be life-saving, but few people really want everything possible done to extend life. Roman Catholic moral theology is quite explicit that extraordinary means—that is means that serve no useful purpose or means that would be gravely burdensome—are morally expendable. Most Protestant thinkers concur while Jewish and Orthodox Jews hold that life is sacred, and there is a moral duty to preserve it. Even those persons, however, believe that when a person is dying, it is acceptable—in fact even required—to step aside so that the dying process can continue. Secular thinkers, such as the members of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, likewise affirm that the voluntary choice of a competent and informed patient should determine whether or not life-sustaining therapy will be undertaken."

THE HISTORY OF LIVING WILLS

This means that there is no such thing as the medically correct circumstances for providing or withholding life-sustaining treatment. It

is, therefore, increasingly important that individuals have an opportunity to express their wishes about terminal care, whether to make sure that treatment will be stopped or will continue.

For many years informal letters expressing such wishes—such as the ones following the models proposed by Concern for Dying, a national death education organization—have been available for guidance. The Catholic Hospital Association has prepared its own version, which it calls the Christian Affirmation of Life. Wishes expressed in these informal letters are meant as guidance to one's family, friends, clergy, physician and lawyer. They may be legally binding as treatment refusals under common law, but considerable doubt about their legal force has remained.

Therefore, starting in 1976 in California, states began passing living will legislation that makes clear that a person has the right to execute a document refusing certain kinds of medical treatment. The laws generally provide that there can be no civil or criminal penalty for stopping treatment in accordance with the directive, that any resulting death not be considered a suicide for

continued on page 2

On the Inside

Sample Living Will	3
Missouri's Living Will Law	5
Beyond the Law	5
Contributions	6
Membership	7
Coming Events	8

purposes of insurance, and that a physician must comply with the patient's directive or transfer the patient to another physician. All laws clearly indicate that active killing, even for mercy and even at the explicit request of the patient, is not authorized. By 1985, 35 states and the District of Columbia had passed some version of such a law. What are the issues of controversy?

THE ISSUES OF CONTROVERSY

(1) **Must the person be terminal?**

Most laws provide declarations that may be executed by any competent adult authorizing treatment stoppage, and most limit the activation of such requests to a time when the person is terminal. The Missouri law's definition is typical. In Missouri a terminal condition is an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will

"By 1985, 35 states and the District of Columbia had passed some version of such a law."

occur within a short time regardless of the application of medical procedures. Critics argue that if treatment stoppage is limited to those circumstances, the declaration's value is questionable. The person will die shortly anyway. It would not cover most comatose and vegetative state patients, such as Karen Quinlan, where the patient might live indefinitely if treated. Many have argued that the right of refusal is a much broader right. Catholic theology, for example, holds that some persons might reasonably want treatment stopped if it is gravely burdensome, even if the person is not inevitably and immediately dying.

(2) **What about differences of opinion?** The original proposals for living will legislation all envisioned a simple decision to refuse all life-prolonging treatments. If, however, these choices are based on personally held beliefs and values and there are countless variations in people's views, some provision must be made

for differences of opinion. Most recent laws—including Missouri's and Maryland's—specify that the directive can follow the sample form in the legislation, but that it may be modified and may include other specific provisions. A few laws, such as Maryland's even make clear that a declaration can be written for the purpose of insisting that treatment be provided as well as for refusing treatment.

(3) **Are all treatments refusible?**

Originally most people anticipated that the interventions that would be omitted were complex, high-technology treatments such as ventilators, dialysis machines and complex cancer surgery. More recently, however, the debate has focused on the legitimacy of refusing more simple procedures such as the medical provision of nutrition and hydration through IVs and nasogastric tubes. Many are now arguing that, if the moral justification of treatment refusal is that the treatment serves no useful purpose or is gravely burdensome, it ought to make no difference how complicated the treatment is. They have concluded that even simple procedures such as CPR, antibiotics, and medically supplied nutrition and hydration should be refusible on these grounds. Some persons have even added specific sentences in their living wills making clear that they refuse such treatments. Nevertheless, some state laws, especially those passed in 1985, specifically exclude the refusing of nutrition and hydration, although equally simple procedures such as CPR and antibiotics are viewed as refusible.

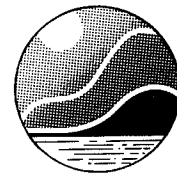
(4) **What about incompetents?**

Unfortunately, many candidates for life-prolonging treatment have

"...the debate has focused on the legitimacy of refusing more simple procedures such as the medical provision of nutrition and hydration..."

either never been competent—e.g., children or the mentally incapacitated

continued on page 7



Midwest Medical Ethics

Editor: Karen Ritchie, M.D.

Associate Editor: Myra Christopher

Midwest Medical Ethics is a quarterly publication of the Midwest Bioethics Center

1200 East 104th St., Suite 217
Kansas City, Missouri 64131
(816) 942-1992

The mission of the Midwest Bioethics Center is to assist individuals and society in responding to the ethical dilemmas of modern medicine and biomedical technology.

BOARD OF DIRECTORS

Chair

Hans W. Uffelmann, Ph.D.
University of Missouri/Kansas City

Secretary-Treasurer

Mary Beth Blake, J.D.
Holbrook and Ellis

President,

Karen Ritchie, M.D.

R.D. Blim, M.D., FAAP

Elizabeth Dayani, R.N.S., M.S.N.

American Nursing Services

Barbara McCool, Ph.D.

Strategic Management Services, Inc.

Robert Weiss, S.J.

Rockhurst College

Rabbi Michael Zedek

Temple B'nai Jehudah

SUBSCRIPTION RATES:

Members of the Midwest Bioethics Center receive Midwest Medical Ethics as a benefit of membership. Individual memberships are \$30 per year. Founding memberships of the Center are \$500 per year. Library subscriptions to Midwest Medical Ethics are \$20 per year. Subscription requests should be addressed to:

Midwest Bioethics Center
1200 East 104th St., Suite 217
Kansas City, Missouri 64131

tated—or, if they have been competent, they have lapsed into incompetency without expressing their wishes. The majority of laws, however, speak only to the rights of competents, leaving open the question of how decisions should be made for those who cannot or have not expressed their wishes.

Critics have urged that, if incompetents have the right to be spared from useless or burdensome treatments, incompetents should have the same right. Of course, since the danger of abuse is great, careful protections would have to be built in. Several states—including Arkansas, Louisiana, New Mexico, Texas and Virginia—make some provision for execution of a directive for an incompetent by a guardian. Any such guardian directive, of course, can be reviewed by the courts if it is suspect. The policy, in effect, merely extends the idea that parents may consent (or refuse to consent) for treatments for their children.

(5) Can surrogate decision-makers be named?

One criticism of living wills has been that persons may not know in advance exactly what treatments will be considered for them. New technologies may leave considerable doubt even if the patient has expressed a general desire to have treatment stop or

continue. As an alternative several of us have suggested—as far back as 1976—that in addition to a substantive advance directive one might designate an agent or proxy to make medical decisions in situations where one cannot speak for oneself. The

Every jurisdiction except the District of Columbia now permits a durable power of attorney.

President's Commission endorsed this approach, suggesting that the existing legal mechanism of the durable power of attorney could be used to designate an agent with legal authority to make medical decisions. Several states (including Delaware, Florida, Louisiana, Virginia and Wyoming) have incorporated this approach into their living will legislation. Every jurisdiction except the District of Columbia now permits a durable power of attorney.

Finally, several intriguing, more specific questions remain. For example, could a person specifically request that he be moved from one state to another in order to be in a more favorable environment for having wishes respected? Can a person instruct his or her agent to dismiss any physician who is not

complying with the patient's or agent's wishes? Could a person refuse, or insist upon, specific treatments such as nutrition, hydration, CPR or antibiotics?

Increasingly, the question of authority to decide for or against various treatments while one is terminally ill is being seen simply as an extension of the more general issue of the right of persons to consent or refuse to consent to treatment. That right exists in common law—whether one is terminal or not. It probably includes the right to refuse simple as well as complex treatments. New laws may be necessary to clarify that the next of kin is presumed to have the authority to make medical decisions unless the individual has designated someone else for the task or unless the next of kin has his or her decision overturned by a court as being too unreasonable to be acceptable. In the meantime, now that there is a wide range of opinions among both professionals and lay people about treatment refusal, it is probably more crucial than ever that persons take advantage of the provisions of the various living will laws to make their wishes known.

Robert M. Veatch, Ph.D. is Professor of Medical Ethics at the Kennedy Institute of Ethics, Georgetown University, Washington, D.C.

MEMBERSHIP

Members of the Midwest Bioethics Center receive:

- a subscription to **Midwest Medical Ethics**
- discounts at Center educational events
- notices of area conferences
- members are invited to the Center's journal club, a bimonthly seminar which discusses current issues in medical ethics

Institutional memberships are also available. Call us for details.

Membership is open to any interested person, health professional, clergy, or lay person. Join us!

Midwest Bioethics Center
1200 East 104th St., Suite 217
Kansas City, Missouri 64131
Phone (816) 942-1992

Please enroll me as a member of the Midwest Bioethics Center

- Individual membership \$30 for one year
- Founding membership \$500 for one year
- I would like information regarding an institutional membership
- I am enclosing a tax-deductible contribution in the amount of \$_____

Name: _____

Institution: _____

Address: _____

City/State/Zip: _____

The following people might be interested in Center membership

Name: _____ Name: _____

Address: _____ Address: _____

City/State/Zip: _____ City/State/Zip: _____