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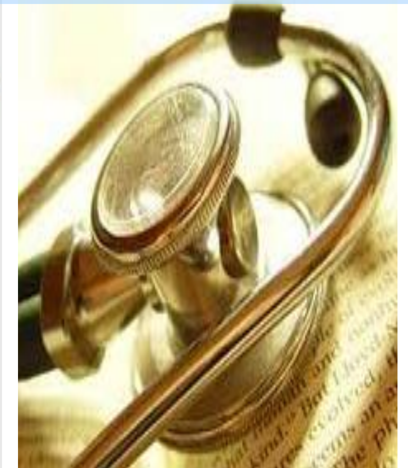
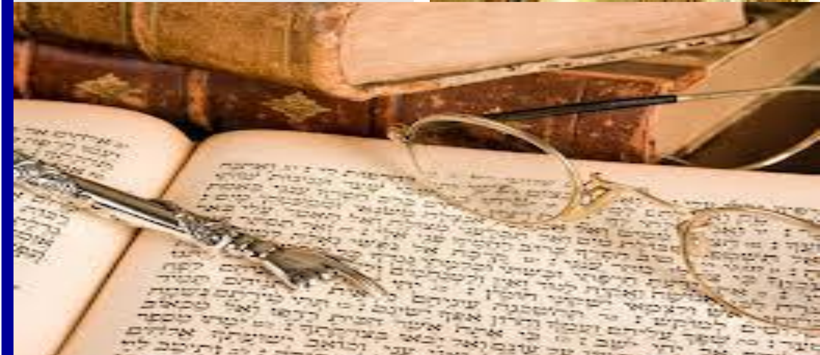
Jewish Medical Ethics & End-of-Life Care





Based On A Series Of Lectures Given By

Dr. Barry Kinzbrunner

Executive Vice President & Chief Medical Officer,
Vitas Innovative Hospice Care

At The Annual

NIJH Accreditation Conferences

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N I J H

Dedicates this Booklet to

Dr. Barry Kinzbrunner

Executive Vice President &
Chief Medical Officer,
Vitas Innovative Hospice Care

For His Dedication and Commitment To
Jewish Hospice and For His Illuminating Lectures
Each Year

At The Annual

NIJH Accreditation Conference

Rabbi Dr. Maurice Lamm
President and Founder, NIJH

Shirley Lamm
Executive Director, NIJH

While you are discussing final arrangements with both sons, the older son states: "My rabbi told me that Jews are not allowed to be cremated. We made this mistake with mom because I did not know any better, but I will not allow us to make the same mistake with dad. He has to have a proper Jewish burial and we have to sit shiva."

The younger son wants to honor his father's wishes and have him cremated and is not interested in sitting shiva.

How could this conflict be managed?

It is important to recognize that according to traditional Jewish law cremation is never allowed (although some rabbis in the Reform movement now allow cremation). From the older sons perspective his father's decision to choose cremation was wrong and should not be implemented. While Jewish law demands that one maintain respect for one's father, this respect does not allow a child to violate Jewish law, even if the father requests it. Just as a son could not get his father a ham sandwich (which violates the Jewish dietary laws) even if he asked for it, he cannot follows his wishes and cremate him because it is against Jewish law.

Having recognized the older son's objection, it is necessary to find out from the sons what each of their issues are and attempt to reach a solution that they both can accept, if possible. Sometimes, these disputes are insoluble, and then secular law, which will honor the wishes of the patient, will prevail. However, it is critical that when facilitating these types of discussions between family members, that all sides of the issue, including the thought processes beliefs of the involved family members and/or other interested parties, are understood.

We hope this booklet enlightens you to the Jewish issues in end of life care. A rabbi must always be consulted as each case is unique, but the principles and applications give us a broad understanding of Jewish Medical Ethics and end of life care.

Jewish Medical Ethics: A Review

In order to create a common language with secular medical ethics, Jewish medical ethics redefines the four main Georgetown ethical principles: Autonomy, Beneficence, Non-Maleficence, and Justice, in a fashion that is compatible with Jewish law and Jewish values.

1. Autonomy: Autonomy is commonly defined as the right of an individual to choose from any all alternatives offered based on his or her personal values or beliefs. While Judaism certainly respects an individual's right to choose, the major difference between the Jewish and secular definitions of autonomy is that the Jewish definition, in some sense, "voluntary" limits one's choices to those that are consistent with G-d's law, as defined in the Torah and other Jewish sources.

2. Beneficence: Beneficence is commonly defined as the obligation of healthcare providers to provide patients with care that is beneficial. Judaism agrees with this but adds that patients are also obligated to seek beneficial treatment.

3. Non-maleficence: Non-maleficence is the avoidance of harm, and since most medical treatments have some risk of side effects than can be harmful to some, one generally considers the potential for harm against the potential benefit that can be gained. Judaism sees this value in much the same fashion.
4. Justice: Justice can be divided into two types:
    a. Social Justice: This can be defined as determining what is good for the society as a whole.
    b. Distributive Justice: In the face of limited resources, distributive justice allows for the allocating or rationing of the available resources based on where they will do the greatest good for the society. Jewish law is compatible with this idea, and this principle is the basis for the Israeli national health care system, which is a national managed health care model.

End of Life Care Decision Making

When applying these principles to various issues related to end of life care, it must be remembered that the patients must be considered terminally ill according to Jewish definitions (which will be reviewed below). While, under Jewish law, there are general rules that apply to end of life care decision making, decisions that affect specific patients should be made, as done in hospice care in general, on a case-by-case basis, as there is some degree of flexibility and the ability to make exceptions within the framework of Jewish law. Therefore, a rabbi who is an expert in Jewish medical ethics must be involved in the decision making process in order to be able to apply the general law to the specific circumstances of the patient being cared for. Not all community rabbis are experts in this area, and while patients are encouraged to seek out their own rabbis, if the rabbi is not knowledgeable he has an obligation to consult a rabbi who has the necessary expertise.

It is also important that the rabbi who is being asked to make a specific recommendation about a patient speak directly with the patient's physician. More often than not, the doctor speaks with the family, and the family then speaks with the rabbi. The challenge in this situation is that the family may not relate all of the relevant information about the patient to the rabbi, in which case, if the rabbi renders a ruling without consulting with the physician, the ruling will be based on incomplete information. Only by speaking directly with the physician can the rabbi be assured of having all the necessary information necessary to make a recommendation to the patient and family that is compatible with Jewish law and takes into account the patient's specific circumstances.

Terminal Illness Defined by Jewish Law

There are two basic definitions of terminal illness under Jewish law. The first is a patient who has a prognosis of one-year or less, which is some sense, is more "liberal" than the Hospice Medicare Benefit requirement of six months or less. However, it must be noted that in most states in the US, the definition of

and that patients would never be abandoned. Sometimes, despite understanding these explanations, the patients, families, and/or rabbis will say "but that is not what happens in the hospitals in my town." If that is the case, it is important to ensure that this is not true, or if true, to correct the problem, and then provide additional reassurance that this will not happen going forward.

Returning to Case # 3, is the wife's statement that she does not want CPR and your response that you will write a DNR order sufficient to truly know what the patient wants?

It is possible, for example, that as the patient is currently symptom-free, if she suffered a cardiac event that she would, in fact, want CPR. This needs to be asked of the patient. If she states "No" then we could proceed with addressing the objections of her husband. If she said "Yes" then you would need to clarify at what point in her illness she would no longer want CPR and document this, so that you can revisit this issue at the appropriate time.

Assuming the patient still does not want CPR, and you have explained to the patient and her husband what a DNR order represents, what would you do if the wife and husband continue to disagree?

If there is a true disagreement, one option might be to have her consider, in addition to a living will stating her wishes, designating a health care surrogate other than her husband to ensure her wishes are carried out. However, this would seem to be a somewhat drastic approach that will place the patient and her husband in continued conflict. So what should we do? There are no easy answers. One approach to consider would be, with the patient's permission, to have a meeting with their rabbi in order to fully apprise him of medical situation and explain a DNR order really means.

CASE # 4

Returning to Case # 1: The patient has deteriorated to the point where death is imminent. When he was alert and aware, the patient stated that he wanted to be cremated and his ashes mingled with those of his wife, who had been cremated when she passed away.

CASE # 3

You are meeting with a 75year old female with advanced breast cancer to lung and bone. Her disease is progressive despite multiple successive programs of hormonal therapy and chemotherapy, and she has decided not to continue the treatments since they are no longer helping her. She is still functional and relatively symptom free. With her at the meeting are her husband, her son, and her daughter.

The goal of the meeting is to discuss various care options going forward, her goals of care, and to have her create an advance medical directive. As you discuss various issues, you raise the question of whether or not she would want CPR should she suffer a cardiac or respiratory arrest. She states that she would not want CPR, at which point you state "OK, then I will place a DNR order on your chart." Her husband immediately states: "Wait a minute/ The Rabbi said that you should never agree to a DNR order, because then they will not treat you at all.

Although to hospice professionals, the idea that DNR means "Do Not Treat" is incorrect, the perception that it does is out in various communities including the many facets of the traditional Jewish community. Rabbis in many communities will caution their congregants against agreeing to sign a DNR because then they won't be treated, rather, the healthcare system will just "put them in the corner and wait for them to die." Many patients and families feel this way even without the input from a rabbi. Therefore, as this is an issue that hospice professionals will encounter, how should it be addressed?

When this issue is being raised with patients and families or with rabbis, it is important to educate them regarding what a DNR actually means. It is important to explain that the only interventions that would be withheld would be cardiac compressions, electric shock therapy to the heart, and endotracheal intubation and mechanical ventilation. Reassurance needs to be provided that interventions that are appropriate for treatment and control of various symptoms that the patient may experience would continue

terminal illness that is utilized in advance directives is much more flexible, and often includes various forms of irreversible neurological conditions (i.e. dementia, vegetative state, coma) that, with proper supportive care may have a prognosis of greater than one year. While in our secular society, these patients may sometimes be considered terminally ill if they choose to forgo certain types of supportive care (i.e. tube feedings), according to Jewish law, patients with these types of irreversible neurological conditions would not be considered terminally ill as they might live for several years with good basic supportive care, and a decision to forgo basic supportive care (i.e. tube feedings) would generally not be consistent with Jewish law.

An illustrative example of this would be the case of Terri Schiavo, who was an unfortunate young woman who ended up in a permanent vegetative state for many years. When it became clear to her husband that she was not going to recover neurologically, he believed that she would not want to continue to live the way she was, and decided to have her feeding tubes discontinued. Her parents objected, and this led to a very unfortunate public dispute over the correct course of action. While Terri Schiavo was not Jewish, a Jewish patient in her position who was committed to following Jewish law would not be allowed to have the feeding tube removed for two reasons:

1. Food and fluid are considered basic care by most rabbis even when provided artificially (see discussion below).
2. Since she had no major intercurrent illnesses or other comorbid illness to adversely affect her prognosis, she had a prognosis greater than one year and would not be considered terminally ill under Jewish law.

Discontinuing feedings in such a patient would result in death due to lack of nutritional support, which would be against Jewish law.

The second definition of terminal illness under Jewish law is called "*Goses,*" which could be best defined today as "actively dying." In the Talmud, an ancient Jewish source, a *goses* is generally defined as someone in the last 3 days of life. However, with the increase in medical knowledge and technology, limiting the *goses* to the last 3 days of life is not precise enough for our times.

Additionally, one cannot know when the last 3 days of life begins until after the patient has died. Hence, it seems prudent to equate *goses* with a patient who is "actively dying." Of interest is that in classic Jewish literature, one of the signs of the associated with a *goses* is the presence of upper airway secretions, often called the "death rattle" by hospice professionals. Knowing a patient is a *goses* can be important, as Jewish law teaches that one should only provide basic care to a patient in this state. Rabbi M. Feinstein, one of the most famous twentieth century rabbis and who made many of the rules of modern Jewish medical ethics, ruled that a patient in this condition should receive basic care should be kept clean and comfortable. However, interventions that will not benefit the patient, including such routine tasks as checking the patient's blood pressure, should not be done as it can cause the patient unnecessary distress.

Interventions in Terminally Ill Patients Defined by Jewish Law

Assisted suicide and euthanasia are not allowed under any circumstances according to Jewish law. While in the US, physician assisted suicide is allowed in 3 states, and being considered in others, the active taking of a human life, even if the person is a *goses*, is absolutely prohibited by Jewish law. Judaism believes that life is given and taken by G-d. It is not up to us to decide when a person's life should end.

The decision of a medically competent terminally ill person to refuse care is permitted if the care being offered if proven to be ineffective or futile, if it will only serve to delay the dying process, and/or if the terminally ill person is experiencing pain and suffering that will not be relieved by the intervention. These same conditions would allow care to be withheld from a terminally ill patient who is not medically competent.

Withdrawing of care from a terminally ill patient, however, is generally not permissible unless the intervention can clearly be viewed as an "impediment to death." For example, if a patient is a *goses*, actively dying, and someone is playing loud music that is agitating the patient and delaying the dying process, the person can

Again, there are basically two options:

1. Continue to maintain her on the ventilator and let nature take its course, as without brain stem activity she will soon die.
2. Remove her from the ventilator at this time as she is legally dead according to secular law.

Given the husband's prior position it is most likely that he would opt for immediate ventilator removal with coordination with the transplant team.

For the parents who are Orthodox Jews, their position may very well hinge on which Jewish definition of death they accept. If they believe that total brain including brain stem death is the Jewish definition of death, then the parents might agree to the son- in-law's wishes. However, if they believe that death under Jewish law is only established when the heart stops, then the parents would still consider her to be alive and would object to having the patient removed from the ventilator. Since they may understand that the patient's condition is terminal even if she remains on the ventilator, they might agree to option one above. While Jewish law would not allow the ventilator to be withdrawn, Jewish law does allow new interventions to be withheld. How taking this approach might affect the ability of the transplant team to remove various organs (other than the heart) for donation is unclear, and if her organs cannot be donated this might create more anguish for the patient's husband.

One final point is that legally the husband has the final say (unless the patient had a durable health care power of attorney appointing her parent(s) as healthcare surrogate), although it is hoped the family will work out their differences peacefully. However, it is often very difficult to satisfy all concerned parties in these situations.

A neurology consultant evaluates the patient and makes a diagnosis of persistent vegetative state. You arrange a meeting with the husband and the parents, all of whom have been actively involved in the care of the patient, to discuss further care options.

What are the possible options for care that are available?

At this point, there are two possible options for care:

1. Continue to provide mechanical ventilation and after a tracheostomy (which is necessary for chronic ventilator care) is done, transfer the patient to a chronic care facility.
2. Remove the patient from the mechanical ventilator which will likely result in the patient's death as she is ventilator dependent.

The husband believes his wife would not want to live this way, and therefore wants her removed from the ventilator. Since she is ventilator dependent, and it is anticipated she will die following extubation, he also wants to donate her organs for transplantation.

The parents vehemently disagree and want their daughter to have a tracheostomy and remain on the ventilator as long as necessary

The husband, trying to be respectful to his in-law' s wishes, agrees to allow her to have a tracheostomy and remain on the ventilator for several months to see if there is any neurological improvement and then have her re-evaluated.

About 2 weeks later, the patient's condition deteriorates. Repeat neurological evaluation determines that she is now clinically "brain dead" with no spontaneous respirations at all.

You again meet with the husband and parents to discuss options.

What are the options and issues now?

be asked to lower the volume or stop playing the music in order to reduce the patient's agitation and allow the natural dying process to continue. On the other hand, a mechanical ventilator, which may be seen by some as an "impediment to dying," is considered by Jewish law to be "life sustaining" and hence, it cannot be actively withdrawn.

Armed with these general rules regarding refusal, withholding, and withdrawing care, several key end of life issues can be examined:

1. Pain: The treatment of pain is mandatory as Judaism does not support the idea that one has to experience pain and/or suffering. Pain should be treated with appropriate amounts of analgesics, including opioid analgesics. While some are concerned that there is a significant risk of shortening life if opioid analgesics are used, this is pharmacologically incorrect as patients become tolerant to the respiratory depressant effects of the medications with chronic use. Patients should also receive appropriate psychosocial and spiritual counseling to address the non-physical causes of pain and suffering.

2. CPR: CPR may be refused or withheld since the medical literature demonstrates that in elderly patients with advanced chronic illness, CPR is ineffective and has significant complications. It is important to stress that agreeing to a DNR order (which indicates that one is declining CPR) does not mean "Do Not Treat."

3. Nutrition and Hydration: Unlike most interventions, all orthodox and some conservative rabbis consider the provision of nutrition and hydration to be "basic care" even when it is provided artificially (i.e. PEG tube, hypodermoclysis). Therefore, traditional Jewish patients should be provided with food and/or fluid in appropriate amounts that will allow them to maintain dignity and comfort while the harmful effects of overfeeding (aspiration pneumonia) and overhydration (edema, pulmonary congestion, and other signs of fluid overload). Most conservative rabbis and other rabbis from less traditional Jewish movements consider the provision of food and fluid by artificial means to be consistent with

medical interventions, which they are comfortable withholding or withdrawing if they believe it is not beneficial to the patient.

Regarding the legal requirement of informed consent and truth telling, one should be careful to provide information in a thoughtful way, leaving room for hope, as often talked about by Rabbi Lamm. However, Jewish law does allow one to withhold information if it is believed that the information will be harmful to the patient and this clearly conflicts with the legal concept of informed consent. The way this can be resolved is by being sensitive to how much information the patient wants or needs to know, and by giving the patient the necessary information in a fashion that keeps them positive and hopeful.

Advance directives are permitted by Jewish law. A "Health Care Power of Attorney" is permissible in all streams of Judaism including traditional Judaism. This is because the patient who wants decisions made according to Jewish law will designates a rabbi who is expert in Jewish medical ethics as a surrogate decision maker. As discussed above, it is the rabbi who, as the expert in Jewish law, will know what Jewish law would say to do in the specific situation that the patient is in at any particular time. A "Living Will" is somewhat more challenging, especially in the traditional Jewish world, as the document states what the patient does or does not want if s/he is terminally ill. Traditional Jews would include in the "living will" a provision that the instructions regarding what interventions they or do not wish should be based on their current condition after consultation with a designated rabbi.

Organ donation is permissible by Jewish law. However, among Orthodox rabbis, there is a major disagreement over how death is defined, which creates significant challenges regarding the donation of hearts, since potential donors have to be declared dead prior to donation. Some rabbis define death as the irreversible cessation of spontaneous respirations which can occur when the entire brain, including the brain stem, has ceased to function. Since patients in this situation can be declared deceased while still being

patient would have done if he could have decided for himself.

c. The patient may not have an advance directive. In this situation, state surrogacy laws would come into play. In most states, multiple children have equal say, and therefore the sons would have to reach some kind of consensus regarding their father's care.

It would seem prudent therefore, that whether or not the patient improves following the adjustment in analgesia, that a family meeting be held with the two sons, and if possible and agreed to by all parties, including the religious son's rabbi. The treatment plan regarding adjustments in analgesics and other possible causes of the changes in the patient's condition can be discusses. Issues regarding the mother's death and how her care might be affecting decisions around the father's care can also be addressed. The inclusion of the rabbi, if agreed to, is important, to ensure that the rabbi has an accurate picture of the patient's medical condition and prognosis, since up to this point he has only spoken with the son. Whether the situation will be resolved with this meeting is unknown and ongoing conversations based on changes in the patient's condition will likely be needed.

CASE # 2

The patient is a 23 year old female, married for one year, who was in a severe auto accident. She suffered major head trauma, and has been cared for in the ICU for a little over 1 month. She remains unresponsive with no signs of any cognitive activity, and she remains ventilator dependent despite several attempts at medical weaning.

She is the daughter of the local orthodox rabbi in the community. It is well known that while she was in college she became less observant in her faith. She and her husband of one year, who is also Jewish, belong to the local reform temple. While her parents have not been happy with her religious choices, they have accepted them and they had a good relationship prior to the auto accident.

possible options:

a. Enteral tube feeding: Enteral feeding via a PEG tube would be an appropriate consideration if the patient had a prognosis measured in months and if he was stable enough medical condition to tolerate the medical procedure. If his prognosis is weeks to only a couple of months, and/or his medical condition is less stable, NG tube feedings could be considered, although the family must be made aware of the potential significant discomfort that the patient might experience from the tube. In either case, the amount of feedings should be monitored carefully as patients remain at risk for aspiration pneumonia, especially if they are being overfed.
b. Hypodermoclysis: If the patient has a prognosis of days to 1-2 weeks, subcutaneous hydration via hypodermoclysis is a reasonable alternative to tube feeding. Generally, patients receive 500-1000 cc of fluid per day through a small silastic catheter. This is enough fluid to sustain the patient without risking complications of fluid overload.

4. Advance directive and responsibility for medical decision making: It is not known whether the patient has an advance directive.

a. If he has a "living will" which gives specific instructions on his wishes regarding food and fluid then on a legal level this would have to be followed, despite the fact that, if the patient opted to forgo artificial nutrition and hydration, the religious son would object.
b. If he has a durable health care power of attorney that specifically names one or both of his sons as surrogate(s), then the individual(s) named would be able to make medical decisions for the patient. Keep in mind, however, that the decision of the surrogate(s) has to be consistent with what the

supported by mechanical ventilation and can still have a beating heart, these individuals can donate their hearts. Some rabbis define death as the irreversible cessation of cardiac function. Since the heart has to stop beating for these individuals to be declared deceased, they cannot be heart donors.

CASE PRESENTATIONS

The goal of these case presentations is not to give answers but to raise the issues that come forth in these cases.

(The following are cases that were presented and discussed with the audience, as examples of applying these principles. There are comments from Dr. Kinzbrunner as he interacted with the audience.)

CASE #1

The patient is a 79 year old male with end stage cerebrovascular disease and mild multi-infarct dementia. He has been somewhat responsive to verbal stimuli and he has been taking food and fluids by mouth.

The patient is being cared for in a long-term care facility and has a Stage IV sacral decubitus as a complication of his illness. He was married for 47 years until his wife died two years ago. Prior to death, she had suffered from advanced dementia, had been fed with a PEG tube for about 18 months, and ultimately succumbed to severe aspiration pneumonia.
He has two sons. He and his family are of the Jewish faith. He and his younger son are not observant, while the older son has recently become observant.

The patient has been experiencing significant pain in the area of the decubitus ulcer throughout the day as well as with the dressing changes. He has been medicated with one tablet of Vicodin every 4 hours round the clock, with an additional prn dose one half hour before dressing changes. Recently due to an increase in his discomfort despite the analgesia, his medication was changed to morphine, immediate release 10 mgs every 4 hours around the clock with an additional prn dose prior to dressing changes.

After several days on this regimen, the patient is more comfortable, but he has also become increasingly somnolent and is no longer eating or drinking. The younger son is comfortable with the situation as he is primarily concerned with the patient's level of comfort. He also believes that his father would not want to suffer like his mother had.

However, the older son, upon learning of the change in his father's condition, comes to the nursing home demanding to speak with you. When you arrive, he demands that the patient's pain medicine be stopped and that he have a feeding tube placed for the purpose of providing artificial nutritional support since this is what his rabbi told him that he had to do. The younger son, who is also present, begins to argue with his brother.

What are the issues the need to be addressed in this case? What would you recommend?

Identified issues include pain management, the increasing somnolence, the provision of hydration and nutrition to the patient, whether or not there is an advance directive, and who is responsible for making medical decisions for this patient. Although all of these issues are interrelated, they will be addressed individually.

1. Pain management: The patient had persistent pain on Vicodin, and while his pain improved with the change in analgesia to morphine, he developed increasing somnolence. Assuming that the somnolence is due to the increase in analgesia, it would be prudent to make some adjustments in the patient's analgesia to see if the somnolence resolves. Measures that could be taken would include:
    a. Reduce the analgesia by stopping the morphine and resuming the Vicodin. Since the Vicodin was insufficient to control the patient's pain, however, ensuring that there is additional analgesia available for breakthrough pain would be important.
    b. Ensuring that the patient is medicated with an additional dose of Vicodin (or 50% of the

bioequivalent amount of morphine) 20-30 minutes prior to dressing changes.
    c. Another alternative to treat the painful decubiti would be to consider topical morphine. While morphine is not absorbed through normal skin surfaces, it has been shown to be effective when applied topically to damaged skin. This is likely due to opioid receptors in local tissue since the morphine is not absorbed systemically.
    d. If one felt that the patient's pain was clearly improved on the new dose, one could also consider adding a psychostimulant, such as methylphenidate or an amphetamine, both of which have been shown to have positive effects on opioid induced somnolence.

   If one or more of these measures is tried and the patient's somnolence improves to the point that the patient to start eating again, the issue regarding feeding the patient is resolved for the moment.

2. Somnolence: While it most likely that the somnolence is due to the increased analgesia, it is also possible that the two are not related. Possibilities that would need to be considered if his mental status does not improve after the analgesia is adjusted could include infection, metabolic or electrolyte disturbances, or the beginning of the dying process. The question of how aggressively to pursue these possibilities would depend on the patient's response to the change in analgesia and the potential chances of being able to reverse one of these other conditions if the patient's mental status does not improve.
3. Provision of artificial nutrition and/or hydration: Assuming the patient's mental status does not improve, then, based on whether the patient does or does not have an advance directive (see # 4), a decision as to whether to provide the patient with food and/or fluid will be made. If it is decided that the patient requires food and/or fluid, there are several