For everything there is a season,
and a time for every matter under heaven:
a time to be born, and a time to die;
a time to plant, and a time to pluck up what is planted;
a time to kill, and a time to heal;
a time to break down, and a time to build up;
a time to weep, and a time to laugh;
a time to mourn, and a time to dance;
a time to cast away stones, and a time to gather stones together;
a time to embrace, and a time to refrain from embracing;
a time to seek, and a time to lose;
a time to keep, and a time to cast away;
a time to rend, and a time to sew;
a time to keep silence, and a time to speak;
a time to love, and a time to hate;
a time for war, and a time for peace.

[Ecclesiastes 3:1–9 (Revised Standard Version)]

The challenge is, of course, to discern just when the proper time for a given activity has arrived. The author of Ecclesiastes appears, in general, to be quite pessimistic about the capability of the human mind to fathom the details of cosmic purposes. The thematic refrain of that book is the lament: "Vanity of vanities, all is vanity!"

And yet physicians cannot avoid this challenge. Medical practices inevitably affect the determination of these "times," and hence physicians, once involved, cannot avoid influencing these "times"—by default, even if not by conscious design. Continuing intensive, life-prolonging efforts to refrain from "playing God" may amount to "playing God" in the other direction by dragging out the dying process with pain and anguish for all involved.¹ The proper "time to die" is neither too early nor too late.

¹. It must be acknowledged that some do claim to find positive value in suffering: some strengthen character through enduring it courageously; others find meaning in suffering by regarding it as a sort of punishment. These belief systems explain why a minister counseling a patient to accept pain medications may be more influential than a physician who gives the same advice. The guidelines developed in this chapter provide for these belief and value systems, as well as for those that see no redeeming value in the suffering of terminal illness.
This, then is the issue explored in this chapter. What standards can be employed to help determine the appropriate limits for therapeutic efforts or life-sustaining treatment? What is the role of the patient in making these determinations? What is the role of the patient’s family and friends? What legal guidelines bear on these decisions?

1 Determination of Death

One obvious limit to therapeutic efforts is death. There is clearly no point in continuing treatment after the patient has died, and indeed it might even be considered a desecration of the body to do so. However, the determination of even this boundary is not totally clear.

Some of the problematic dimensions of declarations of death are nicely illustrated in the film *The Wizard of Oz*. Dorothy and her house have just dropped into the Land of Oz, right on top of the Wicked Witch of the East. The Munchkins are dancing around celebrating their liberation from the witch’s oppression when the voice of caution intervenes. The town officials emerge onto the steps of City Hall and interject the following:

*Munchkinland*

*Town Council (unison):* "We’ve got to verify it legally, to see if she is morally, ethically, spiritually, physically, positively, absolutely, undeniably, and reliably, DEAD."

In response to this call, the coroner emerges from City Hall, ceremoniously walks over to the recently arrived house, and for a moment peers under it where the witch’s feet are sticking out (still encased in the ruby slippers). Then he returns to the steps of City Hall and sings his report to the Mayor and the members of the Town Council gathered there:

*Coroner:* "As coroner, I must aver

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I thoroughly examined her.
And she's not only merely dead;
She's really most sincerely dead."

His claim to thoroughness would certainly be questioned by any pathologist, but
in spite of that technical reservation, the incident illustrates the multifaceted nature
of determinations of death. The parameters provided by the Town Council are
especially illuminating here, for they recognize clearly that determination of death
is not merely a medical issue, but also one of law, ethics, and religion. In the
discussion that follows, we shall see how these myriad issues are involved in
determinations of death.

At the most general level, death is defined as “the irreversible cessation of vital
functions.” But this definition leaves several important questions unanswered.

1.1 “Irreversible”

The determination that the cessation is irreversible requires a prediction, and no
prediction about the future can be 100% certain. There is always some possibility
(even if only one chance in a billion) that one more shock or a few more minutes of
external cardiac massage would reinitiate vital functions.

Furthermore, the prediction of irreversibility may become a self-fulfilling
prophecy. If further attempts to restore vital functions are abandoned on the basis
of this judgment, then the likelihood of the judgment’s being proven false
decreases still further.4

It was this concern with predictive accuracy that prompted development of the
modern medical operational definition of death. Until the eighteenth century,
determination of death was not considered a medical matter. In most cases a
physician would not be in attendance at the time of death. The family would
determine on its own that death had occurred and would initiate the preparation of
the body for funeral rituals and burial. One important step in the change from this
pattern was an article, published in 1740 in a French medical journal by a young
physician named Jean Jacques Winslow, entitled “The Uncertainty of the Signs of
Death and the Danger of Precipitate Interments and Dissections” (see Alexander
1980, 25–31). Winslow urged that physicians be summoned for pronouncements
of death and that medical science work to develop operational criteria for making
these determinations. Winslow’s interest in this issue was not entirely academic.
As a child, he had been chronically ill and had awakened on at least two occasions
to find himself in a coffin and at the center of a wake! (Fortunately for him,
embalming was not done in those days; the body was merely washed. He was also

3. Ibid.
4. The component of irreversibility can also serve to distinguish death from those situations of
reversed cardiac arrest or temporary hypoxia from which people have awakened and reported certain
bizarre experiences. Whatever is going on in these situations (and we do not delve into this issue here),
it is not that they have experienced death and returned to tell us about it, since by definition death
involves irreversible cessation of function.
lucky to have regained consciousness before the burial.) No doubt partly as a result of his own experience, he proposed an extremely conservative operational criterion of death: putrefaction.

This operational test was not adopted, but the medical community did accept the general point that a medical criterion should be developed. After a good deal of discussion, tests related to respiration became the accepted medical means of determining death. (One such test still portrayed in movies is the placing of a mirror to the nose to check for breath, the moisture in which clouds the mirror.)

1.2 "Vital Functions"

Why was Winslow's proposal to make putrefaction the operational criterion of death not accepted? One reason may relate to public health considerations: it is unhealthy to leave corpses lying around until they begin to rot. Another reason was undoubtedly aesthetic: it is extremely distasteful to delay preparing a corpse for burial until after it has begun to rot. But there appears to be yet a deeper reason, which stems from a fundamental, philosophical understanding of what it is to be a human being. In our shared view of what constitutes the person, it seems that he or she has lost what is essential to be a living human being long before putrefaction of the flesh sets in. The core of being a human person has more to do with the functioning of the body than with the organic integrity of the flesh.5

The question of what human functions are "vital," then, is a philosophical one. The issue is to discern what traits are so fundamental to our understanding of what it is to be human that, once they have irreversibly ceased, we would say that the person no longer exists.

At an earlier stage of technological development, the philosophical niceties underlying this question may have been less important in practice. Cessations of any of a variety of bodily functions were operationally equivalent as indications of death. In those days it was beyond the capability of medical science to sustain other bodily processes when certain central processes had failed. For example, if the patient stopped breathing, an energetic bystander might shake her vigorously (perhaps shouting the patient's name) in hopes of "waking her up again," or the group might watch anxiously for a few moments to see if signs of breathing reemerged, but few other interventions were even attempted. Thus cessations of breath and heartbeat (which are the most readily observable of the central bodily functions) were plausible operational criteria of death.

Nowadays technology is more effective and selective, however. Medical science is capable of maintaining heart and lung function, for example, after the brain has irreversibly ceased to function. Thus, we must be correspondingly more precise in our understanding of what functions are fundamental or vital.

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5. As it turns out, putrefaction is not even a sufficient condition for determining death, since it is possible for putrefaction to occur while significant life processes continue. Thus a patient may have a gangrenous foot while heart, lungs, and brain continue to function more or less normally.
If we consider a human being a fundamentally physical organism, for example, then we might favor retaining the traditional operational criteria of determining death that center on heart and lung function. In this view, a person is still alive as long as the key organic processes of respiration and circulation are maintained, even if conscious life is irreversibly lost and heart and lung processes are maintained artificially by a mechanical ventilator.

If we consider a human being as fundamentally a consciousness, then we might favor operational criteria of death in terms of neocortical function. (This involves, of course, acceptance of the physiological premise that the neocortex is the organic seat of these functions.) In this view, that heart and lung functions could be maintained (indeed, in rare cases, these might even exist spontaneously) is unimportant to the judgment that the person has died. Irreversible cessation of the functions of conscious awareness and the capability to interact with others marks the death of a person, even though certain processes of the body continue to function.

If we regard a human being as fundamentally an integration of mental and physical processes, then we might favor operational criteria of death in terms of whole-brain function. As long as any brain function remains, the sense of the person as that which enlivens the body is not entirely lost. However, as soon as brain function ceases altogether, that sense vanishes. Thus it is appropriate to declare the person dead even if other processes (i.e., respiration and circulation) are continuing with technological assistance.

1.3 Statutory Definitions of Death

Society has expressed strong preferences among these possibilities. For several centuries the determination of death has been left to professional medical judgment. However, a number of state legislatures recently have passed statutory definitions. The process began in 1970 when Kansas enacted the nation’s first such law. Over the next ten years more than half of the 50 states enacted in one form or another statutes specifying what constitutes death.

All of these gave prominence to the operational criteria related to whole-brain function, although they dealt with them in some distinctly different ways. For example, the Kansas statute provided for determinations both in terms of "absence of spontaneous respiratory and cardiac functions" and "absence of spontaneous brain function," without any indication of when one is to be preferred to the other (presumably the choice is left to the individual physician's discretion). Several other states specified that brain criteria were to be applied "if artificial means of support preclude a determination that these functions have ceased." (This would appear to limit the physician's discretionary authority to employ them in other situations.) Several states required independent confirmation of death by a second physician. Others required such confirmation only when removing organs for
transplantation. Others did not require that a physician be involved in making the determination at all, allowing the coroner to determine death in certain cases and not requiring this official to be a physician.

In 1981 the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research proposed a model uniform statute, designed to resolve discrepancies between the various states’ statutes. [See President’s Commission (1981). This volume contains texts of the states’ legislation as of 1980. It also contains “Guidelines for the Determination of Death,” drawn up by a medical panel and originally appearing in JAMA 246 (1981):2184–2186.] It reads as follows:

**Uniform Determination of Death Act**

An individual who 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,

is dead. A determination of death must be made in accordance with accepted medical standards. (President’s Commission 1981, 2)

This statute has already been adopted by a number of states (including the authors’ home state of Tennessee), and other states are likely to follow suit in the next few years.

The practicing physician should be aware of the law on this matter in his own state. Even more important, these legislative developments ought to prompt reflection on the underlying issues and a reexamination of one’s own attitude toward dealing with patients at the end of life.

Of course, one might question the appropriateness of a law that dictates medical practice in this area. However, this is a fact accompli in many states; thus ignoring it amounts to an act of civil disobedience. If the law says that patients lacking brain function are dead, then in legal terms it may be inappropriate to continue respiratory support, just as it obviously would be inappropriate to keep a patient in a hospital bed (and especially to bill for services rendered) long after the patient’s cardiac and respiratory functions had ceased irreversibly.

In short, a translation of attitudes is required to honor the new operational criteria of death. Whatever was regarded as inappropriate with regard to “chest dead” patients under the old understanding is now inappropriate toward “brain dead” patients, and whatever was appropriate toward “chest dead” patients (e.g., autopsy, preparation for burial, etc.) is now appropriate toward “brain dead” patients. This extends even to language: a “brain dead” patient for whom cardiac and respiratory functions are restored following an arrest has not been “resuscitated” or “revived.” She is still dead, even though those organic functions are continuing. More serious, of course, is the question of whether it is appropriate to take action to restore these functions when brain function is lost.
1.4 "Pronouncing" Death

The physician is called to "pronounce" death. This suggests an important social ritual (Peschel and Peschel 1983; Shem 1978, 71–72). The social role of pronouncing death goes beyond the technical act of diagnosing that death has occurred. In an important sense, the patient has not died until the physician certifies that he has.

One important aspect of this social ritual is its impact on the family and close friends of the patient. Pronouncement of death marks an end to "hoping" (i.e., a "time to dance"?) and initiates the grieving process (i.e., a "time to mourn"). The timing of this pronouncement, the style of communication with the family, and the preparation for it greatly influence the adjustment they will make. This is a situation in which the physician has an obligation to serve the interests of the survivors, in addition to his or her obligations to the (primary) patient.

Wherever there are dual loyalties, a conflict may arise. For example, the physician treating a comatose dying patient may conclude on the basis of his knowledge of the patient’s fundamental values that this person would prefer not to be resuscitated and yet the family may not yet be prepared for the patient to die. Honoring the values of the patient would dictate nonresuscitation; serving the needs of the family would dictate maintaining artificial support for awhile to give the family more time to adjust to the inevitable outcome. You as the physician must determine which of these obligations takes priority in a given situation.

This may be part of what the American College of Physicians (ACP) Ethics Manual intends to convey when it says: "There may be circumstances in which the physician may elect to support the body when clinical death of the brain has occurred, but there is no ethical standard that dictates he must prolong physical viability in such a patient by unusual or heroic means" [ACP 1984a (Manual), 26–27; 1984b (Annals), 265]

Additional obligations may influence the decision in this case. A principle of reverence for life may be interpreted to dictate aggressive efforts to extend life as long as possible, or alternatively, it may be interpreted to prohibit extending life for the purpose of promoting the interests of others.

2 Other Limits to Treatment

Even more difficult decisions must be made in situations in which death may be near but has not yet occurred. Contemporary medical technology and skill provide physicians with the awesome power to postpone death, and with this power (as with any power) comes the burden to make responsible decisions about its use. Intensive life support measures are undoubtedly beneficial in certain situations, e.g., when they sustain the body as it recovers from a critical but reversible insult. However, the benefit of these measures is doubtful if they only prolong an
inexorable downhill course. The challenge is, of course, to discern which of these you are presented with in a given case. Is this "a time to heal" or "a time to die"?

In the following pages you will be asked to consider the appropriate role of the various parties concerned with these decisions, and the standards to be used in the decision making. Three resources from which the discussion will draw heavily are included for your reference: 1) a summary of the recommendations from the President's Commission report *Deciding to Forego Life-Sustaining Treatment*, in Section 2 of Appendix II; 2) relevant sections from the ACP Ethics Manual, in Appendix III; and 3) the relevant statements from the AMA Judicial Council, in the following section.

2.1 AMA Policy Statements

2.14 Quality of Life. In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued.

In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected (I, III, IV, V)

2.15 Terminal Illness. The social commitment of the physician is to prolong life and relieve suffering. Where the observance of one conflicts with the other, the physician, patient, and/or family of the patient have discretion to resolve the conflict.

For humane reasons, with informed consent a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to let a terminally ill patient die, but he should not intentionally cause death. In determining whether the administration of potentially life-prolonging medical treatment is in the best interest of the patient, the physician should consider what

6. This contradicts—at least as applied to the medical situation—the claim of Ecclesiastes that there can be "a time to kill." This point is discussed further in Section 2.4.
the possibility is for extending life under humane and comfortable conditions and what are the wishes and attitudes of the family or those who have responsibility for the custody of the patient.

Where a terminally ill patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis, all means of life support may be discontinued. If death does not occur when life support systems are discontinued, the comfort and dignity of the patient should be maintained. (I, III, IV, V) (Judicial Council of the AMA 1984, 10–11)

2.2 Limits Set by Patients

The term “patient-set limits” is used to refer to any of the several different ways in which patients may indicate preferences that amount to limiting medical treatment. The first task is to recognize the several forms this may take and to consider the appropriate response by the physician to each.

2.2.1 Varieties of Patient-Set Limits

A. Religious Constraints This is the sort of patient-set limit to treatment addressed most often by the courts and usually involves the Jehovah’s Witnesses, who accept all forms of medical treatment except blood transfusions. This position will be discussed at some length in Section 2.2.2. It is not the most common form of patient limitation of treatment.

B. Not Seeking Treatment As discussed in Chapter 1 (Section 1.2.4.A.3), the vast majority (as much as 75–90%, by some estimates) of incidents the individual would describe as a state of illness are managed entirely without recourse to the medical system. People will merely “tough it out,” apply home remedies or over-the-counter preparations, and/or seek assistance from nonmedical friends. This behavior can be viewed as a form of patient-set limit to medical treatment.

The social structure of informed consent prohibits overriding these decisions. If the situation is perceived as serious, friends may try to persuade the person to go to a medical facility for treatment, but except in the case of a public health danger, an incompetent patient, or a minor, the patient cannot justifiably be forced to submit to treatment.

These incidents most often involve fairly minor illnesses, and here no serious ethical problems arise. In a self-limiting condition, for example, self-treatment may be as effective and efficient as submitting to medical treatment. Chicken soup provided by Mama may be the treatment of choice.

However, the same behavior is sometimes manifested in life-or-death situations (although it usually is not perceived as such by the parties involved, as when a man insists that his chest pain is merely heartburn and takes an antacid and lies down to
rest, only to die from a myocardial infarction as he lies there). Here, obviously, matters are more serious. Chicken soup is not the treatment of choice for a myocardial infarction.

In some cases the decision not to seek medical treatment is based upon a highly articulated theoretical understanding of the nature of health and illness (e.g., Christian Science), but this sort of rationale is not always present. Situations do occur in which the participants understand the seriousness of the condition and the benefits to be gained from medical treatment, but (accurately or not) they judge that they have no access to medical care, e.g., the case of a family with no money to pay for treatment and too much pride to accept "charity," or the family that has been judged to abuse medical institutions in the past and now believes that its members will not be admitted without an advance cash deposit.

Most often, however, the decision not to seek treatment hinges on some presuppositions (many of them misjudgments) about the nature of health and disease:

1. The condition is not serious.
2. Nonmedical remedies will be effective in overcoming it.
3. "What you don’t know cannot hurt you" (and thus one is safe as long as no diagnosis is made).
4. Hospitals are places one goes to die (and thus one is somehow protected from death by staying away).

Obviously, many of these presuppositions are not rationally justified. However, it is difficult for physicians to counter these misconceptions head-on since those who hold them do not present themselves to the medical system. Thus one-on-one patient education cannot be begun.

One social obligation of physicians is to promote public health education that provides a more enlightened view of the nature of health and illness, to overcome resistance to treatment based on unfounded superstition. Appropriate self-care should be encouraged, but the public needs to be educated to recognize situations in which it is unwise to attempt self-care.

C. Unheralded Noncompliance The sort of patient-set limit to treatment that arises most frequently within the medical setting is unheralded noncompliance. Physicians become accustomed to having a certain proportion of patients who simply fail to return for recommended follow-up appointments. Some of these are

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7. The construction of these educational materials also involves ethical elements. For example, in communicating the importance of seeking medical diagnosis and following treatment regimens for diseases such as hypertension, diabetes, etc., to those who have not yet sought treatment, care should be taken not to cause anxiety for those who are currently under treatment and yet still concerned about the long-term effects of a chronic disease. One measure that could mitigate this effect would be to include in all educational materials the assurance (to the extent appropriate) that careful medical management dramatically reduces the risks of catastrophic sequelae from the disease in question.
probably receiving medical care elsewhere, but some employ this tactic to avoid recommended treatment entirely.

Even more frustrating is the patient who simply ignores (wholly or in part) the treatment regimen recommended by her physician and allows the hypertension, diabetes, or other disease process to rage on unchecked. This may have life-threatening consequences, but generally these are not dramatically apparent immediately after ceasing the regimen. Thus noncompliance may continue for some time, much to the frustration of the health care professionals who detect it and try to persuade the patient to follow the treatment regimen. But eventually this may reach a life-threatening stage: the noncompliant diabetic patient may be brought to the hospital with diabetic ketoacidosis, or the hypertensive patient who ignores treatment may be admitted with a stroke. Once stabilized, such patients may continue their noncompliance.

In a way, medicine here is the victim of its own successes. Patients have such strong faith in the ability of medical professionals to rescue them from catastrophic situations that they underestimate the danger of their own irresponsible behavior. Indeed, the most difficult cases of this sort involve patients who themselves have been rescued from dire straits repeatedly in the past. They seem to assume that, no matter what they do to themselves in the future, the doctors can restore them to a relatively normal state.

This type of treatment refusal is difficult to deal with. The treatment regimen involved is an on-going process that cannot be monitored at every stage by health-care professionals. Home health-care visits might be used to provide periodic reminders, but constant monitoring ("handholding") is totally unfeasible.

The only hope for combating this behavior lies in aggressive patient education to impress upon the patient the dangers of nontreatment and the benefits of treatment. This may be especially difficult to accomplish in cases in which the patient receives secondary gains from illness. Here, at least in the short range, the loss of these secondary gains may outweigh the benefits from treatment. Even without this factor, it may be difficult to communicate to patients the importance of benefits that are remote and less visible in order to offset the disvalues of treatment that are close at hand and quite palpable.

D. Treatment Refusal It is also not uncommon for patients to take the initiative by refusing recommended treatment explicitly when it is proposed. Some patients undergoing chemotherapy for tumors announce that they wish to suspend treatment; some on chronic dialysis announce that they want to withdraw from it; others for whom radical procedures such as amputation are seen as the only hope for cure or extension of life refuse to sign the consent form for surgery. It is a recurrent phenomenon in hospitals for a patient to refuse to continue all treatment being offered and to carry out this refusal by leaving the hospital "AMA" (against medical advice).
The ethical principle of autonomy is often taken to imply that any and all of these forms of refusal of treatment are to be respected equally. Also court reactions generally have not distinguished between one situation of refusal and another. This reaction by the legal system is heavily influenced by one of two foundations of the informed-consent principle: the criminal category of battery. To authorize touching requires an explicit consent, but nontouching does not require the same weight of justification—it is the "default" state of affairs. As Robert Veatch puts it:

It makes no sense to talk about getting a patient's consent to nontreatment, whether that patient be terminally ill or not... One does not consent to nontouching. Nontouching is the initial presumption of autonomous individuals barring any consent that establishes a medical relationship.

Legally and morally, treatment without consent is assault and battery. Conversely, consenting to nontreatment is like consenting to not having assault and battery committed. (Veatch 1981, 207–208)

However, as explained in Chapter 1, informed consent is also grounded in a principle of autonomy or self-determination; this principle can form a basis for distinguishing forms of refusal that should be honored from those that perhaps should not. From the discussion of autonomy in Chapter 2 (Section 2.3.1), it should be clear that many of these acts of refusal are not sufficiently deliberative or grounded in core personal values to be considered autonomous. Rather, they are based on the whims of the moment or unexamined emotional reactions to some element of the treatment proposed. But, if this is so, then nothing about the principle of autonomy requires that these sorts of refusals be honored.

If physicians can be faulted for providing inadequate information and emotional support before enlisting consent to treatment (and they can, as indicated in Chapter 1), then patients can similarly be faulted for rejecting treatment without making every effort to gain and assimilate information and deliberate on the basis of it. Refusal of treatment is a choice no less than acceptance of treatment, and the same responsibilities of autonomy apply. Treatment refusal can be seen as a privilege that must be earned, not an automatic right to be exercised on any basis one chooses. Another way to express this point is to say that achieving autonomy is a responsibility both of caregivers and patients and not a license for the patient to choose on any basis whatsoever.

A method for achieving autonomous participation of patients in setting limits to treatment is sketched in the following paragraph and elaborated in Section 2.2.3ff.

**E. Negotiated Limits** The discussion of informed consent in Chapter 1 (Sections 2 and 3) developed the notion of shared decision making by negotiation with the patient. This approach is applicable throughout the clinical course, including life-threatening stages of illness. The patient must be provided with all relevant information if he is to share fully in decision-making about his care, and the emotional support stressed as a component of information exchange will assist him
in coming to grips with the realities of his situation and will enable him to employ
this information in rational deliberation. Indeed, at every stage of illness, one goal
of the doctor-patient accommodation process (DPA) ought to be helping the
patient clarify his personal values and relate them to the realities of his medical
condition.

Through this process the patient may develop firm preferences regarding
aspects of the management of his illness. These preferences may include a desire to
set certain limits to medical treatment.

This is the form of patient-set limit to treatment addressed in Sections 2.2.3 and
2.2.4. However, before turning to the task of developing a policy for this sort of
situation, let us examine in some depth one of these other varieties of treatment
refusal.

2.2.2 Religious Constraints: Jehovah’s Witnesses Refusal of blood trans-
fusions by Jehovah’s Witnesses is based on an interpretation of certain scriptural
passages, such as

Every creature that lives and moves shall be food for you; I give you them all, as
once I gave you all green plants. But you must not eat the flesh with the life, which
is the blood, still in it. (Genesis 9:3–4)

If any Israelite or alien settled in Israel eats any blood, I will set my face against
the eater and cut him off from his people, because the life of a creature is the
blood, and I appoint it to make expiation on the altar for yourselves; it is the blood,
that is the life, that makes expiation. Therefore I have told the Israelites that
neither you, nor any alien settled among you, shall eat blood. Any Israelite or
alien settled in Israel who hunts beasts or birds that may lawfully be eaten shall
drain out the blood and cover it with earth, because the life of every living creature
is the blood, and I have forbidden the Israelites to eat the blood of any creature,
because the life of every creature is its blood: every man who eats it shall be cut
off. (Leviticus 17:10–14)

But you must strictly refrain from eating the blood, because the blood is the life;
you must not eat the life with the flesh. You must not eat it, you must pour it on the
ground like water. If you do not eat it, all will be well with you and your children
after you; for you will be doing what is right in the eyes of the LORD.
(Deuteronomy 12:23–25)

These passages cite not only the rule itself, but also the reason behind it:
“because the life of a creature is the blood.” In other words, their view is that the
soul or individual identity is contained in the blood. Thus receiving someone else’s
blood “contaminates” one’s individual integrity. An analogous situation that
might strike us at a similar emotional level would be the prospect of a partial brain
transplant: suppose an experimenter proposed to remove half of your brain and
replace it with tissue from another person. Most people would react with revulsion
and fear that they would no longer be the *same person* as a result of such a procedure. That is much the same as the Jehovah's Witness' reaction at the thought of a blood transfusion.

The scriptural texts also make clear that the context of the injunction against "eating blood" is one of rules governing hunting and food preparation. However, Jehovah's Witnesses interpret the rule to apply to taking blood into the body in any form and by any means. Is this a reasonable construction of the scriptural passages cited?

Many Christian groups refrain from acknowledging this and other Old Testament rules by invoking the "new covenant" contained in the New Testament. However, in response to this, Jehovah's Witnesses refer to a New Testament passage that seems to reaffirm that the prohibition against blood applies to Christians as well. The text comes from Acts, in the context of the debate that went on for some time in the early Christian church about how much of Jewish law should be imposed on gentile converts. The elders of the church at Jerusalem met to discuss this question and settled on the following list (conveyed in a letter to the church at Antioch; emphasis is added):

> It is the decision of the Holy Spirit, and our decision, to lay no further burden upon you beyond these essentials: you are to abstain from meat that has been offered to idols, *from blood*, from anything that has been strangled, and from fornication. If you keep yourselves free from these things, you will be doing right. (Acts 15:28–29)

Recently, the group has issued some further clarification of the scope of the prohibition:

> Witnesses view [these scriptures] as ruling out transfusion of whole blood, packed RBCs, and plasma, as well as WBCs and platelet administration. However, Witnesses' religious understanding does not absolutely prohibit the use of components such as albumin, immune globulins, and hemophiliac preparations; each Witness must decide individually if he can accept these. (Dixon and Smalley 1981, 2471)

It should be noted that Jehovah's Witnesses are generally willing to accept responsibility for the risks they choose to run. They usually announce their religious affiliation to the physician at their first contact and are understanding if the physician indicates an unwillingness to treat them. They have tried to persuade surgeons to attempt a variety of surgical procedures (including open heart surgery) without blood transfusions. Furthermore, church leaders have worked with the legal counsel of the AMA to develop a document (Form P-47) in which the patient absolves the physician and hospital of all legal responsibility for harm resulting from their foregoing blood transfusions (Office of the General Counsel 1979, 85), and individual Witnesses are willing to fill out this document. (Indeed, often they bring copies when they enter the hospital.) Most of the problem cases arise in crisis
situations, when the need for blood was not anticipated and thus was not discussed in advance.

These cases have frequently been taken to court. The courts have often authorized intervention against the wishes of patient and/or family when the patient is a minor, but they have almost always honored refusals by competent, adult Jehovah’s Witnesses who are not ambivalent in their expression of refusal.

2.2.3 Lynn Languish (the Final Chapter) To give a concrete focus to the discussion of the patient’s role in treatment decisions, consider the specific clinical situation of Lynn Languish, first introduced in Chapter 1, Section 1.2.1.B and further developed in Chapter 2, Section 2.3. Now you will hear another chapter of her story.

Ms. Languish’s lymphadenopathy did turn out to be associated with cancer of the breast. Over the 20 months since diagnosis was made, she has gone through numerous and varied treatment modalities.

She refused to submit to a mastectomy (although this was your initial recommendation—she disagreed that it was “a time to rend, and a time to sew”), so you referred her to an oncology team you knew would be open to a lumpectomy procedure. This was followed by a combination of radiotherapy and chemotherapy.

For some months, things went quite well. Side effects from the treatments were well tolerated. Her emotional adjustment was bolstered by regular visits with you and also by her active involvement in a counseling group associated with the oncology service.

Six months ago, however, she presented with bone pain. Tests confirmed widespread bone metastases. These have since spread to the lumbar spine, despite intensive therapeutic efforts that included hormone therapy.

She has become more and more discouraged as this progression has continued. (This reaction is, of course, understandable; you and the oncology team have felt pretty much the same way.) Nevertheless, her will to live is strong, and although she has hesitated and pondered, she has eventually accepted every new treatment modality offered to her.

For the past ten days, she has been confined to a bed in the Oncology Unit. She is never free from pain. At times the pain is so intense that she is incoherent and disconnected in her attempts at communication. Generally, though, she remains lucid. She is barely able to move. You judge that the end will not be long in coming.

However, the oncologist with whom you and she have been working has not given up hope. Today he has come to discuss with you a new protocol he would like to propose to Ms. Languish. He asks you to accompany him to talk with her about it.

How should you respond to him? Consider the following choices:

1. Agree to help persuade Lynn to accept the treatment.
2. Agree to accompany the oncologist to see Lynn, primarily to be sure that the information about risks and benefits is presented to her fully.

3. Agree only to ask Lynn if she would like to see the oncologist and hear about his proposal for treatment.

4. Veto in advance any idea of such a presentation.

5. Agree to accompany the oncologist, but plan to see Lynn alone first to let her know in no uncertain terms your professional recommendation that she not accept the proposed treatment.

6. Other (specify): ________________________________________________________________

2.2.4 Physician Responsibilities Concerning patient-set limits to treatment, the physician has the following responsibilities:

1. To maintain a presumption on the side of sustaining life, but also actively to attempt to discern the appropriate limits to this policy.¹

The AMA Judicial Council endorses a parallel principle and also indicates its limits (see the "Quality of Life" opinion quoted in Section 2.1). When there is reasonable doubt that the "time to die" has arrived, efforts to sustain life should be continued with vigor. However, at the same time, physicians must face the difficult task of prognosis. To suppress doubts about the appropriateness of continued life-sustaining measures in a given situation, or to avoid gaining information that could create such doubts, is to shirk one dimension of medical responsibility at this stage of the clinical course. When such doubts arise, they must be investigated as fully and energetically as therapeutic possibilities so that sufficient information is gained to enable all parties to make a sound, well-grounded decision.

When the "time to die" has arrived, it is a misuse of medical knowledge and skill to prolong the agony of all concerned. Instead, the goal should become to help patient, family, and caregivers recognize this fact and accept it gracefully.

Thus, in the case of Lynn Languish, hope for this new protocol must be tinctured with a strong dose of realism in assessing her present condition. In general, any form of patient resistance to a treatment recommendation (whether expressed openly or nonverbally through noncompliant behavior) should prompt a reassessment of the clinical decision by the physician. Be sure the recommendation is sufficiently justified to warrant "making a case out of it."

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¹ See recommendation 2 in the President's Commission report Deciding to Forego Life-Sustaining Treatment, listed in Appendix II, Section 2.
2. To provide information, emotional support, and recommendations to patients.

This is a natural extension of the duty of informed consent, both in its theoretical justification and in its practical execution. This responsibility is most readily carried out within the framework of continuity of care. The steady but gradual process of informed consent described in Chapter 1, Sections 2 and 3, leads naturally, when the irreversibility of the disease process becomes more and more obvious, to sharing this information with the patient, assisting her in dealing with it emotionally, and guiding her on this basis toward decisions about the appropriate limits to treatment.

The President’s Commission endorses this principle in several places. Its report on informed consent states:

7. Patients should have access to the information they need to help them understand their conditions and make treatment decisions. (President’s Commission 1982, 4; see Appendix II, Section 1)

In its report on limits to treatment, the Commission offers a recommendation specifically for dealing with decisions concerning seriously ill newborns that could, with only slight modification, be applied to all patients:

16. Decisionmakers should have access to the most accurate and up-to-date information as they consider individual cases.

—Physicians should obtain appropriate consultations and referrals.

—The significance of the diagnoses and the prognoses under each treatment option must be conveyed to the [patient.] parents (or other surrogates).

(President’s Commission 1983, 7; see Appendix II, Section 2)

Along similar lines, the AMA Judicial Council holds that the patient and family should be given information about the options, benefits, and risks, and about how the patient’s condition affects the potential for human relationships; in addition, any questions they have should be answered (see “Quality of Life” opinion quoted in Section 2.1).

If this responsibility has been carried out, Lynn should have by now a realistic understanding of her prospects and you, as her physician, should have in turn a thorough understanding of her fundamental values. Unless she has already indicated she will accept no further treatment, the new protocol should be offered to her, but care must be taken to avoid overstating its promise.

If the primary reason for attempting this treatment is to gain knowledge that could be of therapeutic benefit to future patients at earlier stages of disease progression, then it should be proposed only if it has been ascertained previously that research values are important to her. And in that case, the primary purpose ought to be made clear to her. (It should not be thought that this would make her acceptance of the protocol unlikely. Research values are quite important to many
patients at this stage. They take great comfort in the hope that they may spare someone in the future from the suffering they are currently going through. These patients are to be admired for such a demonstration of benevolence under difficult circumstances, but care must be taken to ensure that their choice is fully voluntary and not unduly influenced by professional eagerness for knowledge.

3. To guide patients to formulate preferences on the basis of their own fundamental values.

This is an aspect of the comforting and supporting role of the physician. This may be one of the most difficult tasks the physician confronts: to enable the patient to face the disturbing prospect that medical technology will be unable to rescue her and to help her choose between the tragic alternatives that remain.

It is tempting to shield the patient from these decisions and take them upon your own shoulders. However, the same considerations that support giving the patient a voice in less momentous and tragic decisions apply with equal force in this context. Patients have individual values that make a difference in these choices, and they ought to have the opportunity to shape the ending of their lives in terms of these values. Lynn’s will to live may reflect a fundamental value of hers, but only she herself can determine whether it is still important enough to justify the treatment now being proposed. Another patient may be ready to give up the fight at an earlier stage. This, too, should be accepted graciously once it is determined that the decision is based on a realistic understanding of the situation and expresses the patient’s fundamental values.

If the basis of the patient’s refusal is irrational, the physician has an obligation to guide the patient to think the matter through again. (Meanwhile, until this process has been completed, the response to any life-threatening crisis that arises should be dictated by 1) the presumption in favor of sustaining life, and 2) the option that would offer an opportunity for renegotiating the DPA covering this situation.)

4. To negotiate with the patient a course of action that is mutually acceptable to all parties centrally involved.

This is an extension of the process of DPA discussed at length in Chapter 1. The physician also may have fundamental values that influence his role in this relationship. The final decision should result from a process of shared decision making involving patient, physician, and others who are significantly affected.

One chief danger is that caregivers will allow their own core values and beliefs to dominate the negotiations. For example, with the goal of supporting the patient’s “having hope,” caregivers may propose a level of treatment far in excess of what would be needed to achieve this. Rather it is what is required for the maintenance of hope in themselves. At this stage of illness, “hope” may mean to
the patient no more than an assurance of company and comfort to the end, not a promise of cure or even prolongation of life.

If no mutually acceptable decision can be reached, and the physician cannot in good conscience cooperate with the patient’s wishes, then the only recourse may be to sever this doctor-patient relationship and help the patient find another physician who could reach an agreement with her. This tragic outcome should be an absolute last resort. The depth of the relationship may be an important source of support for the patient in this difficult time, and it may not be possible to establish a new relationship of equal depth in the brief span of life that remains. Thus you should search your conscience thoroughly before taking this step, to be quite sure whether, and to what extent, the motive for stepping away from this patient at this time includes considerations such as

1. a “vanity trip”
2. a personal difficulty in dealing with death
3. an emotional reaction to this patient’s death
4. an interest in sustaining the institution’s image.

To sever a relationship at this stage of care would appear to be justified only on the basis of a clearly defensible moral position or a deep disagreement about fundamental life values.

This is one of many reasons why it is best for physicians and patients to talk about these issues relatively early in the physician-patient relationship, so the general outlines of a DPA covering terminal situations can be developed in advance. It would have to be filled in later with the details of the actual situation, to be sure, but general boundaries can be agreed upon in advance—for example, whether a plan of aggressive life-sustaining treatment is to be continued at all costs, or whether it is regarded as more appropriate to suspend intensive efforts when a realistic prognosis indicates the end is near.

5. To assist patients in carrying out these mutually agreed-upon goals.

The physician will play an especially important role in communicating these decisions to the other caregivers, and in relating them to institutional and social policy. If, for example, Lynn Languish decides not to accept the protocol, it may fall to you as her primary physician to persuade the aggressive oncologist to accept this decision. On the other hand, if she accepts it (against your better judgment), then the oncologist may have to remind you of the case in its favor. This may be a “time to cast away” treasured judgments (or at least to rethink them thoroughly) so that it can be “a time to keep” your trust with this patient.

When goals of cure have been abandoned, a goal of providing for the patient’s comfort and dignity should be substituted. This may require actions that will have the effect of hastening death. (Some of the internal complexities of this stage are discussed in Section 2.4.)
6. To assist patients in communicating these decisions to family and friends, and to support these people in their process of coping with the decisions.

At this stage of events, the physician-patient relationship expands to include responsibilities toward the survivors, even if they are not your primary patients. Consideration of the impact of decisions on the survivors ought to be an element in the process of deliberation and negotiation, and care and concern should be shown in guiding them to accept the inevitable outcome and the choices that have been negotiated with the patient.

The family may have reached a state of acceptance in advance of the patient, and thus may be prepared for death to come; indeed, in some cases, the family may be almost eager to "get the ordeal over with." However, if the patient still desires to continue aggressive measures, the family should be guided to see the basis of the patient’s position. The same process happens in reverse when the patient is prepared for the inevitable and the family is not.

2.3 Dealing with Families’ Decisions

The family and close friends of the patient have a significant influence on the patient’s thinking and decisions at every stage of illness, but their role becomes especially important in terminal illness. The death of the patient may be a monumental event in their lives. They are the people whose on-going association with the patient can be a source of deep comfort and support, or in bad circumstances, a considerable hindrance to the accommodation of the patient to his or her terminal state.

Western society pays lip service to the social importance of the family unit. In the situation of terminal illness, the physician must acknowledge this importance in her actions.

2.3.1 Family and the Competent Patient In the case of the competent patient, the physician may often become a "go-between." Both the patient and members of the family may ask the physician for information about the seriousness of the condition, and they may express thoughts about decisions that have to be made. But often it becomes obvious that they are not talking to each other about these things. Indeed, it is not uncommon for several clusters to form within the patient’s family and social circle, with none of them communicating fully with the others and the physician unable to determine which of them is preeminent in serving the patient’s interests. One useful service the physician can render here is to prompt these parties to communicate openly with one another and to facilitate this communication (which is understandably difficult for all involved) when it does begin to occur.
A. Primacy of Patient Preference  Self-determination is a personal right of the competent, adult patient; thus, when the patient and family are on different wavelengths, the patient’s preferences must be honored. However, with proper attention to communication, a confrontation on these issues can be avoided in many cases.

For example, if a patient expresses to you, his physician, definite wishes to withdraw from treatment or not to be resuscitated, you should ask whether he has talked these decisions over with the family. If he has not, offering to assist him in discussing his wishes with the family (or perhaps even to convey his wishes to the family on his behalf) could help avoid future misunderstandings on all sides. If the family finds it difficult to discuss these matters or to accept the patient’s decision, you can work with them further—in a gradual and supportive way—to explain the facts of the patient’s situation, the basis of the patient’s choices, and the importance for the emotional well-being of the patient (and indeed, of the family as a unit) of their understanding and support.

If you are unwilling or unable to dedicate time and effort to sorting out complex family situations, you may want to enlist the assistance of other members of the health-care team to work with the family in depth. In a setting with a coordinated health-care team, it is not necessary for every team member to go over each item of information with the patient and family. A clinical “division of labor” may prevail here. It is imperative, of course, that all relevant information be communicated by someone or other. Responsibility for coordination of information exchange is most naturally assigned to the primary physician. (Similarly, it ought not be necessary to go over all the information with each family member individually. Family members have a duty to share information they have been given among themselves (with a proviso to follow). Family members sometimes invoke a principle of confidentiality to justify keeping to themselves what the physician has told them, but there is no valid principle of confidentiality between family member and physician that would apply in this case.)

This interaction with the family should not be considered a diversion from patient care. If you can generate support and understanding from the family, the effects on the patient may be more significant than large doses of pain control medications or lengthy counseling sessions on your part.

B. Confidentiality and Family Involvement  Discussions with the family may test the principle of confidentiality. Strictly speaking, confidentiality is a right of the individual patient, and one steps beyond the bounds of confidentiality by disclosing any information to anyone outside the health-care team without express permission from the patient. The ACP Ethics Manual stresses this point:

The problem should not be discussed with his family unless the patient authorizes such a discussion. . . . Physicians should not breach the confidential nature of the physician/patient relationship by discussing the patient’s care with
persons who are not authorized by the patient to be made aware of the patient’s diagnosis, prognosis, or treatment. . . . Physicians should understand that mere blood relationship does not by itself allow a family member to know about or authorize the medical treatment of a patient. [ACP 1984a (Manual), 28–29; 1984b (Annals), 265]

However, as the author of Ecclesiastes points out, there is “a time to keep silence, and a time to speak.” To insist on the letter of the law here may have a “chilling” effect on important relationships. When a concerned family member encounters you in the hallway of the hospital and asks how the patient is doing, refusing to disclose any information, explaining that you must first get express permission from the patient, may cause a strain in your relationship with an ally with whom you may need to work closely to provide support to and make decisions about the patient in the final stages of his life. This situation can sometimes be avoided by explaining to the patient in advance that you will discuss his case with the family; however, if the patient is having difficulty facing the situation himself and is perhaps finding it awkward to disclose essential information to you, bringing up the possibility of your passing information on to family members may further inhibit him. If the patient expresses a wish that certain matters not be discussed with the family, your response may be to encourage the patient to change his mind and allow open communication, rather than simply accepting his wishes as the last word on the matter. However, disclosure should not proceed unless and until the patient has been persuaded to authorize it.

If you encounter family members with questions, one useful approach is to begin by sounding them out about how much information the patient himself has provided. If the patient has been completely open with them, it does not appear to violate the spirit of the principle of confidentiality for you to correct and interpret the information they already have. However, if it becomes obvious that the patient has been guarded, you would be wise to provide only the most general information until you discuss with the patient the reasons in favor of open communication (or learn from him the reasons why it is advisable to provide information to particular persons).

2.3.2 Patients of Questionable Competence If the competence of the patient is in doubt, family members may be enlisted to assist in assessing the degree of impairment. Since they are most familiar with the patient’s normal functioning, they are in a good position to provide information relevant to a determination of competence.

The family also may assist in ascertaining the patient’s core values. This can be an aspect of determining competence, and it can also form a basis for decision making when the patient is incapable of participating fully in the process.
It is advisable, from both legal and ethical viewpoints, to include the family in decision making. Although it is true that "family members and next of kin have no legal authority to make crucial decisions on behalf of adult patients unable to make decisions on their own behalf, unless that authority is specifically given by the act of a judge granting guardianship powers (or in several states, by a statute)" (Jonsen et al. 1982, 146–147), it is going too far to say that family members "have no legal, ethical, or moral standing to enforce their desires unless a court declares the patient to be legally incompetent and appoints a guardian to make treatment decisions for the patient" [ACP 1984a (Manual), 28; 1984b (Annals), 265]. The legal status of family involvement in decision making without recourse to the courts has never been addressed explicitly by courts, which is understandable since the cases brought before them can hardly have the feature of not being brought before a court (See President’s Commission 1983, 131–132).

However, the moral warrant for including the family in decision making is strong, stemming from principles of respect for the family as a key social unit. [For a sensitive discussion of this point, see Deciding to Forego (President’s Commission 1983, 127–129).] Even in legal terms, it is still important to consult family members. After all, they will be around after the patient has died, and they may be left with ill feelings toward the action. In other words, they may feel that it is a "time to cast . . . stones" (i.e., through legal action) if they believe the decision was arbitrary (i.e., if they were not included in making it). Furthermore, it can be of benefit both to patient and family in facing the outcome to make them feel "ownership" of the plan of action (or inaction).

The President’s Commission wisely counsels involvement of the family in informal ways and avoidance of formal court actions in most situations. (See Appendix II, Section 2, recommendation 9, fifth entry.)

2.3.3 Family and Incompetent Patients  Both the President’s Commission and the AMA Judicial Council acknowledge that the patient’s family provides the prime candidates for surrogate decisionmakers for incompetent patients. The ACP departs from this view only to endorse seeking official legal guardianship or conservatorship in more cases than the other two groups recommend.

The President’s Commission stresses that the standard for decision making ought to be what the patient would have wanted in terms of his or her own deepest personal values. If this cannot be determined (e.g., a patient who was never competent to formulate personal values or who never communicated them to others), then the patient’s best interests ought to be the guideline for decisions.

The physician’s responsibilities here include 1) supplying information to family or guardian, on the basis of which the most enlightened decision possible can be made, and 2) providing emotional support to aid in making best use of this
information. However, the physician's role does not end here. He must continue to serve as an advocate for the patient, evaluating the family's decision in the light of his own understanding of the patient's values and best interests. If there is reason to believe the family is making an inappropriate decision, the physician should 1) prompt the family to think the matter through again, 2) bring other members of the health-care team into the discussion and/or perhaps consult an institutional review committee, and 3) perhaps initiate court review of the matter if an inappropriate decision still is proposed.

2.3.4 Alternatives to Family Decision The family is not automatically vested with authority to make decisions for incompetent patients. In some cases, it may be more appropriate for friends of the patient to occupy this role than for any family member, e.g., when the family has not maintained close contact through the years and the friend is in a much better position to know the patient's fundamental personal values.

In the past the patient may have indicated a preference about the person who should make decisions; if so, every attempt should be made to honor this. There are a variety of ways in which the patient might state her preference: 1) through personal communication with you as her physician, or with her minister or some other trustworthy professional; 2) through an annotation on an advance directive ("Living Will") document; and/or 3) through the formal legal mechanism of a durable power of attorney. The last of these has the most solid legal standing (see President's Commission 1983, Appendix E, 390-437). The others may require confirmation through court action. The physician in his role as patient advocate may have the responsibility to initiate the requisite court action and he may also play an important role in the proceedings that result. You should seek the advice of legal counsel about the appropriate procedures in your locality for such situations. You also have an ethical responsibility to assure that the steps taken are indeed in the best interests of your patient and not (for example) primarily undertaken to serve the interests of other parties.

Finally, more and more patients are communicating their preferences about limits to treatment by means of advance directive documents. A growing number of states have statutes that enable and regulate this process; in the states that have not taken such action, a properly executed "Living Will" can carry significant weight in court as evidence of the patient's wishes. Many of these documents are vague and general, however, so it is best for you to explore further the personal values of a patient who presents such a document to you (perhaps encouraging him to add to the document more specific guidelines on which you agree).