

Nebraska Coalition for Compassionate Care

AN EDUCATIONAL GUIDE ON END-OF-LIFE CARE LAW AND PUBLIC POLICY IN NEBRASKA



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1. INTRODUCTION

1.1 INTRODUCTION

Postponing death is one of the primary goals of medicine and health care. In the past century, we have made tremendous advances in the fields of biomedical science and technology. Today, patients with life-threatening illnesses are treated in sophisticated hospitals by multi-disciplinary teams of highly specialized health care professionals using complex technologies and the latest drugs. These efforts at the bed-side are supported in the background by an enormous system of pharmaceutical industries, scientific laboratories, and educational institutions, as well as insurance companies, software developers and medical product manufacturers.

In all the hustle and bustle of modern health care, an individual patient's wishes can easily get lost. This is even more true for vulnerable patients who suffer from a terminal illness or are dying. One of the major objectives of end-of-life care law and public policy is to safeguard the rights and interests of individual patients.

Unfortunately, these laws and policies are often misunderstood by health care providers and family members. Instead of advancing compassionate end-of-life care, laws and policies become barriers to compassionate end-of-life care. This EDUCATIONAL GUIDE is intended to reverse this unfortunate tendency. It will show that Nebraska's laws and public policies, if properly understood and applied, foster effective yet compassionate and respectful health care, the kind of care we owe our fellow human beings on the final earthly leg of that journey called human life.

1.2 END-OF-LIFE CARE AND LEGAL LIABILITY

1.2.1 Do I run legal risks when providing end-of-life care?

Not anymore than other kinds of medical care. It is a false and unfortunate myth that end-of-life care professionals face different and much more serious legal risks.

Providing compassionate health care to dying patients is a rewarding endeavor. But it is also very challenging. There are many barriers to the administration of compassionate end-of-life care. Patients may lack adequate insurance coverage; effective medications often have bad side-effects; access to care facilities may be limited due to large distances; there may not be family members living nearby to assist in the care giving; providing effective care may entail legal risk for the provider. Whereas many of these barriers are real and serious, we believe that the legal risks are no more significant at the end of life than in other care settings.

Almost all health care involves practical risks and therefore some legal risks as well. Every professional health care provider can be held responsible for his or her actions, both ethically and legally. Care providers are expected to be competent and diligent. Prescription of the wrong medications, failure to inform patients, or carelessness in administering treatment all can result in legal liability or disciplinary sanctions. In this regard, professionals who provide end-of-life care face legal risks as similar to thoracic surgeons, intensive care nurses, physical therapists working in rehabilitation clinics, or dentists specializing in pediatric care.

1.2.2 When Nebraska law doesn't specifically permit a particular medical intervention, should I assume it is illegal?

No. If the law is silent about a particular practice, it does not at all mean that practice is illegal. On the contrary; it's more likely that the practice is perfectly lawful. Health care providers should be mindful of the fact legislatures and courts generally become active only when there are conflicts. This means that there are many laws prescribing what must be done in certain contentious situations and even more laws prohibiting what absolutely may not happen. But there are few laws describing normal routines or best practices.

For example, Chapter 20 of Nebraska’s statutes is devoted to Civil Rights and contains the so-called *Rights of the Terminally Ill Act*. The name of the Act suggests it is very comprehensive, covering all the rights of terminally ill patients. In reality, it only covers one patient right, that is, the right to draft a living will. That does not mean, however, that Nebraska’s dying patients have only this one right. It simply means that at the time the Act was considered, this was the only patient right that demanded the Unicameral’s attention. Indeed, the very first section of the Act explicitly states that this new Act in no way restricts or terminates other existing rights [20-402(2)].

Many of the comments in this GUIDE are not supported by explicit statutes or court decisions, simply because there was never a need for the legislature to address the issue in a law and nobody ever contested the practice in court. While there is no guarantee that all of these comments will hold up if challenged in court, they do represent the prevailing ethical and legal thought in the matter.

1.2.3 Can I use this GUIDE instead of legal counsel from an attorney?

No. This GUIDE is intended to educate Nebraska’s end-of-life care professionals about Nebraska’s statutes, jurisprudence and health policy in the area of end-of-life care. The emphasis here is on “education.” **EVEN THOUGH THE AUTHORS HAVE STRIVEN TO BE ACCURATE AND UP-TO-DATE, THIS GUIDE SHOULD NOT BE USED AS A SUBSTITUTE FOR PROFESSIONAL LEGAL COUNSEL.** Each year, many of Nebraska’s laws are amended, our courts reach new verdicts on a daily basis, and changes in Federal law continue to affect Nebraska’s legal landscape. If the unusual complexity of a case so demands, legal counsel should be sought. However, this GUIDE will make clear that Nebraska’s Legislature and Courts intend to foster rather than hinder the provision of competent and compassionate end-of-life care.

1.3 THE NATURE AND SCOPE OF THIS GUIDE

1.3.1 For whom has this GUIDE been written?

The GUIDE has been written first and foremost for Nebraska’s professional end-of-life care providers – physicians, nurses, social workers, ministers etc. However, it may also be a useful resource to patients and their family members. The quality of

health care in general and end-of-life care in particular will be greatly increased if patients, their family members, and health care professionals communicate, share both expectations and anxieties, hopes and disappointments, information and feelings. We hope that this GUIDE will foster effective communication about the legal ramifications of end-of-life care among all involved.

1.3.2 How should I use this GUIDE?

This GUIDE can be used in many different ways. Those seeking a comprehensive overview may want to read it cover to cover. However, the GUIDE is divided into four separate sections that can be studied separately. Those looking for a information on a particular problem may want to peruse the detailed Locator in front. Finally, we remind the users of this printed resource that an electronic version will be produced in the near future (available from the Coalition’s webpage at <http://www.nebrccc.org>), which contains many links to full-text statutes and court decisions as well as other useful resources. The on-line version will also be updated as soon as new legal developments occur, which is obviously not possible for the printed guides already in circulation.

1.3.3 What kinds of issues are covered in this GUIDE?

As mentioned, there are four sections to this GUIDE. The first section (Chapter 3) covers decision-making. Particular attention is paid to the rights of patients, such as the right to be informed, to refuse life-saving treatment, and to execute an advance directive. The second section (Chapter 4) is devoted to the actual provision of care. We look, for example, at what a physician can do to ease a patient’s pain and at the difference between terminal sedation and euthanasia. In the third section (Chapter 5) we review the issue of withholding and withdrawing medical treatment. In the fourth and final section (Chapter 6), we briefly look at the time following the patient’s death.

1.3.4 How can I find the actual legal text of the articles cited in this EDUCATIONAL GUIDE?

The Nebraska statutes are available on line at <http://statutes.unicam.state.ne.us>. The statutes are divided into 90 topical Chapters. Each specific provision is given a hyphenated number. The digit(s) before the hyphen refer to the Chapter; the digits after the hyphen refer to the article and the section within the article. For example,

Section 20-411 can be found in Chapter 20 on Civil Rights, Article 4 on the Rights of the Terminally Ill, and is the 11th section in that Article.

Readers are forewarned that the labels used in the Nebraska statutes are somewhat at odds with common parlance. One would have expected the 90 topical Chapters to be divided into “sections,” and each section into numbered “articles.” In fact, the Chapters are officially divided into “Articles,” and these are in turn divided into numbered “Sections”. In this GUIDE, we follow the official legal terminology.

Note that certain sets of sections have been given a specific name. For example, Sections 20-401 to 20-416 together are also called the *Rights of the Terminally Ill Act*. However, any such named act is always integrated into one of the existing 90 Chapters at a fitting place.

In this EDUCATIONAL GUIDE, all references to sections in the Nebraska statutes have been placed in brackets, for example [Nebr. Stat. 20-411]. In the on-line version of this GUIDE, the sections will be “hot-linked” such that clicking on them will immediately call up the actual text of the section.

All other references to resources are likewise placed in brackets. The complete bibliographic citations for these works can be found in the Reference section in the back of the GUIDE.

Note, finally, that all references between parentheses, for example (§ 3.1.1), refer to paragraphs in the EDUCATIONAL GUIDE itself.

2. DEFINITIONS

2.1 INTRODUCTION

Once a law has been adopted by the legislature, it remains in force until it is amended or repealed. Some of our Nebraska laws have been on the books for years or even decades. But even if the text of a law remains unchanged, there is the possibility that its interpretation will vary significantly because the English language evolves continuously and so do the biomedical sciences and the social organization of society. The meaning of certain words can change as the years go by. Consequently, the meaning of the law can unintentionally change as well.

Take the term “died” or “death.” Until the latter part of the 20th century it was quite clear to everybody what was meant by the phrase “the patient has died” or “upon the death of the patient.” It meant the patient’s heart had stopped beating and her breathing had ceased. But since the invention of cardiopulmonary resuscitation, the fact that a person’s heart has stopped beating does not at all mean she has died. Or consider the term “nutrition.” A law requiring a nurse to always provide his or her patients with adequate “nutrition” would have meant something very different half-a-century ago when the only form of nutrition was regular food provided by mouth. But today, we can also administer nutrients through intravenous lines and a variety of tubes that bypass the patient’s mouth. If fifty years ago legislators adopted such a law requiring nurses to always provide adequate nutrition, they never contemplated all these new technologies and so it is not at all clear that they intended to include all forms of artificially administered nutrition.

The literal text of a particular law is one thing; its interpretation is quite another. And it is the interpretation that matters. Legislators know this. Hence, they often include definitions of key terms in the bill. For example, Section 20-403 of Nebraska’s *Rights of the Terminally Ill Act* states:

For the purposes of the Rights of the Terminally Ill Act, unless the context otherwise requires:

(1) Adult shall mean any person who is nineteen years of age or older or who is or has been married

(2) Attending physician shall mean the physician who has primary responsibility for the treatment and care of the patient

Note, too, that the definitions are “for the purposes of the Rights of the Terminally Ill Act” only. Indeed, different statutes may use different definitions for the same terms. This can lead to confusion as the examples provided below point out.

More importantly, the examples will show that even if definitions are provided, ambiguity often remains. Such ambiguity will only be resolved when cases are brought to court where the applicable law is tested and interpreted. As it turns out, very few end-of-life cases have been brought before the Nebraska courts and therefore there is a lack of jurisprudence that could resolve ambiguities.

2.2 SOME DEFINITIONS

2.2.1 How is “terminal illness” defined in Nebraska law?

Terminal condition is defined in quite different ways in the Nebraska statutes. In the statute governing living wills, it is defined as:

an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time [Nebr. Stat. 20-403(11)].

However, in the statute on health care powers of attorney, it is defined as:

an incurable and irreversible medical condition caused by injury, disease, or physical illness which, to a reasonable degree of medical certainty, will result in death regardless of the continued application of medical treatment including life-sustaining procedures [Nebr. Stat. 30-3402(13)].

If we assume that the “opinion of the attending physician” in the first definition reflects the “reasonable degree of medical certainty” mentioned in the second definition, there remain two important differences.

According to the first definition, a patient is terminally ill if he cannot stay alive without life-sustaining treatment. For example, Nancy Cruzan (see § 7.1) was terminally ill because she would – and did – die when the ventilator was removed. But according to the second definition, she was not terminally ill because the ventilator appeared to be an effective means of keeping her alive. According to the second definition, a patient is terminally ill only if all life-sustaining treatments have become ineffective.

The second difference between the two definitions lies in the limiting time factor mentioned by the first definition: “within a relatively short time.” The statute does not specify what that means: two weeks, six months, one-and-a-half year? No such time limit is stipulated by the second definition.

Finally, Section 71-7802 defines the terms that are used in the *Hospice Licensure Act*. The section does not define “terminal illness” but it does define a “hospice patient” to be:

a patient who is diagnosed as terminally ill with a medical prognosis that his or her life is six months or less if the illness runs its normal course and who with informed consent is admitted into a hospice program [Nebr. Stat. 71-7802(5)].

It is unclear how exactly this definition should be read. Is the statement “with a medical prognosis that his or her life is six months or less if the illness runs its normal course” an explanation of “diagnosed as terminally ill,” or should these be read as different patient characteristics, both of which must apply before a patient can be a hospice patient?

One reason to suspect that “terminally ill” should be read to mean exactly the same as “with a medical prognosis that his or her life is six months or less if the illness runs its normal course,” is the definition used by the Federal Health Care Financing Administration in the context of hospice care. The Code of Federal Regulations defines “terminally ill” as:

the individual has a medical prognosis that his or her life expectancy is 6 months or less if the illness runs its normal course [42CFR418: Sect. A, § 3].

However, there are many perfectly curable diseases (e.g., pneumonia) that will cause the patient to die within six months if the illness goes untreated and “runs its normal course.” Surely not every patient who has such a disease that could kill him is terminally ill.

2.2.2 How is “life-sustaining treatment” defined in Nebraska law?

The *Rights of the Terminally Ill Act* defines “life-sustaining treatment” as:

any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the process of dying or maintain the qualified patient in a persistent vegetative state [Nebr. Stat. 20-403(5)].

The most problematic aspect of this definition is the phrase “only to prolong the process of dying.” This “process of dying” is not defined by the Act and it is not at all clear to either lay people or health care professionals what exactly this is. Yet the definition hinges on it.

The comparable statute on powers of attorney for health care provides a different definition. It defines a life-sustaining procedure as:

any medical procedure, treatment, or intervention that (a) uses mechanical or other artificial means to sustain, restore or supplant a spontaneous vital function and (b) when applied to a person suffering from a terminal condition or who is in a persistent vegetative state, serves only to prolong the dying process [Nebr. Stat. 30-3402(8)].

This definition contains the same ambiguity as the former one. But it is also more restrictive because it refers only to “mechanical or artificial means.” While “mechanical” is a relatively clear term, “artificial” is not. For instance, this definition evidently applies to mechanical ventilation and to cardiac resuscitation with a defibrillator. But the language suggests it does not apply to manual cardio-pulmonary resuscitation (See also § 2.2.3).

2.2.3 How is “artificial nutrition and hydration” defined in Nebraska law?

Nebraska law does not define this term as such. The statute on powers of attorney for health care defines “the usual and typical provision of nutrition and hydration” as “delivery of food and fluids orally including by cup, eating utensil, bottle or drinking straw” [Nebr. Stat. 30-3402(14)]. The statute also states that this kind of provision of nutrition and hydration is not a life-sustaining measure as defined in the statute, that is, not an artificial means of sustaining a vital function [Nebr. Stat. 30-3402(8)].

Given these two definitions, one can reasonably deduce that artificial nutrition and hydration is best defined as: Any delivery of nutrition or hydration that is *not* provided and consumed orally by cup, eating utensil, bottle or drinking straw and other such usual and typical means of consuming food and drink. Any feeding by tube or IV that bypasses the mouth, hence, qualifies as artificial nutrition and hydration.

2.2.4 How is “palliative care” defined in Nebraska law?

The *Hospice Licensure Act* defines palliative care as:

treatment directed at controlling pain, relieving other physical symptoms and emotional symptoms, and focusing on the special needs of the hospice patient and hospice patient’s family as they experience the dying process rather than treatment aimed at cure or prolongation of life [Nebr. Stat. 71-7802(7)].

2.2.5 How is “death” defined in Nebraska law?

For many centuries the medical criteria used to determine when a person was dead remained virtually unchanged. When heartbeat and respiration permanently ceased, the patient was pronounced dead. Common law quite naturally adopted the same heart-lung criteria for identifying the moment of “legal” death. With the aid of modern sophisticated medical equipment, however, it has become possible for the human heart to go on beating, and the lungs to continue contracting and expanding for days or even weeks after the brain has entirely ceased to function. This medical development has led to the concept of “whole brain death.” It is assumed that

some brain function is necessary for a person to be alive. Conversely, when all brain function has ended, the person must have died.

Nebraska Law follows the federal *Uniform Determination of Death Act* and hence accepts both the traditional cardio-pulmonary criterion of death as well as the more recent brain death criterion. Section 71-7202 determines that death has occurred when an individual has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem.

3. DECISION-MAKING

3.1 INTRODUCTION

The history of medicine and health care has been a history of silence. In their training, physicians were instructed not to share the diagnosis with the patients and to make all decisions for their patients. Only in the 20th century did a new model for the relationship between care provider and patient emerge. Instead of a paternalistic model, in which the physician behaved like a father does towards his child, a cooperative model arose. The care provider and the patient now are expected to be partners in the healing process. This new model has led to the development of a large number of new patient rights that should guarantee that patients are, indeed, partners in the healing process. For example, patients now have a right to be informed about their care, to review their own medical records and to refuse medical interventions they do not want to undergo.

In this section we will examine the current rules and rights that govern the decision-making process. We will first look at the competent patient, that is, the patient who has the capacity to participate in the decision-making process about his or her own health care. Next, we will examine how decisions should be reached when the patient is not able to participate in the decision-making process. Finally, we will look at the role of the care provider in this process.

3.2 TREATMENT OF COMPETENT PATIENTS

3.2.1 Should I assume that the dying patient is incompetent or competent?

Competent. Unless the patient is a minor, the law assumes that patients are capable of participating in the decision-making about their own health care. This is a fundamental change from the history of medicine in which patients were assumed incompetent. For more than 2,000 years, it was thought that illness and pain clouded patients' minds. Revealing the diagnosis, it was believed, could easily lead patients to give up hope. So physicians were taught to make virtually all decisions

for their patients. Today, all adult patients in principle must be assumed competent (see § 3.3) for a discussion of the definition and determination of incompetence).

3.2.2 What about children?

Children/minors do not have the legal capacity to consent to or refuse treatment. The age of adulthood for medical matters differs from state to state. In Nebraska, the age of majority is relatively high: 19 (although younger persons who are or have been married are considered adults). Minors are legally incompetent to decide about their own health care and consent to proposed medical treatment (except for certain specified exceptions such as drug and alcohol treatment and treatment for sexually transmittable diseases). Nevertheless, minors should be involved as much as possible in the decision-making process, particularly if the child is older, for the minor is the patient.

3.2.3 Doesn't sickness and pain render the patient incompetent?

Not necessarily. In section 3.3 we will discuss when a patient is incompetent and how decisions about the care of those patients can be made. It is important, however, to emphasize that as a rule an adult patient should be assumed competent. The fact that the patient is in pain, sick, anxious, depressed, terminally ill, suicidal, or dying does not *automatically* render the patient incompetent.

3.2.4 What role does the family play in the decision-making while the patient is still competent?

Legally, none. Unless a patient is a minor or has been determined incompetent, there are only two people who can claim a legal right to participate in the decision-making process: the patient and his or her health care provider. Physicians and other health care providers generally have no obligation to contact or seek the input of family members or the patient's next of kin in such situations. The patient's right to informational privacy, in fact, prohibits the physician or other provider from discussing a patient's case with any third party without the patient's consent. The patient can invite family members into the decision-making process, but the family members cannot legally claim a right to be informed about the competent patient's diagnosis or to make decisions about the competent patient's medical treatment. (For more details about patient privacy protection, consult the federal HIPAA regulations that were adopted in 1996).

The Patient’s Right to Consent

3.2.5 Where does the patient’s right to consent come from?

One of the most important medical-ethical principles nowadays is the principle of respect for patient autonomy. This principle was adopted from the world of politics. The Founding Fathers of the United States of America recognized that power to govern comes from the citizens. A government is legal only if the people consent to, i.e., can freely choose their own governors. Or in the words of Justice Brandeis: “The makers of our Constitution ... conferred the right to be let alone.” [*Olmstead v. United States*, 277U.S. 438, 478 (1928), Brandeis, J., dissenting].

In the 20th century, this political principle was applied to the world of health care as well: Competent patients may not be forced to undergo medical treatment, even if such treatment is presumably in their own best interests. Patients must freely choose, i.e., consent to undergo such treatment. The Courts have long recognized a person’s right to accept or reject proposed medical treatment. In 1914, Justice Cardozo made the famous statement that “every human being of adult years and sound mind has the right to determine what shall be done with his body.” [*Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 105 N.E. 92 (1914)]. In the words of the Supreme Court that decided the famous Nancy Cruzan case: “the patient generally possesses the right not to consent, that is to refuse treatment”(see § 7.1).

VERBAL VS. WRITTEN CONSENT

Patients do not have to grant consent in writing. Conversely, a competent patient can verbally withdraw an earlier consent for treatment.

This means, for example, that if a competent patient states she no longer wants to be ventilated or resuscitated, such a verbal directive invalidates any previous oral or written consent to such treatment.

3.2.6 Do I have to get consent or can I begin treatment as long as the patient doesn’t refuse?

Unless an emergency exists, always get consent. Although the right to consent essentially is a right to refuse treatment, it is not up to the patient to refuse. It is often thought that a physician can treat until the patient refuses. But this is legally incorrect. Rather, no treatment can legally be initiated unless and until the patient explicitly consents to the proposed treatment (except in an emergency situation; see § 3.2.8).

3.2.7 Surely, it is better to treat a patient without the patient’s consent than to let harm come to the patient?

No. From a legal perspective, any medical treatment that is provided against the patient’s wishes, or even without the patient’s consent, may amount to civil or criminal battery. In the words of Justice Cardozo, “a surgeon who performs an operation without his patient’s consent commits an assault” [*Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 105 N.E. 92 (1914)]. Even treatment that is competently performed and appears to have taken care of the patient’s medical need can be harmful to the patient, simply and merely because the patient

EXPLICIT VS. IMPLIED CONSENT

Consent need not be obtained for every separate aspect of proposed medical interventions. For example, if a patient grants consent for a laboratory examination of her blood, this consent *implies* consent to the drawing of the blood as well as the individual tests to be performed. Conversely, the consent to undergo surgery does not imply consent for anesthesia since anesthesia carries its own risks. The patient must be informed about these risks and grant explicit/express consent for the anesthesia.

LEGAL NOTE

Note that the mere failure to obtain informed consent under Nebraska law does not in itself constitute grounds for recovery of damages for professional negligence. It must be proven the patient would not have undergone the treatment and, hence, not have suffered the injury, had she been properly informed. The lack of informed consent must be the proximate cause of the injury and the damages claimed [Nebr. Stat. 44-2820]. However, failure to obtain informed consent may create liability for an intentional tort (e.g., battery or assault).

had not consented to it (for an exception, see § 3.2.8).

3.2.8 Can I provide emergency care without the patient’s consent?

Yes. An exception to the obligation to obtain a patient’s “express/explicit consent” arises in the case of an emergency. If the delay in treatment necessary to obtain the patient’s consent would likely result in significant harm to the patient, the physician may proceed to treat the patient. Similarly, if the patient is unconscious or otherwise unable to consent and the treatment must be given immediately, the physician need not wait until the family or guardian has been contacted. In such emergency situations, the physician may treat on the basis of a “presumed consent.” (for a more detailed discussion of presumed consent in emergency situations, see § 3.4).

3.2.9 Do I have to get the patient’s consent in order to continue treatment?

Yes. Medical treatment can only be given with the patient’s consent. Generally it will be both morally and legally wrong to force medical treatment onto the patient. In the absence of a court order requiring treatment, it is unlawful to administer medical treatment when such treatment goes against the wishes of the patient. Whenever the health care provider is not sure whether the patient (still) wishes the care, it behooves him/her to explicitly ask. This evidently has to happen before care can be initiated. But one can easily think of other situations where doubt can arise. For example, the treatment doesn’t work as well as expected or the side-effects turn out to be much more burdensome than predicted. Even the simple fact that treatment has been going on for a long time may have caused the patient to change his/her wishes.

**IMPLIED VS. PRESUMED
CONSENT**

Sometimes, this form of consent in medical emergencies is called “implied consent.” However that use of the term “implied consent” is confusing since there is no act on the part of the patient “implying” consent. The consent is simply presumed by the care givers.

The term “implied consent” is better reserved for consent to components of a more comprehensive intervention to which the patient has already consented (see Text Box on p. 16).

Whenever treatment is not (or is no longer) in accordance with the patient’s wishes, it may become a form of battery. Health care providers, hence, should regularly check with the patient whether the patient wishes the treatment to be continued (see also § 3.2.11).

3.2.10 Can the patient refuse life-saving and life-sustaining treatments?

Yes. The right of self-determination included the right to refuse even “life-saving surgery” [*Natanson v. Kline*, 186 Kan. 393, 350 P.2d 1093 (1960), *clarified*, 187 Kan.186, 354 P.2d 970 (1960)]. In other words, a patient can refuse any and all medical interventions, even if the result is a serious risk to life or health, or even death [Gosfield 2000, Vol. 1, p.8-11, § 8:9; see also *Lasley v. Georgetown Univ.*, 842 F. Supp. 593 (D.D.C. 1994)]. Except in emergency situations (see § 3.2.8), patient consent must be obtained for life-saving and life-sustaining treatments as well.

3.2.11 Can the patient refuse life-sustaining treatment that has already been started?

Yes. In principle there is no difference between refusing a proposed treatment that has not yet begun, or refusing treatment that has already begun. A patient can refuse both. Conversely, the health care provider needs the consent of the patient both to initiate and to continue treatment (see also § 3.2.9). In other words, a health care provider should not ask the patient for permission to withdraw life-sustaining treatment (e.g., the artificial feeding tube or the ventilator). Instead, the health care provider should periodically discuss these interventions with the patient to make sure that the patient still desires their continuation.

3.2.12 Do I have to continue treating the patient when the patient rejects my treatment recommendation?

Yes. If a patient refuses certain medical interventions, even those that have been initiated, the physician cannot abruptly stop caring for the patient and immediately terminate the therapeutic relationship. The physician cannot force the patient into consenting by threatening to abandon the patient. The physician can terminate the relationship with reasonable notice.

3.2.13 I know the patient can refuse any and all treatments I have to offer.

Can the patient also demand treatment from me?

No. Both the patient and the physician must agree about the treatment plan. For example, a Jehovah’s Witness patient can refuse blood transfusions, but cannot demand that a surgeon perform a complicated heart surgery without the use of a transfusion. Likewise, a terminally ill patient cannot refuse any and all proposed pain medications until the physician has only narcotics left – and then insist that the physician prescribe narcotics.

The competent patient can refuse any treatment, but not demand just any treatment. According to Federal law, the patient’s right to request or refuse treatment "must not be construed as a mechanism to demand the provision of treatment or services deemed medically unnecessary or inappropriate." [Code of Federal Regulations, Chpt. 42, Sect. 482.13: Patients' Rights, §2].

The Right to Information

3.2.14 What happens if the patient consents to a treatment, but has not been adequately informed?

The consent is invalid. The right to decide is useful only if you know what you are deciding. But patients generally know little about medicine. Unless the health care provider explains the diagnosis and treatment options, a right to decide is rather useless. In other words, even if a patient consents to the proposed treatment, that consent could still be invalid if the patient was not given sufficient information about the treatment.

3.2.15 What kinds of information must be given?

The patient must receive all the information that is relevant for him or her to make a wise decision. At a very minimum, that includes information about:

- a. the diagnosis;
- b. all treatment alternatives that are feasible and acceptable from a medical perspective;
- c. the risks and benefits of these alternatives, including financial aspects;
- d. the prognosis for each of these alternatives;

- e. the consequences if the patient refuses each of the alternatives.

The patient should also be given the opportunity to ask questions.

3.2.16 How much information must be given?

It is practically impossible for a health care provider to share all he or she knows with the patient. This raises the question how much information must be given to the patient? Ethically, the answer would be: all that is relevant to or needed by the patient. However, for legal purposes this is too vague. How much information must be given legally differs per state. Some states insist that the physician share all information that “any other reasonable patient” would want to receive. However, Nebraska still abides by the so-called “competent professional” standard.

Nebraska’s *Hospital-Medical Liability Act* defines informed consent to mean consent to a procedure based on information which would ordinarily be provided to the patient under like circumstances by health care providers engaged in a similar practice in the locality or in similar localities [Nebr. Stat. 44-2816; see also *Smith v. Weaver*, 225 Neb. 569, 573-74, 407 N.W.2d 174, 178 (1987) and *Eccleston v. Chait*, 241 Neb. 961, 968-69, 492 N.W.2d 860, 865 (1992)].

3.2.17 Can the patient demand access to his/her own medical records?

Yes. Not only do patients have the right to be informed by their health care providers, they also have the right to review the medical records that pertain to them personally and obtain copies [Nebr. Stat. 71-8403].

Nebraska law specifies that “patients need access to their own medical records as a matter of fairness to enable them to make informed decisions about their health care and correct inaccurate or incomplete information about themselves” [Nebr. Stat. 71-8401].

3.2.18 Can anyone else claim a right to information about the patient?

Nebraska law grants each patient the right to confidentiality [Nebr. Stat. 27-504]. The care provider should discuss with the patient whether (s)he wants to grant other people (e.g., family members) access to information regarding the diagnosis or treatment of the patient’s physical, mental, or emotional condition. A note of the patient’s decision should be made in the patient’s record (see also § 6.3.2).

3.3 TREATMENT OF INCOMPETENT PATIENTS

In the foregoing sections, we have discussed the rights of the competent adult to participate in the decision-making process regarding his/her own health care. Many patients, however, are not capable, or are no longer capable of participating such that their decisions are truly autonomous. If health care providers were to abide by the wishes of a seriously demented patient, a trauma victim in shock, or a cancer patient with severe, as-of-yet uncontrolled pain, the health care provider might well end up harming the patient.

Incompetence

3.3.1 How is incompetence defined?

When a patient is unconscious, severely mentally handicapped, highly intoxicated, or for any other reason incapable of making any decision at all, he is clearly incompetent. However, if the patient has some understanding of what is happening around him, but his judgment is clouded by factors such as fear or mental or physical illness, the analysis becomes more difficult.

Unfortunately, there is no agreement about the exact nature of and criteria for establishing competence. The legal, medical and ethical literature is replete with different definitions. Even the vocabulary is confusing, for some prefer the term “capacity” over “competence.” (The term “capacity” is sometimes reserved to refer to the clinical condition of the patient, whereas “competence” denotes the legal status, but there is no consensus about this use of the terms).

Nebraska law does not define competency either, at least not clearly so. The *Rights of the Terminally Ill Act* merely refers to being “of sound mind” [Nebr. Stat. 20-404] and “able to make decisions regarding the administration of life-sustaining treatment” [Nebr. Stat. 20-405]. The Health Care Power of Attorney statute defines “incapable” as “the inability to understand and appreciate the nature and consequences of health care decisions, including the benefits of, risks of, and alternatives to any proposed health care or the inability to communicate in any manner an informed health care decision” [Nebr. Stat. 30-3402(7)].

A generic definition is provided by the *Nebraska Short Form Act*: “Incompetence shall mean disability or incapacity of any principal as ascertained, determined, or established by applicable provisions of the Nebraska Probate Code or by applicable provisions of a contingent durable power of attorney or a present durable power of attorney” [Nebr. Stat. 49-1513]. But this definition does not *actually* tell us what incompetence means.

The most extensive definition is found in the statute concerning the protection of disabled persons. It defines an “incapacitated person” as “any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability,

PRACTICAL GUIDELINES FOR DETERMINING INCOMPETENCE

1. The initial determination of a patient's capacity to make health care decisions is made by the treating physician. Although “competence” is a legal standard, it is the physician who applies that standard in the vast majority of cases. Every time a physician obtains consent from a patient, the physician, in effect, has decided that the patient is mentally able to consent. In most situations, the patient's mental capacity or lack thereof is clear, and nothing further is required.
2. When the physician has doubts about the patient's comprehension and capacity to make health care decisions, the physician's next step should be to obtain a consultation from another physician with appropriate expertise. A judgment by someone not directly involved in treating the patient gives the appearance of greater objectivity and may insulate the treating physician from later charges that a conflict of interest or bias affected his or her determination. If the patient's judgment is clouded by factors such as drugs or infection, an attempt should be made to remove the impediment before proceeding.
3. If it is still not possible to determine whether the patient has capacity, the general rule is that the issue should be referred to a court for determination. As a practical matter, however, if the patient is agreeing to the procedure or expressing no opinion, the physician can simply obtain consent from whichever surrogate would make the decision if the patient were incompetent. If no surrogate is available, or if the patient is objecting to treatment and his or her capacity is unclear, guidance must be obtained from a court [Macdonald, § 18.05[3], p. 18-58].

chronic use of drugs, intoxication, or other such cause (except minority) to the extent that the person lacks sufficient understanding or capacity to make or communicate responsible decisions concerning himself or herself” [Nebr. Stat. 30-2601(1)].

Although this definition is extensive, it contains some problematic terms. For example, what is meant by a “responsible decision”? Who decides whether the decision is responsible? The attending physician? But that would mean that any patient who makes a decision that the attending physician deems irresponsible (e.g., to refuse artificial ventilation) thereby proves himself to be incompetent. Such an interpretation of Section 30-2601(1) would undermine the very purpose of the patient’s right to respect of his/her autonomy. Indeed, a patient’s *actual* decision should not determine the patient’s competence to make decisions (see also § 3.3.5, 3.3.6).

3.3.2 Should I assume that a dying patient is competent or incompetent?

A patient is competent unless and until determined incompetent. The only patient who is generally incompetent by law is a minor (see § 3.2.2).

3.3.3 If a patient is incompetent to handle his finances, is (s)he automatically incompetent to decide about health care as well (and vice versa)?

No. Competence is specific to the decisions to be made. That is to say, a person may be incapable of managing his financial affairs. There may even be a court appointed guardian to manage the patient’s financial assets. Nevertheless, that person may be competent to make decisions about his or her health care. The reverse is true as well. The fact that a patient is deemed incompetent to make decisions about his/her health care does not imply incompetence for any other purpose [Nebr. Stat. 30-3416].

3.3.4 How is a patient’s incompetence assessed?

Nebraska’s law governing powers of attorney for health care sets certain requirements for the determination of incompetence [Nebr. Stat. 30-3412]:

1. The determination shall be made in writing by the attending physician; indeed the attending physician shall regularly check that the patient continues to be incompetent [Nebr. Stat. 30-3419(1)];
2. A second consulting physician must confirm the initial determination of incompetence;
3. Neither of these two physicians may be the patient’s agent holding the power of attorney [Nebr. Stats. 30-3406(1) & 3412(1)].
4. Both physicians must document in the patient’s record their findings stating the cause and nature of the patient’s incapacity.

In contrast, the Nebraska statute on living wills requires only the attending physician to determine the patient incompetent, triggering a transfer of decision-making authority [Nebr. Stat. 20-405]. No second physician is required.

Unfortunately, neither statute provides criteria for the actual assessment of (in)competence. This void reflects a wide-spread lack of agreement among lawyers, ethicists and clinicians regarding how patient decision-making competence should be assessed.

A generic test for decision-making competency is as follows: Is the individual, though possibly senile, impaired, or mentally ill, able to:

- (i) understand the elements of an informed consent (see § 3.2.15),
- (ii) memorize and process relevant information;
- (iii) reach a health care decision freely; and
- (iv) and is that person able to articulate his or her decision? [Welie & Welie 2001]

In some cases where competency is in question, it may be necessary to obtain a judicial determination of competency [Nebr. Stats. 30-3415 & 3417(5)].

3.3.5 If a patient refuses life-sustaining treatment, doesn't that prove that (s)he is incompetent?

No. When assessing a patient's competence, the *actual* decision by the patient is not decisive, but the patient's ability to reach decisions and/or the process by which the patient reaches decisions is. Yet it routinely happens that the patient's decision drives the competency assessment. Few physicians will question a patient's competence when the patient agrees with the physician's own proposal. Yet the fact that a patient agrees does not itself prove she is competent. Physicians generally will only question a patient's competence when the patient refuses treatments proposed and advocated by the physician. But again, the fact that a patient refuses life-saving treatment or other interventions that are medically indicated does not *itself* render the patient incompetent.

Several court decisions regarding competence have made clear that the law is increasingly reluctant to deprive a patient of the right to consent or to "second guess" the appropriateness of his or her decision. Basically, if the patient understands what is being asked, and if the patient knows the nature of the proposed treatment and the consequences of his or her

INCOMPETENCE AND REFUSAL OF TREATMENT

The attitude that the law takes towards the determination of mental capacity to consent is illustrated by a Massachusetts case. In *Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978), physicians wanted to amputate a gangrenous leg from a 77-year old diabetic. Mrs. Candura refused to consent stating that she had no wish to live as an invalid or in a nursing home. Her daughter filed a petition seeking appointment as a temporary guardian with authority to consent to the operation on behalf of her mother.

The trial court found that although Mrs. Candura was depressed and had periods of confusion and a distorted sense of time, she clearly appreciated the consequences of her decision, including the hastening of her death. Nonetheless, the trial court found Ms. Lane incompetent under a reasonableness of the decision standard.

The appellate court reversed, stating: "[t]he irrationality of her decision does not justify a conclusion that Mrs. Candura is incompetent in the legal sense. The law protects her right to make her own decision to accept or reject treatment, whether that decision is wise or unwise" [*Id.* at 1235-36]. The court found that since Mrs. Candura had the capacity to make a decision and to understand its consequences, she was legally competent.

decision, the patient will be considered competent. This conclusion may be reached despite the fact that the decision is not one that most persons would reach or appears irrational to family members or health care providers.

Legal Consequences of Incompetence

3.3.6 What are the legal consequences of incompetence for the patient?

If a patient is incompetent, it means that (s)he is not, or is no longer, capable of making health care decisions. The authority to make such decisions is transferred to someone else.

3.3.7 If a patient is incompetent and legally cannot give consent, can I now treat without an informed consent?

No (except in emergencies). If a patient has been determined to be incompetent, it means the patient cannot grant consent to proposed treatments. As stated earlier (see § 3.2.6), medical treatment may not be provided without the consent of the patient. Except in medical emergencies, all medical interventions require the explicit consent, *prior to* treatment, by the patient him- or herself (or when appropriate the legally recognized surrogate decision-maker).

The health care provider cannot justify his/her initiating treatment simply because the patient does not refuse. Rather, since the patient is incompetent to consent, the physician must obtain consent from the authorized surrogate decision-maker. In the subsequent paragraphs, we will review how such consent can be obtained.

3.3.8 If a patient is incompetent and refuses treatment, can treatment be forced onto the patient?

Yes, but only under certain circumstances.

We have seen that a competent patient has the right to refuse treatment. But this statement does not tell us anything about the right of incompetent patients to refuse treatment. What should the health care provider do if an incompetent patient resists or protests against the medical treatment that is being provided? Can

an incompetent patient be forced to undergo medical treatment once consent for such treatment has been obtained elsewhere?

This thorny dilemma continues to be the source of much bioethical and legal debate. However, Nebraska law provides a clear answer. It allows for such forced medical treatment if it is administered by a physician or therapist (or a person assisting that care provider at his or her direction) and such force is used for the purpose of administering a recognized form of treatment which the health care provider believes to be adapted to promote the physical or mental health of the patient [Nebr. Stat. 28-1413(3)]. Of course, such force may only be applied in a medical emergency or if consent has been obtained from a person legally authorized to grant it (see below).

Obtaining Consent for the Treatment of Incompetent Patients

3.3.9 If a competent patient consents, and then becomes incompetent, can I still treat on the basis of that consent?

Yes. If a patient consents to a particular treatment or refuses it, that decision has a lasting effect. For example, consider a patient with uncontrollable pain who wants to be sedated. Once the drugs are administered, the patient loses consciousness and is no longer competent to make decisions. However, the physician can continue the sedation based on the initial consent by the patient. The reverse is true as well. If a patient has refused treatment, and then becomes incompetent, that refusal has a lasting effect.

In rare instances, problems could arise. Bioethicist James Childress has described a case of a competent patient with end-stage-renal disease who, upon very careful consideration, refused further dialysis. However, as the toxic substances accumulated in his body, he became delirious and begged to be dialyzed again. What should the physician do? The physician in the case decided to abide by the request made while the patient was still competent, rather than the new request which was not reached competently [Childress 1982, p. 224-25].

Of course, a consent once given does not remain valid forever. As pointed out earlier (§ 3.2.9) health care providers should verify at appropriate intervals that the patient still wishes to be treated. But this becomes impossible when the patient has

lost his/her competence. At some point into the treatment, the health care providers will have to obtain consent from a source other than the patient, to justify continuation of that treatment.

3.3.10 How can I obtain consent for treatment of an incompetent patient?

Except for the scenario described in § 3.3.9, the health care provider will need to obtain consent from some other source if the patient is incompetent to grant that consent. In a nutshell, there are three methods for obtaining that consent:

- (i) The patient may grant or withhold consent in advance of becoming incompetent. This is usually called a “living will.”
- (ii) A person other than the patient steps into the patient’s place and ascertains what the patient would have decided if the patient had still been competent. This is usually called a substituted judgment by surrogate or proxy.
- (iii) If there is no living will and it is unclear what the patient would have chosen had the patient still been competent, the authorized surrogate decision-maker, in consultation with health care providers and family members, will try to determine what is objectively beneficial to the patient, a so-called best interest judgment.

There is a lot of debate among bioethicists and health lawyers about the advantages and pitfalls of each of these sources. But it is generally believed, and particularly by the courts, that advance directives are the best decision-making mechanism and best-interest judgments are the worst alternative.

3.4 PRESUMED CONSENT IN EMERGENCY SITUATIONS

3.4.1 What about medical emergencies? If the patient is incompetent and cannot consent, does that mean I cannot treat?

No, emergency treatment can be administered. An exception to the requirement of a patient’s express consent arises in the case of an emergency. If the delay in treatment necessary to obtain the patient’s consent would result in significant harm

to the patient, the health care provider may proceed to treat the patient on the basis of a so-called presumed consent.

Presumed consent can also be invoked if the patient is unconscious or otherwise unable to consent any time soon, and the treatment must be given immediately to prevent significant harm, particularly if such harm will be irreversible. In such instances, the health care provider need not wait until the family or guardian has been contacted.

Similarly, it is generally held that if an unanticipated condition arises during surgery, the surgeon may proceed to treat that condition rather than require the patient to face the risk and inconvenience of a second surgical procedure, provided it is the surgeon's professional judgment that the condition requires attention and the additional treatment can be accommodated in the operation already begun [MacDonald et al, *Health Care Law*, § 18.02[b]].

However, a presumed consent can only be invoked if the patient is incompetent and there is no other source of consent. If there is time to speak to the patient, if the patient regains consciousness, or if the legally authorized surrogate decision-maker (see § 3.5.5) arrives in the emergency room, express consent must be obtained from the patient or the patient's agent.

3.4.2 What if I have initiated emergency treatments on the basis of a presumed consent; but the patient regains competence and now refuses those treatments?

Treatment must be halted. A presumed consent is valid only as long as the patient is incompetent and there is no other source of consent. As soon as the patient regains competence (or the legally authorized surrogate decision-maker arrives), consent no longer may be presumed. Instead, the health care provider must obtain consent from the competent patient (or her surrogate decision-maker). If the patient (or the surrogate) refuses consent for the treatments already initiated on the basis of a presumed consent, those treatments must be discontinued.

3.4.3 What about ambulance personnel? Must they always presume consent for resuscitation and life extending interventions?

This is not fully clear. Nebraska's *Emergency Medical Services Act* [Nebr. Stats. 71-5172 to 71-5194] was enacted to insure the optimal provision of emergency medical care. Unfortunately, the Act contains very little information about the issue of consent.

One section suggests that a patient who objects to emergency medical treatment on religious or other grounds cannot be forced to undergo such treatment or to be transported to a hospital [Nebr. Stat. 71-5193]. The question is, of course, what is meant with "objects to." If a competent patient explicitly declares she does not want to be treated or transported, that would most assuredly qualify as an objection under this Act.

Most problematic is that nothing is said about objections voiced in the patient's living will (see § 3.5.4, 3.5.16) or by the authorized surrogate decision-maker (§ 3.5.5). On the other hand, nothing in the statutes on living wills and on powers of attorney suggests that these advance directives would not apply to medical emergencies. In fact, both suggest they apply to any and all licensed health care providers [Nebr. Stats. 20-403(4), 20-405(4) & 30-3402]. Since no exceptions are made for medical emergencies, advance directives would equally apply in those situations.

3.5 ADVANCE DIRECTIVES

3.5.1 What is an advance directive?

An advance directive is a written statement which reliably shows that a patient has made certain arrangements regarding future health care *in advance of* becoming incompetent. This statement is first and foremost directed at the health care providers, hence the name advance *directive*. However, it is not a "directive" in the sense of "demand." As outlined earlier, a patient can refuse any and all medical interventions, but cannot demand medically inappropriate interventions from the health care provider. Health care providers are only obligated to provide treatments that are medically indicated (see also § 3.2.13). An advance directive is a mechanism

to preserve a patient’s right to accept or refuse medical treatment if the patient is ever mentally or physically unable to choose or communicate his or her wishes.

3.5.2 What kinds of advance directives are there?

Nebraska law recognizes two types of advance directives, the “living will” (see § 3.5.4, 3.5.16) and the “durable power of attorney for health care” (see § 3.5.5).

3.5.3 What is the history behind advance directives?

Modern advance directives have many different and diverse historical predecessors. This also means that legal instruction regarding advance directives has ended up in different statutes. The sections governing living wills are found in Nebraska’s Revised Statutes, Chapter 20 on Civil Rights, Article 4. However, the sections concerning powers of attorney are found in a totally different chapter, that is, in Chapter 30 on Decedents’ estates; protection of persons and property, Article 34.

Because Nebraska has defined and regulated living wills in the *Rights of the Terminally Ill Act*, a Nebraska living will only becomes operative once the patient has become incompetent *and* is in a terminal condition or persistent vegetative state. There is no such additional restriction placed upon a Nebraska power of attorney for health care.

From a theoretical perspective, advance directives are not restricted to end-of-life care situations. They are simply meant to provide competent patients the option of *directing* their own health care *in advance of* becoming incompetent. While that health care may be end-of-life care, it need not be so. Indeed, some laws, such as the 1990 Federal *Patient Self-Determination Act* (PSDA), do not restrict advance directives to end-of-life care situations.

3.5.4 What is a “living will”?

The living will is one type of an advance directive (see § 3.5.1). It is a written statement that spells out what kinds of (end-of-life) health care the patient would (or would not) like to receive under certain specified circumstances.

The living will is analogous to a will (or testament) written by a person to determine how the inheritance should be allocated after death. The main difference is that a

living will pertains to the health care of the still *living* person. Furthermore, a regular will can cover almost any issue whereas the living will is specific to health care matters.

Nebraska adopted a set of statutes governing living wills in 1992, called the *Rights of the Terminally Ill Act* [Nebr. Stats. 20-401 to 20-416]. The Act grants patients the right to write a living will and requires health care providers to abide by that will. However, the Act only concerns declarations governing the withholding or withdrawal of life-sustaining treatment [Nebr. Stat. 20-404]. It is not clear whether this means that living wills in which certain forms of treatment are consented-to in advance, rather than refused, have no binding power in Nebraska. The Act simply does not consider such declarations.

The Act also provides a draft form, but the living will does not have to be written in that particular format in order to be valid [Nebr. Stat. 20-404(2)].

3.5.5 What is a “durable power of attorney for health care”?

A competent adult can authorize another person to act on his or her behalf, that is, to function as his or her “attorney.” For example, one may grant one’s friend the “power of attorney” to sell one’s car. Likewise, Nebraska law [Nebr. Stats. 30-3401 to 30-3432] enables each competent patient (called the “principal”) to grant another adult the “power of attorney” to make health care decisions on the patient’s behalf should the latter become incompetent to do so. The person designated by the patient to make health care and medical treatment decisions on his or her behalf is given the same powers the patient may have or could enforce on his or her own behalf.

Unlike many other powers of attorney that pertain to a one-time event only (such as the sale of a car), the power of attorney for health care typically is durable. It “endures” or continues until the patient has either revoked the directive or died [Nebr. Stat. 30-3410].

The “durable power of attorney for health care” qualifies as an advance directive, because it has to be written by the patient in advance of becoming incompetent [Nebr. Stat. 30-3411]. It only becomes operative when the patient has become incompetent and remains operative only as long as the patient is incompetent.

The Act also provides a draft form, but the power of attorney does not have to be written in that particular format in order to be valid [Nebr. Stat. 30-3408(1)].

3.5.6 If my patient wants to write an advance directive and asks my advice, should I recommend a living will or a power of attorney?

It is difficult to say because of several difference between these two types of advance directives.

As pointed out earlier, in principle both living wills and powers of attorney are strategies by which the patient can express his/her wishes in advance of becoming incompetent. Each strategy has advantages as well as disadvantages.

For example, one advantage of a living will is that the patient can specify what kinds of treatments (s)he does or does not want to undergo in certain circumstances. The problem is that it is so difficult to predict the future; the patient’s circumstances and conditions at the time a living will is implemented are seldom the same as when the living will was drafted. When creating a power of attorney, there is no need to predict the future; all one needs is a trusted individual. The disadvantage here is that the patient does need such a trusted individual who will be able to make good decisions on the patient’s behalf. Neither strategy is perfect.

However, there are some additional limitations to consider because of Nebraska’s dissimilar laws on living wills and powers of attorney. In Nebraska, a living will is of use only if the patient wants certain treatments to be *withheld or withdrawn* [Nebr. Stat. 20-404(1)]. The statute does not say anything about *consenting to* treatments in advance. Moreover, the living will only applies to situations in which the patient is “in a terminal condition or in a persistent vegetative state” [Nebr. Stat. 20-405(2)].

Under Nebraska’s laws, health care powers of attorney can have a much broader reach than living wills. The power of attorney concerns virtually all health care decisions. However, there is a catch as well. If the patient wants her agent to make end-of-life type decisions, specifically forgoing life-sustaining treatments (e.g., a ventilator), the patient must explicitly grant such authority to the agent when she drafts her “power of attorney for health care” [Nebr. Stat. 30-3418(2)]. If the patient fails to do so, the agent cannot be presumed to have the authority to make such life-and-death decisions.

But even if the patient explicitly grants such authority to the agent, that authority can only be exercised by the agent once the patient is “in a terminal condition or in a persistent vegetative state” [Nebr. Stat. 30-3418(2)]. This shows that in end-of-life care situations, the legal differences between the living will and the power of attorney are smaller than in other care situations.

But then again, the definition of “terminal condition” differs in the two statutes. A patient with a living will is considered terminally ill only if (s)he is expected to die “within a relatively short time” [Nebr. Stat. 20-403(11)]. The patient with a power of attorney is not required to die so soon in order to be deemed “in a terminal condition.” No specific time period is mentioned, only that death is inevitable [Nebr. Stat. 30-3402(13)] (for a more detailed discussion of the definition of “terminal condition,” see § 2.2.1). The patient who is worried about a prolonged dying process hence may want to write a power of attorney rather than a living will, or issue both.

3.5.7 What if my patient wants to assign me the power of attorney to make health care decisions on his/her behalf?

A health care provider can be a patient’s agent for health care, but Nebraska law sets certain restrictions. A health care provider *cannot* serve as the patient’s agent if (s)he is:

- (i) the patient’s attending physician;
- (ii) an employee of the attending physician
- (iii) owner/operator of, or employee in a health care facility in which the patient presently resides or has been admitted.

(For some additional restrictions as well as exceptions to these exceptions, see 30-3406).

3.5.8 Can someone write both a “living will” and create a “power of attorney for health care” at the same time?

Yes. Nebraska’s statutes on health care powers of attorney state that the patient’s agent, when making decisions on the patient’s behalf, must abide by the patient’s own instructions set forth in the power of attorney document *or elsewhere* [Nebr. Stat. 30-3417(1) - *emphasis added*]. This means that a patient can either incorporate a

living-will-like directive into the power of attorney document, or write two separate documents. In either case, the patient’s agent would have to consider the stipulations of the living will before making decisions on behalf of the patient.

3.5.9 If a person has both a “living will” and issued a “power of attorney for health care,” but the two are not in agreement, what should I do?

Nebraska law specifies that the power of attorney for health care supersedes any conflicting preexisting directive [Nebr. Stat. 30-3420(5)(a)]. However, it also states that the patient’s agent holding the power of attorney must abide by the patient’s own instructions regarding her own health care [Nebr. Stats. 30-3417(1) & 34-3418(1)(a)]. Unless there is clear evidence that the patient wanted her pre-existing living will set aside, and fully relies on the agent holding the power of attorney, health care providers should be hesitant to follow instructions from a patient’s agent when the patient’s own living will suggests another course of action. Advice of legal counsel should be sought in these cases.

3.5.10 How do I know that a patient’s “advance directive” is valid?

Both the Nebraska statutes on living wills and those on powers of attorney for health care provide a standardized form. However, neither the living will nor the power of attorney has to be written in that particular format to be valid [Nebr. Stats. 20-404(2) & 30-3408(1)].

The requirements for living wills and powers of attorney are largely the same.

1. The advance directive must be written;
2. The patient to whom the directive pertains is identified;
3. The patient was competent when issuing the advance directive (see also 3.5.12);
4. It was signed and dated by the patient (although a living will can also be signed by another person at the direction of the patient);
5. And it is witnessed by at least two adults or a notary public.

In addition, a *power of attorney for health care* must also:

6. Identify the patient’s agent; and
7. Specifically authorize the agent to make “health care decisions” on behalf of the patient in the event the patient is incapable.

3.5.11 What should I do if I am not sure that the advance directive is valid?

Whenever a patient has become incompetent to make health care decisions, yet there is no advance directive available, it behooves the health care provider to involve family members present in the decision-making process. However, if the health care provider has not seen (a copy of) the signed advance directive herself, she is not obligated to abide by the directions of the person claiming to hold the health care power of attorney for the patient [Nebr. Stat. 30-3417(6)]. Although the Act governing living wills does not contain a similar explicit paragraph, one may reasonably assume a health care provider is not required to abide by the alleged stipulations of a hypothetical living will when the living will itself is not available for inspection.

However, once the advance directive has become available for review by the health care provider, (s)he does not have to be certain that it is valid indeed. After all, that may sometimes be very difficult to verify. As long as there is no reason to question the validity of the document, Nebraska law allows the care provider to follow that advance directive [Nebr. Stats. 20-214 & 30-3425].

3.5.12 Can a patient still issue a legally binding advance directive after (s)he has become incompetent to grant or withhold an informed consent?

No. Since an advance directive is itself a form of consent, the same criteria that apply to a regular informed consent apply. Most importantly, an informed consent is valid only if the patient is competent to reach such a decision. The same is therefore true of an advance directive. The patient must be competent in order to issue a legally binding advance directive. As the name indicates, an advance directive should be written in advance of becoming incompetent.

If a health care provider has good reason to believe that the patient was not competent when the advance directive was written or believes it was really written by family members and then signed by the patient while incompetent, the care provider should not act on that advance directive. Legal counsel should be sought instead.

However, in the absence of credible evidence to the contrary, the health care provider should presume that the patient was competent when (s)he wrote the advance directive [Nebr. Stats. 20-413 & 30-3403(2)].

3.5.13 Is an advance directive legally binding on the care provider?

Yes. If properly executed by the patient (see § 3.5.10), an advance directive is binding on all care providers, that is to say, physicians and all other health care providers [Nebr. Stat. 20-405(4)]. (For an exception to this rule, see § 3.5.22.)

No health care provider, whether individual or facility, is required to honor any instruction stemming from an advance directive if doing so would be contrary to deeply held religious or moral beliefs. In such a situation, the health care provider should promptly inform the patient (or the patient’s agent) of this fact and discuss it [Nebr. Stats. 20-404(3) & 30-3428]. If no resolution can be achieved, the health care provider should assist in transferring the patient to another health care provider who is willing to abide by the instructions in the advance directive [Nebr. Stats. 20-409 & 30-3428].

3.5.14 Is an advance directive executed in a state other than Nebraska legally binding in Nebraska?

Yes. Nebraska law recognizes advance directives written in other states [Nebr. Stats. 20-414 & 30-3408(4)]. And the reverse is true as well: A properly executed Nebraska advance directive is legally binding in most other states. However, there are exceptions. Some states may limit what kinds of medical care can be directed by means of an advance directive (an example is the withdrawal of artificially administered nutrition and hydration). Patients who have more than one place of residence or travel frequently may want to obtain expert legal advice.

3.5.15 Should I be worried about additional legal risks when a patient has an advance directive?

No. Both the statutes on living wills and on powers of attorney for health care list a number of penalties for violation of the law. However, most of these have to do with intentional wrong doing on the part of the health care provider, such as coercing a patient to write an advance directive living will, forging of a living will, or concealing a power of attorney.

There is no additional legal risk for the well-intentioned health care provider who wishes to treat the patient optimally and in accordance with the advance directive.

The statute on powers of attorney specifically states that the health care provider who acts in good faith shall not be guilty of a criminal offense [Nebr. Stat. 30-3423(2)]. Similar assurances are given by the statute governing living wills statute [Nebr. Stat. 20-410].

But in addition to these safeguards, there is also the general advice to health care providers (including institutions) not to become overly cautious and legalistic when a patient presents with an advance directive. The *Rights of the Terminally Ill Act* specifically states that the provisions in the act “shall be applied and liberally construed so as to effectuate its general purposes” [Nebr. Stat. 20-416]. In paying attention to the letter of the law, health care providers should make sure its spirit is not thwarted. Although the literal text of a particular living will cannot be ignored, health care providers must make sure that their interpretation of the will is in accord with the intent of that living will as best as can reasonably be determined.

3.5.16 When the patient (or a family member) hands me an advance directive, what do I have to do with the document?

No doubt, it would be advantageous if individuals consult with their (primary) health care providers in the development of an advance directive. However, this often does not happen. If the health care provider has not been consulted by the patient when the advance directive was developed and written, it would be prudent for that health care provider to carefully read and discuss the advance directive with the patient as soon as (s)he receives the document.

Once this is done, the advance directive must be added to the patient’s record. The *Federal Patient Self-Determination Act* (see § 3.5.2) instructs the health care facility to make sure that the advance directive is added to the patient’s record.

3.5.17 When does the advance directive become operative?

An advance directive only becomes operative once the patient has become

CONTINGENT POWER OF ATTORNEY

The durable power of attorney for health care only becomes operative when the patient is incompetent. In other words, it is contingent on the patient’s incompetence. For this reason, the durable power of attorney for health care is a “contingent power of attorney” as defined in Section 49-1511.

incompetent. But this is not the only condition. Depending on the type of advance directive, there are other conditions.

As mentioned, there are two types of advance directives: “living wills” and “powers of attorney for health care.” Nebraska law deals with these two advance directives in two different statutes. Consequently, there are some inconsistencies. One area of inconsistency concerns the commencement of the advance directive.

The law on powers of attorney health care states that these directives become operative as soon as the patient has been deemed incompetent by the attending physician and any physician consulted [Nebr. Stat. 30-3411].

But the law on living wills sets forth as many as four criteria, all of which must be met before the living will becomes operative [Nebr. Stat. 20-405]:

- (i) The living will has been communicated to the patient's attending physician; and
- (ii) The patient is determined by the attending physician to be in a terminal condition or in a persistent vegetative state; and
- (iii) The patient is determined by the attending physician to be unable to make decisions regarding the administration of life-sustaining treatment, and
- (iv) The attending physician has notified a reasonably available member of the patient's immediate family or guardian, if any, of his or her diagnosis and of the intent to invoke the patient's declaration.

The inconsistencies are quite obvious:

- (1) The statutes governing living wills are more restrictive than those governing powers of attorney for health care. Most striking is the fact that a living will only becomes effective when the patient is terminal or in a persistent vegetative state (but also see § 3.5.19).
- (2) Only one physician, the attending physician, is required to deem the patient incompetent for purposes of the living will, whereas two physicians are prescribed by the statutes governing powers of attorney for health care.

3.5.18 If the advance directive states I should not give cardiac resuscitation, but the patient says she wants to be resuscitated, which directive should I follow?

The patient's. An advance directive only takes effect once the patient has become incompetent. Whenever and as long as the patient is competent (i.e., not proven incompetent – see § 3.3.2), the patient is personally in charge; the advance directive has no legal force whatsoever [Nebr. Stats. 20-412(5) & 30-3417(2) & 30-3419].

If the wishes of a competent patient are at odds with the advance directive, this paradox should be discussed with the patient. The patient may have changed his/her mind and forgot to adjust the advance directive. If so, the patient should be urged to change the advance directive.

Note, too, that Nebraska law allows a competent patient to revoke his/her advance directive at any time and in any manner [Nebr. Stats. 20-406 & 30-3420(1)]. As soon as the health care provider learns about the revocation, either from the patient him/herself or from a witness to the revocation, the advance directive is void.

A real dilemma arises when the patient has become incompetent (e.g., due to advanced Alzheimer's disease), but his/her statements and/or behavior makes clear that (s)he is very unhappy with the care provided in accordance with the advance directive.

Nebraska law is not fully consistent where such thorny dilemmas are concerned. The law governing powers of attorney for health care suggests that this advance directive can only be revoked by a competent patient [Nebr. Stat. 30-3420(1)]. However, the law also states that if an incompetent patient protests against the decisions by her agent holding the power of attorney, the patient's own decisions shall prevail unless and until the patient's incompetence has been confirmed by a county court [Nebr. Stat. 30-3417(5)].

The law on living wills gives a different answer. It states that a patient may revoke her living will declaration at any time and in any manner *without regard to the patient's mental or physical condition* [Nebr. Stat. 20-406]. This suggests that an incompetent patient, though lacking legal capacity to issue a new or revised living will, can still legally revoke her living will. When an incompetent patient protests against the treatments provided in accordance with her own living will, that protest could be

interpreted as a revocation of her living will. Given the instructions in the law on health care powers of attorney as described above, it seems legally prudent to respect an incompetent patient's objection to the stipulations of her own living will unless and until the patient's incompetence has been confirmed by a county court (see also § 3.3.8).

3.5.19 Can a patient refuse life-sustaining treatments through an advance directive, such that she will die if those treatments are withheld or withdrawn?

Yes. The purpose of the advance directive is to extend the decision-making rights of a competent patient into the time that the patient has become incompetent. Since a competent patient can legally refuse any and all medical treatment, including artificially administered nutrition and hydration, the patient in principle can do so as well via an advance directive.

The act governing living wills is quite clear that any and all medical treatments that are not necessary for pain relief and regular care can be refused by the patient in her living will [Nebr. Stats. 40-404(1) & 20-408(1) & (2)]. In principle, the law on the power of attorney for health care allows for equally far-reaching refusals. However, the patient must explicitly grant her agent the authority to withhold consent for life-sustaining measures. If the patient has failed to do so, the instruction from the agent to forgo life-sustaining treatment may be followed only if it can clearly be proven in some other manner that the patient intended to grant her agent such authority [Nebr. Stat. 30-3418(2)].

There is, however, one difference between a competent and an incompetent patient. A competent patient can always refuse any type of life-sustaining treatment (see § 3.2.10). Under Nebraska law, an incompetent patient's refusal of life-sustaining treatment, issued via an advance directive, may only be honored by the health care providers if the patient is either "in a terminal condition or in a persistent vegetative state" [Nebr. Stats. 20-405 & (30-3418(2))]. (For a definition of "terminal condition," see § 2.2.1.)

3.5.20 Can a patient even refuse artificially administered nutrition and hydration through an advance directive?

Yes. Nebraska's laws once again are not fully consistent when it comes to refusing artificially administered nutrition and/or hydration. The act governing living wills

suggests that such interventions are comparable to any other life-sustaining medical treatments. That is to say, no exception is made for these two interventions [Nebr. Stat. 20-404(1)]. However, the law governing powers of attorney for health care does contain special instructions for these two medical interventions. The patient's agent has *no* authority to withhold or withdraw consent for artificially administered nutrition and hydration *unless*:

- (a) the patient is suffering from a terminal condition or in a persistent vegetative state (actually, this condition holds true for living wills as well); and
- (b) the power of attorney for health care *explicitly* grants such authority to the agent or the intent of the patient to have artificially administered nutrition or hydration withheld or withdrawn under such circumstances is established by clear and convincing evidence [Nebr. Stats. 30-3417(1)(c) & 30-3418(2)].

Note that the physician is always morally and legally required to make sure that the patient is not in pain or otherwise uncomfortable and, to that avail, may have to use artificially administered nutrition and/or hydration [Nebr. Stats. 20-408(2) & 30-3426]. However, if artificially administered nutrition and/or hydration is not necessary to achieve relief of pain and discomfort, it must be forgone if the patient has opted against it.

Note, finally, that the emphasis here is on *artificial*. Food and drinks that are provided in the usual and typical ways may never be forgone, nor should any other form of routine patient care [Nebr. Stats. 30-3402(8) & 3418(3)].

3.5.21 What should I do if, in following the advance directive, the patient could get harmed?

Nebraska law makes clear that the health care provider is always required to abide by reasonable standards of medical care [Nebr. Stats. 20-410 & 30-3428]. The health care provider must exercise the same independent medical judgment as (s)he would in the care of a competent patient [Nebr. Stat. 30-3427]. This means that a patient cannot, via an advance directive, force a physician to provide care that violates those standards.

The same is true if a patient refuses treatment by means of an living will, or if the patient's agent holding the health care power of attorney does so on behalf of the patient. The physician remains ethically and legally responsible to provide treatment

necessary for a patient's comfort care or alleviation of pain (assuming the patient has not explicitly refused such care as well) [Nebr. Stats. 20-408(2) & 30-3426 & 30-3418(3)].

Given these obligations on the part of physicians and other health care providers, it would be prudent for the patient to discuss with his or her primary care physician the stipulations of the living will before the document is finalized. For the same reasons, the law on the health care power of attorney specifically requires the patient's agent to consult with the patient's attending physician and other medical personnel as appropriate [Nebr. Stat. 30-3418(1)].

Whenever a physician or health care provider fundamentally disagrees with the provisions of a living will or the instructions of the patient's agent, believing they are at odds with good medical practice or deeply held religious or ethical beliefs, the patient or his/her legally authorized decision-maker should be immediately informed about this. If necessary, the patient should be transferred to another physician or hospital (see § 3.5.13).

3.5.22 What should I do if, as a result of my following the advance directive, the unborn child of a pregnant patient may die?

If the unborn child is not likely to survive to viability, regardless of the treatments given or forgone, the pregnant patient's advance directive should be followed. The situation changes, however, if the unborn child is likely to reach viability when medical treatment is continued. In that case, such medical treatments may not be withheld or withdrawn, even if the living will or the patient's agent holding the power of attorney states that those treatments must be forgone [Nebr. Stats. 20-408(3) & 30-3417(1)].

3.6 DECISION-MAKING IN THE ABSENCE OF AN ADVANCE DIRECTIVE

3.6.1 If there is no AD, does that mean that the patient wants me to provide any and all life-sustaining treatments?

No. Even though advance directives generally are written by persons who wish to limit the medical treatment they shall undergo if incompetent, the fact that someone did *not* issue an advance directive should not and legally may not be interpreted as a sign that she wants any and all treatment. Indeed, the *absence* of an advance directive may not be interpreted to reflect the wishes of the patient in any which way [Nebr. Stats. 20-412(4) & 30-3430].

3.6.2 If there is no AD, who carries the decision-making authority for the patient?

In the absence of an advance directive, someone else will have to carry final decision-making authority and responsibility. We can distinguish between two categories of patients: Minors (see § 3.6.3) and incompetent adults (see § 3.6.8).

The Dying Child and Parental Decision-making

3.6.3 What are the rights of parents to decide about the health care for their children?

Nebraska law defines parents as the “natural guardians” of their minor children (for a definition of “guardian,” see § 3.6.9) [Nebr. Stat. 30-2608]. This means that parents have “custody” over their children, that is, the authority and responsibility to make decisions on behalf of their children, including health care decisions.

However, the parents' rights to custody can be suspended or terminated by the appropriate court [Nebr. Stat. 43-292], in which case the Nebraska Department of Health and Human Service becomes the child's caretaker [Nebr. Stat. 43-292]

3.6.4 What if the patient is still a minor from a purely legal perspective, but clearly mature enough to make decisions him/herself?

Nebraska has a fixed age at which moment a person becomes an adult (19 years) and competent to make health care decisions. Such a fixed age of majority has the advantage of legal clarity. But it is of course a fiction that someone suddenly, from one day to the next, becomes an adult. The capacity to make decisions about one's own health care is not gained overnight. Other states, therefore, have chosen to make a person's majority contingent on his actual maturity. But this approach

entails two new problems: (1) How do we determine whether a youngster is mature enough, that is, competent; and (2) at what age does the youngster get the benefit of the doubt and is assumed to be mature enough, even if we cannot prove his maturity?

AMA CODE OF MEDICAL ETHICS

§ 5.055: Physicians who treat minors have an ethical duty to promote the autonomy of minor patients by involving them in the medical decision-making process to a degree commensurate with their abilities...

Where the law does not require otherwise, physicians should permit a competent minor to consent to medical care and should not notify parents without the patient’s consent. Depending on the seriousness of the decision, competence may be evaluated by physicians for most minors. When necessary, experts in adolescent medicine or child psychological development should be consulted. Use of the courts for competence determinations should be made only as a last resort.

NOTE: The Code of Medical Ethics of the American Medical Association does not constitute positive law and its instructions do not have legal force in Nebraska (or any other state or federal court).

Nebraska law does not provide for any exceptions to its fixed majority age (except for certain specified medical interventions such as alcoholism counseling). Parents, hence, retain the parental right to decide until their child turns 19.

However, if a patient of 18 years forcefully objects to a medical treatment, that objection at the very least should make the health care provider wonder whether it is in the patient’s best interest to undergo the treatment. The parents’ consent does not prove that the treatment is indeed beneficial. Conversely, if the parents refuse treatment, but the patient clearly wants to be treated, the parents’ refusal may be grounds for suspension of their parental rights (see § 3.6.5).

3.6.5 Can parents refuse life-sustaining treatment for their children?

Yes, but not with the same freedom as adults can for themselves. Parents are required to take good care of their children, which includes health care. But not all health care is beneficial to patients, and that is true unfortunately for minor patients as well. Sometimes, medical interventions are futile or even harmful. In such cases, life-sustaining care may properly be withheld or withdrawn at the request of the parents [Gosfield § 8:14; see also

Custody of a Minor, 385 Mass. 697, 434 N.E.2d 901 (1982) and *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991)].

However, the situation changes if parents willfully neglect to provide the child with care necessary for his or her health. This is a ground for termination of parental rights when the court finds such termination to be in the best interests of the child [Nebr. Stats. 43-292 & 43-292(3)].

The crucial question is, of course, whether in a specific case the initiation or continuation of life-sustaining treatment is in the child’s best interests. If the health care providers think it will benefit the child, but the parents or guardian refuses the care anyway, the refusal probably will not be upheld by the courts. Courts almost invariably authorize life-sustaining care over parental objections, even if those objections are on religious grounds, provided there is both a strong medical consensus favoring treatment and a good prognosis [Gosfield § 8:14].

It is important to remember that the patient’s right to refuse medical treatment, including life-sustaining medical treatment, is grounded in the right “to-be-let-alone” (see § 3.2.5). Even if a patient makes a mistake or a foolish decision, still he should not be forced to undergo medical treatment. In final resort, the patient must be allowed to-be-left-alone, even if it means he will die. But the right “to-be-let-alone” does not entail a right to

THE CASE OF BABY TABATHA

In 1997, the Nebraska Supreme Court considered the case of baby Tabatha. The baby had been abused by the parents and parental custody was suspended. The Department of Health and Human Services was therefore charged with the authority and responsibility of the baby’s medical care.

It decided to withdraw life-sustaining treatment because the baby was in an irreversible comatose state and life-sustaining treatment would not improve her extensive brain damage. The Supreme Court agreed with the Department’s medical findings. Nevertheless, it reversed the Department’s decision that life-sustaining treatment should be withdrawn because of the parents’ opposition to that withdrawal.

Although the Supreme Court based its decision largely on procedural issues, the decision reflects the common legal practice of erring on the side of life-sustaining treatment (In the interest of *Tabatha R.*, 252 Neb. 687 (1997) No. S-96-552, Filed June 20, 1997).

The parents later agreed that the ventilator be withdrawn and baby Tabatha died subsequently.

make sure that one's own children are left alone as well. The United States Supreme Court has summarized this principle well:

Parents may be free to become martyrs themselves. But it does not follow [that] they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves [Health Law Practice Guide, Vol. 1, p. 8-26, 27 § 8:14. *Prince v. Massachusetts*, 321 U.S. 158, 170, *reb'g denied*, 321 U.S. 804 (1944)].

3.6.6 Can parents demand life-sustaining treatment for their children?

No. Patients do not have the right to demand medical treatment (see § 3.2.13). A health care provider is obligated to provide medical treatment only if it is beneficial to the patient. The same is true for parents deciding on behalf of their children. Of course, the crucial question is always whether a particular medical intervention is in fact beneficial. Since a decision to withhold or withdraw generally results in the death of the child and is, as such, irreversible, the courts generally will err on the side of life-sustaining treatment.

3.6.7 What can I do if I think that the parents are not making decisions in the best interests of their terminally ill child?

Although it is certainly possible to involve the courts in an attempt to have parental custody suspended, the first step should always be to seek understanding. Litigation seldom results in win-win outcomes; at the very least, it will result in additional stress and anger for all people involved as well as bureaucracy and delays.

One must ask oneself why the parents are deciding as they do. What are the reasons behind their decision? And why are the health care providers unable to convince the parents otherwise? Parents of terminally ill children are under tremendous stress and they generally feel completely powerless. Health care providers must make an extraordinary effort to involve them in the decision-making process in a constructive and compassionate manner.

However, health care providers retain a personal and professional obligation to the patient. The child, not the parents, is the patient. If no agreement about the patient's best interests can be reached, in spite of extensive and constructive

deliberations with the parents, the health care provider may not “give in” and simply do what the parents request. In extreme situations when the parents' decisions would amount to abuse, the health care provider is obligated to involve legal authorities.

Decision-Making for an Incompetent Adult in the Absence of an Advance Directive

3.6.8 When the incompetent patient is an adult, but there is no advance directive, who makes the decisions?

If the patient is an adult, but has not issued an advance directive, there are again two scenarios. A guardian makes the decisions (see § 3.6.9) or a proxy does (see § 3.6.13). The first scenario involves the courts, the second does not.

3.6.9 What is a guardian?

A guardian is a person appointed by a court to guard over the well-being of another person who is him- or herself unable to foster his or her own well-being (the so-called “ward”). Specifically, this means that the guardian is authorized and obligated to manage the ward's property and other personal affairs, including matters of health care.

If the court finds that the ward is fully unable to handle his own affairs, the court can authorize the guardian to make any and all decisions on behalf of the ward (so called “full guardianship”). In all other cases, the court will only grant “limited guardianship.” This means that the court will specify in which areas the ward is unable to decide for himself and what authority and responsibilities the guardian has, for example, in the area of medical care [Nebr. Stat. 30-2620].

Unless the court has determined otherwise, the guardian “may give any consents or approvals that may be necessary to enable the ward to receive medical, psychiatric, psychological, or other professional care, counsel, treatment, or service” [Nebr. Stat. 30-2628(3)].

3.6.10 What is a guardian ad litem?

Whenever a patient's case ends up in court, and the court worries that the patient is not able to adequately advocate his/her own case, the court can appoint a "guardian ad litem." This guardian is authorized to advocate for the best interests of the patient, but only for the purposes of this particular court case ("ad litem").

3.6.11 Can a guardian refuse life-sustaining treatment?

Yes, but not with the same freedom as an adult can for him or herself. A guardian of an incompetent patient is comparable with a parent of a minor child. Although a guardian has decision-making rights and duties similar to those of a parent, which therefore includes the right to refuse life-sustaining treatment, the irreversibility of such a decision usually motivates the courts to err on the side of life-sustaining treatment.

3.6.12 If the court has appointed a guardian, but there also appears to be an agent who holds the power of attorney for health care, who makes the health care decisions?

According to the law governing powers of attorney for health care, the agent holding that power has the highest priority in decision-making, unless the court decides otherwise [Nebr. Stat. 30-3420(5)(b)].

3.6.13 If there is no guardian, who makes the health care decisions ?

Nebraska law has no statutory provisions governing non-emergency situations in which the patient is adult, incompetent, has not written an advance directive and for whom no guardian has been appointed. Yet these situations are quite common in modern health care. Many terminally ill patients at some moment may end up incompetent as a result of their illness (e.g., dementia) or the medical treatment provided (e.g., large doses of psychoactive medications).

This legal vacuum may seem troublesome to health care providers, because they are used to clear guidance from the biomedical sciences. It may seem strange to them that the legislature has not addressed a situation as common as the dying patient who has become incompetent but has not left an advance directive.

Here, it is important to remind the reader of the warning in the Introduction to this GUIDE (see § 1.2.2): The fact that a particular behavior is not covered by the law does not mean it is illegal. The law is written primarily to resolve conflict situations. As long as there is no conflict, there is no need for the law to step in. The fact that Nebraska's legislature has not passed a law covering these kinds of scenarios could simply mean that in Nebraska there have not been many serious legal conflicts regarding the non-emergency treatment of incompetent patients without an advance directive.

However, various other state legislatures have addressed these situations. Typically, those statutes list and rank the people who have the right to make decisions on behalf of incompetent adults in the absence of an advance directive or a guardian. That rank-ordered list generally reflects the common routines in clinics: If the patient is incompetent, care providers typically turn to the spouse or else to siblings, mature children, or parents. Hence, those statutes are also known as "familial consent" statutes. But the lists can also include other close friends or acquaintances of the patient. Hence the more encompassing name: "proxy consent" or "consent by proxy."

Since Nebraska law does not have statutes that address these situations, in case of conflict involvement of a court may be inevitable and the appointment of a guardian is the likely end-result.

However, in the statute on guardians, a similar rank-ordered list of persons who may be appointed as guardian is given [Nebr. Stat. 30-2627]. The first on the list is anyone holding the power of attorney, but after that come, in order of priority:

- (2) The spouse of the incompetent patient;
- (3) An adult child of the incompetent patient;
- (4) A parent of the incompetent patient (or a person nominated by a deceased parent)
- (5) Any relative of the incompetent patient with whom the patient has resided for the past six months;
- (6) A person nominated by the one who is caring for or paying benefits to the patient.

It therefore seems legally prudent for health care providers to abide by this same list when seeking a proxy decision-maker for the incompetent adult patient in the absence of an advance directive and a court-appointed guardian.

3.6.14 How should the guardian or proxy go about making decisions on behalf of the patient?

As is true of the agent holding the power of attorney [Nebr. Stats. 30-3417(1) & 30-3418(1)(a)], the guardian is expected to “consider and carry out the intent of the ward expressed prior to incompetency to the extent allowable by law” [Nebr. Stat. 30-2628(3)]. These statutory instructions reflect the prevailing legal opinion that decisions on behalf of incompetent patients should preferably be substituted judgments rather than best interest judgments.

In a *substituted judgment*, the decision-maker tries to step into the shoes of the patient and decide what the patient would have decided had he been competent himself. Written instructions or oral statements from the patient while still competent are an important source of information on which to base such a substituted judgment.

But sometimes, the patient has left no such personal information. This could happen, for example, when a young adult becomes incompetent due to severe trauma or if an adult patient has never been competent before due to lifelong mental illness. In such cases, the decision-makers cannot make a substituted judgment. Instead, they have to make a so-called *best interest judgment*. The proxy should consent only to those treatments that appear to be in the best interest of the patient. The proxy should consider the benefits and burdens for the patient of various alternatives, as well as the likely effectiveness of those alternatives.

Although these two decision-making strategies are often blended, there is a fundamental difference between the two. A competent patient has the right to refuse all medical treatment, including life-sustaining treatment. Consider a patient who has always made it clear that he would not ever want renal dialysis. Suppose this patient becomes seriously ill and incompetent before he has written an advance directive. Suppose furthermore that this patient is in need of renal dialysis and all physicians and family members are convinced that dialysis is in the best interest of this patient. If the proxy decides on the basis of a best interest judgment, she will consent to the renal dialysis. But if she decides on the basis of a substituted judgment, she will have to refuse dialysis because she knows that’s what the patient would have done had he been competent.

3.7 THE ROLE OF THE HEALTH CARE PROVIDER IN DECISION-MAKING FOR INCOMPETENT PATIENTS**3.7.1 Can the patient’s agent or guardian make decisions without involving the patient’s attending physician or other health care provider?**

No. Both the person holding the power of attorney for health care and the guardian are required to act on behalf of the patient. Generally, decisions about health care cannot be made responsibly by the patient’s agent if (s)he does not consult with medical experts. Indeed, Nebraska law specifically requires the agent holding the power of attorney for health care to “consult with medical personnel, including the attending physician” [Nebr. Stat. 30-3418(1)].

3.7.2 Can I refuse to execute the decisions from the patient’s agent?

As pointed out earlier (see § 3.5.21), the health care provider has a professional duty to keep the patient from harm (principle of non-maleficence). Even the patient himself cannot compel the health care provider to initiate treatment that is harmful to the patient; an agent or guardian acting on behalf of the patient most certainly cannot force a health care provider to begin harmful medical treatment.

A health care provider has the right to refuse requests for treatments that are at odds with the standards of sound medical practice (see § 3.2.13). Conversely, if the

health care provider recommends treatment that is clearly of benefit to the incompetent patient, but the patient's agent or guardian refuses to consent to such treatment, it may be necessary to involve a court.

TO TREAT OR NOT TO TREAT

Note once again that a request from a competent patient or the patient's agent to *forgo* or *discontinue* life-sustaining treatment is not to be interpreted as a request for harmful treatment, even if the patient will subsequently die.

Withholding or withdrawing life-sustaining treatment that has been refused by the patient or her legal agent may be harmful to the patient, but it is not something harmful *done to* the patient by the health care provider. Withholding or withdrawing treatment is not itself treatment; it is *not* treating the patient. Hence, a health care provider cannot invoke his or her right to refuse harmful treatment when the patient or the patient's agent wants treatment withheld or withdrawn.

If a health care provider believes that the agent's refusal of life-sustaining treatment is not in the patient's own best interests, the health care provider may have to go to court and argue that the patient's agent is not exercising his or her authority in a responsible manner. The court can decide to withdraw the power of attorney from the agent and appoint a guardian instead.

4. PROVIDING END-OF-LIFE CARE

4.1 INTRODUCTION

From a medical perspective, compassionate end-of-life care requires three things: (1) The patient is involved in the treatment planning and decision-making process; (2) optimal relief of pain and other symptoms is provided, using all drugs and other means that are available and legally sanctioned; (3) interventions of which the burdens clearly outweigh the benefits should be foregone. In the former chapter, we reviewed the first of these three. In this chapter, we look at the provision of palliative care. In the next chapter we will cover the third issue.

For many patients, the process of dying is accompanied by pain and other distressing and depressing symptoms. However, the science and practice of medicine at the dawn of the 21st century has yielded a wealth of remedies for most of these symptoms. Pain and most symptoms can be adequately managed. Unfortunately, many clinicians are hesitant to make optimal use of these remedies. As a result, some patients suffer unnecessarily.

There are many causes for physicians' undertreatment of patients towards the end of life, ranging from inadequate training to unfounded fears about addiction. Most of these causes are beyond the scope of this GUIDE. However, one cause will be addressed in this GUIDE: Physicians' fear of legal repercussions. Physicians worry that prescribing high doses of narcotics and other controlled substances will result in action by the Drug Enforcement Agency (DEA) or even criminal prosecution.

This chapter will address the legality of prescribing and administering controlled substances. It will become evident that the health care provider – whether physician, nurse or pharmacist – who uses these drugs in the normal practice of his or her profession and in accordance with the standards of good health care practice has virtually nothing to fear from the law.

4.2 PAIN TREATMENT

4.2.1 Can I get into legal trouble if I prescribe certain kinds of drugs to relieve a patient's pain?

Certain drugs are prohibited by law (e.g., marijuana and all other so-called Schedule I drugs). They cannot be prescribed for legitimate medical purposes either, because by definition Schedule I drugs cannot be used for medical purposes [USC 21,812]. However, the State of Nebraska wants physicians to use all other drugs, including controlled substances, that are effective and necessary to relieve suffering. Following new legislation in 1999, Nebraska law now states that “principles of quality medical practice *dictate* that the people of Nebraska have access to appropriate and effective pain relief.” [Nebr. Stat. 71-2418(1) - *emphasis added*]. The statute goes on to encourage physicians “to view effective pain management as part of quality medical practice for all patients with pain, acute or chronic, including those patients who experience pain as a result of terminal illness” [Nebr. Stat. 71-2418(2)].

4.2.2 Even if the State of Nebraska supports the use of controlled substances for pain relief, isn't there still a legal risk under federal law?

Oversight of the prescribing practices of physicians takes place at both the state and federal levels. The *Drug Abuse Prevention and Control Act* and the *Federal Food, Drug, and Cosmetic Act* regulate the narcotics used in pain relief. The *Uniform Controlled Substances Act* is administered by the federal Food and Drug Administration (FDA), which evaluates and approves drugs before they can be available for medical use. The Nebraska version of the *Uniform Controlled Substances Act* can be found in Chapter 28, Article 4 (and it can be cited as “*Uniform Controlled Substances Act*” as well [Nebr. Stat. 28-438]).

The *Uniform Controlled Substances Act* divides such drugs into five different schedules. Schedule II substances include morphine, meperidine (Demerol), oxycodone (Percodan), and fentanyl (Sublimaze). These are some of the most frequently prescribed substances for pain management.

The Act allows physicians to prescribe and pharmacists to dispense controlled substances, provided they serve a legitimate medical purpose [Code of Federal

Regulations, Title 2, Vol. 9, Part 1306: Prescriptions, Sec. 1306.04]. And just to make this point absolutely clear, the Nebraska statute explicitly states that a physician or other health care provider who prescribes or administers a controlled substance in accordance with Nebraska’s law, shall not be subject to criminal prosecution under the *Uniform Controlled Substances Act* [Nebr. Stat. 71-2419].

Finally, the Drug Enforcement Administration (DEA), which is responsible for the enforcement of the *Uniform Controlled Substances Act*, also supports the use of controlled substances for legitimate medical needs. In a recent court case (Dec. 15, 2004) against a physician engaged in illegal drug trafficking, DEA Administrator Karen P. Tandy said, “DEA remains committed to striking a balance between promoting pain relief for patients in need and preventing abuse of pain medications. There has been no change in our enforcement strategy, and doctors should remain confident in their ability to treat patients in pain. In the same vein, the DEA *Physician’s Manual* states that “[c]ontrolled substances have legitimate clinical usefulness and the prescriber should not hesitate to consider prescribing them when they are indicated for the comfort and well-being of patients” [1990 edition, § 24; at the time of printing of this NCCC Guide, this Manual is being revised by the DEA. However, the very same statement is still in place in the updated 2004 *Pharmacist’s Manual* so it is likely to return in the updated *Physician’s Manual* as well]. The Controlled Substances act does not define what constitutes legitimate medical practice nor does it set forth standards of medical practice.

4.2.3 Can I give an unusually large dosage of pain killers?

Yes. Nebraska law specifically states that a physician can “prescribe, dispense or administer a controlled substance *in excess of* the recommended dosage for the treatment of pain” [Nebr. Stat. 71-2418(3) - *emphasis added*]. The statute sets three conditions:

1. First, the pain of the patient must warrant this unusually high dosage. This would be the case if the patient’s pain does not respond to drugs with fewer or less harmful side-effects, or to lower doses of the controlled substance [Nebr. Stat. 71-2419(1)].
2. Second, the purpose of the drugs must be the relief of pain only; the drugs may not be given to hasten or cause a patient’s death [Nebr. Stat. 71-2419(2)] (see also § 4.3.9).

3. And third, giving such a high dosage must conform to the policies and guidelines for the treatment of pain adopted by the Board of Examiners in Medicine and Surgery [Nebr. Stat. 71-2419(3)].

4.2.4 Given the Board’s authority and discretion, do I have legal certainty when prescribing high doses of pain killers?

The Board of Examiners is charged by the Nebraska Legislature to adopt policies and guidelines for the treatment of pain, to which a physician must conform. However, the Board is expected to draft policies and guidelines that will ensure that physicians who are engaged in the appropriate treatment of pain are not subject to disciplinary action [Nebr. Stat. 71-2420].

The Board has indeed issued these *Guidelines*. They are based on the *Model Guidelines for the Use of Controlled Substances for the Treatment of Pain* adopted by the House of Delegates of the Federation of State Medical Boards of the United States in May of 1998. Note that in October of 1999 these *Model Guidelines* were also adopted by The National Association of State Controlled Substances Authorities (NASCSA), a non-profit educational organization aimed at increasing the effectiveness and efficiency of state and national efforts to prevent and control drug abuse.

In the preamble of the Nebraska Guidelines, we find the same encouragement for adequate and effective pain management as in the Nebraska statute quoted above (see § 4.2.1). The Board next assures physicians that it is not at all interested in disciplining physicians who act in accordance with the principles of good medical practice. Even if a physician is forced by the circumstances of the case to go beyond the recommendations of the Board, the Board will not take disciplinary action against that physician, provided good cause is shown for such deviation [Section 1].

4.2.5 How can I make sure that the Nebraska Board of Examiners will not discipline me if I prescribe or administer high but effective doses of controlled substances?

The Nebraska statutes [Nebr. Stats. 71-2418 & 2419] and the *Guidelines for the Use of Controlled Substances for the Treatment of Pain* issued by Nebraska’s Board of Examiners in Medicine and Surgery make clear that physicians are expected and encouraged to provide adequate pain relief, even if high doses of controlled substances are

required. Time and again, the *Guidelines* emphasize that physicians should not fear disciplinary action from the Board or other enforcement agencies for prescribing, dispensing, or administering such drugs for a legitimate medical purpose and in the usual course of professional practice.

Of course, the Board is also responsible for disciplining physicians who abuse their medical privilege and seek to prescribe or use these drugs for other than legitimate medical purposes. However, a national review of disciplinary actions by medical boards for overprescription of drugs between 1990 and 1996 revealed that very few (less than 5%) concerned the inappropriate treatment of chronic pain. Instead, those disciplinary actions typically were aimed at physicians who abused those drugs personally or prescribed for other illegal purposes [Martino 1998].

In order for the Board to quickly distinguish between legitimate and illegitimate use, the prescribing physician should keep good records about the patient's condition, treatment, and unrelieved pain: "The Board will judge the validity of prescribing based on the physician's treatment of the patient and on available documentation, rather than on the quantity and chronicity of prescribing" [Section 1]. Suggestions for record keeping are provided in Section II of the *Guidelines*.

4.2.6 Is it legally safest to prescribe and administer only moderate doses of pain killers?

The 1999 statute on the administration of pain medications does not explicitly cover underprescription of pain medications. However, the statute does state that the "principles of quality medical practice dictate that the people of Nebraska have access to appropriate and effective pain relief" [Nebr. Stat. 71-2418(1)]. This powerful statement makes two things clear.

First, Nebraska's patients have a statutory right to effective pain relief. And second, it finds that such effective pain relief is part and parcel of sound medical practice. A physician who intentionally underprescribes, just to be legally safe, is not abiding by the "principles of quality medical practice." The State Board of Medical Examiners, hence, has grounds to discipline a physician who intentionally underprescribes. It may well follow the lead of the Oregon Board which has issued the following forceful policy statement:

Appropriate management of all of these types of pain is the treating physician's responsibility. The standard of care allows neither overtreatment nor undertreatment. As such, the Board will consider clearly documented undertreatment of pain to be a violation equal to overtreatment, and will investigate allegations in the same manner [BME Statement of Philosophy on Pain Management, 1999].

In 2004, the Federation of State Medical Boards in 2004 followed suit and passed a model policy on the use of controlled substances for the treatment of pain, which is intended to guide both prescribing physicians and state medical boards. The revised policy notes that the state medical board will consider inappropriate treatment, including the undertreatment of pain, a departure from an acceptable standard of practice.

Very few lawsuits have been filed on behalf of patients who were not provided with adequate pain medications. However, in recent years, the number of such cases has been increasing steadily. In 1990, a North Carolina court awarded \$15 million to the family of a patient because the patient while dying, had not received the prescribed pain medications from the nursing home staff [for a discussion of this case, see Shapiro 1996]. In 1997, the US Supreme Court emphasized the importance of adequate pain relief with almost as much vigor as it rejected physician-assisted suicide. And most recently, a California physician was sued for both malpractice and elder abuse because of his failure to adequately treat the patient's pain [see American Medical News, March 20, 2000]. On June 13, 2001, a jury in Alameda County found the physician guilty of elder abuse and ruled that Dr. Wing Chin must pay \$1.5 million to the children of William Bergman, who died of lung cancer in 1998 at the age of 85 [*Beverly Bergman et al. v. Wing Chin, M.D.*, Eden Medical Center, 2001, Case No. H205732-1, Alameda Superior Court, CA; the award was later reduced to \$250,000]. (For additional examples, see Tucker 2004, and Vaglianti & Grinberg 2004).

4.2.7 What do I do if the patient or the patient's family members do not want me to administer controlled substances?

It is rare that a patient who is in severe pain would refuse effective medications, even if they are controlled substances. Family members of an incompetent patient or other authorized surrogate decision-makers are more likely to refuse, but their refusal is generally based on a lack of knowledge or misunderstanding that the

drugs will turn the patient into a “drug addict” or even kill the patient (for a discussion of the difference between assisted suicide and pain management, see 4.3.9). In such situations, it is important that patient and family members are properly educated.

The Nebraska Board of Examiners in its *Guidelines for the Use of Controlled Substances for the Treatment of Pain* provides a detailed Informed Consent form that can be used when consent must be obtained for the administration of controlled substances.

In the end, the patient as always retains the right to refuse any medical treatment, including pain treatment (see § 3.2.6). However, if family members of an incompetent patient or other legally authorized surrogate decision-makers refuse on behalf of the patient, the physician must consider whether those making decisions are actually behaving as a responsible agent for the patient should. The physician retains his/her own professional obligation to protect the patient against poor care (see § 3.5.21).

4.2.8 Can the health care facility prevent me from prescribing appropriately high doses of controlled substances?

No. According to the findings of the Nebraska Legislature, health care facilities and hospices should not forbid or even restrict the appropriate use of controlled substances for the treatment of pain [Nebr. Stat. 71-2418(4)].

4.2.9 Can an insurance provider refuse to pay for controlled substances?

No. According to the findings of the Nebraska Legislature, a third-party payer should not forbid or even restrict the appropriate use of controlled substances for the treatment of pain [Nebr. Stat. 71-2418(4)].

4.2.10 What should I do if I fear that my patient, though in severe pain, nevertheless will abuse the medications I prescribe, or even sell them?

A physician can never be sure that a patient will use the prescribed medications properly and not stockpile, sell or otherwise abuse them. Unfortunately, there are some patients who will use their drugs for illegal purposes, even if they are in need of those drugs.

As is the case with any kind of prescription, the physician must be mindful of the possibility of abuse. However, that possibility - usually remote - should not result in patients who are truly in need of adequate pain treatment being undertreated. Indeed, the Nebraska Board of Examiners in its *Guidelines for the Use of Controlled Substances for the Treatment of Pain* does not want the physician to be overly cautious. All that is required is that the physician gives “special attention...to those pain patients who are at risk for misusing their medications and those whose living arrangement pose a risk for medication misuse or diversion. The management of pain in patients with a history of substance abuse or with a comorbid psychiatric disorder may require extra care, monitoring, documentation, and consultation with or referral to an expert in the management of such patients” [Section II,5].

For patients who are terminally ill or in a long term facility, the physician can arrange with the pharmacist that the prescription for narcotics is filled in installments over a period of up to 60 days (see § 4.2.16).

The Role of The Nurse and Nurse Practitioner

4.2.11 Do I have the same legal protection as physicians if I administer high doses of controlled substances?

Nebraska law does not distinguish between physicians and nurses where the administration of controlled substances is concerned. Provided the same conditions are met (see § 4.2.3), a nurse who follows a physician’s prescription and administers such pain medications in excess of the recommended dosage is liable neither to criminal prosecution nor to disciplinary action [Nebr. Stat. 71-2419].

The Role of the Pharmacist

4.2.12 Am I at risk of prosecution by the Drug Enforcement Agency if I dispense controlled substances?

Federal law places the responsibility for the proper prescribing and dispensing of controlled substances on the prescribing practitioner, but a “corresponding responsibility” rests with the pharmacist who fills the prescription. If a prescription appears not to be written “in the usual course of professional treatment” it may not

be filled by the pharmacist [Federal Regulations, Title 21-Food and Drugs, Vol. 9, Part 1306: Prescriptions, Sec. 1306.04].

However, the DEA specifically assures pharmacists in its 2004 edition of the *Pharmacist's Manual* that controlled substances can be legally dispensed by the pharmacist:

A pharmacist need not fear DEA action if he/she dispenses controlled substances in good faith pursuant to a prescription issued for a legitimate medical purpose. It is the position of the DEA that controlled substances should be prescribed and dispensed when there is a legitimate medical need.

4.2.13 If I am presented with a prescription for an unusually high dosage of a controlled substance, can I legally dispense it?

Yes. The Drug Enforcement Agency specifically reminds pharmacists that patients may develop tolerance to narcotics, requiring ever higher dosages:

Pharmacists should recognize that drug tolerance and physical dependence may develop as a consequence of the patient's sustained use of opioid analgesics for the legitimate treatment of chronic pain. It is also important to understand that the quantity of drugs prescribed and frequency of prescriptions filled alone are not indicators of fraud or improper prescribing [*Pharmacist's Manual*].

Furthermore, Nebraska law specifically grants immunity from the Federal *Controlled Substances Act* for a pharmacist who dispenses or administers pain medications in excess of the recommended dosage, as long as the same three conditions listed above are met (see § 4.2.3). A pharmacist who dispenses such pain medications is liable neither to criminal prosecution nor to disciplinary action [Nebr. Stat. 71-2419].

4.2.14 Can I dispense controlled substances if the prescription is faxed to the pharmacy?

Yes. All prescriptions for Schedule III-V drugs can be dispensed on the basis of a faxed prescription [DEA *Pharmacist's Manual*], However, Schedule II controlled

substances require that the original prescription is brought to the pharmacy. The prescription can be faxed in advance, but the original is required at the time the drugs are actually dispensed [DEA *Pharmacist's Manual*].

However, there are four exceptions. Schedule II drugs can be dispensed on the basis of a faxed prescription:

- In case of an emergency, provided the word “Emergency” is written on the faxed prescription [Nebr. Stat. 28-414(1)(b)] (For additional requirements, see the *Code of Federal Regulations* or the DEA *Pharmacist's Manual*).
- When the patient is a hospice patient. The words “Hospice Patient” have to be written on the prescription [Nebr. Stat. 28-414(1)(c)(ii)]. Although the *Uniform Controlled Substances Act* still states that the patient has to be a *resident* of a hospice, the *Code of Federal Guidelines* allow faxed prescriptions for any patient *enrolled* in a hospice *program* [21 CFR 1306.11].
- When the patient is undergoing home infusion palliative therapy [Nebr. Stat. 28-414(1)(c)(ii)].
- When the patient is a resident of a long term care facility [Nebr. Stat. 28-414(1)(c)(iii)].

In situations listed above, the faxed prescription serves as the original [DEA *Pharmacist's Manual*].

4.2.15 Can I dispense controlled substances if the prescription is phoned-in?

Prescriptions for Schedule III-V drugs can be phoned-in [DEA *Pharmacist's Manual*]. However, prescriptions by phone for Schedule II drugs are only allowed in emergency situations. The pharmacist has to write the prescription down and make sure that all the required information is included [Nebr. Stat. 28-414 (3)(b)]. Within seven days, a written prescription must be provided to the pharmacy. Additional cautionary rules are outlined in the DEA *Pharmacist's Manual* and the *Code of Federal Regulations*.

4.2.16 Can I refill a prescription for narcotics and other controlled substances on Schedule II?

A Schedule II prescription cannot be refilled. A new prescription from the prescribing physician is required [Nebr. Stat. 28-414(1)(a)]. However, there are two exceptions to this rule [Nebr. Stat. 28-414(1)(d)(ii)]. A physician can issue a prescription with a duration of up to 60 days, which the pharmacist may partially fill multiple times, if the prescription specifically states that:

- the patient is terminally ill, or
- the patient is a resident of a long-term care facility.

For additional cautionary rules when partially filling a prescription, see the DEA *Pharmacist's Manual* and the *Code of Federal Regulations*.

Note: Partially filling prescriptions for the patients in the above mentioned categories can also minimize the amount of narcotics a patient has on hand (see also § 4.2.10), spread the patient's medication costs by only billing for quantities as they are dispensed, and help prevent costly waste of left-over drugs upon the patient's death.

4.3 ASSISTED SUICIDE AND EUTHANASIA

4.3.1 How is suicide defined?

Suicide is best defined as intentionally bringing about one's own death. The emphasis here is on the word "intentionally." The person causing his or her own death must have wanted and planned his own death, and taken action to achieve that end (see also § 4.3.4).

4.3.2 How is assisted suicide defined?

According to Nebraska law, "a person commits assisting suicide when, with intent to assist another in committing suicide, he aids and abets him in committing or attempting to commit suicide" [Nebr. Stat. 28-307]. Key here is that the person assisting in suicide must *intend* to assist. The pharmacist who dispenses a prescribed dosage of narcotics, unaware that the patient plans to commit suicide, is not guilty

of assisting in suicide if the patient takes all tablets at once and dies. (For the distinction between assisted suicide and euthanasia, see § 4.3.3.)

4.3.3 How is euthanasia defined?

Euthanasia is not defined in the criminal code. As the synonym "mercy killing" reveals, euthanasia is a form of "killing," that is, intentionally ending another human being's life. It is important to emphasize that the patient's death is not an accidental consequence. It is the intended consequence of the act of euthanasia; the patient is supposed to die as a result of euthanasia. Even though mercy is the motive (that which "moves" or "drives" the perpetrator to commit euthanasia), death is the intent (that which the perpetrator "strives to" achieve by his/her actions).

Euthanasia differs from assisted suicide in that the person euthanizing the patient is committing the final act. The patient is being killed. In assisted suicide, the person is helping the patient, but it is the patient who finally ends his or her own life.

4.3.4 If a patient refuses life-sustaining treatment, and dies subsequently, would that qualify as suicide?

Not all instances in which someone causes his own death constitute suicide. Sometimes people engage in very dangerous sports, thereby causing their own death. Even if they knew the sport was very dangerous, they still did not intend to die when they engaged in it. Sometimes people try to rescue someone else, thereby endangering their own life. If a fireman tries to rescue a person from a blazing fire, bringing about his own death, that does not mean he committed suicide. He did not intend to die. Even if the situation was very dire, he probably was hoping to escape death. And since he did not intend to bring about his own death, he did not commit suicide (see § 4.3.1).

The same is true of patients. A refusal of life-sustaining treatment is not necessarily a sign that the patient wants to die. The patient may have concluded that the burdens of that treatment far outweigh the benefits. The patient therefore decides to forgo that treatment. Patients often forgo medical interventions for that very reason. It just so happens that the treatment at hand is a life-sustaining intervention, the only life-sustaining intervention. But the mere fact that it is the only option left to sustain life does not make the burdens of such treatment any less. A patient may still conclude that the burdens outweigh the benefit of sustaining life.

That does not mean the patient wants to die. If there were an alternative, a life-sustaining treatment that would not entail the same serious burdens, the patient might well agree to that option. But there is no such alternative. Refusing that burdensome life-sustaining treatment is not a choice for death, it is not a case of suicide. It is merely the acceptance of human mortality and medicine’s limited and imperfect means of sustaining life.

The Nebraska statutes on living wills and powers of attorney for health care specifically state that a patient’s decision to forego life-sustaining treatment does not amount to suicide [Nebr. Stat. 20-412(1)] and may not be interpreted as such, for example to invoke a “suicide exclusion” in a life-insurance policy [Nebr. Stats. 20-412(2) & 30-3429(2)].

4.3.5 Is physician-assisted suicide legal in Nebraska? What about euthanasia?

Both are illegal. The statute governing assisting suicide states that assisting in suicide is a Class IV felony [Nebr. Stat. 28-307]. A Class IV felony is punishable by a maximum five years imprisonment, or ten thousand dollars fine, or both. There is no minimum penalty [Nebr. Stat. 28-105]. A Class IV felony charge is the lowest of nine classes of felonies charged by the state of Nebraska. Therefore, while assisting suicide is a felony, the penalty could be quite minimal.

A NEBRASKA CASE OF “MERCY KILLING”

One day in the fall of 1998, Mr. Bob Z shot to death his 74-year-old wife Phyllis, who was at that time a resident of the local county hospital. They had been married for 56 years. Mrs. Z had undergone surgery and chemotherapy for colon cancer earlier that year. Presently, she was being treated for a compression fracture to her spine. Because of restlessness, she had to be restrained at times.

When Mr. Z arrived to visit his wife on this fateful day, he and a nurse tried to calm Mrs. Z and get her back into bed, but to little avail. Mrs. Z protested, kicked and used inappropriate language. At one point, Mr. Z allegedly told his wife: “Phyllis, I can't take this anymore.” Mrs. Z was restrained again and the nurse left. Mr. Z then went outside to get a .22-caliber pistol from his car, returned to his wife's room, and shot her point-blank in the right temple.

Mr. Z admitted killing his wife but maintained that he only wanted to end her suffering. He claimed he had been told that the cancer had spread and Phyllis was dying. He had also turned the gun on himself after killing his wife, but it had jammed.

Mr. Z originally was charged with first degree murder and use of a deadly weapon to commit a felony, but pleaded no contest in February 1999 to a reduced charge of manslaughter. In July, he was sentenced to two to five years in prison. Mr. Z was paroled after serving one year of his prison term.

Assisting in suicide is illegal in any and all circumstances. The law does not make an exception for health care providers such as physicians. It is as illegal for a physician to assist in another person’s suicide as it is for a lay person. Likewise, no exceptions are made about the victim. It does not matter whether the victim is a healthy person or a terminally ill patient.

The same is true for euthanasia. From a legal perspective, euthanasia qualifies as homicide, that is, killing another person [Nebr. Stat. 28-302]. Depending on the definition of euthanasia, different sections in Nebraska’s criminal code will apply. If euthanasia is defined as the carefully planned administration of lethal drugs in order to end a patient’s life without that patient’s request, the act may legally qualify as murder in the first degree [Nebr. Stat. 28-303].

However, prosecutors generally will bring forth a lesser charge because they know it is very difficult to convince a jury when a physician appears to have acted out of

mercy, even if the physician clearly intended and planned the patient to die [Alpers 1998].

4.3.6 Isn't it inconsistent that suicide is legal in Nebraska, but assisted suicide is a crime?

No. The fact that some behavior is not prohibited by the criminal law and, in that sense is legal, does not mean that the behavior is right and just. In fact, the senators of the Nebraska Unicameral may agree that some behavior is very wrong, but not prohibit it by law when legal prohibition is not an effective way to prevent the behavior.

Suicide is such a case. It was prohibited by law for many centuries in many countries and US states. However, it became clear that such a prohibition does not effectively prevent suicides. If anything, it will only result in more successful suicide attempts. Consider a person who is so desperate that he considers suicide. The knowledge that he may land in jail if his attempt is unsuccessful will only make him more diligent. He will make sure that his attempt is successful.

But this argument does not apply to people assisting in suicide. If they know that they may end up in jail, they will not be more eager to assist and be more effective. Rather, they will be more hesitant to assist. Hence, it does make legal sense to criminalize assisting in suicide, but not the act of suicide itself.

Note that the *Rights of the Terminally Ill Act* specifically states that the patient's right to refuse medical treatment "is subject to certain state interests in preserving life, preventing homicide and suicide, protecting dependent third parties, and maintaining the integrity of the medical profession" [Nebr. Stat. 20-402(1)].

4.3.7 How is it possible that physician-assisted suicide is illegal in Nebraska but legal in Oregon?

In 1997, the United States Supreme Court concluded that there exists no constitutional right to assisted suicide (*Washington v. Glucksberg*: 521 U.S. 702 (1997) and *Vacco v. Quill*, 521 U.S. 793 (1997)). Hence, states such as Nebraska that wish to prohibit assisted suicide can do so.

However, states are also free to legalize assisted suicide, which is what Oregon has done.

In years past, several times a bill aimed at legalizing physician-assisted suicide and euthanasia was introduced to the Nebraska Unicameral. However, the bill never enjoyed sufficient support to be voted into law. Consequently, both assisted suicide and euthanasia remain criminal offenses under Nebraska law.

4.3.8 Can I be charged with physician-assisted suicide if I withdraw a life-sustaining treatment that the patient has refused, and the patient subsequently dies?

No. Since the refusal of life-sustaining treatment is not always a case of suicide (see § 4.3.4), withdrawing life-sustaining treatment at the request of the patient is not assistance in suicide either. Physicians frequently are forced to withdraw treatments because they are too burdensome for the patient. In and of itself it does not matter what kind of treatment it is, reconstructive surgery of severely burned limbs or renal dialysis of a terminally ill patient. If the patient dies subsequently, death is caused by the disease process, not the physician.

Moreover, the physician is legally obligated to stop treatment that is refused by a competent patient. The patient must consent before any treatment, including life-sustaining treatment, is given. If a competent patient refuses by withholding consent for treatment, the physician has no choice but to forgo the proposed intervention (see § 3.2.10). Hence, from a legal perspective, a physician can never be charged with physician-assisted suicide if (s)he withholds or withdraws treatment that has explicitly been refused by a competent patient who has been properly informed.

THE OREGON LAW

The Oregon law governing physician assisted suicide was implemented on October 27, 1997 and is called the *Oregon Death with Dignity Act* (1994). Oregon's law allows doctors to prescribe, but not administer, lethal doses of drugs for patients with less than six months to live. The law requires two doctors to agree the patient has less than six months to live, is mentally competent and has made a voluntary decision. Two other witnesses must agree the request is voluntary [Or. Rev. Stat. § 127.800-897 (1999)].

The Nebraska *Rights of the Terminally Ill Act* specifically states that death resulting from the withholding or withdrawal of life-sustaining treatment in accordance with the Act “shall not constitute, for any purpose, a suicide or a homicide” [Nebr. Stat. 20-412(1)].

4.3.9 Can I be charged with physician-assisted suicide if I prescribe pain killers or other medications that may shorten a patient’s life?

It is unlikely. If the medications are prescribed and administered in accordance with professional guidelines, for legitimate medical purposes, and with adequate documentation in the medical record, there is no significant legal risk. Indeed, the law specifically encourages adequate pain management for patients who experience pain as a result of a terminal illness [Nebr. Stat. 71-2418].

The crucial question is of course what counts as a legitimate medical purpose. Relief of pain and suffering unquestionably is a legitimate medical purpose. Causing (or assisting in causing) the patient’s death definitely is not.

However, the mere fact that the physician *knows* the medications may shorten the patient’s life does not mean such shortening of the patient’s life is also the *purpose* of the medications. Virtually all medications have certain undesirable and even harmful side-effects. Those side-effects are called *side-effects* precisely because they are not the intended effects of the medications. They are the inevitable effects that we unfortunately cannot prevent from occurring along with the intended effects.

When the patient’s pain cannot be effectively relieved by drugs with fewer or less harmful side-effects, the physician may prescribe and administer more potent drugs notwithstanding those undesirable side-effects. Nebraska law specifically states that a physician should be able to prescribe such drugs, as long as the patient’s death is not the purpose of the prescription or administration [Nebr. Stat. 71-2418(3)].

4.3.10 In the unfortunate event that my patient dies as a result of my administering controlled substances in excess of the recommended amount, how can I ever prove that I did not intend the patient to die?

Records are the best defense. The physician who wants to be prepared for the rare instance that (s)he is examined by law enforcement authorities should keep

adequate records. Document the patient’s condition and the existence of unrelieved pain notwithstanding attempts at mitigation with other drugs or lower doses.

Evidently, records do not provide immunity. However, it should be emphasized once more that the State of Nebraska is clearly interested in advancing effective pain management. Prosecutors who act on behalf of the State of Nebraska and its citizens hence will not prosecute a health care provider unless there is strong evidence that the provider has indeed misused controlled substances in an attempt to end the patient’s life.

Second, the physician does not have to prove (s)he is innocent of a crime. The burden of proof is always on the person making the accusations (i.e., the prosecutor or anyone else bringing charges against the care provider). Like everyone else, the physician is assumed innocent until proven guilty of a crime.

Third and most important, the prosecutor has to prove that the drugs were prescribed or administered with the specific intent and purpose of ending the patient’s life and not of relieving pain.

A review of the literature revealed that virtually all cases in which physicians were prosecuted for homicide involved cases in which the physician prescribed or administered drugs that do not have an acknowledged palliative purpose (such as potassium chloride), suddenly increased the morphine dose dramatically (e.g., seventeen times), or combined pain killers with other actions that clearly revealed their intent to end the patient’s life (e.g., obstructed the endotracheal tube with gauze) [Alpers 1998].

And last but not least: if the patient is no longer competent, active involvement of the family and consent by the legally authorized surrogate decision-maker are important. In those instances in which charges were brought against physicians, typically one or more of the patient’s relatives felt they were not involved or did not understand what was happening, and subsequently contacted the authorities [Alpers 1998].

5. FORGOING FUTILE CARE

5.1 INTRODUCTION

The art of end-of-life care has as much to do with curative treatments forgone as with the palliative treatments given. It is crucially important that patients, family members and health care providers acknowledge and accept that there are limits to the power of modern medicine. Not all diseases can be cured, not all traumas healed. There comes a time when curative interventions are no longer beneficial; indeed, such treatments can become harmful to the patient. This Chapter is concerned with forgoing (i.e., withholding or withdrawing) treatments that are no longer beneficial to the patient.

It is not easy to determine when medical interventions should be forgone. This is in fact a 2,500 year old dilemma. As early as the days of Hippocrates, we can find warnings in the medical literature not to continue treating patients who are overcome by their disease. But when are patients “overcome” by their disease? How can we determine whether a particular intervention has become extraordinary or futile for a particular patient and, hence, should be forgone?

This question continues to be a source of debate among clinicians, ethicists and legal scholars. Consequently, there is very little in terms of legal guidance. When the courts are asked to make decisions about such cases, they typically evade the question, focusing instead on the patient’s right to consent to or refuse treatment.

5.2 WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT

5.2.1 Is there a difference between withholding and withdrawing care?

In most cases, there is no ethical difference between withholding life-sustaining care, that is, not initiating it in the first place, and withdrawing care that has already been initiated. Most assuredly, it is psychologically more difficult to withdraw than to withhold life-sustaining treatments and technologies. Ethically they are the same.

Consider the two conditions for medical treatment to be ethically justified. First, the treatment must be medically indicated. From a medical perspective there must be a sound reason to provide the treatment. This means there must be a diagnosed medical need, the proposed treatment must be effective, and the expected benefits of the treatment must outweigh the adverse side-effects. Second, the patient must consent to the proposed treatment.

If either of these two conditions is not or no longer met, the medical treatment is not ethically justified. If the treatment has not yet been initiated, it obviously should not be started. But even if it has been started, it should not be continued if there is no longer sufficient ethical justification for it.

If we lose sight of the sameness of withholding and withdrawing treatment, we may end up creating some very problematic dilemmas. Health care providers may be hesitant to try life-sustaining measures of uncertain benefit because they fear that once these have been started, they have to be continued infinitely. In his dissenting opinion in the famous *Cruzan* case, Supreme Court Justice Brennan worried that a “troubling wrong occurs when a treatment that might save life or improve health is not started because the health care personnel are afraid that they will find it very difficult to stop the treatment if, as is fairly likely, it proves to be of little benefit and greatly burdens the patient.”

Forgoing Treatment at the Patient’s Request

ETHICAL NOTE

There are two situations in which medical treatment should be forgone. One is that the patient refuses the treatment. The other is that the treatment does not appear effective and beneficial.

We have pointed out that in the latter case clinicians often have greater difficulty withdrawing treatment of insufficient benefit once it has been started than withholding such treatment in the first place. However, from an ethical perspective, the argument could be made that there is a stronger ethical obligation to withdraw treatments that do not appear effective and beneficial. After all, if a treatment is withheld, we will never know for sure whether it would have been effective and beneficial. But if a treatment is started and turns out not to be effective and/or beneficial, we have concrete evidence that supports withdrawing treatment.

5.2.2 Do I have to withhold or withdraw treatment if it is refused by a competent patient?

Yes. As pointed out earlier (see § 3.2.10), a competent patient can withhold or withdraw consent for any kind of medical treatment, including life-sustaining treatment. Naturally, the health care providers should carefully examine whether this refusal of treatment truly represents the wishes of the patient or reflects the patient's dissatisfaction with the care provided. For example, the patient may feel that he is not sufficiently involved in the planning process, not listened to, not being taken seriously. However, if competent, the patient has the ethical and legal right to refuse even life-sustaining treatment.

5.2.3 If a patient refuses life-sustaining treatment, and I withhold or withdraw such treatment, doesn't that mean I am assisting in the patient's suicide?

No. From a legal perspective, a physician should never be charged with physician-assisted suicide if a competent patient, after receiving adequate information, explicitly refuses life-sustaining treatment (for a more detailed reply, see § 4.3.8).

Note also that the law on living wills specifically states that if a patient dies when care is withdrawn or withheld in accordance with the *Rights of the Terminally Ill Act*, that course of events "shall not constitute, for any purpose, a suicide or homicide"[Nebr. Stat. 20-412(1)].

5.2.4 If a patient refuses artificial ventilation, becomes short of breath, and then demands medications to relieve his suffering, can I provide those medications?

Yes. As pointed out earlier (see § 3.2.13), a patient cannot force the physician into providing certain treatments. For example, the patient cannot use his right to refuse treatment and bluntly reject all non-narcotic pain killers, until only the option of a narcotic is left and demand that the physician prescribe the narcotic for his unrelieved pain. However, the situation is different if a patient refuses a treatment because it is no longer beneficial or because its side-effects are too burdensome. If a ventilator is removed for these reasons, the patient retains the right to be provided with all other palliative options.

Although there is no Nebraska Court decision evidencing this conclusion, decisions in both California and Georgia have underscored and affirmed this patient right [see: *State vs. McAfee*, 259 Ga. 579, 385 S.E.2d 651 (1989); see also Shapiro 1996].

Note, too, that the Nebraska *Rights of the Terminally Ill Act* emphasizes that a patient's refusal of life-sustaining treatment by means of a living will "shall not affect the responsibility of the physician or other health care provider to provide treatment... for a patient's comfort care or alleviation of pain"[Nebr. Stat. 20-408(2)].

Forgoing Treatment Against the Patient's Request**5.2.5 Do I always have to offer all life-sustaining interventions to my patient?**

No. A physician is obligated to discuss with the patient all options that, in his or her expert medical judgment, provide a realistic solution to the patient's medical problem. A physician may not propose treatments that are useless for the problem at hand or are very likely to cause more harm than good to the patient. For example, a physician may not prescribe penicillin for a patient with a viral infection (against which antibiotics are ineffective) or for a patient who previously has had a severe allergic reaction to penicillin.

The same rule applies to end-of-life care scenarios. If a treatment is unlikely to relieve the diagnosed medical need, or is clearly going to be too burdensome, the physician may not propose this particular treatment. In the words of the Council on Ethical and Judicial Affairs of the American Medical Association:

Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefitting their patients. Patients should not be given treatments simply because they demand them. Denials of treatment should be justified by reliance on openly stated ethical principles and acceptable standards of care [Code of Medical Ethics, 1998-99 edition: Current Opinions 2.035:"Futility"].

5.2.6 Can a patient - or a family member - demand that I initiate or continue life-sustaining treatment, even if I think such treatment has become futile?

No. A patient cannot simply demand life-sustaining treatment (see also § 3.2.13). A physician may only offer treatment that in his or her professional judgment will benefit the patient. Of course, the fact that the patient demands life-sustaining treatment is a very strong indicator that the treatment is likely to benefit the patient. But sometimes patients are misinformed or misunderstand, believing that treatments will be effective even though there is no scientific evidence supporting that expectation.

This is even more likely to happen when the patient is incompetent and family members or others with surrogate authority must make decisions on the patient's behalf. It is difficult to let go of one's own life; but it is even more difficult to let a beloved other person go. Family members or surrogate decision-makers may feel obligated to insist that "everything is tried and done." In such instances it is important that health care providers consider these wishes. But the health care providers' primary duty is to protect the patient against undue and harmful demands for treatment.

Cardiopulmonary Resuscitation

5.2.7 Do I always have to resuscitate a patient in the event of a cardiopulmonary arrest in the absence of a DNR order?

This is not clear. There is considerable scientific evidence that Cardio-Pulmonary Resuscitation (CPR) is not a very effective therapy, particularly not for hospitalized patients suffering from terminal conditions. In most instances, the CPR efforts cannot reestablish cardio-pulmonary function or the patient dies soon thereafter.

In spite of the poor outcome overall, CPR is justifiable in genuine emergency situations, that is, when patients unexpectedly suffer an arrest. In emergency situations a patient's consent for treatment that could be life-saving may be presumed (see § 3.4).

But we have seen that all non-emergency medical treatment requires the prior consent of the patient before it can be initiated (see § 3.2.6). If the health care team expects that a particular patient in the near future will suffer a cardiac arrest, the team must explain this expectation to the patient, discuss the option of CPR, and obtain the patient's consent for such resuscitation. It would be both immoral and

illegal to withhold such information from the patient and, when the arrest occurs, provide CPR on the basis of a presumed consent.

Consider the analogous example of a Jehovah's Witness patient who is diagnosed with an aneurism of the aorta, requiring surgery. The surgeon knows that in all likelihood, the patient will lose a lot of blood during the surgery and require a transfusion. He also knows that this patient, being a Jehovah's Witness, probably will refuse the transfusion. So instead, the surgeon simply does not inform the patient of this problem. He initiates the surgery, and when the patient does, indeed, lose too much blood, he declares a medical emergency and initiates a transfusion on the basis of a presumed consent. Such a maneuver would be both immoral and illegal.

Nevertheless it has become common practice in most hospitals to always initiate CPR in the event of a cardio-pulmonary arrest, unless there is a specific order in the patient's chart not to resuscitate, a so-called Do-Not-Resuscitate (DNR) order.

5.2.8 Do I need the patient's consent to enter a Do-Not-Resuscitate (DNR) order in the patient's chart?

Yes; it is an anomaly of sorts, but it is necessary. If Cardio-Pulmonary Resuscitation (CPR) were treated like all other medical interventions, there would be no need for Do-Not-Resuscitate (DNR) orders. After all, one generally does not obtain consent from a patient *not* to do something. Rather, the health care provider must obtain consent in order *to do* something to the patient. As pointed out earlier (see § 3.2.6), without the patient's consent, a health care provider generally cannot provide treatment. Medical emergencies constitute the only exception to this rule (see § 3.4).

However, CPR is the only medical intervention for which consent is required *not* to do it. Even though this goes against the ethical and legal principles for medical care in general, it has become routine to resuscitate all patients, emergency patients as well as patients who were known to be at risk of an arrest, without their consent (see § 5.2.7).

The net result of this anomalous manner of handling CPR is that a DNR-order today is seen as a medical decision requiring the consent of the patient or the patient's agent. This can create very troublesome dilemmas for clinicians when they know that CPR of a particular patient is very unlikely to be effective (< 1% when

the patient has metastatic cancer), and more likely to result in harmful neurological side-effects (20%), but the surrogate decision-maker insists that CPR be tried anyway.

5.2.9 What about ambulance personnel? Do they have to abide by a DNR order?

As pointed out earlier (see § 3.4.3), Nebraska's *Emergency Medical Services Act* does not provide much guidance to ambulance personnel where issues of consent are concerned. On the one hand, the competent patient clearly has the right to consent and, hence, refuse certain treatments. On the other hand, the various statutes governing advance directives appear to apply equally to ambulance personnel.

This would suggest that if a valid advance directive containing a DNR order is on hand, CPR should not be initiated by the ambulance personnel. And if CPR has already been initiated, it should be discontinued when this DNR order is presented to them.

Nutrition and Hydration

5.2.10 Can I forgo artificially administered nutrition and hydration when the patient (or the patient's family) refuses such interventions?

Yes. As was pointed out earlier, a patient has the right to refuse artificially administered nutrition and hydration. The competent patient can do so by withholding consent for these interventions; the incompetent patient can do so via a living will or by issuing special instructions to his/her agent when issuing a power of attorney for health care (see § 3.5.19). If a patient, or the patient's agent, withholds or withdraws consent for a medical intervention, that intervention cannot be initiated or continued. [See also: *Bowia v. Superior Court*, 179 Cal. App. 3d 1127, 1145, 225 Cal. Rptr. 297, 306 (1986)].

5.2.11 Do I always have to administer artificial nutrition and hydration, as long as the patient (or the patient's family) does not refuse such interventions?

No. A physician may only recommend the initiation of artificially administered nutrition and/or hydration when there is a medical indication for such an intervention. The patient's condition must warrant the intervention and the intervention must be effective. In this regard, there is no difference between artificial nutrition and hydration on the one hand, and antibiotics, a ventilator or other life-sustaining medical interventions on the other hand.

There is ample medical evidence that artificially administered nutrition and hydration are not always beneficial for the patient. Indeed, they can be harmful to the patient [see, e.g., Mitchell *et al.*, 1997]. Hence, there may be situations where the physician should not start or continue artificial nutrition and/or hydration, even if family members or legally authorized surrogate decision-makers ask for such intervention.

The emphasis here is on the word *artificial* administration. Regular provision of food and fluids by mouth may not be withheld or withdrawn (unless a competent patient refuses to eat and drink and force would be required to make the patient do so).

6. ONCE THE PATIENT HAS DIED

6.1 INTRODUCTION

Good end-of-life care does not stop when the patient has died. Surviving relatives are in need of compassionate support. The body of the deceased must be taken care of. We owe those bodily remains respect and several laws are in place to help us do so properly.

6.2 DETERMINATION OF DEATH

6.2.1 On what grounds is a patient determined to have died?

As pointed out earlier (see § 2.2.5), Nebraska accepts both irreversible cardiac death and whole brain death as criteria of a patient's biological death.

6.2.2 Who formally determines that the patient has died?

The attending physician (or any other physician who attended to the dying person) must certify the patient's death. This is done by completing and signing that part of the certificate of death entitled "medical certificate of death." The physician must indicate the disease and/or other causes leading to the patient's death. The physician must complete the certificate within twenty-four hours from the time of death and in his or her own handwriting [Nebr. Stat. 71-605(2)]. If for any reason the attending physician cannot do so, the "coroner's physician" (i.e., a physician appointed by the county coroner to assist in various functions of the coroner's office), will do so [Nebr. Stat. 23-1820].

6.2.3 Who fills out the "certificate of death"?

The funeral director in charge of the funeral is responsible for making sure that the certificate of death is filled out. A standardized form is available from the Department of Health and Human Services. However, the part of the certificate

called the "medical certificate of death," must be completed personally by a physician (see § 6.2.2, 6.2.3).

6.2.4 Are copies of the death certificate available to family members?

Yes. Copies of death certificates are provided by the Nebraska Department of Health and Human Services Bureau of Vital Statistics if certain criteria are met. These criteria are listed in Title 174 (art. 004) of the Nebraska Administrative Code, which can be downloaded from the web-site of the Nebraska Department of Health and Human Services. A form to request a copy of a death certificate is available from this website.

Death of a Child

6.2.5 Are there any special regulations when a child dies?

Nebraska's legislature has passed several laws that specifically pertain to the death of a child. These concern autopsy of the child's body [Nebr. Stat. 23-1824] and an in-depth, multi-disciplinary review of the death itself [Nebr. Stats. 71-3404 to 71-3411].

6.2.6 Is autopsy of the corpse of a minor patient always legally required?

Nebraska law [Nebr. Stat. 23-1824] requires that an autopsy is performed when a minor (i.e., someone under the age of 19) dies a sudden death, unless the cause of death is readily recognizable (e.g., trauma resulting from an accident), and the death did not occur under suspicious circumstances, no autopsy is required.

6.3 PATIENT RIGHTS THAT EXTEND AFTER THE PATIENT'S DEATH

6.3.1 Can the patient decide how his/her corpse shall be used or disposed of after his/her death?

Yes. Nebraska law assigns each individual the right to make such decisions. For example, the patient can decide to donate her organs for transplantation, biomedical research or for the education of future health care providers (see § 6.4). The patient likewise has the right to decide what shall happen with her bodily remains in terms of burial or cremation (see § 6.5). However, there are certain restrictions placed on these kinds of decisions, particularly if the patient's death may be the result of an illegal act or the cause of death is unclear. In such cases, the coroner can order an autopsy of the corpse (see § 6.2.6).

6.3.2 What happens to patient rights such as confidentiality and access to the patient's medical records? Can family members demand access to the records?

Nebraska's statute governing access to medical records do not discuss what happens to a patient's medical records upon the patient's death. However, it is specifically stated that "a provider shall not be required to disclose confidential information in any records concerning another patient or family member who has not consented to the release of the record." [Nebr. Stat. 71-8403]

In addition, Section 27-504(3), which deals with professional confidentiality in the context of a court proceeding, would suggest that the patient's right to confidentiality continues after death. It should also be pointed out that the World Medical Association's *International Code of Medical Ethics* (last revised in 1983) specifically states that the patient's right to confidentiality endures after death.

The patient's right to confidentiality is not absolute during life, and hence not after death either. However, the cited regulations suggest that the patient's right to confidentiality in principle endures after death and probably should only be violated for exceptional and serious reasons, and not simply because a family member would like to see the patient's records.

6.4 POST-MORTEM ORGAN DONATION

Post-mortem donation of one's body or certain organs and tissues is regulated in the Nebraska Statutes by sections 71-4801 through 71-4812. According to section 71-4812, this set of statutes is also known as the *Uniform Anatomical Gift Act*, to indicate that this law is similar to the Anatomical Gift Acts of other states.

6.4.1 Can the patient decide to donate his/her organs for transplantation?

Yes. The patient has the right to donate his/her organs for the purpose of post-mortem organ transplantation [Nebr. Stat. 71-4802 (1)].

6.4.2 Can the patient decide to donate his/her organs for any other purpose than organ transplantation?

Yes. Nebraska's *Uniform Anatomical Gift Act* lists the purposes for which a person may donate his or her organs or whole body. In a nutshell, there are only three justifiable purposes:

- (1) Therapy of another person, specifically by means of blood transfusion or organ transplantation;
- (2) The education of future physicians and dentists; or
- (3) Research aimed at the advancement of the biomedical sciences.

6.4.3 Can a minor decide to donate organs?

A minor who are 18 years and "of sound mind" can. [Nebr. Stat. 71-4802].

6.4.4 If a person can donate organs, can (s)he also sell his/her organs?

No. Nebraska law does allow for reimbursement of expenses of people who give away their body. However, even if the recipient reimburses the donor, for all legal purposes the transaction remains a "service," not a sale [Nebr. Stat. 71-4001].

6.4.5 Can family members consent to organ donation?

Yes. The *Uniform Anatomical Gift Act* specifies that in addition to the organ donor himself, certain other people can consent to the removal of organs. The *Uniform*

Anatomical Gift Act [Nebr. Stat. 71-4802(2)] rank-orders them as follows, whereby a person in a lower rank cannot override the decision of a person in a higher rank:

- (a) The spouse;
- (b) An adult son or daughter;
- (c) Either parent;
- (d) An adult brother or sister;
- (e) A guardian of the person of the decedent at the time of death; and
- (f) Any other person authorized or under obligation to dispose of the body.

6.4.6 What happens if surviving family members disagree amongst themselves about post-mortem organ donation?

It depends on the rank of the person objecting (see § 6.4.5, 6.4.6). If the person objecting to the post-mortem organ donation is of the same or higher rank, consent for organ donation cannot be given [Nebr. Stat. 71-4802(2)]. Moreover, the intended recipients of the organs (for example, the transplantation team) may not accept the gift if they know of such objections by equally or higher ranked persons [Nebr. Stat. 71-4802(3)].

6.4.7 Can family members consent to organ donation even if the actual organ donor had made clear that she did not want to donate organs after her death?

No. If the persons specified in § 6.4.5, 6.4.6 know about objections by the deceased patient to organ donation, they cannot consent to post-mortem organ donation [Nebr. Stat. 71-4802(2)]. Moreover, the intended recipients of the organs (for example, the transplantation team) may not accept the gift if they know of such objections by the now deceased patient [Nebr. Stat. 71-4802(3)].

6.4.8 If the patient has declared herself to be an organ donor, but the family objects to the organ donation, whose decision prevails?

The donor's. Given that the patient has the right to decide how his/her corpse shall be used or disposed after his/her death (see § 6.3.1), that the patient's wishes prevail. After all, it is her body, not the body of the surviving relatives. Indeed, Nebraska's *Uniform Anatomical Gift Act* confirms that such a donation takes effect immediately upon death and is no longer conditional on the consent of family members [Nebr. Stat. 71-4802(2)].

In addition, the Nebraska statute governing interment reiterates that a person may leave instructions about post-mortem organ donation. The statute next demands that the "person ... entitled to control the disposition of the remains" (i.e., the family members in most cases) "shall faithfully carry out the directions of the decedent" [Nebr. Stat. 71-1340]. This would suggest that a family member acts illegally when he or she tries to block post-mortem organ donation against the patient's explicit instructions.

6.4.9 If the patient has left a written declaration (e.g., an organ donor card) stating that she wants to be an organ donor, but the family objects, do I run legal risks when I proceed with the organ removal?

As pointed out earlier (§ 6.4.8), the Nebraska *statutes* do not grant family members the right to block organ donation when the deceased him/herself has already made his/her wish to be an organ donor known.

In addition, the Nebraska statute governing interment also states clearly that the transplant team or hospital cannot be held liable for removing and accepting the patient's organs in accordance with the patient's written instructions [Nebr. Stat. 71-1340].

6.4.10 If a patient does not want to be an organ donor, what does (s)he need to do?

Since people other than the patient can consent to organ donation (see § 6.4.5, 6.4.6), it is important that the person who absolutely does not want to be an organ donor makes her objections clear, first and foremost to family members, but also to his or her physician, and in the patient's advance directive (if the patient has one). The Nebraska *Uniform Anatomical Gift Act* does not allow physicians to proceed with organ removal when they know the patient was against organ donation.

6.4.11 Since consent for organ donation can be given by the deceased patient's surviving relatives, even if the patient was not a declared organ donor, do I as the attending physician have to discuss organ donation with the family?

No, the physician does not have to personally talk with the family, but (s)he should make sure that the appropriate organ procurement officer in the facility does so.

More specifically, Federal law requires that the hospital notify the Organ Procurement Organization (or the OPO designee) of patients whose death is imminent or who have died in the hospital. The OPO then determines medical suitability for organ donation. In collaboration with the designated OPO, the family of each potential donor is informed of its options to donate organs, tissues, or eyes, or to decline to donate. This discussion with the family must be initiated by an organ procurement representative or an individual who has completed the necessary education for this task [42CFR482.45].

However, according to Nebraska law no discussion about organ donation has to be initiated if the attending physician (i) is aware that the deceased patient was opposed to post-mortem organ donation, (ii) believes or has reason to believe that the patient's religious beliefs are at odds with organ donation, or (iii) already knows that the person who has to consent is not going to grant consent [Nebr. Stat. 71-4815(2)].

Nebraska Law also requires the physician who completes the medical certificate of death to indicate whether organ donation for the purpose of transplantation was considered and whether consent was granted by one of the persons listed in § 6.4.5, 6.4.6 [Nebr. Stat. 71-4816].

6.4.12 If I am the physician certifying the death of an organ donor, can I then immediately proceed with the preparation for organ removal?

No. Nebraska law prohibits the physician who attends to the patient at his or her death, or who certifies the patient's death, to participate in procedures for actually removing and transplanting organs. This is to assure that treatment decisions will not be colored by a desire to retrieve a patient's organs. The only exception concerns the enucleation of eyes of the deceased organ donor [Nebr. Stat. 71-4807(2)].

6.5 CREMATION AND BURIAL

6.5.1 Who determines how the body of the deceased is to be disposed?

Any person can leave legally binding instructions about what should happen to his or her body after death. However, if the deceased has not left specific instructions, Nebraska law [Nebr. Stat. 71-1339] specifies and ranks (in descending priority) the persons who have the authority to make decisions about the disposition of the remains:

- (1) The surviving spouse
- (2) Adult child of the deceased
- (3) A surviving parent of the deceased
- (4) An adult brother or sister of the deceased
- (5) An adult person who legally is next in line to inherit
- (6) The State Anatomical Board; or
- (7) The county board of the county in which death occurred.

6.5.2 Is a permit required to arrange for burial or cremation and, if so, how is such permit obtained?

Once the death certificate has been completed, interment can be arranged by a licensed funeral director. However, if the deceased is to be cremated, a permit for cremation must be issued by the county attorney (or by his or her designated representative). The county attorney will use a standard form prepared by the Department of Health and Human Services [Nebr. Stat. 71-605(4)].

7. CASE EXAMPLES

7.1 *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990)

In this case, hospital employees refused to honor the request of Nancy Cruzan’s parents to terminate her artificial nutrition and hydration, since that would result in death. Lester and Joyce Cruzan, Nancy’s parents and co-guardians, sought a court order directing the withdrawal of their daughter’s artificially administered nutrition and hydration equipment after it became apparent that she had virtually no chance of recovering her cognitive faculties. The Supreme Court of Missouri held that because there was no clear and convincing evidence of Nancy’s desire to have life-sustaining treatment withdrawn under such circumstances, her parents lacked authority to effectuate such a request. The United States Supreme Court affirmed, stating that the United States Constitution does not forbid Missouri to require that an incompetent’s wishes as to the withdrawal of life-sustaining treatment be proved by clear and convincing evidence.

The Supreme Court considered whether Cruzan had a right under the United States Constitution that would require the hospital to withdraw life-sustaining treatment under the circumstances. The Court stated the common law rule that even the touching of one person by another without consent and without legal justification constitutes battery. The Court also referred to its 1891 ruling in *Union Pacific R. Co. v. Botsford*, 141 U.S. 250, 251 that “[n]o right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”

The doctrine the Supreme Court speaks of is informed consent, which was aptly described by Justice Cardozo while on the Court of Appeals of New York: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages.” The informed consent doctrine is firmly entrenched in American tort law. The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is to refuse treatment.

The common law doctrine of informed consent is viewed as generally encompassing the right of a competent individual to refuse medical treatment. The Supreme Court held that the Due Process Clause of the Fourteenth Amendment provides a constitutionally protected liberty interest in refusing unwanted medical treatment [*Jacobson v. Massachusetts*, 197 U.S. 11, 24-30 (1905)]. However, determining that a person has a liberty interest under the Due Process Clause does not end the inquiry. Whether a person’s liberty interests have been violated must be determined by balancing his liberty interests against the relevant state interests [*Youngberg v. Romeo*, 457 U.S. 307, 321 (1982) and *Mills v. Rogers*, 457 U.S. 291, 299 (1982)].

The Supreme Court held for purposes of the Cruzan case that an assumption exists that “the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition” [*Cruzan* at 279]. The issue in *Cruzan*, of course, involved the removal of artificially administered nutrition and hydration from an incompetent person. Missouri law allows for such removal, however, the State has established procedural safeguards to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent. Missouri law requires that evidence of the incompetent’s wishes as to the withdrawal of treatment be proved by clear and convincing evidence. The question in *Cruzan*, then, is whether the United States Constitution forbids the establishment of this evidentiary requirement by the State. The United States Supreme Court held that it does not.

The Supreme Court ruled that a state may put safeguards into place such as Missouri’s clear and convincing evidence rule, which is applied when a guardian seeks to discontinue artificially administered nutrition and hydration of a person diagnosed to be in a persistent vegetative state. However, the Court also held that the Due Process Clause of the Fourteenth Amendment protects an interest in life as well as an interest in refusing life-sustaining medical treatment.

7.2 *Vacco v. Quill*, 521 U.S. 793 (1997)

Three New York physicians and three gravely ill patients (who died before the U.S. Supreme Court decision was handed down) sued the State’s Attorney General claiming that the ban against physician-assisted suicide violates the Fourteenth Amendment’s guarantee of equal protection of the laws. The plaintiffs believed that terminally ill competent persons who wish to hasten their deaths by self-administering prescribed drugs are treated differently than those who wish to hasten their deaths by directing the removal of life support systems. The Supreme Court held that New York’s prohibition on assisting suicide does not violate the Equal Protection Clause.

The Equal Protection Clause embodies a general rule that States must treat like cases alike, but may treat unlike cases accordingly [*Plyler v. Doe*, 457 U.S. 202, 216 (1982)]. The Supreme Court held that the New York statutes outlawing assisted suicide neither infringe fundamental rights nor involve suspect classifications and are, therefore, entitled to a strong presumption of validity. The Court found there is no distinction because *everyone*, regardless of physical condition, is entitled, if competent, to refuse unwanted lifesaving medical treatment; *no one* is permitted to assist a suicide. Laws that apply evenhandedly to all unquestionably comply with the requirement of equal protection.

Petitioners argued that ending or refusing lifesaving medical treatment is basically the same as assisted suicide. The Second Circuit agreed with the plaintiffs in ruling that the ban violated the Fourteenth Amendment, however, the Supreme Court found a major distinction between *letting* a patient die and *making* a patient die. The Supreme Court ruled that the two acts are different, and New York, consistent with the Constitution, may treat them differently.

The Supreme Court also held that New York’s ban on physician-assisted suicide is rationally related to legitimate state interests. The State interests include: prohibiting intentional killing and preserving life; preventing suicide; maintaining physicians’ role as their patients’ healers; protecting vulnerable people from indifference, prejudice, and psychological and financial pressure to end their lives; and avoiding a possible slide towards euthanasia.

7.3 *Washington v. Glucksberg*: 521 U.S. 702 (1997)

Three terminally ill patients, four physicians, and a nonprofit organization brought an action against the state of Washington for declaratory judgment that the statute banning assisted suicide violated the Due Process Clause of the Fourteenth Amendment of the United States Constitution. The United States Supreme Court held that: (1) the asserted right to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause, and (2) Washington’s ban on assisted suicide was rationally related to legitimate government interests.

The Court examined our Nation’s history, legal traditions, and practices and concluded that Anglo-American common law has punished or otherwise disapproved of assisting suicide for over 700 years, that rendering such assistance is still a crime in almost every State and that such prohibitions have never contained exceptions for those who were near death. In light of our Nation’s history, the Court concluded that the respondent’s asserted “right” to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause.

The United States Supreme Court has regularly observed that the Due Process Clause specially protects those fundamental rights and liberties that are, objectively, deeply rooted in this Nation’s history and tradition. The Court determined that the question becomes whether the “liberty” specially protected by the Clause includes a right to commit suicide and the right to assistance. The Court held that to hold for such a right would require the reversing of centuries of legal doctrine and practice, and strike down the considered policy choice of almost every State.

The Court noted that the decision in *Cruzan* regarding the right to refuse artificially administered nutrition and hydration was not deduced from abstract concepts of personal autonomy, but was grounded in the Nation’s history and traditions, given the common law rule that forced medication constitutes battery, and the long legal tradition protecting the decision to refuse unwanted medical treatment. No such history was found promoting suicide.

The Court further held that the constitutional requirement that Washington’s assisted suicide ban be rationally related to legitimate government interests was unquestionably met. The Court determined the interests to include prohibiting intentional killing and preserving human life; preventing the serious public health

problem of suicide, especially among the young, the elderly, and those suffering from untreated pain or from depression or other mental disorders; protecting the medical profession's integrity and ethics and maintaining physician's role as their patients' healers; protecting the poor, the elderly, disabled persons, the terminally ill, and persons in other vulnerable groups from indifference, prejudice, and psychological and financial pressure to end their lives; and avoiding a possible slide towards voluntary and perhaps even involuntary euthanasia. The Court held that the relative strengths of the various interests need not be weighed exactly, since they are unquestionably important and legitimate, and the law banning assisted suicide is at least reasonably related to their promotion and protection.

7.4 *In re Farrell*, 529 A.2d 404 (1987)

This New Jersey case illustrates a situation in which the patient's competency was at question. The patient, suffering from amyotrophic lateral sclerosis, wished to have her ventilator disconnected, even though her attending physician informed her that she would die. The physician, concerned about the patient's state of mind, proceeded to have her evaluated by a psychologist, who pronounced her mentally well, "not clinically depressed," and in need of no psychiatric treatment. The psychologist, in fact, later testified in court that the patient had made an informed, voluntary, and competent decision to forgo further ventilator support.

By the time the case got to the New Jersey Supreme Court, the patient had died, still connected to her ventilator. However the court persisted in rendering a decision on the merits, "because of the extreme importance of the issue and the inevitability of [similar] cases arising in the future." The court described the following decision-making procedures, which it believed would be sufficient to permit without court approval the removal of medical treatment from a competent but disabled adult being cared for outside of a healthcare institution: Two non-attending physicians must examine the patient and determine (a) that the patient is competent; (b) that the patient is properly informed about the prognosis, the alternative treatments available and the risk involved in the withdrawal of the life-sustaining treatment; and (c) that the patient's decision is voluntary and has not been coerced. Then, the patient's right to decide must be balanced against the four potentially countervailing state interests: (1) preserving life; (2) preventing suicide; (3) safeguarding the integrity of the medical profession; and (4) protecting innocent third parties [*In re Farrell*, 108 N.J. 335, 529 A.2d 404, 410,413-14 (1987)].

7.5 *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 196 Cal. Rptr. 484 (1983)

In this case, a patient underwent surgery during which he suffered a cardiorespiratory arrest. He was revived by medical and nursing personnel and immediately placed on life support equipment. The patient suffered severe brain damage, leaving him in a vegetative state that was likely to be permanent. The prognosis for the patient's recovery was extremely poor. The patient's wife and eight of his children requested, in writing, the removal of all machines sustaining his life. The life support was removed; however, the patient continued to breathe on his own. There was no improvement in the patient's condition; therefore, artificially administered hydration and nutrition were removed two days following the removal of cardio-respiratory life support. The patient died sometime thereafter.

In this case, there were no formal guardianship proceedings, and judicial approval had not been sought. The court ruled that the wife was the proper person to act as surrogate and would have been appointed by the court to make the decision anyway. The court upheld the right of the family to remove life support, hydration, and nutrition for an incapacitated patient while stating that although a duty existed to provide life-sustaining machinery in an emergency, the duty did not exist once the situation became futile.

7.6 *Schiavo ex rel Schindler v Schiavo*, 2005 WL 681652 & 665257 (11th Cir 2005).

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9. GLOSSARY OF TERMS USED

Ad Litem	For the purposes of a particular court case (see <u>Guardian ad Litem</u>)
Advance directive	Instructions by a patient to a health care provider given in advance of that patient becoming <u>incompetent</u> . Usually in written form and legally binding in all of the United States if properly executed. Two primary formats: <u>living will</u> and <u>power of attorney</u>
Assisted suicide	More correctly referred to as “assisting in suicide.” Act of facilitating the suicide by another person.
Autonomy	Derived from the Greek word “auto-nomos”: self-law or self-determination. Originally used as a political term: ruled, governed by the self. Used in opposition to <u>heteronomy</u> : determined, governed by the other. Used by the 18 th century German ethicist <u>Kant</u> to characterize the kind of moral rules that are self-evident and do not rely on external proof. For example: The rule never to break a promise, is an autonomous rule. After all, the very notion of a promise implies that it cannot be broken; if it were permissible to break a promise, there would be no point in making a promise. In 20 th century American law, autonomy refers to the individual citizen's right to be left alone, i.e., to remain free from state-sanctioned coercion. In bioethics, the term autonomy refers primarily to a patient's determining his or her own medical care. Patients have a right to respect of their autonomy, i.e., health care providers must take a patient's own health care related wishes, values, and choices very

	seriously (see also: <u>principle of (respect for) autonomy</u>).
Battery	Intentionally or recklessly causing offensive physical contact or bodily harm (e.g., administration of a drug, amputation of the wrong leg, or a physical examination) for which the victim has not given <u>consent</u> .
Beneficence	Doing what is good (for patients). Distinguished from <u>nonmaleficence</u> .
Best interest judgment:	Judgment about what is objectively in the patient's medical interests. Although a best interest takes into account the wishes and unique needs of the individual patient, it is not synonymous with what the patient wants because people can want what actually is harmful to them.
Capacity	Of patients: The factual ability to understand the nature of his or her medical condition and to make relevant decisions about his or her own health care. See also <u>competence</u> .
Compassion	Virtue of “suffering together,” i.e., “feeling along” with the suffering of another human being and staying close to that suffering patient.
Competence	When said of patients: Patient decision-making competence (also called decision-making capacity). The ability, for legal purposes, of a patient to make decisions about his or her own health care. See also <u>capacity</u> . When said about health care providers: The knowledge and skillfulness of the health care provider that allows him or her to practice in accordance with the technical standards of his or her profession.

Competent professional standard: Standard by which the actions of a health care provider are assessed by comparing the work of the health care provider with the work of “the average yet competent peer,” that is, with the work of colleagues in his or her community. Distinguished from reasonable patient standard.

Confidentiality The state of being (kept) secret, specifically of patient related information and documentation.

Consent Freely given authorization by the patient to proceed with a proposed diagnostic or therapeutical intervention.

CPR Cardio-pulmonary resuscitation. A set of medical interventions aimed at reactivating the patient’s heart beat and breathing when one or both of these have suddenly stopped (see also DNR-order)

DEA Drug Enforcement Agency. Federal agency charged with the task of combating misuse and abuse of drugs.

DNR-order Do-Not-Resuscitate order. A directive, entered into the patient’s chart, not to provide CPR if the patient suffers a cardio-pulmonary arrest.

Double effect The phenomenon that a particular action has more than one effect, specifically one good and one evil effect. Principle of double effect: The ethical thesis that under certain conditions, an action which has an evil effect (in addition to a good effect) may be justified in spite of the evil effect. These conditions include: The act may not be intrinsically evil; only the good effect may be intended; the bad effect may not be the means to the good effect; and the good effect is significantly

more important than the bad effect and cannot be attained without causing the bad effect.

Durable Enduring, lasting. Specifically of a power of attorney for health care, indicating that this authorization not only concerns one specified health care decision, after which the authorization loses its force, but retains its force until it is explicitly revoked; hence it endures after the patient has become incompetent.

Ethical In this Guide: Pertaining or related to ethics. In other literature and in common parlance often used as a synonym of moral, i.e., good, fair or just.

Ethics Critical study of morality using philosophical methods of analysis.

Euthanasia Literally a good death or a good dying process. Act of intentionally ending the life of a person, generally using medical means in order to make sure that the dying process is “good.” Synonym of mercy killing.

Explicit consent Consent that is clearly and unmistakably stated by the patient herself for a specified intervention. Opposite of implied consent and presumed consent.

Expressed consent Synonymous with explicit consent

Fiduciary Based on trust (Lat: fides).

Forgoing treatment In this GUIDE, used generically to encompass both withholding medical treatment not yet started and withdrawing treatment that has already been started.

Futile	Useless Of medical treatment: treatment that does not protect or foster a patient’s health (even though it may be effective in restoring the function of a particular organ).
Guardian	A person appointed by a court to guard over the well-being of another person who is him- or herself unable to do so (the so-called “ward”). Specifically, this means that the guardian should manage the person’s property and other personal affairs, including matters of health care. Guardian ad litem: Guardian appointed by a court to advocate for the best interests of the patient, but only for the purposes of this particular court case (“ad litem”).
Hippocrates	Ancient Greek physician (±460 - ±377 BC); mostly known because of the extensive body of medical writings attributed to him, collected as the Corpus Hippocraticum. His name continues to be associated with the famous “Hippocratic Oath” although this oath actually may not have been written by Hippocrates.
Immoral	Bad, evil, contrary to the standards of morality.
Implied/Implicit consent	<u>Consent</u> (for an intervention that is a necessary part of a treatment plan) that is not given explicitly by the patient, but that can logically be inferred from the patient’s previous <u>explicit consent</u> for a treatment plan or other conduct. Opposite of <u>explicit consent</u> . Sometimes also used as synonym of <u>presumed consent</u> for medical emergencies.
Incompetent	Opposite of competent (see <u>competence</u>)

Indication	Grounds to begin medical treatment based on the medical needs (rather than simply the wishes) of a patient.
Informed consent	<u>Consent</u> that is based on information (about diagnosis, prognosis, treatment options, risks, etc.) as provided by the health care provider and received and understood by the patient.
Intent/Intention	The aspect of a human act that makes the act goal-oriented (rather than accidental) and gives the act direction (rather than being random). Intention turns an event into a human act and, more specifically, into the act of a particular acting person.
Intentionally	Done with intent; aimed at a predetermined goal. Opposite of accidental, coincidental or unavoidable.
Living will	A type of <u>advance directive</u> that specifies in writing which treatments a patient does (not) want to undergo. See also <u>power of attorney</u> .
Mercy killing	Act of ending another person’s life whereby the person is motivated to do so by mercy (rather than greed, anger or some other evil motive). Although mercy is the <u>motive</u> , death is the <u>intent</u> and the act therefor remains a form of homicide. Synonym of <u>euthanasia</u> .
Moral	Possessing characteristics that make it relevant from the perspective of <u>morality</u> and, therefore, an object of <u>ethical</u> enquiry or assessment. Quality of being in accordance with the standards of <u>morality</u> , good, right, fair, or just. Opposite of <u>immoral</u> .

Morality	Morality is the normative structure of human life as it has been made concrete in specific rights and duties, rules and laws, ideals, virtues and vices.
Motive	That which moves or prompts a person to act in some manner. Distinguished from <u>intent</u> .
Negative right	Claim towards another person not to be restrained or harmed in some form. Also called liberal rights because negative rights foster liberty or freedom.
Neglect	Failure to intervene when one should have intervened
Nonmaleficence	Abstaining from harm-doing (to patients). Distinguished from <u>beneficence</u>
Palliative care	Health care that is aimed at relieving the symptoms of a patient’s disease, rather than striving for a cure or extension of life. Also called “comfort care.”
Parental	By the parents.
PAS	<u>Physician-assisted suicide</u>
Paternalism	Treating patients as a father (Lat: pater) treats his small children. In other words, making decisions on behalf of one’s patient for the presumed good of the patient but without involving the patient in the decision-making process. Also called “parentalism”, that is, behaving as a parent towards one’s patients. Soft or weak paternalism: Making decisions on behalf of one’s patient when one does not know the patient’s own opinion in the matter. Hard or strong paternalism: Making decisions on behalf of one’s patient contrary to the patient’s expressed wishes.

Power of attorney	A type of <u>advance directive</u> specifying who will make decisions on behalf of the patient if the patient becomes incompetent. See also <u>living will</u> .
Presumed consent	Authorization to proceed with medical treatment that is based on the presumption that the patient would have consented to the treatment had (s)he been able to consent. Presumed consent can only be invoked in an emergency type situation where there is no proxy who can consent on the patient’s behalf, and then only for the kind of emergency care that patients typically consent to.
Physician Assisted Suicide	The act of a physician helping a patient to end his own life. Since PAS refers to the physician who helps, rather than the patient who ends his own life, a more correct name would be: “Physician Assistance in Suicide.” Not to be confused with <u>euthanasia</u> .
Proxy	Someone <i>close to</i> the patient who is authorized to make decisions about health care on behalf of the patient. See also <u>surrogate</u> .
Proxy consent	<u>Consent</u> for treatment granted by a <u>proxy</u> on behalf of the patient when the latter is <u>incompetent</u> . See also <u>Substituted consent</u> .
Reasonable patient standard	Standard by which the actions of a health care provider are assessed by comparing the work of the care provider to that which would be expected by most reasonable patients (i.e., the well-informed, general patient population). Opposite of <u>competent professional standard</u> .
Right	Claim that one person can make towards another person, entailing a duty on the part of the other

	<p>person either not to act in some way (negative right), or to act in some way (positive right).</p>	<p>Voluntary</p>	<p>Freely, in accordance with one’s free will; not constrained by outside interference or coercion by others.</p>
Schedule	<p>Of drugs: One of five “schedules” or categories of drugs. Schedule I concerns illegal narcotic drugs. Schedule II concerns drugs that can be used for medical purposes but have a high potential for addiction and abuse.</p>		
Side-effect	<p>Undesirable and unintended (though possibly foreseen) effect of an intervention or medication.</p>		
Substituted consent	<p>A specific form of <u>proxy consent</u> in which the proxy tries to substitute for the patient and consents to what he thinks the patient would have consented to had the patient been able to decide herself. See also <u>substituted judgment</u>.</p>		
Substituted judgment	<p>Judgment that mimics what (presumably) the patient would have decided had she been competent. See also <u>substituted consent</u>.</p>		
Surrogate	<p>Someone who is authorized <i>to speak on behalf</i> of the patient when the latter is incompetent to make health care decisions. See also <u>proxy</u>.</p>		
Surrogate consent	<p>Synonymous with <u>proxy consent</u></p>		
Tort	<p>A violation of a duty (e.g., of due care) and any other wrongful act (other than a breach of contract) that injures another person and for which the law imposes civil liability. Distinguished from a criminal act.</p>		
Value	<p>The quality that makes something of interest and worth.</p>		

LIST OF SEE/SEE ALSO

- In the LOCATOR, replace all “[Indent]Zsea” by *see*
- Delete all “,0”
- Hyphenate decision making (etc.)
- Add page number to Locator in Index

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