MAKING DECISIONS ABOUT MEDICALLY ASSISTED NUTRITION AND HYDRATION IN LONG-TERM CARE

A Guide

for Residents, Proxy Decision Makers, and Caregivers

prepared by

The Ethics Committee

Stonehill Communities

Dubuque, Iowa

Second Edition 2014

This booklet is meant to help residents, family members, significant others, and other caregivers in understanding and making decisions about one way of assisting residents 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;
- ethical principles guiding decisions about using or forgoing medically assisted nutrition and hydration.

Some cases will be presented to help you understand how the ethical principles are applied. We have also included a "personal worksheet" to help you go through the steps of making a decision about using or forgoing medically assisted nutrition and hydration.

In addition to providing this booklet, Stonehill's Ethics Committee is available to meet with you and help you work through these decisions.

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 resident instead of the person taking in food and water by mouth. It is different than hand feeding a resident.

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.

The PEG tube and the jejunostomy tube are most likely to be used at Stonehill Care Center.

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

A resident may have eating and swallowing problems due to such conditions as a stroke, Parkinson's disease, ALS (Lou Gehrig's disease), Alzheimer's disease and other dementias, or cancerous growths. A feeding tube might be considered in such cases.

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

As a Catholic health care facility, Stonehill Communities provides care in accord with the *Ethical and Religious Directives for Catholic Health Care Services.* These directives give us ethical 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 ljfe 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.* (No. 58)

This directive gives the following guidance:

- In general, there is an obligation to provide medically assisted nutrition and hydration to persons 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 the person's life or would be excessively burdensome for the person or would cause significant physical discomfort for the person.

- When a person 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. This grounds the first ethical principle: In general, there is an obligation to provide medically assisted nutrition and hydration to persons in need of it. However, this obligation is *not* absolute. It is ethically permissible to forgo (that is, withhold or withdraw) medically assisted nutrition and hydration when this procedure cannot reasonably be expected to prolong the person's life or when it is excessively burdensome for the person or when it would cause significant physical discomfort for the person. In particular, medically assisted nutrition and hydration may well not be obligatory when the person'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. (http://tpals.org/ftube4.htm)

On the other hand, there are cases in which a feeding tube will not be successful in prolonging someone's life. A person 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. 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. 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 ethically 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. Fr. Tad Pacholczyk of the National Catholic Bioethics Center describes a case in which a feeding tube has become "excessively burdensome" for a particular person and may ethically 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. (*The Catholic Globe* Dec. 24, 2009: 13)

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 for Long-Term Care

Below are hypothetical examples of situations in which decisions have to be made about using medically assisted nutrition and hydration which are likely to arise in long-term care. 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 resident. Good decision making involves both *ethical principles* and the *medical facts of the case.*

CASE 1

Florence and Gerald Lang, both in their early seventies, are residents of Assisi Village. 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 Gerald is not himself. He falls several times in his apartment during the day and frequently coughs. In the evening he tells his wife that he "just doesn't feel quite right." Gerald is driven by his wife to the hospital emergency room to be checked out.

In the ER Gerald 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 Gerald and Florence. Among other things, he recommends the insertion of a feeding tube to help Gerald get adequate nutrition. Florence, however, has always been afraid of feeding tubes. She persuades Gerald to "take 24 hours to think about it" before making a decision.

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 sick person. 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. This is certainly true of Gerald.

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

Now suppose that the following happens in the case of Gerald Lang:

A feeding tube is inserted. Gerald undertakes a program of rehabilitation which includes both physical therapy and working with a speech therapist on his swallowing problem. Within two months Gerald's overall condition improves markedly. He can be taken off the feeding tube and resume normal eating.

However, six months after completing rehab, Gerald's health begins to decline. He moves from Assisi Village to the Care Center. Not too long thereafter, Gerald has another and more severe stroke. A feeding tube is again inserted to boost nutritional intake. However, this time the feeding tube causes Gerald to have diarrhea, and he develops aspiration pneumonia.

What is significant is that the feeding tube is now causing diarrhea and aspiration pneumonia for Gerald. 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 ethically.

This situation also illustrates that the effect of a feeding tube on a particular person can vary over time. While the feeding tube was helpful to Gerald 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

Hattie Parker, an 87-year-old resident of Stonehill Care Center, 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.

Hattie is now refusing to eat. The care center sends Hattie 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 care center staff arranges a meeting with Hattie's daughter, Emma, whom Hattie 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 Hattie's care plan. Should a feeding tube be placed to provide nutrition for Hattie? Or should a decision be made to forgo a feeding tube and place Hattie in Hospice care?

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 persons with particular diseases and conditions. For example, when dealing with long-term care residents 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. Since, in such cases, tube feeding cannot reasonably be expected to prolong life over hand feeding, there is no ethical obligation to use the tube feeding in preference to oral feeding by hand.

Tube feeding has not been shown to prevent aspiration, health 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 difficulty 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.

Thus there is likely no ethical obligation to initiate tube feeding for Hattie because it will not increase her longevity and may have complications which are very burdensome for her. However, Hattie should be fed orally by hand as she is able to take food. Her previous refusal to eat may be related to moderate dysphagia (swallowing problems) which requires modifications in her diet. In order to encourage Hattie to take food orally, caregivers may need to offer her preferred foods or enhance their own skills in hand feeding. 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.

Although her quality of life is diminished by dementia, Hattie 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. Because he has become so debilitated and the caregiving demands on his wife have become so great, he is admitted to Stonehill Care Center. He is not expected to live long and continues under Hospice care. Because of the cancerous growth blocking his intestinal tract, Stephen cannot get adequate 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 facility's administrator to express concern that a feeding tube had not been used for him. They say that they can understand withholding a feeding tube from a dying person who is mentally "out of it" and doesn't know what is going on, but they worry about withholding a feeding tube 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. The administrator suggests that Sarah and Ron meet with the facility's ethics committee to discuss their concerns.

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" (no. 58).

In fact, there is evidence that *persons who are allowed to die without assisted nutrition and hydration may die more comfortably than persons who receive conventional amounts of intravenous hydration.* Dehydration can reduce swelling and increase comfort in someone 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 person 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.

Since Stephen's death was imminent, there was likely no ethical 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 Persons in a Vegetative State?

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

After the vegetative state has continued for at least one month, the person is said to be in a *persistent vegetative state*. A person 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. 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. The Catholic Church does not concur in this judgment. Medically assisted nutrition and hydration is considered part of the normal care due to a sick person. However, medically assisted nutrition and hydration may be withdrawn from someone in a permanent vegetative state if the procedure itself has become ineffective in prolonging the person's life or excessively burdensome for the person.

PVS is a relatively rare condition, affecting about 1 in 10,000 persons in the United States. Thus it is highly unlikely that you, or anyone you know, will ever be in PVS.

Personal Worksheet for _____

- What is the resident's current health situation?

- Why is medically assisted nutrition and hydration being considered? (e.g., not getting enough nutrition by mouth, swallowing problems)

- Will medically assisted nutrition and hydration work to prolong the resident's life?

- Is medically assisted nutrition and hydration likely to improve the resident's health and/or quality of life? If yes, how so?

- Is medically assisted nutrition and hydration likely to be temporary or permanent?

- What have health care providers told you about the risks and potential complications of medically assisted nutrition and hydration? How likely are these to occur in the case of this resident?

- Is the resident likely to become agitated with having a feeding tube?

- Is the resident suffering from advanced dementia?

- Is the resident very near death?

- Has the resident 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?

If you would like to meet with the Ethics Committee for further discussion, contact the Administrator of Stonehill Care Center to arrange an ethics consult.

This worksheet is adapted from *Making Choices: Long Term Feeding Tube Placement in Elderly Patients* by S.L. Mitchell, J.M. Tetroe, and A.M. O'Connor (2008). http: //decisionaid.ohri.ca/docs/Tube Feeding DA/PDF/TubeFeeding.pdf Accessed 2011

Sources Consulted

Alzheimer's Association, *Assisted Oral Feeding and Tube Feeding*. http://www.alz.org/alzwa/documents/alzwa Resource EOL_FS_Oral Feeding.pdf Accessed 2011.

American Dietetic Association, "Position of the American Dietetic Association: Ethical and Legal Issues in Nutrition, Hydration, and Feeding." *Journal of the American Dietetic Association* 108 (2008): 873-82.

American Dietetic Association, "Position of the American Dietetic Association: Issues in Feeding the Terminally Ill Adult." *Journal of the American Dietetic Association* 87 (Jan.-April 1987): 78-85.

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.

American Neurological Association Committee on Ethical Affairs. "Persistent Vegetative State: Report of the American Neurological Association Committee on Ethical Affairs." *Annals of Neurology* 33/4 (April 1993): 386-90.

Candy, Bridget; Sampson, Elizabeth L.; Jones, Louis. "Enteral tube feeding in older people with advanced dementia: Findings from a Cochrane systematic review." *The International Journal of Palliative Nursing* 15/8 (2009): 396-404.

Congregation for the Doctrine of the Faith. *Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration* and *Commentary* (August 1, 2007). http://www.vatican.va> Holy See English> Roman Curia> Congregations > Doctrine of the Faith> Doctrinal Documents.

Fine, Robert L. "Ethical Issues in Artificial Nutrition and Hydration." *Nutrition in Clinical Practice* 21 (April 2006): 118-25.

Finucane, Thomas E.; Christmas, Colleen; Travis, Kathy. "Tube Feeding in Patients with Advanced Dementia." *Journal of the American Medical Association* 282/14 (October 13, 1999): 1365-70.

Gillick, Muriel R. "Rethinking the Role of Tube Feeding in Patients with Advanced Dementia." *New England Journal of Medicine* 342/3 (January 20, 2000): 206-10.

Hallenbeck, James. *Fast Facts and Concepts #10 Tube Feed or Not Tube Feed?,* 2nd ed. (August 2005; edited March 2009). Medical College of Wisconsin, EPERC (End of Life/Palliative Education Resource Center). http://www.eperc.mcw.edu/fastEact/ff_10.htrn Accessed 2011.

Idziak, Janine M. *Ethical Dilemmas in Allied Health,* 2nd ed. Dubuque, IA: Kendall Hunt Professional, 2009.

Ina, LI. "Feeding Tubes in Patients with Severe Dementia." *American Family Physician* 65/8 (April 15, 2002): 1605-1611.

John Paul II. "Care for Patients in a 'Permanent' Vegetative State." *Origins* 33/43 (April 8, 2004): 737-40.

Meier, Diane E.; Ahronheim, Judith C.; Morris, Jane; Baskin-Lyons, Shari; Morrison, R. Sean. "High Short-term Mortality in Hospitalized Patients with Advanced Dementia." *Archives of Internal Medicine* 161 (Feb. 26, 2001): 594-99.

Mitchell, SL, Tetroe JM, and O'Connor AM. *Making Choices: Long Term Feeding Tube Placement in Elderly Patients*. 2008. http: //decisionaid.ohri.ca/docs/Tube Feeding DA/PDF/TubeFeeding.pdf Accessed 2011.

Multi-Society Task Force on PVS. "Medical Aspects of the Persistent Vegetative State," Part One. *New England Journal of Medicine* 330/21 (May 26, 1994); 1499-1508

Murphy, Lynne M. "Percutaneous Endoscopic Gastrotomy Does Not Prolong Survival in Patients with Dementia." *Archives of Internal Medicine* 163 (June 9, 2003): 1351-53.

Pacholczyk, Fr. Tad. "Are feeding tubes required?" *The Catholic Globe* (December 24, 2009): 13.

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 Accessed 2011.

Sheehan, Miles, SJ. "Feeding Tubes: Sorting Out the Issues." *Health Progress* 82/6 (Nov.-Dec. 2001): 22-27.

Sulmasy, Daniel P. "Preserving Life? The Vatican and PVS." *Commonweal* 134/21 (Dec. *7,* 2007): 16-18.

"Turning Points in ALS – Feeding Tubes: Page 4" http://tpals.org/ftube4.htm Accessed 2011.

Zerwekh, Joyce C. "The Dehydration Question." *Nursing* 83 (January 1983): 47-51

Case Studies

Case 1 adapted from Turning Points in ALS — Feeding Tubes: Page 4 http://tpals.org/ftube4.htm Accessed 2011.

Case 2 adapted from http://www.iaapa. com/is-it-ethical-to-provide-enteral-tube- feedings-for-patients-with-dementia/article/179939. Accessed 2011.

Case 3 adapted from Janine M. Idziak, Ethical Dilemmas in Long-Term Care, 2nd ed. Dubuque, IA: Kendall Hunt Professional, 2009