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Preface

Ethics is an integral part of the foundation of nursing. Nursing has a distinguished history of concern for the welfare of the sick, injured, and vulnerable and for social justice. This concern is embodied in the provision of nursing care to individuals and the community. Nursing encompasses the prevention of illness, the alleviation of suffering, and the protection, promotion, and restoration of health in the care of individuals, families, groups, and communities. Nurses act to change those aspects of social structures that detract from health and well-being. Individuals who become nurses are expected not only to adhere to the ideals and moral norms of the profession but also to embrace them as a part of what it means to be a nurse. The ethical tradition of nursing is self-reflective, enduring, and distinctive. A code of ethics makes explicit the primary goals, values, and obligations of the profession.

The Code of Ethics for Nurses serves the following purposes:

- It is a succinct statement of the ethical obligations and duties of every individual who enters the nursing profession.
- It is the profession's nonnegotiable ethical standard.
- It is an expression of nursing's own understanding of its commitment to society.

There are numerous approaches for addressing ethics; these include adopting or subscribing to ethical theories, including humanist,feminist, and social ethics, adhering to ethical principles, and cultivating virtues. The Code of Ethics for Nurses reflects all of these approaches. The words "ethical" and "moral" are used throughout the Code of Ethics. "Ethical" is used to refer to reasons for decisions about how

one ought to act, using the above mentioned approaches. In general, the word "moral" overlaps with "ethical" but is more aligned with personal belief and cultural values. Statements that describe activities and attributes of nurses in this Code of Ethics are to be understood as normative or prescriptive statements expressing expectations of ethical behavior.

The Code of Ethics for Nurses uses the term *patient* to refer to recipients of nursing care. The derivation of this word refers to "one who suffers," reflecting a universal aspect of human existence. Nonetheless, it is recognized that nurses also provide services to those seeking health as well as those responding to illness, to students and to staff, in health care facilities as well as in communities. Similarly, the term *practice* refers to the actions of the nurse in whatever role the nurse fulfills, including direct patient care provider, educator, administrator, researcher, policy developer, or other. Thus, the values and obligations expressed in this Code of Ethics apply to nurses in all roles and settings.

The Code of Ethics for Nurses is a dynamic document. As nursing and its social context change, changes to the Code of Ethics are also necessary. The Code of Ethics consists of two components: the provisions and the accompanying interpretive statements. There are nine provisions. The first three describe the most fundamental values and commitments of the nurse; the next three address boundaries of duty and loyalty, and the last three address aspects of duties beyond individual patient encounters. For each provision, there are interpretive statements that provide greater specificity for practice and are responsive to the contemporary context of nursing. Consequently, the interpretive statements are subject to more frequent revision than are the provisions. Additional ethical guidance and detail can be found in ANA or constituent member association position statements that address clinical, research, administrative, educational, or public policy issues.

The Code of Ethics for Nurses with Interpretive Statements provides a framework for nurses to use in ethical analysis and decision-making. The Code of Ethics establishes the ethical standard for the profession. It is not negotiable in any setting nor is it subject to revision or amendment except by formal process of the House of Delegates of the ANA. The Code of Ethics for Nurses is a reflection of the proud ethical heritage of nursing, a guide for nurses now and in the future.

Provision 1.

The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems.

1.1 Respect for human dignity - A fundamental principle that underlies all nursing practice is respect for the inherent worth, dignity, and human rights of every individual. Nurses take into account the needs and values of all persons in all professional relationships.

1.2 Relationships to patients - The need for health care is universal, transcending all individual differences. The nurse establishes relationships and delivers nursing services with respect for human needs and values, and without prejudice. An individual's lifestyle, value system and religious beliefs should be considered in planning health care with and for each patient. Such consideration does not suggest that the nurse necessarily agrees with or condones certain individual choices, but that the nurse respects the patient as a person.

1.3 The nature of health problems -The nurse respects the worth, dignity and rights of all human beings irrespective of the nature of the health problem. The worth of the person is not affected by disease, disability, functional status, or proximity to death. This respect extends to all who require the services of the nurse for the promotion of health, the prevention of illness, the restoration of health, the alleviation of suffering, and the provision of supportive care to those who are dying.

The measures nurses take to care for the patient enable the patient to live with as much physical, emotional, social, and spiritual well-being as possible. Nursing care aims to maximize the values that the patient has treasured in life and extends supportive care to the family and significant others. Nursing care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care. This is particularly vital in the care of patients

and their families at the end of life to prevent and relieve the cascade of symptoms and suffering that are commonly associated with dying.

Nurses are leaders and vigilant advocates for the delivery of dignified and humane care. Nurses actively participate in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted or unwanted treatment and patient suffering. The acceptability and importance of carefully considered decisions regarding resuscitation status, withholding and withdrawing life-sustaining therapies, forgoing medically provided nutrition and hydration, aggressive pain and symptom management and advance directives are increasingly evident. The nurse should provide interventions to relieve pain and other symptoms in the dying patient even when those interventions entail risks of hastening death. However, nurses may not act with the sole intent of ending a patient's life even though such action may be motivated by compassion, respect for patient autonomy and quality of life considerations. Nurses have invaluable experience, knowledge, and insight into care at the end of life and should be actively involved in related research, education, practice, and policy development.

1.4 The right to self-determination - Respect for human dignity requires the recognition of specific patient rights, particularly, the right of self-determination. Self-determination, also known as autonomy, is the philosophical basis for informed consent in health care. Patients have the moral and legal right to determine what will be done with their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed judgment; to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment; to accept, refuse, or terminate treatment without deceit, undue influence, duress, coercion, or penalty; and to be given necessary support throughout the decision-making and treatment process. Such support would include the opportunity to make decisions with family and significant others and the provision of advice and support from knowledgeable nurses and other health professionals. Patients should be involved in planning their own health care to the extent they are able and choose to participate.

Each nurse has an obligation to be knowledgeable about the moral and legal rights of all patients to self-determination. The nurse preserves, protects, and supports those interests by assessing the patient's comprehension of both the information presented and the implications of decisions. In situations in which the patient lacks the capacity to make a decision, a designated surrogate decision-maker should be consulted. The role of the surrogate is to make decisions as the patient would, based upon the patient's previously expressed wishes and known values. In the absence of a designated surrogate decision-maker, decisions should be made in the best interests of the patient, considering the patient's personal values to the extent that they are known. The nurse supports patient self-determination by participating in discussions with surrogates, providing guidance and referral to other resources as necessary, and identifying and addressing problems in the decision-making process. Support of autonomy in the broadest sense also includes recognition that people of some cultures place less weight on individualism and choose to defer to family or community values in decision-making. Respect not just for the specific decision but also for the patient's method of decision-making is consistent with the principle of autonomy.

Individuals are interdependent members of the community. The nurse recognizes that there are situations in which the right to individual self-determination may be outweighed or limited by the rights, health and welfare of others, particularly in relation to public health considerations. Nonetheless, limitation of individual rights must always be considered a serious deviation from the standard of care, justified only when there are no less restrictive means available to preserve the rights of others and the demands of justice.

1.5 Relationships with colleagues and others - The principle of respect for persons extends to all individuals with whom the nurse interacts. The nurse maintains compassionate and caring relationships with colleagues and others with a commitment to the fair treatment of individuals, to integrity-preserving compromise, and to resolving conflict. Nurses function in many roles, including direct care provider, administrator, educator, researcher, and consultant. In each of these roles, the nurse treats colleagues, employees, assistants, and students with respect and compassion. This standard of conduct precludes any and all prejudicial actions, any form of

harassment or threatening behavior, or disregard for the effect of one's actions on others. The nurse values the distinctive contribution of individuals or groups, and collaborates to meet the shared goal of providing quality health services.

Provision 2 The nurse's primary commitment is to the patient, whether an individual, family, group, or community.

2.1 Primacy of the patient's interests - The nurse's primary commitment is to the recipient of nursing and health care services --the patient--whether the recipient is an individual, a family, a group, or a community. Nursing holds a fundamental commitment to the uniqueness of the individual patient; therefore, any plan of care must reflect that uniqueness. The nurse strives to provide patients with opportunities to participate in planning care, assures that patients find the plans acceptable and supports the implementation of the plan. Addressing patient interests requires recognition of the patient's place in the family or other networks of relationship. When the patient's wishes are in conflict with others, the nurse seeks to help resolve the conflict. Where conflict persists, the nurse's commitment remains to the identified patient.

2.2 Conflict of interest for nurses - Nurses are frequently put in situations of conflict arising from competing loyalties in the workplace, including situations of conflicting expectations from patients, families, physicians, colleagues, and in many cases, health care organizations and health plans. Nurses must examine the conflicts arising between their own personal and professional values, the values and interests of others who are also responsible for patient care and health care decisions, as well as those of patients. Nurses strive to resolve such conflicts in ways that ensure patient safety, guard the patient's best interests and preserve the professional integrity of the nurse.

Situations created by changes in health care financing and delivery systems, such as incentive systems to decrease spending, pose new possibilities of conflict between economic self-interest and professional integrity. The use of bonuses, sanctions, and incentives tied to financial targets are examples of features of health care systems that may present such conflict. Conflicts of interest may arise in any domain of nursing activity including clinical practice, administration, education, or research. Advanced practice nurses who bill directly for services and nursing executives with budgetary responsibilities must be especially cognizant of the potential for conflicts of interest. Nurses should disclose to all relevant parties (e.g., patients, employers, colleagues) any perceived or actual conflict of interest and in some situations should withdraw from further participation. Nurses in all roles must seek to ensure that employment arrangements are just and fair and do not create an unreasonable conflict between patient care and direct personal gain.

2.3 Collaboration - Collaboration is not just cooperation, but it is the concerted effort of individuals and groups to attain a shared goal. In health care, that goal is to address the health needs of the patient and the public. The complexity of health care delivery systems requires a multi-disciplinary approach to the delivery of services that has the strong support and active participation of all the health professions. Within this context, nursing's unique contribution, scope of practice, and relationship with other health professions needs to be clearly articulated, represented and preserved. By its very nature, collaboration requires mutual trust, recognition, and respect among the health care team, shared decision-making about patient care, and open dialogue among all parties who have an interest in and a concern for health outcomes. Nurses should work to assure that the relevant parties are involved and have a voice in decision-making about patient care issues. Nurses should see that the questions that need to be addressed are asked and that the information needed for informed decision-making is available and provided. Nurses should actively promote the collaborative multi-disciplinary planning required to ensure the availability and accessibility of quality health services to all persons who have needs for health care.

Intra-professional collaboration within nursing is fundamental to effectively addressing the health needs of patients and the public. Nurses engaged in non-clinical roles, such as administration or research, while not providing direct care, nonetheless are collaborating in the provision of care through their influence and direction of those who do. Effective nursing care is accomplished

through the interdependence of nurses in differing roles--those who teach the needed skills, set standards, manage the environment of care, or expand the boundaries of knowledge used by the profession. In this sense, nurses in all roles share a responsibility for the outcomes of nursing care.

2.4 Professional boundaries - When acting within one's role as a professional, the nurse recognizes and maintains boundaries that establish appropriate limits to relationships. While the nature of nursing work has an inherently personal component, nurse-patient relationships and nurse-colleague relationships have, as their foundation, the purpose of preventing illness, alleviating suffering, and protecting, promoting, and restoring the health of patients. In this way, nurse-patient and nurse-colleague relationships differ from those that are purely personal and unstructured, such as friendship. The intimate nature of nursing care, the involvement of nurses is important and sometimes highly stressful life events, and the mutual dependence of colleagues working in close concert all present the potential for blurring of limits to professional relationships. Maintaining authenticity and expressing oneself as an individual, while remaining within the bounds established by the purpose of the relationship can be especially difficult in prolonged or long-term relationships. In all encounters, nurses are responsible for retaining their professional boundaries. When those professional boundaries are jeopardized, the nurse should seek assistance from peers or supervisors or take appropriate steps to remove her/himself from the situation.

Provision 3 The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient.

3.1 Privacy - The nurse safeguards the patient's right to privacy. The need for health care does not justify unwanted intrusion into the patient's life. The nurse advocates for an environment that provides for sufficient physical privacy, including auditory privacy for discussions of a personal nature and policies and practices that protect the confidentiality of information.

3.2 Confidentiality - Associated with the right to privacy, the nurse has a duty to maintain confidentiality of all patient information. The patient's well-being could be jeopardized and the fundamental trust between patient and nurse destroyed by unnecessary access to data or by the inappropriate disclosure of identifiable patient information. The rights, well-being, and safety of the individual patient should be the primary factors in arriving at any professional judgment concerning the disposition of confidential information received from or about the patient, whether oral, written or electronic. The standard of nursing practice and the nurse's responsibility to provide quality care require that relevant data be shared with those members of the health care team who have a need to know. Only information pertinent to a patient's treatment and welfare is disclosed, and only to those directly involved with the patient's care. Duties of confidentiality, however, are not absolute and may need to be modified in order to protect the patient, other innocent parties and in circumstances of mandatory disclosure for public health reasons.

Information used for purposes of peer review, third-party payments, and other quality improvement or risk management mechanisms may be disclosed only under defined policies, mandates, or protocols. These written guidelines must assure that the rights, well-being, and safety of the patient are protected. In general, only that information directly relevant to a task or specific responsibility should be disclosed. When using electronic communications, special effort should be made to maintain data security.

3.3 Protection of participants in research - Stemming from the right to self-determination, each individual has the right to choose whether or not to participate in research. It is imperative that the patient or legally authorized surrogate receive sufficient information that is material to an informed decision, to comprehend that information, and to know how to discontinue participation in research without penalty. Necessary information to achieve an adequately informed consent includes the nature of participation, potential harms and benefits, and available alternatives to taking part in the research. Additionally, the patient should be informed of how the data will be protected. The patient has the right to refuse to participate in research or to withdraw at any time without fear of adverse consequences or reprisal.

Research should be conducted and directed only by qualified persons. Prior to implementation, all research should be approved by a qualified review board to ensure patient protection and the ethical integrity of the research. Nurses should be cognizant of the special concerns raised by research involving vulnerable groups, including children, prisoners, students, the elderly, and the poor. The nurse who participates in research in any capacity should be fully informed about both the subject's and the nurse's rights and obligations in the particular research study and in research in general. Nurses have the duty to question and, if necessary, to report and to refuse to participate in research they deem morally objectionable.

3.4 Standards and review mechanisms - Nursing is responsible and accountable for assuring that only those individuals who have demonstrated the knowledge, skill, practice experiences, commitment, and integrity essential to professional practice are allowed to enter into and continue to practice within the profession. Nurse educators have a responsibility to ensure that basic competencies are achieved and to promote a commitment to professional practice prior to entry of an individual into practice. Nurse administrators are responsible for assuring that the knowledge and skills of each nurse in the workplace are assessed prior to the assignment of responsibilities requiring preparation beyond basic academic programs.

The nurse has a responsibility to implement and maintain standards of professional nursing practice. The nurse should participate in planning, establishing, implementing, and evaluating review mechanisms designed to safeguard patients and nurses, such as peer review processes or committees, credentialing processes, quality improvement initiatives, and ethics committees. Nurse administrators must ensure that nurses have access to and inclusion on institutional ethics committees. Nurses must bring forward difficult issues related to patient care and/or institutional constraints upon ethical practice for discussion and review. The nurse acts to promote inclusion of appropriate others in all deliberations related to patient care.

Nurses should also be active participants in the development of policies and review mechanisms designed to promote patient safety, reduce the likelihood of errors, and address both environmental system factors and human factors that present increased risk to patients. In addition, when errors do occur, nurses are expected to follow institutional guidelines in reporting errors committed or observed to the appropriate supervisory personnel and for assuring responsible disclosure of errors to patients. Under no circumstances should the nurse participate in, or condone through silence, either an attempt to hide an error or a punitive response that serves only to fix blame rather than correct the conditions that led to the error.

3.5 Acting on questionable practice - The nurse's primary commitment is to the health, well-being, and safety of the patient across the life span and in all settings in which health care needs are addressed. As an advocate for the patient, the nurse must be alert to and take appropriate action regarding any instances of incompetent, unethical, illegal, or impaired practice by any member of the health care team or the health care system or any action on the part of others that places the rights or best interests of the patient in jeopardy. To function effectively in this role, nurses must be knowledgeable about the Code of Ethics, standards of practice of the profession, relevant federal, state and local laws and regulations, and the employing organization's policies and procedures.

When the nurse is aware of inappropriate or questionable practice in the provision or denial of health care, concern should be expressed to the person carrying out the questionable practice. Attention should be called to the possible detrimental affect upon the patient's well-being or best interests as well as the integrity of nursing practice. When factors in the health care delivery system or health care organization threaten the welfare of the patient, similar action should be directed to the responsible administrator. If indicated, the problem should be reported to an appropriate higher authority within the institution or agency, or to an appropriate external authority.

There should be established processes for reporting and handling incompetent, unethical, illegal, or impaired practice within the employment setting so that such reporting can go through official channels, thereby reducing the risk of reprisal against the reporting nurse. All nurses have a responsibility to assist those who identify potentially questionable practice. State nurses

associations should be prepared to provide assistance and support in the development and evaluation of such processes and reporting procedures.When incompetent, unethical, illegal, or impaired practice is not corrected within the employment setting and continues to jeopardize patient well-being and safety, the problem should be reported to other appropriate authorities such as practice committees of the pertinent professional organizations, the legally constituted bodies concerned with licensing of specific categories of health workers and professional practitioners, or the regulatory agencies concerned with evaluating standards or practice. Some situations may warrant the concern and involvement of all such groups. Accurate reporting and factual documentation, and not merely opinion, undergird all such responsible actions. When a nurse chooses to engage in the act of responsible reporting about situations that are perceived as unethical, incompetent, illegal, or impaired, the professional organization has a responsibility to provide the nurse with support and assistance and to protect the practice of those nurses who choose to voice their concerns. Reporting unethical, illegal, incompetent, or impaired practices, even when done appropriately, may present substantial risks to the nurse; nevertheless, such risks do not eliminate the obligation to address serious threats to patient safety.

3.6 Addressing impaired practice - Nurses must be vigilant to protect the patient, the public and the profession from potential harm when a colleague's practice, in any setting, appears to be impaired. The nurse extends compassion and caring to colleagues who are in recovery from illness or when illness interferes with job performance. In a situation where a nurse suspects another's practice may be impaired, the nurse's duty is to take action designed both to protect patients and to assure that the impaired individual receives assistance in regaining optimal function. Such action should usually begin with consulting supervisory personnel and may also include confronting the individual in a supportive manner and with the assistance of others or helping the individual to access appropriate resources. Nurses are encouraged to follow guidelines outlined by the profession and policies of the employing organization to assist colleagues whose job performance may be adversely affected by mental or physical illness or by personal circumstances. Nurses in all roles should advocate for colleagues whose job performance may be impaired to ensure that they receive appropriate assistance, treatment and access to fair institutional and legal processes. This includes supporting the return to practice of the individual who has sought assistance and is ready to resume professional duties.

If impaired practice poses a threat or danger to self or others, regardless of whether the individual has sought help, the nurse must take action to report the individual to persons authorized to address the problem. Nurses who advocate for others whose job performance creates a risk for harm should be protected from negative consequences. Advocacy may be a difficult process and the nurse is advised to follow workplace policies. If workplace policies do not exist or are inappropriate--that is, they deny the nurse in question access to due legal process or demand resignation--the reporting nurse may obtain guidance from the professional association, state peer assistance programs, employee assistance program or a similar resource.

Provision 4 The nurse is responsible and accountable for individual nursing practice and determines the appropriate delegation of tasks consistent with the nurse's obligation to provide optimum patient care.

4.1 Acceptance of accountability and responsibility - Individual registered nurses bear primary responsibility for the nursing care that their patients receive and are individually accountable for their own practice. Nursing practice includes direct care activities, acts of delegation, and other responsibilities such as teaching, research, and administration. In each instance, the nurse retains accountability and responsibility for the quality of practice and for conformity with standards of care.

Nurses are faced with decisions in the context of the increased complexity and changing patterns in the delivery of health care. As the scope of nursing practice changes, the nurse must exercise *judgment in accepting responsibilities, seeking consultation, and assigning activities to others* who carry out nursing care. For example, some advanced practice nurses have the authority to issue prescription and treatment orders to be carried out by other nurses. These acts are not acts of delegation. Both the advanced practice nurse issuing the order and the nurse accepting the order are responsible for the judgments made and accountable for the actions taken.

4.2 Accountability for nursing judgment and action - Accountability means to be answerable to oneself and others for one's own actions. In order to be accountable, nurses act under a code of ethical conduct that is grounded in the moral principles of fidelity and respect for the dignity, worth, and self-determination of patients. Nurses are accountable for judgments made and actions taken in the course of nursing practice, irrespective of health care organizations' policies or providers' directives.

4.3 Responsibility for nursing judgment and action - Responsibility refers to the specific accountability or liability associated with the performance of duties of a particular role. Nurses accept or reject specific role demands based upon their education, knowledge, competence, and extent of experience. Nurses in administration, education, and research also have obligations to the recipients of nursing care. Although nurses in administration, education, and research have relationships with patients that are less direct, in assuming the responsibilities of a particular role, they share responsibility for the care provided by those whom they supervise and instruct. The nurse must not engage in practices prohibited by law or delegate activities to others that are prohibited by the practice acts of other health care providers.

Individual nurses are responsible for assessing their own competence. When the needs of the patient are beyond the qualifications and competencies of the nurse, consultation and collaboration must be sought from qualified nurses, other health professionals, or other appropriate sources. Educational resources should be sought by nurses and provided by institutions to maintain and advance the competence of nurses. Nurse educators act in collaboration with their students to assess the learning needs of the student, the effectiveness of the teaching program, the identification and utilization of appropriate resources, and the support needed for the learning process.

4.4 Delegation of nursing activities - Since the nurse is accountable for the quality of nursing care given to patients, nurses are accountable for the assignment of nursing responsibilities to other nurses and the delegation of nursing care activities to other health care workers. While delegation and assignment are used here in a generic moral sense, it is understood that individual states may have a particular legal definition of these terms.

The nurse must make reasonable efforts to assess individual competence when assigning selected components of nursing care to other health care workers. This assessment involves evaluating the knowledge, skills, and experience of the individual to whom the care is assigned, the complexity of the assigned tasks, and the health status of the patient. The nurse is also responsible for monitoring the activities of these individuals and evaluating the quality of the care provided. Nurses may not delegate responsibilities such as assessment and evaluation; they may delegate tasks. The nurse must not knowingly assign or delegate to any member of the nursing team a task for which that person is not prepared or qualified. Employer policies or directives do not relieve the nurse of responsibility for making judgments about the delegation and assignment of nursing care tasks.

Nurses functioning in management or administrative roles have a particular responsibility to provide an environment that supports and facilitates appropriate assignment and delegation. This includes providing appropriate orientation to staff, assisting less experienced nurses in developing necessary skills and competencies, and establishing policies and procedures that protect both the patient and nurse from the inappropriate assignment or delegation of nursing responsibilities, activities, or tasks.

Nurses functioning in educator or preceptor roles may have less direct relationships with patients. However, through assignment of nursing care activities to learners they share responsibility and accountability for the care provided. It is imperative that the knowledge and skills of the learner be sufficient to provide the assigned nursing care and that appropriate supervision be provided to protect both the patient and the learner.

Provision 5 The nurse owes the same duties to self as to others, including the responsibility to preserve integrity and safety, to maintain competence, and to continue personal and professional growth.

5.1 Moral self-respect - Moral respect accords moral worth and dignity to all human beings irrespective of their personal attributes or life situation. Such respect extends to oneself as well; the same duties that we owe to others we owe to ourselves. Self-regarding duties refer to a realm of duties that primarily concern oneself and include professional growth and maintenance of competence, preservation of wholeness of character, and personal integrity.

5.2 Professional growth and maintenance of competence - Though it has consequences for others, maintenance of competence and ongoing professional growth involves the control of one's own conduct in a way that is primarily self-regarding. Competence affects one's self-respect, self-esteem, professional status, and the meaningfulness of work. In all nursing roles, evaluation of one's own performance, coupled with peer review, is a means by which nursing practice can be held to the highest standards. Each nurse is responsible for participating in the development of criteria for evaluation of practice and for using those criteria in peer and self-assessment.

Continual professional growth, particularly in knowledge and skill, requires a commitment to lifelong learning. Such learning includes, but is not limited to, continuing education, networking with professional colleagues, self-study, professional reading, certification, and seeking advanced degrees. Nurses are required to have knowledge relevant to the current scope and standards of nursing practice, changing issues, concerns, controversies, and ethics. Where the care required is outside the competencies of the individual nurse, consultation should be sought or the patient should be referred to others for appropriate care.

5.3 Wholeness of character - Nurses have both personal and professional identities that are neither entirely separate, nor entirely merged, but are integrated. In the process of becoming a professional, the nurse embraces the values of the profession, integrating them with personal values. Duties to self involve an authentic expression of one's own moral point-of-view in practice. Sound ethical decision-making requires the respectful and open exchange of views between and among all individuals with relevant interests. In a community of moral discourse, no one person's view should automatically take precedence over that of another. Thus the nurse has a responsibility to express moral perspectives, even when they differ from those of others, and even when they might not prevail.

This wholeness of character encompasses relationships with patients. In situations where the patient requests a personal opinion from the nurse, the nurse is generally free to express an informed personal opinion as long as this preserves the voluntariness of the patient and maintains appropriate professional and moral boundaries. It is essential to be aware of the potential for undue influence attached to the nurse's professional role. Assisting patients to clarify their own values in reaching informed decisions may be helpful in avoiding unintended persuasion. In situations where nurses' responsibilities include care for those whose personal attributes, condition, lifestyle or situation is stigmatized by the community and are personally unacceptable, the nurse still renders respectful and skilled care.

5.4 Preservation of integrity - Integrity is an aspect of wholeness of character and is primarily a self-concern of the individual nurse. An economically constrained health care environment presents the nurse with particularly troubling threats to integrity. Threats to integrity may include a request to deceive a patient,to withhold information, or to falsify records, as well as verbal abuse from patients or coworkers. Threats to integrity also may include an expectation that the nurse will act in a way that is inconsistent with the values or ethics of the profession, or more specifically a request that is in direct violation of the Code of Ethics. Nurses have a duty to remain consistent with both their personal and professional values and to accept compromise only to the degree that it remains an integrity-preserving compromise. An integrity-preserving compromise does not jeopardize the dignity or well-being of the nurse or others. Integrity-preserving compromise can be difficult to achieve, but is more likely to be accomplished in situations where there is an open forum for moral discourse and an atmosphere of mutual respect and regard.

Where nurses are placed in situations of compromise that exceed acceptable moral limits or involve violations of the moral standards of the profession, whether in direct patient care or in any

other forms of nursing practice, they may express their conscientious objection to participation. Where a particular treatment, intervention, activity, or practice is morally objectionable to the nurse, whether intrinsically so or because it is inappropriate for the specific patient, or where it may jeopardize both patients and nursing practice, the nurse is justified in refusing to participate on moral grounds. Such grounds exclude personal preference, prejudice, convenience, or arbitrariness. Conscientious objection may not insulate the nurse against formal or informal penalty. The nurse who decides not to take part on the grounds of conscientious objection must communicate this decision in appropriate ways. Whenever possible, such a refusal should be made known in advance and in time for alternate arrangements to be made for patient care. The nurse is obliged to provide for the patient's safety, to avoid patient abandonment, and to withdraw only when assured that alternative sources of nursing care are available to the patient.

Where patterns of institutional behavior or professional practice compromise the integrity of all its nurses, nurses should express their concern or conscientious objection collectively to the appropriate body or committee. In addition, they should express their concern, resist, and seek to bring about a change in those persistent activities or expectations in the practice setting that are morally objectionable to nurses and jeopardize either patient or nurse well-being.

Provision 6

The nurse participates in establishing, maintaining, and improving health care environments and conditions of employment conducive to the provision of quality health care and consistent with the values of the profession through individual and collective action.

6.1 Influence of the environment on moral virtues and values - Virtues are habits of character that predispose persons to meet their moral obligations; that is, to do what is right. Excellences are habits of character that predispose a person to do a particular job or task well. Virtues such as wisdom, honesty, and courage are habits or attributes of the morally good person. Excellences such as compassion, patience, and skill are habits of character of the morally good nurse. For the nurse, virtues and excellences are those habits that affirm and promote the values of human dignity, well-being, respect, health, independence, and other values central to nursing. Both virtues and excellences, as aspects of moral character, can be either nurtured by the environment in which the nurse practices or they can be diminished or thwarted. All nurses have a responsibility to create, maintain, and contribute to environments that support the growth of virtues and excellences and enable nurses to fulfill their ethical obligations.

6.2 Influence of the environment on ethical obligations - All nurses, regardless of role, have a responsibility to create, maintain, and contribute to environments of practice that support nurses in fulfilling their ethical obligations. Environments of practice include observable features, such as working conditions, and written policies and procedures setting out expectations for nurses, as well as less tangible characteristics such as informal peer norms. Organizational structures, role descriptions, health and safety initiatives, grievance mechanisms, ethics committees, compensation systems, and disciplinary procedures all contribute to environments that can either present barriers or foster ethical practice and professional fulfillment. Environments in which employees are provided fair hearing of grievances, are supported in practicing according to standards of care, and are justly treatedallow for the realization of the values of the profession and are consistent with sound nursing practice.

6.3 Responsibility for the health care environment - The nurse is responsible for contributing to a moral environment that encourages respectful interactions with colleagues, support of peers, and identification of issues that need to be addressed. Nurse administrators have a particular responsibility to assure that employees are treated fairly and that nurses are involved in decisions related to their practice and working conditions. Acquiescing and accepting unsafe or inappropriate practices, even if the individual does not participate in the specific practice, is equivalent to condoning unsafe practice. Nurses should not remain employed in facilities that routinely violate patient rights or require nurses to severely and repeatedly compromise standards of practice or personal morality.

As with concerns about patient care, nurses should address concerns about the health care

environment through appropriate channels. Organizational changes are difficult to accomplish and may require persistent efforts over time. Toward this end, nurses may participate in collective action such as collective bargaining or workplace advocacy, preferably through a professional association such as the state nurses association, in order to address the terms and conditions of employment. Agreements reached through such action must be consistent with the profession's standards of practice, the state law regulating practice and the Code of Ethics for Nursing. Conditions of employment must contribute to the moral environment, the provision of quality patient care and professional satisfaction for nurses.

The professional association also serves as an advocate for the nurse by seeking to secure just compensation and humane working conditions for nurses. To accomplish this, the professional association may engage in collective bargaining on behalf of nurses. While seeking to assure just economic and general welfare for nurses, collective bargaining, nonetheless, seeks to keep the interests of both nurses and patients in balance.

Provision 7 The nurse participates in the advancement of the profession through contributions to practice, education, administration, and knowledge development.

7.1 Advancing the profession through active involvement in nursing and in health care policy - Nurses should advance their profession by contributing in some way to the leadership, activities, and the viability of their professional organizations. Nurses can also advance the profession by serving in leadership or mentorship roles or on committees within their places of employment. Nurses who are self-employed can advance the profession by serving as role models for professional integrity. Nurses can also advance the profession through participation in civic activities related to health care or through local, state, national, or international initiatives. Nurse educators have a specific responsibility to enhance students' commitment to professional and civic values. Nurse administrators have a responsibility to foster an employment environment that facilitates nurses' ethical integrity and professionalism, and nurse researchers are responsible for active contribution to the body of knowledge supporting and advancing nursing practice.

7.2 Advancing the profession by developing, maintaining, and implementing professional standards in clinical, administrative, and educational practice - Standards and guidelines reflect the practice of nursing grounded in ethical commitments and a body of knowledge. Professional standards and guidelines for nurses must be developed by nurses and reflect nursing's responsibility to society. It is the responsibility of nurses to identify their own scope of practice as permitted by professional practice standards and guidelines, by state and federal laws, by relevant societal values, and by the Code of Ethics.

The nurse as administrator or manager must establish, maintain, and promote conditions of employment that enable nurses within that organization or community setting to practice in accord with accepted standards of nursing practice and provide a nursing and health care work environment that meets the standards and guidelines of nursing practice. Professional autonomy and self regulation in the control of conditions of practice are necessary for implementing nursing standards and guidelines and assuring quality care for those whom nursing serves.

The nurse educator is responsible for promoting and maintaining optimum standards of both nursing education and of nursing practice in any settings where planned learning activities occur. Nurse educators must also ensure that only those students who possess the knowledge, skills, and competencies that are essential to nursing graduate from their nursing programs.

7.3 Advancing the profession through knowledge development, dissemination, and application to practice - The nursing profession should engage in scholarly inquiry to identify, evaluate, refine, and expand the body of knowledge that forms the foundation of its discipline and practice. In addition, nursing knowledge is derived from the sciences and from the humanities. Ongoing scholarly activities are essential to fulfilling a profession's obligations to society. All nurses working alone or in collaboration with others can participate in the advancement of the profession through the development, evaluation, dissemination, and application of knowledge in practice. However, an organizational climate and infrastructure

conducive to scholarly inquiry must be valued and implemented for this to occur.

Provision 8 The nurse collaborates with other health professionals and the public in promoting community, national, and international efforts to meet health needs.

8.1 Health needs and concerns - The nursing profession is committed to promoting the health, welfare, and safety of all people. The nurse has a responsibility to be aware not only of specific health needs of individual patients but also of broader health concerns such as world hunger, environmental pollution, lack of access to health care, violation of human rights, and inequitable distribution of nursing and health care resources. The availability and accessibility of high quality health services to all people require both interdisciplinary planning and collaborative partnerships among health professionals and others at the community, national, and international levels.

8.2 Responsibilities to the public - Nurses, individually and collectively, have a responsibility to be knowledgeable about the health status of the community and existing threats to health and safety. Through support of and participation in community organizations and groups, the nurse assists in efforts to educate the public, facilitates informed choice, identifies conditions and circumstances that contribute to illness, injury and disease, fosters healthy life styles, and participatesin institutional and legislative efforts to promote health and meet national health objectives. In addition, the nurse supports initiatives to address barriers to health, such as poverty, homelessness, unsafe living conditions, abuse and violence, and lack of access to health services.

The nurse also recognizes that health care is provided to culturally diverse populations in this country and in all parts of the world. In providing care, the nurse should avoid imposition of the nurse's own cultural values upon others. The nurse should affirm human dignity and show respect for the values and practices associated with different cultures and use approaches to care that reflect awareness and sensitivity.

Provision 9 The profession of nursing, as represented by associations and their members, is responsible for articulating nursing values, for maintaining the integrity of the profession and its practice, and for shaping social policy.

9.1 Assertion of values - It is the responsibility of a professional association to communicate and affirm the values of the profession to its members. It is essential that the professional organization encourages discourse that supports critical self-reflection and evaluation within the profession. The organization also communicates to the public the values that nursing considers central to social change that will enhance health.

9.2 The profession carries out its collective responsibility through professional associations - The nursing profession continues to develop ways to clarify nursing's accountability to society. The contract between the profession and society is made explicit through such mechanisms as

(a) The Code of Ethics for Nurses
(b) the standards of nursing practice
(c) the ongoing development of nursing knowledge derived from nursing theory, scholarship, and research in order to guide nursing actions
(d) educational requirements for practice
(e) certification, and
(f) mechanisms for evaluating the effectiveness of professional nursing actions.

9.3 Intraprofessional integrity A professional association is responsible for expressing the values and ethics of the profession and also for encouraging the professional organization and its members to function in accord with those values and ethics. Thus, one of its fundamental responsibilities is to promote awareness of and adherence to the Code of Ethics and to critique the activities and ends of the professional association itself. Values and ethics influence the power structures of the association in guiding, correcting, and directing its activities. Legitimate concerns for the self-interest of the association and the profession are balanced by a commitment to the social goods that are sought. Through critical self-reflection and

self-evaluation, associations must foster change within themselves, seeking to move the professional community toward its stated ideals.

9.4 Social reform - Nurses can work individually as citizens or collectively through political action to bring about social change. It is the responsibility of a professional nursing association to speak for nurses collectively in shaping and reshaping health care within our nation, specifically in areas of health care policy and legislation that affect accessibility, quality, and the cost of health care. Here, the professional association maintains vigilance and takes action to influence legislators, reimbursement agencies, nursing organizations, and other health professions. In these activities, health is understood as being broader than delivery and reimbursement systems, but extending to health-related sociocultural issues such as violation of human rights, homelessness, hunger, violence, and the stigma of illness.

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American Nurses Association, *Code of Ethics for Nurses with Interpretive Statements*, Washington, D.C.: American Nurses Publishing, 2001

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CLINICAL MANAGEMENT GUIDELINES FOR OBSTETRICIAN–GYNECOLOGISTS

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Prenatal Diagnosis of Fetal Chromosomal Abnormalities

The prevalence of chromosomal abnormalities in clinically recognized early pregnancy loss is approximately 50% (1). Aneuploid fetuses account for 6–11% of all stillbirths and neonatal deaths (2). Chromosome defects compatible with life but causing significant morbidity occur in 0.65% of newborns, and another 0.2% have structural chromosomal rearrangements that will eventually affect reproduction (3). Although it is not possible to identify all aneuploidies antenatally, screening and diagnostic programs to detect the most common autosomal trisomy in liveborn infants, Down syndrome, are well established. This document will provide clinical management guidelines for the prenatal detection of these aneuploidies.

This Practice Bulletin was developed by the ACOG Committee on Practice Bulletins—Obstetrics with the assistance of Katharine Wenstrom, MD. The information is designed to aid practitioners in making decisions about appropriate obstetric and gynecologic care. These guidelines should not be construed as dictating an exclusive course of treatment or procedure. Variations in practice may be warranted based on the needs of the individual patient, resources, and limitations unique to the institution or type of practice.

Background

Down syndrome and other autosomal trisomies primarily occur as the result of meiotic nondisjunction, which increases with maternal age. Genetic amniocentesis has been offered to women who will be age 35 years and older at delivery because at this age the incidence of trisomy starts to increase rapidly and because the midtrimester risk of Down syndrome roughly equals the most often quoted risk of procedure-related pregnancy loss (1/200) (Table 1). However, only 12.9% of all children are born to women age 35 years and older (4). Therefore, even if all women older than 35 years requested amniocenteses, only a minority of Down syndrome pregnancies would be identified. Because younger women have the majority of pregnancies, younger women give birth to the majority of children with Down syndrome (5).

Table 1. Midtrimester and Term Risk of Down Syndrome or Any Aneuploidy

Maternal Age	Midtrimester		Term Liveborn	
	DS	All Aneuploidies	DS	All Aneuploidies
33	1/417	1/208	1/625	1/345
34	1/333	1/152	1/500	1/278
35	1/250	1/132	1/384	1/204
36	1/192	1/105	1/303	1/167
37	1/149	1/83	1/227	1/130
38	1/115	1/65	1/175	1/103
39	1/89	1/53	1/137	1/81
40	1/69	1/40	1/106	1/63
41	1/53	1/31	1/81	1/50
42	1/41	1/25	1/64	1/39
43	1/31	1/19	1/50	1/30
44	1/25	1/15	1/38	1/24
45	1/19	1/12	1/30	1/19

Abbreviation: DS, Down syndrome.

Adapted from Hook EB, Cross PK, Schreinemachers DM. Chromosomal abnormality rates at amniocentesis and in live-born infants. JAMA 1983;249:2034–2038. Copyrighted 1983, American Medical Association.

Screening and Testing for Genetic Abnormalities

Of Down syndrome pregnancies, 97% occur in families with no previous history of the syndrome (6). Screening tests are used to identify those women who are not known to be at high risk but are nevertheless carrying a fetus with Down syndrome. Screening tests have a high false-positive rate because the threshold for declaring a screening test result positive is set to capture most individuals who truly have the condition at the expense of including some who do not. Women with positive screening test results should be offered a definitive diagnostic test such as amniocentesis or chorionic villus sampling (CVS).

Second-Trimester Screening

Maternal Serum Screening

Until the mid-1980s, there was no way to identify younger women at risk of having children with Down syndrome. Down syndrome screening for younger women was initiated when researchers discovered that the mean level of maternal serum alpha fetoprotein (AFP) in pregnancies complicated by fetal Down syndrome is 0.7 multiples of the (normal) median (MoM) (7–9).

It was soon discovered that human chorionic gonadotropin (hCG) levels are higher (2.04 MoM) and unconjugated estriol levels are lower (0.79 MoM) in Down syndrome pregnancies (10–13). The relative risks derived from maternal serum levels of these three analytes are used to modify the maternal age-related risk. This protocol has been validated extensively and has become the preferred Down syndrome screening test for women younger than 35 years (13–16). At a cutoff chosen to produce a 5% or greater screen-positive rate, the multiple-marker screening test identifies approximately 60% of all Down syndrome pregnancies in women younger than 35 years. In women 35 years and older, it detects 75% or more of all Down syndrome cases and certain other aneuploidies. The screen-positive rate increases with maternal age (Table 2) (17). Some laboratories use the midtrimester Down syndrome risk of a 35-year-old woman as the screen-positive cutoff. Other laboratories select a screen-positive cutoff that will result in an acceptable balance between a high detection rate and a low screen-positive rate (usually 1:190 or 1:200). The basis of these screening protocol calculations of risk is the maternal age-related risk of Down syndrome, a risk based on previously lower rates of birth to women older than 35 years, which may now be obsolete. Screening protocols may benefit from revision using current data on maternal age.

Maternal blood sampling can be performed between 15 and 20 weeks of gestation but is most accurate when performed between 16 and 18 weeks of gestation. Accurate pregnancy dating is essential. If the estimated date of delivery is changed after the test results have returned, it is important to recalculate the results or provide the laboratory with a new blood sample if the original specimen was drawn at less than 15 weeks of gestation.

Table 2. Multiple-Marker Down Syndrome Screening Test Detection and Screen-Positive Rates, According to Maternal Age

Maternal Age	Screen-Positive Rate (%)	Detection Rate (%) (with Estriol)
20	2.4	41
25	2.9	44
30	5.0	52
35	14.0	71
40	40.0	91

Modified with permission from Haddow JE, Palomaki GE, Knight GJ, Cunningham GC, Lustig LS, Boyd PA. Reducing the need for amniocentesis in women 35 years of age or older with serum markers for screening. N Engl J Med 1994;330:1114–1118. Copyright ©1994 Massachusetts Medical Society. All rights reserved.

The multiple-marker screening test also can detect approximately 60–75% of fetuses with trisomy 18 when separate analysis is performed that uses low levels of all three analytes with or without consideration of maternal age (18, 19). Although serum screening does not detect other aneuploidies with great frequency, the aneuploidies likely to be missed by serum screening usually are ultimately lethal (eg, trisomy 13) or are sex-chromosome abnormalities not associated with profound mental retardation or other severe physical or developmental limitations.

The contribution of estriol measurement is a subject of debate, with some centers offering AFP plus hCG alone. Some investigators consider free beta subunits of hCG (β-hCG) to be superior to the intact hCG molecule, but neither has been definitively proven to be superior. New analytes also are constantly being tested. Dimeric inhibin A is the most promising new second-trimester analyte and is now used by some commercial laboratories in combination with the three traditional analytes. With a screen-positive rate of 5% or less, this new four-analyte combination appears to detect 67–76% of Down syndrome cases in women younger than 35 years (20, 21).

Ultrasound Screening

Aneuploid fetuses may have major anatomic malformations, often discovered by chance during an ultrasound examination performed for another indication. All abnormalities involving a major organ or structure, with a few notable exceptions, or the finding of two or more minor structural abnormalities in the same fetus, indicate high risk for fetal aneuploidy (22–24) (Table 3). Structural anomalies can have many etiologies; if an aneuploidy is suspected, only a karyotype analysis of fetal cells can provide a definitive diagnosis.

Table 3. Aneuploid Risk of Major Anomalies

Structural Defect	Population Incidence	Aneuploidy Risk	Most Common Aneuploidy
Cystic hygroma	1/120 EU–1/6,000 B	60–75%	45X (80%); 21,18,13,XXY
Hydrops	1/1,500–4,000 B	30–80%*	13,21,18,45X
Hydrocephalus	3–8/10,000 LB	3–8%	13,18, triploidy
Hydranencephaly	2/1,000 IA	Minimal	
Holoprosencephaly	1/16,000 LB	40–60%	13,18,18p-
Cardiac defects	7–9/1,000 LB	5–30%	21,18,13,22,8,9
Complete atrioventricular canal		40–70%	21
Diaphragmatic hernia	1/3,500–4,000 LB	20–25%	13,18,21,45X
Omphalocele	1/5,800 LB	30–40%	13,18
Gastroschisis	1/10,000–15,000 LB	Minimal	
Duodenal atresia	1/10,000 LB	20–30%	21
Bowel obstruction	1/2,500–5,000 LB	Minimal	
Bladder outlet obstruction	1–2/1,000 LB	20–25%	13,18
Prune belly syndrome	1/35,000–50,000 LB	Low	18,13,45X
Facial cleft	1/700 LB	1%	13,18, Deletions
Limb reduction	4–6/10,000 LB	8%	18
Club foot	1.2/1,000 LB	6%	18,13,4p-,18q-
Single umbilical artery	1%	Minimal	

Abbreviations: EU, early ultrasonography; B, birth; LB, livebirth; IA, infant autopsy.

*30% if diagnosed ≥24 weeks; 80% if diagnosed ≤17 weeks

Data from Shipp TD, Benacerraf BR. The significance of prenatally identified isolated clubfoot: is amniocentesis indicated? Am J Obstet Gynecol 1998;178:600–602; and Nyberg DA, Crane JP. Chromosome abnormalities. In: Nyberg DA, Mahony BS, Pretorius DH. Diagnostic ultrasound of fetal anomalies: text and atlas. Chicago: Year Book Medical, 1990:676–724

First-Trimester Screening

Maternal Serum Analytes

Many maternal serum analytes have been evaluated for possible use for first-trimester Down syndrome screening, although preliminary data remain controversial and testing is not yet standard of care. The most discriminatory analytes at this gestational age appear to be β-hCG and pregnancy-associated plasma protein A (PAPP-A) (25, 26). The median free β-hCG in affected Down syndrome pregnancies is approximately 1.79 MoM, whereas the median PAPP-A is approximately 0.43 MoM. Because of the low correlation between these two analytes, each contributes unique biologic information to the screening test. The combination of free β-hCG, PAPP-A, and maternal age appears to yield detection and false-positive rates comparable to second-trimester serum screening (63% and 5.5%, respectively) (27). Unfortunately, free β-hCG may not be higher in Down syndrome pregnancies until 12 weeks of gestation, and PAPP-A seems to lose its discrimination value after 13 weeks of gestation, making accurate assessment of gestational age and careful timing of the screening test essential (28).

Nuchal Lucency Measurement

Nuchal lucency measurement has been suggested as another screening test for Down syndrome in the first trimester. The ultrasound finding of an increase in the size of the normal, clear area behind the fetal neck early in pregnancy is associated with an increased incidence of Down syndrome, congenital heart disease, and other congenital anomalies. Although the precise etiology and significance of the nuchal lucency are unknown, the finding may reflect accumulation of lymph fluid related to delayed development of the lymphatic ducts. An increased nuchal lucency measurement in combination with maternal age has been reported to identify 27–89% of Down syndrome pregnancies, with a screen-positive rate of 2.8–9.3% (28). Some of this wide variation may result from differences in techniques for measuring and criteria for defining an increase. Other factors include differences in study population, ultrasonographic technique, sonographer training, definition of screen positivity, and the quality of both pregnancy and pediatric follow-up. Much of the early work was derived from women at high risk (eg, prior to scheduled CVS or amniocentesis in women age 35 years or older), and results of trials in unselected low-risk women have produced conflicting results (29–31). Variability in Down syndrome detection rates is likely to be caused by the existence of significant methodologic limitations for many of the studies. Many of the reports provide minimal information on the extent of pregnancy or pediatric follow-up; therefore, underascertainment of cases of Down syndrome is likely.

Clinical Considerations and Recommendations

▶ *Who is at high risk and should be offered prenatal diagnosis for fetal aneuploidy?*

Women with singleton pregnancies who will be age 35 years or older at delivery should be offered prenatal diagnosis. The midtrimester risk that a pregnant 35-year-old woman is carrying a fetus with Down syndrome is 1/250 (32); the risk of any aneuploidy is 1/132 (Table 1). These numbers are higher than the term risks because a large proportion of aneuploid pregnancies are spontaneously aborted before term delivery. The risks at term are 1/384 for Down syndrome and 1/204 for all aneuploidies.

In addition to women age 35 years and older, patients with a risk of fetal aneuploidy high enough to justify an invasive diagnostic procedure include the following:

- *Women who have previously had pregnancies complicated by autosomal trisomy.* The chance that such a woman could have another pregnancy with the same or a different autosomal trisomy is approximately 1% until her age-related risk exceeds 1; then it is assumed to equal her age-related risk.
- *A fetus with a major structural defect identified by ultrasonography.* The discovery of one major or two or more minor fetal structural abnormalities increases the likelihood of aneuploidy sufficiently to warrant fetal genetic testing (22–24). However, detection of a fetal defect known not to be associated with aneuploidy (eg, fetal cleft lip discovered during an ultrasound examination ordered because the mother has a cleft lip) or an isolated malformation not usually associated with aneuploidy may not require further testing (Table 3).
- *Women who have previously had a pregnancy complicated by a sex chromosome aneuploidy.* If the previous child had an extra X chromosome, the chromosome may be maternal or paternal in origin. If it is maternal, it is age related. As with autosomal trisomies, the recurrence risk is 1% until the maternal age-related risk exceeds 1%. A woman whose previous child was karyotype 47,XYY is not at high risk of recurrence, because the extra chromosome in this situation is paternal in origin. The karyotype 45,X has a very low recurrence risk. Parents of children with

47,XYY or 45,X karyotypes may still request prenatal diagnosis in future pregnancies for reassurance.

- *Men or women with a chromosome translocation.* Women or men carrying balanced translocations, although phenotypically normal themselves, are at risk of producing unbalanced gametes, resulting in abnormal offspring. For most translocations, the observed risk of abnormal liveborn children is less than the theoretic risk, because a portion of these gametes result in nonviable conceptions. In general, carriers of chromosome translocations identified after the birth of an abnormal child have a 5–30% risk of having unbalanced offspring in the future, while those identified for other reasons (eg, during an infertility work-up) have a 0–5% risk (1). Genetic counseling may be helpful in such situations.
- *Men or women who are carriers of chromosome inversions.* An inversion occurs when two breaks occur in the same chromosome, and the intervening genetic material is inverted before the breaks are repaired. Although no genetic material is lost or duplicated, the rearrangement may alter gene function. Each carrier's risk is related to the method of ascertainment, the chromosome involved, and the size of the inversion and, thus, should be determined individually. The observed risk is approximately 5–10% if the inversion is identified after the birth of an abnormal child and 1–3% if ascertainment occurs by some other means (1). One exception is a pericentric inversion of chromosome 9, which is a population variant of no clinical consequence.
- *Parental aneuploidy.* Women with trisomy 21 or 47,XXX and men with 47,XYY usually are fertile and have a 30% risk of having trisomic offspring. In men with a normal karyotype who have oligospermia and undergo intracytoplasmic sperm injection to conceive, there is an increased incidence of abnormal karyotype in the sperm. However, this has not been reflected in an increase in karyotypically abnormal offspring in these pregnancies.

▶ *How is fetal aneuploidy diagnosed?*

Amniocentesis. Traditional genetic amniocentesis usually is offered between 15 and 20 weeks of gestation. Many large, multicenter studies have confirmed the safety of genetic amniocentesis, as well as its cytogenetic diagnostic accuracy (greater than 99%) (33). The fetal loss rate is approximately 0.5% (34), and minor complications occur infrequently. These include transient vaginal spotting or amniotic fluid leakage in approximately 1–2% of all cases and chorioamnionitis in less than one in 1,000 cases. Needle injuries to the fetus have been reported but are very rare when amniocentesis is performed under continuous ultrasound guidance. Amniotic fluid cell culture failure is uncommon.

Safe performance of genetic amniocentesis requires specialized training and ongoing experience. Several studies have confirmed that the incidence of pregnancy loss, blood-contaminated specimens, leaking of amniotic fluid, and the need for more than one needle puncture are related to the experience of the operator, the use of a small-gauge needle, and ultrasound guidance (35–37).

Early amniocentesis, performed from 11 weeks to 13 weeks of gestation, has been widely studied, and the technique is similar to traditional amniocentesis (38–40). However, early amniocentesis results in significantly higher pregnancy loss and complication rates than traditional amniocentesis. In a recent multicenter randomized trial, the spontaneous pregnancy loss rate following early amniocentesis was 2.5%, compared with 0.7% with traditional amniocentesis (41). The overall incidence of talipes was 1.4% after the early procedure, compared with 0.1% (the same as the background rate) after traditional amniocentesis, and membrane rupture was more likely after the early procedure. Finally, significantly more amniotic fluid culture failures occurred after the early procedure, necessitating an additional invasive procedure for diagnosis. For these reasons, many centers no longer offer early amniocentesis.

Chorionic Villus Sampling. Indications for CVS are similar to those for amniocentesis, except for a few rare genetic conditions that require chorionic villi for diagnosis. Chorionic villus sampling generally is performed at 10–12 weeks of gestation. The primary advantage of CVS over amniocentesis is that results are available much earlier in pregnancy, which provides reassurance for parents when results are normal and, when results are abnormal, allows earlier and safer methods of pregnancy termination.

Placental villi may be obtained through transcervical or transabdominal access to the placenta. Skill in ultrasound-guided procedures and extensive specialized training are required before attempting CVS, and maintenance of skills with regularly scheduled procedures is essential. Some active cervical infections (such as chlamydia or herpes) are a contraindication to transcervical CVS. Relative contraindications to CVS include vaginal infection, vaginal bleeding or spotting, extreme anteversion or retroversion of the uterus, and patient body habitus precluding easy access to the uterus or clear visualization of intrauterine structures with ultrasonography (42–44).

Several major collaborative trials report success rates of more than 99% with cytogenetic analysis and total pregnancy loss rates of 0.6–0.8% for CVS in excess of

traditional amniocentesis (33, 45–48, 49). As with early amniocentesis, the reported excess loss rate may result from the CVS procedure itself, but it also may incorporate the expected spontaneous loss rate between 9 and 16 weeks of gestation. Patients considering CVS should be counseled that there may be a slightly higher risk of pregnancy loss associated with CVS than with traditional amniocentesis (34).

Although there have been reports of an association between CVS and limb reduction and oromandibular defects, the risk for these anomalies is unclear (50). In an analysis by the World Health Organization, an incidence of limb reduction defects of 6 per 10,000 was reported, which is not significantly different from the incidence in the general population (49). However, a workshop on CVS and limb reduction defects sponsored by the U.S. National Center for Environmental Health and the Centers for Disease Control and Prevention concluded that oromandibular–limb hypogenesis appeared to be more common after CVS. It found the risk is highest when CVS is performed before 9 menstrual weeks (51). In addition, a panel convened by the National Institute of Child Health and Development and the American College of Obstetricians and Gynecologists concluded that oromandibular–limb hypogenesis appeared to be more common among CVS-exposed infants and appeared to correlate, but may not be limited to, CVS performed earlier than 7 weeks (50). Women considering CVS who are concerned about the possible association of CVS with limb defects can be reassured that when the procedure is performed after 9 menstrual weeks, the risk is low and probably not higher than the general population risk.

Cordocentesis. Cordocentesis, also known as percutaneous umbilical blood sampling (PUBS), involves puncturing the umbilical vein under direct ultrasound guidance. Karyotype analysis of fetal blood usually can be accomplished within 24–48 hours. The procedure-related pregnancy loss rate, including all indications for the procedure, has been reported to be less than 2% (34, 52).

▶ *Is there a role for chromosomal analysis when a fetal ultrasound marker of aneuploidy is identified during an ultrasound examination undertaken for an unrelated indication?*

A variety of second-trimester ultrasound findings have been associated with Down syndrome. Although identification of a major anomaly indicates the need for diagnostic follow-up, ultrasound markers are less strongly associated with aneuploidy. Many of these ultrasound markers have not been well studied in unselected, low-risk women. It is, therefore, unclear how to interpret many of these findings in a given patient particularly in conjunction with age and serum screening results. Some ultrasound markers associated with Down syndrome include nuchal fold thickness, shortened femur or humerus, pyelectasis, and hyperechogenic bowel. Although some ultrasound markers have been confirmed by multiple investigators to be associated with Down syndrome, others have been described in only one series or have been found to have contradictory associations with Down syndrome across studies (53, 54). The lack of uniformity in the definition of an abnormal finding (eg, how to define a shortened femur) and the lack of consensus on which markers are most significant make this screening approach complex.

Several series have attempted to determine which of these ultrasound markers are most predictive of fetal Down syndrome; short femur and humerus (alone or in combination) and nuchal fold thickening appear to be most promising (55, 56). Most series have found that a combination of two or more positive findings substantially increases risk and warrants further counseling regarding invasive testing. The degree to which an individual patient's risk is increased over age-related and serum analyte calculated risk is unclear. These ultrasound markers have been associated with aneuploidy only if identified in the second trimester.

▶ *Is ultrasonographic screening useful in pregnant women identified to be at high-risk for fetal aneuploidy?*

For the woman at high risk for fetal Down syndrome, usually by virtue of age or multiple-marker screening test results, an ultrasound examination may support the need for prenatal diagnosis. This is particularly true if one of the ultrasound markers for Down syndrome is present or if a gross fetal abnormality is seen. Much more commonly, the ultrasound examination is normal. It has been suggested that the absence of any ultrasound evidence for Down syndrome may decrease the risk sufficiently in high-risk women to avoid amniocentesis. Most invasive testing for Down syndrome occurs in women with a risk just above established cutoffs. Therefore, even a small decrease in the risk of Down syndrome, as determined by normal ultrasound results, may put such women in a lower risk category and avoid the need for invasive testing. This decrease in risk could have a significant impact on the overall number of invasive diagnostic tests performed.

Some studies suggest that the risk for Down syndrome may be reduced by 45–80% over the risk cited before the normal ultrasound examination with knowledgeable interpretation of these markers (57–59). These rates are based on ultrasound examinations performed by

experienced operators. Several small studies have been published describing rates of Down syndrome detection between 68% and 93% using various scoring indexes combining maternal age and ultrasound markers. These studies report false-positive rates between 17% and 27% (58, 60, 61).

Risk adjustment is possible only if the ultrasound abnormalities are rigidly defined and the portion of Down syndrome fetuses with them is known. Many investigators have suggested that these measures are laboratory specific, and data may not apply in other centers (62). In addition, ultrasound markers often include anatomic abnormalities as well as biometric measures. The reproducibility of significant ultrasound findings and the magnitude of the decrease in risk for aneuploidy are not yet firmly established. The use of ultrasonographic screening for Down syndrome in high-risk women to avoid invasive testing (eg, women age 35 years and older) is, therefore, controversial and should be limited to specialized centers (55, 57, 63).

▶ *How should a finding of an isolated choroid plexus cyst be further evaluated?*

Choroid plexus cysts arise in the choroid plexus of the lateral ventricle and are typically recognized by ultrasonography in the early to middle second trimester. Choroid plexus cysts may be associated with trisomy 18 (64, 65), which has prompted consideration of the need for invasive testing of the fetus if detected. A meta-analysis reported that the risk of trisomy 18 associated with isolated choroid plexus cysts in all women (all ages combined) is 1/374 (64). Another analysis evaluated published data from more than 200,000 ultrasound examinations and determined that only in women age 32 and older, the presence of an isolated choroid plexus cyst increases the midtrimester risk of trisomy 18 enough to justify genetic testing of the fetus (65). Two recent studies found that with an isolated choroid plexus cyst, testing was justified only if serum screening results were abnormal or the patient was older than 35 years (66, 67). However, in these studies, cysts were commonly noted at the time of genetic amniocentesis; thus, the mother's age at diagnosis also may affect incidence. Therefore, with detection of an isolated choroid plexus cyst, further testing is necessary only if serum screening results are abnormal or the patient is older than 32 years at delivery.

▶ *Is there a role for serum screening in women who will be age 35 years and older at delivery?*

Because the maternal age-related risk of Down syndrome is the basis of the serum screening protocol, both the Down syndrome detection rate and the screen positive rate increase with maternal age (Table 2) (13). The screen-positive rate for all women age 35 years and older is approximately 25%; for women age 40 years, it is 40%; and by age 44, it is approximately 70% (17, 68).

Counseling should include discussion of age-specific multiple-marker screening detection rates and screen-positive rates, the detection rate of aneuploidies other than Down syndrome, the identity and prognosis of the aneuploidies likely to be missed by serum screening, and the risks and benefits of replacing a diagnostic test with a screening test. Counseling should be provided by a practitioner familiar with these components.

▶ *How does prenatal diagnosis differ in multiple gestations?*

Diagnostic options are more limited in multiple gestations (69). In women with twins, the risk of trisomy 21 should be calculated by considering the maternal age-related risk of Down syndrome and the probability that either or both fetuses could be affected. Counseling in this situation should include a discussion of options for pregnancy management if only one fetus is found to be affected. These options include terminating the entire pregnancy, selective second-trimester termination of the affected fetus, and continuing the pregnancy. It has been estimated that the midtrimester risk of fetal Down syndrome in a twin pregnancy in women age 33 years is approximately the same as the risk for that of a singleton pregnancy in women age 35 years, thus justifying counseling for amniocentesis (70, 71).

Scant data exist concerning fetal loss with twin gestation and amniocentesis or CVS. According to some small series, the fetal loss rate with amniocentesis in multiple gestations is approximately 3.5%; this was not higher than the background loss rate for twins in the second trimester in one series with a control group (52, 72, 73). Similar information for twin gestations from small, nonrandomized series exists for CVS (73–75).

A complex counseling issue arises in the presence of a monochorionic twin gestation, in which case the likelihood of discordance in the karyotype is low, and patients may opt for having a karyotype analysis performed on a single fetus. However, in order to offer this option to a patient, the diagnosis of monochorionic twin gestation must have been made with a high degree of confidence. There are no data concerning loss rates following amniocentesis in higher-order multiple gestations.

- ***Can women who are younger than 35 years (at delivery) elect to have genetic amniocentesis?***

Because of the inherent risk of fetal aneuploidy (Table 1), women younger than 35 years may request genetic amniocentesis. Each patient should weigh the risk of amniocentesis against her desire to determine whether the fetus has an abnormal karyotype, in the context of her own values and beliefs. Consequently, some patients younger than 35 years may request genetic amniocentesis primarily rather than only after abnormal maternal serum or ultrasound screening.

- ***Should Down syndrome screening be performed in the patient who would decline pregnancy termination?***

Prenatal diagnosis is not performed solely for the purposes of pregnancy termination; it can provide useful information for the physician and the patient. If it is determined that the fetus has an aneuploidy, management of pregnancy, labor, and delivery can be optimized (76).

Summary of Recommendations

The following recommendation is based on good and consistent scientific evidence (Level A):

- Early amniocentesis (<13 weeks) is not recommended because of the higher risk of pregnancy loss and complications compared with traditional amniocentesis (15–17 weeks).

The following recommendations are based primarily on consensus and expert opinion (Level C):

- Women with singleton pregnancies who will be age 35 years or older at delivery should be offered prenatal diagnosis for fetal aneuploidy.
- Patients with a risk of fetal aneuploidy high enough to justify an invasive diagnostic procedure include women with a previous pregnancy complicated by an autosomal trisomy or sex chromosome aneuploidy, a major fetal structural defect identified by ultrasonography, either parent with a chromosome translocation, and carriers of a pericentric chromosome inversion or parental aneuploidy.
- A combination of one major or two or more minor ultrasound markers of Down syndrome substantially increases risk and warrants further counseling regarding invasive testing.
- The use of ultrasonographic screening for Down syndrome in high-risk women (eg, women age 35 years and older) to avoid invasive testing should be limited to specialized centers.
- With an isolated choroid plexus cyst, testing is indicated only if serum screening results are abnormal or the patient will be older than 32 years at delivery.
- Cervical infections with chlamydia or herpes are contraindications to transcervical CVS.
- Counseling for amniocentesis in a twin pregnancy in women age 33 years is indicated because the midtrimester risk of fetal Down syndrome is approximately the same as for that of a singleton pregnancy at age 35 years.
- Nondirective counseling before genetic amniocentesis does not require a patient to commit to pregnancy termination if the result is abnormal.

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Studies were reviewed and evaluated for quality according to the method outlined by the U.S. Preventive Services Task Force:

- I Evidence obtained from at least one properly designed randomized controlled trial.
- II-1 Evidence obtained from well-designed controlled trials without randomization.
- II-2 Evidence obtained from well-designed cohort or case–control analytic studies, preferably from more than one center or research group.
- II-3 Evidence obtained from multiple time series with or without the intervention. Dramatic results in uncontrolled experiments also could be regarded as this type of evidence.
- III Opinions of respected authorities, based on clinical experience, descriptive studies, or reports of expert committees.

Based on the highest level of evidence found in the data, recommendations are provided and graded according to the following catetories:

Level A—Recommendations are based on good and consistent scientific evidence.

Level B—Recommendations are based on limited or inconsistent scientific evidence.

Level C—Recommendations are based primarily on consensus and expert opinion.

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The Bright Misplaced Line: Persistent Vegetative State and Withdrawal of Artificial Sustenance

One of the most troublesome issues with end-of-life decision making is the withdrawal of tube feeding. With the decision in Wisconsin in the Edna M.F. *case, the withholding of tube feeding has become more problematical. Ultimately, that decision rests on a medical issue: whether the person was in a persistent vegetative state. This article examines some of the historic case law on this issue, then reviews some of the medical literature on the effects of the withdrawal of tube feeding, then reviews case law developments in other states, and finally articulates what would be a workable approach to this difficult issue.*

By James A. Jaeger

> The litigation has to do, in final analysis, with her life,—its continuance or cessation,—and the responsibilities, rights and duties, with regard to any fateful decision concerning it, of her family, her guardian, her doctors, the hospital, the State through its law enforcement authorities, and finally the courts of justice.[1]

One of the most controversial issues relating to end-of-life decision making is the question of withdrawal of what is generally referred to as "tube feeding" or "non-orally-ingested nutrition and hydration" or "artificial nutrition and hydration." For example, Wisconsin's first "Natural Death Act,"[2] which authorizes advance directives regarding end-of-life care, did not permit the withdrawal of tube feeding. It was not until passage of the Durable Power of Attorney for Health Care Act in 1990 that this option was authorized in Wisconsin.[3] Then, in 1991, the Natural Death Act was amended to allow withholding or withdrawing tube feeding.[4]

For those individuals who, through lack of knowledge or foresight, do not leave advance medical directives, the situation has been further complicated by the 1997 decision of the Wisconsin Supreme Court in *In the Matter of the Guardian-*

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ship and Protective Placement of Edna M.F.,[5] which severely limited the authority of a guardian of the person of an incompetent individual to direct the withholding or withdrawal of tube feeding.[6] Because of this decision, persons who have not left advance directives or otherwise clearly made their wishes known during their lifetime may be subjected to tube feeding and have their dying process prolonged in situations where, given the opportunity, they might have decided that this is not what they would want.

In this article I will first examine some of the historic case law on this issue, then review some of the medical literature on the effects of the withdrawal of tube feeding, then review some case law developments in other states, and finally try to articulate what I believe would be a more workable approach to this difficult issue.[7]

Case Development

One of the seminal cases addressing this issue was *In re Quinlan*.[8] This case involved a young New Jersey woman, Karen Ann Quinlan, who at age 22 stopped breathing for two successive 15-minute periods. As a result, she suffered brain damage and entered a persistent vegetative state.[9] Because she could not breathe without assistance, she was placed on a respirator. When it became apparent that she would not recover, and after much soul-searching, her father, Joseph Quinlan, petitioned for appointment as the guardian of her person with the explicit authority to remove the respirator, with the expectation that this would result in her death. This request was opposed by her doctors, the hospital, the county prosecutor, the State of New Jersey, and the guardian ad litem. The trial court appointed Mr. Quinlan as guardian of the estate but declined to appoint him guardian of the person and grant the relief he sought. He appealed and the matter was certified by the New Jersey Supreme Court.

After preliminarily finding that Ms. Quinlan "can *never* be restored to cognitive or sapient life"[10] and that the "character and general suitability of Joseph Quinlan as guardian for his daughter, in ordinary circumstances, could not be doubted,"[11] the court went on to consider the specific relief requested by Mr. Quinlan in this case. Mr. Quinlan advanced three arguments: (1) that the failure to appoint him guardian interfered with his free exercise of religion; (2) that keeping Karen on the respirator was cruel and unusual punishment in violation of the Eighth Amendment; and (3) that failure to grant the relief sought denied Karen and Joseph their rights to privacy.[12] The court summarily rejected the first two arguments but held that Karen's right of privacy was violated by continuing her on the respirator.[13]

The New Jersey court balanced the interests of the state in preserving human life and defending the rights of physicians to exercise their best professional judgment against the right of privacy of the individual, as developed by the U.S. Supreme Court.[14] In applying this balance, the New Jersey court stated:

> We think that the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State's interest. It is for that reason that we believe Karen's choice, if she were competent to make it, would be vindicated by the law.[15]

The court went on to state that because the only "practical way" for Karen Ann Quinlan to exercise her right to privacy would be through the actions of a guardian, the guardian should be appointed and allowed to exercise the right.[16] The court concluded its opinion by considering issues related to standards of medical practice and possible criminal liability for the physicians and determined that neither one was sufficient to dissuade the court from its primary holding. Therefore the court appointed Joseph as guardian and authorized him to discontinue the respirator.[17]

While the *Quinlan* case set standards for the use of respirators,[18] issues related to tube feeding continued to be undecided. As discussed below, because of societal norms regarding the provision of food and liquids to ill and dying persons, this issue remains much more controversial.

The U.S. Supreme Court was confronted with the tube-feeding issue in 1990 in *Cruzan v. Director, Missouri Dep't of Health*.[19] The *Cruzan* case involved a young woman who was severely injured in an automobile accident. As a result of the accident, she suffered severe brain damage and was in a persistent vegetative state, defined by the U.S. Supreme Court as "a condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive function."[20] As distin-

guished from Karen Ann Quinlan, Nancy Cruzan was able to breathe without the aid of a respirator. However, there came a point when she was no longer able to orally ingest food or fluids and was kept alive only by the use of a gastric tube. At this point her parents requested that the tube feeding be discontinued. Nancy's health care providers declined to carry out this request without court approval. The parents then applied to the Missouri courts for authority to discontinue tube feeding. The trial court held that Nancy had a "fundamental right" under the state and federal constitutions to refuse or direct the withdrawal of "death prolonging procedures." The trial court further held that certain statements she had made some years before indicated that her desire would be to have the tube feeding discontinued.[21] On that basis the trial court authorized the parents to withdraw the tube feeding. The case was appealed to the Missouri Supreme Court, which reversed in a divided vote.

The Missouri Supreme Court held that there was a common-law right to refuse treatment, but it was unwilling to elevate that right to constitutional status. However, the court held that the statements attributed to Nancy were not "clear and convincing evidence" of her wishes and therefore the state interest in the preservation of life took precedence.[22]

The U.S. Supreme Court, in an opinion by Chief Justice Rehnquist, upheld the Missouri Supreme Court.[23] The majority opinion first made an extensive analysis of state cases on the common-law requirement of informed consent to medical treatment and the concomitant right to refuse such treatment. It held that a right to refuse treatment does exist that may be exercised on behalf of an incompetent patient by his or her surrogate decision maker, such as a guardian or conservator.[24]

This finding was consistent with the position of the Missouri Supreme Court. However, the next issue raised by the Cruzans was whether the Fourteenth Amendment to the U.S. Constitution prohibited the state of Missouri from imposing the "clear and convincing" evidence standard. In analyzing this argument the Court agreed that an individual had a constitutionally protected liberty interest in refusing unwanted medical treatment, including the use of feeding tubes.[25] However, the Court held that in the case of incompetent persons the state's right to ensure the preservation of life allowed it to insist on "clear and convincing" evidence of the wishes of the incompetent person, even in the face of such a liberty interest. The Court stated:

> In our view, Missouri has permissibly sought to advance these interests through the adoption of a "clear and convincing" standard of proof to govern such proceedings. The function of a standard of proof, as that concept is embodied in the Due Process Clause and in the realm of factfinding, is to instruct the factfinder concerning the degree of confidence our society thinks he should have in the correctness of factual conclusions for a particular type of adjudication. . . . We think it self-evident that the interests at stake in the instant proceedings are more substantial, both on an individual and societal level, than those involved in a run-of-the-mill civil dispute. But not only does the standard of proof reflect the importance of a particular adjudication, it also serves as "a societal judgment about how the risk of error should be distributed between the litigants." *Santosky, supra,* 455 U.S. at 755; *Addington, supra,* at 423. The more stringent the burden of proof a party must bear, the more that party bears the risk of an erroneous decision. We believe that Missouri may permissibly place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment. An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment, at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.[26]

After *Cruzan*, an incompetent individual's right to be free of unwanted medical treatment will depend on the existence of either an "advanced directive" such as a living will or power of attorney for health care dealing with the question or some other evidence of his or her intent that will satisfy a particular state's evidentiary standards applicable to this issue. Without such evidence, the state may insist on the continuation of life-sustaining/prolonging treatment.

Wisconsin Cases

In Wisconsin, there are two critical cases relating to end-of-life decision making by guardians: *In re the Guardianship of L.W.*[27] and *In re the Guardianship of Edna M.F.*[28] In these two cases, the Wisconsin Supreme Court has attempted to set guidelines for guardians making end-of-life decisions for incompetent wards. In my view, the end result of these cases is flawed, especially *Edna M.F.*, because they too narrowly constrict the ability of guardians to make appropriate decisions for their wards.

Initially we must recognize that competent individuals have the ability to engage in advance planning for end-of-life health care decision making, especially as it relates to the withholding or withdrawal of tube feeding. In both the Power of Attorney for Health Care and the Declaration to Physicians, an individual may elect to forgo or terminate tube feeding.[29] The families of individuals who have the foresight to deal specifically with these issues will have the authority to carry out their wishes relating to end-of-life care. However, for those persons who have not executed one of these documents, the road is much more difficult.

The case of *In re L.W.* involved a 79-year-old chronically mentally ill, institutionalized individual who, according to the court, "may never have been competent."[30] In early 1989, he suffered from cardiac arrest resulting in a determination by his physicians that he was in a "chronic, persistent vegetative state."[31] The doctors proposed to the guardian that all life-sustaining medical treatment, including artificial nutrition and hydration (tube feeding), be discontinued. The guardian applied to the court for permission to terminate the life-sustaining medical treatment, including tube feeding. The trial court granted the request and the guardian ad litem appealed to the Supreme Court. While the case was pending, L.W. died of natural causes. Notwithstanding his death, the court chose to resolve the case.[32]

The court first addressed the issue of whether "an incompetent individual such as L.W. has the right to refuse unwanted medical treatment."[33] It concluded that such a right emanated from the common-law right of informed consent, from the Fourteenth Amendment to the U.S. Constitution, and from Article I, Section 1, of the Wisconsin Constitution.[34] In so doing, the court cited *Cruzan* and the actions of the Wisconsin Legislature in enacting Wisconsin Statutes Chapters 154 and 155.[35]

The court then addressed what it considered an issue of "first impression" in Wisconsin, namely whether the right to refuse unwanted medical treatment includes the right to refuse artificial nutrition and hydration.[36] The court stated:

> We recognize, as other courts have, that the provision of food and water to one incapable of oral self-nourishment raises unique concerns. Unlike most medical technological advances of a mechanistic nature, it is difficult to view nourishment as anything but normal and essential human care. It is difficult not to view the withdrawal of artificial feeding as inducing death through starvation and dehydration. . . . (footnote omitted) There is however no compelling distinction between artificial feeding and other forms of medical treatment. As succinctly stated by the New Jersey Supreme Court:
>
> > Once one enters the realm of complex, high-technology medical care, it is hard to shed the "emotional symbolism" of food. However, artificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions are significantly different from bottle-feeding or spoonfeeding—they are medical procedures with inherent risks and possible side effects, instituted by skilled health-care providers to compensate for impaired physical functioning. Analytically, artificial feeding by means of a nasogastric tube or intravenous infusion can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own. *In re Conroy*, 98 N.J. at 372–373, 486 A.2d at 1236 (citations omitted).[37]

The court also found support for the proposition that tube feeding is more akin to medical treatment than ordinary care in Justice O'Connor's concurrence in *Cruzan*: "Artificial feeding cannot readily be distinguished from other forms of medical treatment."[38]

The court then turned to the question of whether the right to refuse "all unwanted life sustaining medical treatment" extends to incompetent persons and concluded that it clearly did. "An incompetent person does not relinquish the right to refuse unwanted treatment by virtue of incompe-

tency."[39] The guardian ad litem argued that Wisconsin should adopt the stance of Missouri and require proof of an individual's wishes by "clear and convincing evidence." The court rejected this suggestion, stating:

> Relatively few individuals provide explicit written or oral instructions concerning their treatment preferences should they become incompetent [footnote omitted]. The reasons for this are undoubtedly myriad: ignorance, superstition, carelessness, sloth, procrastination or the simple refusal to believe it could happen to oneself. This failure to act is not a decision to accept all treatment, nor should society's increasing ability to prolong the dying process make it one. To adopt the clear and convincing standard would doom many individuals to a prolonged vegetative state sustained in a life form by unwanted, perhaps detrimental, means that are contrary to the person's best interest. Moreover the legislature in the adoption of chs. 154 and 155, carefully pointed out that failure to execute a living will or power of attorney for health care creates no presumption that the person consents to the use or withholding of life-sustaining procedures.
>
> Thus the stated legislative policy is to leave the decision, if not declared by the patient, to be determined as a matter of common law—and the common law, where the individual was never competent or where the conduct of the individual while competent never was of a kind from which one could draw a reasonable inference upon which to make a substituted judgment, requires that decision to be resolved by a surrogate decision maker acting in the best interests of the incompetent.[40]

Having placed the decision on refusal of unwanted medical treatment for incompetents in the hands of a "surrogate decision maker," the court then faced the question of whether the standard to be used by the decision maker in making the end-of-life decision is to be the "best-interests" or "substituted judgment" standard. The primary concern of the court was that applying the substituted judgment standard to L.W. was all but impossible because that standard requires that the decision maker know what the ward wanted. In the case of L.W., it was impossible to know what he wanted, since as the court found he was probably never competent.[41] Thus the court opted for a best-interests standard, while recognizing that if the incompetent person's wishes are known, it is in his or her best interests to follow those wishes.[42] The court then reached its penultimate holding in this case:

> In conclusion then we hold that a guardian may consent to the withholding or withdrawal of life-sustaining medical treatment on behalf of one who was never competent, or a once competent person whose conduct never was of a kind from which one could draw a reasonable inference upon which to make a substituted judgment, when:
>
> (1) the incompetent patient's attending physician, together with two independent neurologists or physicians, determine with reasonable medical certainty that the patient is in a persistent vegetative state and has no reasonable chance of recovery to a cognitive and sentient life; [footnote omitted] and (2) the guardian determines in good faith that the withholding or withdrawal of treatment is in the ward's best interests, according to the objective factors outlined below [footnote omitted].[43]

The court identified the following "objective factors" to be considered by the guardian as follows:

> The degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.[44]

In applying these factors the court cautioned guardians to

> Assess these factors from the standpoint of the patient, and . . . not substitute his or her own view of the "quality of life" of the ward. As the *Rasmussen* court explained, the guardian's determination of what is in the ward's best interests necessarily involves an assessment of "the value that the continuation of life has for the patient," but should not involve "the value that others find in the continuation of the patient's life. . . ."[45]

The court also pointed out other considerations, such as the view of the institution's ethics committee and the views of relatives of the ward.[46]

Finally, the court discussed the potential state interests that must be considered in cases of this type.

> Courts have identified four relevant state interests: (1) preserving life; (2) safeguarding the integrity of the medical profession; (3) preventing suicide; and (4) protecting innocent third parties.[47]

The court addressed each of these in turn and concluded that none of them overcame the right of the guardian for L.W. to assert his right to refuse unwanted treatment. As a result of the *L.W.* decision, Wisconsin guardians appeared to have the right, without seeking court approval, to consent to the withdrawal of life-sustaining treatment, including artificial nutrition and hydration or tube feeding, at least in the case of persons in a persistent vegetative state.

Five years later, the Wisconsin Supreme Court revisited this issue in the *Edna M.F.* case.[48] This case, which appeared at first blush to have facts only slightly different from *L.W.*, came to a dramatically different result.[49]

The ward in *Edna M.F.* was described in the majority opinion as follows:

> Edna M.F. is a 71-year-old woman who has been diagnosed with dementia of the Alzheimer's type. She is bedridden, but her doctors have indicated that she responds to stimulation from voice and movement. She also appears alert at times, with her eyes open, and she responds to mildly noxious stimuli. According to these doctors, her condition does not meet the definition of a persistent vegetative state. In 1988, a permanent feeding tube was surgically inserted in Edna's body. Edna currently breathes without a respirator, but she continues to receive artificial nutrition and hydration. Edna's condition is not likely to improve.[50]

The other principal difference between *Edna M.F.* and *L.W.* is that Edna was an individual who, prior to succumbing to Alzheimer's disease, was described as a vibrant individual who would have been competent to execute an advance medical directive but did not do so.[51] The court found that the only statement she made regarding her wishes as to life-sustaining treatment was a 30-year-old statement to the effect that "I [Edna] would rather die of cancer than lose my mind."[52]

Edna's niece requested that the tube feeding be discontinued. The request was referred to the ethics committee of the nursing home, which decided it would permit the withdrawal of the tube feeding if all family members agreed. One refused to do so in writing on religious grounds and so the guardian filed a petition with the Wood County Circuit Court to approve withdrawal of the feeding tube. The circuit court denied the petition and the case was brought to the supreme court on a bypass procedure.[53] The supreme court, in a majority opinion by Justice Steinmetz, upheld the circuit court.

The court reviewed the *Quinlan, Cruzan,* and *L.W.* line of cases and concluded that incompetent persons have the right, through their surrogate decision makers, to refuse unwanted medical treatment.[54] However, relying on *In re Guardianship of Eberhardy,*[55] the court observed that while all persons, whether competent or incompetent, have the same constitutional rights, "the uninhibited exercise of those rights may be hedged about with restrictions that reflect the public policy of protecting persons of a distinct class."[56]

The court then considered whether a guardian of a person who is not in a persistent vegetative state could consent to the withdrawal of tube feeding. The court held that "if [a] person is not in a persistent vegetative state, this court has determined that as a matter of law it is not in the best interests of the ward to withdraw life sustaining treatment, including a feeding tube, unless the ward has executed an advance directive or other statement clearly indicating his or her desires."[57] The court explained its rationale for this "bright line" test as follows:

> One of the main reasons that this court in L.W. limited the scope of its holdings is the fact that The American Academy of Neurology explains that people in a persistent vegetative state do not feel pain or discomfort. L.W., 167 Wis. 2d at 87, note 17. In the case at bar, Edna M.F. is not in a persistent vegetative state and could therefore likely feel the pain and discomfort of starving to death. Even a competent person cannot order "the withholding or withdrawal of any medication, life-sustaining procedure or feeding tube" if "the withholding or withdrawal will cause the declarant pain or reduce the declarant's comfort" unless the pain or discomfort can be alleviated through further medical means. Wis. Stat. 154.03(1). See also Wis. Stat.

155.20(1). In the case where withdrawal of life-sustaining medical treatment, including nutrition or hydration, will cause pain or discomfort, then, the competent and incompetent person have exactly the same rights.[58]

The court then tried to bolster its position by positing a "slippery slope" to euthanasia if the position of the guardian for Edna were adopted.[59] I will suggest below that, given the criteria established in *L.W.*, there is no reasonable basis for the slippery slope argument.

The court then discussed what the guardian would have to show regarding Edna's wishes when it came to end-of-life care.

> Even though Edna M.F. is not currently existing in a persistent vegetative state, if her guardian can demonstrate by a preponderance of the evidence a clear statement of Edna's desires in these circumstances, then it is in the best interests of Edna to honor those wishes [footnote omitted]. See L.W., 167 Wis. 2d at 79–80. The reason this court requires a clear statement of the ward's desires is because of the interest of the state in preserving human life [footnote omitted] and the irreversible nature of the decision to withdraw nutrition from a person.[60]

The court concluded that the evidence presented regarding Edna's wishes was not sufficient to overcome the state's presumed interest in maintaining her biological life, and the relief sought by the guardian was denied.[61] There were several concurring opinions expressing different views on how to prove the existence of a persistent vegetative state, but none differed with the underlying rationale of the case, namely that a persistent vegetative state was the appropriate "bright line."[62] It is that underlying assumption that I question.

The Medical Issue

Ultimately, the decision in *Edna M.F.* turned on a medical issue, namely whether Edna was in a persistent vegetative state (PVS). But, I think it important to look behind that question to what I believe to be an even more important one: what was the justification for establishing PVS as the "bright line" test for deciding when a guardian could withdraw artificial nutrition and hydration? This was not an issue in *L.W.* because it was agreed that he was in a persistent vegetative state. However, in two footnotes, Chief Justice Heffernan set forth his views at length:

Footnote 15 to the majority opinion in *L.W.* stated:

> We stress the unique status of individuals in a persistent vegetative state, and the fact that this opinion is strictly limited to persons in such a condition. As the President's Commission concluded:
>
> The primary basis for medical treatment of patients is the prospect that each individual's interests (specifically, the interest in wellbeing) will be promoted. Thus, treatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible.[63]

At footnote 17, the court continues the discussion:

> The dissent urges that the incompetent patient must be protected against the potential pain and discomfort involved in the withdrawal of artificial nutrition and hydration. Dissenting Op. at 96-99. However, this concern is inapplicable to this case because individuals in a persistent vegetative state cannot experience pain or discomfort. The American Academy of Neurology states:
>
> Persistent vegetative state patients do not have the capacity to experience pain or suffering. Pain and suffering are attributes of consciousness requiring cerebral cortical functioning, and patients who are permanently and completely unconscious cannot experience these symptoms. There are several independent bases for the neurological conclusion that persistent vegetative state patients do not experience pain or suffering. First, direct clinical experience with these patients demonstrates that there is no behavioral indication of any awareness of pain or suffering. Second, in all persistent vegetative state patients studied to date, postmortem examination reveals overwhelming bilateral damage to the cerebral hemispheres to a degree incompatible with consciousness or the capacity to experi-

> ence pain or suffering. Third, recent data utilizing positron emission tomography indicates that the metabolic rate for glucose in the cerebral cortex is greatly reduced in persistent vegetative state patients, to a degree incompatible with consciousness.[64]

In the majority opinion in *Edna M.F.*, Justice Steinmetz restated the *L.W.* rationale:

> One of the main reasons that this court in L.W. limited the scope of its holdings is the fact that The American Academy of Neurology explains that people in a persistent vegetative state do not feel pain or discomfort. L.W. 167 Wis. 2d at 87, note 17. In the case at bar, Edna M.F. is not in a persistent vegetative state and could therefore likely feel the pain and discomfort of starving to death. Even a competent person cannot order "the withholding or withdrawal of any medication, life-sustaining procedure or feeding tube" if "the withholding or withdrawal will cause the declarant pain or reduce the declarant's comfort" unless the pain or discomfort can be alleviated through further medical means. Wis. Stat. 154.03(1). See also Wis. Stat. 155.20(1). In the case where withdrawal of life-sustaining medical treatment, including nutrition or hydration, will cause pain or discomfort, then, the competent and incompetent person have exactly the same rights.[65]

The concurring opinions in *Edna M.F.* all seem to accept the basic rationale, namely that PVS is the appropriate "bright line." They merely discuss how PVS should be diagnosed. No one questions the basic premise, namely that PVS is the appropriate standard.

The underlying rationale of both *L.W.* and *Edna M.F.* can be stated as follows: (1) withdrawal of nutrition and hydration causes pain; (2) pain is to be avoided; (3) persons in PVS do not feel pain; and therefore (4) it is only appropriate to withdraw artificial nutrition and hydration for those who feel no pain—namely those in the PVS condition.

What if this argument could be attacked at one or more of its logical connections? What if, for example, it were shown that the withdrawal of artificial nutrition or hydration did not cause pain but in fact may ease pain? And, what if there are other conditions where the patient does not feel pain? What then is left of the basis for the conclusion, begun in *L.W.* and continued in *Edna M.F.*, that PVS is the only condition where withdrawal of nutrition and hydration is permissible? As the following discussion will show, there is a considerable body of medical authority for the proposition that the withdrawal of artificial nutrition and hydration in dying patients may relieve rather than cause pain and discomfort. In light of that authority, I submit that the decision in *Edna M.F.* should be reexamined and that guardians of incompetent individuals should have broader authority to make end-of-life decisions for their wards.

The Medical Literature

A review of the medical literature on the topic of the effects of dehydration on terminally ill patients has led me to conclude that it is more likely than not that the pain and suffering referred to by Justice Steinmetz in the *Edna M.F.* opinion[66] does not occur. The nature of the problem is stated as follows:

> The general impression among hospice clinician (sic) is that starvation and dehydration do not contribute to suffering among the dying and might actually contribute to a comfortable passage from life. In contrast, the general impression among the public and non-hospice medical professionals is that starvation and dehydration are terrible ways to die. Scientific support for either viewpoint has been scanty, and yet modern medical practice has reflected an aversion to allowing a person to starve to death.[67]

As many commentators point out, the issue is often the "symbolism" that is associated with providing food and fluids to dying persons. It is thought that this is "ordinary care" and the least that one can do for a dying person. However, as one commentator pointed out,

> Although tube feeding has been likened to the provision of food and water [footnotes omitted], it does not resemble eating or drinking in any way except for its symbolism . . . . In addition to these problems [arising from tube feeding], there are less obvious ones. Tube feeding is a passive process that bypasses the sensory input of the patient. . . . A feeding tube may produce anxiety or fear in the confused patient who has some awareness. These patients may not understand the purpose of the tube and may attempt to dislodge it. . . . Tube feeding, in general, is devoid of the interpersonal aspects of ordinary feeding, which in itself can be a comforting encounter; tube

> feeding also lacks the sensory qualities of real food and drink, which might provide the patient with a modicum of pleasure.[68]

Of course, for many of the patients we are considering, oral ingestion of food and water is not a possibility. Even if they are not in a persistent vegetative state, they may be in another condition that similarly renders them unable to eat or drink.[69] In fact, in the *Cruzan* case, the Supreme Court agreed that the provision of artificial nutrition and hydration constituted medical care rather than ordinary care for the patient.[70]

However, the issue posed by the court in *Edna M.F.* was not whether the provision of artificial nutrition and hydration was ordinary care, but rather whether the withdrawal of such nutrition and hydration caused pain and suffering. The conclusion of a number of commentators, based both on general observations in the clinic and specific studies, is that such withdrawal does not cause pain and in fact might actually enhance the comfort of the dying patient. A monograph containing case studies of three terminally ill patients in 1993 concluded that "there are benefits to dehydration and detriments to hydration in this population." In each case reported, there was an increase in alertness and apparent comfort when artificial nutrition and hydration were discontinued.[71] The article suggested the reason for this phenomenon is that

> [i]n patients in advanced stages of dehydration, enhanced comfort may be due to the release of pain relieving substances. . . . Another possible explanation for the absence of symptoms is that ketones produced during starvation have an anesthetic effect which has been shown in the squid axon.[72]

Another study, reported in the *Journal of the American Medical Association* in 1994, monitored 32 "mentally competent terminally ill patients" in a nursing home. The conclusion of the study was summarized as follows:

> In this series, patients terminally ill with cancer generally did not experience hunger and those who did needed only small amounts of food for alleviation. Complaints of thirst and dry mouth were relieved with mouth care and sips of liquids far less than that needed to prevent dehydration. Food and fluid administration beyond the specific requests of patients may play a minimal role in providing comfort to terminally ill patients.[73]

In this study, the investigators found that terminal patients from whom food was withdrawn experienced comfort despite the withdrawal of food. This was attributed to the increased fat metabolism and production of ketone, which served as an energy source for peripheral tissues and the central nervous system. They concluded that

> In patients with advanced cancer and malnutrition, there has been no consistent benefit of aggressive nutritional support on morbidity or mortality nor has there by consistent reversal of the metabolic abnormalities that occur in these states. . . . Studies of voluntary fasting demonstrate that subjects become not only anorectic but are also comfortable. . . .The major symptom noted in our subjects and in another study of severe dehydration however was that of thirst and/or dry mouth (these could not be differentiated in our patients). The symptoms were completely relieved with ice chips, sips of liquid, lip moisteners, hard candy and mouth care. The lack of fluid intake also generally produced the positive effects of decreased secretions, as evidenced by few episodes of prolonged choking and infrequent need for suctioning in our patients.[74]

The author of this article also observed:

> In caring for terminally ill or chronically ill patients, tube feedings are often initiated to alleviate the anxiety of caregivers and families of patients. . . . Caregivers, patients, and families need to be educated that loss of a normal appetite is commonly observed in dying patients and does not substantially contribute to their suffering.[75]

A 1995 article reviewed much of the then-current literature on the topic of dehydration of terminally ill patients and came to a similar conclusion.[76] This study noted a decided split of opinion with respect to rehydration of the terminally ill between doctors practicing in a hospital setting and those in a hospice. The article cited one study that showed that 40 percent of doctors in a hospital setting reported that they would use artificial hydration for a comatose patient with "wide-

spread malignancy" whereas none of the hospice physicians would do so. The authors suggested that a benefits/burden analysis is appropriate in this situation:

> However, it may be that the issue we need to address is our assessment of likely benefit, rather than attempting to quantify medical intrusion. Our responsibility here is not to take a stance on the appropriateness of artificial rehydration, but to make individual unprejudiced clinical assessments in the light of the patient's (or their representative's) own preferences for treatment and our knowledge of the evidence concerning that treatment. In the uncomplicated deterioration from end-stage metastatic malignancy, in which the patient becomes unable to take oral fluids, there is no evidence that artificial hydration will provide any benefit. . . . Doctors need to be careful that a decision to prolong life temporarily in the terminal phase is an objective one in the interests of the patient, rather than a means of minimizing their own feelings of responsibility and even guilt.[77]

This review of the medical literature leads to the conclusion that the withdrawal of tube feeding and hydration does not, as asserted by the majority in *Edna M.F.*, cause pain and suffering. If this is the case, then the "bright line" test asserted in *Edna M.F.* (and drawn from the prior *L.W.* case) does not hold up in light of the apparent medical facts. In fact, it appears from this literature that the provision of artificial nutrition and hydration may be causing the very pain and suffering that the court is trying to avoid.[78] For this reason, I submit that the approach adopted by the court in *Edna M.F.* does not lead to an appropriate resolution of the dilemma faced by guardians of incompetent individuals who are in conditions where withholding or withdrawal of artificial nutrition and hydration is medically indicated.

Decisions in Other States

In addition to reviewing the Wisconsin cases on this topic, I also looked at cases in nine other states that were decided after *Cruzan*.[79] While there were a number of other decisions, these seemed to present a representative sample of the decisions that followed *Cruzan*.[80] To analyze these cases, I have identified a number of key issues and compared how other states dealt with the problem in contrast to Wisconsin. I have included a table in the appendix to this article that summarizes my findings. Again, this will not be an in-depth analysis, but it will attempt to provide an overview of what is going on.

Persistent Vegetative State

In both *L.W.* and *Edna M.F.*, the wards were in a persistent vegetative state. In *Edna M.F.* the existence of this condition was deemed the critical problem in the case. In five of the cases reviewed, the ward was also in a persistent vegetative state. In three of the cases, the ward was not. One of the cases does not explicitly state the medical condition. All of the wards in these cases were severely incapacitated. There is no real correlation between the existence of PVS and the outcome of the case. In only three of the cases is there any discussion of PVS and then only to assert that persons in that condition do not feel pain. This is done to counteract arguments regarding pain from withdrawal of hydration and nutrition.

Advance Directives

In both of the Wisconsin cases, there were no advance medical directives. Not surprisingly, that was also the case in all but one of the nine other cases reviewed. In the one case where there was an advance directive, there was an issue of whether it was in effect since there was a factual question as to whether the ward's condition was terminal. I say this is not surprising because where there is an advance medical directive, the guardianship court should not get involved.

Source of Right to Refuse Treatment

The Wisconsin cases based the right to refuse treatment both on the common-law notion of informed consent and on the U.S. and Wisconsin Constitutions. In contrast, six of the nine jurisdictions reviewed based the right of refusal strictly on the common-law right of informed consent and most explicitly refused to reach the constitutional issue. Two of the courts relied on constitutional grounds, typically the right to privacy, and one court based the right on public policy as announced by the legislature. It is interesting that all of the courts found that there was a right to refuse treatment. The big issue was how that right is to be implemented in the case of an incompetent patient.

Standard for Decision

The Wisconsin cases adopted a best-interests test to guide the guardian in making his or her decision. These cases then discussed the criteria to be used by the guardians to make their decisions. In seven of the nine other decisions reviewed, the courts applied some variant of the substituted judgment standard. They felt that the most important inquiry was what the ward said he or she would want with respect to end-of-life care and directed that the guardian must do his or her best to ascertain what that intent was. The intent could be expressed orally or in writing and could sometimes be inferred from other facts of the individual's life. These courts rejected the best-interests test out of a fear that it would impose someone else's ideas as to quality of life. In only one of the cases was the best-interests standard adopted, and in one of the cases the standard was not discussed. Note that in *Edna M.F.*, for persons not in a persistent vegetative state, the inquiry as to the previously expressed wishes of the ward does not differ markedly from the substituted judgment adopted by the other courts.

Standard of Proof

The Wisconsin Supreme Court explicitly rejected the clear-and-convincing standard approved by the U.S. Supreme Court in *Cruzan*, opting instead for a preponderance-of-the-evidence test. This is clearly against the trend disclosed in the nine cases reviewed. Six of the nine cases adopted a clear-and-convincing evidence test, while one adopted a preponderance-of-the-evidence approach. In two of the cases it was not possible from the opinion to ascertain what evidentiary standard was applied. Given the fact that most of these courts were looking to the intent of the ward as to end-of-life decisions, it is not surprising that a high level of proof would be required.

The Outcomes

Given the foregoing discussion, one might assume that the courts would be hostile to the withdrawal of artificial nutrition and hydration, given the substantial hurdles established for the guardians. Yet in six of the nine cases reviewed (not counting the Wisconsin cases that split evenly) in the final analysis, the courts permitted the withdrawal of artificial nutrition and hydration. Even though the procedural and substantive barriers have been high, in the end the courts have appeared sympathetic to the individual situations of the wards as they applied their standards. In one of the cases in which an individual was found not to be in a PVS, the court refused to allow withdrawal of tube feeding. Yet, in two other cases where PVS was not shown, the court nonetheless allowed tube feeding to be withdrawn.

Conclusion

What may we conclude from this brief review of other cases? First, concerning a number of questions, Wisconsin's position differs from the norm in other states. Second, as a general rule the other courts, like the court in *Edna M.F.*, seek to place high barriers to exercise of the right to refuse treatment when that treatment is artificial nutrition and hydration, even though all of the courts agree that such provision is medical treatment rather than ordinary care. However, notwithstanding such barriers, the courts remain sympathetic to the plight of seriously incapacitated individuals and find ways to permit the withdrawal of artificial nutrition and hydration.

A Suggested Resolution

Just as in the *Wizard of Oz*, where the solution to Dorothy's problem of how to return to Kansas was always at her feet, so too I believe the solution to the problem of withdrawal of artificial nutrition and hydration has been presented to us by the Wisconsin Supreme Court in the *L.W.* case. *L.W.*, when you take away the unfortunate language relating to persistent vegetative state, provides a workable framework for resolving the tube-feeding question. As we recall, the Wisconsin Supreme Court held in *L.W.* that where an incompetent person's own wishes could not be identified, the guardian should apply a "best-interests" test based on objective factors:

> In making the best interests determination, the guardian must begin with a presumption that continued life is in the best interests of the ward. Whether that presumption may be overcome depends upon a good faith assessment by the guardian of several objective factors.

Objective factors the guardian may consider include:

> [T]he degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.[81]

This analysis is similar to the "benefits/burdens" analysis used by medical ethicists:

> Doctors are both morally and legally justified in withholding or withdrawing any treatments that are not beneficial to their patients. Given that the patient is certainly dying, the ethical imperative remains that of imposing no greater burden than benefit on the patient (i.e., optimum symptomatic management) rather than attempts to postpone the point of death.[82]

By adopting such an approach, the guardian who is making a decision regarding tube feeding for an incompetent patient, and the patient's doctor, are placed in the same position as if the patient were competent. The doctor can make the same benefits/burdens analysis he or she would make in the case of any other patient and make an informed medical decision based on that analysis. The guardian can weigh the various "objective factors" noted above, as well as the guardian's personal knowledge of the views and values of the ward, and make an informed judgment that should be in the ward's best interests.

It seems to me that this approach avoids many of the problems created by the substituted judgment test applied in the other states. Under substituted judgment, there can be a long, involved, and frankly often tortured analysis of the desires of the incompetent person when, in all likelihood, he or she may never have really considered or discussed the issue with any particular insight. Thus, the search for the intent of the individual will often be quite futile or facile. This tends to render the presumed basis for this test, carrying out the ward's wishes, ineffectual.

The *L.W.* approach (without PVS) also responds to Justice Steinmetz' "slippery slope" argument in *Edna M.F.* The *L.W.* factors provide a reasonable framework for end-of-life decision making by guardians. They would not sanction euthanasia for its own sake. Rather, a careful analysis of the circumstances of the patient and the benefits and burdens of the continuation of artificial nutrition and hydration to the patient would be the paramount considerations. Will mistakes be made and decisions made for improper reasons? Perhaps. But the fact that the individual is or is not in a persistent vegetative state will not change the possibility and consequences of a wrong decision. And I maintain that it is more likely that a correct decision (one in the best interests of the ward and probably closer to what the ward would have wanted in most cases) will be made under the analysis in *L.W.* (free of the PVS restriction) as opposed to the *Edna M.F.* analysis.

Conclusion

In the final analysis, the thesis of this article is that the *Edna M.F.* decision should be revisited in a case where the scientific and medical basis for its con-

Appendix
Comparison of Right-to-Die Cases

Case Name	PVS	Std. of Decision	Std. of Proof	Source of Right	Discuss Pain	Outcome	Adv. Directivee
In re Fiori	Yes	Sub. judgment	Other	Common law	No	Withdraw	No
In re Meyers	Yes	Best interests	Unclear	Common law	Yes	Withdraw	No
In re Doe	Yes	Sub. judgment	Preponderance	Leg. policy	No	Withdraw	No
In re Martin	No	Sub. judgment	Clear and conv.	Common law	No	Not withdraw	No
Mack v. Mack	Yes	Sub. judgment	Clear and conv.	Common law	No	Not withdraw	No
Land v. Edwards	Yes	Sub. judgment	Clear and conv.	Common law	No	Withdraw	No
In re Longway	Not clear	Sub. judgment	Not discussed	Common law	Yes	Not withdraw	No
In re Browning	No	Not discussed	Clear and conv.	Constitution	No	Withdraw	No
In re Tavel	No	Sub. judgment	Clear and conv.	Constitution	Yes	Withdraw	No

clusions can be reexamined in light of modern experience, especially in the hospice setting. The current position of the court often creates an untenable situation for families and their advisors since there is often more flexibility in end-of-life decision making where there is no guardian (even in the absence of an advance directive) than where a guardian has been appointed. In addition, the fact that feeding tubes, once installed, might not be able to be removed could lead to unintended consequences. For example, doctors and families might be more reluctant to start the feeding tube when it could possibly do some good, out of the fear that if things do not work out as planned, the ward and his or her family might be condemned to a prolonged dying process. Providing more flexibility to guardians can avoid these problems without jeopardizing other significant community interests. It is time to take another look.

Endnotes

1. *In re* Quinlan, 355 A.2d 647, 651 (N.J. 1976).
2. *See* WIS. STAT. § 154 (1983).
3. *See* WIS. STAT. § 155 (1990).
4. *See* WIS. STAT. § 154 (1991).
5. 563 N.W.2d 485 (Wis. 1997).
6. For purposes of this article I will use the generic term "tube feeding" to refer to the provision of nutrition and/or hydration by means of a feeding tube, whether a nasogastric tube, a gastronomy, or other means.
7. Note that neither the review of the case law nor of the medical literature is intended to be an exhaustive review of this topic. Rather, some of the key cases are identified to set a framework for the discussion.
8. 355 A.2d 647 (N.J. 1976).
9. This was described in the opinion as involving a "subject who remains with the capacity to maintain the vegetative parts of neurological function but who . . . no longer has any cognitive function." *See* 355 A.2d at 654. However, she was not "brain dead." *Id.*
10. *Id.* at 655.
11. *Id.* at 657.
12. *Id.* at 651–58.
13. *See* 355 A.2d at 664. The court rejected Mr. Quinlan's claim of a parental right to privacy under these circumstances.
14. *See* Eisenstadt v. Baird, 405 U.S. 438 (1972); Stanley v. Georgia, 394 U.S. 557 (1969); Griswold v. Connecticut, 381 U.S. 479 (1965).
15. 355 A.2d at 664 (emphasis added).
16. *See id.*
17. What happened next is of some interest. After the respirator was disconnected, Karen continued breathing on her own, was moved to a nursing home, and continued to live for several years, albeit being subject to tube feeding.
18. *See generally* 355 A.2d at 647.
19. 497 U.S. 261 (1990).
20. *Id.* at 266.
21. *See id.* at 268.
22. *Id.*
23. *Id.* at 287.
24. *See* 497 U.S. at 269–78.
25. *See id.* at 278.
26. *Id.* at 282–83.
27. *See generally* 482 N.W.2d 60 (Wis. 1992).
28. *See generally* 563 N.W.2d 485 (Wis. 1997).
29. *See* WIS. STAT. §§ 155.20(4), 154.03. This was not always the case. When Chapter 154 was first enacted, it did not permit the withholding or withdrawal of tube feeding (then referred to as "non-orally ingested nutrition and hydration").
30. 482 N.W.2d at 63.
31. *Id.*
32. *See id.* at 64–65.
33. *Id.* at 65.

34. *Id.*

35. 482 N.W.2d at 65–66.

36. *Id.* at 66.

37. *Id.* at 66.

38. *Id.* at 66.

39. *Id.* at 67.

40. 482 N.W.2d at 67–68.

41. *See id.* at 68. One should note that even for persons who were competent at one time, but who never executed advance medical directives, it is often equally impossible to know what their wishes are regarding life-sustaining treatment. Many people simply are unwilling to discuss this topic or have never done so. Anecdotally, I would observe that in my practice of doing powers of attorney for health care, I cannot remember one case where a client chose to check "no" in the box relating to tube feeding, meaning, as I tell them, that this would probably result in tube feeding in every circumstance. Nearly everyone I have dealt with wants the agent to have discretion to remove feeding tubes when the agent decides that the only result of the feeding tube is to prolong the dying process.

42. *See* 482 N.W.2d at 70.

43. *Id.* at 71–72. In the next section of this paper, I will discuss the appropriateness of limiting a guardian's authority to persons in a "persistent vegetative state."

44. *Id.* at 72.

45. *Id.* at 73.

46. *See id.* at 73–74.

47. 482 N.W.2d at 74.

48. 563 N.W.2d at 485.

49. It is probably no coincidence that the author of the majority opinion in *Edna M.F.*, Justice Steinmetz, was the sole dissenter in *L.W.*

50. 563 N.W.2d at 487. Justice Abrahamson, in her concurring opinion, suggests that the statement of facts in the majority opinion does not, in her words, "do justice" to the factual record. She states: "Ms. F. breathes without assistance but in all other respects is dependent on others for her care and continued existence. Ms. F.'s muscles have deteriorated to the point where her limbs are contracted and immobile. She demonstrates no purposeful response, such as withdrawal, to tactile, aural or visual stimuli; she makes non-specific responses to pinching or tapping of the arm or sternum. There is also some testimony suggesting Ms. F. occasionally may track movements in the room with her eyes. Two attending physicians testified; only Dr. Erickson, however, was asked to opine on whether Ms. F. was in a persistent vegetative state at the time of his examination of her. Dr. Erickson testified as follows: The definition [of persistent vegetative state] as described in the Journal of Neurology in January 1989 requires that there be no behavioral response whatsoever over an extended period of time, and that no voluntary action or behavior of any kind is present. As I testified before, Edna, in my opinion, has provided evidence of some minimal response to stimulation from her surrounding, and so in the strict definition, I would have to say that she approximates but does not entirely meet that definition of the persistent vegetative state." 563 N.W.2d at 492.

51. 563 N.W.2d at 492.

52. *Id.* at 487.

53. *See id.* at 487.

54. *See id.* at 487–89.

55. 307 N.W.2d 881 (Wis. 1981). *Eberhardy* involved a petition to authorize the guardian of an incompetent person to consent to her sterilization. The court in *Eberhardy* declined to permit the sterilization.

56. 563 N.W.2d at 489.

57. *Id.* at 489–90.

58. *Id.* at 490.

59. *See id.*

60. 563 N.W.2d at 490.

61. *See id.* at 491.

62. *Id.* at 490–91.

63. 482 N.W.2d at 72.

64. *Id.* at 73.

65. 563 N.W.2d at 490. To be sure, the Steinmetz opinion also raises the specter of "euthanasia" and asserts that the court will not go down that "slippery slope." *Id.* However this seems to be added baggage to the opinion and is not central to the position that he takes.

66. *Id.* at 490. While I make no pretense that this is an exhaustive review of the literature (or that I have any medical expertise), as will be seen I have reviewed a significant number of different sources and they are fairly uniform in their conclusions. I invite someone with more medical knowledge than I have to make a more complete review of this area. I am satisfied from my review to make the conclusions that I will make in the body of this article.

67. Ira Byock, *Patient Refusal of Nutrition and Hydration: Walking the Ever-Finer Line*, AM. J. OF HOSPICE & PALLIATIVE CARE, March/April 1995, at 8.

68. Judith C. Ahronheim, *Nutrition and Hydration in the Terminal Patient*, 12 CLINICS IN GERIATRIC MED., 379, 380–81 (1996).

69. "In the most advanced stages of Alzheimer's disease, cumulative strokes, advanced Parkinson's disease, other neurodegenerative conditions, and profound traumatic brain injury, patients are totally dependent on others for all aspects of care, and may be mute, bedridden and unable to eat [footnotes omitted]. In some cases they are indistinguishable for those in a persistent vegetative state." Ahronheim, *supra* note 68, at 379.

70. 497 U.S. at 274.

71. Maria Andrews et al., *Dehydration in Terminally Ill Patients*, 93 POSTGRADUATE MED., 201, 201–203 (1993).

72. *Id.* at 203, 206.

73. Robert McCann et al., *Comfort Care for Terminally Ill Patient*, 272 J.A.M.A. 1263 (1993).

74. *Id.* at 1266.

75. *Id.*

76. Kilian Dunphy et al., *Rehydration in Palliative and Terminal Care: If Not—Why Not?*, 9 PALLIATIVE MED., 221, 226 (1995).

77. *Id.* at 226.

78. Additionally, the passage quoted from the Ahronheim article is instructive. There are many ilnesses that can create conditions that have the same effect as persistent vegetative state. Ahronheim, *supra* note 69, at 379. Thus, even if the court's rationale has any basis, using persistent vegetative state as the "bright line" still does not make sense.

79. *In re* Fiori, 673 A.2d 905 (Pa. 1996); *In re* Doe, 583 N.E.2d 1263 (Mass. 1992); *In re* Martin, 538 N.W.2d 399 (Mich. 1995); In the Matter of Tavel, 661 A.2d 1061 (Del. 1995); *In re* Guardianship of Myers, 610 N.E.2d 663 (Ohio Com. Pl. 1993); Mack v. Mack, 618 A.2d 744 (Md. 1993); Land v. Edwards, 858 S.W.2d 698 (Ky. 1993); *In re* Estate of Longway, 549 N.E.2d 292 (Ill. 1990); *In re* Guardianship of Browning, 568 So. 2d 4 (Fla. 1990).

80. While there are numerous pre-*Cruzan* cases discussing this issue, the post-*Cruzan* experience is more relevant because of the issues resolved in *Cruzan*, namely the affirmation by the Supreme Court that there is a protected right to refuse unwanted medical treatment.

81. 482 N.W.2d at 72.

82. Dunphy et al., *supra* note 76, at 226–27. *See also* Byock, *supra* note 67, at 11. "Proportionality is commonly explained as a weighing of the risks versus potential benefits of a proposed intervention."

Legislative & Legal

Compiled by Susan Armacost
Legislative Director

Wisconsin Right to Life has long been recognized as one of the most respected and effective lobbying organizations of any kind in the state. As a result of the work you support, numerous pro-life state and federal laws now protect and save human lives. Of course, much remains to be done and your help through letter-writing and calling your legislators will make a difference!

Symbol Key: ✓ = Legislation Supported by Wisconsin Right to Life
⊘ = Legislation Opposed by Wisconsin Right to Life
ACTION! ☎✉ = Your action requested.

= State Legislation
= Federal Legislation

Federal Legislative Update

✓ Federal Partial-Birth Abortion Ban Act: After passing both the U.S. House and U.S. Senate, President Bush is waiting to sign this legislation into law. The measure is currently in a conference committee to work out differences in the House and Senate versions. Unfortunately, as soon as the president signs the ban into law, it will immediately be challenged in court by abortion advocates.

✓ Unborn Victims of Violence Act (H.R. 1997 / S. 1019): This legislation would recognize unborn children as separate victims when they are killed or injured during the commission of a federal crime. Opponents of the legislation, namely the radical pro-abortion lobby, are promoting an "alternative" bill that would not recognize the unborn child as a separate victim. The House version (H.R. 1997) was approved by a Committee in July. The Senate is expected to vote on the Senate version of the legislation (S. 1019) this summer. Please call and email Sen. Feingold and Sen. Kohl to urge their support of S. 1019. Also urge them to reject the "one victim" bill being promoted by the pro-abortion lobby. Sen. Kohl can be emailed by first going to his website at http://kohl.senate.gov and typing in your email message in the place provided. You can call Sen. Kohl toll free at 1-800-247-5645. To email Sen. Feingold, first go to his website at http://feingold.senate.gov and type in your message in the place provided. Sen. Feingold does not have a toll free number. Call him at 202-224-5323. **NOTE: Sen. Feingold has already indicated his opposition to S. 1019 and support for the bogus "one victim" alternative bill! Sen. Kohl as yet has not stated his position. Also call your U.S. House member in support of H.R. 1997 and in opposition to the "one victim" alternative bill.**

For contact information for all your federal legislators, visit the website of the National Right to Life committee at *www.nrlc.org* or call Wisconsin Right to Life toll free at 877-855-5007

State Legislative Update

✓ **CONSCIENCE CLAUSE BILL (AB 67):** Authors: Rep. Jean Hundertmark (R-Clintonville) and Sen. Carol Roessler (R-Oshkosh). AB 67 overwhelmingly passed the Assembly in May. The bill is now in the State Senate where a public hearing is expected in late summer or early fall. This legislation would protect pro-life health care professionals from being forced to participate in activities related to abortion, assisted suicide, euthanasia and unethical research involving the deliberate destruction of human life. Please contact your State Senator in support of AB 67.

✓ **BAN ON HUMAN CLONING (AB 104 / SB 45):** Authors: Rep. Steve Kestel (R-Elkhart Lake) and Sen. Joe Leibham (R-Sheboygan). This legislation would ban the cloning of human embryos for any reason. Opponents of AB 104/SB 45 are advancing a phony cloning "ban" which would allow the cloning of human embryos for the