

Decisions at the End of Life

*"Precious in the sight of the Lord
is the death of his saints."*

by Catherine A. Marco, M.D.

As members of the Church, we believe that our Heavenly Father, in His divine judgment, chooses the appropriate time of death, the essential step and passageway to the next and more perfect life. Although medical technology has created many possibilities for increasing the quality and duration of life in many cases, its use must be appropriately and cautiously implemented. The role of medicine and technology should be to assist in providing cure and comfort to patients in need, rather than the artificial postponement of the natural process of dying.

The end of life is a time of complex emotions and feelings for the patient, family, and friends, and may also be a time for making many important decisions about the best treatments and interventions for the dying patient. Although some feel that aggressive medical therapy should be employed in many cases, it may not be appropriate for many terminally ill patients.² Decisions should be carefully and prayerfully considered by the patient, family, and physician, with the best interests of the dying person at heart.

Death is a Natural Part of Life

We have a unique understanding of death, and its crucial role in the fulfillment of the plan of salvation. "Returning from earth to life in our heavenly home requires passage through, and not around, the doors of death. As seedlings of God, we barely blossom on earth; we fully flower in heaven."³

"A good name is better than precious ointment; and the day of death than the day of one's birth."⁴

Death should be accepted as a natural part of life.⁵ Particularly when death is anticipated, usually through chronic illness or disease state, the dying process can and should be a time for reflection, family togetherness, and comfort and peace. It should not be a time of suffering or pain. Relief of suffering should be the goal of medical interventions, rather than direct interference with the natural process of dying.

Autonomy in Decision-Making

Some believe that every attempt should be made to prolong the life of a dying patient, using every available technologic and medicinal technique. However, the artificial prolongation of life may accomplish nothing more than increasing the duration of suffering. In such circumstances, the appropriate decision may be to choose only medical interventions which are likely to improve the

comfort and quality of life for the patient.⁶ Autonomy (derived from the Greek *autos*, meaning "self" and *nomos* meaning "rule") refers to the right of patients to make their own health-care decisions.⁷ As one of the primary principles of medical ethics, we respect patient autonomy.

Decisions about treating the terminally ill should be carefully and prayerfully considered by the patient, family, and physician, with the best interests of the dying person at heart.

Our duty is to inform and play a crucial role in assisting the patient and family in making important decisions at the end of life.

Various life-sustaining technologies should be considered only when the quality of life will be positively affected. If the only likely result is the artificial prolongation of suffering, their use may be inappropriate. Following is a brief discussion of common end-of-life interventions which may be appropriately used, or withheld, in certain settings.

Ventilators

Ventilators are used appropriately in a variety of clinical settings, and their use in terminally ill patients may at

times be appropriate for acute, treatable complications, such as pneumonia. Complications of artificial ventilation should be considered, such as iatrogenic infection, barotrauma, oxygen toxicity, subglottic stenosis, tracheomalacia, etc. Artificial ventilation may not be appropriate for patients who are unlikely to recover from the underlying illness.

Cardiovascular Support Drugs

Pressors such as dopamine, norepinephrine, and related drugs serve to support blood pressure and cardiac output for patients with hypotension. Although their use may be appropriate in certain settings, they are unlikely to be of long-term medical benefit in terminally ill patients.

Antibiotics and Other Medications

Most antibiotics are generally well tolerated, are not often associated with pain or complications, and are often successful in treating acute infections. Allergic reactions to antibiotics do occur, but are generally easily treated. In general, antibiotics may be appropriately administered for identified infections.

Other appropriate medications which may be indicated in terminally ill patients for symptomatic relief might include anxiolytics, antiemetics, and other agents.

Artificial Nutrition and Hydration

Food and water are among the most basic physical needs of all living creatures. From the day of birth, every living thing seeks them. Some believe that it would be cruel to withhold them from a dying patient. In fact, nutrition and hydration should always be available to the patient who wants them.

However, the time may come for a dying patient when there is no appetite, no thirst, and no strength to eat or drink. At such times, the decision must be made whether to offer artificial nutrition and hydration by the intravenous route, by nasogastric tube, by gastrostomy tube etc. Artificial nutrition and hydration may be appropriate in situations which are treatable, and expected to improve. At other times, when death is inevitable, it may be appropriate to withhold these artificial treatments. The common myth that such actions would cause suffering, as the patient "starves to death" is actually untrue. These patients generally do not suffer, and it affords a quiet way for nature to take its course.

Several studies have shown that hunger and thirst are minimal or nonexistent in terminally ill patients,⁹ and that slowing and cessation of oral intake is a natural part of the dying process.^{10,11} In fact, the discomfort and

complications of artificial feeding (which may include pain, coughing, pneumonia, or other infections, etc.) may actually increase the discomfort of the dying patient.¹²

Pain Control

Pain is all too often a significant problem for the dying patient. It is one of the common reasons for contempla-

Several studies have shown that hunger and thirst are minimal or nonexistent in terminally ill patients, and that slowing and cessation of oral intake is a natural part of the dying process. These patients generally do not suffer, and it affords a quiet way for nature to take its course.

tion of suicide in terminally ill patients.¹³ One recent study showed that 70-90% of patients with advanced cancer suffer significant pain. Fortunately there are numerous options for pain control today, and these should be utilized to provide maximum comfort for the patient. Concerns about the possibility of addiction are unwarranted; in fact, narcotics are often the treatment of choice for severe pain.¹⁴

Nearly all types of pain can be controlled, using a variety of therapeutic options such as oral medications (narcotics, nonsteroidal anti-inflammatory drugs, and others), medication patches, patient-controlled analgesia, nerve blocks, spinal or epidural analgesia, and others. If the patient is still in pain, there are likely other therapeutic options to consider and consultations with a pain specialist may be indicated.

Complementary therapies may be considered for some patients, such as massage, acupuncture, biofeedback, and physical therapy.

Many pain medications may cause drowsiness, constipation, or other side effects which may be undesirable to some patients, yet well tolerated in others. For example,

Marie Curie's last words were, when offered pain medication: "I don't want it."¹⁵ Yet D.H. Lawrence's last words in the same setting, were: "I think it's time for the morphine."¹⁶

Anxiety and Depression

Untreated anxiety and depression are common near the end of life. Patients may suffer from fear of dying, or fear of the unknown. One recent study showed that one-fourth of terminal cancer patients have untreated anxiety or depression. If such symptoms are present, consultation with the primary physician or a psychiatrist is recommended. Treatment is available and can greatly improve the comfort for the patient.

Choosing the Setting for the Patient

Many patients prefer to die at home. It may be preferable to peacefully pass away in the company of loved ones, rather than merely be encircled by the cold arms of technology. However, this is often difficult for family and friends. When the patient deteriorates, relatives often feel

Advance directives are of particular importance to the dying patient, who may not wish heroic measures taken, such as ventilators and other life support systems and drugs.

uncomfortable and call for help. This may initiate a cascade of treatment which was never desired and may be against the patient's wishes. Patients and families should decide in advance which setting is appropriate for them (home, nursing home, hospital, etc.), and prepare for natural events near the end of life. They may appropriately choose to reduce the number of hospitalizations, doctor visits, treatments, and blood tests, and enjoy more meaningful time at home. The physician and treatment team should be of assistance in offering resources and education for expectations and appropriate actions, if the choice is to die at home.

Advance Directives

An advance directive is a legal document stating the patient's wishes, in the event he/she is unable to express them.^{17,18} Often the advance directive states preferences in the event that life support is required, and may refuse certain interventions if not thought to be of medical benefit.

Advance directives are of particular importance to the dying patient, who may not wish heroic measures taken, such as ventilators and other life support systems and drugs.

Medical power of attorney is another important document which designates a particular person who may make health care decisions in the event the patient is unable to do so. Often a spouse, parent, or adult child is designated. Persons of all ages and states of health may benefit from completing a medical power of attorney. Open discussion with the patient regarding their wishes is crucial, as physicians and spouses often do not fully understand resuscitation preferences.¹⁹

Family Support

The love, friendship, assistance, support, and companionship of family is of crucial importance to the dying patient. Care should be taken that medical interventions do not interfere with this important aspect of the patient's well-being.

During a time of illness, communication may become of utmost importance. It may be a time for sincere expressions of love and testimony. Many prophets have uttered most sincere testimony as their last words. For example, Enos wrote: "And I soon go to the place of my rest, which is with my Redeemer; for I know that in him I shall rest. And I rejoice in the day when my mortal shall put on immortality, and shall stand before him; then shall I see his face with pleasure, and he will say unto me, Come unto me, ye blessed, there is a place prepared for you in the mansions of my Father. Amen."²⁰

Support Groups

Support groups can offer important service to both the dying patient and family. Comfort may be gleaned from others experiencing similar trials. Hospice is an organization established in 1974 to provide palliative and support services for dying patients. It may be of great value to many dying patients and families, and may offer assistance in the form of support groups, education about the dying process, home health care, and other services. Several studies have shown that hospice care can improve the quality of life of dying patients.

Mourning

"Irrespective of age, we mourn for those loved and lost. Mourning is one of the deepest expressions of pure love... The only way to take sorrow out of death is to take love out of life."²¹

The mourning process is an important part of recovery for loved ones. Sorrow and mourning are normal, even for those with an understanding of the importance of

"He, the Son of God . . . is our only true comfort, when the dark shroud of earthly night closes about us as the spirit departs the human form."

death for eternal progression. During communications with the patient and family, it is important to recognize that these are normal reactions to the dying process.

"It is true it is grievous to part with our friends. We are creatures of passion, of sympathy, of love, and it is painful for us to part with our friends. We would keep them in the mortal house, though they should suffer pain. Are we not selfish in this? Should we not rather rejoice at the departure of those whose lives have been devoted to doing good, to a good old age?"²²

Conclusion

"Whenever the cold hand of death strikes, there shines through the gloom and the darkness of that hour the triumphant figure of the Lord Jesus Christ. He, the Son of God, who by his matchless and eternal power overcame death.... He is our comfort, our only true comfort, when the dark shroud of earthly night closes about us as the spirit departs the human form."²³

In conclusion, all decisions made near the end of life should have as a goal the fulfillment of the comfortable and meaningful passage from this life to the next. Medical technology may play a role, but need not be administered in all cases if inappropriate. Comfort, relief of symptoms, and support for the dying patient and family are of great significance throughout the dying process.

"And because of the redemption of man, which came by Jesus Christ, they are brought back into the presence of the Lord; yea, this is wherein all men are redeemed, because the death of Christ bringeth to pass the resurrection, which bringeth to pass a redemption from an endless sleep, from which sleep all men shall be awakened by the power God when the trump shall sound; and they shall come forth, both small and great, and all shall stand before his bar, being redeemed and loosed from this eternal band of death, which is a temporal death."²⁴

Catherine A. Marco, M.D., is an Assistant Professor of Emergency Medicine at the Johns Hopkins University School of Medicine.

REFERENCES

1. Psalm 116:15
2. Caplan AL: Medicine without end? Trends in Health Care, Law and Ethics 9:37-38, 1994.
3. Russell M. Nelson, May 1992 Conference Report, p. 72
4. Ecclesiastes 7:1
5. McCue JD: The naturalness of dying. Journal of the American Medical Association. 273:1039-43, 1995.
6. Council on Ethical and Judicial Affairs, American Medical Association: Decisions near the end of life. Journal of the American Medical Association, 267:2229-2233, 1992.
7. Beauchamp TL and Childress JF: Principles of Biomedical Ethics, New York: Oxford University Press, 1994, 120-181.
8. Weatherill GG: Pharmacologic symptom control during the withdrawal of life support: lessons in palliative care. AACN 6:344-351, 1995.
9. McCann RM, Hall WF, Groth-Junker A: Comfort care for terminally ill patients: the appropriate use of nutrition and hydration. Journal of the American Medical Association 272:1263-66, 1994.
10. Ashby M and Stoffell B: Artificial hydration and alimentation at the end of life: a reply to Craig. Journal of Medical Ethics 21: 135-140, 1995.
11. Morrison RS and Morris J: When there is no cure: Palliative care for the dying patient. Geriatrics 50:45-51, 1995.
12. Jett LG: Comfort at the end of life. Journal of Nursing Administration. 25:55-60, 1995.
13. Council on Scientific Affairs, American Medical Association: Good care of the dying patient. Journal of the American Medical Association 275:474-478, 1996.
14. Librach SL: Special issues in pain control during terminal illness. Canadian Family Physician 41: 415-419, 1995.
15. Brandreth G: Famous Last Words and Tombstone Humor, New York: L. Sterling Publishing Co., 1989, p. 25.
16. Brandreth, Ibid, p. 44.
17. Nazerali N: Counseling the elderly on decision making for the end of life. Canadian Family Physician 41: 829-833, 1995.
18. Miles SH, Koepf R., and Weber EP: Advance end-of-life treatment planning. Archives of Internal Medicine 156: 1062-68, 1996.
19. Uhlmann RE, Pearlman RA, and Cain KC: Physicians' and spouses' predictions of elderly patients' resuscitation preferences. Journal of Gerontology 43:M115-121, 1988.
20. Enos 1:27
21. Russell M. Nelson, May 1992 Conference Report p. 72.
22. Brigham Young, DBY, 371.
23. Gordon B. Hinckley, "This Glorious Easter Morn", Ensign, May 1996, p. 67.
24. Mormon 9:13