

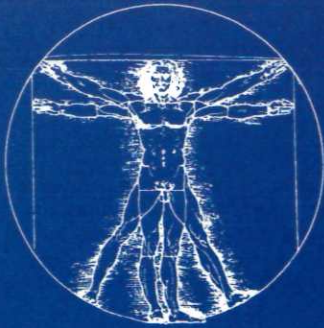
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

University of Maryland Francis King Carey School of Law *Year 1994*

Mid-Atlantic Ethics Committee
Newsletter, Fall 1994

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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LIVES IN THE BALANCE: GUARDIANSHIP REFORM

Mr Z., an elderly man, arrives at the hospital in an ambulance after a neighbor finds him wandering, disoriented, disheveled and improperly dressed, close to a busy intersection. He is admitted and is found to be suffering from the effects of several small strokes, a bladder infection, dehydration and malnutrition. With treatment, his physical condition improves, but his mental confusion remains.

Sylvia Dee, a discharge planner at the hospital, calls a neighbor, and learns that Mr. Z has lived alone since his wife died five years ago. The neighbor thinks Mr. Z might have some relatives, but she's new to the area and doesn't really know. Mr. Z is no help in this regard. Since his condition has stabilized, the hospital's Utilization Review Committee has notified him that Medicare coverage for his stay will expire in three days. Ms. Dee feels pressure from the hospital accounting office to discharge such patients as soon as possible so that the hospital is not left with an uncollectible debt. She does not think Mr. Z can manage on his own at home, and she knows a bed is available at a nearby nursing home. However, the nursing home will not

Letter From the Editor

This issue's theme is guardianship, a legal process currently fraught with ethical pitfalls. As you will note, legislatures are beginning to "rethink" the necessity of guardianship in certain cases. Ethics committees, however, can play an essential role in screening cases and determining if appointment of a guardian is necessary as well as improving the fairness and protection afforded patients who require guardians. This involvement must begin early on in the guardianship process, if it is to be effective in untangling the myriad of ethical issues which are so often involved. It is hoped that this newsletter will stimulate discussion on ways in which to do this.

Janice P. Rosenzweig

admit Mr. Z unless he has a responsible party to sign the nursing home contract and guarantee payment. What to do?

Ms. Dee picks up the phone and calls an attorney who is on retainer with the hospital. The attorney agrees to file guardianship proceedings against Mr. Z immediately, asking that the Circuit Court appoint someone to act as the

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NETWORK NEWS

Baltimore Area Ethics Committee Network (BAECN)

Ray Donovan, M.D., a retired
surgeon from St. Agnes Hospital,
Baltimore, and **Dave Taratino, M.D.**,
Assistant Professor of Anesthesiology
at Shock Trauma, Baltimore were the
featured speakers at the October
meeting of the BAECN. The topic,
"DNR in the OR," precipitated a good
discussion on the ethical issues which
arise in the OR as a result of hospital
policies.

On December 6th, the Network
meeting will focus on, "Standards for
Ethics Committees." It will be held at
4:30 p.m. at Sinai Hospital, Baltimore.

It is the BAECN's goal to become a
clearinghouse for hospital policies on
ethical issues. To assist them in
becoming a resource for institutions
that are in the process of drafting such
policies, they are requesting that
hospitals send copies of their current
policies on ethical issues to **Jack Syme,**
M.D., President, BAECN, Department
of Neurology, St. Agnes Hospital, 900
Caton Avenue, Baltimore, MD 21229.

In addition, the BAECN is offering
to do retrospective consultation on
decisions made by ethics committees.
For help in reviewing a case, send a
request with an outline of the issues to
Dr. Syme at the above address.

For more information about any of
the Network's activities, call Dr. Syme
at (410) 368-3020.

Washington Metropolitan Bioethics Network (WMBN)

The WMBN had a very successful
September meeting on the topic,
"What Makes Effective Ethics Com-
mittees." The program featured a
panel discussion by members from
ethics committees of two area hospi-
tals, one hospice and one from the
Visiting Nurses Association. The
following are just some of the excel-
lent suggestions for improving the
effectiveness of ethics committees that
came out of this meeting:

- Culturally diversify the membership;
- Send only active members annual invitations to retain their membership;
- Emphasize the "advisory" nature of the committee;
- Increase the comfort level of physicians to approach the committee;
- Remain focused on ethical concepts, instead of, medical treatment choices, and;
- Strive for better communication and feedback to all parties involved.

The next Network meeting will be held on November 1, 1994 from 4-6 p.m. at Arlington Hospital in Arlington, VA. The topic is, "Ethical Issues in Emergency Care," in light of the changes in Maryland and Virginia law. One issue to be explored is what to do in the case of terminally ill patients with DNRs when ER technicians, summoned by a 911 call, are required to institute CPR? **Henry Silverman, M.D.**, Chairman of the Ethics Committee at University of Maryland Medical System will provide a case study and an ER tech from Virginia and the director of a trauma center in D.C. will participate in the discussion.

For more information about Network activities contact **Joan Lewis** at the District of Columbia Hospital Association (202) 682-1581.

Virginia Bioethics Network (VBN)

The Second Annual meeting of the VBN was held on October 28-29 at the Holiday Inn on Afton Mountain. At this dinner meeting, **Ellison Conrad, M.D.**, President of the VBN, discussed next year's goals.

A draft of the "Recommendations for Guidelines for Procedures and Process and Education and Training to Strengthen Bioethics Services in Virginia," previously distributed to all VBN members, was also debated. A vote on these "Recommendations" is expected in 1995.

Edward M. Spencer, M.D., Director of Outreach, Center for Biomedical Ethics at the University of Virginia, announced that the next DHEP courses will be held from March 27-April 1, 1995 at the University of Virginia. DHEP, an intensive 6-day course of study for health care professionals from hospitals and other health care institutions, is designed to facilitate or strengthen the implementation of an ethics program within these institutions. For further information please call (804) 924-5974.

Bioethics Network of Southeastern Virginia (BNSE)

The Bioethics Network of Southeastern Virginia has been very active over the last year and has a full schedule of meetings planned. (See Calendar on page 11.)

A special program, "Saturday in Bioethics", set for February 4, 1995, will address the topic, "Prolonging Life in a Newborn or at the End of Life: Why do we? Who Benefits? Who is Harmed?" For more information on this program which will be held in Virginia Beach, VA contact Julia West, MSW at (804) 548-2911.

West Virginia Bioethics Network (WVBN)

The Network Forum, "Part II-Developing Expertise in Ethics Consultation," held in September, drew a crowd of 138 participants to hear Jackie Glover, PhD., an ethicist from Children's Medical Center in D.C., give advice on the steps which lead to successful ethics consultations.

The Wilhelm S. Albrink Memorial Lectureship entitled "Moral Decision Making: Slogans, Principles, Coin Toss or the Seat of Your Pants," is scheduled for November 2, 1994. See the Calendar for more details.

GUARDIANSHIP AND ALTERNATIVES: THE ROLE OF ETHICS COMMITTEES

When a patient does not have family members, has not appointed an agent to make decisions for them, and lacks decision making capacity, it may be necessary for a hospital or nursing home to petition the court for appointment of a guardian to make decisions on behalf of the resident. Guardianship law is determined at the state level. In many states there are two types of guardians: 1) a guardian of the property, in some states referred to as a conservator; and 2) a guardian of the person. Standards for appointment of a guardian differ from state to state but in general, a guardian of the property may be appointed when an individual lacks the ability to manage his property or financial affairs, and a guardian of the person when an individual is unable to care for his or her personal needs, e.g., food, clothing, shelter, safety, healthcare. Many states further require that guardianship only be considered as a last resort--all other "less restrictive alternatives" must be considered first. This is because the appointment of a guardian is a drastic measure depriving an individual of certain basic rights.

If a court determines that a guardian is necessary it must also decide who to appoint as guardian. For a resident with no family or close friends the court may have to appoint a disinterested party or a public guardian. A public guardian is typically a state agency such as the state office on aging or the department of social services.

In the hospital setting, when a patient is without family and lacks decision making capacity, if the patient must be discharged to a nursing home, sometimes the home will require that a guardian of the property be appointed to sign the admissions contract on behalf of the patient. Under this scenario, a hospital may either initiate guardianship proceedings on its own, through its own legal counsel's office,

or through a lawyer or law firm that it hires to draw up the papers and file the guardianship petition. Alternatively, the hospital may be able to contact a public agency, such as Adult Protective Services, to petition for guardianship. Often hospitals are reluctant to petition the court for appointment of a guardian themselves because of the costs involved. In addition to the legal fees it may also be necessary to have a physician testify in court as to the competency or capacity of the resident and the physician must be paid for his time. The cost for this process may be over \$1,000. However, hospitals may also be concerned about the time required to go through a public agency to file the guardianship petition. In some areas, it may take several months. The time for appointment is typically much shorter if the hospital initiates the process itself. As a result, if the hospital is interested in a quick discharge it may be willing to initiate the guardianship proceedings. In some cases, the hospital will incur the costs of this proceeding, in others, the hospital's attorney may be able to petition the court for an order granting attorney's fees from the ward's assets.

In the nursing home setting, there is usually less urgency about appointing a guardian and nursing homes go to great lengths to avoid initiating a guardianship proceeding. If a guardian is absolutely necessary the home will typically go through a public agency to petition the court for the appointment. The nursing home itself would rarely take on the burden of petitioning court, as often the patient who needs the guardian is a Medicaid recipient and would not have sufficient assets to cover the cost of the proceeding.

Sometimes health care facilities wait until an emergency arises and rely on state law authorizing health care providers to make decisions for patients without obtaining informed consent in emergency situations.

Recognizing the difficulties of going to court for appointment of a guardian and the lack of patient protections involved when health care providers make "emergency" treatment decisions

Cont. on page 4

Guardianship and Alternatives

Cont. from page 3

for patients who lack family members or other surrogates, a few states have recently passed laws that allow a health care ethics committee acting with the patient's attending physician to "substitute" for a guardian. For example, in Arizona a physician in consultation with the facility's ethics committee may make health care treatment decisions for patients who are unable to communicate and the physician cannot locate a designated surrogate. Also, in Georgia, a physician is required to consult with an ethics committee and gain the committee's concurrence before he or she may write a do not resuscitate order for a patient who lacks capacity and a surrogate to consent to such an order.

The New York State Task Force on Life and the Law, in its report, When Others Must Choose: Deciding for Patients Without Capacity,¹ rejected the legal approach of going to court for a guardian when patients in a hospital or nursing home lack capacity and surrogates to speak on their behalf. The Task Force based this rejection on several factors including the perception that court decisions are not necessarily qualitatively better than decisions reached at the facility level. In cases about treatment decisions, they said, judges tend to defer to physicians' recommendations in any case. Instead the Task Force proposed a series of procedural models with varying levels of patient protection depending on the seriousness of the decision to be made. For routine medical decisions, i.e., drawing blood for tests or providing medication for high blood pressure or other procedures that are minimally invasive and involve little or no risk to the patient but are clearly beneficial, a physician may make the decision acting alone. For major medical treatment, that is, procedures that involve any significant risk or invasion of bodily integrity, produce substantial pain or discomfort, have a significant recovery period, or require a significant period of chemical or physical re-

straint, the Task Force recommends that the attending physician make the decision after conferring with other relevant caregivers and after obtaining the recommendation of a second physician, designated by the hospital or nursing home. If there is a difference of opinion between the attending and the second physician, the ethics committee should be consulted. Finally, for decisions regarding the withholding or withdrawal of life sustaining treatment, the process must include the attending physician's medical judgment, a second medical opinion, consultation with other facility staff who have cared for the patient, and full consideration and approval of the decision by the institution's ethics committee.

Given the obstacles to court-appointed guardians in many cases, this may be the beginning of a trend in state law. States may begin to allow health care providers with certain procedural safeguards, including review by an institutional ethics committee or other committee, to make health care decisions for isolated patients who lack decision making capacity as an alternative to a court appointed guardian.

In Maryland, a task force on Guardianship Law has drafted a proposal for a three-person panel that would make decisions involving major medical treatment for individuals who have no surrogate and who are incapable of deciding themselves. Until more states change their laws, however, health care facilities must be sure that the rights of isolated patients who are unable to make their own decisions are protected. In some cases, this may necessitate court appointment of a guardian.

Note

1. New York State Task Force on Life and the Law, When Others Must Choose, pp.162 - 168.

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OVERVIEW: GUARDIANSHIP LAWS IN MARYLAND, DC AND VIRGINIA

An increasing number of older persons are affected by guardianship, the judicial process that transfers decision making responsibility from an individual, who has been determined to be unable to manage his own affairs, to another. Interest in guardianship matters was enhanced in 1987 by a series of Associated Press stories that studied the guardianship system in all fifty states and the District of Columbia.¹ The study revealed that the system had serious shortcomings, such as: lack of due process protections; unclear and outdated standards for incapacity; untrained guardians; and courts with inadequate resources to monitor the activities of the guardian.

As a result of the study, virtually every state has made some change in its guardianship system. Several trends in reform have emerged from this activity. This article reviews several trends in legislative reform that have significant implications for older persons in guardianship proceedings. The statutes of the District of Columbia, Maryland and Virginia will be used to illustrate these trends.

Definition of Incapacity

The statutory definition of incapacity is critical because it establishes the basic inquiry regarding a person's need for guardianship. Traditional definitions provided few guidelines on the type of conduct for which a person might be found incapacitated. Some focused almost exclusively on the person's "status" or "condition." Unfortunately, these definitions are sometimes inadequate because labels or diagnoses of physical or mental disability may not provide a meaningful indication of a person's ability to function independently. Virginia and Maryland take this approach. In Virginia, an individual who the court determines has a mental condition (mental illness or mental retardation)

that renders the person incapable of taking care of his person or handling and managing his estate is “legally incompetent” and the court may appoint a committee for him.² This is an incompetency determination that strips the individual of all his rights. On the other hand, a person is “legally incapacitated” if the court determines that because of a mental or physical condition the person is, either wholly or partially, incapable of taking care of himself or his estate.³ The court may appoint a guardian of the estate, person or both for him. This is not an incompetency determination.

In Maryland, when a person is unable to manage his property and affairs effectively because of physical or mental disability, disease, habitual drunkenness, addiction to drugs, imprisonment, compulsory hospitalization, confinement, detention by a foreign power or disappearance, and needs a guardian of the property, the court may determine him to be a “disabled person.”⁴ If the person lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person, then for the above reasons except physical disability, detention by a foreign power or disappearance, the court may also determine him to be a “disabled person,”⁵ and appoint a guardian of the person.

The use of vague, normative standards to judge a proposed ward’s behavior does not promote neutral fact-finding, but invites arbitrary findings of incapacity. It increases the risk of an individual losing control over his life because of idiosyncratic behavior.

Newer definitions tend to eliminate the emphasis on labels and replace them with objective standards to evaluate a person’s ability to make decisions. These definitions focus on functional abilities and discourage value judgments. D.C. has adopted this pure functional approach to defining incapacity. An “incapacitated individual” is an adult whose ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that he or she lacks the capacity to manage

all or some of his or her financial resources or to meet all or some essential requirements for his or her physical health, safety, habilitation, or therapeutic needs without court ordered assistance or the appointment of a guardian or conservator.⁶ This approach should help ensure that guardianship is imposed only when it is truly needed.

Presence at the Hearing

One of the most striking findings of the Associated Press report was that ninety-two percent of the files noted the respondent’s absence from the hearing, or failed to indicate whether the respondent had attended the hearing. The three jurisdictions take different approaches to this issue. All have made the effort to increase the likelihood that the respondent will be present at the hearing.

Virginia provides the respondent the right to attend, but does not mandate attendance.⁷ The law does not dictate whether the court must determine the reason the respondent did not attend the hearing. Instead, the court relies on the respondent to make a request to be present, or upon the certification of the guardian ad litem that the respondent has been informed of the right to be present.

D.C. and Maryland mandate the presence of the respondent at the hearing. The D.C. statute requires the respondent’s presence “unless good cause is shown for the absence.”⁸ Under this provision, the absence of the respondent must not only be noted, but information showing good cause for the absence must be included in the record. The Maryland law goes even further. It states:

The person alleged to be disabled is entitled to be present at the hearing unless he has knowingly and voluntarily waived the right to be present because of physical or mental incapacity. Waiver or incapacity may not be presumed from nonappearance but shall be determined on the basis of factual information supplied to the court by counsel or a representative appointed by the court.⁹

Like D.C., the lack of information in the record concerning the absence of

the respondent raises questions about whether the respondent’s due process rights are violated, if a guardian is ultimately appointed.

Representation of the Respondent

The role of the attorney who represents the respondent in guardianship proceedings has long been controversial. D.C., Maryland and Virginia all grant respondents the right to retain their own attorneys to represent their interest. The issue is more complicated when respondents do not retain their own attorneys.

Virginia appoints a guardian ad litem to represent the interests of the respondent in all cases.¹⁰ Traditionally, the role of guardians ad litem has been to serve as eyes and ears of the court, by making an independent determination of what is in the respondent’s best interest. The guardian ad litem reports his findings and recommendations to the court. Virginia law follows this concept. In addition, it has expanded the role so the guardian ad litem must ensure that the respondent’s due process rights are protected. The guardian ad litem must certify to the court that the respondent has been advised of the right to: 1) be present at the hearing and all other stages of the proceedings; 2) compel the attendance of witnesses; 3) present evidence in his own behalf; and 4) confront and cross-examine all witnesses providing evidence.¹¹ It is unclear whether the court will appoint an attorney to represent the respondent if recommended by the guardian ad litem at the request of the respondent. Ethically, the guardian ad litem cannot serve both functions.

Unless the respondent has retained his own counsel, Maryland law requires the appointment of an attorney to represent the respondent in all actions for the appointment of a guardian of the person.¹² There is no similar provision for such appointment when a petition is filed for a guardian of the property. The law does not clarify the role or identify the duties of the attorney. Therefore, one can assume that the attorney must represent the respondent like any other client.

Cont. on page 6

Overview

Cont. from page 5

There seems to be some confusion in the state about the effect of Maryland Rule R76 which indicates:

The court in its discretion may appoint an attorney who shall investigate the facts of the case and shall report, in writing, his findings to the court.

This language is very much like that used to describe a guardian ad litem. This role may be legitimate in an action for the appointment of a guardian of the property. However, an attorney appointed to represent a respondent in an action for a guardian of the person cannot act in this capacity unless expressly directed in the order of appointment. Even in that case, the statute still seems to require the appointment of an attorney to represent the respondent.

In D.C., the law is clear. Unless the allegedly incapacitated individual is represented by counsel, the court shall appoint an attorney to represent the individual in the proceeding.¹³ The appointment of counsel is required in all actions and the statute includes the duties and role of the attorney:

The duty of counsel . . . is to represent zealously that individual's legitimate interests. At a minimum, this shall include:

- 1) personal interviews with the subject of the intervention proceedings;
- 2) explaining . . . the nature and possible consequences of the proceeding, the alternatives available, and the rights to which the individual is entitled; and
- 3) securing and presenting evidence and testimony and offering arguments to protect the rights of the subject . . . and further that individual's interests.¹⁴

Clearly, the attorney must represent the client's wishes, and not substitute his judgment for what he believes to be in the client's best interests. This distinction can have a substantial impact on guardianship proceedings that are contested. A person who has an advocate to represent his interests is much more likely to have a decision tailored to his particular needs.

These illustrations are representative of guardianship provisions and trends

around the country. All three jurisdictions currently have committees and task forces reviewing their guardianship laws with the idea of reforms in mind. As these reforms are legislated, it is imperative that the court implement them properly. Otherwise, reforms in the law will not change the proceedings in the courtroom.

1. *Associated Press, "Guardians of the Elderly: An Ailing System," Special Report (1987) [A.P. Report].*
2. *Va. Code Ann. § 37.1-128.01 (Supp. 1994).*
3. *Va. Code Ann. §37.1-128.04 (Supp. 1994).*
4. *Md. Est. & Trusts Code Ann. §13-101(e) (Supp. 1993).*
5. *Md. Est. & Trusts Code Ann. §13-101(e) (Supp. 1993).*
6. *D.C. Code §21-2011(11) (Supp. 1993).*
7. *Va. Code Ann. §37.1-132 (Supp. 1994).*
8. *D.C. Code §§21-2041(h) and 21-2054(e) (Supp. 1993).*
9. *Md. Est. & Trusts Code Ann. §13-705(e) (Supp. 1993).*
10. *Va. Code Ann. §§37.1-128.1B and 37.1-132 (Supp. 1994).*
11. *Va. Code Ann. §37.1-133.1 (Supp. 1994).*
12. *Md. Est. & Trusts Code Ann. §13-705(d) (Supp. 1993).*
13. *D.C. Code §§21-2041(d) and 21-2054(a) (Supp. 1993).*
14. *D.C. Code §21-2033(b)(Supp. 1993).*

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Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee in the region and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Study From a Virginia Hospital

A 58 year old white male, residing in a local homeless shelter, exhibited suicidal ideations and tendencies, and was brought to the hospital psychiatric center for evaluation, and subsequently, was involuntarily admitted. The patient did not have any family or significant others. He was not compliant, although not violent. Having suicidal ideations, as well as indications of several suicidal attempts, the court found the patient to be incompetent. The hospital sought guardianship to assist in the decision making process with regard to his treatment.

After a medical workup, authorized by the guardian and the hospital, it was discovered that the patient had terminal colon cancer. It was also determined that a powerful regimen of chemotherapy might lengthen the patient's life by twelve to eighteen months. Unfortunately, this medication is known to cause significant nausea and vomiting, in addition to other severe side-effects. The patient refused the medication, but was forced to receive this treatment against his will. The patient became delusional, insisting that it was the chemotherapy that was causing his cancer.

The nursing staff, physicians, and guardian sought assistance from the Bioethics Committee of the hospital for advice in the determination and evaluation of ethical treatment options. Some of the questions put before this committee included: Is it reasonable to discontinue treatment that may preserve life, although at a significantly reduced quality of life? If so, does the patient's desire to discontinue treatment carry any weight given the court's adjudication of his incompetency, his suicidal ideations and his delusional state?

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Case Discussion: Comments From an Attorney

This case raises both substantive and procedural issues with respect to the appropriate role of the institution's Bioethics Committee. In addition, the case illustrates what many in the field know all too well: it is generally better to deal with most bioethical issues at the earliest opportunity, than to wait and do so later.

The Initial Decision to Treat

Since this case concerns the propriety of reversing a course of treatment which was consented to, not by but on behalf of the patient, a decision to withdraw treatment should be made on the same basis as was the initial authorization. Therefore, a discussion about the reasonableness of a decision to discontinue chemotherapy and what weight, if any, should be accorded the patient's refusal, must include an analysis of the initial decision to commence the chemotherapeutic regimen. Understanding that initial decision is of vital importance and the Bioethics Committee must, consequently explore this issue.

The forced administration of chemotherapy is assumed to have been authorized by the patient's guardian. Inasmuch as many chemotherapy regimens may involve experimental treatment, the importance of obtaining valid informed consent to such treatment cannot be overlooked. Presumably, the Committee will discover that the guardian considered the risks and benefits to the patient from receiving chemotherapy and concluded that the benefits outweighed the risks, including the risk of foregoing treatment. Hopefully, the Committee will also determine that the guardian specifically concluded that the known adverse side effects of treatment (as well as the unknown risks) were outweighed by the benefits associated with a possible increase in the patient's life by 12 to 18 months. One must wonder, however, whether the patient, in a lucid interval would concur in such assessment and

arrive at the same decision. A related issue is whether the court order establishing the guardianship contemplated and enabled decisions of this magnitude or whether the court intended only for the guardian to make decisions with regard to the patient's mental health treatment. If the latter, it makes sense to go back to court to enlarge the surrogate's power in consideration of the patient's condition.

The Decision to Discontinue Treatment

Taking up the questions of the reasonableness of discontinuing treatment and whether to accord any weight to the patient's apparent desire to forego treatment, two responses come to mind. Assuming that the guardian acted within the scope of the court's guardianship appointment and in accordance with the patient's best interests and gave valid and effective informed consent to commence the chemotherapy regimen, it seems not only unreasonable, but inappropriate, to discontinue a potentially life lengthening course of treatment. The autonomy of this patient has been surrendered to the legally designated surrogate decisionmaker, the guardian. It makes no sense to attribute decisional weight to the patient's protestations because such objections are not viewed as emanating from a rational thought process. Indeed, if a decision were to be made to discontinue chemotherapy without the guardian's consent, what would be the source of authority for any such decision. In this context, therefore, the Ethics Committee can only confirm that informed consent to treatment was obtained.

Best Interest of the Patient

On the other hand, this case may be viewed as one in which the surrogate decisionmaker—the guardian—appears (to the treatment team) not to be acting in the patient's best interests and to the extent the patient's preferences are at all discernible, the treatment decision appears to be at odds with such preferences. In this situation, it seems appropriate for the Bioethics Committee to become involved and explore whether the guardian's decision making is centered on the patient's best

interests. It seems unreasonable, however, for the Committee to go beyond this role by attempting to insert itself as the decisionmaker on the question of discontinuing treatment or the arbiter between the guardian and an incompetent ward. Assuming the Committee has not been legally empowered to wrest decision making power from the patient or the patient's surrogate, the Committee should not effect a change in the treatment course without the assent of the guardian. As an attorney, I would be quite uncomfortable with giving any ethics committee that much rope.

If, after reviewing the facts, it is evident to the Committee that the guardian is not acting in the patient's best interests, it would be appropriate to challenge the guardian on this issue. If the guardian is unwilling to reassess his or her decision making, the matter can always be brought before the court—the source of the guardian's authority. Notwithstanding the patient's evident desire to discontinue treatment, and without a court order, it would be unreasonable for the Bioethics Committee (or the hospital for that matter) to discontinue treatment authorized by the guardian. Nothing in the facts presented indicate that the guardian's authority to speak for the patient has been curtailed or revoked.

If the guardian is willing to reassess the decision to commence chemotherapy, he or she should be encouraged to ascertain, as much as possible, the patient's basic values and preferences. Failing an ability to do that, I would recommend that the guardian talk, not only to medical oncologists, but also to cancer patients currently undergoing treatment, who are willing to share their story, so that the guardian can have a better appreciation for how a rational patient responds to the core question: is the adversity of chemotherapy worth the expected benefit?

Submitted by
Matthew D. Jenkins, J.D., Partner
Hunton & Williams
Richmond, VA

Case Discussion: Comments From a Physician

The central question in this case is whether the ethics committee and the guardian, acting on behalf of an incompetent patient, lacking advance directives, must adopt a vitalist principle: prolong life at any cost. This case is especially difficult as the patient appears to reject life, given his repeated attempts at suicide. Here, the committee must not only wrestle with the general problems of applying a substituted judgment or best interest test, but also with the choice of whether to accept a mentally ill patient's assessment that life is not worth living, or to explicitly override his wishes.

The Question of Competency

The courts deem suicidal patients incompetent on the assumption that their feelings reflect irrational and profound depression -- sane persons would not choose to take their own lives. In general, from the legal perspective, no consideration is given to the possible causes of the patient's feelings, nor to the likelihood that the patient will ever achieve a condition in which such feelings were not present. Further, the state's interest in life per se is thought to justify paternalistic intervention when a patient represents a danger to himself.¹ While, ethically, incompetence based on suicidality does not necessarily reflect generalized incapacity to make any and all medical decisions², in this case, the patient's mental state directly affects a decision regarding life lengthening chemotherapy. To the extent that his suicidal tendencies are irrational, his capacity to decide is impaired. In these circumstances, the committee should not support the patient's refusal of chemotherapy, nor, using a best interest assessment, consider the patient's apparent lack of desire to live. Given the absence of a presuicidal reference point, recommending chemotherapy seems the path of least resistance, as well as, consistent with the ethical

commitment to treat and to prolong life.

Best Interest of the Patient

Best interest judgments are inherently problematic in our American environment, which is so heavily weighted toward respect for individual preference, however idiosyncratic.³ Absent adequate information about an individual's general values or specific preferences, one must ask what a "reasonable person" would do in similar circumstances.⁴ One model for such decision making proposes a "community standard", invoking as the reference group the patient population served by a particular facility.⁵ While an attractive concept, this idea raises questions about how to identify the appropriate reference population. Hospitals typically do not serve homogeneous patient groups. Our own institution cares for incompetent, isolated individuals of many ethnic extractions, and socioeconomic or educational backgrounds. In this case, would the majority of patients in the hospital, to which this patient was involuntarily committed, share his values and experience?

The patient's social situation might also lead conscientious committee members' to mistrust their own capacity to make a best interest judgment on his behalf. A committee of reasonably healthy, socially and economically comfortable individuals may realize that it is too easy for them to accept a homeless, deluded man's assessment of his life as not worth living. To offset these social biases and to avoid discriminating against this vulnerable man the committee might, therefore, recommend treatment. When this concern is coupled with a mistrust of suicidality as a competent expression of will, the committee's safest moral course is to choose treatment which prolongs life, however compromised.

Another fact, which favors compelled treatment, is that the patient is homeless. This makes it unlikely that he is insured. As a result, even comfort care, through a home or in-patient hospice, may be unavailable. By insisting on treatment, the committee may believe it is ensuring the patient's

access to pain relief and comfort measures that he might otherwise not receive.

Recommending chemotherapy will, however, only temporarily solve the committee's and the clinicians' dilemma. This man's condition will continue to deteriorate, necessitating rescue efforts which are more and more invasive, with increasingly lower probabilities of success. As a result, prior to the patient's death, the committee will continue to face questions about how much therapy he should be forced to undergo.

A Mental Health Treatment Approach

One alternative is for the committee to recommend coercive treatment with the goal of enhancing the patient's capacity to make a decision (thereby enhancing his autonomy), rather than for the beneficent purpose of cancer treatment.⁶ Using this approach, a vigorous trial of therapy, for both his delusional state and his depression would precede a decision regarding chemotherapy. If he responds to treatment, a more reasonable discussion of cancer therapy will then be possible. Further, when such patients are in remission from their mental illness, they can be encouraged to enact advance directives in which they might consent to rehospitalization and treatment during future relapses.⁷ In this case, an advance directive would assist clinicians, in both the management of the patient's mental illness, and his cancer treatment.

In some locales, it might be possible to ameliorate the patient's social situation, for instance, his homelessness, reducing his suicidal thoughts. However, rational decision making for all patients is expected to take into consideration the reality of their familial and economic situation as they contemplate treatment. Ethics do not require the removal of all the burdens that might make this man unhappy or that lead him to refuse treatment, but only to mitigate, insofar as possible, demonstrably irrational ideation about his illness, its treatment, and its potential impact on his future.

What if the patient does become capable of understanding his disease,

its prognosis and the implications of treatment; is no longer delusional, demonstrates capacity to decide, but remains pessimistic, even suicidal, despite an appropriate course of treatment? At this point, the committee must consider that the patient's emotional state is a fixed condition of his life. If no social or medical intervention is able to reverse it, his hopelessness may not be morally different than one patient's irremediable pain or another's fear of future disability. If the latter's decisions about medical treatment are respected, then it seems only equitable to afford the same respect to the choices of this patient.

But what if psychiatric treatment fails to resolve the patient's delusions and/or inability to understand his condition and options? What if adequate psychiatric treatment cannot be enforced legally? In these circumstances, the committee should not recommend chemotherapy.

If he were not homeless, nor had a history of suicidality, but was rather an irreversibly incompetent, fifty-eight year old white male, without advance directives or identifiable surrogates, would we feel obliged to choose chemotherapy on his behalf? Here, the Saikewicz case⁸ provides insight. Joseph Saikewicz, at fifty-seven, had never been competent due to mental retardation, just as the patient in this case has no discoverable competent past. Similarly, Mr. Saikewicz faced treatment for cancer. The decision in the Saikewicz case, based on compassion for the potential sufferer, was to forego treatment. Likewise, in the case of our fifty-eight year old homeless man, neither our misgivings about psychiatric illness and suicidality, nor our collective responsibility for this man's homelessness should interfere with compassionate decision making. The ethics committee should, therefore, recommend comfort care for this patient rejecting burdensome efforts to prolong his life, which this patient cannot comprehend.

1. Childress J. *Who Should Decide*. Oxford University Press, New York and Oxford, 1982, pp 157-162; Greenberg, DF. *Interference with*

a Suicide Attempt, in Biomedical Ethics. Mappes TA and Zembaty JS. eds. McGraw-Hill, Inc. New York 1991, pp.326-330.

2. Buchanan AE and Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge University Press: New York and Cambridge. 1989; pp.317-325; 342-346.

3. Gutheil TG, and Appelbaum PS. *Substituted Judgment: Best Interest in Disguise*. Hastings Center Report 13(3): 8-11, 1983.

4. *The concept of the "reasonable person" has been elaborated primarily within the context of case law related to informed consent. See (e.g.): Canterbury v. Spence, 464 F.2d at 786-87.*

5. Emanuel LL and Emanuel EJ. *Decisions at the End of Life: Guided by Communities of Patients*. Hastings Center Report 23 (5):6-14, 1993.

6. Buchanan A and Brock D, *supra*.

7. Buchanan A and Brock D. *Ibid*, pp 350-357.

8. *Superintendent of Belchertown State School v. Saikewicz, 373. Mass. 728, 370 N.E.2d 417 (1977).*

Submitted by

Gail J. Povar, M.D., M.P.H.

Chair, George Washington University
Hospital Ethics Committee
Washington, D.C.

WEST VIRGINIA ADOPTS NEW GUARDIANSHIP STATUTE

During the 1994 legislative session, The West Virginia Legislature repealed West Virginia's archaic guardianship laws, substituting a new system which provides greater procedural safeguards. This new guardianship law has dramatically changed the procedure for establishing a guardianship in West Virginia.

Under the new system, guardians and conservators replace committees. Guardians are charged with the responsibility of looking after an individual's personal affairs while conservators are responsible for managing a person's estate and financial affairs.

Petitions for the appointment of a guardian or conservator are filed in the circuit courts and may be heard by either a circuit court judge or a mental hygiene commissioner, who is a lawyer. Regardless of who hears the case, the state's circuit court rules of evidence and procedure must be followed.

Other significant aspects of the new law include:

- The appointment of limited guardianships and conservator-

ships, when appropriate, tailored to address the individual needs of persons alleged to need protection;

- The provision of legal notice to parties in language that is easy to read and comprehend;
- The establishment of minimum training requirements for persons who are appointed guardians and conservators;
- The establishment of minimum supervision and visitation requirements for guardians and conservators;
- Increased reporting requirements for guardians and conservators; and
- Revision of outdated terminology referring to individuals needing protection.

The Guardianship and Conservatorship Act is the keystone of guardianship reform in West Virginia, completing an array of recent legislation designed to protect the most vulnerable citizens in our society.

Submitted by

Patrick D. Kelly, Esq.

Steptoe & Johnson

Attorneys at Law

Charlestown, West Virginia

MARYLAND'S HEALTH CARE DECISIONS ACT ADVISORY COUNCIL MEETS

In August, Maryland Governor William Donald Schaefer appointed the Health Care Decisions Act Advisory Council. Created by an Executive Order signed by Governor Schaefer in March of this year, the Council includes the following 19 members:

Torrey Brown M.D.

Chairman, Secretary of Natural Resources

The Hon. Rosalie S. Abrams

Director, Office on Aging

Rabbi Joel H. Zaiman

Chizuk Amuno Congregation

Gerard F. B. Miller, Consultant

Neetu Dhawan-Gray

Executive Director, Commission on Aging and Retirement Education

Steven A. Levenson, M.D.

Medical Director, Asbury

Methodist Village

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Advisory Council

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Office of the Attorney General

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Edmund D. Pellegrino, M.D.

Director, Center for Clinical Bioethics
Georgetown University Medical Center

The Council, established to monitor the implementation of the Maryland Health Care Decisions Act, has met twice and will meet again on November 30th.

Lives in the Balance

Cont. from page 1

property. Two doctors fill out forms certifying that because of his illness, Mr. Z is unable to make or communicate responsible decisions concerning his person and property. An attorney appointed by the court, comes by to see Mr. Z, but only stays a few minutes after a nurse tells him that Mr. Z is "a bit confused". Three days later, the

Circuit Court calls the case and the two lawyers approach the bench. They tell the judge that they have agreed that Mr. Z needs a guardian. The judge signs an order naming the local Office on Aging, under the Public Guardianship Program, guardian of Mr. Z's person and the attorney for the hospital the guardian of Mr. Z's property. That same day, the attorney signs Mr. Z into the nursing home. He also contacts a realtor to put his house on the market, and an auctioneer to sell his furniture and personal belongings. The guardian intends to liquidate all of Mr. Z's assets to pay for his nursing home care.

In the course of searching Mr. Z's house for bank records, the attorney's paralegal finds the name and address of Mr. Z's son, who is in the Army in Germany. The son is contacted and flies home immediately. He is dismayed to learn what has happened to his father, who is now still physically weak but able to understand what has gone on. The guardian tells Mr. Z and his son that he is now in control of the money, and that since Mr. Z has been found incompetent, he has no further say in the handling of his assets or money.

As this example illustrates, in some Maryland jurisdictions, it has become all too easy to obtain guardianship, often when there are less restrictive measures available.

In many states guardianship of an adult results in the complete abolition of that person's civil rights. The person is reduced to the status of a child, so he or she no longer has the right to decide where to live, how to spend money, and what medical treatment to receive. It is important, therefore, that the procedure be fair, its use limited and then, only as a last resort. In many cases, alternatives could be used to prevent this wholesale deprivation of rights. In Mr. Z's case, there should have been a more thorough search for responsible relatives, and serious consideration of home health services, instead of automatic nursing home placement.

The use of guardianship proceedings in Maryland has grown rapidly and with the aging of the population, the need for guardianships will only increase.

The Maryland Guardianship statute provides that guardianship should be an adversary proceeding, and that the person threatened with guardianship has certain due process rights. For example, an attorney must be appointed to represent the person, there is a right to a jury trial, and to an evidentiary hearing on the matter. However, these procedures are often ignored, and guardianship cases are frequently paid scant attention by the court. Attorneys fail to defend their client against the guardianship, and often join in the request after a cursory investigation. These problems are not unique to Maryland; they exist in many states, with the result that the subjects of guardianship are stripped of their rights without regard for their wishes or needs.

A task force organized by the State of Maryland Office on Aging has been working to revise the guardianship statute to prevent abuses and to find alternatives to guardianship. A comprehensive reform proposal is being readied for the 1995 legislative session. One suggestion is to authorize a three member volunteer panel to consent or withhold consent for medical treatment for an incompetent person who has no surrogate. This plan is modeled on a New York program in place for several years. Reforms to the guardianship statute include clarification of the role of the attorney for the alleged disabled person, and a procedure for insuring that expedited guardianships, such as Mr. Z's, are more carefully examined before they become final.

Losing the ability to carry on with one's life is a sad milestone. Those working for guardianship reform hope to prevent situations such as Mr. Z's, so that there is as little intrusion into the person's life as possible, while still assisting with essential needs.

A conference on guardianship reform will be held at the University of Maryland School of Law on November 16, 1994, to explore these issues. (See calendar in this newsletter.)

Submitted by

Joan L. O'Sullivan, J.D.

Assistant Visiting Professor of Law
University of Maryland School of Law
Baltimore, Maryland

ETHICS COMMITTEE EDUCATION PROJECT

“Educating Healthcare Ethics Committees,” a project supported by the Fund for the Improvement of Postsecondary Education, US Dept. of Education, is about to begin its third and final year. The project provides on site, intensive education programs for

ethics committees in hospitals, long-term care institutions, and home health agencies. Each program is planned to meet the particular ethics committee’s needs.

Project directors draw from a faculty of 25 ethics consultants (physicians, nurses, philosophers, and attorneys) for these education programs. Although the grant for this program does not completely fund the program, the

level of cost-sharing is generous.

In each of the past two years, the project has conducted programs for twenty ethics committees, and an additional twenty are to be completed in the final year. Any ethics committee that is interested in the project should call either of the project directors: Stuart Spicker at (713) 798-3511 or Judy Ross at (310) 476-4940 or (604) 886-0271.

CALENDAR OF EVENTS

NOVEMBER

- 1st Washington Metropolitan Area Bioethics Network Meeting, 4:00 p.m. Topic: “Ethical Issues in Emergency Care,” Arlington Hospital, Arlington, VA. Contact Joan Lewis at (202) 602-1581.
- 1st Bioethics Network of Southeastern VA Meeting, 7:00 p.m. Topic: “Informed Consent & the Law,” Speakers: Sandy Colby, RN & Joyce Wood, J.D., Auditorium, Hofheimer Hall, Norfolk General Hospital, Norfolk, VA. Contact Julia West, MSW at (804) 548-2911.
- 2nd The Wilhelm S. Albrink Memorial Lectureship in Bioethics. Topic: “Moral Decision Making: Slogans, Principles, Coin Toss or the Seat of Your Pants,” Speaker: Danner Clouser, PhD, Dir., Medical Humanities Program, Hershey Medical Center, Penn State University, to be held at Robert C. Byrd Health Sciences Center of WVU, Morgantown, WV. For more information contact Cindy Jamison at (304) 293-7618.
- 4th The Sister Margaret James Lecture, “Sherlock Holmes and Medical Diagnosis,” a talk by Kathryn Hunter, PhD, 4:00 p.m., St. Agnes Hospital, Baltimore, Maryland. For more information contact Henry Silverman, M.D. at (410) 706-6250.
- 16th “Guardianship in Crisis: Discussion of the Problem and Proposed Solutions,” 8:00 a.m.-12:30 p.m., a conference sponsored by the Law and Health Care Program, U of MD School of Law at Westminster Hall, Baltimore, MD. For more information call (410) 706-7239.
- 17th “Trauma/Critical Care in the 90’s: Ethical Perspectives,” 7:30 a.m.-5:30 p.m., a workshop sponsored by the R. Adam Cowley Shock Trauma Center and the U of MD Medical System, Hyatt Regency Hotel, Baltimore, MD. For more information call (410) 328-2399.
- 18th The Medical Humanities Hour, 1:00-2:00 p.m., Topic “Rationing Beneficial Care: Can It Be Done Ethically?” Speaker: Dan Brock, PhD, Shock Trauma Auditorium, U of MD Medical System, Baltimore, MD. Contact Henry Silverman, M.D. at (410) 706-6250.

DECEMBER

- 6th Washington Metropolitan Bioethics Network Meeting, 4:15 p.m. Topic: “End of Life Decisions Based on Faith,” U.S. Soldiers and Airmen’s Home, Washington, D.C. Contact Joan Lewis at (202) 602-1581.
- 6th Bioethics Network of Southeastern VA Meeting, 7:00 p.m., a panel discussion. Topic: “Surrogate Decision Making: Doctors Responsibilities and Surrogate’s Rights,” Auditorium, Hofheimer Hall, Norfolk General Hospital, Norfolk, VA. Contact Julia West, MSW at (804) 548-2911.
- 6th Baltimore Area Ethics Committee Network Meeting, “Standards for Ethics Committees,” 4:30 p.m., Sinai Hospital, Baltimore, MD. Contact Jack Syme, M.D. at (410) 368-3020.
- 9th The Medical Humanities Hour, 1:00-2:00 p.m., Topic: “History of Human Experimentation and Informed Consent,” Speaker: Alan T. Lefor, MD, Shock Trauma Auditorium, U of MD Medical System, Baltimore, MD. Contact Henry Silverman, M.D. at (410) 706-6250.

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