

**MAKING DECISIONS ABOUT MEDICALLY ASSISTED
NUTRITION AND HYDRATION**

Guiding Principles from the Catholic Moral Tradition

second edition

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This pamphlet is meant to help patients, family members, and other caregivers in understanding and making decisions about one way of assisting patients with their nutritional needs. It will explain:

- the procedure of medically assisted nutrition and hydration;
- when the use of medically assisted nutrition and hydration may be considered;
- moral principles guiding decisions about using or forgoing medically assisted nutrition and hydration.

Some cases will be presented to help you understand how the moral principles are applied.

What is meant by *medically assisted nutrition and hydration*?

Medically assisted nutrition and hydration is sometimes referred to as “artificial nutrition and hydration” or as “assisted nutrition and hydration” or as “tube feeding.” Basically, it involves using a tube to deliver nutritional substances and water to a person instead of the person taking in food and water by mouth. It is different than hand feeding someone.

What forms can medically assisted nutrition and hydration take?

- *Peripheral intravenous feeding* consists in a needle inserted into a vein in the arm.
- A *nasogastric (NG) tube* is a thin plastic tube inserted through the nose into the stomach or into the first portion of the small intestine.
- A *percutaneous endoscopic gastrostomy (PEG) tube* is inserted through the skin into the stomach.
- A *jejunostomy tube* is placed in the small intestine.
- *Central intravenous feeding*, also known as *total parental feeding* or as *hyperalimentation*, is the insertion of a catheter into a central vein near the heart. (1)

When might the use of medically assisted nutrition and hydration be considered?

Medically assisted nutrition and hydration may be used on a short-term basis following an accident or following surgery when the patient temporarily cannot eat. (2) Such short-term uses of medically assisted nutrition and hydration to help a patient through a temporary health crisis are not controversial.

Medically assisted nutrition and hydration can also be used for longer periods of time in circumstances in which the patient cannot get adequate nutrition and hydration by mouth. For example:

- A patient may be unable to swallow or have difficulty swallowing e.g., because of a head injury, ALS, a stroke, or Parkinson's disease.
- A patient may have a blocked gastrointestinal tract due to cancer.
- A patient may lack enzymes necessary to absorb nutrients in the intestines.
- A patient may have a normal mouth, stomach, and intestinal tract but is adverse to or uninterested in eating. (3)

It is when medically assisted nutrition and hydration is or may be used for a prolonged period of time that difficult decisions can be faced about initiating, continuing, or discontinuing its use.

What Moral Principles Guide Decision Making about Medically Assisted Nutrition and Hydration?

The *Ethical and Religious Directives for Catholic Health Care Services* from the United States Conference of Catholic Bishops give us moral principles for making decisions about using or forgoing medically assisted nutrition and hydration:

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration becomes morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive

and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort. (4)

This directive gives the following guidance:

- In principle, there is an obligation to provide medically assisted nutrition and hydration to patients in need of it.
- However, there are cases in which it is morally permissible to forgo (withhold or withdraw) medically assisted nutrition and hydration.
- The following standard is to be used for determining when it is permissible to forgo medically assisted nutrition and hydration: the procedure cannot reasonably be expected to prolong life or would be excessively burdensome for the patient or would cause significant physical discomfort for the patient.
- When a patient is drawing close to inevitable death, the use of medically assisted nutrition and hydration may well not be obligatory.

Providing someone with nutrition and hydration, even by medically assisted means, is considered part of the normal care due to the sick person. (5) This grounds the first moral principle: In principle, there is an obligation to provide medically assisted nutrition and hydration to patients in need of it. However, this obligation is *not* absolute. It is morally permissible to forgo (that is, withhold or withdraw) medically assisted nutrition and hydration when this procedure cannot reasonably be expected to prolong the patient's life or when it would be excessively burdensome for the patient or when it would cause significant physical discomfort for the patient. In particular, medically assisted nutrition and hydration may well not be obligatory when the patient's death is imminent.

What are benefits and burdens of medically assisted nutrition and hydration?

Tube feeding can have the important benefit of prolonging, and even improving the quality of, someone's life. This is true, for example, of persons suffering from ALS (Lou Gehrig's disease). Here is the true story of one ALS patient:

My wife has been displaying symptoms of ALS for 2-3 years, but we just got the diagnosis in January. She has severe bulbar symptoms, making chewing virtually impossible. In November, it was suggested that she might want to look into having a feeding tube installed. By this time she had lost over 20 lbs. because she couldn't eat enough. We were doing Ensure drinks and pudding; she would start trying to eat first thing in the

morning and then eat (at a very slow rate) virtually all day long. By Christmas time she was down to less than 80 lbs. and we couldn't wait until the scheduled date for the feeding tube. She ended up in the ICU for 2 weeks because of her inability to intake enough nutrition.

We have had the PEG (feeding tube) for 4 months now... Her quality of life has been so much improved by the PEG. Most likely she would have passed away months ago without it. Does it interfere with things? No, not really. She is hooked up to the feeding pump at night and gets 1200 – 1500 calories that way. When she isn't hooked to the pump, the tube is out of sight and out of mind. It gives us a way to administer medications without needing to swallow. She is still mobile so it is important to her that the tube not tie her down to a bed, and it doesn't.

The PEG...allows her to do things besides spend entire days trying to get enough nutrition to stay live. (6)

On the other hand, there are cases in which a feeding tube will not be successful in prolonging someone's life. A patient may be suffering from such severe heart, kidney, or liver failure that his or her body cannot process, metabolize, or excrete the nutrients or fluids supplied through the feeding device. (7) Or again, a feeding tube may not work because the tube itself has developed complications such as infection or bleeding, or because it has become entangled in the bowels so that the bowel tissue dies and can no longer absorb nutrients. (8) In such cases, medically assisted nutrition and hydration is a futile procedure in a very basic physiological sense. Since it will not work to prolong the person's life, it is morally permissible to withhold or withdraw it.

While feeding tubes can be beneficial, they do have certain risks. For example, use of a PEG tube can bring about diarrhea, nausea, vomiting, or aspiration pneumonia. (9) Fr. Tad Pacholczyk of the National Catholic Bioethics Center describes a case in which a feeding tube has become "excessively burdensome" for the patient and morally may be withdrawn:

...if someone is very sick and dying, perhaps with partial bowel obstruction, the feeding tube may cause them to vomit repeatedly, with the attendant risk of inhaling their own vomit, raising the specter of lung infections and respiratory complications. The feeding tube under these conditions may become disproportionate and unduly burdensome, and therefore non-obligatory. (10)

When someone is serving as a proxy decision maker, he or she should try to evaluate the benefits and burdens of medically assisted nutrition and hydration *as the person s/he represents would judge them.*

Illustrative Examples

Below are hypothetical examples of situations in which decisions have to be made about using medically assisted nutrition and hydration. **These examples are presented for educational purposes only. Decisions about using or forgoing medically assisted nutrition and hydration must always be made on a case-by-case basis, taking into account the specific physical condition of the patient.** Good decision making involves both *ethical principles* and the *medical facts of the case*.

CASE 1

John and Mary Smith are both in their early seventies. They maintain an active lifestyle physically. Both play golf several times a week during warm weather. During the winter they are among the daily “mall walkers.”

However, today John is not himself. He falls several times in his home during the day and frequently coughs. In the evening he tells his wife that he “just doesn’t feel quite right.” John is driven by his wife to the hospital emergency room to be checked out.

In the ER John is diagnosed as having suffered a mild stroke, and is hospitalized. His coughing continues, and a swallowing test is performed which indicates that he is experiencing some swallowing difficulties (dysphagia) as a result of the stroke.

The specialist who has been called in has a conference with John and Mary. Among other things, he recommends the insertion of a feeding tube to help John get adequate nutrition. Mary, however, has always been afraid of feeding tubes. She persuades John to “take 24 hours to think about it” before making a decision.

Commentary

The provision of nutrition and hydration, even when medically assisted, is part of the normal care due to the sick person. And there are cases in which medically assisted nutrition and hydration can be of distinct benefit to a patient. If a person has swallowing difficulties following a stroke but previously had a good quality of life, high functional status, and only minimal co-existing diseases, then tube feeding is likely to prolong the person’s life. (11) This is certainly true of John.

For these reasons a feeding tube should be used for John at the present time. Indeed, the tube feeding may only be needed as a temporary support and could eventually be removed when the person regains swallowing capabilities. (12)

Now suppose that the following happens in the case of John Smith:

A feeding tube is inserted. John undertakes a program of rehabilitation which includes both physical therapy and working with a speech therapist on his swallowing

problem. Within two months John's overall condition improves markedly. He can be taken off the feeding tube and resumes normal eating.

However, six months after completing rehab, John's health begins to decline. He finally decides to move to a long-term care center because of the strain care giving is placing on his wife.

Not too long thereafter, John has another and more severe stroke. A feeding tube is again inserted to boost nutritional intake. However, this time the feeding tube causes John to have diarrhea, and he develops aspiration pneumonia.

Commentary

What is significant is that the feeding tube is now causing diarrhea and aspiration pneumonia for John. These are serious side effects of the feeding tube. And these serious side effects are "burdens" of the feeding tube, which could justify its removal from a moral point of view.

This situation also illustrates that the effect of a feeding tube on a particular patient can vary over time. While the feeding tube was helpful to John in recuperating from his first stroke, use of a feeding tube after his second stroke is causing additional physical problems for him. Thus use of a feeding tube needs to be monitored on an ongoing basis. It might be appropriate to use a feeding tube for a particular person at one point in time but appropriate not to use it later.

CASE 2

Alice Parker, an 87-year-old nursing home resident, is in the advanced stages of Alzheimer's disease. She no longer recognizes her daughter and son when they come to visit her, and she is not oriented to the date or place. She needs assistance with all her daily living activities.

Alice is now refusing to eat. The care center sends Alice to the emergency room of the local hospital because the staff has observed that she has difficulty swallowing. A swallow study is performed by a speech therapist and indicates moderate dysphagia (swallowing problems) with signs of aspiration.

The nursing home staff arranges a meeting with Alice's daughter, Emma, whom Alice has named as her proxy decision maker in her durable power of attorney for health care. They want to discuss with Emma the next steps to be taken in Alice's care plan. Should a feeding tube be placed to provide nutrition for Alice? Or should a decision be made to forgo a feeding tube and place Alice in Hospice care? (13)

Commentary

In making decisions about using or forgoing medically assisted nutrition and hydration, it is important to consult with health care professionals about current clinical data on tube feeding for patients with particular diseases and conditions. For example, when dealing with patients with *advanced dementia*, there is no evidence to suggest a difference in longevity between persons who have tube feeding and persons provided with assistance in regular oral feeding. (14)

Tube feeding has not been shown to prevent aspiration, heal pressure wounds, or improve nutritional status in persons with advanced dementia. It does not have these benefits for persons with advanced dementia. Moreover, tube feeding may be accompanied by substantial burdens including recurrent and new onset aspiration, tube-associated and aspiration-related infection, increased oral secretions that are difficult to manage, discomfort, tube malfunction, and pressure wounds. Persons suffering from advanced dementia may need to be restrained to prevent them from pulling out the feeding tube. In fact, studies have shown that long-term care residents with advanced dementia and a feeding tube frequently need to be taken to a hospital emergency room to address tube-related complications. [15]

Thus there is likely no moral obligation to initiate tube feeding for Alice because it will not increase her longevity over hand feeding and may have complications which are very burdensome for her. However, Alice should be fed orally by hand as she is able to take food. (16) Her previous refusal to eat may be related to moderate dysphagia (swallowing problems) which requires modifications in her diet. In order to encourage Alice to take food orally, caregivers may need to offer her preferred foods or enhance their own skills in hand feeding. (17) It should be kept in mind that oral feeding may be one of the few remaining pleasures and a time for socialization for a person with advanced dementia. (18) Although her quality of life is diminished by dementia, Alice retains her dignity as a human being and deserves our care.

CASE 3

Stephen Redding, 72, has been fighting colon cancer for five years. He has undergone numerous rounds of chemotherapy. Initially, the chemotherapy seemed to stop the growth of the cancer, but in the last five months it has been ineffective. For this reason, Stephen has recently decided to discontinue the treatments and to use Hospice services.

Stephen's condition continues to deteriorate. He is not expected to live long and continues under Hospice care. Because of the cancerous growth blocking his intestinal tract, Stephen cannot get much nutrition by normal means. In consultation with his oncologist, Stephen decides against having a feeding tube placed. Stephen tells everyone that he is "ready to die" and just wants to be kept as comfortable as possible until that time comes. Ten days later, Stephen dies.

A few days after Stephen's death, Stephen's daughter Sarah and her husband Ron go to the director of Hospice to express concern that a feeding tube had not been used for him. They say that they can understand withholding tube feeding from a dying person who is mentally "out of it" and doesn't know what is going on, but they worry about withholding tube feeding from someone who was mentally alert and talked to them when they came into the room---even though they know the person was near death and didn't say that he was hungry. (19)

Commentary

The *Ethical and Religious Directives for Catholic Health Care Services* notes that, "as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort" (20).

In fact, there is evidence that *patients who are allowed to die without assisted nutrition and hydration may die more comfortably than patients who receive conventional amounts of intravenous hydration. (21)* Dehydration can reduce swelling and increase comfort in a patient suffering from edema (swelling of the body caused by excess body fluids) or ascites (fluid in the abdominal cavity). Cough and congestion may be lessened because secretions in the lungs are diminished. A dehydrated person has less urine output so that problems with incontinence are lessened. Since there is less fluid in the gastrointestinal tract with dehydration, a patient may experience a decrease in nausea, vomiting, bloating, and regurgitation. Indeed, dehydration leads to death in ways that produce a sedative effect on the brain just before death, thus decreasing the need for pain medication. (22)

Since Stephen's death was imminent, there was likely no moral obligation to initiate medically assisted nutrition and hydration for him. The person's state of consciousness --- whether the person is awake and aware or has reduced unconsciousness or is unconscious --- does not make a difference in itself. In any case in which a person's death is imminent, what is important is that medically assisted nutrition and hydration may well be burdensome and is not likely to prolong the person's life or provide comfort to him or her.

Should Medically Assisted Nutrition and Hydration Be Provided to Patients in a Vegetative State?

A *vegetative state* is one form of unconsciousness due to severe brain damage. It is deceptive to observers because the patient goes through sleep-wake cycles so that there are times when the patient's eyes are open. However, the patient gives no evidence of being aware of self or the environment, and is unable to interact with others. The patient gives no evidence of sustained, reproducible, purposeful or voluntary behavioral responses to stimuli. The patient gives no evidence of understanding or using language.

However, some brain functions (namely, functions of the hypothalamus and brain stem) are sufficiently preserved to allow the patient to survive with medical and nursing care. (23)

After the vegetative state has continued for at least one month, the patient is said to be in a *persistent vegetative state*. (24) A patient in a persistent vegetative state is said to enter a *permanent vegetative state* when the diagnosis is that the condition is irreversible and the chance that the person will regain consciousness is very, very small. (25) Some use the term “persistent vegetative state” less precisely as an umbrella term to include both the persistent and permanent vegetative states.

Some have taken the position that, once the vegetative state is diagnosed as being permanent, this is sufficient reason to withdraw the medically assisted nutrition and hydration that is keeping the person alive. (26) As indicated by the *Ethical and Religious Directives for Catholic Health Care Services* (see above), the Catholic Church does not concur in this judgment. Medically assisted nutrition and hydration is considered part of the normal care due to any sick person, including patients in chronic and presumably irreversible conditions. (27) However, medically assisted nutrition and hydration may be withdrawn from a patient in a permanent vegetative state if the procedure itself has become ineffective in prolonging the patient’s life or excessively burdensome for the patient. (28)

CASE 4

Don Burns, 35, and Louise Richardson, 32, have been married for six years. They have two children, Jessica, 4, and Eric, 2. All her life Louise has had heart problems because of a congenital heart defect. She feels very fortunate to have been able to carry the two children she now has. Both Don and Louise have established promising careers as attorneys.

Late one afternoon, a neighbor finds Louise lying on the front porch of her home. Apparently, Louise had stopped home on her way to pick up her children at the day care center when something happened to her. The neighbor calls 911. The paramedics who arrive tell the neighbor that Louise has suffered a cardiac arrest. CPR is administered to restore her heart beat, and she is taken to the emergency room of the local hospital.

When her husband arrives at the hospital, he finds that Louise has been put in the intensive care unit (ICU) and placed on a ventilator. Three weeks go by, and Louise remains “out of it.”

Sometimes her eyes are open but she doesn’t seem aware of anyone in the room. She doesn’t speak, and when the doctor tries to get her to respond to simple commands, she doesn’t. She is now able to be taken off the ventilator and can breathe on her own, but

she must be fed through a tube. A neurologist who examines Louise diagnoses her as being in a “vegetative state.”

Louise is transferred to a long-term care facility since there is no special treatment the hospital can provide for her at this point. Her care at the nursing home includes tube feeding, turning her in bed periodically to prevent pressure sores, maintaining appropriate hygiene, and range of motion exercises to minimize limb contracture.

Four months after admission to the nursing home, Louise’s condition remains unchanged. She is again examined by a neurologist, who tells Don that his wife is now in a “permanent vegetative state” and that it is highly improbable that she will ever regain consciousness.

Don is devastated by this news. Two days later he contacts the neurologist and tells him that he wants the feeding tube removed from his wife so that she can be allowed to die. “I love her too much,” he says, “to allow her to continue to exist in this way.” (29)

Commentary

According to Catholic teaching, it would not be permissible to remove the feeding tube from Louise *just because she is in a permanent vegetative state*. As Pope John Paul II affirmed, continuing the minimal care of food and water is part of our respect for the dignity of the human person: “I feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life. ...Even our brothers and sisters who find themselves in the clinical condition of a ‘vegetative state’ retain their human dignity in all its fullness. The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help. ... The evaluation of probabilities, founded on waning hopes for recovery...cannot ethically justify the cessation or interruption of *minimal care* for the patient, including nutrition and hydration.” (30)

Now suppose that the following happens in the case of Louise:

Don finally agrees to continuing care for Louise in the nursing home, including use of a feeding tube.

Louise has now been in the nursing home for a year and remains in a vegetative state. She is suffering periodic bouts of feeding tube site infections. Louise’s physician meets with her husband, Don, to discuss a care plan. The doctor tells him that perhaps it is time to think about removing the feeding tube.

Commentary

From a moral point of view, use of the feeding tube has now changed significantly. This is because the repeated infections associated with the feeding tube make its use burdensome for the patient. (31) At this point, it would be ethically permissible to withdraw the feeding tube from Louise.

It should be kept in mind that the vegetative state is a different condition than severe dementia or a coma. (32) The persistent/permanent vegetative state is a relatively rare condition, affecting about 1 in 10,000 persons in the United States. (33) Thus it is unlikely that you, or anyone you know, will ever be in this condition.

* * * * *

In working through your decision about using or forgoing medically assisted nutrition and hydration, it may be helpful to keep the following questions in mind and to discuss them with your health care providers:

- What is the patient's current health situation?
- Why is medically assisted nutrition and hydration being considered for the patient? (e.g., not getting enough nutrition by mouth, swallowing problems)
- Will medically assisted nutrition and hydration work to prolong the patient's life?
- Is medically assisted nutrition and hydration likely to improve the patient's health and/or quality of life? If yes, how so?
- Is medically assisted nutrition and hydration likely to be temporary or permanent?
- What are the risks and potential complications of medically assisted nutrition and hydration for this patient?
- Is the patient likely to become agitated with having a feeding tube?
- Is the patient suffering from advanced dementia?
- Is the patient very near death?
- Has the patient ever made any explicit statements about wanting or not wanting tube feeding in terms of its benefits and burdens? In written advance directives? Orally?
- Are there alternatives to using medically assisted nutrition and hydration (e.g., better hand feeding procedures)?
- Who will make the decision about using or not using medically assisted nutrition and hydration?
- Are there any questions you would like to have answered before making the decision?

- What is currently your overall “leaning” about using or not using medically assisted nutrition and hydration? What factors are significant for you in feeling this way? (34)

Most health care facilities have ethics committees which are willing to meet with patients and families faced with difficult decisions about using or forgoing treatments. The ethics committee will not make the decision for you but will help you work through the process of coming to a decision.

NOTES

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3. *Ibid.*
4. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services* (2009), no. 58. <http://www.usccb.org>.
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8. Daniel P. Sulmasy, “Preserving Life? The Vatican and PVS.” *Commonweal* 134/21 (Dec. 7, 2007): 16-18.
9. Quality Collaborative, Monroe County Medical Society, Rochester, NY. *Benefits and Burdens of PEG Placement*. [http://www.compassionandsupport.org/pdfs/professionals/life-sustaining/Benefit and Burdens.pdf](http://www.compassionandsupport.org/pdfs/professionals/life-sustaining/Benefit%20and%20Burdens.pdf) Accessed 2011.
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12. *Ibid.*

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15. American Geriatrics Society, *Feeding Tubes in Advanced Dementia Position Statement* (May 2013). <http://www.americangeriatrics.org/files/documents/feeding.tubes.advanced.dementia.pdf> Accessed 2014.

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24. *Ibid.*
25. *Ibid.* In the case of a traumatic brain injury (e.g., brain injury due to a car accident), the vegetative state can be considered permanent twelve months after the injury. In the case of a nontraumatic brain injury (e.g., brain injury due to a cardiac arrest), the vegetative state can be considered permanent after three months. Multi-Society Task Force on PVS. "Medical Aspects of the Persistent Vegetative State," Part Two, *New England Journal of Medicine* 330/22 (June 2, 1994): 1572-79.
26. Kevin O'Rourke, OP and Patrick Norris, OP, "Care of PVS Patients Catholic Opinion in the United States" in Arthur L. Caplan, James J. McCartney, and Dominic A. Sisti, *The Case of Terri Schiavo Ethics at the End of Life* (New York: Prometheus Books, 2006), pp. 213-19.
27. "In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care." United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, no. 58.
28. The quote in note 26 continues: "Medically assisted nutrition and hydration becomes morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or [would] cause significant physical discomfort...". *Ibid.*
29. This case is adapted from Idziak, *Ethical Dilemmas in Allied Health*, pp. 132-33.

30. John Paul II. "Care for Patients in a 'Permanent' Vegetative State," nos. 3-4.
31. Michael R. Panicola, "Withdrawing Nutrition and Hydration," *Health Progress* 82/6 (Nov.-Dec. 2001): 28-33.
32. In a coma, the patient's eyes remain closed and the person appears to be asleep but cannot be aroused. The patient does not go through sleep-wake cycles as happens in the vegetative state. Multi-Society Task Force on PVS. "Medical Aspects of the Persistent Vegetative State," Part One; American Neurological Association Committee on Ethical Affairs. "Persistent Vegetative State: Report of the American Neurological Association Committee on Ethical Affairs."
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